FANCONI ANEMIA RESEARCH FUND, INC.

FAMILY NEWSLETTER

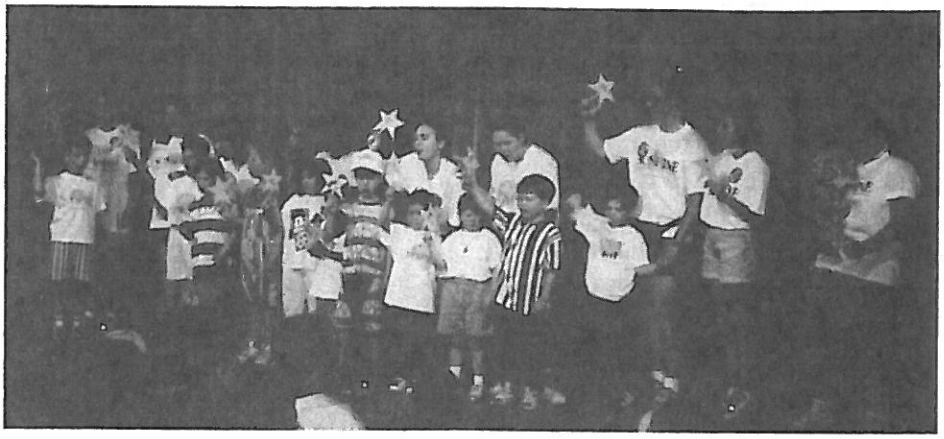
#21 A Semi-annual Newsletter on Fanconi Anemia for Families, Physicians and Research Scientists Winter, 1997

Isolation of FA-A Gene Announced at Eighth Annual Symposium

More than 150 scientists from around the world met in Madison, Wisconsin October 10-12, 1996 for the Eighth Annual FA Scientific Symposium. The University of Wisconsin School of Medicine generously co-hosted the event and sponsored a tribute dinner for pioneer FA research scientist and treating physician, Nasrollah Shahidi, MD. (See related article on page 6.) Among conference highlights were the following:

continued on page 5

HIGHLIGHTS



Closing program at Camp Sunshine

Camp Sunshine Beckons May 15-21, 1997

Once again our wonderful hosts from Point Sebago, Maine have invited FA families to join each other late this spring at Camp Sunshine. Make your travel plans now!

Participants consistently rate the Camp Sunshine experience as extraordinary. FA families learn of the latest discoveries in FA science. They share joys, and the challenges and sorrows of coping with illness and loss. FA children, adults, siblings and families meet in an activity-filled atmosphere of relaxation, invigoration and caring warmth.

Camp check-in will start on Thursday, May 15 at 2:00 p.m., followed by the Welcome Dinner. Scientific presentations will be held each morning. Afternoons will be filled with support groups, fun activities and plenty of free time. Children enjoy a full recreational program. This is an outstanding opportunity to share concerns and feelings with families going through the same experiences.

We especially encourage those who are newly-diagnosed families or from other nations to join us. We look forward to meeting new families and renewing old friendships. One family who attended last year said "We enjoyed all of it—just to be together with all the other families and talk was wonderful."

Registration materials were sent separately. If you have not received yours, please call the office. We hope to see you at Camp Sunshine. ◆

MEDICAL NEWS

Two Groups Isolate FA-A Gene

by Joyce L. Owen, PhD

Two groups of scientists announced at the Eighth Annual FA Scientific Symposium that they have isolated the FA-A gene. The two papers were published in the November issue of *Nature Genetics.*

One group, led by Hans Joenje (recipient of the FARF Award of Merit last May) of the Free University of Amsterdam, found the gene by expression cloning, the same method used by Manuel Buchwald to isolate the FA-C gene in 1992. The other group, led by Chris Mathew of Guy's Hospital in London, used linkage analysis. Both groups were supported in part by the Fanconi Anemia Research Fund.

The same issue of *Nature Genetics* carried an editorial by Alan D'Andrea on the significance of the isolation of the FA-A gene.

Mutations in the FA-A gene account for about 65% of all FA cases. Taken together with the 10-15% of cases represented by the previously discovered FA-C gene, scientists now know the gene defect in 75-80% of FA patients. Most of the FA-A mutations identified appear to be different from one another. By contrast, the vast majority of FA-C mutations fall into just a few groups.

The FA-A protein is found in the cytoplasm of the cell, and not in the nucleus. This is true of the FA-C

continued on page 5

Mosaicism in Fanconi Anemia: Amsterdam-Wurzburg Research Project

Hans Joenje from the Free University of Amsterdam, The Netherlands and Holger Hoehn from the University of Wurzburg, Germany are collaborating on a study of mosaicism (the presence of both normal and FA cells) in FA patients. See Joenje's article in this issue of the *Science Letter.*

The Wurzburg group uses a high resolution cell cycle assay that detects subtle differences in cell cycle behavior in blood cells from FA patients. By studying the blood of a number of older patients, they hope to find out whether mosaicism for cells with defective and normal cell cycle behavior could explain the absence of bone marrow failure in these patients, and whether the presence of normal cells may have occurred via intragenic recombination.

Mosaicism may be important in treatment of FA patients. For example, a normal cell clone may be resistant to the conditioning regimen of chemotherapy and radiation which precedes bone marrow transplantation and may thus cause transplant failure.

The Amsterdam and Wurzburg groups greatly appreciate the help of the FA patients who participated in this research project. ◆

Alternate Donor Transplants: Minnesota's Experience

At the October Scientific Symposium, John Wagner reported on the results of 21 FA patients who have received alternate (from unmatched or unrelated donors) bone marrow transplants at the University of Minnesota. Apart from the first seven FA transplants done in Minnesota, donor marrow has been T-cell depleted by elutriation. Because the outcomes of alternate transplants had been poor in the past, only high-risk patients were transplanted in this study. See Wagner's article in this issue of the *Science Letter.*

The probability of survival in this alternate transplant group was 45%. Even some of the patients with leukemia at the time of transplant appear to be long-term survivors.

Wagner continues to change his protocol in an effort to improve outcomes. And while his results are far from ideal, at least there is now some hope for those who do not have an HLA-identical sibling donor. ◆

New Delivery System for Human Growth Hormone on the Horizon

Most children with FA are small, and some of them are treated with human growth hormone (HGH). Daily injections of HGH are not too pleasant. What about monthly injections? Two biotechnology companies, Alkermes (Cambridge, MA) and Genentech (South San Francisco, CA), report success in putting HGH into tiny biodegradable capsules, or "microspheres," which break down slowly in the body, delivering the hormone over a long period of time. A single injection of HGH microspheres in monkeys delivered the hormone for over a month. These microspheres may soon be available for medical use. ◆

Your FA Research Dollars at Work January 1 - December 31, 1996

Complementation Group, Gene Identification and Mutation Studies

Arleen Auerbach, *Rockefeller University*	75,734
Fré Arwert, *Free University of Amsterdam*	79,950
Hans Joenje, *Free University of Amsterdam*	88,408
Chris Mathew, *Guys Hospital, London*	60,312

FA Protein Function

Manuel Buchwald, *Hospital for Sick Children, Toronto*	31,100
Maureen Hoatlin, *Oregon Health Sciences University*	68,683
Mark Kelley, *Indiana University*	44,815

Developing Effective Treatments

Robert Arceci, *Children's Hospital Medical Center, Cincinnati*	72,287
Nyla Heerema, *Indiana University*	7,100
John Wagner, *University of Minnesota*	54,182
David Williams, *Indiana University*	22,276
Total Research Funded 1996:	**$604,847**

Need for Monitoring Older FA Patients

by Lynn & David Frohnmayer

In September, 1996, our 23-year-old daughter Kirsten developed difficulty in swallowing pills. Fearing a malignancy of the throat or esophagus, we immediately requested an endoscopy. Kirsten swallowed a small camera, and her throat, esophagus and stomach were visible on a TV monitor. The physician took biopsies of various tissues. Fortunately, no malignancy was detected. The procedure was painless.

In consultation with various physicians, we have decided to do an endoscopy on an annual basis, pap smears twice a year, a thorough examination of her tongue and mouth every six months and an annual dermatological evaluation. Kirsten is extremely careful about oral hygiene, and needs no encouragement to prevent unnecessary infection. Our goal is detection of a malignancy while it might be small enough for surgical removal. We welcome physicians' comments or additions to this list. A disclaimer: these are our personal concerns and should be discussed with your treating physician. ◆

FARF Website

Visit the Website of the Fanconi Anemia Research Fund, Inc.

http://www.rio.com/~fafund

- Over 1700 visits in the first four months.
- Information about FA, Newsletters online, frequent updates, links to other organizations, link to online Handbook. ◆

Apoptosis – What Is It?

by Joyce L. Owen, PhD

"Apoptosis" is one of the science buzzwords of the 90s. It means "programmed cell death," an essential process in development of the embryo and throughout life. Cells that are no longer needed by the organism (for instance, old blood cells) kill themselves. How do the cells know when to kill themselves? What happens if they fail to kill themselves? What happens if they kill themselves when they aren't supposed to? And what does all this have to do with FA?

There are several complex pathways by which signal-molecules outside a cell can trigger that cell to commit suicide. One of these pathways involves a cell surface protein called "Fas". The Fas protein is found on the surface of many types of cells. Fas protein receives a specific suicide message when it binds to an extracellular protein called Fas-ligand. The Fas protein then relays the signal into the cell, and the cell dies.

Certain autoimmune diseases occur when the Fas protein is defective. It can no longer relay the suicide message into the cell. Certain T cells do not die when they should, and instead attack the patient's own tissues. In this case disease is due to **failure** of apoptosis.

Another autoimmune disease, insulin-dependent diabetes, may be due to **too much** apoptosis; the immune system appears to trigger the insulin-secreting cells of the pancreas to commit suicide. Some neurodegenerative diseases are also thought to result from too much apoptosis. In some cases, molecules which regulate the signals that bind to Fas are defective. The signals reach Fas in great abundance, thus triggering premature death of nerve and brain cells.

How does apoptosis relate to FA? A number of scientists believe that the bone marrow failure associated with FA may be a result of **too much** apoptosis. Groups led by Grover Bagby and by Johnson Liu (see articles by Bagby, by Buchwald and by Wang, et. al. in this issue of the *Science Letter*) are seeking to define how at least one FA protein, FA-C protein, is involved in controlling apoptosis in normal and FA bone marrow cells. So far, both groups have evidence, at least in the C complementation group, that apoptosis is at the heart of the bone marrow failure that is a hallmark of FA. Bagby and Markus Grompe discovered that FA cells are hypersensitive to interferon-γ, an extracellular protein which activates the Fas pathway for apoptosis. Liu's group reports that mouse cells which overexpress the normal human FA-C protein actually **suppress** the apoptosis pathway. While much work remains to be done to confirm the role of the FA-C protein in apoptosis, this line of research seems very promising, and may explain more than bone marrow failure in FA-C patients; failure to suppress apoptosis during fetal development may also account for the skeletal abnormalities seen in some patients. ◆

FA Research Laboratories Supported by the National Institutes of Health in 1996

Arleen Auerbach*, The Rockefeller University

Alan D'Andrea, Gary Kupfer, Dana-Farber Cancer Center, Boston

Manuel Buchwald*, Hospital for Sick Children, Toronto, Canada

Ken Burtis*, University of California, Davis

Mary Dinauer, Indiana University

Grover Bagby, Oregon Health Sciences University

Muriel Lambert*, New Jersey University of Medicine and Dentistry

Robb Moses*, Oregon Health Sciences University

Markus Grompe*, Oregon Health Sciences University

Hagop Youssoufian, Brigham and Women's Hospital, Boston

**Received early support from the FA Research Fund*

Treatment of Patients with Growth Factors: The Cincinnati Experience

Earlier editions of this newsletter announced trials at various medical centers of cytokines, or "growth factors" as a method of trying to improve FA patients' blood counts. Dr. Richard Harris of Children's Hospital in Cincinnati reported his results at the Scientific Symposium (See this issue of the *Science Letter*).

Harris and his colleagues have administered a combination of G-CSF and Erythropoietin ("Epo") to more than 20 FA patients. All but one showed significant increases in neutrophil counts; one-fifth of the patients experienced a sustained increase in platelet counts and one-third showed a noticeable rise in hemoglobin counts.

Harris reported that the best responses were seen in patients who began the trial with a platelet count greater than 30,000. Harris also found that more than half the patients who responded initially lost their response by one year.

Even if the response to these growth factors ultimately is lost, Harris concludes that the FA patient can delay using androgens by a year. This has the benefit of reducing the risk of androgen side effects for that period as well as improving later bone marrow transplant outcomes (prior androgen users have poorer survival rates than those who have been androgen-free). ◆

Two Groups Isolate FA-A Gene

continued from page 2

protein as well, suggesting that these proteins are **not** involved in DNA repair (as was once thought) or in gene regulation. Both proteins seem to be unique; they are not structurally related to any other known protein, or to one another.

The FA-A gene discovery will advance FA science in several ways:

- In the future, diagnosis of suspected FA cases and family prenatal diagnosis can be confirmed decisively at the molecular level.
- Gene therapy for FA-A patients may soon be underway.
- As has been true with mutations in FA-C, scientists may be able to predict how different mutations in the FA-A gene affect the clinical appearance, the prognosis, and therefore, the timing of potential treatment options (including marrow transplantation) for FA-A patients.
- The FA-A gene discovery will help scientists untangle the mysteries of Fanconi anemia. The proteins encoded by the several FA genes may act in a complex (several proteins bound to one another), or they may act in a pathway, each one carrying out a different step. How does the absence of any one of the proteins (or the presence of a defective one) lead to the birth defects, progressive anemia, leukemia, and susceptibility to other cancers that typify FA? As each gene is isolated, it will provide additional information to unravel what may be a novel pathway. ◆

Eighth Annual Symposium

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- Preview of the announcement in the November, 1996 issue of *Nature Genetics* that two independent research groups had isolated and cloned the FA-A gene. There were also reports of mutation analysis of this gene, and a report on the protein encoded by the gene. (See related story on page 2.)
- Updates on developments in bone marrow transplantation for FA patients at a wide range of disease stages. Discussion included complications of alternate transplants, and strategies for improving outcome. (See related article about alternate donor transplants on page 2.)
- Extensive discussion of the FA-C protein function, including its role in apoptosis (see related story on page 4) and its binding to a cell cycle protein.
- Reports of the discovery and meaning of FA "mosaicism" (cases where the FA patient exhibits two populations of cells: those which contain FA mutations, and are sensitive to crosslinking and chromosome breakage, and those which are normal). See related story on page 2.
- The FA-D gene has been localized on its chromosome, and will probably be cloned soon.

The conference was productive and received strongly positive evaluations from attendees. See the accompanying *Science Letter* for more detailed reports. ◆

Sedation for Vital Bone Marrow Aspirations and Biopsies

by Lynn and David Frohnmayer

In many clinics and hospitals, an FA patient's bone marrow aspiration or biopsy is the cause of pain, tears and parental agony. This does not have to be true. We report these observations because it is increasingly clear that an FA patient's bone marrow *must* be monitored closely to (1) track the progress of marrow failure; (2) look for the appearance (and sometimes disappearance) of abnormal clones and (3) guide the timing of therapies such as bone marrow transplantation.

We remember vividly when parents, doctors and nurses held down the limbs of our children while the hematologist extracted bone marrow fluid (an aspiration) or a small bone "plug" (a biopsy) from a hip bone. When we entered the world of bone marrow transplantation two years ago, we learned that bone marrow procedures can be performed quickly and absolutely painlessly.

For Kirsten and Amy, the most useful drugs for bone marrow procedures have been fentanyl (for pain control) and propofol (for short-term, total sedation). The patient is usually unconscious for only the few minutes it takes to complete the procedure. Our daughters have had no memory of discomfort, and actually speak of a pleasurable sensation as they drift off to sleep. Both actually look forward to the event!

Amy has had three bone marrow procedures during the past year and a half. We made each one a special event complete with shopping expeditions and a dinner out with her father. Kirsten has had eighteen aspirations over the past two years. Obviously, doing this painlessly was a big priority!

This procedure may not be available in every community. It is more expensive to do a bone marrow biopsy under general anesthesia, and the presence of an anesthesiologist is required. Some insurance companies may not pay for this procedure. In our home town this can be performed at our local hospital only in a surgery room, not in an out-patient clinic setting.

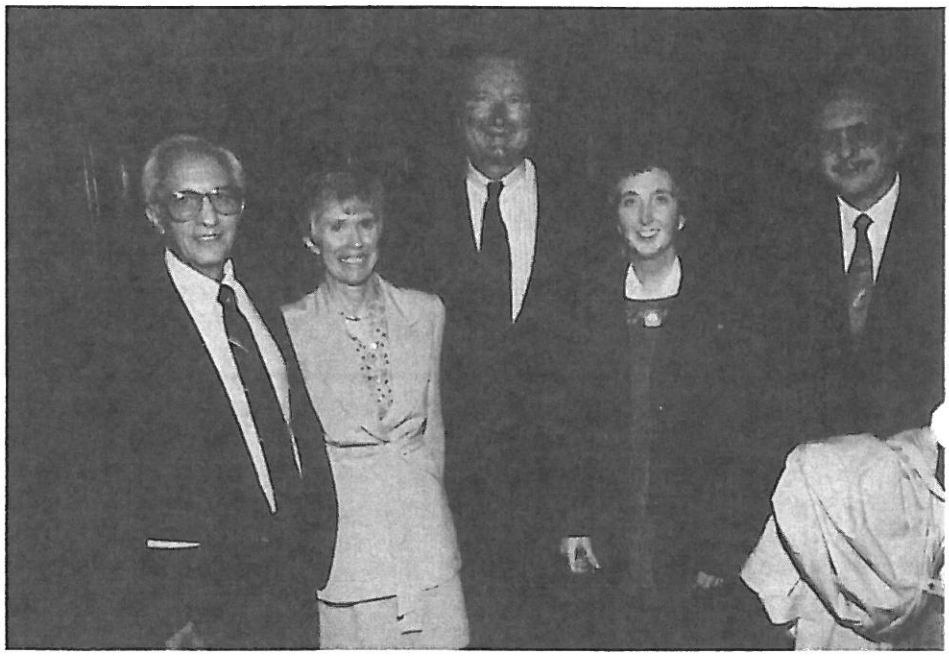
An obvious disclaimer: we are not physicians, and cannot offer medical advice. Your own physician must decide if this is appropriate for you or your child. We personally endorse it. We all have extraordinary tensions in our lives, and painful tests only increase the stress and discomfort that we and our children must endure. ◆

Shahidi Honored at Scientific Meeting

Nasrollah Shahidi, MD, an early pioneer in FA research, was honored by colleagues, patient groups, students and the Fanconi Anemia Researc Fund at a ceremonial dinner in Madison, Wisconsin on October 10, 1996.

Shahidi's scientific career includes education in Persia, France and the United States. He pioneered the use of androgen therapy for FA patients, and he has explored a wide variety of innovative avenues for treatment of many hematologic disorders.

On behalf of the Fanconi Anemia Research Fund, and with great enthusiasm, Lynn and Dave Frohnmayer presented an engraved clock and the first "Lifetime Achievement Award" to Dr. Shahidi for his exemplary scientific achievement and his generous and caring outreach to families in need. ◆



left to right: Nasrollah Shahidi, Lynn Frohnmayer, David Frohnmayer, Kirsten Frohnmayer, Ralf Dietrich

FAMILY NEWS

Bobby Rosen

by Dan Rosen, Anaheim, California

Dan Rosen spoke lovingly of his son Bobby, at Bobby's funeral services on November 19, 1996. We quote from his deeply moving remembrance.

Two years ago I stood next to Bobby at his Bar Mitzvah filled with the pride and love only a parent can know. Today I speak of Bobby filled with the uncontrollable sadness and loss that only a parent can know.

For almost 15 years Bonnie and I imagined this day in our minds and hearts but always with the hope that the day would never really come. We always were encouraged by Bobby's enthusiasm, expectations, confidence and love for life.

These last few days I have awakened each morning around 5 a.m. and I have been reminded of Bobby as a baby. He and I always got up for his morning feeding around that time, not really to eat, but to greet the day. He never wanted to miss anything. Bobby loved life. He loved so many things.

Bobby loved music. All music. From folk to rock to punk to groups I never heard of. Going to concerts was among his greatest joys. He always searched the Sunday paper to

continued on page 12

Why Him? Why Us? Rekindling the Heart and Soul

By Carol Siniawski, Cincinnati, Ohio

I think the hardest part of this FA situation is searching for the answer to "Why him?" What had Jake done to deserve such a punishment as this? To be forced to take such a difficult journey at such a young age? So many doctors, shots, pills, needle sticks, blood tests, transfusions, only to end up someday undergoing a bone marrow transplant when current success rates, although increasing, are still frightening to a parent. I am saving for his college education and I may never spend it.

You see, I grew up in a religious environment. We practiced our religion at home, at school, at work. I may not have understood all the reasons for what was happening around me, but I had faith that the Superior being had a much bigger picture than I. I was just not able to see that perspective.

The first real test of my faith was the passing of my husband's 35 year old sister from brain cancer. It was a very difficult year for us. We had not yet suffered such a seemingly wasteful loss. Joyce was young, brilliant and energetic. It was difficult trying to understand why she was needed elsewhere and could no longer be here with us on earth. I did not like it, nor did I understand it, but I accepted it.

The second and almost permanently damaging test of my faith was Jake's diagnosis of FA. At the time he was my only child. After that, I fell away from my religion and could not reason in my own head why life must be this way. If the Superior being was loving and caring, then why must my son suffer like this? I was angry for a year and a half.

My sister, Connie, brought me a book that has been influential in warming my heart and soul again, turning back towards the Superior being and asking for the strength to get through this. The book has also helped me in my search for an answer to "WHY?" The book is entitled *When Bad Things Happen to Good People* by Kushner. Connie gave the book to me, and at first I refused to read it. I was angry and

continued on page 14

Kirsten Frohnmayer: A Pioneer's Journey

By Lynn Frohnmayer

On January 6, 1995, a routine blood test revealed that our daughter, Kirsten, had acute myelogenous leukemia. I remember vividly sitting on the stairs staring into space, overwhelmed by shock and horror and thinking "that's it; there's nothing we can do now to help her." Her closest donor was an unrelated, one antigen major mismatch. Dr. Harris' words from a recent presentation rang through my mind. Six such FA transplants had been attempted, and all had failed. Kirsten's chances were zero.

I was overcome with unspeakable sadness. Kirsten was in her senior year at Stanford, and was loving every minute of her life. She had a great circle of friends, a new boyfriend, and thrived as a student in human biology. Now she had leukemia and we felt we had no good options.

My paralysis was short-lived. Maybe there was some new approach of which we were totally unaware. A flurry of phone calls followed. The first was to the Fred Hutchinson Cancer Research Center. They had been actively searching for a donor for Kirsten since the discovery of an abnormal clone the previous year, when she was diagnosed with myelodysplasia. This was now an emergency; if any potential donor needed DR typing, it had to be done at once. The Hutch intensified our search immediately.

Our Fund had worked with world class researchers, physicians, and transplant experts for many years. A telephone conference call and scores of individual calls followed. An early call to an FA researcher provided useful advice. A rough translation: "Go to a large center, a center with a great deal of experience in doing unrelated transplants, a center that deals constantly with serious complications."

Dr. Norma Ramsay from the University of Minnesota had spoken at one of our Family Meetings. I recalled that a few of their FA patients had survived unrelated transplants, even with leukemia, although the donors had been matched or mismatched in a minor, not major locus. We believed that Kirsten would suffer from horrendous graft vs. host disease unless some of the donor's T cells could be removed. Ramsay referred me to her colleague, John Wagner, MD, who had had recent success using a T cell depletion method called elutriation. This had never been attempted with an FA patient. With thoroughness and patience, Wagner explained this method. Kirsten, David and I visited the University of Minnesota Transplant Center and decided to attempt her transplant there. Two weeks had elapsed since her diagnosis with leukemia.

Kirsten's transplant occurred on February 9, 1995. She suffered very little toxicity from the preparatory regimen, engrafted on day 13, and experienced no graft vs. host disease. Bone marrow evaluations on days 21 and 100 confirmed that she had her donor's marrow and was disease-free. Throughout the transplant she exercised daily and felt amazingly well. The horrific complications we had anticipated did not materialize.

Kirsten worked hard on her recovery and in early June, she returned home to Oregon. On June 18, she graduated Phi Beta Kappa with her class from Stanford University. She felt weak and often nauseated, but gradually her strength began to return.

Our struggle was far from over. At her routine six-month-exam, pathologists identified a small population (4.8%) of her distinctive leukemic blasts in her bone marrow. She was in the early stages of relapse. We returned to Minnesota for one round of chemotherapy with ARA-C. Tests then showed that Kirsten was in remission.

After considerable consultation, we decided to pursue a new approach in an attempt to maintain Kirsten's remission. We were hopeful that her donor's T cells would recognize her leukemia cells as foreign, and would kill them. Thanks to the kindness of her unrelated donor, additional donor T cells were harvested, and some were sent to the laboratory of Dr. Claudio Bordignon of Milan, Italy. These cells were then transfected with the tk gene, which made the cells very sensitive to the killing effects of a drug called gancyclovir. Should these cells cause unmanageable graft vs. host disease, they could perhaps be eliminated by infusions of gancyclovir. In October, Kirsten and I travelled to Italy for an infusion of T cells. Immediately upon our arrival, however, a routine chest x-ray detected an aspergillus fungal infection in her lung. Dr. Bordignon was reluctant to give her a large dose of T cells given this infection. Instead,

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Kirsten Frohnmayer

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She was given a reduced number, and simultaneously was treated for aspergillus. On November 22, 1995, she was given a larger dose of T cells. However, by then her white count had begun to decline, a possible indicator of early relapse. A bone marrow aspiration in early December indicated that Kirsten's leukemia was returning, once again.

In January, 1996, we returned to the University of Minnesota. Kirsten's fungal lesions were surgically removed. In February and again in March, she underwent two courses of chemotherapy. She was given an infusion of her donor's stem cells to aid in bone marrow recovery, and another infusion of T cells to help eliminate residual disease. On May 2, 1996, Kirsten was again found to be in remission from leukemia.

A few words cannot possibly capture the nightmare we endured during those months. Kirsten suffered an adverse drug reaction which caused her to become psychotic for several days. She endured many fevers and infections. At one point, doctors firmly believed she had an aspergillus fungal infection in her central nervous system and in her lungs, and told us she had but a short time to live. Somehow, in spite of all predictions, Kirsten began to improve.

Kirsten and I returned to Oregon in June. In early July, we traveled back to Milan, Italy, for yet another infusion of donor T cells.

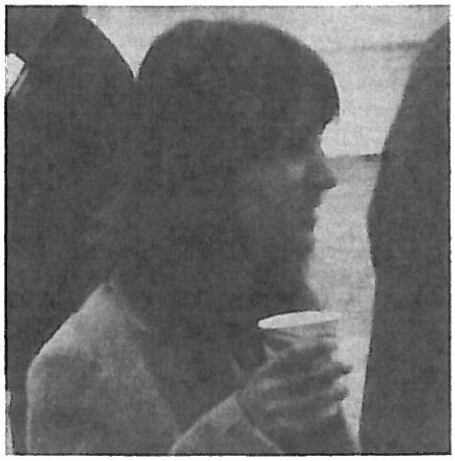
The road to recovery has been uneven and extremely bumpy. High-dose chemotherapy left Kirsten with ataxia (slow, slurred speech and initially serious balance problems). We also believe that drug toxicity damaged the small capillaries which supply blood to the center of each retina, resulting in greatly reduced vision. (Her sight has now improved to 20/80 in her better eye; the other eye sees very little). She has a lung infection, bladder problems, and generalized weakness.

In spite of the negatives, we have much for which we are grateful. Against all the odds, Kirsten is alive. Her leukemia could return at any time, and if that happens, our options are few and dismal. So far, bone marrow aspirations since May show no disease. Her speech has improved considerably. Her eyesight is far better than we feared it might be. Her days are filled with physical therapy, speech therapy and doctors' visits, and some of her problems are slowly resolving. Most important of all, she maintains, for the most part, a positive attitude. She has plans for her future and accepts the fact that much progress must be made before she can reach her goals. She can live with this. How we treasure the presence of this remarkable young woman in our lives!

Please do not wait until you or your child has leukemia if you hope to attempt a bone marrow transplant. We waited because we saw no positive alternative. No one had survived the kind of transplant facing Kirsten. But this is no longer true. Although odds are still not good (see Wagner article in this issue of the *Science Letter*), several one-antigen, major mismatch transplants have been successful in FA patients. Leukemic relapse following transplantation is a very real possibility. Eliminating AML is extremely difficult, especially in FA patients who cannot easily tolerate toxic chemotherapies. Do at least annual bone marrow aspirations, (greater frequency is wise if an abnormal clone is detected), watch clonal progression, and if the patient's condition warrants it, consider transplantation before development of myelodysplasia or leukemia. Please discuss this advice with your physician. ◆

Sanchia Gosztonyi

Sanchia Gosztonyi from London, England, joined us at Camp Sunshine last May, and charmed everyone with her determination and love of life. We deeply regret informing our readers that Sanchia passed away on November 3, 1996 at the age of 32. Prior to her death, Sanchia wrote an article from which we quote, in part.



One can find many depressing things to say about FA. Feelings such as shock, anger, depression, resentment and fear are all bleak and pessimistic feelings, although anger can be a productive force as it can lead to change and a determination to fight. On many occasions I feel this way, but increasingly, I have found I am resolved to my situation, although as the poet Dylan Thomas asked of his father, why did he not "rage, rage against the dying of the light?" To those people who have lost a child or children or are in the process of this, no one can feel as you do. I personally find it easier when I consider wider issues in the world such as starvation and poverty, AIDS, cancers and Alzheimers—which are all awful. For this helps me to see that life is terminal for everyone.

The children I have seen and met at Camp Sunshine all have endearing qualities and through my observations, most show creativity which may be an aspect unique to FA patients. Many have a kind of super-human strength either mentally, or for those on androgen therapy, definitely physical. These traits can be used advantageously in life.

My philosophy is, for those with FA, you are your disease. This doesn't mean you don't have to battle with it, but accept it as a "fact" even though many of those so-called facts are little known. In other words it is a fact you are diagnosed with FA, but it is not a fact that you will die at a certain age or remain petite. If that had been the case with me then I would have been dead at eleven and been 4'2"; I am just under 5 feet and I have obviously made it through my younger years.

Obviously the adults have survived where statistically they should not have. That is hope.

Sanchia never gave up her hope, and she shared her multitude of talents with us generously (see her wonderful cartoon on page 17 of the Handbook.*) We hope Sanchia's family and friends take comfort from how warmly we always will remember her.* ◆

In Loving Memory

Joey Adamson
1/17/84–11/9/96

Andrea Alcazar
10/13/86 –9/16/96

Badrinarayanan, B.
6/9/75–8/19/96

Niki Bond
10/1/77–4/25/96

Jerid DeMarco
5/6/86 –11/3/96

Sanchia Gosztonyi
8/2/64 –11/3/96

Jacquelyn Letman
4/20/89 –1/16/97

Mark Muhlen
12/5/89– 8/31/96

Chi Danielle Neumann
4/3/81 –8/19/96

Bobby Rosen
12/20/81–11/15/96

Dany Salguero
12/13/89–12/19/96

Kurt Schroeder
1/15/97 (age 36)

Salo Family Welcomes Gift

Holiday news from Lori and Erik Salo of Longmont, Colorado was especially joyous. A healthy daughter, Miranda Rose, was born on October 15, 1996. The Salos' two-year-old daughter, Emily, has Fanconi anemia. Lori writes:

"Our gift of a second daughter is likely to be our gift of keeping our first daughter! Miranda is a perfect bone marrow match for Emily!!! We have great hopes that a future bone marrow transplant will stop the failure of Emily's bone marrow. Miranda's cord blood was successfully saved and frozen in a bank in Minneapolis. The stem cells from it will be used for the transplant."

Lori also spoke glowingly of their family experiences at Camp Sunshine:

"Last May we attended Camp Sunshine in Portland, Maine for the second time. It is such a blessing to be able to spend 5 days with other families dealing with the same problems and feelings we are. It is good to see the older kids and some adults with Fanconi's and how well they deal with it. It brings us hope. This year we were lucky enough to travel with another family in Denver, whose daughter, Molly, is four months older than Emily. It was fun to spend that time together for the girls and us! We are really looking forward to next May and reuniting with all of our friends for relaxation, education and fellowship again." ◆

We Welcome New Families Who Have Joined Our Support Group

Maria Jose Ferriera Cespedes

Rua Atlio Piffer N-28
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Editors' Note and Disclaimer

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Change of Address

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Bobby Rosen
continued from page 7

see which concerts were coming up. When he was four, he and I traveled to San Diego to see a Billy Joel concert and ten years later his cousins took him to see Billy Joel again. For his graduation from junior high he allowed Bonnie, Hayley and me to take him to an Alice Cooper concert.

Bobby loved movies. I don't think there was a movie made that he didn't like. Ask him how he wanted to spend an afternoon and he would invariably say "let's go to see a movie."

Bobby loved his T-shirts. This boy never had enough T-shirts. His idea of a great souvenir was another T-shirt.

Bobby loved his suit. He loved to look good. Put him in a suit and tie and he felt good, looked good and could put in a twelve hour workday at my office during his school vacations.

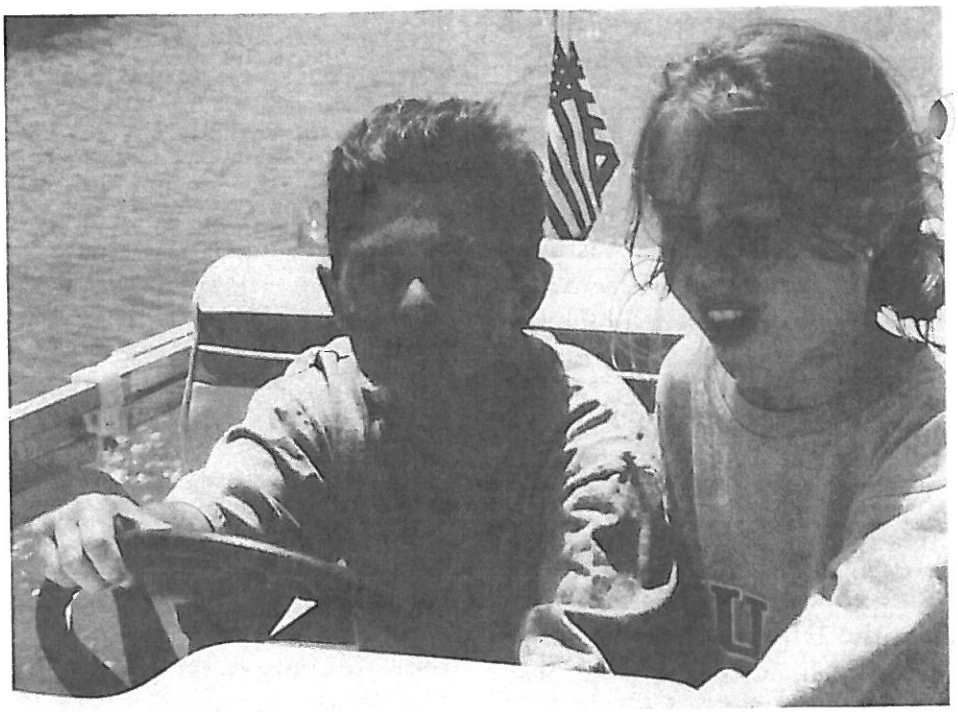
Bobby had great hair—must have been from Bonnie's side of the family. But he also liked his head buzzed and was truly happy when he lost his hair to the chemotherapy.

Bobby loved his guitar... signed by Bon Jovi. Though he didn't play he loved to show friends and family this prized possession.

Bobby loved his bicycle. He would just ride up and down the street for hours. But he always wore his helmet.

Bobby loved his trip to Israel. I have always believed that he had an innate spirituality about him and his desire to visit Israel confirms that.

Bobby loved his earrings. He was the first boy in his fifth grade class to get his ear pierced. He liked to do things a bit on the edge.



Bobby Rosen with sister Hayley

Bobby loved to ski. He wasn't allowed to participate in many sports because of a fear of injury but with skiing we just loaded him up with platelets and off he went. He was careful and daring at the same time.

Bobby loved to play video games. Before he went in for his transplant he wanted a Sony Playstation and while he was in he received many gifts of games. He decided that when he went home he would leave the Playstation and all the games in the oncology intensive care unit so that other kids would have it to pass the time. We honored his wish and left the video game for the children.

Bobby loved parties. He always had fun. When we made the decision to undergo a bone marrow transplant what did Bobby want? ... a party. He had a great pre-transplant party with family and friends.

Bobby loved girls. Bobby loved girls. Bobby loved girls.

Bobby loved his friends.

Bobby loved his family. He enjoyed all the times together. Just seeing him react to relatives he was meeting for the first time at his Bar Mitzvah made us realize how truly special our families are.

Bobby loved life. He enjoyed every moment and I think people were drawn to him because of that He wrote poetry and sang rock songs; he was special.

When Bobby was born and diagnosed with Fanconi anemia we asked all the questions. We were told that the odds were against him growing to manhood. We were told to put a helmet on him, teach him quiet, sit-down games and shelter him as much as possible.

Instead we taught him to ride bicycle, took him skiing, gave him glider plane flying lessons and tried to fit as much as possible into his life

We experienced wonderful years. Bobby remained healthy

continued on next page

Hallway

By Bobby Rosen (Undated)

Standing at the end of a dark hallway straining for my eyes just to see. Tryin' to figure out if I'm still dreamin'.

Or am I still in reality? Searchin' for a vision to seep into my brain. Lord I ain't scared of nothin'. I just wanna get to the end of the hallway and go back home. I'm a wanderer, hey yeah and I'm a fighter. But I don't know where home is yet. A stranger came up to me just the other day and said "Hey, boy do you know where the hallway to home is?" Sometimes I want to live sometimes I want to die, but all I want to do is to find my way back home. Standin' at the end of a new dark hallway straining for my eyes just to see. Searchin' for a new vision to seep into my brain. Maybe I'll get lucky and find my way back home. Standin' in the rain on a stormy night. But now I know that I will never find the hallway to home. I'm starin' blankly into the darkness, seein', if there might be somewhere to go. I'm a runaway tryin' to find a place that I can call my home. Where am I runnin' to, can you answer that for me? I finally got the strength to walk down the hallway and see what's in store for me. It don't look like much but it's somethin' to try. Things are lookin' good for a change, maybe I could make something of my life. I found a name for my hallway, it's the hallway of chance. And I'm leavin' this place 'cause I found the hallway to home.

Bobby Rosen

continued from previous page

except for his occasional short hospitalizations and transfusions, all of which were just part of his routine. His years were full of wonderful experiences.

But even Bobby and his incredibly positive attitude couldn't hold back the onset of leukemia and the deterioration of his bone marrow. We no longer had a choice and we grabbed our only chance, the only remedy, a bone marrow transplant. Bobby had no fear, no anxiety and no doubt. He was going to be cured. And when he was told that he had to undergo his third transplant because the first two had not been successful his response was "you gotta do what you gotta do."

I truly believe that he never gave up. His will was too strong. He wanted to live. His body just got tired.

I don't think I will ever truly understand why Bonnie and I were the lucky ones to be given the opportunity to be Bobby's parents and I genuinely am thankful for that. We cherished every minute of the time we had together and I hope that we as his parents did not fail him. I can say that, in the face of insurmountable odds, we DID see our son grow to manhood, despite his chronological years. He was truly a good person, a sweet and gentle man, a wonderful son and the best brother. He touched all of us with his courage, his love, his warmth, and his unique personality. I know all our lives are far richer for having known him.

I am going to miss my boy. ◆

Hayley's Remembrance

Bobby was the best brother in the world and still is. He always was there to comfort and take care of me. If I woke up with a bad dream Bobby's bed was my first choice for reassurance that everything was fine. He would take me in and talk to me and make me feel better. Sometimes he would come in my room at 2:00 in the morning and sit and stay with me till I fell asleep.

When I found out he had leukemia I was frightened and nervous. I didn't want to see him, but when I went in his room and started crying all he did was hold me and tell me everything was going to be all right. When we were growing up we were inseparable. Whatever Bobby did I did. It was always Hayley and Bobby, never just Hayley and never just Bobby.

During the time he was in intensive care and my mom and dad would sit me down and tell me how sick he was I would say to them, "I know, but the nurses are taking care of him and he'll be home." I believed so hard that he was coming home, him leaving me was a very big shock.

Everyone said he was tired, but I know he wasn't. His body was tired. Bobby would've fought forever if he could. I know that he's in peace and resting now. Probably hanging out with Jim Morrison & Jimmy Hendrix and Jerry Garcia.

I know that he's with Papa Larry, Papa Hal, Great Grandpa Irving and everybody told me Mima's already scooped him in her arms. Even though he's with our wonderful family it hurts me to know that I can't talk to him face to face anymore. ◆

Why Him? Why Us?

continued from page 7

had stopped looking for answers long ago. Being angry was easier. It took over eight months, but I finally read the book. I did not start the book with an open mind. I was angry, remember? But to my surprise, the book won me over. It addresses the "why" question. Although it does not serve up an answer for everyone, at least I no longer felt guilty about my anger. It is written by a religious leader and he shares some thoughts and emotions about the loss of his son to illness. I was so impressed that I bought a few extra copies and kept them on hand to share with others in need. I currently do not have a single extra copy in the house! I am grateful that my sister shared that book with me, although I may never have told her.

Just recently Connie gave me a second book, *Chicken Soup for the Soul*, by Canfield and Hansen. This book, too, has helped me deal with not having acceptable answers to "why Jake?" The book is a compilation of short, heart-warming stories. This book, also, does not serve up answers for everyone, but I have found that my heart is warming up, just a bit.

I still do not like the FA situation, by any stretch of the imagination, nor do I understand why the Superior being must have all of these children somewhere else and not here on earth with their families. I am able now, though, to accept where we are. I have not given up hope, mind you. I am not yet certain how much influence I have in the final outcome, but I do know I can improve the quality of life we lead now. I can let go of some of that anger and focus my energy on more productive emotions. Anger is not productive. These books helped me arrive at this point. Maybe I needed some kind of push from some force besides a well-meaning friend who had no idea what this is like. If either of these books can have a positive influence on just one other FA family, that justifies my need to write this article. Thanks, Connie, for sharing the books with me. May others reap the benefits, just as I have. ◆

Regional FA Gathering Held in New Jersey

by Barbara Adler Brecher

On November 24, 1996, a regional FA family meeting was held at Tomorrow's Children's Institute (TCI) at Hackensack University Medical Center. Sixteen families from New Jersey, New York, Connecticut and Washington, D.C. attended. Barbara Adler Brecher, the FA coordinator, Linda Ader, social worker and Tracy Kralik, child life specialist organized the meeting.

The morning session included two brief educational updates. Arleen D. Auerbach, Ph.D., from The Rockefeller University, spoke about the identification of the FA-A gene and mutation screening to identify FA-A patients currently underway in her lab. Members of Auerbach's laboratory team also attended.

Dr. Alfred Gillio from the Department of Pediatric Hematology-Oncology of Hackensack University Medical Center spoke about advances in the current treatment of FA patients including the use of oxymetholone and growth factors. He also discussed issues concerning bone marrow transplantation and the use of umbilical cord blood as a source of stem cells.

In the afternoon, parents and adult FA patients met with each other and discussed issues of mutual concern in a support group setting. Linda Ader, who led the discussion, stated that for many families who are not able to participate in the annual family meeting at Camp Sunshine, this is an opportunity to exchange information.

Throughout the day, FA patients and their siblings engaged in therapeutic activities in the TCI playroom and in peer and sibling support groups. At the end of the day, the kids expressed their eagerness to come back and to do it again! Iris Frank, mother of patient Rebecca Frank, remarked that she found it very comforting to be able to exchange information with other

continued on page 16

Use of Logo

This is just a reminder to our FA families: please use our logo or letterhead only after you have consulted the staff of the FA Research Fund, and received their approval. This is necessary to be sure our messages are accurate and consistent. It also helps to avoid legal complications. We are happy to collaborate on fundraisers and mailings.

Santiago Gomez, Rocío Gutiérrez and John Wagner. The Gomez family had prepared a special book containing all of Gaston's medical history since his diagnosis with FA.

New FA Group in Mexico

by Rocío Gómez Gutiérrez, Jalisco, Mexico

We received this note from Rocío Gutiérrez after she attended Camp Sunshine with her brother Santiago Gomez whose son Gaston has FA.

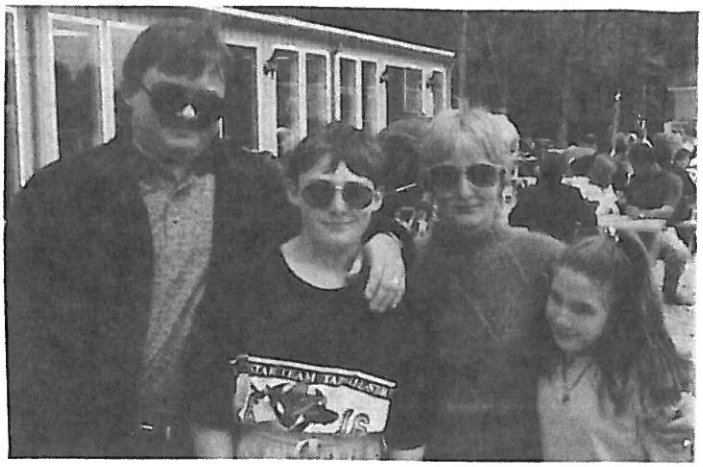
I would like to express my sincerest feelings toward the time I spent at Camp Sunshine. For me it was a wonderful experience. The fact that so many youth and adults were participating voluntarily to offer families care, comfort and guidance and to give special attention to the children was something I had never felt before.

The organization and the presentations of the speakers were extraordinary. The conference was of great interest for us, particularly because we did not know about FA. In general to live together with so many other people who have the same suffering as Gaston was most gratifying and of much value to our family.

I was moved so much that now I want to do something for the patients with FA in my country. I am forming an association of Anemia of Fanconi Esperanza de Vida (which means "Hope for Life"). I will have the opportunity to give information through the radio that was offered to us at camp. We hope to give information about FA to a major group of doctors, not only locally but nationally.

I send you cordial greetings from Santiago and Adriana and especially my own greetings. ◆

International Families at Camp Sunshine



Rick, Alex, Anne & Natasha Dudarenko, Lancashire, England, returned for their third visit to Camp Sunshine. Rick & Anne are active leaders in the European Link for Fanconi Anemia.

left to right: Irma Sassone, Argentina; Mayra & Carlos Salguero, Ringgold, Georgia, born in Guatemala helped translate for Spanish-speaking families at camp; Damaris & Jesus Cabrera, Cuban-born, residing in Spain. Dr. Jesus Cabrera recently translated the 2nd edition of the handbook into Spanish (to be published soon.)

Lelania & Celeste (front row); Chris, Dawn & Charles Church (back) The Church family travelled all the way from Capetown, South Africa. Members of their church, of which Charles is the pastor, helped raise funds so they could attend Camp Sunshine.

International Family News in Brief

From Japan, we received word of the struggles of the A. Kawasaki family.

Their son, Hiroshi, was born in Tokyo on July 7, 1994. When Hiroshi was nearly two, and after months of surgeries, diagnostic concerns and worries over the meaning of his short stature, Hiroshi developed acute myelogenous leukemia, and the underlying diagnosis of FA was confirmed.

Hiroshi's older sister, Sayaka, who suffers from another serious disorder, was nonetheless a perfect HLA match. The bone marrow transplant went very smoothly, to the great joy of the family. The family also expressed gratitude for support and information supplied by the FA Research Fund.

We have since heard that Hiroshi's leukemia has returned, and send our messages of concern for this brave and devout family.

Hiroshi Kawasaki

From a remote community in Saskatchewan, Canada comes news from the O'Neil family.

They expressed effusive praise for the information, help and support they have received from Leslie Roy and others who work at the FA Research Fund office.

Sons Justin and Jeff were suspected of having FA. Jeff was successfully transplanted, but shortly thereafter lost his graft and passed away.

The O'Neil's odyssey of anguish has been especially difficult and puzzling because other members of the family have experienced anemia, and yet the FA diagnosis still is not certain. Hans Joenje of Amsterdam is now studying the family in the hope that a definitive conclusion can be established. "Thanks to the FA Fund, Justin will be better off and we as parents will no longer suffer the burden of not knowing where to turn next time." ◆

Hiroshi's sister, Saya

Regional FA Gathering

continued from page 14

parents in similar situations.

The families were also introduced to the multidisciplinary staff at TCI which includes physicians, psychologists, social workers, child life specialists and an educational liaison. FA patient, Kristie Armstrong, age 12 and child life specialist Tracy Kralik recalled Kristie's transplant at Hackensack and showed a journal that Kristie kept to record her experience. Kristie underwent a matched sibling transplant in July, 1996. In October, when Kristie was ready to return to school, TCI educational liaison Sarah Finely arranged a school reentry visit. A TCI multidisciplinary group including BMT nurse clinician, Jeanette Haugh, spent the morning with Kristie's teachers and classmates reviewing for them Kristie's transplant experience and easing Kristie's transition back to everyday activities.

The meeting was supported by the Ira Sohn Research Fund. Because of the meeting's success, we plan to make this an annual event. We also hope to establish support groups for the parents, patients and siblings which will meet throughout the year. ◆

FUNDRAISING

Faces of FA Video Premiered: Copies Available for Your Next Fundraiser

On January 26, 1997, the new video, *The Faces of FA*, was premiered before a highly appreciative audience at "Treetops", the elegant residence of the Oregon Chancellor of Higher Education in Eugene, Oregon. Guests included scientists, philanthropists and long-time supporters of the FA Research Fund. Admiral Elmo Zumwalt, Jr., retired Chief of Naval Operations and immediate past president of the National Marrow Donor Program was the featured speaker.

The video, produced by Jerry Joffe and Linda DeSpain, and narrated by actor Edward James Olmos, features FA patients, families and researchers. It includes scenes from Camp Sunshine, scientific meetings, and family interviews.

This 17-minute presentation tells the FA story clearly and accurately, and with great power. It is an ideal centerpiece for fundraising presentations to charitable organizations, civic clubs, businesses, and major donors. Physicians may preview the video for its possible use with new FA patients. It may be used for free broadcast on the community access channels of your local cable television stations.

Thanks to our producers and families for helping with this 18-month project. We are specially grateful to the Collins family for asking their friend Edward James Olmos to donate his services, and to Sony Corporation, which will duplicate the video on VHS format free of charge for use by our families and supporters. ◆

Participants in the Fanconi Anemia Relay Ride

Raffle and Bike Relay Help Raise Money

Two family fundraising efforts for FA research came to our attention:

• **Bob and Nancy Losekamp of Cincinnati, Ohio** have two grandchildren affected by FA, Nikki (9) and Eric Lee (4) Losekamp of Mason, Ohio. Bob and Nancy sponsored a raffle with donated prizes and circulated a "collectible" showcase to interested persons throughout the U.S. Local media coverage was extensive, and increased FA awareness. The Losekamp effort generated substantial help for Nikki and Eric's medical cause, and $1,000 for the FA Research Fund. Many thanks!

• **Ken and Jeanne Atkinson of Englewood, Colorado** sponsored an imaginative and daring two-day bicycle relay fundraiser for FA, the Fanconi Anemia Relay Ride, all the way from Quinter, Kansas to Parker, Colorado, a distance of 300 miles! The intrepid cyclists survived heavy rain, dirt roads that turned to mud, high winds, tornado warnings, monster hills (what—in Kansas?), a sinus infection, and a runaway bike wheel that escaped into a wheat field and went into hiding there. Doesn't that sound like fun? Afterwards, riders, friends and family joined the Atkinsons for a celebration meal at their home in Englewood, Colorado. This wonderful event has raised over $33,000 for FA research. Thank you, Atkinsons, for your imagination, courage and generosity. ◆

Family Fundraising Efforts

From June 15, 1996 through December 31, 1996, seventy-six families raised funds or made individual contributions for a total of $245,995. We received additional funds from the Combined Federal Campaign and United Way, which we were unable to attribute to specific families. Please let us know if your hard work is generating these contributions!

There is a direct correlation between our ability to fund scientific research and the rapidity of scientific progress. The exciting news of a second gene discovery can be traced, in part, to the hard work of our families. We must not relax our efforts until this devastating illness no longer threatens the lives of wonderful children and young adults.

Our support group now numbers 470 families. If everyone would make an effort, we could do much more. Mike and Beth Vangel have put together a wonderful Fund Raising Kit which provides concrete assistance to any family wishing to tackle a fundraising letter or event. Contact the FA Research Fund and a kit will be sent to you immediately. Remember, you really can make a difference!

We are deeply grateful to each and every family who worked hard to support our research fund over the past six and a half months:

$90,000 - 100,000

Lynn, Dave & Kirsten Frohnmayer

$10,000 - 40,000

Ken & Jeanne Atkinson
Susan & Chris Collins
Allen Goldberg & Laurie Strongin
Chris Scaff
Stuart Cohen & Deane Marchbein

$2,000 - 5,000

Linda & Mark Baumiller
Tracy & Joseph DeMarco
Peg LeRoux
Rene LeRoux
Alison & Steve McClay

$1,000 - 2,000

Khalid & Susan Bin Faris
Lynnette Chandler
Maria & Pat Gleason
Jennifer & Robert Kiesel
Beth & Eric Losekamp
Sheila & David Muhlen
Jack & Lisa Nash
Rick & Lynn Sablosky
Karen & Bryan Siebenthal
Debby & Jeff Slater
Mike & Beth Vangel
Sandy & Marc Weiner

$500 - 1,000

Vicki & Andrew Athens
Chris Byrd
Janice & Ed Duffy
Greg & Diane Hayes
Terry & Therese Robertson
Daniel & Bonnie Rosen
Karen Steingarten
Robert & Linda Scullin
Matt & Diane Senatore

Up to $500

Alexis Ayers
April Benton
John & Elaine Beyer
Dolores Ceresa
Richard Day
Dottie Day
Chick Deeks
Peter & Tami Dunstan-Adams
Lynn Baervoets
Nancy Fena
Neil & Iris Frank
Melody & Gary Ganz
The Gettelman Family
Greg Gill
Paula & David Guidara
Irene & John Kalman
Y.R. Kantharajendra
Leardon Keleher
Lila Keleher
Leslie & Barbara Lawrence
Myra & Mike Lewis
Gayle Licari
Bill & Jackie Lucarell
Jack & Pamela McCarty
Michael & Pam McCoury
Cecelia Meloling
John & Barbara Miller
Griff & Cecilia Morgan
Catherine & David Neumann
Ron & Fredi Norris
Vicki Phillips
Marla & Tom Plummer
Aaron & Jean Randolph
Shirley Ricker
Lori & Erik Salo
Martin & Linda Sankey
William & Connie Schenone
Joanne Sileo
Carol & Jim Siniawski
Jeanne Stefanowski
Sharon Swanson & Dennis Lowe
Janice & Richard Thomas
Susan & Mark Trager
Nancy & Reese Williams
Tanya & Mark Wright

"The capacity to care is the thing that gives life its deepest meaning and significance."

~ Pablo Casals

Families Meet the Tiger Challenge

In May of 1996 the Tiger Foundation of New York awarded a $75,000 challenge grant to the FA Research Fund. Raise that amount within one year, said the Trustees, and Tiger will match it with another $75,000. Twenty-six FA families and hundreds of their friends contributed a total of $91,334 between June and December, meeting the challenge five months ahead of the deadline.

FA research has moved rapidly since 1991 with the help of the Tiger Foundation's outstanding philanthropy. Tiger grants have supported major studies such as the identification of FA gene complementation groups A, B, C, D, and E, and the cloning of genes FA-C (1992) and FA-A (1996). Early findings reveal that mutations in FA-C and FA-A together cause Fanconi anemia in at least 75 percent of patients worldwide.

With this latest award, Tiger contributions now total $555,000. Half of that total has been offered to FA families as fundraising challenges, thereby doubling funds raised for research. ◆

FA-A Gene Discovery Featured in *Discover*

An article in *Discover* magazine on "The Genes of 1996" highlights nine human disease genes found last year. One of them is the FA-A gene! ◆

FA Families Surpass 1996 Fundraising Goal

Tiger Challenge Grant Met in Only Six Months

1996 Family Fundraising Goal: $350,000

Tiger Challenge Grant	$75,000
Match Funds Raised	$91,334
Total Tiger Challenge	$166,334
Other Family Fundraising	$269,320
Total FA Family Funds Raised	**$435,654!**

We Honor Our Benefactors
January 1 – December 31, 1996

Albank of New York
Ancala Marketing, Inc.
Vic Alfonso Cadillac-Oldsmobile
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James and Marion Miller Foundation
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Trinity United Methodist Church
Rose E. Tucker Charitable Trust
The Woodard Family Foundation

We also extend our deepest gratitude to the many thousands of caring families, friends, and scientists who contribute to our mission around the world.

Ten Reasons Not to Raise Funds for Fanconi Anemia Research

1. I don't like to ask for help.
2. I'm a private person and believe people should handle their own problems, including medical ones, privately.
3. I don't want people to feel sorry for us.
4. I don't want other children or adults to treat my child differently.
5. I doubt my small effort would ever help.
6. I'm too busy to add another stressful project to my life.
7. I wouldn't know where to begin.
8. Publicity could be psychologically harmful to my child.
9. I don't know any rich people.
10. Others in the group are doing fundraisers, so my help is not really needed.

One Reason Why You SHOULD Raise Funds for Fanconi Anemia Research

1. You can possibly help save the life of your child or children, your spouse or other family member, or even your own life, and you certainly will help save lives of those in the future who are afflicted by this terrible disorder.

The National Marrow Donor Program Celebrates Tenth Anniversary

The National Marrow Donor Program (NMDP), now ten years old, has more than 2.7 million potential donors registered. For information on how to register as a donor, follow the links on our website, http://www.rio.com/~fafund, or call the FA office. Donors from ethnic minority groups are especially needed! ◆

NINTH INTERNATIONAL FANCONI ANEMIA SCIENTIFIC SYMPOSIUM

will be held

September 18-21, 1997

at an East Coast Location to be announced

Sponsored by

the National Heart, Lung and Blood Institute (NIH)

the Office of Rare Diseases (NIH)

&

the Fanconi Anemia Research Fund, Inc.

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Newsletter Editors
Lynn & Dave Frohnmayer and Joyce Owen

Layout and Design
Tanya Harvey

WE THANK THE FOLLOWING DONORS:

Printing
Image Masters Printers, Eugene, OR

Support for Distribution
The Edwin & June Cone Fund of the Oregon Community Foundation