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Angels in Our Midst

Angels on the Web: Helping Children and Their Families Cope With AIDS

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Abstract and Introduction

Abstract

Angels in our Midst features stories of healthcare workers who reach underserved groups without the resources or opportunities for good healthcare, such as teens, the poor, the incarcerated, the uninsured elderly, or those in third-world or emerging nations. If you are an "angel" or know of someone who is, drop us an email at hgoldhagen@webmd.net and let us know how the person or program is improving the health of the world, especially if the program can be adapted or followed by others.

Introduction

HIV infection ranks as the seventh leading cause of death for US children aged 1-4 years.^[1] According to UNAIDS, 11.8 million children and adolescents are living with HIV/AIDS in the world today.^[2] But it is not only illness and imminent death that loom over HIV-infected children; it is also the threat of losing their parents, who are often also HIV-positive, and the general feelings of deprivation and isolation that characterize a life of chronic disease.

Almost all HIV-infected children acquire the virus through perinatal transmission. The risk of perinatal transmission is increased if the mother has advanced HIV disease, increased levels of HIV in her bloodstream, or a low CD4+ cell count; if she uses intravenous drugs; or if she breastfeeds. Before 1985, when screening of the nation's blood supply for HIV began, some children were infected through transfusions of HIV-contaminated blood; less commonly, children have been infected by HIV-infected adults during episodes of sexual or physical abuse.^[3]

For about 20% of HIV-infected infants, the symptoms of the disease become severe in the first year of life; most of these children die before their fourth birthday. The remaining 80% of infected children have a slower rate of disease progression, many not developing full-blown AIDS until they reach school age or become adolescents. Children with HIV are visited by numerous and frequent bacterial infections — if severe, these infections can cause seizures, fever, pneumonia, recurrent colds, diarrhea, dehydration, and other problems that often result in extended hospital stays and nutritional problems.^[3]

The vast majority of children in the United States suffering from HIV disease belong to minority groups and live in inner cities, where poverty, inferior housing conditions, substance abuse, poor nutrition, and limited access to medical care prevail, compounding the nearly overwhelming challenges these children face. Many HIV-infected children come from homes in which the entire family is infected. Parents who are HIV-positive often have diminished energy and may be overwhelmed by depression, anxiety, and grief — and therefore have an impaired ability to care for their children. Or, the HIV-infected child may be living with aging grandparents who have their own chronic health problems, or with foster parents who are struggling to meet the needs of a sick child.^[4]

Someone Out There Cares

Improving the quality of life of HIV-infected children, particularly those who are economically disadvantaged, is the mission of several organizations that are donating their time, efforts, and financial resources to help these youngsters cope with their disease. These charities, which are truly making a difference in people's lives, are also working toward spreading awareness and education in an effort to prevent the AIDS crisis from claiming even more victims in the future.

Angelwish, Inc.

When Shimmy Mehta, Founder/CEO of Angelwish, was in college, his fraternity house happened to be across the street from a care center specializing in HIV and AIDS care; the center catered largely to a pediatric population. Some students would have walked by the center without stopping to think much about it, but not Mehta. He and his frat brothers felt bad for these kids and started buying holiday presents for them. "We would go to the care centers and ask about the types of gifts the children would like. We found out that they didn't want the big things in life. These kids were lacking such things as a simple watch, or a basketball to play with." It occurred to him that he could ask the center staff for lists of things the kids wanted, and then use that list to drive fundraisers. Over a 3-year period, he organized numerous 3-day, 300-mile bike rides to raise money for the care center and for gifts for the children. "That is where the idea for Angelwish originated," says Mehta. "We realized that we could begin to grant the children's wishes, by connecting donors with the people who work with the children."

Angelwish raises awareness among potential donors through the Internet and by placing informational postcards in New York City City restaurants throughout the year. The organization also contacts community relations representatives at companies and provides instructions on how their employees can make online donations to children living with HIV/AIDS through Angelwish. This has been extremely effective, says Mehta, because he can send a single email about the program to a company, and that point person can disseminate the information to hundreds or even thousands of employees. As an example of this effectiveness, through its connection with Goldman Sachs, Angelwish was able to grant over \$65,000 worth of gifts to children living with HIV/AIDS last year.

Mehta has gotten some corporate financial support, but he is doing the lion's share of financing the Angelwish Web site. At this point, the charity is working with 57 care centers in 20 states, encompassing a population of close to 10,000 children. It has facilitated donations to over 1800 children. No small feat, when you consider that the organization was founded in June 1999. Mehta's goal is to identify a population of about 75,000 children nationally, or about 260 care centers. Based on his projections, by 2005, Angelwish could be facilitating \$6 million in annual donations. His tireless efforts have begun to earn him the recognition he deserves. Last year, Angelwish was awarded the 1809th Daily Point of Light Award. (For more information about this awards program, see <http://www.pointsoflight.org/dpol/ProgramInfo.htm>.)

Check out the Web site for yourself. You can select a care center in your area and view the listing of children in that particular center. When you select a care center, you will automatically link to a list of toys and other gifts these children would want to receive. You then simply provide your billing information, and the purchase and delivery of the gift to your selected child will be taken care of.

Children With AIDS Charity

A few years earlier, when Shimmy Mehta was just a teenager, a group of hospital employees in Paddington, United Kingdom, were embarking on a project similar to that of Angelwish. Recognizing an urgent need to provide services to children infected by HIV or affected in some way by HIV/AIDS, they banded together with the parents of some of the youngsters they were caring for in the pediatrics department of St. Mary's Hospital to form the Children With AIDS Charity (CWAC).

Since 1992, CWAC has been helping children in a variety of ways. Their Hardship Fund offers financial assistance to families with a child infected or affected by HIV/AIDS who are experiencing difficulties in meeting the costs of essential goods and services (such as fuel expenses, winter clothes, linens and blankets, and food). These families are often financially challenged because there is only 1 parent or because the parent with HIV/AIDS is unable to work.

The CWAC Holiday Fund addresses quality-of-life issues by making it possible for these children to receive gifts at holidays and thus feel more like other children. Many children of AIDS patients don't know the exact nature of a parent's illness because of the stigma still attached to this disease, so they are living in an environment of secrecy and isolation.

CWAC's Transport Service provides private transportation to children and their families attending hospital. It is operational in several areas throughout the United Kingdom, including Birmingham, Dundee, Edinburgh, Glasgow, London, and Manchester.

The organization's educational initiatives include dissemination of informative videos and booklets. One video, called "Problem?," describes the real risks of transmission and is used in primary schools and at adult training centers, health promotion units, and nurse training colleges. Another video, "HIV: Risky Business," is aimed at 12- to 15-year-olds and instructs them about safe sexual practices, the risks of drug use, and how to protect themselves against HIV. The booklet "Talking to Children About Illness and HIV" is distributed to health professionals and families. In addition, CWAC has established an information resource center for families and healthcare professionals to access information about pediatric HIV. It is open daily and offers booklets, leaflets, and videos about a variety of issues related to pediatric HIV/AIDS.

You can make an online donation at https://secure.allaboutgiving.org/donatesecure/donate_login.cfm or, if you prefer, you can pay an annual subscription to become a member of the charity. "Become a Friend of CWAC" membership entitles you to vote at the charity's annual general meeting and to receive their newsletter and advance notice of fundraising events, which include walkathons, marathons, and benefit concerts.

Children With AIDS Project of America

Joy and Jim Jenkins couldn't have a baby by natural means because Jim had undergone a vasectomy. At the hospital where Joy worked, she would often ask the obstetrics resident whether there were any "extra" babies who needed adopting. The answer was always no until James Michael came along, a baby who had tested positive for HIV antibodies and needed a home. It took 2.5 years before the adoptive parents learned — to their jubilation — that little James did not have the disease. Because of this amazing experience, "Jim and I longed to do more for other innocent AIDS babies. And so the idea for our Children With AIDS Project, which now dominates our days and nights, was born."

A flurry of newspaper and television stories about the Jenkins' willingness to adopt a baby who had a 30% to 50% chance of developing full-blown AIDS prompted people all over the country to mail in requests. Some of these requests were from agencies trying to place abandoned babies with AIDS, and others were from couples eager to adopt babies with the disease.

"It was clear that a vital cog had been missing in the AIDS network," says Joy Jenkins. "Nobody was bringing together the 'throwaway' babies and those able to give them good homes. Suddenly we knew that James Michael had brought a mission into our lives. We felt no doubt — we had been chosen to match unwanted babies with their potential parents."

This is the focus of the Children With AIDS Project — to provide information about all aspects of adoption and to link potential adopters with children infected with the AIDS virus antibodies. You can actually fill out an application online to adopt a child, and the Children With AIDS Project will forward your information to an appropriate adoption agency.

With individual and corporate support (Sears Business Systems donated a more powerful computer, and friends provided them with more office space), the Jenkins were able to expand rapidly. Within months of starting the project, they had computer records of the names and backgrounds of 255 people in 40 states and Canada eager to adopt the youngest victims of AIDS. The Children With AIDS Project was listed with the nationwide AIDS hotline, and their operation quickly grew to such proportions that Jim now devotes himself to it full-time. (Joy supports the family financially by working five or six 12-hour nursing shifts a week at the hospital.)

On the organization's Web site, you will find a list of volunteer activities you can sign up for, including administrative duties, preparing mailings, assisting with youth AIDS education, starting a local Children With AIDS chapter or affiliate, being a volunteer coordinator, working on awareness education campaigns, doing fundraising or public relations work, computer data entry, providing legal services, offering your graphic design skills, coordinating special events, or being a newsletter reporter.

To make a donation online, you can do your shopping through GreaterGood.com. Up to 15% of each purchase automatically goes to Children With AIDS Project of America.

Elizabeth Glaser Pediatric AIDS Foundation

Founded by the late Elizabeth Glaser, who contracted AIDS in 1981 through a blood transfusion and later unknowingly transmitted the virus to her infant daughter and son, this charity has attracted a great deal of attention from celebrities who have dedicated their support to this cause, and the foundation's frequent fundraisers are well attended by politicians, actors, corporate sponsors, and community leaders. Events include "A Night to Unite," held in Washington, DC, "Celebrity Dodgeball," an annual "Golf Classic," the "Nautica Malibu Triathlon," and an annual ice-skating party at Wollman Rink in Central Park, New York City, called "Kids for Kids." This organization has achieved outstanding fundraising goals; last year's "Kids for Kids" event raised more than \$1.5 million for pediatric research for the treatment and prevention of HIV/AIDS and other life-threatening pediatric diseases.

The foundation describes its mission as follows: "to identify, fund and conduct critical pediatric research that will lead to better treatments and prevention of HIV infection in infants and children, to reduce and prevent HIV transmission from mother to child, and to accelerate the discovery of new treatments for other serious and life-threatening pediatric diseases."

You can donate to the Pediatric AIDS Foundation online or by phone or mail, or, if you prefer, volunteer your time. You can also purchase a variety of items through their Web site, with a percentage of the proceeds going to the foundation; these items include bracelets handcrafted by HIV-infected women from South Africa, Elizabeth Haydon's book *Prophecy* (100% of the authors' royalties are being donated to the foundation), and a variety of "I Love Lucy" memorabilia. Check the Web site for step-by-step instructions on how to order each of these items. Or, you can give through the Workplace Giving Campaign. Another option is to become involved with "Caring for Kids 101," a program that targets college campuses to raise money for the Pediatric AIDS Foundation.

REJOICE: Urban Development Project (RUDP)

About 70,000 of the 1 million inhabitants of the Chiang Mai province of Northern Thailand suffer from HIV/AIDS.^[5] The overextended national medical health system is unable to respond to the medical needs of this growing population, and HIV-positive individuals are often reluctant to seek care and social support because of the stigma they attach to their disease. To make matters worse, the 1997 economic crash contributed further to the demise of Thailand's economy. Industries are losing employees to the AIDS epidemic, healthcare costs are draining the already low incomes of individuals with the disease, and virtually no pharmaceuticals are available in Thailand to combat AIDS.

RUDP grew out of the escalating need for affordable healthcare. Established in 1998, this organization, staffed by 6 full-time and 3 part-time employees and a number of part-time local and foreign volunteers, provides a wide array of medical and social services to the poor, sick, and underserved HIV/AIDS population in this region of Thailand.

These services include a medical home care unit, baby formula distribution (to prevent maternal transmission of the disease through breastmilk), one-on-one counseling services (counseling is provided for free, and anonymous antibody blood testing at a clinic is available for a minimal charge), education/awareness/prevention programs, a condom distribution project, sponsorship of orphans' education, and cremation and temple services.

The medical home care unit, headed by 2 trained medical nurses from the United Kingdom who are assisted by a team of Thai AIDS caregivers and social workers, offers full medical treatment in patients' homes and provides patients and their family members with basic medical training to enable them to care for themselves on an ongoing basis. RUDP is currently offering this medical home care to about 500 adults and children with AIDS on a daily or weekly basis, spanning about 20 impoverished communities and local villages. Their goal is to expand that care, through financial donations, to at least twice that population. In addition to providing home care, RUDP has 14 HIV/AIDS outreach clinics located in Buddhist temples and Christian churches.

RUDP's international fundraising efforts encourage support through general operating grants as well as individual and corporate donations. You can donate through their Web site at <http://www.rejoicecharity.com/rejoice2/donate/donate.html>. In addition to money, the organization needs pharmaceuticals and medical supplies of all kinds (antiviral medications, sterile dressing packs, surgical latex gloves, antifungal creams, diapers, scalp vein sets, suction catheters, etc) as well as blankets, sheets, towels, washcloths, canned baby formula, toiletries, and food items.

A Ray of Hope

The harsh realities of the pediatric (and adult) AIDS epidemic are disturbing, but there are some positive

developments on the horizon. Intense efforts are under way to spread awareness of disease prevention and to improve existing medications. The [Pediatric AIDS Clinical Trials Group](#) (PACTG), a nationwide clinical trials network jointly sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of Child Health and Human Development (NICHD), is developing and refining treatments to prolong survival and improve the quality of life of HIV-infected infants, children, and adolescents.^[3] Researchers are also coming up with better diagnostic tests for infants so that diagnoses can be made soon after birth and therapy can begin as soon as possible. In addition, investigators are studying ways to prevent transmission of HIV from mother to infant.^[3] For instance, PACTG investigators have demonstrated that a specific regimen of zidovudine treatment, given to an HIV-infected woman during pregnancy and to her baby after birth, can reduce maternal transmission of HIV by about two thirds.^[6] Another boon to the HIV-infected population is [Title IV of the Ryan White CARE Act](#), which was authorized in 1990 and reauthorized in 1996. Projects spawned from Title IV have ensured the inclusion of HIV-infected women, pregnant women, children, and adolescents in numerous clinical research trials and have gone a long way toward providing enhanced care for the larger AIDS population. Services are provided by 225 Title IV sites in 25 states and territories.^[7]

Organizations Featured in This Article

Angelwish, Inc.

48 Arthur Drive
Rutherford, NJ 07070
Phone: 201-672-0722; 866-ANGELWISH
Fax: 201-672-0733
Web site: <http://www.angelwish.org>

Children With AIDS Charity

Lion House
3 Plough Yard
London
United Kingdom
EC2A 3LP
Phone: 020 7247 9115 (UK)
+44 20 7247 9115 (outside the UK)
Email: info@cwac.org
Web site: <http://www.cwac.org>

Children With AIDS Project of America

P.O. Box 23778
Tempe, AZ 85285-3778
Phone: 480-774-9718
Fax: 480-921-0449
Web site: <http://www.aidskids.org>

The Elizabeth Glaser Pediatric AIDS Foundation (Headquarters)

2950 31st Street
#125
Santa Monica, CA 90405
Phone: 310-314-1459
888-499-HOPE (toll-free)
Fax: 310-314-1469
Email: info@pedaids.org
Fundraising & Donations: development@pedAIDS.org
Web site: <http://www.pedaids.org>

REJOICE Urban Development Project

Rejoice Urban Development Project
70/1 Amarin Court, Klong Cholarpratan
Moo 6, Suthep Muang
Chiang Mai 50200
Thailand
Phone/Fax: +66-53-806-227

Email: contact@rejoicecharity.com
Web site: <http://www.rejoicecharity.com/rejoice2/home/home.html>

Other Organizations Committed to Helping HIV/AIDS Victims

American Academy of Pediatrics

Pediatric AIDS Coalition

601 13th Street NW
Suite 400 North
Washington, DC 20005
Phone: 800-336-5475

Association for the Care of Children's Health

7910 Woodmont Avenue
Suite 300
Bethesda, MD 20814
Phone: 301-654-6549

An international, multidisciplinary membership organization of healthcare providers, parents, educators, researchers, policy makers, and other individuals that strives to include parents and professionals in a united effort to affect positive outcomes for children. The organization has taken a leading role in defining, promoting, implementing, and supporting standards and policy in family-centered healthcare for children and youth through education, research, advocacy, and the development and dissemination of resource materials.

CDC National AIDS Hotline

Phone: 800-342-2437 (Deaf/Hard of Hearing [TTY]: 800-243-7889)

Division of HIV/AIDS Prevention

National Center for HIV, STD and AIDS Prevention Centers for Disease Control and Prevention

Mail Stop E-49
Atlanta, GA 30333
Fax: 404-639-2007

HIVkids

P.O. Box 6373
Eureka, CA 95502-6373
Phone/Fax: 707-445-8154
Email: info@hivkids.org

A nonprofit organization of volunteers whose mission is to provide food, clothing, shelter, and improved quality of life to children and families who are infected, affected, or orphaned by HIV/AIDS. HIVkids solicits sponsors to purchase birthday and Christmas gifts for affected children — the organization provides the "wish lists."

Love & Action

3 Church Circle
Annapolis, MD 21401
Phone: 800-940-9500; 410-268-3442
Fax: 410-267-7991
Web site: <http://www.loveandaction.org/>

This national, interdenominational, Christian ministry is a nonprofit charity that addresses the mental, spiritual, and physical needs of individuals and families living with HIV/AIDS.

National AIDS Clearinghouse

P.O. Box 6003
Rockville, MD 20849-6003
Phone: 800-458-5231
Fax: 301-738-6616

National AIDS Hotline

Phone: 800-342-AIDS

The National Pediatric HIV Resource Center

15 South Ninth Street

Newark, NJ 07107

Phone: 800-362-0071

Fax: 201-485-7769

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Suggested Readings

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