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*"In fact, all major religions in the US support organ donation and transplantation."*

*The Donation of Human Organs and the Evolving Capacity for Transplantation: Exciting Developments and Future Prospects, page 22*

# Moving from Medicaid to North Carolina Health Choice: Changes in Access to Dental Care for NC Children

Rebecca T. Slifkin, PhD, Pam Silberman, JD, DrPH, Victoria Freeman, DrPH

## Abstract

**Objective:** The objective of this study is to identify the extent to which access to dental care changes as children move from a public program with low provider reimbursement and a reputation of non-compliant beneficiaries to another public program with higher reimbursement levels and enrollees that may be viewed differently by providers.

**Study Design:** The pre- and post-enrollment dental experience of NC Health Choice enrollees who were previously on Medicaid is compared to those who were uninsured prior to NC Health Choice enrollment.

**Data Source:** Parents of newly-eligible NC Health Choice children were sent a survey within two weeks of enrollment to determine their child's experience prior to program enrollment. Respondents were resurveyed approximately 11 months later regarding their child's experiences after receipt of NC Health Choice.

**Principal Findings:** Medicaid recipients were significantly more likely to have had a dental visit within the year before enrolling in NC Health Choice, to report a usual source of care, and have fewer unmet needs than were uninsured children. After enrollment there was improvement for both groups, and differences between the two groups disappeared.

**Conclusions:** Medicaid coverage appears to improve access to dental services for children who would otherwise be uninsured. Increased access to dental services for Medicaid children after enrolling in NC Health Choice may be due to higher provider reimbursement, but may also result from providers' perception that NC Health Choice beneficiaries are a different population and more likely to keep appointments.

**Relevance:** In a time of fiscal crisis, changes to NC Health Choice should be carefully considered to avoid loss of dental care gains afforded by this public insurance program.

Access to dental services for low-income children in the United States is a well-documented problem.<sup>1</sup> Studies of dental access for low-income North Carolina children have found results that are consistent with national data. In a presentation to the North Carolina Task Force on Dental Care Access, Rozier noted that 36% (>31,000) of all NC children entering kindergarten had a history of dental caries and 25% had untreated dental disease.<sup>2</sup> Childhood caries are more prevalent in low-income children and those residing in rural areas without fluoridated water, and low-income children with dental caries are more likely to go untreated.<sup>3</sup>

The absence of regular dental care can impair the health of

children in a number of ways. Untreated dental disease can affect a child's appetite and ability to eat, thereby leading to nutritional or growth problems.<sup>4</sup> A report of the US Surgeon General suggests that children miss approximately 52 million hours of school a year due to dental problems and related care.<sup>5</sup> Further, the inability to access dental services leads to more expensive use of the emergency room for care. In 1997, for example, North Carolina Medicaid paid \$1,686,565 for 62,000 preventable emergency dental visits.<sup>6</sup> Children with oral and craniofacial conditions also can face problems with speech or their psychological well-being. Finally, poor dental health in children can also affect their dental and physical

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health as adults. There is now a growing body of research that suggests an association between periodontal infections and diabetes, heart disease and stroke, and adverse pregnancy outcomes such as prematurity and low birthweight.<sup>7</sup>

Barriers to the receipt of dental care are particularly acute for NC children receiving Medicaid. Only 16% of North Carolina dentists actively participated in Medicaid in 1998, which was at that time one of the lowest rates of participation in the country.<sup>8</sup> Lack of provider participation in Medicaid, coupled with other access barriers, has led to low use of dental services among Medicaid-eligible children. North Carolina Medicaid claims data from 1998 showed that only 12% of children ages 1-5 years, 27% of children 6-14 years, and 19% of children ages 15-20 made at least one visit to the dentist.<sup>9</sup>

A statewide task force convened by the North Carolina Institute of Medicine studied access to dental services among low-income populations in 1999.<sup>10</sup> The task force identified low provider reimbursement levels as the primary barrier to dental provider participation in Medicaid. On average, the North Carolina Medicaid program paid dentists 62% of the usual, customary and reasonable rates (UCR) for 44 of the most common dental procedures for children and only 42% of UCR for other procedures. Dentists reported losing money by seeing Medicaid patients. A 1996 study of North Carolina dentists reported that 56% of dentists in the state would be willing to see more Medicaid patients if reimbursement rates were increased to 80% of UCR.<sup>10</sup> In addition to low reimbursement rates, dentists also stated other reasons for their unwillingness to participate in Medicaid, including a high no-show rate among Medicaid recipients.

In October 1998, North Carolina implemented its State Child Health Insurance Program (SCHIP), called North Carolina Health Choice for Children (NC Health Choice or NCHC). NC Health Choice provides health insurance to uninsured children with family incomes that are too high to qualify for Medicaid but that are at or below 200% of the federal poverty guidelines. Most of the children enrolled in NC Health Choice come to the program immediately after losing Medicaid coverage, either because they are no longer eligible due to an increase in family income or because they are too old to qualify within their income category.

Like 19 other states, North Carolina chose to implement a stand-alone SCHIP program rather than expand Medicaid eligibility. The NC Health Choice program is administered jointly by the NC Division of Medical Assistance (which is responsible for administering the Medicaid program), and the Teachers' and State Employees' Comprehensive Major Medical Plan (hereinafter the State Employees' Health Plan). NC Health Choice is modeled after the State Employees' Health Plan, but includes coverage for vision, hearing and dental services. Blue Cross Blue Shield of North Carolina is contracted to pay NC Health Choice claims, and reimburses dentists for care delivered to children enrolled in the NC Health Choice program at its prevailing commercial dental rates of approximately 100% of UCR. Thus, while NC Health Choice is a form of public insurance, children enrolled in the program have slightly higher family incomes than

children on Medicaid, and their insurance reimburses dentists at a higher rate than does Medicaid.

Although several studies document the difficulties that Medicaid recipients have in accessing dental services<sup>1,11,12</sup> little has been written about the experience of Medicaid recipients as they move to other sources of dental insurance coverage. Further, there have been only a few studies that have examined access to dental services in SCHIP or comparable public insurance programs.<sup>13,14,15</sup> In this study, we compare the dental experience of NC Health Choice enrollees who were on Medicaid prior to NC Health Choice enrollment to that of NC Health Choice enrollees who had no insurance for at least a year prior to NC Health Choice enrollment. The pre-enrollment experiences of these two groups and the change in access once enrolled in NC Health Choice are examined. This analysis will help identify the extent to which access to dental care changes as children move from a public program with low provider reimbursement and a reputation of non-compliant beneficiaries to another public program with higher reimbursement levels and enrollees who may be viewed differently.

## METHODOLOGY

The data for this study were collected as part of a larger evaluation of NC Health Choice conducted by researchers at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill under contract to the North Carolina Division of Medical Assistance.<sup>16</sup> The findings from that study as they relate to access to general health services have been previously reported, as was an earlier analysis of access to dental care for school-aged children that did not consider enrollees' prior dental coverage.<sup>13,17</sup>

Beginning in July 1999, parents of newly-eligible NC Health Choice children were sent a survey within two weeks of enrollment to determine their ability to access medical and dental services for their child prior to enrolling in the program. Respondents to the first survey were resurveyed approximately 11 months later to examine their child's experiences after receipt of NC Health Choice. Although the sample for the larger study was stratified by three age groups (ages 0-5, 6-11, and 12-17 years, all at the time of enrollment in NCHC), in this study we report results for the two older age groups only. Because of survey space limitations, we were unable to ask enough dental care questions to explore why the children in the 0-5 year age group were or were not receiving dental care. An increase in dental service use is expected as these youngest children grow up and more teeth erupt. It is, therefore, difficult to determine the extent to which an increase in dental service use in this age group is attributable to the new NC Health Choice coverage. Patterns of care for children in this youngest age group are also difficult to interpret because there is not consensus between dental and medical professionals as to when children should begin receiving regular dental services. For these reasons, the results presented in this paper pertain only to school-aged children.

Baseline surveys were sent to the parents of 599 younger school-aged children (ages 6-11) and 599 adolescents (ages 12-

17). Seventy-three percent (N=875) responded. Respondents to the baseline survey were mailed a follow-up survey and again 73% responded, for an overall response rate of 53% of the parents originally surveyed. The resultant cohort for whom data were available at both baseline and one year later consisted of 639 children (325 younger school-aged children and 314 adolescents.) In the baseline survey, parents were asked to report whether their child's most recent dental visit had been within the last year, more than a year ago, or never. In the follow-up survey, they were asked if their child had seen a dentist in the year since enrollment in NC Health Choice. Their usual source of dental care and whether their child experienced any dental access barriers were also queried. Parents who reported access barriers were asked why they were unable to obtain needed dental services.

This analysis focuses on two subsets of school-aged children, those who had Medicaid coverage during the entire year prior to their enrollment in NC Health Choice (391 children, referred to as "Medicaid graduates") and those who had no insurance for the year prior to enrollment (201 children, referred to as "uninsured"). Medicaid graduates were defined as those with Medicaid coverage that ended within 31 days of enrolling in NC Health Choice. Since North Carolina provides 12-month continuous eligibility for children enrolled in Medicaid, these children would have been covered for a full year prior to NC Health Choice enrollment. Children in the uninsured group had neither Medicaid coverage nor any other medical care insurance (by parental report) at any time during the year prior to NC Health Choice enrollment. Our survey did not specifically ask whether children had private dental coverage prior to NC Health Choice enrollment, so it is possible that some uninsured children had private dental insurance at some time in the year before NC Health Choice. However, low income families nationally have low dental insurance coverage rates, so it is highly unlikely that many of these children had private dental insurance.<sup>18</sup> The remaining school-aged children (N=47) were excluded from this analysis because their insurance status changed during the year prior to NC Health Choice enrollment, with insurance (typically Medicaid) for part of the year, and no insurance for the remainder of the year. It was, therefore, impossible to determine whether those children's reported dental care experience prior to enrolling in NC Health Choice reflected their experiences while insured or not.

All data were analyzed using STATA 7 statistical software.<sup>19</sup> McNemar's Chi was used to compare change in dichotomous categorical data (yes/no questions) over time. Changes in questions that had multiple, ordered responses were tested for significance with the Wilcoxon signed-rank test. A paired t-test was used to compare changes in means for continuous ordinal data.<sup>20</sup> When data

are presented for all children combined, they have been weighted to adjust for the distribution by age groups of the NC Health Choice enrollees. Throughout the paper, differences in statistics pre- and post-NCHC are considered significant if  $p < .05$ .

At the time of the follow-up survey, the baseline survey was sent to a comparison group of parents of children who were newly-enrolled in NC Health Choice to ensure that observed changes in the original sample were not due to changes in the health care delivery environment. There were no significantly different responses to dental access questions before NCHC enrollment between the two groups. It does not appear that changes in the dental health care environment occurring over the time of our study account for the change observed post enrollment.

## RESULTS

### Demographic Characteristics

Demographic characteristics that might explain differences in access to and/or use of dental services are compared for Medicaid graduates and uninsured children (Table 1). Rural

**Table 1.**  
**Demographic Characteristics**

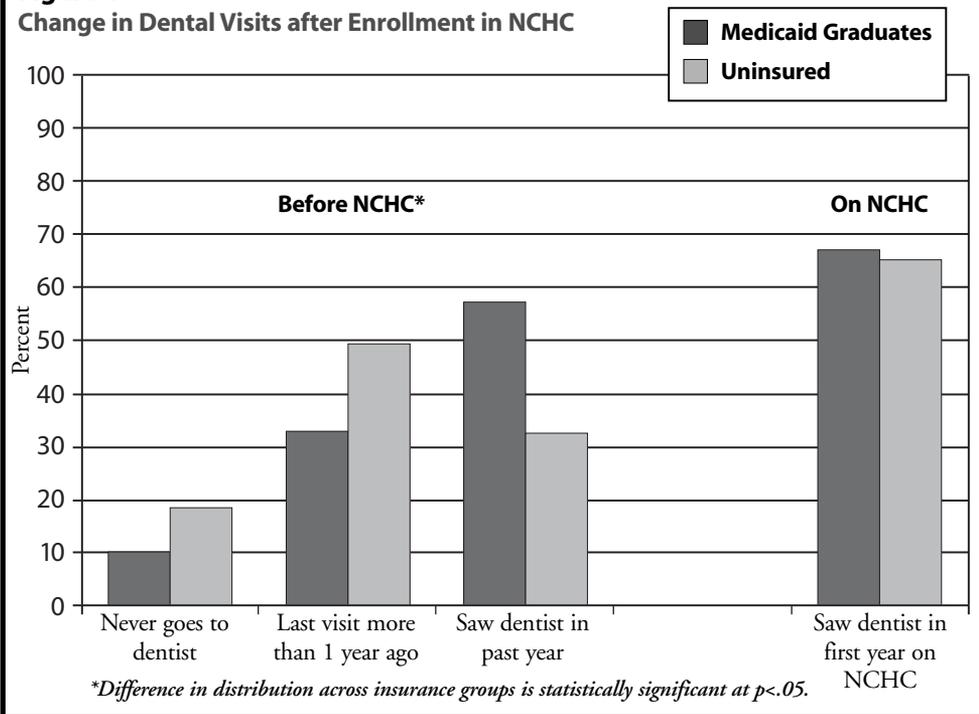
Characteristic	Insurance Status in Year before NCHC Enrollment	
	Uninsured (n=201) %	Medicaid Graduates (n=391) %
Rural Residence*	49	46
Race*		
White	51	42
Black	42	48
Hispanic	3	4
Mother's education*		
Less than high school graduate	15	15
High school graduate	36	44
Some college	35	32
College graduate	15	9

\* The difference in distribution is statistically significant at  $p < .05$

areas traditionally have fewer dentists per population than do urban areas which limits access to care. The difference between the percent of respondents residing in rural areas across the two groups, while statistically significant, is small.

There were significant differences in the racial composition of the two groups. Children who were uninsured prior to NCHC enrollment were more likely to be white (51%) than were Medicaid graduates (42%), and the mothers of uninsured children were more likely to have post-secondary education. Finally, although data on income prior to enrollment in NC Health Choice was not available, it is reasonable to assume that many of the uninsured children had family incomes that were slightly higher than that of the children on Medicaid, which is why they were uninsured rather than on Medicaid.

**Figure 1.**  
Change in Dental Visits after Enrollment in NCHC



**Dental Visits**

In both surveys, parents were asked about the timing of their child's most recent dental visit. They were also asked where their child received dental care. There were significant differences in receipt of dental care prior to NCHC between the two groups: 57% of Medicaid recipients had a dental visit within the year before enrolling in NC Health Choice, compared with only 33% of uninsured children (Figure 1). Parents of uninsured children were more likely to report that prior to program enrollment their child had gone more than a year since receiving dental care (49%) or that s/he had never had dental care (18%), compared to the responses of parents of Medicaid children (33% and 10% respectively).

After program enrollment, differences in receipt of dental care between the two groups disappeared: 65% of previously uninsured children and 67% of Medicaid graduates made a dental visit during their first year on NC Health Choice. Although there was an increase for both groups in the percent of children who received dental care after NCHC enrollment, the improvement was much more dramatic for the uninsured children. The percent of uninsured children who had a dental visit in the previous year doubled after enrollment in NCHC compared to an increase of 18% for Medicaid graduates.

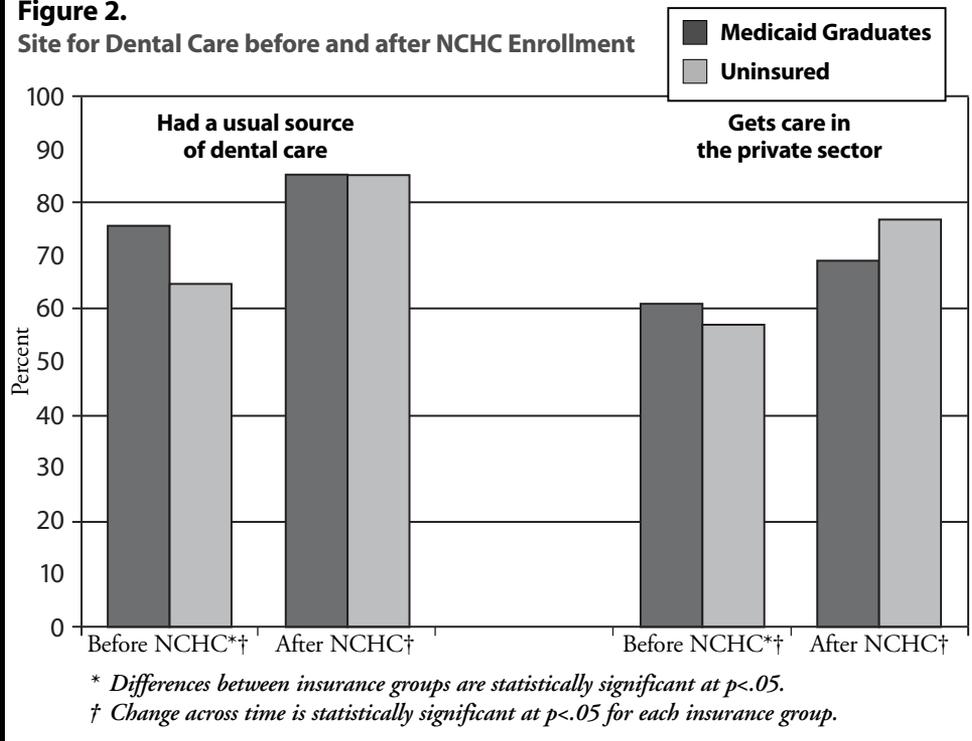
**Source of Dental Care**

Parents were also asked where they took their child for dental care. Children were considered to have a usual source of care if their parents reported taking them to a community clinic or health center, public health department or private dental office. Children were considered to have no usual source if their parent reported that they got care anywhere they could or that they never got care. In the year prior to NCHC enrollment, Medicaid recipients were significantly more likely than uninsured children (76% versus 64%) to have had a usual source of dental care (Figure 2). After enrollment, the percent of children with a usual source of dental care increased to 85% for both groups. As was seen

with dental visits, the improvement was greater for the uninsured group, resulting in no significant difference between groups post-enrollment.

When receipt of care in the private sector is the only consideration, a different picture emerges (Figure 2). Prior to program enrollment, Medicaid children were significantly more likely than uninsured children to receive dental care at a private practice (61% versus 57%). After program enrollment the relationship was reversed, with children who were previously uninsured (77%) significantly more likely to receive care in the private sector than were

**Figure 2.**  
Site for Dental Care before and after NCHC Enrollment



**Table 2.**  
**Barriers to Dental Care**

Characteristic	Insurance Status in Year before NCHC Enrollment	
	Uninsured (n=201) % †	Medicaid Graduates (n=391) % †
Had unmet need for dental care prior to enrollment*	58	33
Barriers prior to NCHC enrollment		
No insurance that would pay for care*	45	17
Not enough money to pay for the care*	51	16
Couldn't find dentist to see child*	6	17
Had unmet need for dental care after enrollment**	17	19
Barriers while on NCHC		
NCHC did not cover care child needed	7	8
Not enough money to pay for care*	3	7
Couldn't find dentist to see child	6	6

\* The difference in distribution between the two insurance groups is statistically significant at  $p < .05$

\*\* The difference within each insurance group prior to and after enrollment is statistically significant at  $p < .05$ .

† Denominator is all children in the insurance group.

Medicaid recipients (69%), although there was a significant increase in private sector access for both groups.

### Reported Unmet Need for Dental Care

Parents were asked if there was any time in the previous six months that they felt their child needed dental care that he or she could not get. For those with unmet need, barriers to care were queried (Table 2). To get a sense of the portion of all publicly insured children facing specific barriers, the percent reporting any particular barrier is reported as a portion of all those responding to the survey, not just those with unmet need for care.

In the six months prior to NCHC enrollment, a greater percentage of parents of uninsured children reported unmet need for dental care (58%) than did parents of Medicaid recipients (33%). For uninsured children, lack of insurance coverage and money were the main obstacles to care. Medicaid parents also reported these barriers, but they were significantly less likely to do so. Surprisingly, parents of 17% of Medicaid recipients (half of those with an unmet need) reported that they did not have insurance that would pay for the care although Medicaid does cover dental services. This may reflect need for a service that Medicaid does not cover, the parent's lack of knowledge about their child's benefits, or may indicate that dentists were unwilling to accept Medicaid coverage, so as to render the child's dental coverage ineffective. An almost equal proportion of Medicaid parents (17% of all Medicaid children and 49% of those with an unmet need) reported that they could not find a dentist who would see their child, an access barrier reported significantly more often for Medicaid recipients than for the uninsured.

After a year on NCHC, significantly fewer parents in both groups reported that their child had unmet need for dental care. On an additional positive note, the percent of Medicaid parents

who reported that they could not find a dentist that would see their child dropped by two-thirds after enrollment in NCHC. Finally, after enrollment Medicaid parents were more likely than uninsured parents to report lack of money as a barrier to care.

## DISCUSSION

The significant differences in access to dental care between the two groups prior to enrollment in NCHC suggest that Medicaid coverage does improve access to dental services for low-income children who would otherwise be uninsured, despite the known problems of low provider reimbursement and the reported reluctance on the part of providers to accept clients they believe will not keep appointments. Prior studies have found that whites and those with higher income and/or education are more likely to use dental services.<sup>4</sup> Those findings, however, might be attributed to private dental insurance coverage as those

same groups are more likely to have such coverage, which itself predicts use of dental services regardless of socio-economic and demographic characteristics.<sup>18</sup> Since the uninsured group in our study was more likely to be white, have higher income and more education, one might expect this group to have greater access to dental services before NC Health Choice than did Medicaid graduates, and the pre-NCHC differences may understate the true difference between the two groups.

In general, the experience of former Medicaid children and uninsured children appears comparable after enrolling in NC Health Choice. Almost the same percentage of children in each group was reported to have visited a dentist in the first year on the program and to have a usual source of care. However, after NCHC enrollment Medicaid children were significantly less likely to report having a private dentist as their source of care than were uninsured children. Consistent with prior research identifying low reimbursement rates as a barrier to Medicaid children's receipt of care,<sup>6</sup> there was an increase in the percentage of Medicaid children who were able to access care in the private sector after NCHC enrollment. But, the fact that after enrollment in NCHC access to the private sector for Medicaid children was more limited than for the previously uninsured may be due to patterns of care prior to enrollment in NC Health Choice. Dental providers in Community and Migrant Health Centers and public health departments are far more likely to accept Medicaid coverage than are many private providers. Thus, Medicaid recipients may have continued to see a public dental provider with whom they had already established a relationship. It is also possible that differences in demographic characteristics between the two groups contributes to the higher likelihood that the previously uninsured group was seen in the private sector, as this group is more likely to be white and more educated.

Moving from Medicaid to NCHC improved dental access for all children in our study. The most obvious explanation for the improved access to dental services for Medicaid children after enrolling in NC Health Choice is the improvement in provider reimbursement, a known barrier to provider participation in the Medicaid program. The fact that NC Health Choice is administered by Blue Cross Blue Shield, coupled with higher reimbursement rates, may convince previously reluctant providers to participate in the program.

However, what is unknown is the extent to which the improved access afforded by NC Health Choice is a result of providers' perception that NC Health Choice beneficiaries are a different population and more likely to keep appointments. The social factors that make keeping appointments difficult, factors such as transportation problems and inflexible work schedules, will not have changed substantially with a child's transition from Medicaid coverage to coverage by NC Health Choice. It is not known if dentists even realize that the major-

ity of NC Health Choice enrollees were previously on Medicaid. There is a public perception that NC Health Choice is a program for the working poor and that Medicaid is a welfare program, even though many children are served by both programs at different times in their lives.

Regardless of motivation of dental providers, NC Health Choice has improved access to dental care for North Carolina's poor children. In a time of fiscal crisis, changes to this insurance program, which currently covers approximately 100,000 children,<sup>21</sup> should be carefully considered to avoid loss of dental care gains afforded by this public insurance program.

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# Race and Colorectal Cancer Screening: A Population-based Study in North Carolina

Deborah A. Fisher, MD, MHS, Karen Dougherty, MSN, ANP, Christopher Martin, MPH, Joseph Galanko, PhD, Dawn Provenzale, MD, MS, and Robert S. Sandler, MD, MPH

## Abstract

**Objective:** National and state data document racial differences in colorectal cancer (CRC) mortality and incidence. Screening for CRC reduces cancer incidence and deaths. Racial differences in colorectal cancer screening behavior may contribute to the racial disparity in incidence and mortality. The purpose of this study was to determine if colorectal cancer screening rates are different between blacks and whites while controlling for potential confounders.

**Study Design:** Cross-sectional survey.

**Data Source(s)/Study Setting:** We used data from the North Carolina Colon Cancer Study, a population-based case-control study conducted in 33 counties of North Carolina. We analyzed data from 598 control subjects who were eligible for colorectal cancer screening.

**Methods:** Trained nurses conducted face-to-face interviews from October 1996 through October 2000.

**Results:** Overall, 50% of the respondents were compliant with CRC screening guidelines. In the multivariable logistic regression model having a regular doctor and participation in a general medical exam were significantly associated with current screening status with odds ratios (OR) (95% confidence interval (CI)) of 3.8 (1.7-8.3) and 3.7 (2.1-6.7), respectively. Older age was a significant predictor of current screening status with an OR (95% CI) of 2.9 (1.7-4.8) for those 60-69 compared to respondents 50-59 and OR 3.2 (1.9-5.5) for those 70 and older compared to respondents 50-59. After adjusting for age, having a regular doctor and participation in general medical exams, race was not significantly associated with current CRC screening status, with an OR of 1.1 (95% CI 0.7-1.6).

**Conclusion:** CRC screening rates in North Carolina were low. Race was not a significant determinant of screening behavior and therefore does not explain the racial disparity in incidence or survival. Older age, having a regular doctor and participating in general medical exams were significant predictors of CRC screening.

**Relevance:** This study reinforces the fact that screening rates in North Carolina are low despite the strong evidence that colorectal cancer screening reduces cancer deaths.

Nationally, colorectal cancer incidence and mortality is higher for blacks than whites.<sup>1</sup> State-level data in North Carolina also reveal this racial disparity.<sup>2</sup> The American Cancer Society and other organizations have endorsed several screening strategies<sup>3,4</sup> because colorectal cancer screening decreases col-

orectal cancer mortality and incidence.<sup>5,6,7,8,9</sup> Racial differences in colorectal cancer screening behavior may contribute to the racial disparity in incidence and mortality. Other possible predictors of colorectal cancer screening behavior include income, insurance status, education, participation in regular

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medical exams, current screening for other cancers, family history, and non-smoking status.<sup>10,11,12,13,14,15</sup> The purpose of this study was to determine if colorectal cancer screening rates are different between blacks and whites while controlling for potential confounders.

## Methodology

We used information from the North Carolina Colon Cancer Study (NCCCS), a population-based case-control study conducted in 33 contiguous counties of central and eastern North Carolina from October 1996 to October 2000. Control subjects younger than 65 were selected from Department of Motor Vehicle Registry tapes. Control subjects age 65 and older were selected from the Centers for Medicare and Medicaid Service's tapes. Trained nurses conducted face-to-face interviews with the subjects. Questions about screening tests included the total number of each test [fecal occult blood test (FOBT), colonoscopy, flexible sigmoidoscopy, and barium enema] done in the past 10 years, the date of the most recent test and whether the most recent test was for screening or a problem. The interviewers also asked about physical activity, tobacco use, family history, occupation, income, health insurance, source of health care, health seeking behavior and health status.

We considered a subject "current" for colorectal cancer screening if he or she had been tested within the time frame endorsed by the American Cancer Society and others at the time of the study: FOBT within one year, flexible sigmoidoscopy within five years, barium enema within five years, or colonoscopy within 10 years beginning at age 50.<sup>3,4</sup> We restricted the study sample to individuals eligible for screening. Thus, we only used data from the control subjects. In addition, we excluded subjects younger than age 50 and those who had tests performed for symptoms or problems. Individuals in the latter category would be at a higher risk for colorectal cancer and therefore would be surveillance candidates and not screening candidates who are, by definition, at average risk for a condition.

## Analysis

Logistic regression modeling was the primary analytic technique. We performed all analyses using PC-SAS Version 8.2 for Windows (SAS Institute, Cary, NC).

We constructed unadjusted and adjusted logistic regression models with colorectal cancer screening status as the dependent variable and race as the independent variable. We developed the adjusted model by first including race and any predictor variables with a p value <0.1 in univariate analysis (chi-square test). We reduced the model by stepwise backward regression. We chose, *a priori*, p<0.05 as the level of significance for the models.

We categorized variables as follows: age (50-59, 60-69, 70 and older), education level (less than high school graduate,

**Table 1.**  
**Characteristics of Study Sample N=598**

Age mean (SD)	67.1	(8.0)
White	353	(59%)
Men	305	(51%)
Education		
<High school graduate	186	(31%)
High school graduate	155	(26%)
Some college	124	(21%)
College graduate	130	(22%)
Insurance		
Government only	121	(20%)
HMO or private	459	(77%)
None	18	(3%)
Annual Household Income		
Less than \$20,000	236	(39%)
\$20-50,000	209	(35%)
Greater than \$50,000	153	(26%)
Married	385	(64%)
Smoking status		
Current	102	(17%)
Former	236	(40%)
Never	258	(43%)
Had a Regular Doctor	552	(92%)
Rural	469	(79%)
<i>SD = standard deviation</i>		

high school graduate, at least some college, college graduate), insurance status [government (Medicare, Medicaid, CHAMPUS, CHAMPVA), private/HMO, none], income (< \$20,000, \$20-50,000, >\$50,000), residence (rural, urban), marital status (married, not married), health status (mental component summary and physical component summary from the Short Form-1216, smoking status (never, former, current), physical activity (MET-minutes per day by quartile) and participation in a general medical exam (yes, no).

The University of North Carolina at Chapel Hill Institutional Review Board approved this study. All subjects gave written informed consent.

## Results

Sixty-two percent of the subjects screened agreed to participate in the NCCCS for a total of 1,051 subjects. After elimination of patients younger than 50 and those with a history of colorectal cancer testing for symptoms, 700 subjects remained. We further excluded 102 subjects with missing data for a response or explanatory variable, leaving 598 subjects. Approximately half all of the patients were men, 59% were white and 41% black. Table 1 lists additional characteristics of the study sample. Univariate analysis revealed associations between current colorectal cancer screening and the following predictor variables at the p<0.1 level: age, income, health insur-

ance type, education, having a regular doctor, marital status, and participation in a general medical exam. In the unadjusted model, race (black vs. white) was not significantly associated with current screening status with an odds ratio (OR) of 0.74 (95% confidence intervals (CI) 0.53-1.02). The adjusted logistic regression model included race (black vs. white), age (50-59, 60-69, (70), income (< \$20,000, \$20-50,00, >\$50,000), having a regular doctor (yes, no) and participation in general medical exams (yes, no). Having a regular doctor, participation in a general medical exam, higher income and older age were significantly associated with current screening status (Table 2). Race was not

Similarly, 55% of those who had participated in a general medical exam were current with colorectal cancer screening while only 20% of those who had not participated in a general medical exam were current. In multivariate analysis, the odds of being up-to-date with colorectal cancer screening were reduced by 74% for those without a regular doctor and for those who had not participated in general medical exams.

Other large survey studies have examined predictors of fecal occult blood testing or lower endoscopy and none have found a clear association between race and participation in the tests. An analysis of the 1997 Behavioral Risk Factor Surveillance System (BRFSS) data, a national telephone survey, found no difference in colorectal cancer screening rates between blacks and whites. Having health insurance and increasing age (up to 79), income, and education were associated with screening status. Healthy behaviors were examined and non-smoking status, seatbelt use, physical activity, increased fruit and vegetable intake and recent cholesterol screening were all associated with current colorectal cancer screening. Participation in medical examinations and having a regular doctor were not examined in this study.<sup>14</sup> Analysis of the 1998 National Health Interview Survey data (NHIS), a face-to face national survey, again found increased education and having insurance predict colorectal cancer screening status. The NHIS study found no association

between race and colorectal cancer screening. The strongest predictor of colorectal cancer screening was having a usual source of care, which, while not identical to continuity of care (i.e. having a regular doctor), is related.<sup>18</sup> Another analysis of the same 1998 NHIS data did find a small but statistically significant association of white race compared to black race or "other race" and reported colorectal cancer screening. One explanation for the discrepancy was that different screening intervals were used in the two studies.<sup>17</sup> A face-to-face interview study performed in the Mid-West found that having had a physician visit in the prior year was a strong predictor of ever having had a FOBT and ever having undergone sigmoidoscopy. Higher education was also a predictor of having had each test. Smoking status was only associated with the FOBT and increased income was only associated with sigmoidoscopy. The sample was over 98% white and therefore racial differences in screening behavior could not be addressed.<sup>15</sup>

While our study does not provide an explanation for the racial gap in colorectal cancer incidence or mortality, it does offer insights to increase colorectal cancer screening participation for the general population. Our results suggest that health maintenance visits and continuity of a primary care provider may be facilitators of colorectal cancer screening participation. The association of higher income and screening behavior is

**Table 2.**  
**Independent predictors of current participation in colorectal cancer screening\***

Variable	Odds Ratio	95% Confidence Intervals
<b>Race</b>		
Black vs White	0.98	0.67-1.43
<b>Household income</b>		
>\$50,000 vs \$20-50,000 per year	2.38	1.47-3.85
>\$50,000 vs <\$20,000 per year	2.86	1.69-4.76
<b>Age</b>		
≥70 vs 60-69	2.84	1.68-4.78
≥70 vs 50-59	3.17	1.89-5.32
<b>Had a Regular Doctor</b>		
Yes vs No	3.79	1.67-8.63
<b>Participated in General Medical Exam</b>		
Yes vs No	3.79	2.13-6.71

\* each item was simultaneously controlled for other items in the table

significantly associated with current CRC screening status, with an OR of 0.98 (95% CI 0.67-1.43).

The sample size was insufficient to construct logistic regression models for gender subsets to explore the relationship between participation in breast or cervical cancer screening and colorectal cancer for women or participation in prostate cancer screening and colorectal cancer screening for men. Gender, itself, was not significantly associated with current colorectal cancer screening at the p<0.1 level in univariate analysis, and therefore, was not included in the logistic regression model.

## Discussion

This North Carolina population study of subjects eligible for colorectal cancer screening confirms other reports of low colorectal cancer screening rates.<sup>13,14,17</sup> Race, however, was not a significant determinant of current screening participation. Income and age were associated with colorectal cancer screening behavior, but the strongest predictors of adherence to colorectal screening guidelines were having a regular doctor and participation in general medical exams. While 53% of the patients with a regular doctor were current with colorectal cancer screening only 17% of those without a regular doctor were current.

likely related to an increased ability to afford the tests, both the costs associated with the test itself and the costs of missing work, traveling to the doctor's office and related expenses. Even in an insured study sample (97%), colorectal cancer screening is not without expense because of variable insurance coverage for colorectal cancer screening and the indirect costs listed above. Increased ability to afford colorectal cancer screening should increase compliance with provider screening recommendations. Additionally, subjects with higher incomes may have been more likely to request screening, knowing that they had the financial resources if the screening was not covered by their health insurance. Ensuring adequate coverage and educating consumers about their colorectal cancer screening benefits are important to increase colorectal cancer screening participation.

The strengths of our study include identification of test indication, determination of all endorsed screening strategies, use of a representative population sample and adequate response rate. The use of radiologic and endoscopic tests for diagnosis or therapy is important, but the accuracy of predictors of screening behavior relies on determination of the test indication. In contrast to the Behavioral Risk Factor Surveillance System (BRFSS) survey, we distinguished between CRC testing for screening and for diagnostic purposes.<sup>2,14</sup> Further, we asked about all recom-

mended screening options allowing us to correctly identify screened patients who may have been missed using surveys, such as the BRFSS and National Health Interview Survey (NHIS) that only asked about certain screening modalities.<sup>14,17</sup> This study has the limitation of using self-reported data without validation from another source. However, a study in a community family practice setting found high correlations for fecal occult blood testing (0.78) and sigmoidoscopy (0.90) when comparing chart audit with patient survey.<sup>19</sup> In addition, two studies in the managed care setting investigating the relative sensitivity of patient survey compared to medical record audit found a 92-96% sensitivity of the survey to detect fecal occult blood testing, 79%-95% sensitivity to detect flexible sigmoidoscopy and an 89% sensitivity for detecting colonoscopy.<sup>20,21</sup>

In conclusion, older age, higher income, having a regular physician and participation in general medical exams were associated with colorectal cancer screening behavior. Several patient, provider and system level factors are likely to be responsible for the low colorectal cancer screening rates in North Carolina and nationally. Our study demonstrates that there are continued financial barriers. It also supports the importance of factors related to the primary care setting. Future directions include testing interventions that increase continuity of primary care and health maintenance visits.

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# POLICY FORUM

## *Organ Donation and Transplantation*

### Introduction

*Gordon H. DeFriese, PhD*

### Issue Brief:

The Donation of Human Organs and the Evolving Capacity for Transplantation: Exciting Developments and Future Prospects

*Erika L. Rager, MD, MPH*

*“The current donor system depends on a patchwork of organ donor cards, driver’s licenses, advanced directives, and durable power of attorney for healthcare statements as vehicles for citizens to state their wishes.”*

### COMMENTARIES

Increasing Donation: Key Factors to Save More Lives

*Lloyd Jordan*

The Gift Relationship in Process: From the Donor to the Recipient

*Julie Landon, RN, CPTC*

The Rapid Development of Solid Organ Transplantation in North Carolina

*Michael R. Mill, MD*

Building a Modern Transplant Center

*J. Elizabeth Tuttle-Newhall, MD*

Some of the Challenges of Organ Donation Among Minority Populations

*Lynt B. Johnson, MD, FACS*

A Minority Perspective: The State of Minority Donation in North Carolina

*Debbie Mann Gibbs*

“What’s in Your Wallet?” Will Your Intentions Be Known?

*Betsy J. Walsh, JD, MPH, and Judy Jones Tisdale, PhD*

### SPECIAL ARTICLE

Giving and Receiving when Vital Organs Fail

*Donald L. Madison, MD  
(with Andrew, Susan, and James Pike)*



# INTRODUCTION

## **Policy Forum:** *Organ Donation and Transplantation*

Almost every week, we hear stories from North Carolina and elsewhere in the nation about an individual who is desperately waiting for word that a bodily organ is available to replace one that is seriously diseased or malfunctioning. Life is both literally and figuratively “in the balance” as the waiting game goes on, sometimes for months or years. Why is it that so few people, particularly so few from minority population groups, are willing to take the necessary steps before the time of their own death to assure both healthcare providers and their families of their intention to donate organs that might save or improve the lives of others? Why are we burying so many of these vital organs day-after-day, rather than extending the lives of those in need? Why is it so difficult to find live donors of organs that might offer the same life-saving benefits, without compromising the health of the donor? These are important questions of health policy significance, as well as tremendously important personal issues for those whose lives have been touched by the events and circumstances which have made either organ donation or receipt major issues of concern.

The other dimension that captured the interest and concern of our editors is that the science and skills of transplantation are now such that most recipients of donated organs have the prospect of living full and functional lives without overwhelming concerns they once would have had with rejection and the need for further transplantation. The rapid diffusion of transplantation technologies and skills and the development of multi-organ transplantation services within our state’s largest hospitals, has given all North Carolinians access to some of the world’s most advanced medical care for conditions where only transplantation offers hope.

In this issue of the *Journal* we are pleased to offer a set of articles providing a broad overview of many of these concerns in the hope that more attention will be given to this important aspect of contemporary medical care for those who could benefit from an expansion of both our donor networks and participation, as well as from the advancing science of transplantation. Erika Rager, MD, MPH, a surgical resident at UNC-Chapel Hill who is currently taking a two-year residency in preventive medicine, offers a comprehensive issue brief on the topic. We are pleased that leading figures from the transplant services of both Duke Medical Center and UNC-Chapel Hill have agreed to participate in this special issue forum. In addition we are pleased to include contributions from our two donor organizations in the state, Carolina Donor Services and LifeShare Of The Carolinas. Because of our concern over the rather low rate of participation of minority populations in organ donation and transplantation, we have invited Dr. Lynt Johnson of Georgetown University, an African American transplant surgeon, and Debbie Mann Gibbs of LifeShare Of The Carolinas to help address these issues. Finally, Contributing Editor Donald Madison, MD, offers an interesting interview with a North Carolina family who has experienced a broad spectrum of these issue first-hand.

For those who may not have previously signed (and had witnessed) a donor card, one is provided in this issue of the *Journal*, which may be clipped and placed in one’s wallet along with a driver’s license.

As always, we invite the comments and reactions of our readers to these and other topical issues covered in these pages.

—Gordon H. DeFrieze, PhD  
*Editor-in-Chief and Publisher*

# The Donation of Human Organs and the Evolving Capacity for Transplantation: Exciting Developments and Future Prospects

Erika L. Rager, MD, MPH

Solid organ transplant is the best treatment and only cure for many people suffering from end-stage disease. Over the past 20 years, improvements in immunosuppression and increasing experience in caring for transplant patients has resulted in massive increases in the use of this therapy. Now, the numbers are truly staggering. As of December 15, 2003, there were 83,686 patients with end-stage organ disease awaiting transplant in the US. In 2002, there were 12,801 deceased and living organ donors; 24,900 patients underwent transplantation; and 6,187 died while waiting on the list.<sup>1</sup> About 56 people receive an organ transplant every day in the US and four North Carolinians die each week waiting for an organ transplant. The therapeutic application of organ transplantation is limited only by a shortage of donor organs.

## Brief history of organ transplantation

Development of organ transplantation as a widely applicable therapy depended on technical advancements in the field of surgery and increased understanding of immune function. The initial technical advancements in vascular anastomosis (surgical techniques to sew together blood vessels) that were necessary for later organ transplantation were developed by French surgeon Alexis Carrel in the early 1900's. Animal studies over the next 50 years resulted in techniques for the transplantation of kidneys, abdominal and thoracic organs.<sup>2</sup>

Based on studies of skin grafting, by the 1940's scientists understood that rejection of transplanted tissues was an immunological event. Initial attempts to modulate the immune system in humans used sublethal doses of total body irradiation to suppress bone marrow production of white blood cells. This immunosuppression led to occasional long-term survival of transplanted organs, but was unreliable. By the early 1960's, researchers were using drugs to suppress the bone marrow. Medication regimens based on azathioprine and prednisone improved patient survival in the 1960's and 1970's, especially for living-related kidney transplants.<sup>2,3</sup> In the late

1970's, the immunosuppressive drug cyclosporine was introduced. Cyclosporine dramatically changed the course of organ transplantation. One-year survival rates increased from 30-60% to 70-90%.<sup>4</sup> Transplantation of kidneys, livers, hearts, and lungs became widespread.

The first transplant that enjoyed long-term success was a living-related renal transplant performed between identical twins in 1954 by Dr. Joseph Murray. In 1990, Dr. Murray was awarded the Nobel Prize for Medicine for his achievements in the field of transplantation. Aside from the first successful renal transplant in 1954, most of the first successful solid organ transplants occurred in the late 1960's.

**Table 1.**  
Milestones in Transplantation in North America

1954	First successful kidney transplant
1966	First successful kidney-pancreas transplant
1967	First successful liver transplant
1968	First isolated pancreas transplant
1968	First successful heart transplant
1981	First successful heart-lung transplant
1983	Cyclosporine receives FDA approval
1983	First successful single lung transplant
1986	First successful double lung transplant
1989	First successful living-related liver transplant
1990	First successful living-related lung transplant

Source: Adapted from [www.optn.org](http://www.optn.org)

Organ procurement and preservation, tissue matching, and immunosuppression are the principal ingredients for successful solid organ transplantation. The technical aspects of the organ procurement operation allow multiple teams to work together to procure all useful organs from a single donor. Modern preservation fluids increase the length of cold ischemic time (time outside the donor's body for transport to the recipient)

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that an explanted organ can tolerate. Preservation fluids are ice-cold solutions that include electrolytes, antioxidants, hydrogen ion buffers and sugars.<sup>5</sup> Appropriate tissue matching depends on blood group matching (e.g. blood type A, B, or O) for all organs. Kidneys are also tissue-matched based on HLA (human lymphocyte antigen) type and lymphocyte (white blood cell) cross-matching tests.<sup>2</sup> Cross-matching mixes the recipient's serum with the donor's lymphocytes to test immunologic compatibility. Today's immunosuppressive regimens typically include three drugs: a glucocorticoid such as prednisone, an antimetabolite such as azathioprine or mycophenolate, and a calcineurin inhibitor such as cyclosporine or tacrolimus.

Transplant centers must have specially-trained transplant surgeons and transplant physicians with extensive qualifications. The OPTN also monitors survival rates at each transplant center, and those who fall below a given threshold level are reviewed.<sup>1,6</sup>

**Table 2.**  
**ABO Blood Type Compatibility**

Transplant	Acceptability
O to non-O	Safe
Rh- to Rh+	Safe
Rh+ to Rh-	Relatively safe
A to non-A	Dangerous
B to non-B	Dangerous
AB to non-AB	Dangerous

*Source: Adapted from Starzl, World J Surg 2000*

### United Network for Organ Sharing

The United Network for Organ Sharing, or UNOS, is a private, nonprofit organization that contracts with the federal government to administer the Organ Procurement and Transplantation Network. The centralized computer network at the UNOS Organ Center links OPO's and transplant centers. All patients on the transplant waiting list are registered with UNOS.<sup>1</sup> On average, UNOS receives 350 calls per day from OPO's.<sup>7</sup>

## STRUCTURE OF THE NATIONAL ORGAN PROCUREMENT AND TRANSPLANTATION SYSTEM

### Current Scope of Solid Organ Transplantation

Solid organs that are transplanted in the US include kidney, liver, heart, lung, pancreas, and small intestine. There is an allocation policy specific to each donor organ. Potential recipients are listed based on objective criteria that include blood type, tissue type, size of organ needed, medical urgency of the recipient, time on the waiting list and distance between the donor and recipient.<sup>1</sup> The process of identifying potential organ donors, placing their organs with appropriate recipients and coordinating the transplant operations is a complicated process involving many organizations working together.

### Organ Procurement and Transplantation Network

The Organ Procurement and Transplantation Network (OPTN) was created by the National Organ Transplant Act of 1984. The OPTN facilitates organ matching. It develops policies and procedures for organ recovery, allocation, and transportation. It also collects, manages and distributes data about organ transplantation. Finally, it provides both professional and public education about organ donation and transplantation. In order to receive Medicare funds, all transplant centers and OPO's must be members of the OPTN. The OPTN has a variety of other members, including independent histocompatibility laboratories, professional organizations, patient advocacy organizations and members of the general public.<sup>1</sup>

All organ transplant programs in the US are members of the OPTN. Members of the OPTN are certified as compliant with the rules that are in place to ensure the public safety, and highest level of care for organ donors and recipients. The OPTN membership bylaws explicitly outline the requirements for a transplant center. Program staffing requirements include a medical director, clinical transplant coordinator (usually a nurse), financial coordinator, and staff to provide social support.

### Regions

The US is divided into 11 regions. North Carolina is in Region 11, along with Kentucky, South Carolina, Tennessee and Virginia.

### Organ Procurement Organizations

Organ Procurement Organizations (OPO's) are private, nonprofit organizations that are members of the OPTN and certified by the Health Resources and Services Administration. Each OPO has its own board of directors and medical director, usually a transplant surgeon or physician. Procurement coordinators work for the OPO. They are highly trained professionals, often nurses, who coordinate each step of the transplant process.

The OPO's are involved in every step of a deceased-donor (cadaveric) organ transplant, from evaluating potential donors, to obtaining consent from the donor's family, placing the organs and traveling with the procurement team to obtain the organs. The OPO's other primary role is to promote organ donation within the community. They engage in public and professional education efforts in the community and in the hospitals they serve.

The OPO's have defined service areas designed to assure maximum effectiveness in organ procurement and equitable distribution of organs. There are currently 59 OPO's. The OPO's serve all the hospitals in their designated geographical areas. North Carolina is served by two OPO's. Carolina Donor Services serves 79 counties in North Carolina, and Danville, Virginia. LifeShare Of the Carolinas serves 23 counties in south-western North Carolina and York County, South Carolina.<sup>1,8,9</sup>

## LEGISLATIVE HISTORY

### Uniform Anatomical Gift Act

The Uniform Anatomical Gift Act (UAGA), promulgated in 1968, established the legal framework for organ donation. A version of the UAGA was adopted in each state and the District of Columbia. The scope of the act is limited to organ procure-

ment. It requires hospitals to establish affiliations with regional organ procurement organizations to coordinate the procurement of organs. The UAGA holds that all citizens aged 18 and over have the right to decide for themselves if they choose to be organ donors. It established the Uniform Organ Donor Card as a legal document. The law does not require the consent of next of kin for the procurement of organs from a brain dead patient with written documentation of intention to donate, such as a signed donor card or driver's license.<sup>10</sup> However, in practice, the OPOs require consent from the patient's family prior to organ donation. The law also establishes the order of priority in obtaining consent: spouse; adult son or daughter; parent; adult sibling; grandparent; and legal guardian.<sup>1</sup>

### **National Organ Transplantation Act**

In 1984 Congress passed the National Organ Transplant Act (NOTA). This act established the Organ Procurement and Transplantation Network (OPTN). The OPTN has two primary goals: to increase the effectiveness and efficiency of organ sharing and equity in the national system of organ allocation; and, to increase the supply of donated organs available for transplantation.<sup>1</sup> NOTA also expressly forbids the buying or selling of organs.

The US Department of Health and Human Services, through the Health Resources and Services Administration, contracts with a private, nonprofit organization to operate the OPTN. Since 1986, the United Network for Organ Sharing (UNOS), based in Richmond, Virginia, has administered the OPTN. UNOS operates the national wait list.

### **Omnibus Budget Reconciliation Act**

A 1986 amendment to the Social Security Act requires hospitals that receive Medicare or Medicaid funding to have written protocols for the identification of potential organ donors and notification of the local OPO. It also requires hospitals to make families aware of the option to donate or to decline to donate. Transplant hospitals are required to be members of the OPTN and abide by the Network's rules. Finally, it added limited coverage for immunosuppressive drugs for Medicare patients.<sup>1,8</sup>

### **Medicare ESRD Program**

Prior to the 1960's, End-Stage Renal Disease (ESRD) was a certain death sentence. In that decade, two powerful treatment options emerged: dialysis and transplantation. Congress created the ESRD Program in 1972. It covers most medical care for almost all ESRD patients. When the program was created, there were 10,000 eligible patients. By 2000, there were over 323,000 patients receiving treatment for ESRD. This number is expected to continue to grow rapidly. Current estimates are that in 2010, there will be 651,000 ESRD patients.<sup>11</sup> For those patients for whom it is medically appropriate, transplantation is preferable to dialysis. It leads to longer life expectancy, better quality of life, and lower costs than dialysis.<sup>12</sup>

### **Other Legislation**

In 1998, the US Department of Health and Human

Services made changes to the Conditions of Participation for hospitals that receive Medicare and/or Medicaid funding in an attempt to increase organ donation. Hospitals are required to notify the local OPO of all deaths or imminent deaths. The individual who initiates family discussions about organ donation must be a representative of the local OPO or someone who has been specially trained to request organ donation.<sup>8</sup> This is not typically a physician. Decoupling the discussions about brain death and organ donation is thought to increase the consent rate. Requests for organ donation that come from someone specially trained, such as an OPO representative, are also thought to increase consent rates.

This year the Organ Donation and Recovery Improvement Act was introduced in the US Senate. If passed, it would fund a public education campaign and hospital organ donation coordination programs. It would also allow reimbursement to organ donor families for travel and subsistence expenses. However, the idea of providing reimbursement to donor families is controversial and in contradiction to the National Organ Transplantation Act.

### **North Carolina Legislation**

The "Gift of Life Act," passed in 1997, requires hospitals to notify the local OPO of all cardiac deaths or impending brain deaths of patients up to age 75. It also designates OPOs as responsible for evaluating all referrals for potential donation and informing families of the option to donate.

## **THE PROCESS OF ORGAN DONATION AND TRANSPLANTATION**

When a transplant center initially decides that a patient with end-stage disease is appropriate for transplant, the potential organ recipient's name and medical information are entered into a computer database at the UNOS Organ Center. At this point, the patient has been "listed" for transplant. The potential transplant recipient then waits on the list until a donor organ becomes available. As the waiting lists grow longer, so do the waiting times. Almost half of all transplant candidates in North Carolina who are waiting for kidney or heart transplants have been waiting more than two years. More than half of those waiting for liver, lung, and heart-lung transplants have been waiting more than two years.<sup>1</sup>

### **Brain Death**

The donor process begins when a local OPO is contacted by a hospital caring for a patient with impending brain death. The vast majority of organs procured from deceased donors come from donors who have sustained brain death under circumstances that allow their respiration and circulation to continue to be supported by artificial means. The acceptance of organ procurement for transplantation depends on understanding the concept of brain death. Under the Uniform Determination of Death Act,<sup>13</sup> drafted in 1980 and adopted by 43 states, death is defined as either irreversible cessation of circulation and respiration, or irreversible cessation of all brain and brainstem

function.<sup>8</sup> Prior to the declaration of brain death, several other diagnoses must be ruled out, including hypothermia, circulatory shock, drug intoxication, metabolic intoxication from kidney or liver failure, and the prolonged effects of neuromuscular blocking drugs.<sup>14</sup>

A physician must certify a patient as brain dead in order for that patient to be an organ donor. The criteria for diagnosing brain death vary from hospital to hospital, but they include some combination of physical exam and other tests. The usual tests include reflexes such as gag, cough and pupillary response to light. An apnea test is performed to determine that the patient cannot breathe without mechanical assistance. A cerebral blood flow test may also be performed to determine whether or not there is blood flowing to the brain.<sup>8</sup>

Brain death can be caused by any condition that interrupts oxygen delivery to the brain. Such conditions include trauma, stroke, intracranial bleed, drowning, carbon monoxide poisoning, drug overdose and others.<sup>8</sup> The most common causes of death for organ donors are head trauma, cerebrovascular accident (stroke), and anoxia (lack of oxygen supply to the brain).<sup>1</sup>

Potential organ donors undergo physiologic changes that require aggressive medical management prior to and after the declaration of brain death. Medical interventions are often required to maintain adequate intravascular volume and blood pressure; maintain body temperature; correct coagulopathy (bleeding disorders); avoid elevated intracranial pressures; and treat hormone imbalances such as diabetes insipidus. The most common complication, occurring in up to 91% of patients, is hypotension (low blood pressure) requiring invasive monitoring and/or support with vasopressors (medicines to increase blood pressure). Timely determination of brain death is important to protect the condition of the donor's organs. A rapid brain death determination protocol can reduce medical failures prior to organ donation and can increase consent rates for donation. It can also increase the number of organs procured per donor to a level well above the national average.<sup>14</sup>

### Organ Allocation and Procurement

After the declaration of brain death, the donor OPO performs a medical evaluation and contacts the patient's family to discuss organ donation. Once the family agrees to donation, the procurement coordinator from the OPO takes over medical management of the donor. At the same time, the coordinator contacts the UNOS Organ Center to begin the process of organ placement.

Each time a donor organ becomes available, the UNOS computer compares characteristics of the donor with each individual waiting for that type of organ. The computer then generates a list of potential organ recipients, the "match-run" list, ranked in order based on characteristics such as blood type, body size, medical urgency, waiting time and location. Factors such as race, religion, gender and financial status do not enter into the equation.<sup>8</sup>

The allocation policy is somewhat different for each organ. In general, organs first are offered to patients awaiting transplant within the OPO in which the organs were donated. They are then offered regionally and nationally. Some organs are offered based on recipient distance (in air miles) from the donor hospital. This policy decreases organ preservation time, thus improving organ quality and recipient outcomes. It also reduces costs to the transplant patient and provides more equitable geographic access to transplantation.<sup>1</sup>

Once the match list is available, the procurement coordinator contacts the transplant team caring for the patient at the top of the list. The transplant surgeon determines whether or not the organ being offered is appropriate for that patient. If so, the organ procurement and transplant operations are scheduled. If not, the procurement coordinator moves to the next patient on the list, calls that patient's transplant team and offers the organ. This process continues until all the available organs from a given donor are placed with transplant recipients.<sup>8</sup>

The accepting transplant teams travel to the donor's hospital, where the procurement operation takes place. Transplant teams from widely separated centers can share organs from a common donor. Surgical techniques allow any combination of organs to be removed. Preserving solid organs depends on rapid intravascular cooling done in situ (in the body), followed by removal of the organs, storage of the organs in ice-cold preservation fluid and rapid transport to the recipients' hospitals.<sup>2</sup> The cold ischemic time is the length of time the organs are on ice, without blood flow. The maximum cold ischemic time limits the amount of time that can pass between organ recovery and the organ transplant.

UNOS functions as the middle-man between the donor OPO and the receiving OPO. The donor OPO receives the match-run list, but does not have access to information about other patients who are listed for transplant. The receiving OPO

can access wait lists for the hospitals that they serve, but cannot see the match-run list. This system was put into place to prevent individual transplant centers from manipulating the donor system.<sup>7</sup>

From the time consent for organ donation is obtained, all costs incurred in the donation process are billed to the OPO.

**Table 3.**  
**Maximum Cold Ischemic Time**

Organ	Preservation Time
Heart and Lungs	4-6 hours
Liver	12-24 hours
Kidney	48-72 hours
Pancreas	12-24 hours
Small Intestine	12 hours

*Source: Adapted from [www.lifesharecarolinas.org](http://www.lifesharecarolinas.org) and Punch, JD.*

### INCREASING THE NUMBER OF ORGANS FOR TRANSPLANT

One of the biggest challenges facing the transplant community at this time is a stagnant number of deceased donors in the face of an ever-increasing need for donor organs.

A number of options for expanding the pool of available organs exist. Increasing the rate of consent by families of potential

donors could expand the pool of deceased donors. Policy changes in consent for organ procurement may increase available organs. Increased use of living donors for kidney, liver and lung transplants is an attractive option, although this practice is debated as it exposes otherwise healthy people to risk of morbidity and mortality. Compensation to donor families, once taboo, is now being debated. Technical changes include

that efforts to increase donation should be concentrated at these larger hospitals.

In March of 2002, Carolina Donor Services surveyed residents in the counties that it serves in an attempt to better understand residents' attitudes and awareness concerning organ donation. They found that families, friends, medical providers and clergy were most likely to influence the intention to be an organ donor. While 97% agreed that "organ donors provide the gift of life" and 93% agreed that "people are dying because there aren't enough organs available," only 56% intend to donate their organs when they die. As compared to whites, African Americans are more likely to be unsure about donating (45% vs. 22%) and are more likely to be opposed to organ donation (21% vs. 12%).<sup>8</sup>

The main factors that motivate North Carolinians to be organ donors are a sense of altruism and practicality. The chance to help someone else or save a life motivates 65% of donors, while 29% say that they intend to be a donor because "I don't need organs when I die." The most commonly reported reason people decide not to be donors is that they think they are too old or unhealthy to donate (26%). Other common reasons are that they never thought about it (19%) or that they are uncomfortable with the idea (15%).<sup>8</sup> Carolina Donor Services used the results of this survey to plan educational interventions to increase organ donation.

Carolina Donor Services also found that only 63% of people know that major religious groups support organ donation. In fact, all major religions in the US support organ donation and transplantation.<sup>8</sup>

### Consent Procedures

The current donor system depends on a patchwork of organ donor cards, driver's licenses, advanced directives, and durable power of attorney for healthcare statements as vehicles for citizens to state their wishes. This is an "opt-in" system; it depends on routine referral of all potentially medically eligible donors to the local organ procurement organization (OPO). Trained professionals from the OPO then initiate contact with the patient's family regarding potential donation. The OPO attempts to ascertain the patient's wishes from documentation and discussions with the family. Even if the potential donor indicated his or her wish to donate, consent is still obtained from the family.

Eighty two percent of Americans believe that the individual, rather than his/her family, should make the decision regarding organ donation. Unfortunately, the same study found that 58% of Americans were unsure about their plans to donate or not to donate after death (30% intended to donate and 12% intended not to donate) and only 38% had discussed their plans with their families.<sup>16</sup>

These numbers are important because, in practice, the OPOs place tremendous weight on the family's wishes when obtaining consent for organ donation. A survey of all OPO's

**Table 4.**  
**Patient Waiting List for Organ Transplants as of January 21, 2004**

Organ Needed	Patients in US	Patients in NC
Kidney	56,519	1,945
Liver	17,283	687
Lung	3,915	220
Heart	3,542	73
Kidney-Pancreas	2,417	96
Pancreas	1,527	15
Heart-Lung	189	17
Intestine	171	1
<b>Total</b>	<b>83,570</b>	<b>2,965</b>

Source: [www.optn.org](http://www.optn.org)

expanded donor criteria and non-heartbeating donors. Biological research aimed at xenotransplantation (animal-to-human transplantation) is ongoing, but this is not currently a viable solution.

### Missed Donors

Over the past 10 years, between five and six thousand organs were procured from deceased donors each year. However, it has been unclear how many potential donors are available but do not donate. Recently, the Association of Organ Procurement Organizations published a large study<sup>15</sup> that indicates 54% of those families asked to donate agreed to do so. Only 42% of potential donors actually became donors. From 1997-1999, it is estimated that about 13,500 potential donors were available each year; this appears to be a stable pool of potential donors. There were about 5,500 actual donors each year. The population base for this study was large, and it probably accurately represents what is happening nationwide. However, the OPOs in the Southeastern United States did not contribute any data to this study.

Increasing the consent rate among potential donor families is one way to significantly increase the number of organs available. In fact, if all potential donors became actual donors, there would be enough hearts and kidneys available to transplant each person added to the list in 2002.<sup>15</sup> This study offered important insight into how this goal might be accomplished. Families of brain dead patients were less likely to donate if the patient was older, non-white or died from a cause other than trauma. Moreover, 89% of potential donors and 91% of actual donors were cared for at hospitals with 150 or more beds; 88% of potential donors who did not ultimately donate were cared for at these larger hospitals. That indicates

found that 48% rank impact on the deceased's family as the most important factor when obtaining consent, while only 12% rank the deceased patient's wishes as the most important factor.<sup>17</sup>

### Other Options for Consent

Some European countries approach consent for organ donation via an "opt-out" system. Citizens are presumed to consent to donation unless they explicitly state that they do not want to be donors. Spain, Austria, France, Portugal, and Belgium have presumed consent policies. The British Medical Association favors such a policy in the United Kingdom.

The Belgian system serves as an interesting example. It allows any citizen to register his objection to donation at the local town hall. A national database tracks those who have opted-out; less than two percent of Belgian citizens have done so. Doctors ask the patient's family to confirm the fact that the patient did not object, rather than asking the family to make the decision to consent to donation. The system also allows physicians to defer procurement for any valid reason. This system, enacted in 1986, led to an increase in the number of organ donors and an increase in the number of organs procured per donor.<sup>18</sup>

Mandated choice is a system that compels competent adults to decide whether or not they wish to be organ donors when they die. The decision could be required when obtaining a driver's license or filing a tax return. Under this system, each person must consider the issue and make a decision; the individual's decision is honored at the time of death.<sup>16</sup>

A Gallup poll conducted in 1993 provides the most recent evidence on public opinion regarding mandated choice. Thirty percent of those surveyed had signed organ donor cards. When asked if they would sign up to donate if mandated choice became law, 63% said yes.<sup>16</sup> Based on the results of this survey, mandated choice would increase the number of available organs. Given that 82% of people think that the individual rather than his family should make the decision about organ donation, and that under mandated choice the individual's decision would be binding, mandated choice could protect individual autonomy while also sparing the potential donor's family an important decision at a difficult time.

A more subtle finding in this study is that the more one thinks about organ donation, the more likely s/he is to donate. Of the 25% who previously gave organ donation serious thought, 76% decided to donate.<sup>16</sup> It appears that mandated choice could further increase organ donation simply by encouraging people to consider the issue on a regular basis. A recent online experiment supported this finding.<sup>19</sup>

The American Medical Association Council on Ethical and Judicial Affairs and the United Network for Organ Sharing both endorse mandated choice.

### Living Donors

One viable option for increasing the number of organ donors is to increase reliance on living donors. In 2001, for the first time ever, there were more living kidney donors than deceased kidney donors. That trend continues. In addition to kidneys, livers, lungs, small intestines and pancreases are available from living donors. Living donors may be related, unrelated loved ones, or strangers. They are usually aged 18-60, physically fit and in good health. They must have a blood type that is compatible with the recipient.<sup>1</sup>

Living donation is handled at the transplant center doing the transplant, rather than through OPOs and UNOS.<sup>1</sup> If the recipient has private health insurance, the costs of living donation are usually covered. Medicare covers the costs of living donation for donors whose recipient is covered under the End-Stage Renal Disease program.

Living donation is common for kidneys. Portions of liver and lung are transplanted with increasing frequency, while living donor pancreas and small intestine transplants remain rare. Use of organs from living donors can be controversial because the process exposes an otherwise healthy person to the risks of a donor operation. For this reason, the evaluation and consent of living donors requires special care. In particular, the transplant center must ensure that the donor's decision is voluntary. The transplant center must disclose all potential risks and benefits to the donor and recipient, including information on medical uncertainties and any alternative treatments for the recipient.<sup>20</sup>

*Some European countries approach consent for organ donation via an "opt-out" system. Citizens are presumed to consent to donation unless they explicitly state that they do not want to be donors.*

Prior to donating an organ, a potential donor should undergo psychosocial evaluation by a mental health professional with special training in transplantation. This evaluator should not be involved in caring for the potential recipient. The goals of psychosocial evaluation are to evaluate social and emotional stability, establish competence to give informed consent, and to ensure that the decision to donate is made without coercion.<sup>20</sup> With these safeguards in place, living donation is a good way to increase the number of organs available for transplant.

The vast majority of experience with living donors is in kidney transplant. Kidneys transplanted from living donors have better outcomes than kidneys transplanted from deceased donors. The organs function better and longer. In fact, the half-life (the time until half of all organs stop functioning) is 21.6 years for organs from living donors, as compared to 13.8 years

for organs from deceased donors. Kidney donation has low rates of complications for the donor, with perioperative morbidity of 1-1.3% and mortality of 0-0.03%.<sup>21</sup>

The UNOS Board of Directors recently endorsed new initiatives to increase donation by living donors. These include coverage under the Family Medical Leave Act and a proposal to reimburse living donors for wages lost during the recovery period following transplantation.<sup>1</sup>

### Compensation for Donors

The National Organ Transplant Act prohibits the sale of organs. For many years, the transplant community was uniformly opposed to the idea of compensating donors. Organ donation is seen as dependent on intangible benefits to the donor's family—a way to create some good from a personal tragedy, gain meaning from death, contribute to the good of society and honor a loved one's wishes.<sup>22</sup>

In recent years there has been a shift in perspective. The possibility of compensating organ donors is now frequently debated by medical professionals and ethicists. A UNOS telephone survey performed in 1990 found that the public was almost evenly split on whether or not organ donors should be compensated in some form. The state of Pennsylvania recently enacted a program whereby \$300 is paid directly to the funeral home to help defray the costs to families of organ donors.<sup>23</sup> Perhaps efforts to increase the tangible benefits of organ donation could increase the rate of donation.

### Other Options for Increasing Organ Supply

Expanded donor criteria refers to the use of organs from donors who previously have been considered medically unacceptable. Expanded criteria include using donors at extremes of age or those with underlying medical illnesses that make them suboptimal donors. It may also include using organs from donors with active infection or colonization, those who have been poisoned, or those who were transplant recipients prior to death. Organs from donors with hepatitis B or C infection can be transplanted into recipients with those infections.<sup>24</sup> As experience with donors previously thought to be unacceptable grows, what constitutes an "acceptable" donor continues to change.

Some technical factors can also contribute to increasing the number of organs available. Kidneys from donors less than five years of age have been considered unusable. However, if they are transplanted *en bloc*, giving two small kidneys to the recipient, outcomes are good. Sometimes a donor liver can be split, thus providing livers for two recipients from one donor organ.<sup>21</sup> Organs,

especially kidneys, can be procured from non-heartbeating donors. This is also known as controlled donation after cardiac death. It is a more complicated procedure and outcomes are not as good as when organs are obtained from brain dead donors.<sup>24</sup>

Xenotransplantation, the use of tissue from an animal donor, may one day provide a solution to the chronic shortage of donor organs. It is not yet a viable option because the human immune response to the animal organ cannot be well-controlled. Also, the potential risks of infectious disease transmission from the animal to the human are poorly understood. In the past, nonhuman primates have been used experimentally to provide organs. In the future, pigs seem most likely to supply organs for transplant because there are fewer ethical concerns than with primates and because they breed quickly. Laboratory research continues and clinical trials may begin soon.<sup>25</sup>

### Conclusions

Efforts to increase organ donation continue. Carolina Donor Services recently partnered with UNC Hospitals and Pitt County Memorial Hospital to engage in an initiative by the US Department of Health and Human Services called the "Organ Donation Breakthrough Collaborative." The collaborative will apply best practices of organ donation processes to attempt to increase donation rates to 75%.<sup>8</sup>

Many people are hard at work developing ways to increase the number of organs available for transplantation. For the time being, education and policy efforts aimed at increasing the consent rate for deceased donation appear to offer the most hope. Consent to donate organs usually occurs in concert with an unexpected, tragic death. Organ donor cards and driver's license notations are an important part of organ donation policy. However, family discussions about organ donation prior to an unexpected tragedy are the best way to spare the family a difficult decision and insure that the patient's wishes are respected.

Transplantation is the best hope for many people with end-stage organ disease. And it works. Each year since 1988, the number of patients surviving more than one year after transplant has increased. The future of organ transplantation, and the future of those waiting for transplants, is limited only by a shortage of donor organs.

*Acknowledgement: I'd like to thank Dr. Michael Mill for his review of this article.*

**Table 5.**  
**Solid Organ Transplants in 2002**

	Patients in US	Patients in NC
Patients who received transplants in 2002	24,897	701
Patients who died while waiting in 2002	6,391	210

*Source: Adapted from [www.carolinadonorservices.org](http://www.carolinadonorservices.org)*

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## WEB RESOURCES

- [www.optn.org](http://www.optn.org)
- [www.unos.org](http://www.unos.org)
- [www.carolinadonorservices.org](http://www.carolinadonorservices.org)
- [www.lifesharecarolinas.org](http://www.lifesharecarolinas.org)
- [www.organdonor.gov](http://www.organdonor.gov)
- [www.shareyourlife.org](http://www.shareyourlife.org)

I, \_\_\_\_\_, have spoken to my family about organ and tissue donation. I wish to donate.  
 Any needed organs and tissue  Only the following organs and tissue

\_\_\_\_\_

The following people have witnessed my commitment to be a donor.

Donor Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Public Information/Referral  
800-200-2672 • 800-252-2672

  
**Carolina Donor Services**

DONOR CARD

Fill out this donor card in the presence of two witnesses, preferably your next of kin, and sign your name in the space provided.

## Increasing Donation: Key Factors to Save More Lives

Lloyd Jordan

In my role as Executive Director of Carolina Donor Services (CDS), the non-profit, federally-designated organ and tissue recovery agency for 78 counties of North Carolina and one Virginia county, I am blessed to know many people who have received the “gift of life” through organ and tissue donation. In fact, there are more than 200,000 Americans living with transplants, people who are alive today thanks to the donor who saved their life.

As glad as I am to know these remarkable recipients, it is even more rewarding to me when I meet donor families, those who have made the selfless decision to donate their loved one’s organs or tissues in order to save another person’s life. The enormous courage, faith and generosity that these people share remind me daily of why I have remained in the field of donation for almost 20 years.

Over the years, I have witnessed remarkable advances in the processes of organ and tissue recovery and transplantation. Advances in medicine, surgery and immunosuppressive drug development have provided us with the ability to help more people than ever before and yet we are limited by one very critical factor—the relatively few number of donors.

### Desperate need for more donors

Sadly, the number of people who need transplants continues to grow steadily each year, reaching 83,000 people nationwide and almost 3,000 here in our state. At the same time, the number of deceased donors has remained almost the same, rising just three percent last year to 6,185 donors. This gap means that almost 17 Americans die each day while waiting for an organ transplant; four North Carolinians die each week before they get the heart, lung, liver, kidney, pancreas or intestine transplant that they need to survive.

Many of these lives could be saved if only more people chose to donate. Nationally, about half of families choose to donate their loved one’s organs when faced with that decision, although the

current consent rate is slightly higher in the area served by Carolina Donor Services. Research shows that the main reasons people chose not to donate are due to a general lack of understanding about donation, as well as misconceptions, such as thinking they are too old to donate (in reality, there is no age restriction for organ donation), believing their religion doesn’t support donation (all major religions do), or an unfounded, but prevalent fear that doctors won’t try to save their lives if they are known donors.

### Strategies to increase the number of people willing to donate

Much of the misinformation and myths that exist can be addressed through public education, which is why our organization devotes so much time and energy to community education and awareness programs in high schools, colleges, churches/faith communities, workplaces, Division of Motor Vehicles offices, the media, and other places where people get information. But, much more needs to be done.

One development that is helping to address the shortage of donors is living donation. The number of living donors—people who give one of their kidneys, or a part of their liver or lung while they’re still alive—has grown significantly, to 6,607 people in 2002. While that increase has certainly had a very positive impact, each living donor can usually save the life of one person, while a deceased donor can potentially save up to eight lives through organ donation and enhance the lives of 50 people through tissue donation. So, ways to increase the number of deceased donors must also be explored.

A number of programs are currently being considered and studied to see if they will impact donation rates in our country. Donor registries, financial incentives and presumed consent are among some of the most widely-discussed and debated issues right now. I should also point out that xenotransplantation (animal-to-human transplant) research, tissue engineering and artificial organ research may also play a role in addressing the shortage of organs,

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**Lloyd Jordan** is the executive director for Carolina Donor Services in Greenville, NC. Last year, Mr. Jordan served as President of the Association of Organ Procurement Organizations (AOPO), the organization that represents the nation’s 59 organ procurement organizations. He is currently Past President of AOPO, and continues to serve as a member of its Executive Committee. He is also a member of the United Network of Organ Sharing (UNOS) Board of Directors. He is recognized as a national leader in the OPO community. He can be reached at [ljordan@carolinadonorservices.org](mailto:ljordan@carolinadonorservices.org) or at 205 Plaza Drive, Suite D, Greenville, NC 27858. Telephone: 252-757-0708.

but these are developing technologies, rather than efforts to increase donation rates. Since our organization is committed to saving more lives by increasing donation, I will focus on efforts in this area.

## *there is no age restriction for organ donation*

group, among those who had to opt-out from being a donor. These findings seem to support the need for further study about the impact of presumed consent on donation rates, as well as research regarding how receptive the American public would be to such a change in our current system.

**Donor Registry.** Thirty-three states now have active donor registries, where a person can sign up to be an organ donor, either on line or via mail. In these states, an individual's donor information is maintained in a secure database that can only be accessed by certain healthcare professionals, including recovery coordinators. Organ, tissue and eye recovery personnel can access the registry information around-the-clock to determine if a person wanted to be a donor, enhancing their ability to ensure a person's wishes are followed. Studies are now underway to determine the effect that registries have on consent and donation rates.

Here in North Carolina, we do not yet have a donor registry, although we are working diligently to change that. State Senator Steve Metcalf (D-Buncombe) has introduced legislation (SB 852) that would allow the state's two organ procurement organizations and eye bank to access the donor records maintained by the Division of Motor Vehicles. The bill passed the Senate and is headed to the House for consideration in May 2004.

**Financial incentives.** Financial incentives for donation are also being considered as a possible way to encourage more deceased donors. Legislation has been introduced in Congress that would authorize the federal government to fund demonstration projects on offering incentives in return for donation. (Right now, the practice is illegal since the National Transplant Act of 1984 outlawed the sale of human organs and tissues). Different possible financial incentives are being discussed, including covering funeral expenses, providing a tax credit to the donor's estate, or a direct payment to the family. While the American Medical Association supports these studies, other groups are opposed due to the ethical dilemmas raised by any form of payment for organs.

**Presumed consent.** Presumed consent, or an "opt-out" system of consent, has also received a lot of attention lately as another possible solution to the donor shortage. In several European countries, including Austria, Belgium, France, Hungary, Poland, Portugal and Sweden, it is assumed that everyone is willing to be a donor, with family consent after death, unless there is written documentation otherwise. The donation rates in these countries are slightly higher than in countries with "opt-in" systems similar to our own.

An interesting study was done recently at Columbia University that seems to support the theory that a "presumed consent" system could potentially boost our nation's donation rates.<sup>1</sup> Three groups of people were involved in this study. The first group was told that they just moved to a new state where it was assumed they would be organ donors, but they were given the choice to confirm or change that status. Another group was told that they would not be considered donors unless they specified they wanted to be. The third group was told simply to choose whether or not they wanted to become a donor. The highest donation rate (82%) was found in the first

group, among those who had to opt-out from being a donor. These findings seem to support the need for further study about the impact of presumed consent on donation rates, as well as research regarding how receptive the American public would be to such a change in our current system.

**Improving hospital systems and public awareness.** Ultimately, the key to increasing donation will likely be a combination of these efforts, along with a continued focus on improving systems that support donation in the hospital setting, as well as an ongoing commitment to public education and awareness activities. At CDS, we have recently begun two new programs that hold promise for the future. One, called the "Organ Donation Breakthrough Collaborative," is an effort being coordinated by the federal US Department of Health and Human Services. The other, called "A License to Give," is a new high school donation curriculum being offered to educators throughout our state.

The collaborative is intended to show that a dramatic increase in the number of lives saved through transplantation is possible. Nationwide, 105 hospitals and 46 organ procurement organizations are participating, including UNC Hospitals in Chapel Hill and Pitt County Memorial Hospital in Greenville. Multidisciplinary teams from each of these hospitals and Carolina Donor Services are working together to learn, adapt, redesign, implement, track and refine their organ donation processes to increase the donation rate to 75% over an eight-month period. If we're successful, we will be able to replicate the "best practices" established through this study in hospitals throughout the rest of the state and country.

The "License to Give" donation education kit, which was named by a ninth grade English class in Elkin, NC, was developed to assist teachers in introducing the topic of donation in a sensitive, engaging way. The free kits, which are available from Carolina Donor Services, as well as other organ/tissue/eye recovery agencies in the state, are just one way that we hope to reach today's youth and tomorrow's generations with life-saving donation information.

## **Conclusion**

Although we have much more work before us, I am encouraged by the developments in organ/tissue donation and transplantation over the last 20 years. I look ahead with hope and optimism that someday our cumulative efforts will result in the end of the national organ transplant waiting list and thousands more lives saved each year, thanks to those who make the decision to donate.

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## The Gift Relationship in Process: From Donor to Recipient

*Julie Landon, RN, CPTC*

The diary below is a day and a half in my life as an organ donation coordinator at Carolina Donor Services. A nurse for almost 17 years, I have been an organ donation coordinator since June 1998. I recount my experiences with a recent organ donor with the hope that it will help others understand the complex emotional and clinical processes involved with donation.

### Sunday

**0730:** I receive a referral from a local hospital about a 22-year-old female, J., who was admitted with an intracranial hemorrhage secondary to an aneurysm.

**0815:** I arrive at the hospital and talk with the staff and the physician concerning the history surrounding her admission. I obtain the patient's course of treatment since admission and inquired about the family and how they are coping. The staff informs me that a Cerebral Blood Flow study has been ordered and is scheduled to be performed at 10:00 a.m.

**0830-1000:** I review the patient's medical chart and recorded medications, blood pressures, heart rate, lab values, any blood products and I.V. fluids given and urine output. I also record any surgical procedures preformed. Then, I call the CDS Medical Director and obtain authorization to follow this patient as a potential organ donor.

**1000-1200:** The brain death exam has been completed (most hospitals use both clinical and apnea tests). The clinical exam consists of testing for the absence of pupillary response; no blink response when the eye is touched (corneal reflex), no cough or gag reflex and no response to painful stimulus. The apnea test confirms absent respirations, which is a mandatory finding to support brain death. The Cerebral Blood Flow study was used as a confirmatory test for brain death.

**1200-1400:** With the brain death exam complete, the physician notifies her husband and parents and explains that J. has died. He answers their questions and tells them the time of her death. The physician informs the family that there is someone available to talk with them about decisions they will have to make. *Note: Legally and medically, brain death and cardiac death are the same as far as pronouncement of death.*

**1400-1500:** The family has informed the nurse they are

ready to speak with me. I find a quiet, private room where I can talk with the family about the opportunity to donate J.'s organs. I answer their questions, which include the steps in the recovery procedure, how long it will take, and whether they can still have an open casket funeral for her. After answering their questions, the family agrees to donation. J.'s husband, her parents, and her husband's parents are there for the conversation. I spend time talking with the family about J. They share with me that she had just been married for one year, that she has a deep religious commitment and that she was always helping other people. J.'s family also shares that she loved the outdoors. While talking with her family, I found it very interesting that they had had a conversation and knew that her wishes were to be an organ donor. The family completed the consent form that would allow for the donation of J.'s heart, lungs, liver, pancreas and kidneys. The family chose not to consent to tissue (e.g. bone, skin) and eye/cornea donation.

**1500-1600:** Family and friends gather at J.'s bedside to say their goodbyes.

**1600-1800:** I call the Medical Examiner to see if there will be any restrictions for donation. Depending on the cause of death, the M.E. can restrict certain or all organs for donation if s/he feels it will interfere with an investigation of the circumstances behind the death. In this case, no restrictions have been set, so the donation can move forward. I send blood for serologies, tissue typing (used for placing the kidneys and the pancreas), and values on patient's current organ function. I also begin initiation of standard orders to maintain the patient's organ functions.

**1800-2200:** I evaluate lab results and make adjustments to I.V. fluids and the ventilator to optimize organ function. Then I call the United Network for Organ Sharing (UNOS) and give them the information on the patient including the patient's height, weight, blood group, age, sex and race. UNOS has all the potential organ recipients listed for the entire country. They will then run a list of recipients that are the same blood group as the patient and close to her height and weight. They will be listed in priority order according to UNOS allocation policies, which vary by organ, with emphasis on placement with local recipients. All of the consults for cardiac and pulmonary function are completed. Next, I start placing organs according to the UNOS list.

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**2200-2400:** The serology and tissue typing results are reported. With these results, I place all the organs for transplantation during this time except the heart because of J.'s size; she was not a match for recipients at our local transplant centers.

## Monday

**2400-0200:** I place both kidneys with UNOS for perfect matches (a perfect match is based on specific DNA tissue typing). The lungs, liver, and the pancreas are placed for recipients listed in North Carolina. I continue to try to place the heart. I call the operating room (OR) to inform them that we would like to go to the operating room around 0400 depending on who would accept the heart and how far they would be coming to recover. *Note: The coordinator is responsible for arranging pick-up and transport of the arriving recovery/transplant teams.*

**0200-0300:** I place the heart with a hospital in New York. The recipient is a 50-year-old male who was farther down on the list for transplant, but whose size most closely matches the donor's. I would imagine he is very excited. The heart team states that they can arrange a flight and will land at the airport at approximately 0400. I call the OR and arrange for a room for 0400. I call a local ambulance service to be waiting at the airport for the heart team from New York to land and bring them to the hospital. Then I call one of our CDS preservation coordinators responsible for flushing the organs during the case with the time he will need to be at the hospital.

**0300-0500:** UNOS calls me back to say the kidneys are accepted for two patients in New York pending the anatomy. I continue with donor management, making changes in I.V. fluids to make sure the organs continue to function optimally. I also find time to work on my paperwork and make copies of the chart, which include an official declaration of time of death, copy of the consent form for donation, and blood type information.

**0400-0500:** The local transplant teams arrive. We take the patient to the operating room. The heart transplant team from New York arrives. Everyone in the operating room introduces himself or herself to each other.

**0425-1030:** An incision is made from the top of the sternum to 2-3 inches below the umbilicus. The thoracic surgeons work in the chest cavity and visualize the heart and lungs. This takes 20-30 minutes, after which they will leave the operating room to find a place to rest. The abdominal surgeon will take from 2-3 hours to reach the point of being prepared to recover the organs. If the pancreas is being recovered, it will add 1-2 hrs to the surgical process. Once the abdominal surgeon is ready, the thoracic surgeons will return to the table. The coordinator will then ask the anesthesiologist to draw 120-200cc's of blood from the patient, which will be used by the transplant centers to test with their recipient's blood to make sure there will be no adverse reactions. After the blood is drawn, 30,000 to 40,000 units of heparin are given to thin the blood. Next, cannulas are inserted in the aorta above the heart, the pulmonary arteries, the descending aorta below the kidneys and the portal vein below the liver. These cannulas are then connected to cold bags of preservative solution called "UW." The circulation is then clamped off just above the heart and below the kidneys. The flush solution is then started so

that all the organs that are to be transplanted are cleared of blood and replaced with the cold preservative. Once the flush is complete which takes 15-30 minutes the heart is then removed. The heart takes approximately 5-10 minutes to remove from the body. The heart should be transplanted within 4 hours after being recovered or there may be irreversible cell and organ damage, which is why most out-of-state heart recovery teams will use jet service to reach their destinations.

The lungs are removed next, which again takes 5-10 minutes. Lungs can remain out of the body for approximately 4-6 hours before possible organ damage develops. The thoracic teams will then place the organs in sterile bags surrounded by sterile ice and "UW."

The abdominal surgeon will take another 2-3 hours to recover the liver, pancreas and kidneys. These organs will also be placed in sterile bags, solution and ice. The surgical teams will take the recovered organs back with them to be transplanted. The kidneys that were accepted by New York will have transportation arranged by UNOS. Usually kidneys are transported by commercial airlines. The kidney can remain on ice for 24 hours before there is concern of damage to organ function. The liver should be transplanted within 8-12 hours and the pancreas within 12-16 hours.

**1030-1100:** The incision is sutured closed; the body is cleaned then taken to the hospital morgue. I call the family to tell them how the recovery went, since that is what they wanted. I also notify the nursing supervisor that the organ recovery is complete. Organ donation will not affect the family's decision to have an open casket or other funeral arrangements. *Note: If the family had consented to eye and tissue donation, this recovery would occur after the organ donation is complete. Tissue donation usually takes from 2-4 hours and eye donation typically takes 30-45 minutes. If the family is going to have an open casket funeral, some types of bone will not be removed. Eye donation does not affect having an open casket funeral. If the patient is a Medical Examiner's case, the M.E. will view the body after all recovery is complete and they will then release the body to the funeral home.*

**1130-1230:** I thank the hospital staff in the OR and on the inpatient unit for their cooperation, answer their questions, and gather my belongings.

**1300:** I go to the office to complete paperwork. After the paperwork is completed, I go home to get some sleep.

**2-3 weeks after donation:** I write a letter to the family informing them of what organs were recovered and transplanted, giving them some general (non-identifying) information about the organ recipients (e.g. their families, work, hobbies) and how well they are doing. With this donor, the heart, lungs, liver, pancreas, and kidneys were transplanted and are functioning well. Hopefully, this information will provide the family with some comfort in their time of grief.

Carolina Donor Services will remain in contact with the donor family for two years or longer, if the family wants to continue a relationship with us. Carolina Donor Services' Life Anew Program invites families to annual Services of Remembrance to honor their loved ones who were donors. The Life Anew Program also facilitates correspondence—and sometimes even face-to-face meetings if both sides request it—between donor families and recipients.

# The Rapid Development of Solid Organ Transplantation in North Carolina

Michael R. Mill, MD

The first successful solid organ transplant between two individuals occurred in Boston in 1954 involving a living-related kidney transplant between twin brothers. The ensuing three decades were filled with dramatic stories of basic science and clinical research resulting in the successful performance of transplants, mostly with cadaver (brain dead) donors, involving the liver, pancreas, heart, heart-lung, and finally isolated lungs. Despite these successes, the overall survivals were largely measured in months and the procedures were only available in a select few transplant facilities. Clinical transplantation did not become a reliable therapy until the work to develop effective immunosuppressant medications resulted in the release of Cyclosporine in 1982. Thereafter, an explosion of activity occurred, with transplant centers opening at many major academic medical centers across the country. The clinical results achieved led transplantation to become standard therapy for end-organ disease of the organs noted above. At the present time, there are 260 transplant centers in the United States, which encompass a total of 835 individual transplant programs (Table 1).

## Transplantation in North Carolina

North Carolina followed the national trend with the development of transplantation programs at each of the academic medical centers. Duke University and the University of North Carolina at Chapel Hill led the way, establishing programs in all transplantable organs. Subsequently programs in selected solid organs have been developed at East Carolina University (kidney), Wake Forest University School of Medicine (kidney,

pancreas, heart) and the Carolinas Medical Center in Charlotte (kidney, heart, liver and pancreas).

At the University of North Carolina School of Medicine-UNC Hospitals, solid organ transplantation began with kidney transplantation in 1968. The heart transplantation program was founded in 1986, and was followed in rapid succession by lung transplantation in 1990, heart-lung transplantation in 1991, liver transplantation in 1991 and pancreas transplantation in 1994. In addition, UNC has further developed the expertise to perform pediatric transplantation in each of the individual organ programs (Table 2).

## The Effect of Transplantation on Medical Education

The rapid development of these programs has led to dramatic changes in the training of medical students, residents, and subspecialty fellows. Medical students now learn the basics of transplantation immunology

**Table 1.**  
Transplant Programs by Organ in the United States  
Medical Centers with Transplant Programs – 260

Organ	Number of Programs
Kidney	245
Liver	122
Pancreas	169
Heart	141
Heart-Lung	82
Lung	76
<b>Total</b>	<b>835</b>

Source: Modified from UNOS Data ([www.unos.org](http://www.unos.org)).

**Table 2.**  
Numbers of Procedures by Transplant Programs  
at UNC Hospitals, 1968 – present.

Organ	Adult	Pediatric
Kidney	941	114
Heart	196	31
Heart-lung	10	3
Lung	225	24
Liver	457	85
Pancreas	3	3
<b>Total</b>	<b>1,832</b>	<b>260</b>

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during their basic science years and are exposed to clinical transplantation during their clerkships. Residency training programs in internal medicine, pediatrics and general surgery, at least at academic centers with transplant programs, now include education and experience with transplantation. In internal medicine and pediatrics, residents (and attending physicians) must learn to care for patients with end-stage organ disease, including when to refer patients for transplantation, and the basic care of these patients post-transplantation when they present with transplant complications (infections, renal failure, and malignancies), in addition to standard health maintenance for the common side-effects of the medications, including hypertension, hypercholesterolemia and diabetes mellitus. General surgery residencies at academic medical centers often include separate clinical services for abdominal transplantation through which the residents rotate.

At UNC-CH, Abdominal Transplantation is now a separate Division within the Department of Surgery with a separate clinical service, a full complement of residents assigned to the service, a transplant fellow, and four attending surgeons, all of whom have completed Abdominal Transplantation Fellowships. General surgery residents gain experience in thoracic transplantation when they rotate on the cardiothoracic surgery service. Our cardiothoracic surgery residents assume responsibility for the heart, heart-lung and lung transplant patients as part of their routine duties. Our faculty at UNC includes three cardiothoracic surgeons who have completed Thoracic Transplantation Fellowships.

Many of the common fellowships now must include experience in transplantation. Adult and pediatric cardiology, gastroenterology, nephrology, infectious diseases, oncology and many other fellowship training programs must now educate their fellows in the care of their specialty-related transplants. In addition, there are now subspecialty fellowship programs specifically in heart failure and cardiac transplantation, hepatology and liver transplantation, and renal transplantation. In surgical training, fellowships have been established in abdominal transplantation, covering liver, kidney, pancreas and most recently intestinal transplantation, and in thoracic transplantation covering heart, heart-lung and lung transplantation. Indeed, medical societies have been founded which focus specifically on transplant medicine. The most prominent are the American Society of Transplant Physicians, the American Society of Transplant Surgeons and the International Society of Heart and Lung Transplantation. In all, an entire new body of knowledge has been added to medical education, largely within the past decade.

Just as medical schools and post-graduate training programs have had to assimilate this new body of knowledge, hospitals have had to evolve as well. All major transplant hospitals must have the appropriate staff and laboratories, as well as the availability of operating rooms, anesthesiologists and trained operating room personnel to perform the transplants and care for the patients afterward. The individual transplant programs are required by Medicare and many insurance programs to ensure thorough evaluation of potential candidates in order to select patients who will be most likely to benefit from the scarce

resource of donor organs and the expensive and complex therapy inherent in transplantation. These teams consist of social workers, psychologists, psychiatrists, nutritionists, physical therapists, financial counselors and transplant coordinators, in addition to the physicians and fellows involved in the program. The ability to perform routine laboratory examinations in addition to assays to measure levels of immunosuppressant medications, to perform microbiology cultures to rule out or identify infections and pathology services to interpret biopsy specimens to identify or rule out rejection, is mandatory. And of course, facilities and personnel must be available to perform the transplant procedures at any time, day or (usually) night. The nurses in the intensive care units and wards must develop the expertise to care for these patients. Many hospitals have developed separate transplant units to centralize and improve care for transplant recipients. In addition to academic medical centers, some larger private hospitals across the country, have developed transplantation programs. Overall, it is a huge investment in resources for hospitals to participate in solid organ transplantation.

## **Transplantation and the Non-Academic Community**

In addition to the tremendous investment by physicians and hospitals to develop transplant programs, physicians all across the state and nation have had to learn about transplantation to care for the ever increasing proportion of their patients who need or have undergone transplant procedures. Like their counterparts in the academic medical centers, they have had to learn when to appropriately refer patients, and perhaps more importantly how to care for their patients' routine and potentially catastrophic post-transplant medical problems, including when to refer the patients back to the transplant center. Graduate medical education programs have helped disseminate this information, though perhaps the greatest source of information comes from the transplant centers, and more specifically the transplant coordinators. These highly trained and skilled individuals, usually nurses, nurse practitioners or physician assistants, are the patient's and their local physicians' lifeline for both routine care and emergency intervention. Our coordinators, as well as those at all centers, work very hard to be effective liaisons between the transplant center and the patients, their local physicians, hospitals and pharmacies. In reality, the entire process could not function without these dedicated individuals.

## **Conclusion**

In the past two decades, solid organ transplantation has progressed from futuristic science fiction to life-saving procedures performed hundreds of times every day throughout the United States (over 23,000 transplants were performed in 2002). North Carolina has assumed its appropriate place in this scientific activity, providing its citizens and others from throughout the country, with these services. This activity has changed the practice and education of physicians, nurses and other medical personnel, and greatly impacted the hospital

services both in the community and the academic medical centers. Given the successes of transplantation, as well as new advances in immunosuppression, potential new sources of donors (non-heart beating human donors and genetically altered animals for xenotransplantation), and other new therapies for end-stage

disease (artificial livers and mechanical assist devices for heart failure), one can predict that 20 years from now, we will have even more sophisticated treatments that will have far reaching effects on medical practice and education, advances likely to eclipse even those of the past two decades.

**Table 3.**

**Transplants by Donor Type and Center in NC**

Transplants Performed: January 1, 1988 - October 31, 2003

	All Donor Types	Deceased Donor	Living Donor	
All North Carolina Centers	All Organs	7,911	6,248	1,663
	Kidney	4,414	2,818	1,596
	Liver	1,300	1,248	52
	Pancreas	59	59	0
	Kidney / Pancreas	329	329	0
	Heart	1,052	1,052	0
	Lung	719	704	15
	Heart / Lung	38	38	0
Wake Forest University Baptist Medical Center	All Organs	957	689	268
	Kidney	835	567	268
	Pancreas	12	12	0
	Kidney / Pancreas	26	26	0
	Heart	82	82	0
	Lung*	2	2	0
Carolinas Medical Center	All Organs	1,709	1,426	283
	Kidney	1,068	785	283
	Liver	262	262	0
	Pancreas	7	7	0
	Kidney / Pancreas	68	68	0
	Heart	304	304	0
Duke University Medical Center	All Organs	2,791	2,390	401
	Kidney	1,119	730	389
	Liver	506	500	6
	Pancreas	37	37	0
	Kidney / Pancreas	197	197	0
	Heart	437	437	0
	Lung	470	464	6
Durham VA Medical Center	All Organs	70	59	11
	Kidney	65	54	11
	Kidney / Pancreas	5	5	0
Pitt County Memorial Hospital	All Organs	617	286	331
	Kidney	596	265	331
	Pancreas	1	1	0
	Kidney / Pancreas	2	2	0
	Heart*	18	18	0
UNC Hospitals	All Organs	1,767	1,398	369
	Kidney	731	417	314
	Liver	532	486	46
	Pancreas	2	2	0
	Kidney / Pancreas	31	31	0
	Heart	211	211	0
	Lung	247	238	9
	Heart / Lung	13	13	0

Source: Based on OPTN data as of January 23, 2004 ([www.optn.org](http://www.optn.org)). \* No longer performing this procedure.

## Building a Modern Transplant Center

*J. Elizabeth Tuttle-Newhall, MD*

Organ transplantation is currently the standard therapy for end-organ failure in those patients medically suitable for transplant. At present, there are over 80,000 patients listed for transplantation in the United States.<sup>1</sup> The United States organ transplant waiting list grows on average 16-20% per year. In the past 10 years, the number of registrants has increased from 23,901 to over 80,000. In contrast, the number of deceased organ donors available has increased from 4,526 in 1991 to 5,985 in 2001.<sup>2</sup> Overall mortality for all patients on the waiting list is 7.5% and continues to grow yearly.<sup>1</sup> The number of transplants performed in the United States has also increased from 12,626 in 1988 to over 22,000 in 2000.<sup>2</sup>

Currently, there are over 300 transplant centers in the United States. While the majority of transplant centers are in academic tertiary care facilities, there are several very successful programs in the private arena. In North Carolina there are three multi-abdominal transplant centers (liver, kidney and pancreas transplants) including Duke University Medical Center, Carolinas Medical Center in Charlotte and UNC Hospitals in Chapel Hill. Both Wake Forest University Baptist Medical Center and Pitt County Memorial Hospital with University Health Systems of Eastern Carolina have abdominal transplant programs that perform pancreas and kidney transplants.

The establishment and maintenance of abdominal transplant programs requires enormous planning and resources. Extensive negotiations must take place to ensure institutional and/or departmental commitments prior to initiation of any program. The recruitment and retention of an expert multidisciplinary team of physicians and nurses follows subsequently. Strategic planning is required to adequately deploy resources, lobby referring physicians, and recruit patients in order to achieve success.<sup>3</sup>

### Infrastructural Support Requirements

Institutional support is paramount to the establishment and maintenance of a successful transplant program. Fiscal investment

is required to establish adequate programmatic infrastructure. Infrastructure is required to not only meet regulatory requirements, but also provides the backbone for provision of excellent clinical care for complex patients. Programmatic infrastructure is required to manage the requirements of data collection and organization that is mandated by the United Network of Organ Sharing (UNOS). Information systems are necessary to capture and organize patient information that is analyzed to determine patient outcome, graft survival and programmatic performance. Required UNOS data are also used regionally and nationally to assess performance of UNOS allocation policies

*Institutional support is paramount to the establishment and maintenance of a successful transplant program.*

to ensure the best patient outcomes and effective utilization of limited resources. Individual programmatic data should be available to assess programmatic performance, not only in terms of clinical outcomes, but in the financial aspects of all phases of transplant as well. Support staff must include not only database managers but also patient contact personnel. Clinical systems must be available to assist in efficient patient access and easy physician referrals. These clinical systems must also facilitate patient throughput once the patient is in the system at the specific transplant center.

Institutions must invest in space and equipment for care of the complex organ failure patient in all of the phases of transplant (pre-operative, peri-operative and post-operative). Clinic space and adequate time in that space must be available for the medical and surgical specialist to see the volume of pre-operative patients necessary to establish a program and assist in the multi-disciplinary management of the post-operative patients. Operating room equipment must be available, and personnel

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must be trained. Call teams should be established for specialized transplant procedures that require a specific level of nursing expertise. Intensive care unit resources must also be available with appropriately trained staff to care for the post-operative and often critically ill transplant recipient. Investment in the clinical enterprise required to support a transplant program can only occur at the institutional level. The incentives for the institution are not only fulfillment of the academic center's mission to provide tertiary levels of care, but also financial gain if the program can achieve a profitable clinical volume.

## Personnel Requirements

Personnel recruitment and retention are of foremost importance to achieving success in any transplant program. Medical, surgical and nursing expertise in transplant are required. For example, a kidney transplant program requires a transplant nephrologist, a transplant surgeon, and several nurse coordinators who have specific interest and expertise in the work-up and management of kidney transplant patients. A kidney transplant program also requires a histocompatibility lab, a lab director and lab personnel to support the transplant program. Social work, medical psychology, financial support staff must all be available to assist those patients who may require evaluation prior to transplant and support during all phases of the transplant process. All of these individuals maintain a pivotal role in the daily management of their particular program. Likewise, liver transplant programs require a transplant hepatologist, a specialized anesthesiologist, critical care specialists, transplant infectious disease specialists, radiologists with experience in transplantation, pathologists and nursing personnel that are familiar with care of

the transplant patient. If the transplant center is associated with a medical school and academic center, lab support and time must be made available to the involved physicians who have an interest in research and/or clinical teaching in order to support the academic and educational missions of their individual institutions. Transplantation requires the development of a multi-disciplinary team of experts who are dedicated to providing excellent clinical care for those patients with organ failure.

## Relationships with Recipient's Referring Physicians

Finally, in order to assure the success of any program, involvement and recruitment of referring physicians and their patients must occur. While transplant patients are specialized in many aspects of their care, their primary and referring physicians are still involved during all phases of transplant. Resources must be available and deployed to ensure adequate communication between the transplant center and the referring physicians in order to ensure the best possible patient care. Ease of communication and exchange of up-to-date information between physicians ensure excellent patient care and patient outcomes. Access for the patients to the transplant centers must be simple and timely in order to expedite work-up and as is of the patient. If the patient is not a candidate for transplant, an alternative care plan can be quickly developed.

In summary, development of a transplant program requires fiscal investment, recruitment and retention of personnel with clinical expertise and the ability to assess and evaluate resources and their outcomes to deliver the best possible quality of care to those patients most in need.

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## Some of the Challenges of Encouraging Organ Donation Among Minority Populations

*Lynt B. Johnson, MD, FACS*

Organ donation and organ allocation remain important issues for patients awaiting transplantation in the United States. The disparity between the number of deceased donors and the number of patients awaiting transplantation continues to widen each year. The number of deceased donors in the United States has remained stagnant at approximately 5,000 donors per year, while the waiting list for organs in 2004 exceeds 80,000 individuals. Each day in the United States 15 patients die while awaiting life-saving transplants. The method of allocation of these precious gifts is of importance to all patients, but is of particular importance to minorities. Although minorities are represented in all end-stage organ diseases, end-stage renal disease has by far the greatest impact on minorities. Diseases such as hypertension and diabetes, which can lead to end-stage renal disease and the need for transplantation, disproportionately affect minorities. Several key questions should be openly discussed and debated in regard to transplantation policy and minorities. Some of these questions might be: Is there proportionate representation of minorities on organ waiting lists? Does race impact organ availability? What are the reasons that waiting time is longer for minorities awaiting kidney transplantation? How can we increase organ availability for minorities? What should be the guiding principles of organ rationing?

For many highly specialized procedures in the United States, racial differences in access to effective medical procedures persist. Minorities are far less represented than their majority counterparts, even when adjustments are made for economic status and education. Coronary artery bypass surgery, total knee and hip replacement, cataract surgery, screening colonoscopy and mammography are examples of such procedures where disparities exist. Access remains a critical issue.

Two significant risk factors for renal disease, hypertension

and diabetes, disproportionately affect African Americans. It is estimated that more 30% of adult African Americans are hypertensive, compared to a 20% incidence in the majority population. More importantly the age of onset in African Americans is earlier, resulting in higher age-adjusted hypertension prevalence. This early onset subsequently leads to more target organ damage and greater overall mortality burden when compared with the majority white population. Although the difference is not as drastic with the incidence of diabetes, the risk of end-stage renal disease in African Americans with diabetes is three times as great as that of the majority population.

Due to the greater burden of disease, the incidence of end-stage renal disease is much higher in African Americans. Thirty-five percent of all patients awaiting kidney transplantation in the United States are African American. In some areas of the country, African Americans account for over 70% of the patients awaiting kidney transplantation. Thus, issues of organ allocation are of paramount importance to understand. Organ allocation begins with timely referral to transplant centers. In a study by Ayanian et al., they showed that despite equivalent desire for transplant, the number of patients referred for evaluation and the number of patients placed on the waiting list were significantly less for African Americans than for their majority white counterparts.<sup>1</sup> One recent proposal to level the playing field is for patients to be assigned waiting time from their initial diagnosis of renal dialysis and not with their referral to the transplant center.

This proposal, if implemented, may allow for those patients with less access to the referral process to gain a more equitable footing. However, there remains some opposition to this proposal in the transplant community. Not only must we provide better access to transplantation, but the method of allocation has great importance

*In some areas of the country, African Americans account for over 70% of the patients awaiting kidney transplantation.*

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since the demand far outweighs the supply of deceased donor organs. For patients listed in 1997, African Americans waited an average of two-and-a-half years longer than their white counterparts on the waiting list. This disparity is most notably accounted for by the limited supply of genetically closely matched organs, and to some extent by the continued use of tissue type matching in the algorithm for kidney allocation. Traditionally it has been shown that in the prior era of immunosuppressant drugs, tissue type matching played a role in the longevity of functioning kidney transplants. As the immunosuppression drugs have improved, these differences have been lessened. Certain tissue types are much more common in the majority of white populations than in minority populations. Since the majority of deceased donors are Caucasian, this limits opportunities for closely matched organs in some instances. Over the years the preference given to tissue type matching has been reduced. The question remains: should we eliminate tissue type matching altogether and apply severity of illness and waiting time as the only factors for recipient selection in kidney transplant allocation? Previous studies have shown that the impact of elimination of tissue type matching reduces long-term kidney survival.<sup>3</sup> It is my belief that this difference may be mitigated by utilizing different immunosuppressive strategies for African Americans than for their majority white counterparts.

Other issues of importance include increasing organ donation, especially in the minority population. The African American deceased organ donor consent rate is far less than it is in the white population. Boulware, et al. recently studied racial and gender issues relating to donation in a Baltimore community.<sup>2</sup> Their results suggest that mistrust of hospitals and concerns about racial discrimination in hospitals accounted for the signif-

icant differences in willingness to donate between non-Hispanic blacks and whites. Black males were particularly resistant to organ donation. White males were most likely to identify themselves as organ donors on a driver's license (65%), compared to white females (60%), black females (38%). Only 19% of black males indicated their willingness to donate. Ironically in the year 2003, in the service area of the greater metropolitan Washington, DC area, the percentages of actual deceased organ donation show great similarity to the data provided by Boulware and her colleagues. Of eligible African American families that were approached concerning organ donation the consent rate was 25%, compared to 60% for the Caucasian population.<sup>2</sup>

Targeted education in the minority community will likely provide greatest benefit to increasing organ donation in the minority population. Central figures of trust within minority communities can be used as advocates for dissemination of this critical information. Dissemination of information regarding the need for organ donation in the minority community will be more effective if simultaneous education about disease prevention occurs, especially in relation to hypertension and diabetes, which ravage our community. The future looks grim with almost 20% of minority group children facing obesity. More often than not, they will carry this problem into adulthood leading to a greater incidence of hypertension and diabetes. We must confront these lifestyle issues now by targeting exercise, nutrition and disease prevention in our children. These and other issues must get on the agenda in our organizations, community and political debates. We need to not only emphasize the needs of end-stage organ disease patients, but also preventive strategies for our communities.

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\_\_\_\_\_, have spoken to my family about organ and tissue donation. I wish to donate.  
 Any needed organs and tissue  Only the following organs and tissue

The following people have witnessed my commitment to be a donor.

Donor Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Public Information/Referral  
800-200-2672 • 800-252-2672

  
Carolina Donor Services

DONOR CARD

Fill out this donor card in the presence of two witnesses, preferably your next-of-kin, (and sign your name in the space provided)

# A Minority Perspective

## The State of Minority Donation in North Carolina

*Debbie Mann Gibbs*

Derrick Floyd will celebrate a big birthday, his 40th, in March. There will be the usual ice cream, cake and presents. What will really make the day special, however, is what will be missing. This year Derrick won't be tethered to a dialysis machine—the piece of equipment that artificially replaced his failing kidneys for three and a half years.

Thanks to the generosity of a donor family, Derrick received a kidney transplant last summer at Carolinas Medical Center in Charlotte. Hello to new-found energy, dark-colored soft drinks and time on the basketball court with son, DJ. Goodbye to

African American.

There are more than 3,000 people in North Carolina on the waiting list for an organ transplant—1,965 need a kidney transplant. The situation is critical for minorities, particularly African Americans.

As of January 14, 2004, there were 1,257 African Americans on North Carolina's kidney waiting list or 64%—a staggering figure considering 21.5% of North Carolina's population is African American.

Minorities represent over half of those on the national kidney

**Table 1.**  
**Organ by Ethnicity: Current NC Waiting List**

	All Organs	Kidney	Liver	Pancreas	Kidney/Pancreas	Heart	Lung	Heart/Lung	Intestine
All Ethnicities	3,065	1,965	684	15	91	73	220	16	1
White	1,521	638	563	13	66	49	181	10	1
Black	1,445	1,261	95	2	25	22	34	6	0
Hispanic	36	24	9	0	0	1	2	0	0
Asian	35	24	10	0	0	0	1	0	0
Other	28	18	7	0	0	1	2	0	0

shunts, loss of work and family time.

Derrick was lucky. His transplant came exactly six months after his mother died of the same kidney disease, focal segmental glomerulosclerosis. Like many African Americans in desperate need of a kidney transplant, the call to tell her a kidney was available did not come in time.

### The Statistics are Startling

According to figures from the United Network for Organ Sharing (UNOS), the organization that maintains the nation's database of waiting-list candidates, 220 North Carolinians died in 2002 (the last full year for which statistics are available) before a compatible organ was found. Ninety-six of them were

waiting list with African Americans comprising 35% and Hispanics, 16%.

The reason for the disparity is simple. African Americans and Hispanics are four times more likely to suffer from hypertension and diabetes, both of which lead to end-stage renal disease. Despite advances in medicine and technology, demand for organs continues to far outpace supply. As a result, minorities are at higher risk for longer waiting times on transplant waiting lists and ultimately, death.

There were 220 people who died in North Carolina in 2002 as a result of the critical shortage of donors. There were 112 whites, compared to 96 African Americans and three Hispanics.

Because of the genetic matching of antigens, minorities have a better chance of receiving a kidney transplant if the donor is

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from the same ethnic background. The common perception that minorities do not donate is not borne out by the statistics.

### National Studies Reflect State Trends

UNOS data indicate that nationwide the proportion of white donors has decreased over a 10-year period while the proportion of minority donors has increased. A study by the Association of Organ Procurement Organizations (AOPO) of death record reviews from 30 organ procurement organizations showed that when African Americans do refuse to donate, the reason is not always the result of a family saying no. In some instances, the potential donor was never referred by the hospital nor was the family ever approached.<sup>1</sup>

Meanwhile in North Carolina, the trend for minority donation is on the upswing. Out of 551 deceased donors in the state in 2002, 143 (or about 25%) were minorities (92 African Americans and 42 Hispanics). Meanwhile, out of 701 citizens who received various types of transplants in 2002, minorities received only 206 of them.

The *Journal of the National Medical Association* published a national study<sup>2</sup> in January of 2002 which showed that the gap between the number of whites and minority groups that received organ transplants actually widened during the 1990's.

While the rates for all groups were similar in 1988, almost 10 years later in 1997:

- Heart transplantation rates for Caucasians were more than five times greater than for African Americans.
- Kidney transplant rates were nearly nine times higher for whites than for other ethnic groups.

No data were collected separately for North Carolina in that study. That, however, has not stopped LifeShare Of The Carolinas and Carolina Donor Services (CDS), the state's two organ procurement organizations, from developing various programs to increase donation rates among the state's minority populations.

LifeShare has formed strategic collaborations with black physicians and lawyer's groups in Charlotte to distribute information on organ and tissue donation to the African American community. The organization has also partnered with the Links, Inc., a black women's civic organization, on a two-year grass-roots project that targets black churches among other groups. CDS received a \$373,000 federal grant from the Health Resources and Services Administration (HRSA) for a three-year study. The project is a campus-wide intervention to increase intent to donate among African American students at four of the state's historically black colleges and universities.

**Table 2.**  
Deceased Donors Recovered in NC by Donor Ethnicity

	To Date	2003	2002	2001	2000	1999	1998	1997	1996	1995	1994	1993	1992	1991	1990	1989	1988
All Ethnicities	2,077	157	161	155	167	147	170	142	138	133	139	109	108	100	101	72	78
White	1,634	123	120	123	124	118	133	104	104	101	113	86	85	81	90	61	68
Black	365	21	28	23	38	27	31	32	31	27	20	22	21	15	9	10	10
Hispanic	52	8	9	4	4	1	5	5	3	3	3	1	1	3	1	1	0
Asian	11	2	2	3	0	0	1	0	0	1	2	0	0	0	0	0	0
Other	13	2	1	2	1	1	0	1	0	1	1	0	1	1	1	0	0
Non-Hispanic Multiracial	2	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0

*Donors Recovered: January 1, 1988 - November 30, 2003*

**Table 3.**  
Transplants in NC by Recipient Ethnicity

	To Date	2003	2002	2001	2000	1999	1998	1997	1996	1995	1994	1993	1992	1991	1990	1989	1988
All Ethnicities	7,969	685	701	693	673	606	633	573	525	483	527	347	349	361	311	245	257
White	5,385	436	495	465	453	412	431	375	343	347	362	242	230	250	225	151	168
Black	2,355	221	186	211	196	183	182	185	167	125	143	96	112	100	76	89	83
Hispanic	85	15	6	8	7	5	3	5	4	5	10	3	3	5	3	1	2
Asian	62	4	5	3	9	4	9	4	4	4	6	1	3	1	2	1	2
Other	81	9	8	6	8	2	8	4	7	2	6	5	1	5	5	3	2
Non-Hispanic Multiracial	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0

*Transplants Performed: January 1, 1988 - November 30, 2003*

## Ad Campaigns Respond to Crisis

Both LifeShare and CDS support national advertising campaigns developed by the national Coalition on Donation. Two of the campaigns consist of a series of print, broadcast and out-of-home public service ads targeted at African American and Hispanic consumers. They have been a good investment of time and effort. To date, they have been played 2,337 times on North Carolina radio and television stations, generating over \$229,000 in donated media time.

The ads are the first to be created as part of national campaigns that are based on research. Focus groups convened among the target groups in several cities across the country, including the southeast, had several similarities. African American and Hispanic participants revealed several barriers to donation including:

- Concern about the fairness of the system
- Lack of available information
- Mistrust of the medical community and fear of being declared dead prematurely

Loletha, a Charlotte transplant recipient, is featured in the African American brochure and on the Coalition's web site at [www.donatelife.net](http://www.donatelife.net). Loletha received a kidney transplant at Carolinas Medical Center in 1993. Like Derrick, she also waited over three years on the transplant waiting list. Since then, she has continued a prosperous career in banking and even more significant, given birth to a daughter, two things she wasn't sure she would ever be able to achieve.

LifeShare and CDS are active members of the North Carolina Coalition on Donation, a local affiliate of the national Coalition on Donation. The Coalition is a not-for-profit alliance of national organizations and local coalitions dedicated to inspiring all people to donate life through organ and tissue donation. Since 1992, the Coalition has developed several ad campaigns and national projects which have been implemented at the local level in North Carolina.

Derrick and his son are featured in a new general market brochure developed by the Coalition coined "Empowering Testimonials." He is one of seven transplant recipients depicted and the only African American. His profile can be found in the newest Coalition brochure.

## You Can Help

How can the public help? There are several ways. Minority transplant recipients and donor family members are available to share their stories with church, school or civic groups. The presentations are free and may be arranged by contacting LifeShare at 800-932-GIVE(4483) or CDS at 800-200-2672.

North Carolina residents are encouraged to get a donor card, sign it and carry it in their wallet. More importantly, everyone is encouraged to share their wishes on organ and tissue donation with their families. In North Carolina, a driver's license is not legally binding. A signed donor card is. A donor card can be obtained by calling either of the OPO's or by downloading one from the LifeShare web site at [www.lifesharecarolinas.org](http://www.lifesharecarolinas.org).

Life is full of decisions. Paper or plastic? Cash, check or charge? All it takes to save the lives of ALL patients in North Carolina who need a transplant is for more people to decide to become donors, to share their organs when they no longer need them.

To borrow a line from the Coalition's African American ad campaign, "When you do nothing, everybody loses."

## REFERENCES

1. Unpublished data from the Association of Organ Procurement Organizations, National Death Record Review Study (1997-1999 data). McLean, VA.
2. Xiao, H, ES Campbell, and K S Song, 2002. A Trend Analysis of Organ Transplantation Among Ethnic Groups. *Journal of the National Medical Association* 94 (1): 15-20.

## Thank You Letter from Derrick to His Donor's Family

*Dear Guardian Angel,*

*How do you begin to thank someone for giving you your life back? I am in constant thanks for your gift of life.*

*I would like to extend great sorrow and compassion for the loss of your family member. I know that the pain of such loss can be unbearable, as I lost my Mother of the same disease that I suffer just six months prior to receiving the kidney.*

*Your gift has made a tremendous change in my life and in the lives of my family. I can now do simple things without the feeling of fatigue or dizziness. I can play catch with my son and attend his football game while standing the entire time. I know that these tasks sound simple, but they were major challenges before you gave me my life back.*

*I thought you might find this poem comforting. As my mother was losing her battle to this disease, she told me that I would receive a kidney and you made it possible. I would like to share one of her favorite poems with you:*

### **If I Knew**

If I knew it would be the last time that I'd see you fall asleep, I would tuck you in more tightly and pray the Lord, your soul to keep. If I knew it would be the last time I would see you walk out the door, I would give you a hug and a kiss and call you back for one more. If I knew it would be the last time I'd hear your voice lifted up in praise, I would video tape each action and word so I could play it back, day after day. If I knew it would be the last time I could spare an extra minute to stop and say, "I love you" instead of assuming you would KNOW I do. Take time to say "I'm sorry," "Please forgive me," "Thank You" or "It's okay," And if tomorrow never comes, you'll have no regrets about today.

*I hope that you find some comfort in those words. I thank God for you and your family daily and we as a family will continue to pray for you. By the way, my family and I would love to meet you.*

*May God Bless You and Keep You.*

**DERRICK DOESN'T THINK ABOUT HIS KIDNEY TRANSPLANT. HE'S TOO BUSY BEING A FATHER.**

"When you think about - this gift of life, it's unbelievable. It costs you nothing. And yet it gives someone else everything. I know. I got my life back."



Kidney disease left Derrick unable to be the husband or father he wanted to be. But a kidney transplant gave him his life back. Now he and his family are making up for lost time, all because someone like you made the decision to be an organ and tissue donor.



**YOU HAVE THE POWER TO DONATE LIFE.**

To find out how, go today to  
[www.lifesharecarolinas.org](http://www.lifesharecarolinas.org)  
or call 1-800-932-4483

## “What’s in your wallet?” Will Your Intentions Be Known?

*Betsy J. Walsh, JD, MPH, and Judy Jones Tisdale, PhD*

Think that little heart on your NC driver’s license makes you an organ donor? Think again! In North Carolina, only a valid donor card is recognized as a legal document for organ donation. The intent on a driver’s license is not enough. This often comes as news to both medical professionals and laypersons alike. “But I already am an organ donor,” most say as they whip out their driver’s license. As the number of organs available continues to fall behind the number of North Carolinians in need, we must dispel this misconception.

The American Medical Association (AMA) encourages healthcare professionals to promote organ donation awareness. In fact, in 1998, the AMA started the “Live and Then Give” program to educate physicians about this issue and to encourage them to promote donor awareness in their communities.<sup>1</sup> While physicians are uniquely positioned to talk with patients about donation, they are not the only ones who can make an impact on the increasing shortage of needed organs. Whether you are a healthcare professional or an interested layperson, you can help—share this message with family, friends, clients, patients, and colleagues.

### Guarantee Your Right to Be an Organ Donor

To guarantee your wishes about organ donation are honored, do the following:

1. **Carry a signed, witnessed donor card.** You can print one off the Internet at Carolina Donor Services ([www.carolinadonorservices.org](http://www.carolinadonorservices.org)), LifeShare Of The Carolinas ([www.lifesharecarolinas.org](http://www.lifesharecarolinas.org)), or the Coalition on Donation ([www.donatelife.net/become.asp](http://www.donatelife.net/become.asp)). The AMA also has a downloadable card on its web site ([www.ama-assn.org](http://www.ama-assn.org)) on the Organ and Tissue Donation page. Sign the card in front of two individuals (not related to you) so that they can serve as witnesses. You can even specify on the card, if you choose, which organ(s) you want to donate. This card is THE legal document in North

Carolina to indicate your desire to be a donor.

2. **Tell your family members.** Let your family know that you want to be a donor so that they do not have to make that decision for you. They will have enough decisions to make if you are ever in a position to donate; make this one for them. Healthcare providers are, understandably, hesitant to act against the wishes of family members in these situations, so ensure your family knows what you want. The decision to donate at the time of death can be heart-breaking if family members do not know their loved one’s wishes about donation. Make a decision about this issue well before this point and share your choice with family members.
3. **Show your decision on your driver’s license.** When renewing your license, say “yes” to the organ donation question. Although the license is not a binding legal document for donation purposes, it does indicate your intent and encourage healthcare providers to begin the dialogue with your family.

### Healthcare Professionals Should Give Patients and the Public the Facts to Make an Informed Choice

Did you know before reading this commentary that the NC driver’s license is not a legally binding document for donation purposes? If not, that is a good place to start the conversation with patients and the public alike. If you did know this fact, you will be surprised at how many people do not know—and many of them are people who want to be donors.

The AMA publishes “Organ Donation Tips for Patient Education” to guide healthcare professionals in this important education effort.<sup>2</sup> One suggestion, for example, is that physicians choose a non-crisis office visit, such as a check-up, to initiate a conversation about donation. And if staff members talk with patients, they should be clear that they are discussing this topic with all patients at the physician’s request. Of course, if patients

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are not receptive to talking about donation, physicians and staff should not pursue the topic. Organ donation is a “gift of life,” and individuals should decide what is right for them. However, more than likely, patients will have questions. Share your knowledge as a healthcare professional to help them make an informed decision about being a donor.

For other healthcare professionals and laypeople, there are plenty of additional resources to help you get involved in raising organ donation awareness. The Coalition on Donation provides several easy-to-implement suggestions to promote donation education ([www.donatelife.net/promote.html](http://www.donatelife.net/promote.html)). This site offers a downloadable web banner, an e-card to send to friends and family, and a presentation kit. The United Network for Organ Sharing (UNOS) offers ideas on its web site for individuals to promote donation in their local areas, as well as a reminder about the Workplace Partnership for Life initiative sponsored by the US Department of Health and Human Services. This campaign encourages US businesses to share information about organ donation in the workplace and encourages workers to sign up as donors. To learn more, simply go to the UNOS web site ([www.unos.org](http://www.unos.org)) and click on the “Help Save a Life” link. Carolina Donor Services provides helpful information for teachers, clergy, minority interests, and employers; click on the “Special Interests” link on the home page ([www.carolinadonorservices.org](http://www.carolinadonorservices.org)). And LifeShare Of The Carolinas invites interested people to contact them for speakers and to learn more about the Workplace Initiative. Additionally LifeShare has a web page dedicated to educating children about donation issues ([www.lifesharecarolinas.org/kids/index.html](http://www.lifesharecarolinas.org/kids/index.html)).

### Answering Patient’s Common Questions About Organ Donation

Here are the most common questions or concerns that you will be asked about organ donation—and facts you can use in responding:<sup>3</sup>

- “I’m afraid that the doctors may not try hard enough to save me if they think my organs will fit someone who needs them.” FACT—healthcare providers will do whatever is necessary to try to save lives. Individuals are eligible to be donors only after they have been declared brain dead.
- “I might want an open casket funeral.” FACT—individuals can still have an open casket funeral if they choose to donate organs. Donating does not affect how an individual looks in an open casket.
- “How much money will it cost my family?” FACT—the answer is \$0. Once a decision is

made to donate, the deceased’s family bears no financial costs from that point forward.

- “What if they take my organs before I’m dead?” FACT—before being eligible for donation, several tests must be made to determine if an individual is brain dead. Only once someone is declared brain dead can that person be eligible to be a donor.
- “I don’t think my religion approves.” FACT—most religions either support donation or make no statement, instead supporting individual choice. Want to look up a particular religion’s stance on donation? Check out Carolina Donor Services’ web page ([www.carolinadonorservices.org](http://www.carolinadonorservices.org)), click on “Get the Facts,” and then on “Religious Views.”
- “What about family members in other states?” FACT—states have different laws governing donation. Visit the Coalition on Donation web site ([www.donatelife.net/](http://www.donatelife.net/)) to learn more about each state’s laws.

After you answer such questions and provide facts, some people may elect to sign a donor card; some may want to review printed material before making a decision, and some may decide against being a donor.<sup>4</sup> Even if individuals elect not to be an organ donor, you have at least provided them with information to make an informed choice.

### Call to Action

At the end of November 2003, 2,976 North Carolinians were on waiting lists hoping for a call to a better life. Healthcare professionals and laypeople alike can save lives. Offer family, friends, colleagues, clients, and patients the same chance by asking them “What’s in your wallet?”

*The opinions in this commentary are those of the authors as individuals and not as representatives of any employer or organization.*

I \_\_\_\_\_, have spoken to my family about organ and tissue donation. I wish to donate.  
 Any needed organs and tissue  Only the following organs and tissue

The following people have witnessed my commitment to be a donor.

Donor Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Public Information/Referral  
800-200-2672 • 800-252-2672

Carolina Donor Services

**DONOR CARD**

Fill out the donor card in the presence of two witnesses, preferably your next-of-kin, and sign your name in the space provided.

### REFERENCES

1. Source: [www.ama-assn.org](http://www.ama-assn.org). Accessed Jan. 15, 2004.
2. Source: [www.ama-assn.org](http://www.ama-assn.org). Accessed Jan. 15, 2004.
3. The sources for these questions and responses (as well as others) can be found on the Carolina Donor Services web site, the
4. You can order or download educational materials and donor cards from UNOS, Carolina Donor Services, LifeShare of the Carolinas, the AMA, and the Coalition on Donation.

## Giving and Receiving When Vital Organs Fail

Donald L. Madison, MD (with Andrew, Jim and Susan Pike)

Andrew Pike is 25 years old. He lives in Chapel Hill. Seventeen years ago, when he was eight, Andrew received a heart transplant. He received a kidney transplant on June 24, 2003. The donor of the heart was an unknown child. Andrew's father, Jim, donated the kidney.

Seventeen years is a long time for a heart recipient to remain free of life threatening complications (although kidney failure was in fact a complication of one of the immunosuppressive drugs that was administered following the heart transplant). Andrew Pike is not yet setting the bar, but he is approaching it. The longest survival for a first heart transplant in a child that Dr. Michael Mill (who heads the heart and lung transplant team at UNC Hospitals) knows of is 25 years.

Andrew's mother, Susan Pike, had been the donor of choice for his new kidney, but she failed to pass muster during the workup.

**SUSAN:** My kidney was fine, but the blood vessels weren't. Instead of being straight and having regular thickness of the walls, mine were curved and had overgrowth of some kind. So the doctor did not want those blood vessels because you must take part of the vessels along with the kidney to transplant. And they thought that it was not going to be good for me to have only one kidney.

**JIM:** They had a name for that condition.

**SUSAN:** Dysplasia. Some kind of dysplasia. It's nice that we've forgotten.

**DLM:** Dysplasia means shaped wrongly.

**SUSAN:** That's me alright.

**DLM:** Actually, it means that something developed wrong. That's pretty common in and around the kidney.

Jim and Susan have another son, Ben, who is six years older than Andrew. Ben lives near Chicago and might also have qualified as a donor except for his high blood pressure. But beyond that physical disqualifier was another, social one: Ben is the recent father of triplets.

When Andrew was born, on the second day of 1979, the Pikes were living in Wilmette, Illinois, a suburb just north of Chicago, not far from the lake.

**ANDREW:** I was born between two of the worst blizzards. I've only heard stories about it. I guess it was the day after I was born that they noticed that I had transposition of the great vessels.

**DLM:** I imagine that it doesn't take long to notice.



Susan, Jim and Andrew Pike

**ANDREW:** I think it was my dad who looked in on me when I was lying in the isolette, and he noticed that I was breathing twice as fast as the other babies. And I was turning blue. After that the cardiologists came in to figure out what was what. I'm a little fuzzy on all the details. But between then and my ninth birthday I had, I think, five open heart operations, with physical therapy, I suppose, after each one, and probably hundreds of tests and procedures. And when I was eight years old I had my heart transplant. I was in the

*Note: For help with this article I wish to thank the Pike family, Erika Rager, MD, Michael Mill, MD, Romulo Colindres, MD, and Jonathan Oberlander, PhD.*

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hospital for seven weeks. Finally, I think it was on Christmas Eve, I was released from the hospital.

It was a struggle to get used to everything after that. I had to relearn a lot of things, because I had a stroke during the procedure.

**DLM:** While you were on the operating table?

**ANDREW:** I think that's the way it happened. And after that the right side of my body was pretty much paralyzed for a while. I had to relearn how to use my right hand, which still has a lot of weakness—a lot of physical therapy after that, speech therapy, too. But it was also a time to celebrate even while I was going through so much hardship. I would have to make sure I wasn't around people with germs, because after an organ transplant—any organ transplant—you have to take anti-rejection medicine, and a side effect of that is that you are immune-suppressed. Well, actually, that's not a side effect; it's the main purpose of it.

It was difficult for me, being at such a young age, to understand why this was all happening to me. I would see my friends, who would be leading normal lives, going to school, playing outside and all that, and they didn't have to deal with any of this. That was probably the most challenging part for me—not having the slightest idea why this should happen to me and not somebody else. I've been on medication since, I guess, day one. My nickname when I was in the hospital used to be Human Pin Cushion, because I had to get so many shots. By now I'd guess it's probably been 2,000 or so. I'm used to it. After the transplant I had to have heart biopsies done, I guess twice a week to start out with, and then every week, and then every other week and so on. Now it's every couple of years.

**DLM:** What are they looking for?

**ANDREW:** A biopsy is the surest way to check to see whether or not I'm experiencing rejection. They take a catheter, which is really a long, thin wire, and insert it into a vein, thread it up to my heart, and take a sample of tissue and then look at it under a microscope to determine if there is rejection. That was probably the most difficult thing for me as a kid in terms of dealing with pain. I would wake up sometimes maybe 10 or 15 minutes before the whole thing was over, and they would have to hold gauze with pressure against the site. I remember that as the most painful thing.

**DLM:** And there has been no sign of rejection?

**ANDREW:** So far, no. Most people experience rejection or coronary artery disease after about 10 years. To go this long without experiencing either of those is—not unheard of, but it's unusual.

Jim and Susan Pike met in Madison, Wisconsin. Susan was a graduate student in Spanish at the University of Wisconsin; and she attended the church where Jim came as Associate Pastor following his graduation from divinity school at Colgate Rochester (in Rochester, New York) and his ordination in the American Baptist clergy.

Susan's roots are in North Carolina and Tennessee. She was born in Elizabeth City and attended school in Lexington and Raleigh before moving to Nashville, where she finished high school and attended college at Vanderbilt. Her father was a Southern Baptist minister who became editor of a Sunday School periodical and other church literature for young people.

Jim grew up in Terre Haute, Indiana. After high school he attended his hometown college, Indiana State. Both of his parents were high school teachers: his mother taught Latin, and his father was a football and basketball coach whose most illustrious pupil—probably—was the Terre Haute Terror, future inductee into the Basketball Hall of Fame, future teammate of both Dean Smith and Bill Russell and, eventually, the most physically imposing one-term sheriff in the history of Vigo County, Indiana. (I think I impressed Jim by knowing that Clyde Lovellette was from Terre Haute.)

After graduate school, Susan taught for five years. She and Jim married and moved to Chicago, where he became Pastor of the Community Church of Wilmette. They lived in Wilmette for 22 years and during that time raised their two boys.

Eight years ago the family came to North Carolina when Jim accepted a call to become Pastor of the Olin T. Binkley Memorial Baptist Church in Chapel Hill.

On the day after he was born Andrew underwent his first heart operation. His congenital malformation included transposition of the great arteries (the aorta emerged from the wrong ventricle and so did the pulmonary artery) with stenosis of the pulmonary valve, along with a faulty tricuspid valve, and a defect of the septum between the two atria (a hole in the wall that separates them) and also of the septum between the two ventricles. Transposition of the great arteries means that the stronger left ventricle is pumping blood into the lungs (instead of out into the body) and that this oxygenated blood when it returns from the lungs comes back to the same side of the heart, only to be pumped through the lungs again and again. At the same time, the right side of the heart is pumping blood out into the body, and this blood returns to the right side of the heart, bypassing the lungs altogether. The entire circulation looks like a figure 8, except that the two loops of the 8 don't connect. One loop has oxygenated blood; the other one doesn't. The only way that any oxygenated blood from the lungs can reach the rest of the body is through the defect: The small hole in the septum between the two atria allows mixing of oxygenated blood from the left heart with deoxygenated blood from the right heart. This mixing allows *some* oxygen—though not enough—to reach the rest of the body. But the greater amount of blood that is being forced into the lungs by the stronger left ventricle causes pulmonary hypertension; and the extra work placed on the weaker right ventricle (which now has to pump against the much greater resistance put up by the circulatory system of the entire body) causes heart failure. So if the defect (hole) between the atria can be enlarged by performing a balloon septostomy, which was Andrew's first operation, more of the blood can be mixed and therefore oxygenated, and the heart failure can be slowed, temporarily.

The balloon septostomy didn't require opening Andrew's chest, but later operations did. When he was 18 months old, he underwent a Mustard Procedure. During this operation (no longer performed in the U.S.) the surgeons actually used the pericardium (the sack that surrounds the heart) to construct a baffle inside the atrium that then forced more of the oxygenated blood returning from the lungs to pass down into the right ventricle, which in transposition of the great arteries is the pumping ventricle for the aorta and the rest of the body. At the same time the surgeons also repaired Andrew's ventricular septal defect, the stenosis of the pulmonary artery, and the tricuspid valve. But during the post-operative course Andrew developed a complication—an infection beneath the sternum, which required a second, clean-up operation.

Three years later, Andrew's heart was again opened, this time because his tricuspid valve was failing. The surgeons then put in a new, artificial St. Jude valve.

**DLM:** When you were very young, before the heart transplant, could you exert yourself at all? What kind of shape were you in physically?

**ANDREW:** I wanted to be active—run, climb, jump—I wanted to do everything, which made it all the more difficult for my mother and father to prevent me from going against the doctors' instructions and what not.

**JIM:** When he was a baby Susan had to check his heart rate



Andrew at seven months with his mother, Susan.

every two hours. Once, we were on vacation, and I can still picture her putting him on the hood of the car and counting his heart rate. It was a pretty constant thing.

**SUSAN:** Later, the doctor had to say things like, "Well, I don't want you to become a couch potato, but..." and asked him not to play quite so hard. Before he was ready for the transplant he won two blue ribbons in the Cub Scout Olympics, which involved foot races, throwing a basketball and the like. And the next week he was in the hospital with congestive heart failure.

Physical activity mixed with a taste for high adventure has been a theme of Andrew's life both as a child and adult. But his active life came to an abrupt deceleration at about age seven.

**SUSAN:** When Andrew experienced a TIA (transient ischemic attack)—I'm going to say he was six and a half—the doctor said, no, he should not use his skateboard anymore, should not ride a bicycle, should not climb trees. And that was hard.

**JIM:** That's when we talked with him about having a heart transplant and asked him whether he wanted to do it. And he said, "Will I be able to climb a tree again?" And I said, "Yes, you will." "Then I want to do it," he said.

Andrew's heart failure progressed from that point. In September of 1987 he underwent yet another heart operation, an attempt to reverse the earlier Mustard Procedure and take greater advantage of the stronger of the two ventricles' capacity to pump blood to his body. The surgeons referred to this as a "last ditch" operation. Susan remembers that Andrew did show some modest improvement afterward, but only for about two weeks. It was clear that he would need a heart transplant to survive.

In 1987 only three centers—Stanford, the University of Minnesota and Childrens Hospital of Pittsburgh—were performing heart transplants in children. Michael Mill was, at that time, the transplant fellow in cardiac surgery at Stanford; he recalls that in those days hearts were "relatively plentiful, mainly because so few centers were performing transplants, and we could establish direct personal relationships with other hospitals that would often put us in touch with a donor." The national organ procurement regulations were still in the future. Today, instead of three hospitals performing heart transplants in children, somewhere between 60 and 70 hospitals have pediatric heart transplant programs. Altogether, the United States now has 141 heart transplant programs (adult and children) and 245 kidney transplant programs. In the year 2000 these centers performed a total of 2,246 heart transplants and 14,283 kidney transplants.

In the summer and fall of 1987 eight-year-old Andrew Pike was in severe congestive heart failure. He needed a transplant; but there was a problem.

**JIM:** We were told that the scars from Andy's previous heart surgeries would keep him from having a transplant. They told us that he wasn't going to make it.

Then our cardiologist—her name was Theresa Berry—went to New Orleans to a heart convention, and she talked to the people from Pittsburgh, and they said that they'd like to see Andy and maybe consider him, but that it would be an exception.

I remember that weekend was Halloween. I had carried him out trick-or-treating, because he couldn't walk at that point; he just didn't have the strength. The next week he was on an "Angel Flight" to Pittsburgh, and a week later he had a new heart.

(NOTE: "Angel Flight" is an umbrella organization of regional associations of volunteer pilots who provide free emergency transportation for medical purposes such as this one.)

**DLM:** So you went to Pittsburgh for evaluation?

**ANDREW:** Well, before the transplant I think everyone had decided that it was going to happen. Right?

**SUSAN:** Well, you had to be evaluated. And the surgeons pointed out that there were risks, including the risk of stroke.



Disney World, July 1987. Suffering from severe congestive heart failure, eight-year-old Andrew would have a new heart four months later.

**JIM:** But they determined after a couple of days that he was a candidate. And the last few days we were just waiting.

**SUSAN:** It just happened that a heart was available after a week. The same donor who gave Andrew a heart also gave a liver and two kidneys.

**DLM:** Do you know anything about the donor or the circumstances of the donor's death?

**SUSAN:** At that time they did not introduce donor families.

But it was a good heart, they said. The doctor would not tell Andrew the gender of the donor. We did understand that an auto accident caused the other person to lose his/her life. And the person was older than Andrew—I think 13—so the heart was a little bigger than what he normally would have had.

**DLM:** When you say that at that time they did not introduce donors' families to recipients and that the doctor wouldn't tell you the donor's gender, it suggests how terribly important it was that the identity of the donor be kept confidential.

**ANDREW:** Yes, and even now, the only way I could meet the family is if I wrote a letter to the organ procurement organization of North Carolina—they have people there who would evaluate the letter and decide whether or not it was possible and appropriate to contact the family. If it was they would make contact and ask them how they felt about this. And if the family wanted to meet with me then that agency would help set it up.

**DLM:** It sounds like you've looked into this.

**ANDREW:** I have, and there was one time about three years ago when I thought seriously about going to see them or at least getting in touch. So I did learn then about how it was done; but in the end I decided that my life just wasn't where I wanted it to be, and I wanted to be at my best when I did that. It's really important to me that I be at least somewhat successful and independent and on my own before I meet them.

**DLM:** So it's still something that you have on your agenda, long term?

**ANDREW:** Yes, it is.

**JIM:** At the time of the transplant we did write a letter to the family, anonymously, and the hospital saw that they received it. We did not hear from them.

**DLM:** After the heart transplant, your main medical problem, besides the need for immunosuppression, must have been rehabilitation from stroke.

**ANDREW:** Yes, the stroke was a main issue. I was in the hospital for seven weeks after the transplant. I did have to take third grade over again. I had missed 117 days of school that year. That was difficult getting stuck back a year away from my friends. How long after the operation did I have to stay there (in Pittsburgh)?

**JIM:** We rented an apartment not too far from the hospital with the help of the social work department there, and Susan and Andy stayed there almost until the middle of February, and then they came home for a few days and then had to go back. Because Andy had to have these biopsies every week or so for so long, it was well into April before we gave up that apartment. But his care was not transferred to Chicago until that summer. So we continued to make trips to Pittsburgh until June or July.

**SUSAN:** Andrew had to deal with the stroke, of course, but



The summer after the heart transplant.

there were other problems. He always had strong side effects from the medications. Cyclosporin and his body were just not compatible. Not only did he have overgrowth of hair, and darker hair—he did not look like his old self. One of his friends told him: “You’re not Andy.” And by junior high and the onset of puberty, he was having terrible headaches that would cause him to miss school. Or he’d get to school and then call me and say, “I’m in the nurse’s office.” They tried to play around with the medication to alter it or do something that would help. And he took Neurontin for a long time—to be sure there were no seizures. We finally sought help from a man who was both a neurologist and knew acupuncture. He was about the only one who could get the headaches to stop.

**JIM:** It turned out that they were Cyclosporin headaches. It took a while for them to decide that. We thought they were migraines.

**SUSAN:** Andrew’s older brother had headaches, so we were predisposed to think that Andrew was getting the same kind. I don’t think they knew then that Cyclosporin in some people caused these severe, debilitating headaches.

**JIM:** One of the immunosuppression problems is warts. Remember that horrible wart, two inches wide, on your foot, the year after the transplant? You were on crutches for a long time.

**ANDREW:** I remember that. It was right on the bottom of my foot, and it hurt. It was not fun.

**SUSAN:** He couldn’t do gymnastics because of it. One of the other patients in Pittsburgh, a little Canadian girl, had little tiny warts all over the bottoms of both feet. She had also had a stroke, but hers was such that she had to learn to write with her left hand. And the Make-A-Wish Foundation gave her a computer so that she could do her work that way.

Andrew is reminded of the part in his story played by the Make-A-Wish Foundation, an organization that took on the important responsibility of providing a pleasurable episode at a painful time.

**ANDREW:** They came into my hospital room—some representatives of the Make-A-Wish Foundation. They asked me what I wanted and, as I remember, the first thing I wanted to do was go skydiving. I’d seen it on TV and I thought it was what I wanted to do. The doctors thought that would be a little too risky for someone who has just had a heart transplant, so that was out. Then I thought about maybe meeting Arnold Schwarzenegger, because he was my hero at



Andrew at 10 years of age. He is holding his “old” heart, which he wanted to see after being told that it was in a repository (of congenitally malformed hearts) at Children’s Memorial Hospital in Chicago.

the time, the big action hero in the movies, and I loved all that stuff. I wanted to be in a movie with him. But then I realized that it would be just meeting and talking to him for maybe 15 minutes and it would be over. Eventually I decided I wanted my own tree house. So the Make-A-Wish Foundation paid for a builder to come to our home and build this two-story tree house with rope ladder, bridge, monkey bars, trap doors, and a slide and a pole and all this fun stuff. It was pretty much the biggest news in our neighborhood. All the kids were really impressed. It was the coolest thing in the world. My brother was disappointed, though. He wanted to go to Hawaii. But he couldn't convince me of that.

Apart from dealing and coming to terms with the side effects of Cyclosporin and Prednisone, Andrew was soon able to lead a more active life than he had ever been able to before.

**JIM:** The summer after the transplant we were at Ben's Little League baseball game. Ben is our older son. And we couldn't find Andrew anywhere. We finally did. He was at the next diamond, and he'd climbed up the backstop and was perched on the top.

**I** asked Andrew when it first became apparent that kidney failure had progressed to the point that he might need a kidney transplant.

**ANDREW:** Well, the kidney failure started when I was born. It came from the heart failure. And then the anti-rejection medication (Cyclosporin) after the heart transplant caused the progression of the kidney failure. So, pretty much that's been going on my whole life. They said that my Creatinine level was OK where it was and as long as it didn't go any higher... But it continued to go higher, little by little. And then ...

**SUSAN:** Wait. When he was in high school, just before we left Illinois, Andrew got a kidney infection. He had to go to Children's Hospital and have a kidney biopsy. And at that point they said that he was 50% below normal functioning. I would say he had more fatigue after that, but it did not become more than that until this past year.

**JIM:** I remember that when we were still in Chicago, and I had just accepted the job at Binkley (in Chapel Hill) and we went to see the doctor, who told us that Andrew had glomerulosclerosis and might need a kidney transplant. I know that's when it was because I said, "How can I go to a new church and have this facing us?" It wouldn't be fair to the new congregation; that was my fear. I remember that Andy and I went for a walk and talked about it, and he encouraged me to do it. I thought—and maybe I said it then: "Well, it feels like God is in this, so it must be alright."

Andrew also remembers the Pike family's decision to move to Chapel Hill, but he recalls a different "sign."

**ANDREW:** Actually, this is the way it was: There was a program by all the singing groups at my high school; all the

groups were there. And the very first song that these 400 or 500 kids sang at that concert was "Nothing could be finer than to be in Carolina in the Morning." That was the sign that it was time to go.

**JIM:** When we got to North Carolina one of the first things we did was to get Andrew connected with a neurologist, a cardiologist, and a nephrologist.

**DLM:** No primary care physician?

**SUSAN:** Oh, yes, Dr. Allen Daugird. And he's done a good job, not only with the ordinary medical things that happen, but also things like helping Andrew get a driver's license.

**ANDREW:** Every couple of years I have to have a form filled out that says that I'm taking all my medications and doing what the doctor says, and so on, and that I can drive a car safely.

**JIM:** Well, after we got here Andrew went to see the nephrologist, Dr. Ronald Falk, and he said that most of the deterioration of the kidneys had probably occurred before the heart transplant. And he weaned Andrew off of the Prednisone he'd been on, which required biopsies once a month for about four or five months to assure that there was no rejection. Prednisone is a mean drug that causes a lot of side effects. Andrew was much better after that for quite a while.

During this time Andrew graduated from Chapel Hill High School, took some classes at Durham Tech, and got a job at Blockbuster Video. He also, finally, indulged his long-held wish to try skydiving.

**ANDREW:** Even today being active is very important to me. And when my kidneys prevented me from doing that, it was really hard. But when I was 19 I wanted to try skydiving. We knew someone in our church whose son did it, and so I got together with them, and I got to do it for the very first time. I remember going up in the airplane and thinking, "I can't believe I'm going to do this." But I was also so excited that it took the fear away. I remember getting to the door of the plane—I was doing a tandem jump so I was actually attached to someone behind me, the expert, who was wearing the parachute. Anyway, I remember kneeling down at the door, looking down 13,500 feet, and thinking this is the most exciting thing I've ever done, this is just awesome! And the next thing I know I'm given a little shove, and I go out, and the first three seconds my stomach did ten or twelve flips. But after that we got into neutral position, which is just hands raised like you are surrendering to the police or something. It was just incredible. We were falling at 120 or 125 miles per hour. It was so fast, and the wind... It was very windy, let's put it that way. And then when he pulled the cord we went from 120 miles an hour to 20 in just a split second. It's just like going from total, complete, amazing exhilaration to the most peaceful experience—because you're just floating down like a bird. I did it seven more times. The next four were tandem (you have to do five tandem) and then I did a few solo. But it eventually became

too expensive. It was about \$150 per jump. But it really taught me something: my limits were not as much as I thought they might be.

So, for much of the time between age eight, when he had his heart transplant and age 24, when he had the kidney transplant, Andrew was an active boy and young man who liked to push his limits and was sometimes able to. Then, last January a year ago he had a scheduled heart biopsy. At the same time the doctors ordered a Creatinine level—he hadn't had that particular blood test (a test of kidney function) for about a year. His serum Creatinine was elevated significantly and alarmingly. The test was repeated every other week, and the level continued to



Graduation day, Spring of 1998. Andrew, posing here with Ben, is 18 years old.

rise until by the end of April it was at seven and a half. By then Andrew was starting to be "...not incoherent, but fuzzyheaded." He was showing the signs of kidney failure.

**ANDREW:** I was feeling a lot of disorientation and dizziness, confusion, and a lot of fatigue.

This is when the testing for a donor began, testing that Susan eventually failed and Jim eventually passed. But Andrew's advanced kidney failure signaled that he could not wait for a transplant. He began hemodialysis. I asked him to describe it.

**ANDREW:** Imagine all of your energy being drained out of your body completely. That's what it was like. I didn't have all that much energy to begin with by then. But it made me feel so miserable. I was tired all the time. The only hope I had of getting better was the transplant.

**DLM:** What was your schedule for the dialysis?

**ANDREW:** Three days a week for two and a half to three hours.

**DLM:** And did you feel different afterward?

**ANDREW:** I felt more disoriented afterward. And very weak. I just think that being on dialysis means that you don't have a life anymore. You're alive, but there's nothing good about it.

**JIM:** My observation was that the day of the dialysis you felt horrible, the next day was not quite as horrible, and the next day you were back in dialysis. On the day off you seemed to feel a little better. But let me go back. Andrew had a temporary port for his dialysis. And when Susan couldn't be a donor Dr. Falk arranged for him to have whatever the next stage is to get started, because this temporary port did not function as well as another kind of dialysis would do—the abdominal kind. What's that called?

**DLM:** Peritoneal.

**JIM:** Yes. Andrew chose that. And he was scheduled to begin it two or three days after I was approved, so they cancelled it. And the surgery was performed a little more than a week later, on June 24. They began testing on Susan in early April and that went on for four or five weeks. And when she was disqualified, they started on me, and I was at the hospital two or three days a week for three weeks just going through the tests. We were both so thoroughly examined it was incredible. I think that at one time I counted that there were 27 different tests that they did on me, including adding tests like colonoscopy. It was so thorough that you wonder how anybody could qualify after all those tests. That I did is a miracle.

**DLM:** You may qualify more easily, though, if you have health insurance.

**JIM:** That's true. Before any of this started they verified that our insurance company would cover all of it, including our testing.

**SUSAN:** However, the insurance will only pay for testing one potential donor at a time. I had to finish before Jim could begin.

**DLM:** Then, I suppose, at some point they said to you, "You pass."

**JIM:** Yes, my blood pressure and cholesterol and lipids were all at acceptable levels. Which was amazing. They told me that if my blood pressure were too high I would be disqualified, or if my cholesterol or lipids were too high. So the testing was

not just to see if I were qualified to give a kidney to Andrew, it was also to see whether I would be healthy enough, whether my health might be compromised by making this donation. And they determined that I was fit, physically. And then we had meetings with the social worker, financial consultant, and an interview with the psychologist to make sure that I was doing this for appropriate reasons. Those were all appointments required by the hospital—in addition to all the medical things. But we had wonderful experiences with all of the staff at the hospital. We're very grateful.

**DLM:** Who does the surgery? It must take two different surgeons.

**SUSAN:** Yes. There are four on staff who do kidney transplants. One was in Afghanistan with the Army. And so they had to schedule it among the other three. Otherwise they could have done it sooner.

**DLM:** What was the post-operative course like for both of you?

**SUSAN:** They told us ahead of time that it would be easier for Andrew than for Jim. The donor would have a harder time because the surgeons would be doing more traumatic things inside—in order to take the kidney out whole. In the recipient they just need a place to put it in. They don't have to twist things around so much.

**JIM:** They did not take out either of Andy's kidneys. So he now has three. But, of course, two of them don't work. They needed a place to put in just one kidney. With me the surgery was more extensive, but we both had quite a time.

**ANDREW:** I remember thinking before the operation that with dialysis I don't have a life. So it was a choice between not having a life and having a life, and if that meant having a transplant.... On the day of the operation they took me in and on the operating table, and before they put me to sleep I thought, "Well, here we go," and, "I hope it works." And when I woke up there were maybe four or five nurses screaming at me, telling me to wake up. I was having a really hard time waking up. I don't know if they were afraid that I was never going to wake up or what, but it seemed like they were screaming their heads off. Finally I did wake up, and as I remember, they put me in a hospital bed, and they brought my dad alongside me on another hospital bed, and we just looked at each other and said, "We did it."

**DLM:** What was the screaming to wake up about? Do you know?

**ANDREW:** I have no idea. Maybe the anesthesia was... I've always had trouble waking up.

**JIM:** Even without anesthesia!

**ANDREW:** Anyway, during the course of the next week I experienced severe cramps and lots of sharp pains where the



Assuming the "neutral position."

incision was made, just like everybody. But it was easier for me to deal with being in the hospital and all the tests and people coming in and out, because I was so used to it. They did say to me that it would be a lot easier for me in terms of the surgery and recuperating from it because I had already been through so many of them. But for my dad it was all very new.

**JIM:** And the transplant was easier for you than for many other recipients because you were already immunosuppressed.

**SUSAN:** And the kidney started working very soon after the operation. So Andy felt better.

**JIM:** The hardest part of the whole thing for me was the fear that I might not be able to do it, that I might be disqualified and that Andrew might have to continue the dialysis, which was so hard. So we were elated when we learned that it could happen, and we went in with a sense of celebration, even though they were very clear that it was going to be a difficult recovery.

They told me to plan to take eight weeks off work, which I did. I think they said, "You'll be able to function after eight weeks off work." But they didn't tell me very vividly how I would feel after that. I found that I needed lots of rest and was very weak and tired. But as for the surgery itself, I just woke up in the room and it was all over and the worst part afterwards was gas pain. They did it laparoscopically—made a four-inch incision and then two other incisions for camera and lights and all. I haven't really noticed any difference in terms of kidney function or urinary function. But regaining my energy level has taken a long time, much longer than I thought. I had mistakenly thought that after eight weeks I would be ready to go back full steam, and that was definitely not the case.

**ANDREW:** After the procedure was done—I don't remember why it happened—I became diabetic.

**SUSAN:** Many people after this surgery become diabetic, and Andrew did, too.

**JIM:** Because of the additional Prednisone.

**ANDREW:** Because of the Prednisone, that's right. And just like anybody with diabetes I had to check my blood sugar levels with the machine, four times a day to start with. And it wasn't until I got out of the hospital, the very first day, that I took it and it was down.

**DLM:** This was an additional dose of Prednisone to guard against rejection of the new kidney?

**ANDREW:** Yes.

**DLM:** With your new kidney do you have to have biopsies or something else that's analogous to the way you still have to test your heart—to see if there's rejection?

**ANDREW:** Luckily, the only thing I have to do now is blood work. It's much easier. I go in once every couple of weeks now, for blood work and to see that all of my medications are where they need to be.

**JIM:** And they're continuing to lower Andrew's medications, like Prednisone, over a period of time, so that he will be taking much less medication after a year.

**DLM:** But transplant recipients must continue to receive some level of immunosuppression medication for their lifetime, isn't that right?

**ANDREW:** Yes, absolutely. Anytime you have an organ transplant there's a foreign object in your body and the immune system's going to think it's not supposed to be there. So it's going to try to kill it. So you have to take immunosuppression to make sure that the immune system won't be strong enough to (do that).

**JIM:** One thing that was very helpful in terms of recovery time was home healthcare. For the first three weeks home, a nurse came here every other day, the first week almost every day. Andrew's wound was open, so it needed to be dressed and packed for about six weeks. And they came to do the blood work for several weeks. It meant that we didn't have to take Andrew and get over to the hospital ourselves. We were very grateful for that service; it made a lot of difference.

**SUSAN:** We also took care of the wound, but being rank amateurs we needed the home healthcare here to get us started. I should point out, too, how very helpful friends and church members were, especially to bring food from church. And then Jim's twin sister, and my sister came; our other son came, and Jim's brother and sister-in-law and niece also came for a couple of days right after the surgery. So we were well supported, and it was good to have them here. So many people have helped, both then and earlier. Andrew's third grade teacher taught him to write again after the stroke. The community where we lived then began a fund to help on their own accord when he needed the heart transplant. They sent letters and a videotape and all kinds of things to the hospital when we had to leave Chicago and go to Pittsburgh, which back then was a place of last resort for kids with severe problems,

when transplants weren't done very frequently.

**DLM:** Is Andrew eligible for Medicare?

**JIM:** Well, that just took effect, what was it, two months ago? We did not apply until after the kidney transplant, although Dr. Daugird had suggested it two years ago.

**DLM:** He would have been eligible then as someone who had end-stage renal disease.

**JIM:** With end-stage renal disease you're automatically qualified for Medicare. But if you get a transplant then the assumption by the government is that you're going to be fine and be back in the workforce. So Medicare coverage lasts for only three years following the transplant. But Andrew is on Medicaid now. And we have yet to experience how that's going to function. I don't know whether Medicaid would have supported a transplant or not. We've been trying to reach someone who will talk to us about questions like that. Of course, I would like to know the facts before we take Andrew off of my private insurance. Which is going to have to happen when I retire, but right now it doesn't. That's one of the big worries of transplant families.

**SUSAN:** How to pay for the medicine.

**JIM:** I have piled up here probably three or four hundred letters from UNC Hospitals that have come in the mail since June 24<sup>th</sup>. Literally—and the cost of the mailing from the hospital must be enormous. And for every one we get from them we get another letter from the insurance company. It's just bizarre. I need a full-time accountant here.

**SUSAN:** When Andrew was quite small, I could recite by heart all of his medications. I had them on the tip of my tongue. In the process of his growing up and taking over his own care, I don't now have all the facts at my fingertips. And I don't have to do it the same way. But it makes me extremely anxious when we start talking about it, because I'm thinking that some of the facts may not be right or that we may not have them straight.

The volume of clinical information that Andrew's father and mother—and now Andrew himself—have had to remember is enormous. Each of the many first-doctor-visits over 25 years in two different communities (three, counting Pittsburgh) involves taking a new history. Finally, the family has gotten in the habit of taking along a four- or five-page synopsis of the history and handing it to the doctor. But, says Jim, "They don't pay attention to that, they still want to hear it all verbally."

**DLM:** I'm wondering, is there a support group, locally, for organ transplant recipients?

**ANDREW:** Well, not long ago I got a letter from a person who had had a heart transplant and a kidney transplant, and who just wanted to get together some people who had had these experiences, to meet casually and talk, and that sort of thing. And I'm planning on getting together with that group, which is just now starting. I don't know much more about it yet.



Brother Ben feeding Andrew's three nephews.

Twice a recipient, Andrew Pike is now an advocate and campaigner for organ donations.

He referred to his own experience when he spoke briefly at church on the occasion of National Organ Tissue Donor Sabbath.

"It marks a chance for you to become a true hero," he told the assembled congregants, mentioning also that one of his own heroes, Michael Jordan, was the Organ and Tissue Donor Spokesperson.

Andrew then told the story of the family that invited him to visit with their ten-year old son, who was in the hospital awaiting a heart transplant. A week after the visit, still waiting for a heart to arrive, the boy died.

A year and a half ago Andrew wrote of the reason the pleasures of his own life had been his. It was "because of the good faith and kindness of one family... whom I have never met..."

Become a donor, he says, "if you are looking for a chance to show God's love. Give the gift of life."

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# Letters to the Editor

## Mental Health Reform

### To The Editor:

Congratulations on your September/October, 2003 issue focusing on Mental Health Reform, a masterpiece of diplomacy. Unfortunately it left out input from, or representation of programs which have been closed, staff who have been discharged or have left and patients who have been informed they will no longer be provided services. Reform is needed, but we need to reform the current implementation. We need to reform the reform.

Doctors Swartz and Morrissey refer to the “mental health care system” as having lagged behind the rest of the nation. In fact the initial development of what was to become the mental health system was a model for the nation in the early 1970s but has remained a “nonsystem”. In his book, *People, Patients and Politics*, Clark Cahow, reviewing the history of North Carolina mental hospitals from 1848 to 1960, cites the need to “comprehend the complex interplay in the roles of the Governor, the Commissioner [now the Director of the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS)], the Legislature and the medical centers.” Further he states “future leaders must remain aware of the continual necessity to sell the concept of this relationship to the ever-changing political community.” Unfortunately, Mental Health has suffered from a lack of leadership from the Governor’s office, administration, the Legislature and the medical centers, since the reorganization of state government at the tail end of Governor Bob Scott’s tenure.

The current implementation of “Reform” is in the process of creating a new bureaucracy in the form of Local Management Entities which will not provide direct services. Moreover it has made divestiture and privatization primary goals, supplanting quality direct patient care and invites corruption in place of what at times may have been misguided efforts to provide services in a few area programs. Doctor Visingardi’s article is brief and cryptic, and refers to “managers of public policy,” “divesting public service,” as activities operant in moving forward. He closes with a question: “Have we positively contributed



to the lives of people with disabilities and their families?” The answer to that at present is not only NO, but we have contributed negatively. His propensity to issuing multipage memoranda, stifling employee input, and issuing invitations to state-level meetings take the place of a process of interaction with the people to be served and serving.

Representative Insko reminds us that the Auditor’s report related to two major issues, a lack of accountability among the local area authorities and the state’s excessive reliance on our state institutions. Both, in fact, are failings of state-level leadership. If the benign neglect of the past continues, the only thing that will come of these efforts will be increased chaos. Perhaps in our more urban areas where political, professional and consumer and public leadership is substantial, what is good will be salvaged. Mr. Campbell (State Auditor) clearly identifies problems of “no funding to create programs” and the fact that “mental health programs had been underfunded for years.” He emphasizes “the local structure for providing services must be in place this time as we shift care back to the community.” However, reform implementation proceeds without funds and alternative services in place. Ms. Flamino provides clarity regarding the separateness of the non-system of mental health, homelessness and criminal justice, a dynamic sure to continue to obscure the true needs.

Dr. Bridges, the long-term optimist, neglects to say that the program of Vance, Granville, Warren and Franklin Counties where he served for over 20 years has been dismantled and the staff discharged without adequate alternative services, only one example of program closures. “A Parent’s Tale” provides ample

*a lack of accountability among the local area authorities and the state’s excessive reliance on our state institutions. Both in fact, are failings of state-level leadership.*

substance and argument for the fact that state/local funded and operated services will always be necessary and the unfortunate likelihood is that those individuals affected by mental illness, developmental disabilities and substance abuse will continue to be the lowest priority of leadership. In view of this it seems that parsimony when it comes to the elaboration of bureaucracy and preservation of current staff and services must assume primary roles.

Finally, it is no coincidence that the golden years of the early 1960s to the mid-1970s saw the Division of MH/DD/SAS led by a number of highly respected licensed medical doctors. The deterioration of the nonsystem occurred parallel to the systematic removal of physician positions. The current reform has been without a physician at the state level until recently, when, after relenting to pressures from the NC Medical Society and NC Psychiatric Association along with that of consumers, one position has been advertised. Consistent with this policy to abolish medical doctors from leadership in programs which are medical, the entire Division continues without a physician director which the General Statutes still called for the last time I looked.

— Nicholas E. Stratas, MD  
DLFAPA

## The Cost of Prescription Drugs

### To The Editor:

I have been reading your latest issue (Vol. 64, No. 6), which is a nice job. I liked the Ingram, Hooker Odom, and Millstein pieces in particular. I disliked Marks, whose European perspective shines through as smug superiority; I don't recall any acknowledgment of the Europe-as-free-rider hypothesis.

The Oberlander piece oversimplifies some things. For example, I don't quite accept the parallel between the original enactment of Medicare and the new drug benefit. To be sure, Congress in 1965 did appease the medical/hospital monopoly and leave costs for future attention. The new bill, however, instead of leaving the



cost issue completely unaddressed, tries to provide some competitive alternatives to price controls on drugs. Original Medicare left the BCBS models in place, and made no provision for competition, which entered the picture only with the HMO Act, the antitrust initiative, and the Reagan administration's attempt to bring HMOs into the program. The new law certainly will hasten the coming train wreck, because there is nowhere near enough money to pay for the entire entitlement package for all who will be entitled to it. Inviting a crisis may not be a bad idea, however, since no one wants to reform Medicare until they have no option. Oberlander may be right that the Democrats will eventually impose drug price controls (he might at least have acknowledged that there's a downside to squeezing industry profits), but it's more likely that the crisis will be of such a magnitude that the whole entitlement philosophy will finally have to be rethought, with a shift to defined contributions—the obvious solution.

In general, the problems with drugs, especially the high cost of promoting them and their inefficient use, lies in the professional paradigm, which says that doctors should make all the choices (perhaps with some input from non-cost-conscious patients) and that health plans should be limited to pleading from the sidelines. Most all of our problems lie ultimately, of course, in a payment system in which health plans are barred from acting as purchasing agents and must be simply payers (at negotiated prices, perhaps) for whatever professionals deem necessary to protect our health.

— Clark Havighurst, JD  
William Neal Reynolds Professor Emeritus of Law  
Duke University

*The new law  
certainly will hasten  
the coming train  
wreck, because there  
is nowhere near  
enough money to  
pay for the entire  
entitlement package  
for all who will be  
entitled to it.*

# The North Carolina Institute of Medicine

Since January 2002,  
Publisher of *The North Carolina Medical Journal*

In 1983 the North Carolina General Assembly chartered the North Carolina Institute of Medicine as an independent, nonprofit organization to serve as a non-political source of analysis and advice on issues of relevance to the health of North Carolina's population. The Institute is a convenor of persons and organizations with health-relevant expertise, a provider of carefully conducted studies of complex and often controversial health and healthcare issues, and a source of advice regarding available options for problem solution. The principal mode of addressing such issues is through the convening of task forces consisting of some of the state's leading professionals, policy makers and interest group representatives to undertake detailed analyses of the various dimensions of such issues and to identify a range of possible options for addressing them.

Members of the NC Institute of Medicine are appointed for five-year terms by the Governor, and each task force convened by the Institute typically includes at least one-third of its membership from among the appointed members. Topics to be addressed through task force efforts are chosen following requests from the Governor, the General Assembly or agencies of state government. In some cases, topics are selected on the basis of requests from a number of stakeholder organizations across the state where this type of analytical process is considered to have potential value.

The NC Institute of Medicine assumed the role of publisher of the *North Carolina Medical Journal* in January 2002 when the North Carolina Medical Society reached the decision to cease support for its publication. The Institute views the *North Carolina Medical Journal* as an extension of its mission. The *Journal* provides a forum for stakeholders, healthcare professionals, and policy makers and shapers to study and discuss the most salient health policy issues facing our state. Like many states, North Carolina is grappling with issues such as an increasing number of uninsured, the unmet health needs of the growing Latino population, a critical shortage of nursing personnel, the health risks of tobacco and obesity, rising prescription drugs costs, mental health system reform, the increasing societal burden of chronic illness care, the threat of bioterrorism and the necessity of assuring adequate public health preparedness—all in the midst of an economic downturn. Each of these issues presents unique challenges to healthcare providers and state policy makers. Yet, a fully implemented task force to consider each of these sets of issues is not feasible. The *Journal* makes it possible to present an organized and balanced overview of some of these issues, six times per year, and allows interested persons the opportunity to engage in the ongoing discussion of these issues throughout the year. The Institute hopes that our readers of the *Journal* will, in this way, become involved in the continuing debate about the most promising avenues for assuring the highest standards of health and healthcare for all North Carolinians.

health policy  
*North Carolina Institute of Medicine*

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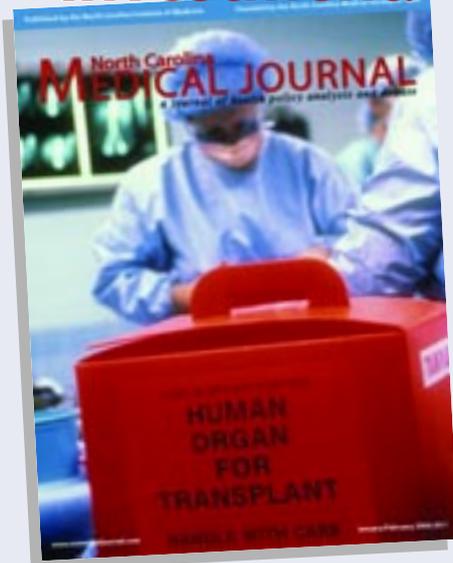
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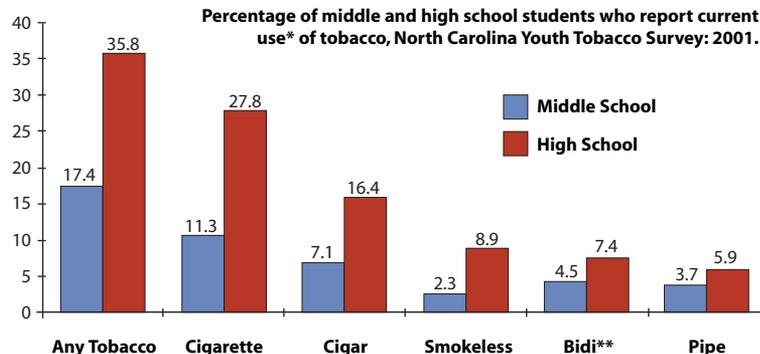
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## Youth Tobacco Use in North Carolina

Tobacco is the leading cause of preventable death in the nation and the state.<sup>1</sup> Many negative health outcomes are associated with tobacco use, most notably lung cancer and cardiovascular diseases.<sup>2</sup> More than 80% of tobacco use starts before the age of 19; therefore prevention efforts among youth are an important opportunity to curb use. Healthcare professionals play a critical role in youth tobacco prevention. Even brief clinical efforts to “ask and advise” lead to a reduction in use or ever starting.

The North Carolina Youth Tobacco Survey (NC YTS) is the largest, most comprehensive source of data on youth tobacco use, behaviors, and attitudes in the state. The NC YTS is conducted in coordination with the North Carolina Department of Public Instruction and the Centers for Disease Control and Prevention. In 2001, more than 10,000 middle and high school students from across the state participated in the survey. The overall survey response rate was 71%. The survey data were weighted to be representative of the entire population of middle and high school students in North Carolina.

Results from the 2001 NC YTS indicate that an estimated 36% of high school and 17% of middle school students had used some type of tobacco on one or more of the past 30 days. There is a marked difference between use by middle (6th - 8th grade) and high school (9th - 12th grade) students for each type of tobacco. Cigarette smoking accounted for the majority of tobacco used in both middle and high school students followed by cigars, smokeless tobacco, bidis, and pipe tobacco. Some students reported using more than one of these types of tobacco during the past 30 days. Most of these percentages are slightly higher than national rates of tobacco use among middle and high school students.



Note: \* Current use of cigarettes, cigars, smokeless tobacco, pipes, or bidis on 1 or more of the 30 days preceding the survey.

\*\* Bidis are small round hand-wrapped cigarettes typically from India.

Based on data from the NC YTS, the state allocated \$18.6 million to address teen tobacco use through the Health and Wellness Trust Fund, created as part of the multi-state Master Settlement Agreement with the tobacco companies. It is hoped that school and community interventions will decrease youth consumption and reduce North Carolina's tobacco-related morbidity and mortality.

1. McGinnis JM, Foege WH. Mortality and morbidity attributable to the use of addictive substances in the United States. Proceedings from the American Association of American Physicians 1999; 111: 109-118.

2. U.S. Department of Health and Human Services. Surgeon General report: the health consequences of smoking. Atlanta, GA:USDHHS, CDC, Office on Smoking and Health, 1981.

*Contributed by Scott Proescholdbell, MPH*

*Tobacco Prevention and Control Branch, North Carolina Division of Public Health*

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## North Carolina Medical Journal: Call for Papers

Herbert G. Garrison, MD, MPH  
Scientific Editor, North Carolina Medical Journal

North Carolina is blessed with some of the finest medical research institutions in the world. The work of the medical scientists that labor in our research facilities becomes complete (in many ways) and public when it is published in peer-reviewed journals.

While medical researchers in North Carolina have many journals to which they can submit their manuscripts, we want them to consider keeping their work here at home. To be more specific, we invite the authors of our state to submit their papers to the *North Carolina Medical Journal*.

The *Journal* seeks papers that convey the results of original research. We are especially interested in publishing research papers that have relevance to the health of the people of our state.

An editor reviews all papers received and those of sufficient quality are peer-reviewed. As with any journal of merit, only papers of high quality will be published. Papers printed in the *Journal* are indexed in the National Library of Medicine's MEDLINE public database.

The *North Carolina Medical Journal* is published six times a year. It is distributed free of charge to the members of the North Carolina Medical Society, the North Carolina Hospital Association, the North Carolina College of Internal Medicine, the North Carolina Academy of Physician Assistants, the North Carolina Board of Pharmacy, the North Carolina Association of Pharmacists, the North Carolina Division of Public Health, the North Carolina Association of Health Plans, and the Medical Review of North Carolina. The *Journal* is available by subscription to others.

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We salute the doctors, dentists, nurses, pharmacists and other health care professionals who generously donate time, skill and financial resources to support North Carolina's free clinics and pharmacies.

In 2003, more than 6,000 volunteers provided more than \$75 million in health care services to 150,000 patients at the free clinics. BCBSNC's own chief medical officer, Dr. Robert Harris, volunteers regularly at the Open Door Clinic in Raleigh. These volunteers are united by one principle: that access to medical care should not be limited by one's ability to pay.

Given the sluggish economy and job losses, free clinics face greater challenges than ever. Most clinics are forced to turn away more patients than they are able to see.

To help address this need, the Blue Cross and Blue Shield of North Carolina Foundation is providing a grant of \$10 million to the North Carolina Association of Free Clinics over the next five years. The grant's goal is to double the number of people that free clinics and pharmacies can serve and to provide statewide access to these facilities. The grant is expected to result in a 50 percent increase in the number of free clinics and pharmacies across our state.

Meeting these ambitious goals will continue to require the commitment of dedicated volunteers. While this grant will provide the impetus for the creation of new clinics, establishing clinics also requires the involvement of community leaders, medical professionals and other volunteers willing to organize and sustain such an effort.

No one entity can solve the problem of the uninsured. However, by continuing to work together, we can all make a big difference.

For more information about free clinics, we would invite you to check out the Web site of the N.C. Association of Free Clinics, at [www.ncfreeclinics.org](http://www.ncfreeclinics.org).

You can learn more about the BCBSNC Foundation at [www.bcbsnc.com/foundation](http://www.bcbsnc.com/foundation).

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