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Section E

AIDS activists take their message, at right, to City Hall recently, urging government leaders to give priority to AIDS research, education and care. Below, David George (left) and David Conlee display their message. At far right, Rodney Blake's face is painted to show his grief for those who have died.



Photos by Steve Gonzales/Staff



Kansas City faces up to AIDS

By Lynn Horsley
Of the Metropolitan Staff

In the three years since the Good Samaritan Project became Kansas City's first grass-roots organization to deal with AIDS, a growing number of individuals and agencies have mobilized to battle the epidemic.

Dedicated advocates have come and gone, attacking the problem intensively until the fight saps their energy and zeal. But fortunately for Kansas City, reserve foot soldiers always seem to be waiting in the wings.

The following profiles feature four persons who are serving in the front lines of this war. They have different styles, personalities and roles, but they share dedication and conviction to their cause.



JON D. BARNETT

Jon D. Barnett is an angry young man. In the fight against AIDS in Kansas City, he is the contentious rebel, sparring with others on the front lines, inflaming emotions that others would rather squelch.

He approaches the battle against AIDS with a fervency that makes him impatient with those who don't share his obsession. His interest is so intense that for months he gave up his construction business to devote full time to educating himself and monitoring the Kansas City community's response to the epidemic.

Where others see progress, he sees room for improvement; where others seek to work quietly through established channels, he is the outsider who motivates by dissent, intolerant of complacency.

Ten months ago, he founded the local chapter of the AIDS Coalition to Unleash Power, a political advocacy group that perceives the fight against AIDS as tantamount to a war. The small core of ACT-UP activists meets weekly and has staged demonstrations and dramatic "die-ins" against businesses that discriminate against employees with AIDS.

They picketed outside a chain of convenience stores when it denied medical coverage to people with AIDS, and provided moral support to an AIDS sufferer who sued his employer after he was fired.

At City Council and AIDS Council meetings, Barnett is the one who can be counted on to speak up for AIDS funding, improved medical services and anti-discrimination measures, goading those who would prefer to ignore him into addressing his concerns.

He risks alienation from friends, who sometimes can't comprehend his sense of urgency, and confrontations with prominent city leaders, who bristle at his aggressive tactics.

"They don't represent the gay community," says Sandy Berkley, Mayor Richard L. Berkley's wife and a strong advocate for AIDS causes. "They just represent a handful of way-out screamers and yellers."

Sandy Berkley is not alone in her view that ACT-UP harasses precisely those who are trying to help people with AIDS. Barnett has his share of critics who contend he would accomplish more if he behaved diplomatically rather than combatively.

Neal Colby, executive director of Catholic Charities, says it is easy to write off ACT-UP as a "small group of zealots" with a "peculiar penchant for alienating people."

But Shirley Fearon, chairman of a committee of AIDS service providers, says ACT-UP fills a definite advocacy purpose, taking on the establishment in a way that traditional health care agencies

See BARNETT, E-4, Col. 1



SCOTT BARROW

Credit Dan Rather for getting Scott Barrow involved in the fight against AIDS.

While he was living in Denver in the fall of 1986, Barrow tuned in one night to Rather's television special "AIDS Hits Home," when it truly hit home for him.

The program included a segment on Kansas City's Good Samaritan Project, the only AIDS hospice in the four-state area of Missouri, Kansas, Iowa and Nebraska. The segment featured an interview with a hospice resident whose face was blacked out but whose voice was distinctive.

"It was a friend of mine," says Barrow, who had lived in Kansas City before moving to Denver. "That's when I thought I wanted to get involved."

He moved back to Kansas City in December 1986, applied for a position at the six-bed hospice and was hired that spring.

The first night Barrow spent as a resident advocate at the hospice — March 18, 1987 — was also the first night he watched someone die. Not since he was 14, when his grandfather died, had he experienced death close up.

Three months later, Barrow became the director of the hospice, where death is a frequent presence. Barrow's role is to create a home where AIDS sufferers can live out their last days with dignity.

It wasn't that way in the early days. Barrow says that when he first started in his job, the hospice did not have the status of a nursing care facility, so when someone died, the police had to be called.

"The whole place would take on a carnival atmosphere," Barrow recalled. "There would be two squad cars, the paramedics had to come, two firetrucks and a hearse. The neighborhood would converge on the front fence waiting for the body to come out."

Three times, Barrow endured such a scene, and then he decided enough was enough.

As housing director, he arranged with the county coroner to declare the hospice a nursing care facility, to keep the funeral arrangements as discreet as possible. Now, the funeral homes can just send a van to the back, and the neighbors aren't even aware of it.

Where once staff and volunteers at the hospice were harassed as they came and went from the home, now they are tolerated. One neighbor even cooks a big pot of spaghetti or stew from time to time for the residents. But Barrow still prefers to keep the address confidential to prevent a backlash of hostility.

Barrow and the residents see his role as that of a benevolent parent, making sure the home runs smoothly.

See HOSPICE, E-4, Col. 1



STEVE HUMMEL

When Steve Hummel was an assistant director for Harvesters — The Community Food Network, he learned how to work cooperatively with 400 pantries, soup kitchens and other non-profit agencies to combat hunger.

Now he is bringing those same networking skills to the fight against AIDS.

As the director of the Good Samaritan Project since last December, he has striven to stabilize that agency's relationships with hospitals and other health care providers.

In this public health crisis, where politics and personality clashes often override humanitarian concerns, and where turf battles can turn competitive, he eschews power plays. His is a calming presence in turbulent waters.

Other social service providers that had turned their backs on the Good Samaritan Project last summer now say there is a new team spirit, and a concerted attempt to avoid duplication of effort or competition for the same funding.

Hummel, with his clean-cut, no-nonsense administrative approach,

See VETERAN, E-4, Col. 1

lots of weight and not responding to medication.

"I thought this was it," he recalled, "because in the media and everything I knew, if you had this, you died."

A priest administered last rites at his mother's insistence. He thought his reputation in the community, where he was a fashion consultant to the carriage trade, would be ruined.

He was frightened. He felt alone and thought the only people who cared were his immediate family and his lover.

But there were others who cared, beginning with the nurses.

"They saw me only as a human being. They didn't look at me with judgment. They made me feel all right, because I didn't feel all right at the time."

Doctors began administering pentamidine to attack the pneumocystis pneumonia, and his body started to respond.

Then came a pivotal event that was as motivating mentally as the medicine was physically. Baptist was a member of the Heartland Men's Chorus, scheduled to give a concert that November to benefit the Good Samaritan Project.

Another chorus member, Phil Bundy, was supposed to read a poem about one man's personal struggle with AIDS at the concert. But he died of AIDS three days before the performance.

The other members of the chorus visited Baptist in the hospital to ask him to take Bundy's place. Baptist said he would do it, against doctors' orders. It was his declaration

of independence and survival.

He eventually returned to work part time, where his fears about his reputation were assuaged; his employer and customers were concerned and humane.

But twice he returned to the hospital, once for complications of the powerful medicine he was taking and once for a repeat bout of pneumocystis. He has since stopped working so he can concentrate his energies on protecting his health. He has nursed a mild case of pneumonia for more than a month. Fatigue is a frequent companion.

"The first issue is my life, myself. I won't overstress for anyone," he explains.

Yet he puts in about three days a week volunteering with the AIDS-affected community, serving on education committees, giving talks and providing counseling.

His lover has the virus, but so far it is dormant. Baptist doesn't like to think about how he would cope if his lover got sick; his partner is the calm, efficient one in a crisis, while he is the emotional one.

At 32, Baptist has had to deal with issues that most people don't confront until they are 70 — making a will, assigning durable power of attorney. And the staggering medical bills — up to \$15,000 in one month — are an ever-present worry even with private insurance.

But for now, he retains his energy and enthusiasm. He refuses to eat, breathe and sleep AIDS. He relishes the theater, movies, time with friends.

"You have to set yourself back from it. A lot of people are so focused that they have lost themselves."

ANTHONY BAPTIST

Anthony Baptist's positive attitude comes across loud and clear on his telephone answering machine, from which his exuberant message wishes everyone a "great day and a great life."

He's wishing it for himself too. He isn't dying of AIDS. He is living with AIDS.

Don't call him an AIDS victim. He has transcended the victim stage to become a survivor.

He symbolizes the new generation of hope that has become a sustaining force for many in the AIDS-affected community. New drugs are prolonging life, and a healthy mental attitude is enhancing the quality of that life for many people with AIDS.

"I'm no exception," Baptist says. "We are ordinary people with extraordinary circumstances, and I'm dealing with it."

Baptist had just returned from a camping trip in October 1987 when he fell seriously ill. He had suffered flu-like symptoms while camping and thought he had asthma. "I didn't perceive myself as associated with anything to do with AIDS."

But the diagnosis at the University of Kansas Medical Center left no room for doubt, and his health failed rapidly. There was so little time emotionally to process what was happening; one week he was camping, the next week hospitalized with a rare form of pneumonia, losing



Talk helps in the daily choice to live

By Lynn Horsley
Of the Metropolitan Staff

Every Thursday evening, a group of 20 to 25 men gathers at a congenial location in Kansas City to talk about the one thing they all have in common — the AIDS virus.

They have come together once a week for more than two years, sharing laughter and tears, fears and frustrations, camaraderie and comfort. They swap tales of their physical ailments and tips on promising treatments. They share advice on insurance and disability benefits. They mix gallows humor with poignant philosophy, deflecting despair with wry wit.

It is one of several support groups in the city for the so-called "HIV challenged" — those who have been diagnosed with the human immunodeficiency virus.

Some of the members appear fit and tan and have suffered few symptoms, while others are battling serious bouts of nausea and internal infections.

Some meetings are emotional, others stoical. Some meetings deal intensely with death and dying, while at others the word AIDS hardly is mentioned.

At one recent meeting, a man seeks advice on how to deal with his mother, who has always before been very optimistic. Suddenly, he says, she has become overprotective and has started "acting like I'm not

"I know what it's like to stare down one road that leads to death and one that leads to living. It would be very easy to let yourself go. You make a daily choice to live."

T.J.

going to get well."

"We've dealt with anger before," the man explains. "This time, it's more fear. Not that I'll die. That I'll hang on and suffer."

"How many times can she be brave?" one man points out, reminding the group that mothers aren't supposed to lose their children.

"I'd confront her," another advises.

"Get it out in the open, if it breaks out in a crying session, so be it," a third counsels.

"I'd tell her to get a grip," says another, as everyone laughs in agreement. They are the ones with the disease, yet often they cope better with it than family members.

Mike, the group coordinator, confides that in the four years since he was diagnosed, he has experienced

the full roller-coaster of emotions, and has found he feels better when he "gets the focus off me" and onto others.

"I had never allowed my mother to share her concerns with me, until a few weeks ago," he says. "It never dawned on me she would be angry, and sad."

On another Thursday evening, the conversation runs the gamut of topics. One man tells of getting a spinal tap, then of watching his sister give birth to a six-pound baby girl.

There is talk of the international AIDS meeting at Montreal and encouraging work on a vaccine by Jonas Salk, the same pioneering physician who developed the polio vaccine.

The disease is still new enough that even the language of AIDS is evolving, and the acronyms abound. First it was PWA for Persons With AIDS, and now it's PLWA, for Persons Living With AIDS.

"Who came up with the term HIV challenged?" one member asks. "I hate that expression."

"Somebody on Jeopardy," someone quips.

"Challenged gives the term you're not giving up," a group facilitator explains. "It's better than AIDS victim."

"Well, we are victims," says the first man, matter-of-factly. But

many people with AIDS want to bury the word victim and the mentality that can accompany it.

There is a strong group dynamic at work, a refreshing absence of self-pity. Members unflinchingly compare notes on hemoglobin counts, transfusions, and catheters. They calmly discuss cytomegalovirus, an infection that can cause blindness, and how to fend it off.

The group leader, Michael, gives an update on his brother, who is seriously ill. "Back in August, his doctor told him he would live only 18 months."

"And he believed her?" another man asks.

"I wouldn't go to a doctor who told me how long I had to live," a third insists.

There is some criticism of an AIDS service organization, but Mike says he has learned he can't completely rely on any AIDS agency for his well-being. "It is up to us to do what we have to do to make sense of our situation," he says.

These are men who have chosen to take charge, to confront adversity in a collective affirmation of friendship, support and hope.

"I know what it's like to stare down one road that leads to death and one that leads to living," says a young man named T.J., as the meeting concludes. "It would be very easy to let yourself go. You make a daily choice to live."

Veteran activist brings skills to AIDS fight

Continued from Page E-1

gets much of the credit for that turnaround.

"He has done a super job," says Sandy Berkley. "He wanted to work with everybody."

Hummel puts his philosophy simply: "We need to concentrate on the person with AIDS rather than the politics."

He points out that the politics of AIDS has polarized virtually every large city across the country.

But now, in Hummel's view, "Kansas City has an opportunity to turn it around and show unified force, so we don't end up with scores of AIDS service providers fighting for the same dollars."

Good Samaritan continues to be Kansas City's foremost direct service agency for people with the virus that is believed to cause AIDS. It

provides emergency assistance, support groups and counseling for about 230 people with the virus and 100 of their family members.

It has established a good relationship with the SAVE Home hospice, the Kansas City Free Health Clinic, and HARC, the Heartland AIDS Resource Council, which runs a free market for people with AIDS.

Hummel still looks back with some wonderment at how he got the job.

In April 1988, he and a group of friends organized a local presentation of the huge NAMES quilt dedicated to people throughout the country who had died of AIDS. Hummel later contributed a panel to the quilt for a best friend who died of AIDS last summer.

Inspired by the success of the quilt project, the sponsors decided to turn their talents to other AIDS

causes, and they created HARC. Hummel served on HARC's board, and learned that Good Samaritan, which had endured a tumultuous summer, was seeking a new director.

He submitted his resume, and his community networking experience convinced the board he was the best for the job.

"I had a very strong feeling he could mend the bridges that had fallen," says Good Samaritan board chairman Jim Rieger. "He absolutely has done that."

Rieger says Hummel and the board have developed strategic plans and firm financial controls for Good Samaritan, giving the agency a "new emphasis on professionalism."

Hummel's vision for coping with the epidemic calls for ever-closer cooperation with other agencies to

reduce costs. This fall, Good Samaritan, SAVE Home and HARC will create a shared computer data base with information on volunteers and clients.

Within the next several years, he envisions establishment of a "whole person" center for people afflicted with the AIDS virus, providing day care, art therapy, testing, workshops and education.

He is also striving to create a supportive environment within Good Samaritan to prevent the rampant turnover among the staff and volunteers that has existed in the past.

"The nature of a crisis disease burns people out quickly," he said. "You end up reinventing the wheel over and over. . . . We need to be in there for the long term, the long haul."

Hospice director helps makes a home for the last days

Continued from Page E-1

The hospice is financed by the SAVE Foundation, and Barrow is also involved in the foundation's efforts to provide several units of alternative housing for people with AIDS who have no other support system.

In May, he finally was able to hire an assistant, a welcome respite because he had not had a weekend off since last August.

He has endured some rough times, most specifically last summer, when the shelter was on the verge of closing because of lack of money. "I envisioned myself sitting on the front porch with six guys."

But the community swiftly raised \$50,000, which helped the hospice limp along until December, when the Missouri General Assembly approved \$100,000 for this year.

The requiem Mass, performed May 25 by the Kansas City Sym-

phony, raised nearly \$100,000. Together, those funds should keep the hospice solvent for about two years.

The home frequently has a waiting list, which at times includes as many as 12 names. During the first five months of this year, eight AIDS patients on the waiting list died in hospitals before spaces became available at the home.

From the time it opened in September 1986 through May of this

year, the home housed 59 men, 56 of whom died. The other three "came in at death's door" but recovered enough to live elsewhere.

AIDS sufferers frequently commit suicide, but so far Barrow has not had to confront any attempts at the hospice.

"The survival instinct is so strong," Barrow observes. "Physically they have no reason to be alive, but they are that scared that they can't let go."

Barnett isn't shy of controversy

Continued from Page E-1

cannot.

Steve Hummel, executive director of the Good Samaritan Project, has at times been on the receiving end of ACT-UP's persistent prodding. Yet he credits the organization with performing a vital role, as "the spur to the community, the conscience."

Barnett bluntly explains his provocative approach toward the silent majority: "I'm convinced no one else will speak out. If I remain silent, then I'm responsible for the continuing lack of action."

Barnett, 32, wasn't always so angry, or so motivated.

There was a time when, like so many other gay men in Kansas City, he preferred to believe the disease was remote, isolated on the East and West coasts. Only when a close friend suddenly went into the hospital 18 months ago and almost died did he wake up to the fact that AIDS was a local threat. Now he dedicates his life to waking others up.

Barnett's own health concerns fuel his consciousness. He has been

tested five times in the last five years for the virus that is believed to cause AIDS. So far, the tests are negative, but Barnett is skeptical of how reliable the tests really are. And he suffers along with friends who test positive.

Sometimes he feels the fight is hopeless, that it already might be too late, that the heterosexual mainstream won't join the fight until their friends start dying.

He doesn't claim any special foresight. "I'm as guilty as everyone else. I didn't get involved until it hit me personally. I ignored it for five years too."

He is making up for lost time. "Anger comes after apathy, denial," he says. "I hope I never move out of anger. It empowers me. The danger is when you keep the anger in."

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