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Hope for Children with AIDS

Pediatric AIDS Foundation

Pediatric AIDS Foundation
1311 Colorado Avenue, Santa Monica, California 90404 (310) 395-9051
Fax: (310) 395-5149

Hope for Children with AIDS

What PAF Has Accomplished in Its First 5 Years

The Pediatric AIDS Foundation is proud of what we have accomplished as a result of your support.

- As of December 31, 1993, PAF has raised $23 million, and has spent 95% on our programs. A full description of all our programs is in this package.
- We have funded 171 researchers around the country working on investigator initiated research projects that are in the areas our Think Tanks have determined to be critical.
- We have led the way in cooperative, directed research with our 3 year ground breaking *Ariel Project for the Prevention of HIV Transmission from Mother to Infant*.
- Our Emergency Assistance Program has funded 268 grants (totaling over $1 million) to hospitals serving pediatric AIDS patients.
- 102 Student Interns have received funding to encourage their future career choices in pediatric AIDS research and care.
- 70,000 units of our Parent Education Program, in English or Spanish, have been distributed, without charge, to PTAs, school systems, education organizations and religious groups nationwide.
- The Pediatric AIDS Foundation's courage and ability to speak out on many issues surrounding HIV has helped to educate thousands of Americans about how the virus is and is not transmitted, that AIDS is a preventable disease, and that people infected with this virus need and deserve support and compassion.

1/94

Pediatric AIDS Foundation

Hope for Children with AIDS

What is PAF? The Pediatric AIDS Foundation (PAF) is a national non-profit 501 (c) (3) organization confronting medical problems unique to children infected with HIV/AIDS. While our office is in Santa Monica, CA, our funds are distributed worldwide.

How is PAF Unique? PAF is focused on creating a future that will offer hope for children with HIV/AIDS. Many organizations are helping children survive on a day-to-day basis by raising money for food, medicine and lodging. PAF, however, is focused specifically on finding medical answers that will bring this hope.

PAF's Primary Goals: Through our *Think Tanks* PAF identifies and funds critically needed pediatric AIDS research around the world. The majority of the funds we raise go directly to researchers. We fund investigator initiated research, as well as the *Ariel Project*, a directed collaborative effort to identify a way to block transmission from an infected mother to her infant.

PAF addresses these additional objectives:

- Providing funds to hospitals around the country which serve children with HIV/AIDS through our *Emergency Assistance Program.*
- Encouraging students to enter the field of pediatric AIDS through our *Student Intern Award Program.*
- Developing and distributing our national *Parent Education Program* for parents of elementary and pre-school age children.

Administration is provided by a small full-time staff, generous volunteers and in-kind donors committed to PAF's mission and growth. PAF's administrative overhead is currently 5%.

The fight against pediatric AIDS is not futile. This is a battle we can win by working together. This is a battle we must win for our children and for ourselves.

The problem we face is urgency. Every month, indeed every day, is critical. Children are dying who could be saved. Children are suffering whose quality of life could be improved. As new drugs are tested, as lives are lengthened, our hope is strengthened.

1/94

CO-FOUNDERS: Susan DeLaurentis/Elizabeth Glaser/Susan Zeegen
1311 Colorado Avenue, Santa Monica, California 90404
TEL: (310) 395-9051 FAX: (310) 395-5149

Pediatric AIDS Fact Sheet

Worldwide Statistics

- The World Health Organization (WHO) predicts that by the year 2000, there will be 10 million children infected with HIV world wide.
- By the end of the 1990's, 10-15 million children will be orphaned by the death of one of their parents through AIDS (WHO).
- In 1990 alone, 1 million children acquired HIV from their infected mother before or during birth (WHO).
- It is estimated that more than 3 million women and children worldwide will die from AIDS during the 1990's, more than 6 times the number of the 1980's.
- During the first 7 months of 1992, WHO estimates 1 million adults contracted HIV, almost half of them women.
- By 1995, AIDS will account for more years of productive lives lost before the age of 65 than all forms of cancer combined.

United States Statistics*

- It is conservatively estimated that as many as 10,000 - 20,000 children in the U.S. may be infected with HIV. According to the CDC definition of AIDS, 4,906 cases of AIDS in infants and children under the age of 13 have been reported through Sept., 1993.
- The percentage of women, children and adolescents currently infected with HIV/AIDS may be as high as 20% of all HIV cases in the U.S.; together this is the fastest growing segment in the population to have HIV.
- Over 6,000 HIV infected women give birth each year in the U.S. Approximately 20 - 30% of these children are HIV infected. This accounts for over 1,800 new HIV infected infants each year.
- Over 50% of children with AIDS have died already. AIDS is the seventh leading cause of death among children aged one to four.
- By the year 2000, AIDS will be one of the fifth leading causes of death among American children, and among children worldwide.
- Nearly 100% of new cases of HIV infection in children result from the virus being passed from an infected mother to her newborn.
- AIDS is now ranked as the fifth leading cause of death among women age 25 to 44.

*Data from the National Institutes of Health and the Centers for Disease Control

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Some Other Facts to Know About HIV/AIDS

- **HIV/AIDS affects children differently than adults.** The manifestations of pediatric AIDS include severe infections, opportunistic infections, as well as failure of growth and development. The variety of manifestations that occur in pediatric AIDS is much larger than in adult patients. Most children with HIV suffer from central nervous system complications, while only a few adults exhibit this problem. Also, because AIDS affects the immune system, children cannot develop antibodies to combat childhood diseases such as chicken pox and polio.
- At this time most infants and children with HIV /AIDS are born into poor and/or fragmented families.
- Children and adolescents with HIV/AIDS still suffer from ostracism and discrimination because of this disease.
- When you have a child with HIV/AIDS you almost always have a family with HIV/AIDS. An infected father or mother can transmit the virus to their partner through sex or sharing contaminated needles. Then an infected mother can pass the virus to her newborn in-utero or during childbirth.
- Children and adolescents with HIV/AIDS frequently have difficulty in getting access to diagnosis and treatment.

National Organizations

If you have specific questions, you might try calling these national organizations:

For general questions about HIV and to find out about clinical trials:
National AIDS Clearinghouse (800) 458-5231

For statistics regarding HIV/AIDS:
Centers for Disease Control (404) 302-2473

For general questions about HIV and for educational materials:
National AIDS Hotline (this is part of the CDC) (800) 342-AIDS

To learn about care of an HIV child (medical care, infection control, psycho-social concerns, education, legal issues):
Wisconsin Div. of Health AIDS/HIV Program (608) 267-5287
Ask for the following book ($5.00 charge):
To Help You - Care of Infants and Young Children who are HIV Positive

For policy guidelines for education leaders:
National Association of State Boards of Education (703) 684-4000
Oregon State Health Division (503) 731-4029
Ask for the materials: AIDS: The Preventable Epidemic Curriculum

For information about establishing AIDS policy and education in the workplace:
National Leadership Coalition on AIDS (202) 429-0930

For questions regarding public policy:
AIDS Action Council (202) 986-1300
National Association of People with AIDS (202) 898-0414

For general questions about HIV (in Spanish or Asian languages):
Bilingual AIDS Hotline (800) 400-7432
Multilingual AIDS Information & Referral Line: (800) 922-2438

For questions about adopting a child with HIV:
National Adoption Information Clearinghouse (301) 231-6512

For questions about HIV children in foster care:
Children with AIDS Project of America (800) 866-2437

For information about developing comprehensive services for children and families, or for public policy issues:
National Pediatric HIV Resource Center (800) 362-0071

For information about the AIDS memorial quilt:
The NAMES Project (415) 863-5511

For any questions regarding pediatric HIV/AIDS, for specific questions about how the disease affects children differently than adults, or for education materials for the parents of elementary or pre-school students:
Pediatric AIDS Foundation (310) 395-9051

If you would like to work with HIV children or
would like to know about AIDS prevention efforts in your area,
call your state or local health department, local hospitals, or your local Red Cross.

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People weekly

Depardieu and costar Andie MacDowell

WHEN AIDS STRIKES A HOLLYWOOD FAMILY

Ten years ago, Elizabeth Glaser was infected with the AIDS virus during a blood transfusion. Unaware, she passed it on to her two children; her daughter, Ariel, died at age 7. "My hope," she says, "is that others can learn from what I've been through."

Ex–*Starsky and Hutch* star Paul Michael Glaser and Elizabeth took their crusade to Congress last year.

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LIFE STYLE / COMICS / TRENDS

SECTION E

WEDNESDAY
MARCH 21, 1990

VIEW

Los Angeles Times

A Star in the AIDS War

Elizabeth Glaser has become an unlikely but premier lobbyist in the campaign against a killer

By GERALDINE BAUM
TIMES STAFF WRITER

WASHINGTON—This would be the happiest time in Elizabeth Glaser's life if it were not the saddest. She is immersed in the flow of life and having a colossal effect on the world around her, yet this intense, driven woman and her family are fighting AIDS.

"If I didn't have AIDS, if I hadn't lost my daughter to it, if my son didn't have it, if my life wasn't so sad, I would be very fulfilled by what I'm doing," says Glaser, 42.

"I'm realizing my highest potential right now. I am able to communicate about something that I think is important way beyond the scope of my own life."

Even though this wealthy wife of actor/director Paul Michael Glaser is atypical of people confronted by Acquired Immune Deficiency Syndrome—she is not poor, not a minority, not an intravenous drug user, not gay—she has emerged as the most powerful person pressing Washington for more money to fight the epidemic.

"She is the premier lobbyist on this issue now," says Tom Sheridan, whose AIDS Action Council is the largest lobbying group for federal AIDS legislation. "In fact, the thousands of people we represent could all gather under the Capitol Dome and not get half the attention that Elizabeth Glaser gets when she comes to town."

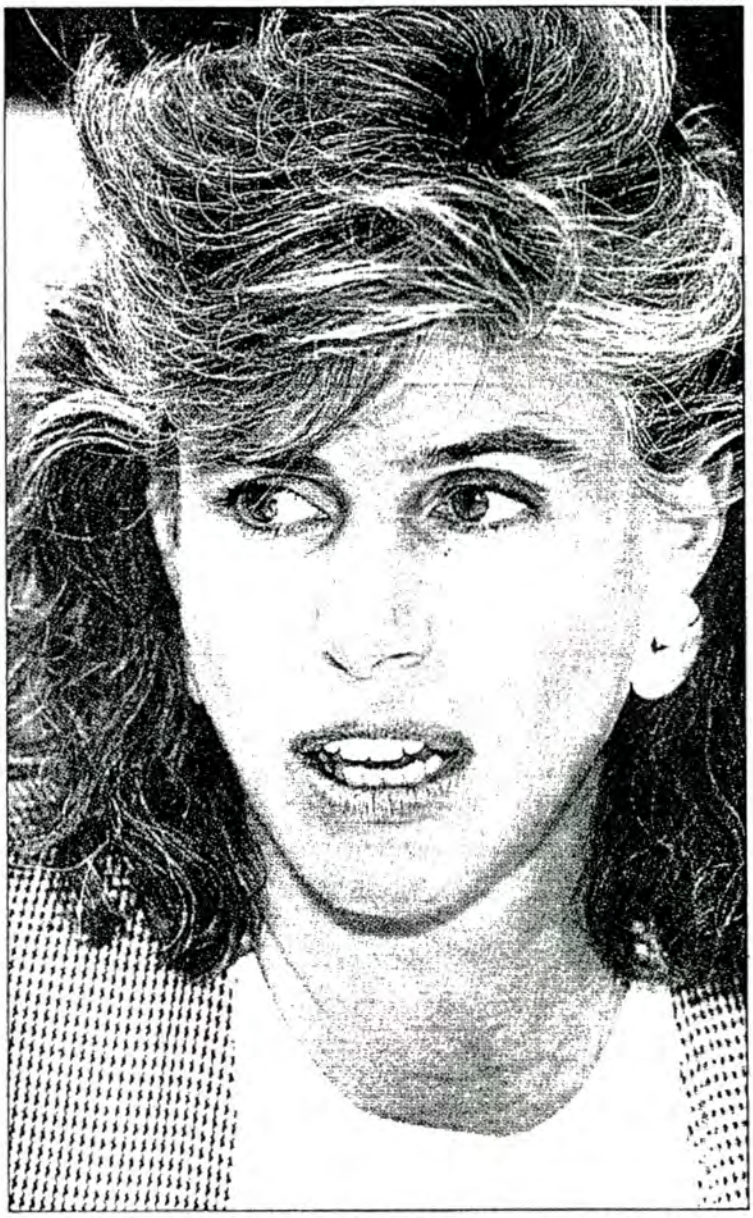
Most AIDS activists simply do not have the cache to go right to then-President Ronald Reagan as Glaser did two years ago when she decided something was wrong with a world that didn't pay enough attention to children dying of the disease.

Most AIDS activists do not begin a day in Washington with ABC's Joan Lunden and end it with ABC's Ted Koppel. They cannot plunk down comfortably in the offices of U.S. senators such as Howard Metzenbaum of Ohio and Orrin Hatch of Utah. Congressmen's wives do not host lunches for them and cry at their compelling stories. And when other AIDS advocates testify before congressional committees, as Glaser did last week, they do not anger the First Lady.

That Elizabeth Glaser is not like most people threatened by this disease is precisely why she has been so effective in Washington, where deep pockets and

Please see GLASER, E6

ALICE EPHESSON



Elizabeth Glaser: "If I didn't have AIDS, if I hadn't lost my daughter to it, if my son didn't have it, if my life wasn't so sad, I would be very fulfilled by what I'm doing." At left, Glaser and Susan De Laurentis on their way to a meeting in Washington.

GLASER

Continued from E1

glamour go a long way in impressing the powerful.

But while the Hollywood glint has propelled Glaser into an influential spot in the federal bureaucracy, that alone cannot be credited for her success. It has come from a combination of her husband's celebrity, her own determination and the appalling reality of her story.

Glaser contracted the HIV virus that causes AIDS in 1981 from a contaminated blood transfusion after the birth of her daughter Ariel.

During breast-feeding, she unknowingly passed the virus to her daughter, and then passed it to her son, born three years later. Ariel died in 1988. Elizabeth and her son both test HIV-positive, but so far show no symptoms of AIDS. The family continued to try to keep their tragedy private—even after Elizabeth had begun traveling to Washington on behalf of AIDS causes in early 1988.

But then in August, 1989, a year after Ariel's death, the Glasers learned that a national tabloid planned to publish their story. Fearful of distortion, they went to the press themselves.

"If the [tabloid] did anything good, it forced Elizabeth's hand and all the horrible things we all worried about happening didn't happen," says Susan Zeegen, a longtime friend who along with Glaser and another friend, Susan De Laurentis, founded the L.A.-based Pediatric AIDS Foundation two years ago. "Her story has raised enormous awareness and a lot of money too. And all her friends stuck by her."

Joel Johnson, Metzenbaum's legislative director, tries to explain why people in Washington listen to Glaser: "She simply is not like most people who come here, make a case and then go home in hopes that everybody will do the right thing. She doesn't let go of a contact or anybody she can talk to."

AIDS advocates have expressed concern that Glaser's impressive pitch for pediatric AIDS funding—there are 2,055 children younger than 13 who are known to have the disease—might distract politicians from the problems of the other 120,000 people who have AIDS, and who, unlike children, are controversial back in the district.

"Who is going to vote against Elizabeth Glaser?" asks Sheridan of the AIDS Action Council. "She has the public image that members of Congress respond to. Believe me, I've been lobbying for seven years and I can't call members of Congress at home. 'Nightline' isn't interviewing me. She has a lot of power and it's important how she uses it."

Glaser says she tries to "carry this mantle" responsibly. In every speech, every interview, every casual conversation, Glaser says she is not lobbying (she even scoffs at the word, saying it implies she gets paid for her work, which she doesn't) for children alone.

"Every person with AIDS is somebody's child," she lectures a reporter. "AIDS is not a political issue. It's a virus and it kills people, no matter who they are."

During a congressional budget hearing here last week, Glaser called on the federal government to spend $70 million more in 1991 on pediatric AIDS research and care but emphasized that money must not be allocated at the expense of other AIDS programs.

"The overall AIDS budget must have what it needs and within that umbrella a pediatric budget must be identified," she testified. "But the pediatric dollars must not be taken from other AIDS programs already under-funded."

There is an urgency in her voice and an intensity in her stare that belie a warmth she exudes.

To be with her is to wonder: What was it like before tragedy swamped her life?

"Paul Michael Glaser and his beautiful wife were like the Ken and Barbie of Hollywood: gorgeous, successful, loving, great friends, great fun, very private, very consumed with each other," says Zeegen.

And now Elizabeth Glaser is completely consumed by a great struggle for life—marshaling her friends and family to raise money, almost $3 million so far, for the Pediatric AIDS Foundation, flying off to Washington, putting the squeeze on politicians, talking on the phone, making connections and finding new ways to make the world realize that the worst thing that can happen to a mother has happened to her—she lost a child—and no one else should have to face that, particularly not her again.

"Sometimes Elizabeth will be off to Washington and she'll say, 'They want the victim-mother from Hollywood,' " Zeegen explains, "and short of anything that would be harmful to her children and her husband, she's not proud, she'll go out and do it."

It is 8:30 in the morning and a limousine carrying Elizabeth and Paul Michael Glaser and their entourage zooms past the sandstone and marble monuments of Washington to Capitol Hill. Elizabeth and Susan De Laurentis have just appeared on "Good Morning America" and are frenetically reviewing their performances.

"You we're *greeeeeeeeeat*," Elizabeth squeals at De Laurentis, slapping her the high five and dissolving into laughter. Then, like a giddy school teacher, Elizabeth points out the sites to Paul, who is sleepily watching the landmarks whiz by.

Although Elizabeth Glaser and De Laurentis have been charging around Washington for two years in an effort to jolt this town into action to help AIDS-inflicted children and families, this is the first time Elizabeth is testifying at a congressional budget hearing before an inferno of television lights.

And this is the first time she has brought Paul along for an appearance.

"This is really big," Elizabeth keeps saying. "Everyone will be there."

Actually, the hearing room is jammed with reporters and pediatric AIDS experts, who are also to testify. But few congressmen show up. Only the two California members of the nine-member Budget Committee are seated on the wooden dais. Glaser doesn't seem dismayed. In fact, she seems thrilled to finally have an audience to present a substantive look at the issues.

Paul is a reluctant accomplice. "I am here to support my wife," he says tersely, the private man annoyed that he is being asked to expose his deepest pain. "I'm the supporting team."

And yet, while Paul is the Hollywood star the cameras have come to gawk at, this is Elizabeth's show. In Washington, among the bureaucrats and politicians, she is the star.

A small, thin woman with green eyes and frosted hair cut in a fashion she admits has been out of style for years, Elizabeth blends well into conservative Washington. She wears a green and black print dress, flesh-colored stockings, low black heels and the requisite string of pearls.

The budget hearing lasts hours but the media stays only long enough to hear the Glasers' testimony. While Paul talks, Elizabeth never takes her eyes off him. His delivery is dramatic and moving.

"I know there are no guarantees," he says, "My family is doing the best they can in a most difficult situation."

Elizabeth is next. Although she had hoped to avoid tears, her voice breaks as soon as she begins talking. "No mother ever really believes her child is going to die," she says tearfully. "I didn't."

After their testimony the Glasers are chased down the halls of the Rayburn Office Building by a media swarm and they submit to a series of interviews in U.S. Rep. Barbara Boxer's crowded office.

It soon becomes apparent that one of the important sound bites of the day will be Elizabeth's comment at the hearing that the Bushes need to get more involved in fighting the epidemic. Elizabeth explains that she had asked to have Mrs. Bush follow in Reagan's footsteps and make a public service announcement about people not discriminating against children with AIDS. But Elizabeth has not received a response from the White House. Later, word comes back from Mrs. Bush's press office that the First Lady feels sideswiped by the Glasers' remarks. "Mrs. Bush is going to hate me, I know," Elizabeth says, "but what I'm saying is important—we have to raise awareness and the Bushes are among the few people who can do it." And in all her interviews she continues to press the need to get the First Lady "on board."

Later, Elizabeth Glaser and De Laurentis begin a marathon of meetings, racing through the labyrinth of federal buildings loaded down with position papers and T-shirts designed by a little boy named Zachary who died of AIDS.

The two women have a series of 15-minute meetings with congressmen or their aides, with whom they deftly discuss the complicated budget negotiations.

Two years ago, Glaser couldn't have found her way from the offices of the Senate to the House, she admits, and she couldn't have differentiated among all the acronyms—like OMB (Office of Management and Budget) or FTE (Full Time Equivalent federal employee).

But now she lights up when a congressman explains to her about "downward negotiations" during budget time and laments how the "peace dividend" will be spent.

"Sometimes, when we're running around like this and talking in this other language I feel like we're in Las Vegas," Glaser says, "and we've completely lost a sense of time and reality."

She also acknowledges that Washington is a fantastic escape: "When I'm here doing business I have to separate myself from emotional reality. I have to close the dam because I can't be effective here if I let all the emotions rule me.

"So I turn it off here and when I go home the emotion I've kept away comes flooding back. It takes two days for me to settle down. We know that now."

By late afternoon of the next day after a lunch meeting with congressional wives, Glaser and De Laurentis regroup in Sen. Metzenbaum's sprawling office, making themselves at home. Sen. Hatch, who sent Glaser flowers after seeing her on television, has an office across the hall and she goes to thank his staff.

Republican Hatch and Democrat Metzenbaum have made a rare bipartisan effort by taking Glaser under their wing. Last year they organized a high-roller fund-raiser for the Pediatric AIDS Foundation in Washington that netted $1 million. The senators provided the premier donors; Glaser brought the stars.

"Are they all using me because of my Hollywood connection?" she asks herself, groping for an explanation for her fantastic success in gaining political access here. "I don't think so. All of these relationships were in place and took a lot of work.

"I have a strong-enough understanding of issues now," she explains on the way back to her hotel, "but sometimes I don't understand the roadblocks we're facing. It's good to have people in these offices to turn to. When I came to Washington that first time, it was Government 101 for me. But it gets easier every time."

Very little in Elizabeth Glaser's life prepared her for her current crusade, but, as she explains it, she was raised to reach out to others.

She grew up in the upper-middle class suburbs of Long Island, the daughter of a businessman and a director of urban renewal.

"I was raised to be politically aware and astute and committed to issues of helping other people," she says. "My mother particularly taught me this. We never talked about those things in fiery debate. My mother simply was an example."

After earning a master's degree in education, Glaser ended up in Los Angeles, where she taught elementary school and fell into what began as a "very L.A." type of romance with Paul Michael Glaser, whom she met while driving down a boulevard. Their life in Hollywood, says Elizabeth, was never glamorous because they chose to be "very private people. It wasn't America's fantasy of Hollywood. I cooked my own meals. I spent a lot of time with my friends. My focus was always children, so when we had our first child I stopped working. I always had wanted to raise my children."

If there was any one moment in which her life was completely transformed, it was not when she found out that she and her children had been exposed to a fatal disease, nor even the day that her daughter died.

Those are surreal memories that she still finds hard to comprehend and discuss.

What remains sharpest in her memory is the day she decided to "change the world." It happened in March, 1988, and she was sobbing on the steps of the hospital where a doctor had just told her that her daughter Ariel had 48 hours to live.

She turned to Lucy Fisher, one of her best friends, and in a haze of tears blurted out, "I have to change the world. I have to see the President. This can't be happening."

An ordinary person would have comforted her pal with a hug, but Fisher was no ordinary friend. She is also the daughter-in-law of Charles Wick, who was Reagan's chief of the U. S. Information Agency and one of his best friends.

"I was so frustrated," recalls Glaser. "I had been fighting for Ari's life, keeping it all quiet from the community . . . yet she was going to die anyway. I felt I had just better do something about it or [my son] and I were also going to die.

"There was so much wrong I didn't know where to begin," she says.

Over the past years, she has not known where to stop.

She will not be "finished," she says, until the government and the doctors take care of the AIDS problem, until there is enough money in the federal budget to root out every possibility and perhaps discover a cure for AIDS.

"You know, there is very little ego involved in all this," she says. "I'm not looking for recognition . . . publicity was the last thing I wanted to have."

But now she is using it to get what she wants:

"One of the things that my life has taught me is that I have nothing to lose by being honest. I don't have the time to play games. I'm also talking about an issue that people really do care about. And until it is handled appropriately, I'm going to keep talking."

Why is Pediatric AIDS Research Important?

Pediatric AIDS research cannot be included with adult research. Drugs that work for adults may not work for children. And drugs that do not work for adults may, in fact, help children.

Almost all of the new cases of pediatric AIDS are children born to infected mothers. Pregnant mothers who carry the AIDS virus pass the virus to their fetuses in a manner not yet understood. Between fifteen and thirty percent (15 - 30%) of children born to HIV-infected mothers contract the disease. The only way to learn how to block transmission from mother to child is through pediatric AIDS research.

HIV/AIDS affects children differently than adults. The manifestations of pediatric AIDS include severe infections, opportunistic infections, as well as failure of growth and development. The variety of manifestations that occur in pediatric AIDS is much larger than adult patients. Most children with HIV suffer from central nervous system complications, while only a few adults exhibit this problem. Also, because AIDS affects the immune system, children cannot develop antibodies to combat childhood diseases such a chicken pox and polio. Furthermore, children sometimes do not advance into puberty.

What is the Relationship Between Pediatric Research and Adult Research?

No research exists in a vacuum, and answers in one area can often benefit other areas. In the case of pediatric research – there are many issues specific to children and pregnant women that can only be studied in those populations. However, the information gained will benefit all persons living with HIV. In the case of cancer research, 80% of the breakthroughs have come form studying pediatric populations -- this is partially because children often respond more powerfully and quickly to new drugs and therapies. So the research the Pediatric AIDS Foundation supports, while focusing on children, will benefit all.

Pediatric AIDS Foundation Programs

The Ariel Project for the Prevention of HIV Transmission from Mother to Infant

In February 1992, a Think Tank was held to define priorities for the prevention of HIV transmission from mother to infant since virtually all new cases of pediatric AIDS are from an infected mother passing the virus to her newborn. Out of this, *The Ariel Project for the Prevention of HIV Transmission from Mother to Infant* was conceived. This project is named after Elizabeth Glaser's daughter, Ariel, who died of HIV infection at age 7.

Unprecedented in its scope, *The Ariel Project* is a "Mini-Manhattan project," bringing together key researchers and clinicians collaborating with a single goal of finding a way to block transmission.

The Pediatric AIDS Foundation has committed $3 million a year for three years to fund this project. The director of the project is Arthur J. Ammann, M.D., an exceptionally experienced pediatric AIDS investigator. He has been active in the field of AIDS since 1981, and involved with PAF since its inception.

An Outside Board of Scientists works with the core group of investigators to define the necessary specific aims, determine the validity of the proposed approaches and the significance of results and future directions. This board is composed of individuals who have expertise in specific areas of the project, but who are not funded by the project. These people are recognized for their ability to direct new ideas in areas where creative thinking is required. Funding of this unique project started in September, 1992.

Think Tanks and Research Grants

When the Pediatric AIDS Foundation (PAF) was founded in 1988, there was not a pediatric AIDS research agenda. From the beginning, the foundation knew things had to be done quickly and innovatively. The primary goal of PAF became to identify this agenda, establish priorities and fund research. Since its inception, PAF has sponsored nine Think Tanks, bringing together not only the brightest minds on the cutting edge of pediatric AIDS research, but creative minds from other disciplines as well. Doctors from the NIH, the CDC and private industry participate alongside researchers from academia. Think Tank topics have included basic pediatric research priorities, growth and nutrition, opportunistic infections, mucosal immunity and maternal-fetal transmission. The conclusions are used to develop PAF's research priorities which are then funded through our grant awards program. Information of our pediatric agenda is also distributed to applicable government agencies and legislators for action on the federal level.

PAF's Think Tanks and research grants have a direct relationship. Our funding cycles are determined by the outcome of each Think Tank. First, an area of pediatric AIDS research which has critical, unanswered questions is chosen. Then, key people in that area are invited to spend a weekend at our Think Tank, sharing ideas and thinking creatively of ways to find answers. The group prioritizes the steps to be taken. Form this, an RFP (Request for Proposal) is developed and sent to researchers around the world. Scientists then submit grant proposals which are reviewed by PAF's scientific committee. The proposals are scored on scientific merit, and funding is awarded based on scores, the goals of the foundation and the amount of money PAF has available.

> I write to extend my gratitude for one of the most invigorating scientific meetings I have ever attended. The level of interchange was galvanizing. Your insistence on a multi disciplinary approach led to a spontaneity and creativity which I have seldom encountered. I hope that you will continue to recruit the best scientific minds, many of whom are not presently investigating pediatric AIDS. If you can convince these investigators to lend a portion of their talents to the problems of pediatric AIDS, then you will win. I believe that you are on the verge of seeing a logarithmic expansion of results. Science can indeed bring hope.
>
> --Margaret Hostetter, M.D., Associate Professor of Pediatrics and Microbiology, University of Minnesota

For additional information, or a complete list of research grants which have been awarded, please contact PAF.

The Pediatric AIDS Foundation Emergency Assistance Program

The Emergency Assistance Program supplies hospitals serving significant pediatric AIDS populations with funds to address their unmet, yet critical, needs.

Presently we are serving close to 100 hospitals around the country with grants up to $6,000 each. Requests may range from funding a partial salary for an extra nurse or social worker, to a needed crib or stroller or piece of medical equipment. This program may also provide transportation funds to help children reach their AIDS treatment centers and not miss appointments due to lack of car fare. A "discretionary fund" is available as well enabling hospital staff to purchase badly needed clothing or food for children who are to be discharged.

This program serves a wide population nationwide. It is a program that every hospital seeing children with AIDS feels is critically needed.

Pediatric AIDS Foundation Student Intern Awards

The goal of the Student Intern program is to encourage students to choose a career in pediatric AIDS research or care. Participants may be undergraduates or graduates and must apply through a sponsor who is their supervisor. This sponsor must be recognized for their contributions to the field of pediatric AIDS. The sponsor must indicate the relevance of their program to pediatric AIDS. The program may be oriented toward fundamental research or clinical research and care.

The total of each award is $2,000 for 8 weeks of work training.

Parent Education Program -- "HIV/AIDS: A Challenge to Us All"

The overall goal of the Pediatric AIDS Foundation Parent Education Program, "HIV/AIDS: A Challenge to Us All", is to establish a guideline for a parent meeting within the context of one school or a small community. This program is geared towards educating the parents of elementary and pre-school students; we do this by providing information and guidelines regarding HIV/AIDS.

The kit, which consists of a parent meeting guide book and two accompanying videotapes, was distributed free of charge in 1992, to 50,000 PTAs and other education organizations across the country. In 1993, an additional 10,000 kits were distributed nationwide, as well as 12,000 Spanish kits which were distributed to Latino communities in major U.S. cities. The guide and one of the videotapes gives all necessary information so any adult can set up a parent meeting in their community. The other videotape demonstrates how parents can answer children's questions about HIV/AIDS with age-appropriate responses.

Pediatric AIDS Foundation

UPDATE: FALL 1993

Having just come back from our 9th Think Tank, we are all constantly amazed at how much the researchers feel PAF has accomplished but how much still remains to be done. One of the questions many people ask is how we decide which research to fund. So we'll take a moment to explain.

First we choose an area of pediatric AIDS research which has critical, unanswered questions. Then we invite key people in this area to spend a weekend at our Think Tank, sharing ideas and thinking creatively of ways to find the answers. The group prioritizes the steps to be taken. From this, an RFP (Request for Proposals) is developed and sent to researchers around the world. Scientists then submit grant proposals which are reviewed by our scientific committee at a meeting. The proposals are scored on scientific merit, and funding is awarded based on scores, the goals of the foundation and the amount of money PAF has available.

It is important for all of you who support PAF to know how you are helping to make a difference. We continue to be the major private funding source for basic pediatric AIDS research.

Some of our accomplishments are noted below — know that we could not do any of it without you.

With love,

Susan DeLaurentis Elizabeth Glaser Susie Zeegen

In just one short year, the "**Ariel Project** for the Prevention of HIV Transmission from Mother to Infant" has gone from a **dream to a reality**. We have 35 HIV-infected pregnant women enrolled in 6 clinical centers around the country. These centers send the blood samples collected from the mothers and their newborns to our central repository in New York City to be frozen and stored. This repository then distributes the samples to our 5 core researchers in New York, Boston, Chicago, Los Angeles and Palo Alto to conduct their studies. The preliminary data of the 5 core researchers was presented to our outside Board of Scientists in September, and all feel that we are on the fast track. We are proud that the entire research community is watching closely, looking at this as a model for collaborative projects that can reach answers faster for AIDS and other diseases.

In addition to our bi-annual Think Tanks, PAF is sponsoring four additional **workshops during 1993**. This attests to the critical importance of one-day action-oriented meetings and PAF's ability to impact research so quickly. These four workshops, focusing on pediatric issues, look at long-term survivors, viral resistance to drugs, HIV-infected women and antibody treatment to prevent HIV infection.

We began our **Student Intern Program** as a way to **encourage young people to enter the field of pediatric AIDS**. PAF has funded 101 interns in 16 different states. These internships provide an opportunity for bright students in high school, college or medical school to work with an experienced sponsor and learn about pediatric AIDS. We are committed to continuing our support — the feedback has been incredible.

In September, PAF distributed 12,000 copies of the **Spanish version** and 10,000 copies of the English version of its national **Parent Education Program**, "HIV/AIDS: A Challenge to Us All." The **Sega Charitable Trust** underwrote this program again this year. Copies of both are available through the foundation office.

The Centers for Disease Control recently reported the latest statistics on the "changing face" of HIV infection — the most dramatic increases occurred in women. Since most of these women are of child-bearing age, it is anticipated that there will be an equally dramatic increase in infants with HIV infection.

We now have a **National AIDS Policy Coordinator**. **Kristine Gebbie**, one of the brightest lights on the first HIV Commission, started her new job August 1. On her way through California, she spent 3 hours at our office, discussing critical pediatric AIDS issues. It is very important that her position exists. Now there is finally a point person on the Federal level for issues surrounding HIV/AIDS.

PAF wants you to know about the **important work** of the **National Pediatric HIV Resource Center**. The Resource Center provides in-depth consultations to health and social service providers and to communities developing comprehensive services for children and families, provides psychosocial and medical training, and is involved in public policy issues in Washington, including issues related to research, prevention and services. For more information call (800) 362-0071.

The **4th annual "A Time for Heroes"** was a huge success. The event was co-underwritten by the **Milken Family Medical Foundation** and **People Magazine**, and raised $1.25 million. The press conference before the picnic gave HIV-infected children a chance to speak to the world. It was a powerful beginning to the day.

Kids For Kids, our **first New York event**, was a spectacular family street fair. Completely underwritten by **Vogue Magazine**, it raised $900,000. A highlight was having everyone participate in creating beautiful murals which now decorate local pediatric AIDS hospitals. We look forward to doing it again in Spring 1994.

Miramax, Live Entertainment and Turner Entertainment Co. underwrote the premiere of **Tom & Jerry - The Movie**. This allowed over 1,000 friends of PAF to attend the event and a fun-filled carnival after the movie. More than 300 members from HIV-infected families were there.

In **New York**, the Riverdale Country School Lower School's **"Children Helping Children"** charity program sponsored a year-long Penny Drive which raised $750. Every child from Pre-K to Sixth Grade participated. Each of their 21 classes went on to design a quilt square. The C.A.R.E. (Children Aware of Riverdale Ethics) Quilt was then raffled off at a spring event, raising $951.42.

Bass Player Magazine ran a **three-month raffle** of a Tobias bass guitar to benefit PAF. As a result, donations were received from their nationwide readership. The donations, mostly only $5 each, raised an amazing $6,220.

The employees of the **Los Angeles Municipal Court** have officially **dedicated** their entire **year to PAF**. They will be having a series of small fund-raising events throughout the year, culminating in an employee family picnic.

Federal and State employees earmarked money for PAF when they participated in their **workplace giving campaigns** in 1992. For anyone with the opportunity to participate in 1993 campaigns, our CFC (Combined Federal Campaign) number is 1533, and we are listed under Children's Charities of America.

One way we keep our overhead at 5% is through our **dedicated** and overworked **staff**. Each day their commitment and caring inspires us to go that extra mile.

How to continue to support PAF: send a **Tribute or Memorial Card**. These cards have PAF's logo on the front and an appropriate message on the inside. Please contact PAF for more information.

We hope this information stimulates creative ideas on how you, your family and your community can get involved. We welcome your thoughts about innovative ways you can participate. Part of our wish list for this year includes a copy machine and paper, a Macintosh computer monitor, a Mac service technician in the Bay area, a Mac software support person in L.A. and Aldus PageMaker.

1311 Colorado Avenue, Santa Monica, California 90404 • (310) 395-9051 • Credit card donations: 1-800-488-5000.

Internal Revenue Service
District Director

Department of the Treasury

Date: MAY 16 1989

Employer Identification Number:
95-4191698
Accounting Period Ending:
December 31
Foundation Status Classification:
509(a)(1) and 170(b)(1)(A)(vi)
Advance Ruling Period Ends:
December 31, 1992
Person to Contact:
Joyce Ann Darby
Contact Telephone Number:
(213) 894-4553
Caveat Applies: Yes

Pediatric Aids Foundation
701 "B" Street, Suite 2100
San Diego, CA 92101

Dear Applicant:

Based on information supplied, and assuming your operations will be as stated in your application for recognition of exemption, we have determined you are exempt from Federal income tax under section 501(c)(3) of the Internal Revenue Code.

Because you are a newly created organization, we are not now making a final determination of your foundation status under section 509(a) of the Code. However, we have determined that you can reasonably be expected to be a publicly supported organization described in section 509(a)(1)*

Accordingly, you will be treated as a publicly supported organization, and not as a private foundation, during an advance ruling period. This advance ruling period begins on the date of your inception and ends on the date shown above.

Within 90 days after the end of your advance ruling period, you must submit to us information needed to determine whether you have met the requirements of the applicable support test during the advance ruling period. If you establish that you have been a publicly supported organization, you will be classified as a section 509(a)(1) or 509(a)(2) organization as long as you continue to meet the requirements of the applicable support test. If you do not meet the public support requirements during the advance ruling period, you will be classified as a private foundation for future periods. Also, if you are classified as a private foundation, you will be treated as a private foundation from the date of your inception for purposes of sections 507(d) and 4940.

Grantors and donors may rely on the determination that you are not a private foundation until 90 days after the end of your advance ruling period. If you submit the required information within the 90 days, grantors and donors may continue to rely on the advance determination until the Service makes a final determination of your foundation status. However, if notice that you will no longer be treated as a section 509(a)(1)* organization is published in the Internal Revenue Bulletin, grantors and donors may not rely on this determination after the date of such publication. Also, a grantor or donor may not rely on this determination if he or she was in part responsible for, or was aware of, the act or failure to act that resulted in your loss of section 509(a)(1)* status, or acquired knowledge that the Internal Revenue Service had given notice that you would be removed from classification as a section 509(a)(1)* organization.

(over)

If your sources of support, or your purposes, character, or method of operation change, please let us know so we can consider the effect of the change on your exempt status and foundation status. Also, you should inform us of all changes in your name or address.

As of January 1, 1984, you are liable for taxes under the Federal Insurance Contributions Act (social security taxes) on remuneration of $100 or more you pay to each of your employees during a calendar year. You are not liable for the tax imposed under the Federal Unemployment Tax Act (FUTA).

Organizations that are not private foundations are not subject to the excise taxes under Chapter 42 of the Code. However, you are not automatically exempt from other Federal excise taxes. If you have any questions about excise, employment, or other Federal taxes, please let us know.

Donors may deduct contributions to you as provided in section 170 of the Code. Bequests, legacies, devises, transfers, or gifts to you or for your use are deductible for Federal estate and gift tax purposes if they meet the applicable provisions of sections 2055, 2106, and 2522 of the Code.

You are required to file Form 990, Return of Organization Exempt from Income Tax, only if your gross receipts each year are normally more than $25,000. If a return is required, it must be filed by the 15th day of the fifth month after the end of your annual accounting period. The law imposes a penalty of $10 a day, up to a maximum of $5,000, when a return is filed late, unless there is reasonable cause for the delay.

You are not required to file Federal income tax returns unless you are subject to the tax on unrelated business income under section 511 of the Code. If you are subject to this tax, you must file an income tax return on Form 990-T, Exempt Organization Business Income Tax Return. In this letter, we are not determining whether any of your present or proposed activities are unrelated trade or business as defined in section 513 of the Code.

You need an employer identification number even if you have no employees. If an employer identification number was not entered on your application, a number will be assigned to you and you will be advised of it. Please use that number on all returns you file and in all correspondence with the Internal Revenue Service.

Because this letter could help resolve any questions about your exempt status and foundation status, you should keep it in your permanent records.

If you have any questions, please contact the person whose name and telephone number are shown in the heading of this letter.

Sincerely yours,

Frederick C Nelson

District Director

ENCLOSURES
FORM 872-C

INTERNAL REVENUE SERVICE
DISTRICT DIRECTOR
2 CUPANIA CIRCLE
MONTEREY PARK, CA 91755-7406

DEPARTMENT OF THE TREASURY

Date: MAR 23 1994

Employer Identification Number:
95-4191698
Case Number:
953363070
Contact Person:
THERESE A. CIOLEK
Contact Telephone Number:
(213) 725-6619
Our Letter Dated:
May 16, 1989
Addendum Applies:
Yes

PEDIATRIC AIDS FOUNDATION
10866 WILSHIRE BLVD 10TH FLR
LOS ANGELES, CA 90024-4300

Dear Applicant:

This modifies our letter of the above date in which we stated that you would be treated as an organization that is not a private foundation until the expiration of your advance ruling period.

Your exempt status under section 501(a) of the Internal Revenue Code as an organization described in section 501(c)(3) is still in effect. Based on the information you submitted, we have determined that you are not a private foundation within the meaning of section 509(a) of the Code because you are an organization of the type described in section 509(a)(1) and 170(b)(1)(A)(vi).

Grantors and contributors may rely on this determination unless the Internal Revenue Service publishes notice to the contrary. However, if you lose your section 509(a)(1) status, a grantor or contributor may not rely on this determination if he or she was in part responsible for, or was aware of, the act or failure to act, or the substantial or material change on the part of the organization that resulted in your loss of such status, or if he or she acquired knowledge that the Internal Revenue Service had given notice that you would no longer be classified as a section 509(a)(1) organization.

If we have indicated in the heading of this letter that an addendum applies, the addendum enclosed is an integral part of this letter.

Because this letter could help resolve any questions about your private foundation status, please keep it in your permanent records.

If you have any questions, please contact the person whose name and telephone number are shown above.

Sincerely yours,

Richard R. Orosco
District Director

Letter 1050 (DO/CG)

Pediatric AIDS Foundation
FAX TRANSMISSION

TO: Kristine Gebbie

FAX#: 202-690-7054

FROM: Elizabeth Glaser

DATE: 23 July '93

NUMBER OF PAGES (INCLUDING THIS PAGE) 2

COMMENTS:

IF THERE ARE ANY PROBLEMS, PLEASE CALL (310) 395-9051.
PAF'S FAX NUMBER IS (310) 395-5149.

Pediatric AIDS Foundation

Hope for Children with AIDS

Ms action needed

23 July 1993

To: Phil Lee
From: Elizabeth Glaser

Dear Phil,

Just a quick note to let you know that I feel very strongly that when the search committee for the Director of AIDS Research is put together that:

Art Ammann and
Mark Harrington

be included on that committee.

Their high intelligence, their commitment to the issue and their ability to work both outside and inside the system make them invaluable in my opinion.

Once again I will say that I hope this process moves quickly, as everyday wasted is precious to those of us infected.

Most sincerely,

Elizabeth Glaser

Elizabeth Glaser
Co-founder

cc: Donna Shalala
Patsy Flemming
Kristine Gebbie

CO-FOUNDERS: Susan DeLaurentis/Elizabeth Glaser/Susan Zeegen
1311 Colorado Avenue, Santa Monica, California 90404
TEL: (310) 395-9051 FAX: (310) 395-5149