



## Angels in the Carolinas: Interfaith Teams Overcome the Stigma of AIDS

Program to provide services to African-American and rural persons with HIV/AIDS

### SUMMARY

Starting in 1997, a faith-based organization in Charlotte, N.C. recruited and trained members of congregations to help HIV/AIDS patients living in African-American and rural white communities in a 13-county area of the Carolinas.

The initiative by the [Regional AIDS Interfaith Network \(RAIN\)](#) of the Southern Piedmont was a response to the rapid spread of AIDS into the region and the disease's disproportionately high toll among African Americans.

The congregation teams—called CareTeams—provided logistical support, such as meals and transportation, as well as friendship and encouragement.

The project was part of the Robert Wood Johnson Foundation (RWJF) [Local Funding Partnerships \(LFP\)](#) national program (for more information see [Program Results](#)).

In addition to RAIN's work, a separate Charlotte organization—the Regional HIV/AIDS Consortium—made grants to support AIDS education, prevention and treatment services in the same 13-county region.

### Key Results

- RAIN trained 30 new CareTeams in white rural areas and 38 teams in African-American communities.
- CareTeams helped HIV/AIDS patients and family members deal with such difficult issues as depression and addiction.
- RAIN staff conducted 191 educational programs attended by a total of 20,000 people.
- The Regional HIV/AIDS Consortium awarded 48 grants to support HIV/AIDS programs serving a total of more than 24,000 people.

## Funding

RWJF supported the project with a grant of \$350,000 from August 1997 to September 2000.

## INTRODUCTION

Three months after Gregory Doster was diagnosed with HIV, two women he had never met appeared at his front door in Rock Hill, S.C., with food and a proposal: Could seven members of Unity Presbyterian Church in nearby Fort Mill, become his support team?

Doster, 48 at the time, was not altogether surprised by the visit. Earlier he had told workers at the local HIV/AIDS service agency that they could give his name to church members interested in helping. Still, Doster was a little reluctant to accept the offer, his wife even more so; they didn't want his medical condition to become common knowledge in their own community. HIV/AIDS can carry an especially harsh stigma in the small-town South. Doster, however, ended up saying yes to his visitors. "I was a Christian. I felt as though He sent them."

That was July 2000, and it is a decision that neither the Dosters nor the church members have regretted. The African-American couple and the seven Presbyterians, all white, have become close friends, sharing Christmases, birthdays, meals and prayer. When his brother died in New Orleans, the team members helped Doster return for the funeral. When Doster was rejected for Social Security disability benefits, they sought congressional assistance and encouraged him to persevere—and successfully so. "They're family," he says.

Doster, who contracted HIV through intravenous drug use, at one point was down to 98 pounds. But he has since put on 50 pounds, helped by the three drugs (Trizivir, Reyataz and Norvir) that he takes to combat the virus. He believes the team's support was also a factor in his improved health. "It gave me a real spiritual outlook—that there were still people out there who care for me," says Doster, a chef for more than three decades before the illness forced him into retirement.

Susan Bullard, one of the two initial visitors from Unity Presbyterian, says that the intervening years have borne out what she and her fellow team members were told when they went through training: that they would get more out of the experience than would the person they were helping. "He's become an inspiration to us," she says of Doster. "We have established the most wonderful relationship with him."

Gregory Doster and Susan Bullard would probably never have come into contact, much less developed a friendship, had it not been for the Regional AIDS Interfaith Network (RAIN) of the Southern Piedmont—a Charlotte, N.C., organization formed as a faith-based response to the burgeoning AIDS problem in the Carolinas. In 1997, RAIN

mounted a special effort to support African-American and rural white HIV/AIDS patients in 13 North Carolina and South Carolina counties surrounding Charlotte.

RWJF helped fund the effort through its matching-grant program, *Local Initiative Funding Partners*. By collaborating with community foundations and other local givers across the country, the Robert Wood Johnson Foundation *Local Funding Partnerships* program seeks to stimulate innovative, community-based projects that improve the health and health care of underserved and vulnerable populations.

## THE PROBLEM

AIDS (Acquired Immunodeficiency Syndrome) is a disease characterized by a weakening of the immune system. It is caused by the human immunodeficiency virus (HIV), which is passed from one person to another through blood, semen and vaginal secretions.

Deborah C. Warren, a Baptist minister, visited a person with AIDS in South Carolina shortly before the man died at age 27. The experience left her convinced that organized religion was ignoring the disease. "This is what faith communities have been about since time eternal—reaching out to people who are ill and suffering," she says. But that was not happening with AIDS, at least not in her part of the Carolinas. "No one was doing anything about it in the faith community that I could tell."

Warren learned, however, that was not the case in Arkansas. A Little Rock organization—the Regional AIDS Interfaith Network (RAIN)—was training church-based teams to support HIV/AIDS patients with logistics, such as meals and transportation, as well as friendship and encouragement. Warren, who was not pastoring a church at the time, visited the Arkansas program and in 1992 initiated a replication in her home area of Charlotte. Called RAIN of the Southern Piedmont, the organization today serves 13 counties in the greater Charlotte area—10 in North Carolina and three in South Carolina. (See [Appendix 1](#) for the list of counties.)

RAIN got under way as the southeastern U.S. was experiencing a rapid increase in HIV/AIDS cases. The disease, which had been considered largely an urban affliction, was spreading into rural areas. In North Carolina, AIDS was a leading cause of death among young people, with African Americans a disproportionately high number of those who died.

As with the Arkansas program, the main focus of RAIN in North Carolina was on organizing congregations to provide support groups—termed CareTeams—to help people infected with HIV, their partners and families. Although Warren and many of her staff come from the Christian faith, she emphasizes that the organization supports people with HIV/AIDS from other religious traditions as well as those with no faith tradition of any kind. RAIN in North Carolina has organized CareTeams among Jewish congregations as

well as in Christian ones, and some individual Buddhists have participated on teams, she says.

In its first four years, with funding from local sources, the organization enlisted more than 800 volunteers representing 50 congregations, including 10 African-American churches. However, the RAIN staff was small. In addition to Warren, the executive director, there was one full-time organizer, Amy E. Brooks, a Unitarian Universalist minister, and a part-time worker, Stephanie R. Speller-Henderson, a minister ordained in the A.M.E. Zion church.

Warren and the RAIN board of directors wanted to expand the organization in order to reach more congregations, especially in African-American and rural white communities. In both, social attitudes stymied acknowledgment of the disease and efforts to help those suffering from it.

"We have a tremendous number of people in rural counties for whom the stigma of HIV is debilitating. Not the disease, the stigma," says Linda Ashley, executive director of the Catawba Care Coalition, the HIV/AIDS service agency in Rock Hill that includes Gregory Doster among its clients. "In a rural area, the risk of your story getting out is physically and emotionally dangerous."

At the same time that RAIN was seeking to expand its reach, a separate Charlotte-based organization, the Regional HIV/AIDS Consortium, was exploring ways to enlarge its grants program that helps fund AIDS education, prevention and treatment services in the same 13-county region.

Created in 1990 by United Way of Central Carolinas and a community philanthropy named the Foundation For The Carolinas, the Consortium raises money from a variety of private sources. It also administers funds allocated to the region under the Ryan White Care Act, federal legislation that funds primary health care and support services for people living with HIV/AIDS.

In its first five years, the Consortium provided some 110 grants, most of them going to either Charlotte/Mecklenburg County, the area's urban center, or to large agencies serving the entire region. The Consortium's leadership wanted to do more to help small agencies in the rural areas, especially those serving African Americans.

In 1996 RAIN applied to the *Local Funding Partnerships* program for a three-year grant to support a collaborative effort with the Regional HIV/AIDS Consortium. The proposal called for the major portion of the grant and matching funds to go to RAIN, mainly for additional staff to strengthen the organization's congregation-based activities. The application set a goal of recruiting, training and supervising 30 to 60 new CareTeams in rural white areas and 15 to 24 new teams in African-American congregations.

A smaller portion of the money would go to the Consortium to enhance its grants program, especially in rural and African-American areas. The application envisioned the Consortium's making 30–60 grants over the three years.

## THE PROJECT

The *Local Funding Partnerships* national program office staff in Princeton, N.J., viewed the proposal positively. Arkansas RAIN, which had previously received an RWJF grant (ID# 021039) through *Local Funding Partnerships*, had proved effective. RAIN in North Carolina was similar, and collaboration with the Consortium gave the proposal an added component. RWJF awarded RAIN a \$350,000, three-year grant starting August 1997.

The *Local Funding Partnerships* program requires that other supporters match the RWJF funding dollar for dollar. At the end of the grant, RAIN reported the project received \$432,115 in matching funds as follows:

- \$150,000 from the Duke Endowment and \$132,115 from the Kate B. Reynolds Charitable Trust to support RAIN's activities.
- \$75,000 each from the National AIDS Fund and the Foundation For The Carolinas to support the Consortium's portion of the project.

The RWJF grant permitted Speller-Henderson to become RAIN's full-time minority program director responsible for working with African-American churches. Brooks organized white rural congregations and served as project director. Using grant funds, the organization initially hired four part-time regional coordinators and assigned each to a geographic quadrant as the contact for congregations in that area. However, the arrangement proved unsatisfactory; the coordinators had other jobs, leaving them insufficient time and flexibility to fully meet project needs. As a result, the organization combined the four part-time positions into one position, which was filled by a woman who had seminary and social work training but was not an ordained minister. (She has since left the staff.)

The grant also helped pay the salaries of Warren and an administrative assistant. Counting employees funded through other sources, the RAIN staff by the end of the grant period totaled seven, including a development director in charge of fund raising.

RAIN staff members promoted the CareTeam concept to church pastors and congregations; recruited and trained CareTeam members, and supervised the teams through phone calls and meetings. The size of the teams varied from a half-dozen members to more than two dozen. A team could care for one patient or several, depending on the members' preference and capacity.

The RAIN staff worked with social workers and case managers in service agencies to identify HIV/AIDS patients needing and wanting assistance and matched these individuals—termed CarePartners—with congregations. Patients often requested a team from a congregation located outside their immediate area in order to prevent people in their own community from learning of their condition.

The RAIN staff also conducted educational programs on AIDS—generally in church settings but sometimes in community centers and facilities for AIDS patients. Typically, the sessions addressed medical, psychosocial and spiritual aspects of HIV/AIDS, including facts and myths surrounding the disease and the need to avoid risky behavior. In black churches, where Speller-Henderson found the denial of the disease especially strong, the programs provided some congregants with their first opportunity to talk to a pastor about their personal experiences with HIV/AIDS.

For its part of the project, the Regional HIV/AIDS Consortium staff solicited and received grant requests, evaluated the proposals and made site visits. In each December of the project period, the Regional HIV/AIDS Consortium awarded grants to about 15 organizations. The grants ranged up to \$10,000 and supported such activities as patient transportation and AIDS prevention education.

In addition to technical assistance provided informally by phone and in meetings, Regional HIV/AIDS Consortium personnel held five grant-writing workshops throughout the region to help agencies develop proposals. Consortium staff members also met with CareTeams to inform them of resources in their local areas. The executive directors of the Consortium and RAIN met periodically to discuss progress.

### **An Example**

Gregory Doster's case provides an example of how the RAIN program worked. The Catawba Care Coalition, which serves the three South Carolina counties in the RAIN area, began in 1994 in response to the HIV/AIDS explosion. The agency provides medical and social services, and case managers track the condition and needs of patients and their families. With a current caseload of more than 300 clients and a scarcity of resources, the staff welcomes RAIN's involvement.

"Those RAIN teams are our hands and feet," says Ashley. "They are like having six more social workers on a case." CarePartners look upon their team as adopted family, she says. "My clients feel they can call up a team member if they're having a bad day."

RAIN and the Catawba Care Coalition also worked together to establish a local system to supply HIV/AIDS patients with deodorant, shampoo, laundry detergent and other personal care products that cannot be purchased with food stamps. Church congregations

take turns keeping a room in a Rock Hill church building stocked with donated items that clients can draw on once a month free of charge.

Fearful of broadcasting their illness, not all clients want a CareTeam, says Ashley. But Doster, a Catawba client, was willing to consider the possibility, and with his permission the staff referred his name to RAIN. Meanwhile, Amy Brooks was organizing a new CareTeam at the 900-member Unity Presbyterian Church in nearby Fort Mill. At a church gathering she briefly explained the CareTeam program and invited anyone interested to a separate, more in-depth meeting.

Susan Bullard was among the church members who responded and later underwent a weekend of training. Brooks, the instructor, provided information about HIV/AIDS and how CareTeams can help people who have the virus. Bullard and her colleagues also heard from veteran team members and CarePartners about their experiences—a service Bullard's team now performs for new teams in other churches.

Unity Presbyterian ended up with enough volunteers to form two teams. Susan Bullard's had seven members, ages 17 to 70—all of them now good friends as a result of their team participation, says Bullard, who is office manager for a family mental health agency in the area. Her team has two other CarePartners besides Doster. One is a woman who has strong family support and wants only a phone call every now and then. The other is a man who needs transportation because his family is not aware of his condition. "Amy Brooks taught us you meet your partner where the need is," says Bullard, the team co-leader.

## Challenges

Misperceptions presented the RAIN staff with major hurdles. In the African-American churches, Speller-Henderson found homophobia an especially strong barrier to overcome. "There was so much fear (and) a lot of myths that people had," she says. One problem was that a number of black ministers viewed the disease as a gay white problem and resisted the idea that some of their own parishioners might be people with AIDS. "There was a lot of denial: 'This is not in my church.'"

Also, some black ministers believed the disease was God's punishment and thus they saw a theological basis for shunning people who had it, she says. The outlook of some clergy was that since these were churchgoers, they could not possibly have the disease in their lives. At the funeral of a person with AIDS, she says, the pastor might attribute death to cancer or another illness, not understanding the underlying cause.

One reason ministers were unaware was that family members were afraid to disclose the disease, says Speller-Henderson. Gregory Doster agrees that African Americans with AIDS are too willing to hide that fact. "There's an old African proverb: He who conceals

his disease cannot be healed. I really believe that," says Doster, who now makes public presentations about his own condition.

Speller-Henderson, who is African-American, sought to overcome many of these difficulties by arranging small discussion groups of ministers. When she established a relationship with a pastor, she encouraged him to invite colleagues to a get-together around a meal provided by RAIN. In these collegial forums, she disseminated statistics about AIDS, including its presence in the local African-American community. For example, about 70 percent of the Catawba Care Coalition's clients are African Americans—more than twice the proportion of blacks in the area's overall population.

As a fellow minister, Speller-Henderson was also able to discuss AIDS from a religious standpoint and address ministers' theological concerns. She gave out information about community resources available to people with AIDS—information the ministers could pass on to congregants who confided in them.

These sessions often resulted in invitations to Speller-Henderson to conduct education prevention programs in the participants' churches. She also attended Sunday services and other regular church functions. "The major piece is we established trust," she says. "We haven't changed everyone's mind, but they're willing to listen to us." One sign of progress was that at a black Baptist church program in North Carolina's Stanly County, the host pastor shared—for the first time in public—the fact that his brother had died from AIDS.

The effort paid off in the development of more African-American CareTeams than RAIN had expected. On the other hand, the effort in rural white communities proved slower and more difficult than anticipated. In its initial years—before receiving the RWJF grant—RAIN made rapid progress among white congregations. But once into the grant period, the staff found what Warren calls "a growing complacency" toward AIDS in the white churches. With the availability of new, more effective medications, concern about the disease seemed to decline, she says. Finding ways to reach the rural white population was a continuing challenge—and the results were disheartening at times, RAIN reported to RWJF.

The scarcity of case managers at some social service agencies was also a problem, making it difficult for RAIN to identify CarePartners in some areas. One county was without an HIV/AIDS case manager for a year and a half.

## RESULTS

RAIN reported the following to RWJF at the conclusion of the grant period:

- RAIN trained 30 new CareTeams in white rural areas and 38 teams in African-American communities. This went contrary to initial expectations and project plans that more CareTeams would be recruited in white rural areas. The majority of these

new teams came on line in the third year—a reflection, says Warren, of the amount of preparatory work necessary with pastors, church boards and congregations.

- CareTeams helped HIV/AIDS patients and family members deal with difficult issues, such as depression and addiction, and prevented an unknown number from giving up or giving in. As an example, a rural CarePartner with HIV/AIDS told the RAIN staff that at one point she wanted to use crack so badly that she could smell it. She called a CareTeam member, who came to her home and talked until the craving had passed. "With the help of my CareTeam and God, I am able this week to celebrate two years clean," the RAIN staff reported the woman as saying.
- RAIN staff conducted 191 educational programs attended by a total of 20,000 people. The grant proposal had projected 72 educational programs. The staff also conducted 15 continuing education programs for CareTeams.
- The Regional HIV/AIDS Consortium awarded 45 grants to support HIV/AIDS programs serving a total of more than 24,000 people, many of them in rural and African-American communities. Included were AIDS prevention programs for at-risk and potentially at-risk individuals as well as programs to help people who already had the disease. The grants included \$85,000 in RWJF money as well as funds from other sources. RAIN itself got a grant in each of the three years to support its outreach efforts in African-American areas. (For a list of all grantees, see [Appendix 2](#).)

## Communications

RAIN publicized the project's objectives and activities through its newsletter, *RAINdrops*. It also issued written press releases about CareTeam training sessions and RAIN fund-raising events. (After the RWJF grant ended, RAIN launched a [website](#) with information on the organization's purpose and activities.)

RAIN and its staff received frequent coverage in the *Charlotte Observer* and other publications in the region. An example is the article that appeared April 14, 1998, in the *Enquirer Journal* of Monroe, N.C., under the headline "RAIN group pours on compassion." The article began, "An organization called RAIN is giving area churches the chance to practice what they preach when it comes to helping others."

RAIN staff member and board chair Michael Kennedy made presentations in several forums, including a session of the U.S. Conference on AIDS in Miami in September 1997. At CareTeam training sessions, RAIN distributed educational materials on HIV/AIDS and the extent of the disease in the Carolinas. In February 1999, RAIN and the University of North Carolina-Charlotte co-sponsored a local display of the Names Project AIDS Memorial Quilt. RAIN and the Consortium staffed booths at the display site, which drew 4,000 to 5,000 people.

The Regional HIV/AIDS Consortium publicized its grants program by mailing requests for proposals to agencies in the area. It also included information in its newsletter, *Update*.

## LESSONS LEARNED

1. **Pastors need help with business planning and fund raising.** RAIN enlisted business and marketing consultants who provided a step-by-step plan for an administrative reorganization and recommended that the board become more heavily involved in fund raising. The project director readily concedes that, as pastors, she and most of her staff had a lot to learn in those areas. (Project Director/Warren)

## AFTERWARD

After the RWJF grant ended, RAIN initially had difficulty making up the lost revenue. However, the organization eventually tapped other sources of funding and survived without staff cutbacks. It now has slots for nine employees and oversees 85 to 90 CareTeams working with a total of about 150 CarePartners, according to Warren.

Funding comes—in roughly equal shares—from North Carolina foundations, individual donors and community fund-raising events. Gay Bingo, a regular series of bingo games in Charlotte, is a major fundraiser for RAIN, bringing in \$80,000 in 2003. The games are supposed to be fun as well as financially helpful; their motto is "A straight line never wins at Gay Bingo, but our straight friends are always welcome." In May 2004—following a feature article on the games in the *Charlotte Observer*—Gay Bingo night drew a record 1,200 people—so many that some had to be turned away for lack of room.

RAIN also raises money by organizing annual AIDS walks in Charlotte. The 2004 walk—held May 1—brought in \$110,000, up from \$60,000 in 2003. The increase stems at least in part from a new [website](#) set up by RAIN to promote the walk.

RAIN also asks churches forming CareTeams to make a contribution to RAIN, although Warren says there is no required amount. The organization has office space in the First United Methodist Church in downtown Charlotte. The space is donated, but RAIN makes a \$200 monthly contribution to the church, Warren says.

RAIN has received national recognition, and the honors have been persuasive with donors as well as gratifying to volunteer workers, Warren says. In 2002 Warren, Brooks, Speller-Henderson and a fourth staff member, Debbie Kidd, a Baptist minister, were among recipients of the Ford Foundation's Leadership for a Changing World award. In March 2004 RAIN was one of seven recipients of the annual Common Ground Award given by Search for Common Ground, an organization in Washington and Brussels, Belgium, that promotes conflict resolution.

Another factor in RAIN's survival, says Warren, is that the organization enlisted the help of two business and marketing consultants after the RWJF grant ended. The consultants provided a step-by-step plan for an administrative reorganization and recommended that the board become more heavily involved in fund raising.

In 2003, Speller-Henderson left the full-time staff to enter an education program in counseling, although she continues to work part-time for RAIN as a consultant. Her assistant, Carl Arrington, a Methodist minister, succeeded her as minority director. The Regional HIV/AIDS Consortium continues to support area agencies with grants totaling \$90,000 to \$115,000 a year.

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## **APPENDIX 1**

### **13 Counties Served by the Regional AIDS Interfaith Network of the Southern Piedmont**

*(Current as of the end date of the program; provided by the program's management; not verified by RWJF.)*

#### **North Carolina**

- Anson
- Cabarrus
- Cleveland
- Gaston
- Iredell
- Lincoln
- Mecklenburg
- Rowan
- Stanly
- Union

#### **South Carolina**

- Chester
- Lancaster
- York

## APPENDIX 2

### Grants Awarded by the Regional HIV/AIDS Consortium during the RWJF Grant Period as Reported by the Regional AIDS Interfaith Network (RAIN) of the Southern Piedmont

(Current as of the end date of the program; provided by the program's management; not verified by RWJF.)

PROJECT YEAR ONE	
Alliance for Children and Youth	\$2,286 for prevention education
Anson County Health Department	\$7,285 for case management of people with AIDS
Brothers United for Change	\$10,000 for AIDS prevention efforts
Charlotte Area Health Education Center	\$3,390 for substance abuse/AIDS education
Cleveland County Health Department	\$4,000 for transportation
Catawba Care Coalition	\$6,400 for food and nutrition supplements
Grace Lutheran Church	\$2,500 for prevention education
Hispanic Latino Community Center	\$5,000 for prevention education
Hospice of Union County	\$2,600 for nutritional supplements
Iredell County HIV/AIDS Task Force	\$5,000 for a volunteer coordinator
The Listening Center	\$1,600 for prevention information
Metrolina AIDS Project	\$10,000 for African-American outreach
Regional AIDS Interfaith Network	\$7,500 for African-American outreach
Positive Connections	\$2,500 for an information and referral service
PROJECT YEAR TWO	
Anson County Health Department	\$6,000 for case management support
Brothers United for Change	\$8,000 for outreach programs among African Americans
Catawba Care Coalition	\$10,000 for a part-time HIV/AIDS clinic
Cleveland County Health Department	\$2,000 for transportation
Gaston County Health Department	\$5,000 for outreach among "high-risk" women
Gaston Hospice	\$6,934 for prevention
Hospice of Union County	\$2,080 for meals
Iredell County AIDS Task Force	\$4,365 for access to care and services
Mecklenburg Council on Adolescent Pregnancy	\$10,000 for a health educator
Regional AIDS Interfaith Network	\$5,000 for implementing CareTeams and services
Rowan Regional Hospital and Home Health	\$10,000 for case management and services
Stanly County Health Department	\$6,000 for case management and services and \$1,000 for prevention education
Union County American Red Cross	\$1,000 for prevention education

Union County AIDS Task Force	\$1,000 for prevention education
York County AIDS Task Force	\$3,000 for medications, transportation and other assistance
<b>PROJECT YEAR THREE</b>	
(RAIN did not report the dollar amounts of the third-year grants, and the consortium's executive director says those records are no longer readily available.)	
AIDS Council of Gaston County	for prevention education
Catawba Indian Nation	for an educational conference
Cleveland County Health Department	for transportation
Friendship Trays	for food and nutrition
Hospice of Union County	for food
Kings Mountain Baptist Association	for food and nutritional supplements
Legal Services of Southern Piedmont	for legal assistance
Loaves and Fishes	for food
Metrolina AIDS Project	for educational opportunities and a second grant for risk-reduction information and service coordination
Regional AIDS Interfaith Network	for work in African-American communities
Rowan Regional Home Health and Hospice	for awareness and prevention and a second grant for case management
York County AIDS Task Force	for emergency assistance
York County Teen Pregnancy Coalition	for education

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