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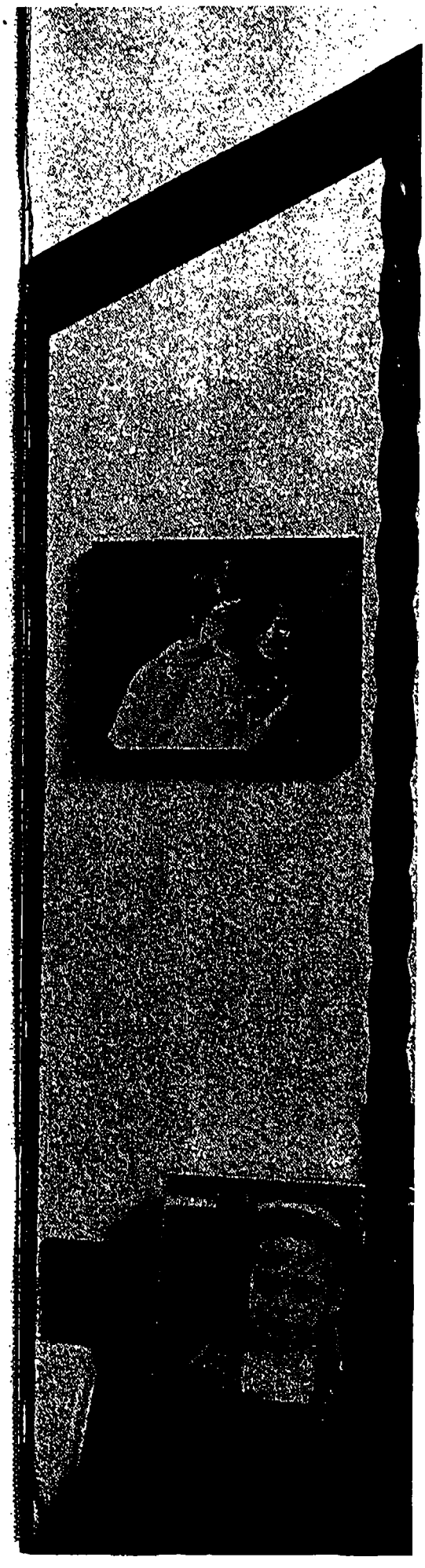


IN THE ABSENCE OF ANGELS

In an exclusive book excerpt, a Hollywood mother movingly describes her family's battle with AIDS

By Elizabeth Glaser and Laura Palmer

A decade ago, before the nation awakened to the daily nightmare that is AIDS, Elizabeth Glaser was infected with the virus through a tainted blood transfusion. She did not know that she had passed the virus on to her two children until her daughter, Ariel, developed the disease at age 4. For more than three years, Elizabeth, 43, and her husband, director Paul Michael Glaser, 47, the former star of the TV series Starsky and Hutch, *kept their painful ordeal private.*

Then in 1989, just after the first anniversary of Ariel's death, the Glasers went public with their story upon learning that a tabloid was about to expose their tragedy in an unauthorized feature. Since then, Elizabeth and writer Laura Palmer have collaborated on In the Absence of Angels, *an inspiring account of the Glaser family's struggles and triumphs, which will be published by G.P. Putnam's Sons in February. "After we found out that my family was HIV-positive," says Elizabeth, "it was clear that I would have to grow as a person more than I had ever imagined in order to find a way to cope. I wanted to let America see how painful it is to be a family battling AIDS and how hard it is to deal with the isolation and discrimination that comes through ignorance."*

The book is more than an anguished account of a mother's loss; it is a testament to one woman's brave refusal to surrender. "If reading my story can help open hearts to people who are battling this disease," says Elizabeth, "then maybe other families will have an easier time." Here is a selection from In the Absence of Angels.

May 1981

There were no words, no sounds, everything was obliterated by a single focus, getting to the hospital. It was as though I were motionless and the scenery was being pulled past me.

When I arrived at Cedars-Sinai Medical Center, my husband, Paul, rushed over, and I could see the fear in his face. I was six months pregnant and had started bleeding. My baby wasn't due for 11 more weeks.

I was diagnosed as having placenta previa, which meant the placenta was growing across my cervix. All we could do was pray that I would stop bleeding, because my child was probably too small to live outside my body. I lay there, day after day, with Paul by my side, waiting.

On the sixth day, I was sent home and told to stay in bed for the rest of my pregnancy. I was so afraid that I did less than whatever the doctor said I could. Each day was a victory, the next, a challenge.

Finally, on Aug. 4, 1981, Ariel Glaser was delivered by cesarean section. She was three and a half weeks early and weighed five pounds, two ounces, but I didn't care. When I looked into her eyes for the first time, I was amazed that this miracle was mine. Our fears were gone.

I was trying to tell the doctors how glad I was that it was over, when I heard the anesthesiologist saying that something was wrong. I couldn't breathe. I hemorrhaged. I was gasping for air. My doctor pushed on my stomach and I could feel the warm blood gushing out. I was too horrified to even scream. What was happening to me?

The transfusions began. I watched the dark red blood drip out of the squat plastic bag, flow through an IV tube and into a vein in my arm. I was transfused with seven pints. After the doctors packed me with cotton I finally stopped bleeding.

It wasn't until I saw my baby daughter again that the weariness and terror began to drift away, to be replaced with an instinctive love. She *was* beautiful, and we had both survived. It was over. I finally fell

▲ Elizabeth's husband, Paul Michael Glaser (right), played Starsky; David Soul was Hutch in ABC's cop series from 1975 to 1979.

► The Glasers in 1986, the year they were diagnosed. "I never imagined," says Elizabeth, "that this is what my life would be about."

asleep, thinking about the wonderful life the three of us had to look forward to.

Three weeks later I saw an article about a new virus called AIDS. I called my obstetrician immediately. "I just read an article in the paper about AIDS, a virus that may be transmitted by blood transfusions. I just got seven pints!"

"Oh, Elizabeth," he said, "you've been through a difficult ordeal, but it's behind you. Relax and enjoy your baby. Your nightmare is over. AIDS isn't ever going to have anything to do with you."

June 1975

I had pork chops, not passion, on my mind when I met Paul 15 years ago. I was coming home from a session with my therapist and determined to defrost two chops and have supper by myself.

I had, in fact, just spent 50 minutes explaining why I didn't need a man. Then, while waiting for the light to change at the intersection of Santa Monica and Beverly Boulevards, I looked at the car next to me. *"Oh, my God, that is the cutest guy I have ever seen,"* I thought. I smiled. He smiled. The light changed.

I turned right. He turned right. I glanced into the rearview mirror and he signaled me over with his arm. I was anxious and jittery as I pulled over. He stepped out of his car and walked toward me. I rolled down my window and he said, "Okay, let me see your driver's license." I looked at him and laughed. He was droll and disarming.

"What are you doing for dinner?" he asked. Thinking of therapy, I told him I was going home and making pork chops. "Wouldn't you rather go out for Chinese food?" "Yes," I said without missing a beat. One therapy session thrown out the window.

We went to Al Fong's in Beverly Hills. It was dark and the food was dreadful. Midway through the moo shu pork I asked Paul what he did. He said, "I'm an actor." I was so disappointed. I had lived in Los Angeles long enough to know that being an actor meant absolutely nothing. "Are you working?" I asked politely. "Actually, I am. I'm in a show that's just been picked up by a network. It'll be on ABC in the fall." "What's it called?" "*Starsky and Hutch.* It's a cop show about two detectives. I play Starsky."

I knew that night that even though he was an actor, this was the man for me. I was 27 and in love. When I looked at Paul I saw happily-ever-after. In September I moved into the one-room bungalow in the Hollywood Hills he shared with a dog named Max.

Paul didn't even have a television. We watched the debut of *Starsky and Hutch* with David Soul, the actor who played Hutch, at the home of David's agent. Everyone, including the stars, felt the show would be cancelled in eight weeks. By Thanksgiving, it was the hottest show on TV, and Paul and David were as famous as rock stars.

Paul and I were both stunned by his instant celebrity status. For years, he had worked steadily, doing everything from Shakespeare to soaps. *Starsky* was not how he imagined becoming famous. There was a lot of adjusting to do. The simple joy of taking a walk on the beach in our jeans and sweatshirts came to a halt. Until you went out in public with Paul, you had no sense of how overwhelming, demanding, and ridiculous being a celebrity was.

During the years that *Starsky* was on the air, we never got involved in the social side of Hollywood. We saved our money, knowing that actors usually have lean times, and wanted to be prepared for that. The price I paid for Paul's celebrity was invisibility. Hollywood people would nod and smile when I would say I was a teacher or, later, an exhibits director at the Children's Museum. I had to find ways to accept that; one solution was to make a life of my own that was independent and strong.

I definitely knew I wanted to be married and have children. I had had a wonderful childhood and was looking forward to starting a family of my own. But Paul's childhood had been more complicated, and marriage and family were scary to him. Paul and I talked it through, and he finally agreed that we'd get married when we were ready to have children.

▶ Elizabeth, who gave birth to Ari (right) at 33, grew up in Hewlett Harbor, N.Y., and earned a master's degree in early childhood education at Boston University. After a two-year marriage to a former classmate, she moved to LA., where she was teaching when she met Paul.

Three months after our wedding in August 1980, I was pregnant. All the goodness in the world seemed to be ours. In nine months I would have what I had always wanted most, a child of my own with a man that I loved.

When Ari was about a year and a half old, we began looking for a larger house. Paul and I wanted more children, and I was trying to get pregnant again. From the moment I walked into the sprawling Mediterranean house in Santa Monica, I knew this was the home for my family. Our children would grow up and go to college, and then Glaser children would come home with Glaser grandchildren.

Everything seemed to be going well. I had gotten pregnant and had miscarried, but was pregnant once more. And on Oct. 25, 1984, I delivered a beautiful son we named Jake.

In the spring of 1985 Paul was offered the job of directing his first feature film, *Band of the Hand.* The film was being shot in Miami, so we packed up the family and rented a house on the beach for the three-month shoot.

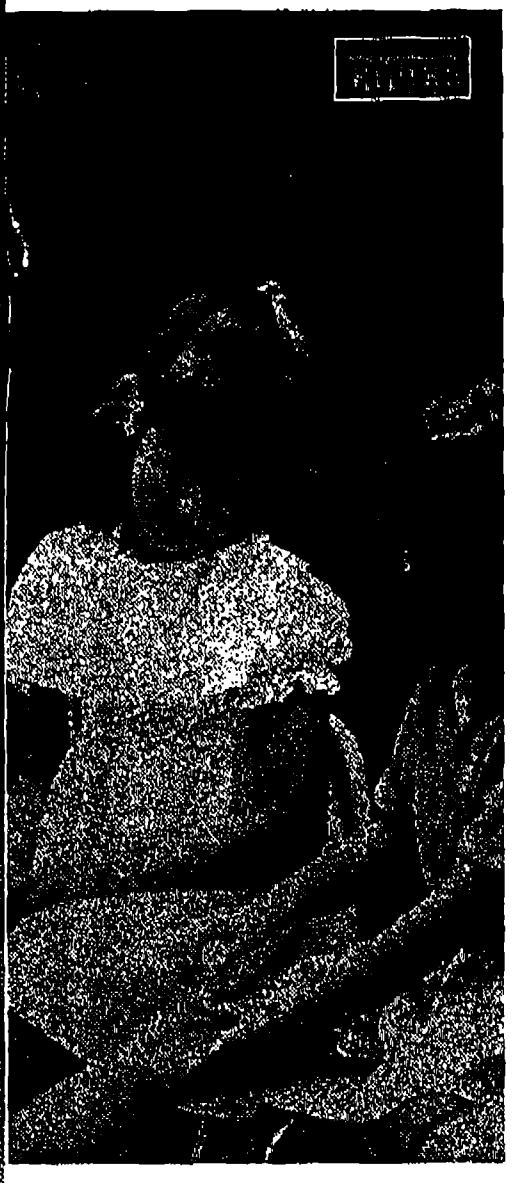
From Miami I took the children to visit my parents, who were living in Puerto Rico. We had just returned from that trip when Ari, who was then 4, started to have stomach aches and cramps. She was in a great deal of pain. We consulted a pediatrician who said that she had probably picked up a bug in Puerto Rico. When Ari didn't get better, I went to another doctor who suggested a stomach specialist. He had Ari hospitalized for more tests. The doctors said they had no idea what was wrong with Ariel, but for the next three days they watched her as if she might die. Once again I saw her life as precarious. I could feel all my dreams and plans start to crumble. My many fears began to return. Without even knowing what was wrong, I was fighting for Ari's life all over again.

By the time we left Florida in November Ariel was stronger, but not well. Doctors there said that she suffered from a blood disorder that usually leads to kidney failure. There was more color in her face and lips, but she still had bouts of diarrhea and would wake up in pain. Over the next few months we were doing test after test, trying to diagnose the underlying cause of Ari's illness. Paul and I had told Ari there was something funny with her blood and that was the reason she was so frequently tired. We told her that the doctors were going to find a way to make her better.

As time went by and things still didn't improve, Ariel was tested for all sorts of unusual diseases including lupus and leukemia. There was also talk of doing a liver and kidney biopsy, but that was postponed. When each test came back negative, I felt we had won another diagnostic round. But Ari's doctor, Richard Fine, wasn't as cheerful. He knew what we didn't—that Ari's diarrhea and low helper T-cells count [an important part of the immune system that fights infection] were symptoms of AIDS.

I don't think I was any more anxious about an AIDS test than I was about anything else. Just as her doctors had ruled out lupus and leukemia, they'd rule out AIDS. We took her in to be tested.

When the phone rang the next day, Paul answered it and after he hung up he said, "They've got to run it again. It's shown



one about our diagnosis because the experiences of other families with AIDS had not been positive. "The world is not ready for your family," was how he put it.

Nevertheless, he said we needed to either tell her nursery school or take her out of it. The Centers for Disease Control guidelines, at that time, said that a child with AIDS should not be in nursery school without first getting permission from the school. It was surreal. Along with this hideous medical diagnosis came instructions on how we needed to handle the rest of the world.

Dr. Stiehm told me that I could test positive and carry the AIDS virus without being symptomatic or showing any signs of the disease. In other words, there was a big difference between being HIV-positive and having full-blown AIDS. Although Jake had tested positive, his other tests were all normal.

I told Dr. Stiehm that I could not live without telling my friends. They had been following Ari's illness since Miami, and their support and concern had been crucially important. Paul and I decided we had two choices. We could tell some friends or we could pick up, sell our house and begin our life all over again someplace else. The life we had known was over. I had to stay strong so I could save my children. Our first steps were perhaps the hardest.

Paul and I decided to confide in only a handful of friends. I told my women friends in person, one by one, and made each of them promise not to tell anyone except their husbands. For some, whose children were playmates of Ari and Jake, finding out that we had AIDS was like finding out that for years their children had been in imminent danger. Most of our friends wanted to stand beside us, but they also wanted assurances that there was no risk to their children. In May of 1986, answers were in short supply and there were no guarantees.

At first, no one would allow their children to come and play at our house. Some friends refused to let my kids come to their homes at all. Some said their children could continue to play with mine, but only at the park. Some dropped out of our lives.

The day after I told my yoga teacher about our diagnosis she called to tell me that she never wanted to see me again. We asked a therapist to see if a child psychiatrist would work with Ari when and if we felt it was appropriate. I was later told that psychiatrists would not see my child, because they were afraid if word leaked they would lose too many other patients.

People were responding so fearfully that I started to feel dangerous myself. The doctors said there was no reason for fear, but that meant nothing because our neighbors and our friends were not doctors. Every time I went into the supermarket, I envisioned everyone slowly and silently moving away as if they had just seen a rattlesnake. It would be nine months before the Surgeon General would appear on television to say flat out that you can't get AIDS from saliva or kissing. And with that information, our lives slowly regained some normalcy.

When we told people, we forced them to enlist in a conspiracy of silence. The quality of our lives now hinged on the ability of our friends to keep quiet. Were word to get out, we knew we would be treated like plague victims for no reason. All of us were very afraid and confused.

What could have stopped the fear and hysteria was strong leadership from the

▲ Paul and Ari took frequent outings together and often spent quiet moments painting and reading at home.

Reagan administration. But in those early years of the epidemic, that leadership was absent. AIDS may one day cost me my life, but community reaction right away cost me the right to live the rest of my life the way I choose. That was my first fight.

It was a time that would almost be unimaginable if we hadn't lived it. It is what all families battling AIDS had to face then. You are told that you and your children may die. You are told that there are no answers now. And then as you are struggling not to completely fall apart, you realize that very few people are going to reach out to help or comfort you. We felt so alone. We wished for an angel who would help us get through it all. But at that time it seemed we had no angels watching over us.

July 1986

One of the telephone calls I dreaded most was to Crossroads Elementary School, where Ari had been accepted. Both Paul and I desperately wanted her to start kindergarten that fall. It was one of the few direct links we had to the future, and it meant so much to Ari. Paul Cummins, the school's headmaster, had no idea why I'd walked into his office. He seemed both confident and relaxed. I took a deep breath before I began.

"We were planning on having our

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▲ The family spent happy summer holidays in Maine. It was there Ari's health seriously began to fail in 1987.

daughter, Ariel, start kindergarten here in September," I said. "But I just found out that she, my son and I are all infected with the AIDS virus." I started to cry. I was sure he would send me away and tell me to find another school. Paul Cummins walked over and put his arms around me. "You are part of our family," he said. "We want you here." He held me as I cried. I left his office feeling both relief and joy. As long as I could see that not every door was going to be closed to us, I could hope.

Ari had spent just one week at Crossroads when Cummins met with the Glasers to explain that the school's board was about to draft an AIDS policy. He was concerned that Ari's presence in the school might jeopardize its passage. So Ari was uprooted and transferred to a nearby public school that already had an AIDS policy, where she remained until the following year, after the Crossroads board had agreed to admit children with AIDS. Says Elizabeth: "It was another hard lesson in how little could be taken for granted."

While I was fighting my battles, Paul was coming to grips with his own private war—a battlefield on which he might lose all those he loved. It was a difficult struggle for him then and it still is now. He worked as much as he could, as that gave him the strength to keep going. Sometimes it is hard for me to believe that my life is real, but trying to imagine being Paul is even more difficult.

Ariel was doing well. Each morning I would sit with her and pick out the hair ribbons she would want to wear. We would stand in front of the bathroom mirror and I would brush her hair 100 times to make it shine. As her hair glistened, silent tears would fill my eyes and my heart would break, knowing that I might lose her. It became impossible for me to ever feel really happy without feeling achingly sad.

That autumn, I kept wishing for things that never seemed to happen. I wished Ari would be invited to someone's house for a sleepover. I wished one of Jake's friends would invite him for a play date. It would be lovely if Paul and I were invited to a dinner party.

At that point in our lives, coping with fear was far worse than coping with AIDS. The fear of rejection or exposure was with us at all times. Most people have nightmares when they sleep, but when you are a family facing AIDS, the nightmare begins fresh each day. Sleep is the only time when I feel just like everyone else. Often I wake up in the morning having forgotten for an instant about AIDS, but that lasts for only a blink of an eye.

In the fall of 1986, the doctors still had no answers. Naively, I thought we were ahead of the game. Since none of us was sick or deteriorating, I felt that maybe if we could just stay strong, doctors would find a cure. Ari was already five years old, while most children with AIDS died by the time they were two.

I felt I had every right to be angry. But what good was it going to do? Would it

longer? I couldn't stop myself from being angry, but I could keep that anger from being trapped inside my body. I would think of a room with two doors. If the anger came in one door, I tried to be sure there was always another door so the anger could get out.

I had to learn to forgive. I had to forgive the blood donor. I had to forgive the doctors, the hospitals, the schools, and I had to forgive fate. I had to forgive God, if there is one, and I had to forgive my friends, who had to forgive me. Right away Paul saw that we would have to forgive everyone, that we would have to let the anger pass right through us. He helped me to learn this. It was bitterly hard. Anger is a poison that will seep into your system and want to stay.

But I still get angry. Sometimes when I am alone in my car I scream, "If you are there, God, I hate you! I hate you for making this my life. I hate you for letting Ari get sick. And I hate you because I don't really think you are there." My throat hurts when I'm done, but I usually feel calmer.

I would feel a painful jealousy whenever I saw people who seemed to have normal lives and healthy children. I would feel an excruciating envy toward strangers and my friends who could have what I never could. And then I would feel very, very sorry for myself.

I learned to let go of all of these emotions that depleted me. I am never going to be able to have what other people have. At some point you begin to accept that this is your life. I've learned that you often have no say in what happens to you, but you can choose how you bear the consequences.

Paul had finished directing *Running Man* in the spring [of 1987], and we had decided we would make our annual summer trip to Maine. We were swimming, boating, hiking or picking wild blueberries on Pleasant Mountain. At night we would make a fire and toast marshmallows. Simple and intense delight. But Ari started to seem weak, and I sensed for the first time that she was beginning to fail. Her appetite diminished and she complained of stomach pain. In past summers she had always been eager to go in the canoe and be by the water, but now that eagerness was gone. As a mother, I knew instinctively that I was losing her.

I called Dick Stiehm in Los Angeles. "We've got to get AZT now," I said. "She's starting to fail." In 1987, AZT was the only treatment that seemed to be effective against AIDS.

"What do you mean? It's ready for me!" Although I hadn't needed to start taking it yet, I knew it was available.

"AZT hasn't been approved for pediatric use. It's just not ready."

"We've got to find a way to get it and use it."

"Elizabeth," he said, "we don't even know the dose to give her. We can't just experiment. It could kill her."

"When will it be ready?"

"In the fall."

I took a deep breath and prayed that we could hold on until then.

By the time we got home, Ari was thinner and weaker, but Dr. Stiehm felt she would still be able to start school. She had her heart set on beginning first grade. It didn't work. Although Ariel looked beautiful with her shiny hair and luminous blue eyes, she frequently had outbursts of ghastly pain. She was a valiant fighter but was only able to finish two weeks of first grade.

As the pain increased, Ari and I became more and more like one person. In her worst moments, my eyes would start to fill with tears and I would say, "Oh, Ari, I wish I could take all your pain into my body. I wish I could make it all go away." She would look right into my eyes and very slowly answer, "But you can't, Mom." We both knew it was true.

We would cherish the good moments more than ever. Paul would take Ari to the end of the block to feed the pigeons, and at night he would lie beside her in bed and make up wonderful fanciful stories.

In the fall parents started getting curious about Ari's long absence from school. Rumors were raging and several parents asked the school's director if Ariel Glaser had AIDS. Each time we found out that someone was asking, our anxiety soared. Paul and I still felt the risks of going public clearly overshadowed any gains. As awful as it had been for us to shoulder the massive weight of the secret for the previous year and a half, we dreaded even more the risk that our children might experience any of the hysterical fear that still surrounded AIDS in many parts of the country.

Paul and I had stopped going out, except with the few who were pledged to secrecy. Our friends worked as hard to protect our privacy as we did. At night, Paul and I would climb into bed exhausted by the strain of just being us. If we talked about our fears, we felt overwhelmed. If we talked about our hopes, it felt like pie-in-the-sky dreaming. So usually, we didn't talk at all.

▲ Avid skiers, the Glasers vacationed *en famille* in Park City, Utah, shortly after Jake's birth in 1984.

Some nights I would just lie there and think how trapped Paul must feel. How hard it was to live with us and how impossible it would be to leave. If he walked away, everyone would think he was such a "bad" guy. But I knew he must have wanted to run away at times. Part of me would have wanted that. But he never said it, we never shared what we were thinking. It was too scary. On a good night we would fall asleep in each other's arms.

Ari was getting weaker and weaker. We had been waiting for AZT all that year and each month it wasn't ready. Paul and I were silently praying that something would change the course of our lives, working hard to keep optimistic.

Shortly before Thanksgiving 1987, Ari was hospitalized with acute pancreatitis. She was released after four weeks but had to continue being fed through an elaborate intravenous system, which Paul and Elizabeth mastered so that they could care for their daughter at home. Ari began taking AZT orally right before Christmas, but the drug had no positive effect.

Through January of 1988 Ari became more confined. By February she stopped walking completely. We didn't know why. The doctors had no answers. I carried her everywhere. She was unable to speak, but we both remembered the words that had already been said. We would still go for long walks. I would put her in the stroller,

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cushioning her with pillows and wrapping a blanket over her legs. Despite the pain and the weariness that she always felt, she never failed to respond to the beauty around her.

In March 1988, nearly two years after our initial diagnosis, the guillotine fell. Ariel got pneumonia and we were back at UCLA again. We learned that her brain had severely atrophied. The doctors said it was irreversible. It was one of the central nervous system complications of AIDS that is quite common in children, though not in adults.

After four days, Dick Stiehm solemnly sat us down and told us that Ari had probably 48 hours to live. She was breathing weakly, but what none of us knew then was that she hadn't given up.

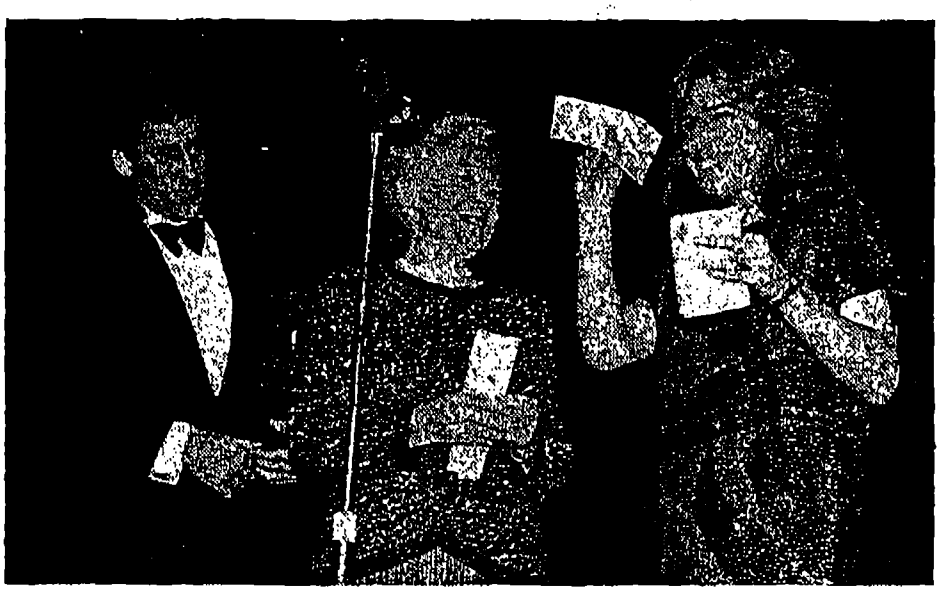
It was not until the doctors told us that there was absolutely no hope that I confronted the possibility of Ari's death for the first time. I sat with a friend and lit one cigarette after another. I was shaking and not yet able to talk. "No one cares if we all die from AIDS," I said. "Something is very wrong. I have to get to the President."

It was in that moment of honest desperation that I realized I could no longer sit quietly in Santa Monica. A mother's job is to save her child; it's a basic animal instinct. But I was failing. I had to do more.

Propelled by anger and frustration, Elizabeth considered ways to take a more active role in AIDS issues without compromising her family's privacy. Ariel survived the pneumonia, yet her health seemed ever more fragile. The day the Glasers brought their daughter home from the hospital, Elizabeth discussed her intentions with Paul.

Paul was silent for a long time and then with great gentleness he said, "I'll support you in whatever you have to do." I gave my husband a big hug and felt a smile spreading across my face. I knew this was the moment when I was taking that hard first step. I didn't know it at the time, but it was the step that has kept me in motion ever since.

As a member of a family struggling with AIDS, I learned that few wanted to help enough to change a system that had become strangled by red tape. The ones who tried were often ignored because AIDS was something many refused to deal with. Someone had to care enough to be willing to shake things up, but I didn't know who it would be. I realized my country was failing me. The compassion as well as the moral and ethical foundations of our society were being tested, and from my point of view, America had let me down.



◀ **Last fall, Helen Hayes honored Elizabeth and gave her a donation on behalf of a Manhattan hospital.**

▶ **Ari, on a Martha's Vineyard beach, in 1987. By then, she had started napping every day.**

Determined to educate herself about AIDS as a national issue, Elizabeth met with physicians, politicians and friends to plan an assault on policymakers in Washington, D.C. Her first goal was to explain that AIDS affects children differently than adults and then to persuade legislators to make federal funds available, specifically for pediatric AIDS research. During her visit to the capital six weeks later, Elizabeth also met Dr. Phil Pizzo, chief of pediatrics at the National Cancer Institute in Bethesda, Md., who had launched the first federal study of AIDS in children. When he learned that Ari had been taking AZT orally with no favorable results, he recommended that she take the drug intravenously. Dr. Stiehm had already tried to get AZT in that form for several of his patients but had failed because it was still only available for trial testing. Elizabeth returned home and refused to give up until she was able to obtain the intravenous drug for her daughter in May 1988.

I sat in my den, relieved that we had succeeded in getting the drug and furious at the inhumanity of a system that cared more about rules than lives. Did I love my child any more than the mother in Harlem, Miami or Newark loved her child? Absolutely not. Did Ari deserve a chance any more than their children? No. Every child with AIDS deserves a chance. And what about the children who had no one to speak for them?

Then, three weeks to the day after we started intravenous AZT, I walked into Ariel's room in the morning and she looked up and said, "Good morning, Mom. I love you." I could hardly believe it. Ari was back! The sky had opened up. I had to find Paul. Maybe miracles did happen. Maybe one was going to happen in our house.

Ari continued to improve over the next six weeks. The intravenous AZT was unwinding her cocoon of paralysis, and her 6-year-old self was still underneath. The whole world had started spinning again.

In March we were told to prepare for a funeral. By May we had a shot at second grade. If Ari could make it, we were all going to make it.

In June, friends arranged a meeting between Elizabeth and the Reagans at the White House, where she appealed to the President to lead the nation on this urgent issue. Although the Reagans welcomed her warmly, their private concern had no positive impact on public policy. The more Elizabeth learned about the government's indifference to the issue of children with AIDS, the more determined she became to form a private foundation to raise funds for pediatric AIDS research.

July 1988

It was one of those beautiful Los Angeles days when the sun, air, sky and sea all seem perfect. I asked Ari if she would like to go down to the Santa Monica pier, which has rides and an amusement arcade with cot-

ton candy and stuffed animals for prizes.

Ari and I went on the Ferris wheel together, around and around, waving wildly, queens of the sky and sea. For a moment, I was experiencing the thrilling unadulterated joy of just being a mom. Maybe there was some part of Ariel that knew this was the last day that she was really going to get to be a little girl.

Two weeks later Ari was readmitted to UCLA hospital. Her white blood cell count had fallen too low, and we had to take her off the intravenous AZT. She was having fevers that we couldn't break. But I persistently believed that this was just another crisis that we would somehow survive. I have never been able to accept endings that I don't like. I fight to make life the way I want it to be, and because of that I never believed that Ari was going to die.

We had Ari's seventh birthday party in the hospital, and Dick Stiehm gave her a UCLA T-shirt and told her it was what she would wear on the day she went home. But Ari had regressed greatly. In a few weeks, we had slid back down the mountain we had climbed since June. Her care was intricate and complex, but all I wanted was to take her home.

Three weeks later, on Friday, Aug. 12th, 1988, we were packing up her things. Ari was lying in her bed and I said to her, "We have to see if you can sit in your stroller, honey." And Ari said, "No, Mom, I'm going to walk home." She couldn't move her legs. I looked at her and said, "Give me a break." Ari said simply, "No, Mom, I'm going to walk home." "All right, Ari," I said. "Go for it."

Paul and I continued getting her things together. It was not until the last 10 minutes of her life that I knew she was dying. And then very quickly she was gone. She was never supposed to die. It was too short a time to have had her. Paul wept and I cried, "Noooo!" It was a "no" that wanted to turn back time. It was a "no" to a world that had failed me. Our beautiful daughter had died. Ariel Glaser had been on the earth for seven years and eight days.

That Sunday, the Glasers held a memorial service for Ariel at home, and on Tuesday, Aug. 16, their daughter was buried next to Paul's father at a cemetery in Boston.

We have left Ari's room just as it was when she was alive. Paul and I decided we couldn't imagine changing it. We each find our way into her room at different times and in different ways to tell her we love her. Her door is always open. It's not maudlin; it's just life. Ari's room remains though Ari is gone and her spirit fills our hearts.

As In the Absence of Angels *continues, it chronicles Elizabeth's evolution from a desperate mother, crying out for action, to an impassioned advocate, in charge of her life and determined to help others. For a look at Elizabeth today, please turn the page.*

Photographs from the collection of Elizabeth Glaser

10

Pediatric HIV/AIDS Fact Sheet

Children

In the U.S

- It is estimated that the number of children infected with HIV in the U.S. is 15,000 through 1994-1995. Note: 31 states require reporting of HIV infection. Two of those states,Connecticut and Texas, have confidential reporting only for children less than 13 years of age and Oregon requires reporting only for children less than 6 years of age.
- AIDS is the seventh leading cause of death for children 1-4 years of age in the U.S.
- Between 15% to 30% of infants born to untreated HIV-infected women become infected with the virus. Studies show that treatment can help reduce the rate of HIV transmission from an infected woman to her baby to less than 8%.
- Of the 12 drugs currently approved for the treatment of HIV/AIDS, only seven are approved for pediatric use: AZT (retrovir), ddI, d4T, 3TC (epivir), Norvir (ritonavir), Viracept (nelfinavir) and Sustiva (efavirenz). No protease inhibitor is approved for infants under the age of two.
- Today, nearly 100% of new HIV infections in children result from an HIV-infected pregnant woman passing the virus to her baby either before or during birth.
- Approximately 30,000 American children have already lost their parents to AIDS.

Worldwide

- UNAIDS estimates that 1,600 children under the age of 15 are infected with HIV each day worldwide.
- 1,200 children die of AIDS each day worldwide.
- By the year 2020, there will be over 40 million orphans under the age of 15 in the 23 countries most affected by HIV. Most of these children will have lost both parents to AIDS.
- Nearly 600,000 children were infected with HIV in 1997, mostly through their mothers before or during birth or through breastfeeding.
- Altogether, 2.7 million children have died of AIDS since the beginning of the epidemic. Another million were estimated to be living with HIV disease at the end of 1997, half of them infected last year alone.

Adolescents

In the U.S

- 25% of new HIV infections in America occur in people under twenty years of age. This represents two new adolescent HIV infections every hour.
- Every year, 3 million American teenagers acquire a sexually transmitted disease, leaving them more susceptible to HIV infection.

Worldwide

- Worldwide, more than half of all new HIV infections acquired after infancy occur among young people 10-24 years of age.
- Of the 30 million persons living with HIV worldwide, at least a third are young people 10-24 years of age.
- Every day, 7,000 young people 10-24 years of age worldwide acquire the virus. This translates into five young people every minute or 2.6 million infections each year.

Women of Child-bearing Age

In the U.S

- AIDS is now ranked as the leading cause of death among African-American women ages 25-44.
- AIDS is now ranked as the third leading cause of death among all American women ages 25-44.
- From 1985 to 1996, the proportion of U.S. AIDS cases in women reported each year increased from 7 percent to 20 percent.

Worldwide

- Approximately 42% of the 21.8 million adults living with HIV/AIDS worldwide are women.
- Nine out of ten HIV-positive women in developing countries have no idea they are infected.
- In the U.S. fewer than 5% of children born to HIV-positive women in 1997 were infected with the virus. In developing countries, the average was between 25% and 35%. There are two major reasons for the difference- breastfeeding practices and access to drugs for reducing mother-to-child transmission.

Data from the Centers for Disease Control and Prevention, UNAIDS and the World Health Organization.

For specific citation information, please contact Chris at 310-314-1459 or e-mail chris@pedAIDS.org

Updated 7/15/98

Back to Home Page

National Organizations (revised 4/8/98)

For statistics regarding HIV/AIDS:

Centers for Disease Control & Prevention (CDC) 301-436-8500

For general information about HIV/AIDS, AIDS related resources & services, prevention materials, referrals & publications, funding information and clinical trials call:

CDC National AIDS Clearinghouse 800-458-5231

For general questions about HIV and for educational materials:

CDC National AIDS Hotline 800-342-AIDS

For general questions about HIV (in Spanish or Asian languages):

Bilingual AIDS Hotline 800-367-2437

For questions or information on international programs:

THE ELIZABETH GLASER SCIENTISTS AWARDS

>

> 1999 HONOREES - PROFILES AND INTERVIEWS

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ROBERT DOMS, M.D., Ph. D.

University of Pennsylvania

Associate Professor, Pathology and Laboratory Medicine

>

Area of Investigation: Study the role of chemokine receptors in HIV infection.

>

Background: In 1996, Dr. Doms led one of five groups that independently >identified the chemokine receptor CCR5 as playing a critical role in the >entry of the most common types of HIV into cells. Working with colleagues >in Belgium, he subsequently found a polymorphism in the CCR5 gene that >renders approximately one percent of Caucasians CCR5 negative - explaining >why some people remain HIV-negative despite repeated exposure to the >virus. The Elizabeth Glaser Scientist Award will help Dr. Doms continue >his studies on HIV pathogensis in the pediatric population.

>

QUESTIONS AND ANSWERS

>

1. How would you explain the significance of your work to a layperson?

My team and I are focused on chemokine receptors - specialized proteins that function at the surface of cells and allow molecules to trigger internal cell processes without actually entering the cell - as tools to understand how the virus works and come up with new therapeutic strategies. If we can stop the virus from getting into the cells, obviously, we can stop the infection -- that is the point of vaccines.

>

For HIV to get into a cell it has to do a couple of things, starting with latching on to the outside of the cell by binding to the CD4 molecule which is found on the surface of cells found in the immune system. It then has to get inside the cell through a process called

Doms lot 3

(14)

membrane fusion. It had been known for some time that CD4 by itself was enough for the virus to latch on to the cell, but was not enough for it to get inside the cell - the virus needed something else to get into cells, and this 'something else' eluded discovery for over a decade. However, in 1996, a molecule or co-receptor called CXCR4 was discovered. In conjunction with CD4 , CXCR4 that allows the virus to get into the cell to start an infection. Interestingly, it was also discovered that CXCR4 worked for some types of HIV but not others. Specifically, it was clear that CXCR4 didn't work for M-tropic viruses, the most common kinds of viruses that infect children and adults. Therefore, it was important
to find the co-receptor that worked for M-tropic viruses because then we can understand how these viruses get into cells and we could find new ways to block it.
>
In 1996, we found that the CCR5 molecule that holds the key for entry of these M-tropic viruses into cells. Then, continuing our work with Marc Parmentier and his colleagues in Belgium, we discovered that one- percent of Caucasians naturally lack CCR5 because of a naturally occurring mutation in the gene. Those individuals who lack CCR5 are highly resistant to HIV infection but are otherwise normal. The goal was then to come up with some kind of strategy to stop the virus from using CCR5 -- to develop an anti-viral drug.
>

2. How will your research under the Foundation grant be implemented in the pediatric HIV/AIDS population?

We now know that viruses throughout the world use CCR5.
That suggests a commonality that allows them to recognize the CCR5 molecule. Just this past summer it was discovered that gp120, the protein that coats the outside of HIV, has a very highly conserved region that interacts with CCR5.
We have discovered a way to trick the virus to expose this conserved region and hope to accomplish one of two things: make antibodies to this region and to then come up with new vaccines that target this region. Secondly, we want to expose the region and come up with drugs that will bind to this area and prevent HIV from using the CCR5 receptor.

Another component of our work will attempt to explain some of the differences in clinical symptoms in people with HIV on the basis of the kinds of co-receptors used by the viruses. We have been able to make antibodies to many of these receptors and we want to find out where these receptors are expressed in both children and adults. This will give us a clue as to which types of cells might potentially be infectable by different types of viruses. It may also help us explain some differences between pediatric and adult AIDS.
>

Doms 2 of 3

(5)

3. What does funding from a Foundation such as ours mean to your creativity as a scientist?

Historically, the system for getting grants almost forces people to be scientifically safe because they are worried that if they propose something too unique, too risky, they simply won't get funded. Funding from a private Foundation enables you to take more risky and creative approaches to new and interesting avenues of research. When you get funding from the Pediatric AIDS Foundation, it is a very substantive grant that allows you to move your research into new and challenging directions.

4. What does it mean to be an Elizabeth Glaser Scientist?

I remember hearing Elizabeth Glaser speak in 1992 at the Convention. It is quite an honor to receive an award named after her. When you ask yourself what you can do as a person to make a difference -- you look to her example as really showing the way. She demonstrated how one individual can make a positive difference.

5. We have come so far in the past decade, what does the next decade of >progress on pediatric HIV/AIDS research look like?

We are making progress and things are much more promising than they have been. There are some effective drug therapies helping a lot of people -- but people can develop resistance and the drugs are just too expensive. In Uganda, there are about a million HIV-positive individuals, but only very few can afford the triple-drug cocktail. We clearly need new therapeutic strategies.

>

Through basic research we are beginning to unravel this very complicated virus. I think we will develop new drugs to target the virus or the chemokine receptors. Obviously, what we really need is a vaccine, but that is going to be a slow and complex process because this virus changes its spots so readily. I think in the next decade there will be more progress in developing drugs to help knock this virus down, but we have to keep working on new ways to come up with a vaccine. New approaches, such as the conserved region approach, are exactly the kind of new investigative angles we need on the vaccine front.

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THE ELIZABETH GLASER SCIENTISTS AWARDS

>>

>> 1999 HONOREES - PROFILES AND INTERVIEWS

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>> Philip Goulder, M.D., Ph.D.

>> Instructor in Medicine

>> Massachusetts General Hospital, Boston

>>

>> Area of Investigation: HIV-infected children progress to disease more
>>rapidly than adults. One possible explanation is that the immune response
>>to HIV is defective in children. This study aims to investigate the cells
>>normally responsible for eliminating virus infections known as Cytotoxic
>>"killer" T-lymphocytes.

>>

>> Background: Dr. Goulder began his investigative career at Oxford where
>>he developed a number of techniques to examine immune function in HIV-1
>>infected children, which is his main area of focus. His experience as
>>a pediatrician and the novel technologies he has developed place him in
>>a unique position to define the role of immune responses in children
>>infected with the virus and will impact our understanding of HIV
>>pathogenesis and the prospects for immunotherapy.

>>

>>

>> QUESTIONS AND ANSWERS

>>

>> 1. How would you explain the significance of your work to a layperson?

Our ultimate goal is to develop a vaccine designed especially for children. We know that HIV-infected children progress to disease more quickly than adults. We also believe that the cells normally responsible for eliminating virus infections, known as Cytotoxic "killer" T-lymphocytes (CTL) play a central role in controlling HIV in adult infection. One possible explanation for the rapid progression generally seen in HIV-infected children is that their "killer" T-cell response is defective in some way. Recent advances in the technology available have allowed us the opportunity for the first time to make a detailed study of the "killer" T cell response in children. The long-term

Goulder 1 of 3

goal is to identify components of the immune response that are important in protecting against HIV disease, and which may ultimately be important to vaccine design.

>>

2. How will your research under the Foundation grant be implemented in >>the pediatric HIV/AIDS population?

>>

We are already studying HIV-infected children here in North America, and we will continue with these studies. However, the global epidemic is concentrated elsewhere, and much of our research effort will focus on HIV-infected mothers and children in South Africa. Over one-third of the Zulu mothers in Durban, South Africa, where our collaborations are centered, are HIV-infected. One other important reason for directing our research effort towards this region is that the commonest strain of HIV worldwide ('clade C') is infecting this South African population, and this is likely to be relevant for vaccine design.

>>

3. What does funding from a Foundation such as ours mean to your >>creativity as a scientist?

Five years of funding provides the stability and support for ambitious and important projects to be planned and carried out. For a pediatrician who research focuses on pediatric HIV,the PAF has international recognition and the close association with it can only be helpful in developing collaborations and setting up studies with people whose priorities and goals overlap with those of the PAF.

>>

4. What does it mean to be an Elizabeth Glaser Scientist?

It is a great honor to be bracketed with the other EG Scientists, who are clearly highly creative and talented individuals. The Pediatric AIDS Foundation deservedly has a reputation for practicing scientific research the way it should be done - that is, in truly collaborative way, so that rapid progress may to be made towards eliminating HIV. I believe that this "team" approach is the right approach and I am very excited to be joining a team whose priorities and research interests overlap so much with my own.

>>

5. This year marks the Foundation's 10th Anniversary. We have come so >>far in the past decade, what might the next decade of progress on

>>pediatric HIV/AIDS research look like?

I would hope the next decade will put us squarely on the path toward developing a vaccine for HIV – for children as well as adults. Ultimately, a vaccine is our only real hope
for impacting this disease. While implementation of a successful vaccine is years away, if we wait to develop HIV vaccines for children until after they are proven effective for adults, we will lose millions of children to this pandemic.

Boulder 3 of 3
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THE ELIZABETH GLASER SCIENTISTS AWARDS

1999 HONOREES - PROFILES AND INTERVIEWS

PAUL JOHNSON, M.D.
HARVARD MEDICAL SCHOOL
Associate Professor of Medicine,
Chairman of the Immunology Division,
Partners AIDS Research Center
Harvard Medical School.

Area of Investigation: CD4+ T helper Cell Function in Macaques to combat SIV infection in Pediatric patients.
CD4+T lymphocytes play a central role in the war between the AIDS virus and the body's immune system.

Background: Dr. Johnson has focused on analysis of HIV-specific cytotoxic T lymphocytes (CTL), research that has established him as a leading investigator in the field of cellular immunology. Since being appointed as Chairman of the Division of Immunology in 1994, Dr. Johnson has led a successful research program focused on immunology related to AIDS pathogenesis and vaccine development. More recent research has analyzed T cell turnover in SIV infection and the development of gene therapy for AIDS.

QUESTIONS AND ANSWERS

1. How would you explain the significance of your work to a layperson?
I am trying to better understand the role that CD4+T cells play in helping children to fight off HIV infection. CD4 cells are the major cells responsible both for fighting off infection and also the main target that HIV infects and destroys. By studying monkeys infected with a closely related AIDS virus, I hope to understand both how quickly CD4+ T-cells are killed and regenerated and also understand how they recognize the AIDS virus. This information should help us could restore those critical immune responses via either treatment with anti-retroviral therapy, immunization or a combination of the two.

2. How will your research under the Foundation grant be implemented in the pediatric HIV/AIDS population?
The hope is that our research with Macaques could help us to design an approach to help boost the immune response against HIV in HIV-infected children. If this is successful, it would help us design techniques for therapeutic immunization - - meaning that it might allow their immune system to better contain the virus

Johnson [redacted]
1 of 2

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replication, either as a supplement to antiviral therapy or if the antiviral therapy fails for some reason, allow them to better contain viral replication without drugs.

3. **What does funding from a Foundation such as ours mean to your creativity as a scientist?**

What's really unique about the Foundation is the group of scientists that are affiliated with it? The chance to interact with the outstanding group of Glaser scientists is an exceptional opportunity. The ability to contrast results and share ideas at the conferences that the Foundation sponsors is very exciting, because that degree of focus and level of interaction is quite unique.

4. **What does it mean to be an Elizabeth Glaser Scientist?**

It's a tremendous honor and responsibility. I've heard so much about Elizabeth over the years and besides the scientific opportunity, it is simply a personal honor for me.

5. **This year marks the Foundation's 10th Anniversary. We have come so far in the past decade, what might the next decade of progress on pediatric HIV/AIDS research look like?**

I would hope the research over the next decade would help us to better understand how we can rebuild the immune system of people infected with the AIDS virus. We have now a number of scientific tools at our disposal and the challenge will be to see how we use those tools to rebuild the immune system to lead to prolonged gains in the health of HIV-infected kids.

Johnson 2 of 2
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THE ELIZABETH GLASER SCIENTISTS AWARDS

1999 HONOREES – PROFILES AND INTERVIEWS

JULIE OVERBAUGH, Ph. D.
Full Member, Fred Hutchinson Cancer Research Center
Seattle

Area of Investigation: Leading an effort to study how HIV virus is transmitted through breast feeding by using a collection of samples from a recently completed clinical trial of breast feeding transmission of HIV in Kenya. Since 1992, Dr. Overbaugh has been a member of the Nairobi HIV/STD Research Project, an international collaborative group based at the University of Nairobi.

Background: In the past decade, strategies to limit HIV transmission to newborns have been implemented in developed countries as a result of research showing the effectiveness of treatment around the time of delivery. Moreover, in developed countries, women infected with HIV are counseled not to breast feed, which further reduces the infant's exposure to HIV. However, in resource-poor settings, many continue not to have access to adequate health care, including new drugs that can prevent their babies from acquiring HIV. In these situations, breast feeding is also more common. Dr. Overbaugh is pursuing studies that are designed to help devise ways to further reduce HIV transmission to infants, including during breast feeding.

QUESTIONS AND ANSWERS

1. How would you explain the significance of your work to a layperson?
I am part of a large, collaborative research team that is conducting a clinical trial that is designed to determine how and when breast feeding transmission occurs. The Foundation project will build on the information we are learning from this trial try and understand what features about the mothers' viruses make it more likely to be transmitted to her infant. For example, how does the genetic makeup of the virus influence transmission and is there a common genetic signature to viruses that infect infants? We are also interested in determining whether the amount of virus that mother has, including virus in breast milk, increases the chances of her infant being infected? AIDS researchers have already shown how to decrease transmission to newborns with a short course of AZT around the time of delivery. Now, we are trying to understand how to develop other ways to reduce HIV transmission to children in situations where access to expensive treatments are impractical.

2. **How will your research under the Foundation grant be implemented in the pediatric HIV/AIDS population?**

One overall goal of studying breast milk transmission of HIV is to provide information to women so that they can make more informed choices about breast feeding. From the viral studies we hope to undertake over the next five years, we hope to understand a lot more about viruses in breast milk so that we can begin to think about therapies more designed to target those viruses. Up to this point, there has been a heavy focus on HIV in the woman's blood. Much of transmission to the infant is actually going on during delivery, while they are in the birth canal. Or, in developing countries, a lot of infection is occurring through breast feeding when they are exposed to the virus in breast milk. We want to now start looking at those secretions and understand what is going on so that people can think more about intervention to target those viruses, instead of just blood viruses.

3. What does funding from a Foundation such as ours mean to your creativity as a scientist?

A lot of what I see from the Glaser Foundation is not just individual creativity but a lot of encouragement to interact and be creative as a group.

3. **What does it mean to be an Elizabeth Glaser Scientist?**

For those of us in the AIDS community, Elizabeth Glaser is one of the heroes who proves that one individual, if they work hard and have a lot of personal strength, they can make good things happen out of something that is inherently bad. I personally feel very proud to have funding from a group that bears her name.

4. **This year marks the Foundation's 10th Anniversary. We have come so far in the past decade, what might the next decade of progress on pediatric HIV/AIDS research look like?**

I think there is a big mental shift that needs to take place (and hopefully will occur in the next decade) -- and that is what to do in developing countries where the therapies used to block HIV vertical transmission aren't really available? I think the next decade of AIDS research might be trying to come up with therapeutic approaches that are affordable and applicable in developing countries. That will be both a big political and scientific hurdle. That is really going to be the focus in terms of a lot of rethinking on how to deal with the problem of vertical transmission. The progress we have made in reducing vertical transmission in some settings has given may AIDS researchers renewed enthusiasm, and we need to continue to design better and better therapies for people who have access to

high quality health care. At the same time, the success in blocking HIV vertical transmission should serve as a source of encouragement to try to understand how the therapies we now have work and then figure out less costly approaches to accomplish the same aim. We have to remember that most HIV transmission is occurring in developing countries, and in it is this setting that we face our major challenge for halting the worldwide devastation of HIV.

ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION

805 15th Street NW, Suite 500, Washington, DC 20005
Tel: 202-371-0099 Fax: 202-371-2044

FAX TRANSMISSION SHEET

TO: **Marsha Berry, Press Office**
Julie Mason, Press Office
Noa Meyer, Speechwriting Office
Patty Solis, Scheduling Office

FROM: **Linda Marson, Communications Director**
PHONE: 202-371-0099 (work) 301-983-8274 (home) and
FAX: 202-371-2044

DATE: **January 22, 1999**

RE: **ELIZABETH GLASER SCIENTIST AWARDS –**
PRESENTED BY FIRST LADY HILLARY RODHAM CLINTON
AT THE NATIONAL PRESS CLUB, JANUARY 28, 1999

Number of pages (including this page):

Hello and thank you to all of you. We are really excited about having the First Lady present the Foundation's Scientist Awards.

ATTACHMENTS:
- O THIS TWO PAGE COVER SHEET
- LOGISTIC MEMO – Labeled A through G
- BACKGROUND MATERIALS – labeled 1-24

I am sending you all the same background information. Do you need proposed talking points? ? Please note that this year commemorates the Foundation's 10th Anniversary and also the attached release on the recently announced FDA regulations involving drugs for children. Paul Glaser will note the Administration's efforts in his introductory remarks for Mrs. Clinton.

Please let me know each of your needs beyond the attached material and we will accommodate you every step of the way!
(page one of two, cover memo)

Cover memo 1 of 2

Attached is an updated agenda/logistical memo that reflects confirmation of the First Lady's arrival time at the National Press Club. This is a PROPOSED agenda and timeline, please let me know your questions, concerns, changes.

I tried to provide as much detail as possible in this memo, particularly the logistics of her actually presenting the four awards to the scientists. Please advise us on what you need from us to accommodate security clearance re: staff, guests and media.

I've attached our DRAFT MEDIA ADVISORY and DRAFT PRESS RELEASE. We would love a quote from the First Lady, if possible

THANK YOU!

(Page two of two, cover memo)

Cover memo 2 of 2

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ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION

January 22, 1999 – UPDATED MEMO

To: **Marsha Berry, Julie Mason, Noa Meyer, Patti Solis**
Office of First Lady
Hillary Rodham Clinton

From: Linda Marson,
Communications Director
CONTACT: 202-371-0099 (work) and 301-983-8274 (home)
FAX: 202-371-2044

RE: **FIRST LADY HILLARY RODHAM CLINTON'S PRESENTATION OF THE ELIZABETH GLASER SCIENTIST AWARDS ON JANUARY 28, 1999**

Thank you!

Below is a proposed rundown for the event. Please tell us what you need regarding background, talking points, security needs, etc. We will accommodate you as requested.

I have also attached a draft media advisory and a draft press release. We will get you background information on all the participants at the award ceremony, including a description of the scientists work in layperson's terms, which will be helpful since Mrs. Clinton will be presenting them with their award and describing, in layperson terms, their work.

The audience for this event will include approximately 75 members of the scientific community, as well as staff and friends of the Foundation. In addition, the media is being invited to attend

(A)

the awards presentation. There will be no Q&A while the First Lady is in attendance. We plan to have an informal Q&A session with the press, our Foundation members and our scientists, following her departure.

Here is a proposed rundown for the event:

EVENT: The Elizabeth Glaser Pediatric AIDS Foundation's Scientist Awards ceremony will take place at the National Press Club, 14th and F Streets, NW, 13th floor, Holeman Lounge, on Thursday, January 28, 1999.

GREETING: It is our understanding, per Patti Solis, that Mrs. Clinton will arrive at the Press Club at 9:50 a.m. She will be greeted (please advise us on where you wish this to take place?) by Foundation Chairman of the Board, Paul Glaser, Foundation CEO, Kate Carr, and Foundation Co-Chair Susie Zeegen.

PHOTOS: We have a "holding room" adjacent to the Holeman Lounge, where the award ceremony is taking place, available for the purposes of photos with our the three Foundation members listed above, as well as the four scientists (and, if possible, their spouses?). Please advise us on what you need for security purposes.

PROPOSED TIMELINE:

9:50 a.m.	**Mrs. Clinton arrives at the National Press Club, 14th and F Streets, NW. Greeted by Foundation contacts, Paul Glaser, Kate Carr and Susie Zeegen. Location: ?**

(B)

9:53 a.m.	**Photo session (White House photographer and a Foundation photographer) with Paul Glaser, Kate Carr, Susie Zeegen, Janis Spire, Executive Director of the Pediatric AID Foundation and the four awardees/scientists: Dr. Doms, Dr. Goulder, Dr. Johnson, Dr. Overbaugh and their spouses?** **Location: "holding room" adjacent to Holeman Lounge.** ***Please note that a few board members may also request photos, if that is possible?**
9:59 a.m.	**Enter Holeman Lounge. Mrs. Clinton can enter through the adjacent "holding room" and proceed directly to a seat next to the podium. She can remain seated until formally introduced for remarks and the award presentation.**

10:00 –10:02 a.m.	**Begin Award Ceremony – Opening remarks and welcome by Kate Carr, Chief Executive Officer, Elizabeth Glaser Pediatric AIDS Foundation. Introduces Susie Zeegen.**
10:02-10:04	**Remarks by Susie Zeegen, Co-Founder, Elizabeth Glaser Pediatric AIDS Foundation. Introduces Mary Fisher.**
10:04-10:08	**Remarks by Mary Fisher, Founder of Family AIDS Network. Introduces Paul Glaser.**
10:08-10:13	**Remarks by Paul Glaser, Chairman of the Board, Elizabeth Glaser Pediatric AIDS Foundation**
10:13-10:14	**PAUL GLASER INTRODUCES THE FIRST LADY**
10:14 – 10:24	**FIRST LADY delivers her remarks from the podium. We will provide suggested talking points:** - **Her history with the Foundation**

(D)

- the work of the Foundation,need to promote innovative, collaborative research, impact of Foundation's research on Pediatric HIV/AIDS and the meaning of the award

10:24 – 10:35

ASKS THE AWARDEES TO JOIN HER AT THE PODIUM, two on each side of her.
Mrs. Clinton continues her remarks – introducing each of the scientists in turn, providing a

- layperson description of the four who are being honored. She gives each of them their award in turn. (the awards themselves will be on a small table, adjacent to the podium). All 4 scientists remain standing until she has concluded.

AWARDEES:

Robert Doms, M.D., Ph. D., University of Pennsylvania

E

Philip J.R. Goulder, M.R.C.P., D. Phil., Massachusetts General Hospital

Paul Johnson, M.D. Harvard Medical School

Julie Overbaugh, M.D., Fred Hutchinson Cancer Center

10:35	**Mrs. Clinton Concludes the awards presentation. Paul Glaser joins her at the podium.**
10:35	**Paul Glaser thanks Mrs. Clinton, who departs through the adjacent holding room.**
10:40	**Mrs. Clinton departs Press Club**
10:36 a.m.	**Paul Glaser introduces Paula Apsell, Executive Producer, NOVA, who** Introduces clip from PBS Special "Surviving AIDS," featuring Foundation Scientist Catherine Luzuriaga

F

10:38-10:40	Paula Apsell introduces NOVA clip
10:40-10:46	NOVA Clip airs
10:46	Paul Glaser or Susie Zeegen conclude the Speakers program.
10:46-10:55	Susie Zeegen and Paul Glaser conduct Q&A With the media

Note: Also seated but not speaking will be Janis Spire, Executive Director of the EG Pediatric AIDS Foundation and Catherine Wilfert, Scientific Director, EG Pediatric AIDS Foundation.

For Immediate Release
November 27, 1998

Contact: Kelli O'Reilly
(310) 314-1459

FDA REGULATIONS ON DRUGS FOR CHILDREN ANNOUNCED

ELIZABETH GLASER PEDIATRIC AIDS FOUNDATION: "THIS MEANS THAT, FINALLY, CHILDREN CAN SHARE IN RESEARCH PROGRESS"

(WASHINGTON, D.C.) – The Federal Food and Drug Administration (FDA) today released final regulations outlining its authority to require pharmaceutical manufacturers to study their products for safety and effectiveness for use by children.

The Elizabeth Glaser Pediatric AIDS Foundation, which has relentlessly pressed the FDA for such regulations, expressed its great pleasure at the release of the final regulations. "Simply put, these regulations mean that -- finally -- children can share in the research progress against disease," said Paul Glaser, Chairman of the Board of the Foundation and the father of an HIV-infected child.

"Most of the time, children have been an afterthought in pharmaceutical research," said Susan DeLaurentis, a co-founder of the Foundation. ""Drug companies have failed to study drugs for safety in children for decades, largely because children are a very small market that doesn't make a big profit. My friend and fellow co-founder, Elizabeth Glaser, was shocked to find that the drugs that were available to treat her for AIDS were not available for her young daughter as well. The current drug company practice is that drugs are not studied for children unless there is a special reason to do so. These regulations will change that practice so that drugs for kids will be studied unless there is a reason not to do so. These regulations will make the future better for children with HIV and for all sick children."

The Foundation is grateful to President Clinton, First Lady Hillary Rodham Clinton and Vice President Gore for their help in making these regulations a reality," added Susan DeLaurentis.

"Separate pediatric studies are needed," said Catherine Wilfert, Medical Director of the Foundation. "Children are not simply little adults. Children – especially young children—metabolize drugs differently and have different reactions to drugs than grownups do. The failure of drug companies to do these studies means that parents and

FDA release 1 of 2

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pediatricians have to choose between ignoring a drug that is effective in adults or exposing a child to a drug of unknown safety. They shouldn't have to make that choice."

The mission of the Elizabeth Glaser Pediatric AIDS Foundation is to identify, fund and conduct critical pediatric AIDS research that will lead to the prevention and treatment of HIV infection in infants and children. This commitment to stimulating collaborative and focused research is unique in the scientific community. #

Noa A. Meyer 10/26/98 12:00:01 PM

Record Type: Record

To: Laura E. Schiller/WHO/EOP, Christine N. Macy/WHO/EOP

cc:
Subject: Gay and Lesbian Accomplishments

There are two documents since Robin is still in the process of merging them. The second one is difficult to open, so I cut it and and it is the attached text. Therefore, no need to open Todd Sommer's doc.

THE CLINTON ADMINISTRATION
A RECORD OF FIGHTING THE AIDS EPIDEMIC

Our common goal must ultimately be a cure, a cure for all those who are living with HIV, and a vaccine to protect all the rest of us from the virus. A cure and a vaccine: that must be our first and top priority. - President Clinton, December 6, 1995

It has been more than 15 years since the epidemic of HIV/AIDS struck our nation. In that time, more than 640,000 Americans have been diagnosed with AIDS and more than 385,000 men, women, and children have died of AIDS. President Clinton has worked hard to reinvigorate the response to HIV and AIDS, providing new national leadership, substantially greater resources, and a closer working relationship with affected communities. Funding for AIDS research has increased by over 65%, and funding for HIV prevention has increased 32%. Funding for the Ryan White CARE Act has increased by over 280%. The Food and Drug Administration has accelerated its drug approval process to record times, taken steps to increase access by women to clinical trials, and issued a new rule requiring better data collection on children. The President has preserved the Medicaid program, providing care to 50 percent of people with AIDS, including 92 percent of children with AIDS.

The Centers for Disease Control estimate that as many as 900,000 Americans may currently be living with HIV or AIDS, and 40,000 to 60,000 Americans are being infected with HIV every year. Women, communities of color, and adolescents are experiencing particularly high rates of infection, with over half of new infections occurring in those under 25 years of age. That is why President Clinton will continue to work to ensure that our nation responds aggressively and compassionately to the challenges created by HIV and AIDS. This fight will not be over until we have a cure and a vaccine to protect all Americans from this deadly epidemic.

PROVIDING NATIONAL LEADERSHIP

Creating the White House Office of National AIDS Policy. Acting as representative to the President, this office brings greater visibility and direction to the war on AIDS by coordinating

and focusing federal AIDS policy and initiatives.

Appointing a National Advisory Council. The President created the Presidential Advisory Council on HIV/AIDS to provide him and his Administration with expert outside advice and clear recommendations on how the federal government should respond to the AIDS epidemic.

Developing a National Strategy. President Clinton convened the first White House Conference on HIV and AIDS as well as the first White House Native American AIDS Policy meeting to encourage multi-level cooperation and a continued dialogue between the various communities fighting this epidemic.

Fighting Discrimination. President Clinton supported the Kennedy-Kassebaum Health Insurance and Portability Act, which bans insurance discrimination against people with pre-existing conditions including HIV/AIDS. He led the fight to repeal the discriminatory ?Doman Amendment,? which would have discharged all HIV+ military personnel; and continues to enforce the Americans with Disabilities Act, which prohibits discrimination against people living with HIV/AIDS. Additionally, the Administration has resolved nearly 800 cases alleging employment discrimination, obtaining monetary benefits of over $6.1 million.

Pushing for an AIDS Vaccine. On May 18, 1997, the President challenged the nation to develop an AIDS vaccine within the next ten years. He has supported that goal by dedicating an AIDS vaccine research center at the National Institutes of Health and encouraging domestic and international collaboration among governments, medical communities and service organizations.

INVESTING IN RESEARCH

Supporting the National Institutes of Health. The Administration has increased NIH AIDS research funds by 67% in five years. In 1993, President Clinton signed the NIH revitalization Act creating a permanent Office of AIDS Research at NIH and investing it with new authority to plan and carry out the AIDS research agenda. He appointed Nobel Prize winner Dr. Harold Varmus to head NIH and world-renowned immunologist Dr. Neil Nathanson to head OAR.

Accelerating AIDS Drug Approval Process. Since 1993, the Food and Drug Administration has approved 9 new AIDS drugs, 20 new drugs for AIDS-related conditions, and three new diagnostic tests. Included in the approvals are drugs known as protease inhibitors, which in combination with previous drugs have shown tremendous promise in the treatment of HIV progression.

Reducing Perinatal Transmission of HIV. The President is working aggressively with states to eliminate perinatal transmission of HIV. As a result of Public Health Service guidelines recommending the use of AZT by HIV+ pregnant women, the number of infants with perinatally acquired HIV dropped 43 percent between 1992 and 1996.

Developing the Forum for Collaborative HIV Research. This new public-private group is designed to catalyze collaborations among government researchers, pharmaceutical companies, third-party payers, and the community to capitalize on recent scientific advances and learn how to optimally use available treatment regimens.

INVESTING IN CARE

Supporting the Ryan White CARE Act. President Clinton in five years has nearly tripled funding for the Ryan White CARE Act, the largest distributor of funds for medical and support services to people living with HIV and AIDS. In 1996, Ryan White funds were first earmarked for the AIDS Drug Assistance Program (ADAP) to help States assist those without insurance to obtain much needed prescription drugs; since then, ADAP funds have increased by over 780%.

Providing Housing and Mental Health Assistance. Since coming to office, President Clinton has more than doubled funds for the Department of Housing and Urban Development's Housing Opportunities for People With AIDS (HOPWA) program. He also awarded the first federal grants though the Substance Abuse and Mental Health Administration to develop comprehensive mental health services for persons living with HIV/AIDS as well as their families and partners.

Protecting Medicaid and Social Security coverage. The President fought to preserve Medicaid coverage for people living with AIDS. Nearly 50% of people with AIDS and 92% of children with AIDS rely on Medicaid for health coverage. He also revised eligibility rules for Social Security Disability Insurance to increase the number of HIV+ persons who qualify for benefits.

INVESTING IN PREVENTION

Supporting the Centers for Disease Control. The Administration has increased funds for HIV prevention at the CDC by 32% in five years. Under the leadership of the Clinton Administration, the CDC reorganized its AIDS prevention efforts to foster greater overall coordination and enhance efforts to reduce sexually transmitted diseases and tuberculosis. The President appointed Dr. Jeff Koplan to head the CDC and Dr. Helene Gayle to head the CDC?s Center for HIV, STD & TB Prevention. In addition, President Clinton appointed former CDC Director Dr. David Satcher as the nation's Surgeon General.

Reaching Out to Local Communities. President Clinton launched a nationwide HIV prevention community planning process to give local communities more authority over the shape and direction of AIDS prevention efforts. He also launched the Prevention Marketing Initiative, focusing on the risk to young adults with frank public service announcements recommending both sexual abstinence and the consistent use of latex condoms.

Keeping Water Clean. The President issued combined CDC and Environmental Protection

Agency guidelines recommending steps to purify drinking water in vulnerable populations against Cryptosporidium, which can be fatal to those with compromised immune systems.

Increasing Access to HIV Prevention Services for Youth. In a directive issued on World AIDS Day 1997, President Clinton instructed each Federal agency to identify all programs under its control that offer opportunities to youth for preventing HIV infection and develop within 180 days a plan through which those programs can increase preventative education as well as support services for those already infected.

---------- Forwarded by Noa A. Meyer/WHO/EOP on 10/26/98 12:00 PM ----------

Robin J. Bachman 10/26/98 11:35:20 AM

Record Type: Record

To: Noa A. Meyer/WHO/EOP

cc: Brenda B. Costello/WHO/EOP
Subject: Accomplishments

gay98.dft

---------- Forwarded by Robin J. Bachman/WHO/EOP on 10/26/98 11:33 AM ----------

Todd A. Summers
10/23/98 01:23:29 PM

Record Type: Record

To: Robin J. Bachman/WHO/EOP, Richard Socarides/WHO/EOP

cc:
Subject: Accomplishments

Here's the updated HIV/AIDS accomplishments - I checked the civil rights cases with Paul Richard - I'll forward his email - Liz Savage from Justice said they've done very few new ones (5?).

I'll be available through signal - on my way to NYC.

I think the final should be vetted through OMB - Richard Turman before it goes out!!! I also think we should add something on the CBC initiative, which is not yet crystallized but which we're announcing on Wednesday.

Todd

ACMP1098.d

The Clinton-Gore Administration
A Record of Progress for Gay and Lesbian Americans

"[W]e have to make sure that for every single person in our country, all Americans means all Americans." -- President Clinton, November 8, 1997

"It is time for all Americans to recognize that the issues that face gays and lesbians in this country are not narrow, special interests, they are matters of basic human and civil rights"

--Vice President Al Gore, September 15, 1997

Fighting Discrimination and Hate

Fighting Anti-Gay and Lesbian Hate Crimes. Last year, the President announced his sponsorship of the Hate Crimes Prevention Act during the historic White House Conference on Hate Crimes. This crucial legislation would strengthen and expand the ability of the Justice Department to prosecute hate crimes by removing needless jurisdictional requirements for existing crimes and by giving Federal prosecutors the power to prosecute hate crimes committed because of the victim's sexual orientation, gender or disability.

The President and Vice President continue to push Congress to pass this important legislation and to speak out against hate. As the Vice President said on September 19, 1998: *"If we allow even a small number of Americans to harbor and act upon malice and intolerance, we all feel the bitter sting of injustice. Let us send a clear message to those would commit crimes of hate: it is wrong, it is illegal, and we will punish you with the full force of our laws... Crimes of hate against all people -- including gays and lesbians --should carry a punishment that is swift and severe."*

In addition to advocating the adoption of the current legislation, as part of the 1994 Crime Act, President Clinton signed the Hate Crimes Sentencing Enhancement Act, providing for longer sentences where the offense is determined to be a hate crime.

Ending Discrimination Against Gays and Lesbians in the Federal Civilian Workforce. President Clinton issued an Executive Order prohibiting discrimination based on sexual orientation in the Federal civilian workforce. This makes the Federal Government the largest employer in the world (1.8 million civilian employees) with a non-discrimination policy covering sexual orientation. And the President, working with a coalition in the House of Representatives, successfully defeated an attempt to overturn this policy. The President also issued an Executive Order mandating

that security clearances no longer be denied based on sexual orientation.

Fighting Discrimination in All Workplaces. President Clinton and Vice President Gore endorsed and are fighting for passage of the Employment Non-Discrimination Act, a bill outlawing discrimination in hiring, firing and promotions based on sexual orientation, making them the first U.S. President and Vice President ever to back civil rights legislation for gays and lesbians. The legislation would ban discrimination based on sexual orientation in the workplace, extending basic employment discrimination protections to gay and lesbian Americans.

Standing Up for Basic Fairness. President Clinton blocked Republican efforts to pass legislation prohibiting unmarried couples from jointly adopting children in the District of Columbia and legislation which would have denied federal housing money to localities with domestic partnership laws.

Fighting Discrimination Against People With AIDS. President Clinton directed the Justice Department and the Equal Employment Opportunity Commission to vigorously prosecute those who discriminate against people with AIDS, leading to actions against health care providers and facilities that violate the Americans with Disabilities Act.

Opposed Anti-Gay Ballot Initiatives. President Clinton strongly opposed anti-gay ballot initiatives in Colorado and Oregon. His two nominees to the Supreme Court voted to overturn Colorado's Amendment 2, declaring such initiatives unconstitutional violations of the Equal Protection clause of the Constitution.

Fighting Discrimination Against People with AIDS in the Military. President Clinton successfully fought for the repeal of the Dornan amendment, which would have required the expulsion of all HIV-positive military service members regardless of their ability to do their jobs. Prior to its repeal, President Clinton took the highly unusual step of unilaterally declaring the law unconstitutional and he instructed the Department of Justice not to defend it in court, becoming the first president since Franklin Roosevelt to take such action.

Helping Those Fleeing Persecution Because of Their Sexual Orientation. President Clinton's Administration is the first ever to grant asylum for gays and lesbians facing persecution in other countries. He sent gay human rights activist Keith Boykin to Zimbabwe as part of an official United States delegation and he investigated human rights abuses of gays and lesbians there.

Banning Insurance Discrimination. President Clinton fought for and signed the Kennedy-Kassebaum Health Insurance Portability and Accountability Act, which bans insurance discrimination against people with pre-existing medical conditions including HIV/AIDS. In addition, President Clinton issued a directive that ensures

that all providers of Federal health insurance abide by non-discrimination rules including sexual orientation.

Fighting Harassment of Students Based on Sexual Orientation. President Clinton's Department of Education has issued landmark guidance that explains federal standards against sexual harassment and that prohibits sexual harassment of all students regardless of their sexual orientation.

Welcoming the Contributions to Service of All Americans

President Clinton has Appointed the Most Inclusive Administration in History. President Clinton is the first President to appoint an openly gay or lesbian person to an Administration post. The President has appointed more than 150 openly gay and lesbian appointees, including:

- Virginia Apuzzo, Assistant to the President for Management and Administration, the highest ranking openly gay or lesbian person ever to serve in the Federal Government and the first openly gay or lesbian Assistant to the President;
- Director of the U.S. Patent and Trademark Office Bruce Lehman, the first openly gay man to be confirmed by the U.S. Senate;
- Fred Hochberg, Deputy Administrator of the Small Business Administration, the first openly gay person to be appointed Deputy in a U.S. cabinet-level agency:
- Assistant Secretary of Housing and Urban Development Roberta Achtenberg, who served in this position from 1993 to 1995;
- Gail Shibley to serve as the Director of External Communications for the Federal Highway Administration;
- The President has also nominated, and continues to fight for, James Hormel to be U.S. Ambassador to Luxembourg -- if confirmed he would be the first-ever openly gay United States ambassador.

Reaching Out to All Communities. This Administration is committed to a policy of inclusion. President Clinton named the first Presidential Liaison to the gay and lesbian community, Marsha Scott. Later, he named the first openly gay senior policy adviser on civil rights issues, Richard Socarides. He become the first sitting president to speak before a gay and lesbian organization on November 8, 1997, when he deliver the keynote address to the Human Rights Campaign National Dinner. In September 1997, the Vice President addressed a reception of the National Gay and Lesbian Task Force, the first Vice President to speak at a gay rights event. In 1998, the Vice President has spoken before the Human Rights Campaign in Washington, D.C. and the Empire State Pride Agenda in New York City. Both the President and the Vice President regularly meet with gay and lesbian leaders.

"I think if we really could create a society where there is opportunity for all and responsibility from all and we believed in a community of all Americans, we could truly meet every problem we have and seize every opportunity we have." --
President Clinton, November 8, 1997

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