FANCONI ANEMIA RESEARCH FUND, INC.

FAMILY NEWSLETTER

#23 A Semi-annual Newsletter on Fanconi Anemia for Families, Physicians and Research Scientists Winter, 1998

New Location for the FA Family Meeting

We've decided to take a big step and change locations for our FA family meeting, thereby securing housing for all families who want to attend. Thanks to those of you who sent suggestions for possible sites, we were able to select the Aurora University's George Williams Campus in Williams Bay, Wisconsin. Leslie Roy, our Family Support Coordinator, visited the site in early December, and was very impressed with the staff, accommodations, and the beautiful campus.

George Williams campus consists of 150 wooded acres including

continued on back page

HIGHLIGHTS

Lakeshore at George Williams Campus

Scientists Explore Research Directions at FA Symposium

The Heart, Lung and Blood Institute, the Office of Rare Diseases of the National Institutes of Health and our Fund co-sponsored the 9th Annual International FA Scientific Symposium in Columbia, Maryland on September 18-20, 1997. Over 120 physicians, researchers and several family members from 10 countries (Canada, Brazil, Netherlands, Germany, Italy, Japan, France, United Kingdom, South Africa and the United States) assembled to hear 35 formal presentations and to share theories and laboratory results.

Evaluations from participants were consistently positive. Researchers agree that support for this annual meeting is one of the most valuable functions of the Fanconi Anemia Research Fund.

Each of the sessions covered a high-priority topic of interest in FA science (see enclosed *Science Letter* for details).

Gene Identification

Hans Joenje of The Netherlands has now identified a minimum of eight complementation groups, A-H, meaning that at least eight different genes are capable of producing the FA phenotype. Mutations in the two genes which have been cloned,

continued on page 5

The International Fanconi Anemia Registry (IFAR)

by Arleen Auerbach, PhD, The Rockefeller University

The International Fanconi Anemia Registry (IFAR), which was started at The Rockefeller University in 1982, continues to collect data pertaining to the diagnosis, genetics, natural history, prognosis, treatment and cancer incidence in FA. We hope to gather information on many variables to better predict the life expectancy for FA patients. We also collect data on relatives of FA patients. An individual's identity is never revealed publicly. Information contained in the Registry is used (1) to establish criteria for diagnosis of Fanconi anemia and to develop methods for carrier testing; (2) to follow the course of the disease in persons who have been treated by various means. Analyses of this information are published in scientific journals to provide information for clinicians caring for FA patients. The registry is expected to provide a stimulus to improved understanding about the diagnosis, course and treatment of FA, and could potentially benefit FA patients.

Blood samples from patients will be tested to quantitate the sensitivity to diepoxybutane (DEB) and to look for somatic mosaicism. DNA will be made from blood samples from all patients and family members (siblings, parents, grandparents, and other family members as appropriate). DNA is stored in all cases for future testing as new FA genes are identified. We can also provide prenatal testing by study of DEB sensitivity, and by DNA analysis where the mutation is known.

We are screening for mutations for the two cloned genes, FA-A and FA-C, in all patients registered in the IFAR. When mutations are identified in FA group A or C, we offer carrier testing for other family members.

As part of our IFAR protocol, we can also provide a complete medical evaluation of patients for all systems that can be affected by FA. This is done in collaboration with Michael Wijnrajch, MD (Pediatric Endocrinologist, New York Hospital-Cornell Medical Center) and Alfred Gillio, MD (Pediatric Hematologist, Hackensack Medical Center). Patients are hospitalized for 3 to 5 days either at the NIH-supported New York Hospital or at Rockefeller University Hospital Clinical Research Center (CRC). There is no charge for all of the testing performed as part of our Clinical Research Center protocols. Patients are evaluated by a variety of specialists familiar with FA, including endocrinology, hematology, neurology, dermatology, gastroenterology, orthopediatrics, cardiology, opthamology, hearing, etc. We especially focus on FA patients with growth failure, and provide a complete endocrinologic evaluation to determine growth hormone status, glucose tolerance, insulin sensitivity, adrenal axis status, pubertal status and thyroid status. Our studies have shown that patients with FA are often short, and that many of these patients have abnormal endocrine function which contributes signifi-

continued on page 4

Upcoming Gene Therapy Trials

Several researchers in the United States and Europe are moving ahead to develop gene therapy trials for Fanconi anemia patients. Some are hopeful that initial trials could begin within the year. A brief update on these efforts:

Christopher Walsh reports that the University of North Carolina's Internal Review Board has tentatively approved a clinical gene therapy trial for retroviral transduction of FA-A bone marrow, mobilized peripheral blood progenitor cells and umbilical cord blood. He writes "We are now beginning the process of FDA approval for both the vector and a clinical trial."

Grover Bagby of Oregon Health Sciences University plans to use a unique retroviral vector that is not being used in other centers. No clinical trials have been set because the vector has not yet been validated. Researchers will use FA-C exclusively until the vector is validated.

James M. Croop of the James Whitcomb Riley Hospital for Children in

continued on page 4

Minnesota Plans New Bone Marrow Transplant Protocol

By John Wagner, MD, Pediatric Bone Marrow Transplant Program

While bone marrow transplantation using a matched brother or sister as a donor has been shown to be effective therapy for the blood and marrow problems associated with Fanconi anemia (FA), many people with FA do not have a suitable related match. Marrow can be obtained from unrelated donors, but transplants using unrelated donor marrow are more difficult due to an increased risk that the marrow will be rejected. In addition, patients receiving unrelated donor marrow have higher rates of graft-versus-host disease (GVHD), an immunologic disorder in which the cells of the donor growing after transplant react to the new body. This disorder can be severe and life threatening. The potential to develop severe GVHD can be decreased by removing T cells from the bone marrow. Unfortunately, the process of T cell removal increases the risk that the new marrow will not take, and this complication is usually fatal.

The Bone Marrow Transplantation Program at the University of Minnesota is developing a procedure to insert a gene into T cells that allows them to be killed with a medication that is relatively non-toxic to normal cells. In this way, T cells can be included with the marrow to enhance the chance of the new marrow growing normally, while providing an increased level of safety against uncontrollable, severe GVHD. The plan is simply to take out the T cells as before, put the "suicide gene" into those T cells and then transplant them along with the other marrow cells collected from the donor. After transplantation, the T cells will help the donated marrow take and grow. If there is no GVHD, the patient will not receive any treatment to kill the T cells. However, if GVHD does occur, the patient will be treated with a drug that will cause the T cells containing the "suicide gene" to die. Wagner anticipates that this gene therapy treatment protocol will be available within the year. ◆

Your FA Research Dollars at Work In 1997/98

Gene Identification and Characterization

Arleen Auerbach *The Rockefeller University*	$77,430
Alan D'Andrea *Dana-Farber Cancer Center*	47,500
Hans Joenje *Free University, Amsterdam*	62,000
Chris Mathew *Guys Hospital, London*	62,205
Jan Pronk *Free University, Amsterdam*	27,378

FA Protein Function

Mark Kelley *Indiana University*	21,669
Hagop Youssoufian *Baylor School of Medicine*	50,825

Therapy Development

Josef Prchal *University of Alabama, Birmingham*	57,791
Chaim Roifman *Hospital for Sick Children, Toronto*	77,500
John Wagner *University of Minnesota*	66,566
Robert Arceci *Children's Hospital Medical Center, Cincinnati*	72,287
Total Research Funded:	**$623,151**

Upcoming Gene Therapy Trials

continued from page 2

Indianapolis, Indiana reports that his group is moving forward on gene therapy protocols for FA patients. A retroviral vector has been developed for expression of the FA-C protein. Preclinical evaluation of this vector has demonstrated its ability to correct mitomycin C sensitivity and to enhance viability in tissue culture cell lines. Expression of the vector in peripheral blood stem cells from one patient resulted in enhanced growth of bone marrow progenitor colonies in vitro.The clinical protocol is currently in the development phase and the cooperative agreements necessary for such a trial are being pursued. Croop anticipates that the trial will open by late fall or winter of this year.

A number of European teams are joining forces to develop gene therapy for FA-A patients. Project leader is Dr. Odile Cohen-Haguenauer (Hospital Saint Louis, Paris); participants are: Gluckman (France), Joenje (Netherlands), Bueren (Spain), Mathew (London), Peschanski (France), Digweed (Germany), and Dokal (London). This project will use a novel vector developed in Dr. Cohen-Haguenauer's laboratory. This three year project, supported by the European Union, is expected to run from 1998 - 2000.

Michael A. Pulsipher and Alan D'Andrea of the Dana-Farber Cancer Institute, Children's Hospital, Harvard Medical School are developing clinical gene transfer trials for FA-A patients. They use a retroviral vector engineered for increased stability and long-term expression. In upcoming trials, investigators hope to improve the rate of gene transfer into long-term repopulating marrow cells or stem cells. They are exploring the use of a virus which has a broad range of infectibility, and is therefore able to transfer genes effectively to many different types of cells. In addition, they can superconcentrate this virus, giving them a better chance of transferring the gene into human stem cells. Preclinical data are promising. Pulsipher and D'Andrea hope to recruit more FA patient volunteers willing to give marrow. They are especially interested in FA patients who are early in their disease process or who have relatively mild bone marrow disease, since marrow from those patients may have larger numbers of stem cells.

Depending upon the extent of the approval process, Pulsipher and D'Andrea should be able to offer clinical gene therapy for FA-A patients during the next 6-24 months. See enclosed *Science Letter* for more details about this project. ◆

International FA Registry

continued from page 2

cantly to short stature. Patients with abnormal findings may benefit from therapy to correct deficiencies. Patients may also benefit from subspecialty evaluations and second opinions. We also provide genetic counseling.

If you are interested in participating in the IFAR, mutation studies, or in the CRC protocol for FA, please ask your physician to contact Dr. Auerbach directly. Dr. Auerbach asks us to emphasize that if newly diagnosed patients or parents wish to speak with her, please use e-mail, FAX, or letter of inquiry first. With an extremely busy schedule and no secretary, this allows her to set aside enough time to provide comprehensive consultation over the phone.

Dr. Arleen Auerbach
Laboratory for Human Genetics and Hematology
The Rockefeller University
1230 York Avenue, Box 77
New York, NY 10021
e-mail: auerbac@rockvax.rockefeller.edu
FAX: 212-327-8262 ◆

FA Clinical Workshop Planned

Treating physicians with experience and a special interest in Fanconi anemia have agreed to organize the first-ever Fanconi anemia clinical workshop. This two-day session will be held in Portland, Oregon in May 1998. The conference will focus on developing standards for diagnosis and treatment of this rare disorder. Organizers believe this workshop will lead to treatment guidelines and to the development of clinical trials which could be extremely useful to family practitioners and to specialists who have limited experience in treating FA.

The meeting will lead to two new publications. The first will be an FA case management guide which will be distributed by mail and through the FA Research Fund's website. We will ask physicians to contribute feedback as they use the guide. We plan to update this publication on a regular basis. The second will be a scientific review article for publication in a clinical journal.

FA Symposium
continued from front page

FA-A and FA-C, account for approximately 75% of FA patients. Scientists presented preliminary results on mutation screening for FA-A. Unlike FA-C, the mutations for FA-A are numerous and often difficult to detect.

FA Gene Products: Apoptosis

The increasingly important subject of apoptosis (the process of cell death) was the subject of five presentations. Grover Bagby of Oregon Health Sciences University described how FA-C hematopoietic cells are sensitive to gamma interferon, and why this discovery is important in understanding premature cell death.

Transgenic and Knockout Animal Models

Manuel Buchwald, Hospital for Sick Children and Markus Grompe, Oregon Health Sciences University discussed recent findings from FA-C mouse models and other researchers explored implications of animal model studies.

Carcinogenesis and Leukemogenesis in FA

This session examined factors leading to or signalling the progression to leukemia in disorders such as FA. The poorly understood role of clonal abnormalities as predictors of leukemia was examined extensively.

Experimental Therapies

The final session explored developments in marrow and stem cell transplantation; further reports on the first FA-C gene therapy trial; preparations by one laboratory for FA-A gene therapy; and speculation on the possibility that spontaneous mosaicism in FA might be an example of "natural" gene therapy. ◆

Clinical Trial Planned for Interleukin 11

The Division of Pediatric Hematology/Oncology at the James Whitcomb Riley Children's Hospital of Indianapolis is developing a protocol to evaluate the safety and efficacy of IL-11 in patients with Fanconi anemia and other bone marrow failure syndromes. IL-11 is a bone marrow growth factor which has recently been shown to increase baseline platelet counts in volunteers, and decrease the platelet depression from chemotherapy in adults being treated for cancer.

There is limited information on administering IL-11 to children. Preliminary reports have indicated that IL-11 decreases platelet depression in children receiving chemotherapy for cancer. The proposed protocol will determine if IL-11 can improve the platelet count in patients with Fanconi anemia, identify the minimal dosage necessary to sustain a response and determine if there are side effects with prolonged administration. The study should open by summer or early fall. Contact physician:

James M. Croop, MD, PhD
Section of Pediatric
Hematology/Oncology
James Whitcomb Riley Hospital
for Children
Room 2720
702 Barnhill Drive
Indianapolis, IN 46202
Tel: (317) 274-8784
Fax: (317) 278-0616
e-mail: James_Croop@iucc.iupui.edu

D'Andrea Receives Research Award

Alan D'Andrea, MD has been awarded the American Academy of Pediatrics Award for Excellence in Research for 1997. He received the award in November at the Academy's annual meeting in New Orleans, in recognition of his research in the genetic and biochemical cause of childhood cancers.

D'Andrea is Associate Professor of Pediatrics at Harvard Medical School. He is a member of the Hematology Division at the Boston Children's Hospital and a member of the Pediatric Oncology Division at the Dana-Farber Cancer Institute. D'Andrea directs a research laboratory at the Dana-Farber Cancer Institute. ◆

Samuel Boudreau, Our Precious Son

by Carole Boudreau

On October 28, 1996, our son Samuel Boudreau was born with multiple birth defects including a TEF (defect in the esophagus), with a missing half thumb, a single kidney and hydrocephalus. The diagnosis was Vacterl with hydrocephalus. A few weeks later, chromosome testing revealed that Samuel also had Fanconi anemia. How could a boy from a small town of 2400 people be born with something so rare? The doctors told us there were only a few cases reported in the world. I could not believe that this nightmare was happening to us. I had decided to have my children as a young mother so I could decrease the risks of having a sick baby. I had my first son, Sylvain at age 22 and Samuel at the age of 24.

Samuel was in the neonatal intensive care unit for a very long six months, mainly because of his TEF. He had his first major surgery at 3 days old which was a failure because they were unable to join his esopha-

continued on page 11

Nose Bleed Management

by Carol Siniawski

Over the last year, Jake has had over 18 nose bleeds. We have learned a great deal by trial and error. I hope other families can learn from our experience.

Jake's platelets have been stable in the 30,000 to 40,000 range for a long time, so the onset of nose bleeds over a year ago caught us by surprise. At first, the nose bleeds started in the middle of the night and would last for hours. We used Afrin and pinched his nose while he sat in our lap. Sometimes so much blood ran down his throat that he would throw it up.

We started paying more attention to his sleeping habits. We noticed that he rubbed the side of his nose with the back of his knuckle while sleeping. Apparently he would rub so hard he would start a nose bleed. Having Jake wear gloves at night minimized the force of the rubbing against the nose. Also, the feeling of the glove material on his nose made him more aware of his actions even while he was asleep. As the frequency of the bleeding decreased, we discontinued use of the gloves.

We also noticed that bleeding would frequently recur within 24 hours. We decided on quiet rest for 24 hours until a good scab could form, even if that meant missing a day of school.

In the middle of the night after hours of bleeding we frequently consulted with the hematology doctor on call at the hospital. Doctors felt that we were doing the right things and that bringing him to the ER would be more traumatic than valuable. They would not pack his nose because packing would probably tear up more tissue and create more damage with such a low platelet count.

The nose bleeds continued after the first hard frost so we ruled out allergies. We tried blaming the problem on the dry winter weather, but we had a humidifier in his room and there was plenty of humidity in the house. We also placed a small bead of vaseline just inside each nostril twice a day, to help keep the tissue from drying out. For a few days after a nose bleed, we'd switch to neosporine to help accelerate the healing process. Nonetheless, once

continued on page 13

The Need for Vigilance
Lynn Welfare's Bout with Cancer

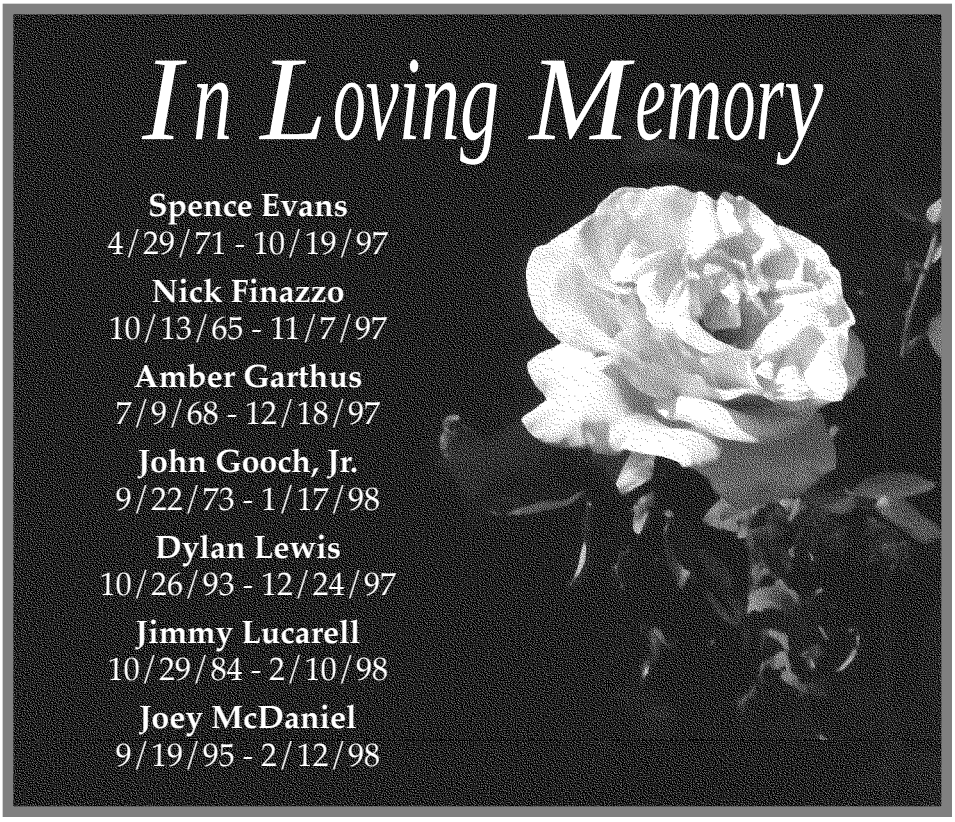
Lynn Welfare and niece Emily

Anyone who has attended FA family meetings in recent years knows Lynn Welfare. She is a woman with boundless energy, affection and a hug for everyone; she is a positive, concerned presence as she cheerfully greets families and children. As we learned at a talent show, Lynn sings, writes music, and plays the piano beautifully. She is a 44-year-old FA patient who has done remarkably well for many years. She is determined to inform as many as she can about this disorder, and is willing to be a "guinea pig" for new therapies, hoping that children and young adults will benefit from her experiences.

In April 1997, Lynn noticed a small sore on her tongue, about the size of half a thumbnail. Her physician believed that the irritation was caused by a tooth. It was treated topically to heal a possible infection. The sore did not go away and instead grew progressively larger. Six months later Lynn consulted her dentist. The dentist directed her to an oral surgeon, who stated he "didn't like the look or the feel of it." She was sent at once to an ear, nose and throat specialist who biopsied the area. A week later Lynn learned that she had a squamous cell carcinoma the size of a thumbnail on her tongue. Two weeks later another suspicious area on her tongue, close to the malignancy, was noted. This proved to be pre-malignant.

On January 6, 1998, the two areas were surgically removed. Mario Hermsen, a researcher from the laboratory of Hans Joenje traveled from Amsterdam to obtain the tissue removed from Lynn's tongue and take it back to Amsterdam, where he will attempt to establish cell lines and study the malignancy. Tissue taken from Lynn's thigh was used as a graft on her tongue. A chest x-ray, MRI of Lynn's upper chest area and an endoscopy of her throat and esophagus revealed no additional malignancies. These areas will be monitored very closely in the future.

Pathologists believe that Lynn's tongue cancer was superficial and that they removed it completely. Lynn wants others to know that if they experience similar symptoms that do not resolve rapidly, they should pursue a diagnosis aggressively. Cancers of the tongue (or of the mouth in general, the throat, esophagus, and reproductive organs in women) are common in older FA patients. Dentists should routinely check for abnormal-appearing tissue; young women need regular PAP smears. Chances of eliminating a malignancy are obviously far better the earlier the problem is detected. Lynn's advice: "be vigilant and very aggressive if you experience unusual symptoms." ◆



Katie O'Connor

A Loving Memorial by her Father, Kevin

Kate loved the things that all kids love—Disney World, video games, beanie babies, amusement parks with their wild rides, Nickelodeon, and so much more. But Katie was a girl who was cursed with an unstoppable, incurable disease which over-shadowed her entire life. This was a situation she was aware of from early on. Fate had dealt her a bad hand, but she refused to withdraw from life. Instead, she embraced it. She had an innate and unending curiosity about the world around her. Wise beyond her years, she had an open heart.

Of course, her love of cats is well known and it is because of that Lorraine, Katie and I got involved with the rescuing of several homeless cats who happened into our life. But Kate loved all aspects of nature—animals, plants, insects. At the age of ten, she became totally absorbed with Pre-Cambrian life forms—things with names like anomalocaris, wiwaxia, and trilobite. She drew huge amounts of illustrations, made clay models and even wrote a play about these creatures. She devoted similar time and energy to a common roadside weed called mullein or "*Verbascum thapsus*", as she liked to put it. Her interests were so varied; she opened many new worlds for us.

Over the years, Kate pursued her varied interests with a quiet dignity and persistence; all the while, she was pursued by Fanconi anemia with innumerable trips to the hospital for medical emergencies and other things no child should ever have to experience.

She was so filled with life and love. Her relationship with her mother, Lorraine, transcended that of mother and daughter. They were, and will always be, inseparable, regardless of anything that happens here on earth. Kate managed to cram a lot of living into her twelve years. Of course, no matter how you slice it, twelve years is way too short a time for a life, no matter how brightly it shines.

Now, we are left here trying to figure out what it all means. I guess some of what we have learned from Kate's time with us is that life is a precious, wonderful thing—no matter how it confronts us. It must never be taken for granted. We miss Katie terribly, but her love of the world and all of us in it will live on forever.

Katie's thirteen year old cousin, Matt, and her fourth grade teacher, Pat Daly, both wrote poems in memory of Katie. We'd like to share them with you. ◆

In Memory of Katie

Others will speak of her,
of her strength,
her depth of spirit,
her fierce will to be.
I will remember the child-woman
playful, intense,
a profundity of curiosity,
imagination,
that stretched her
beyond the confines of the paths
she trod.
Young, wise,
a startling contrast,
though not so much
as she revealed her
soul.
Innocent,
eyes open wide to all,
walking, singing through
dailiness,
heeding creatures, flowers,
inhaling her life's breath,
uttering Aah!,
simple pleasure
at life's simple offerings.
I will remember the gentle touch
of her flame,
smoldering with the
intensity of one
soon to be extinguished.
Others will speak of being touched
by her strength, her courage.
I will remember her beauty,
her heart,
glowing through
her fragile transparent being,
hiding
nothing
and I will speak
only of the joy her life brought
and the catastrophe of her loss.

~ Patricia Daly

Ed Brookover's Bone Marrow Transplant

By Edward & Barbara Brookover

In January 1996, we faced the dilemma most Fanconi anemia families dread: our son Ed's counts were dropping and we had run out of medication options. We chose to go immediately to an unrelated bone marrow transplant. Ed's counts were still high by FA standards and he was in good health.

Today, Ed is approaching the second anniversary of his transplant. He is fully participating in his school's activities. He takes no medication and the BMT appears to be a full success. We would like to share Ed's history and the decisions we made throughout his battle with FA.

Ed was diagnosed with FA in 1988, at age five. His platelet count was 40,000; the other counts were in the low-normal range. He had virtually none of the other physical problems often associated with FA.

Katie

Katie was a special person, that could never be forgotten,
She realized the great gift of life.
She loved everyone,
and didn't care about how you looked, or how popular you are,
she looked for you on the inside.

Although we are sad to see her go,
we all know that she is happy,
and wants us to do the very best we can.
And for Katie, I know I will do that.

~ Matt D'Antonio

Ed's hematologist had never had an FA patient before. As with most FA families, we set out to learn as much as we could. We spoke by phone to experts around the country and found the FA Research Fund as a support group.

We did not place Ed on medication at first as his counts were acceptable.We hoped he would remain stable allowing medical research and new treatments to improve his chances for long-term survival. We allowed him to play Little League baseball and basketball.

No one in the family was an acceptable bone marrow donor for Ed. Nonetheless we assumed that he would someday need a BMT if he were to survive his upcoming ordeal.

At age 7, Ed contracted chicken pox. After recovering, his counts began to drop. He began treatment with oxymetholone and prednisone, and responded immediately. For the next five years, he made many trips to the doctor. We tried to keep his medication at the lowest level possible while allowing him to maintain a somewhat normal life. We monitored his liver and other body functions regularly, looking for potential side effects from his medication. Ed had only one blood transfusion during this time after a bout of spontaneous nose bleeding. In retrospect the transfusion was probably unnecessary.

In the spring of 1995 Ed developed a spot on his liver, probably from years of steroid treatment. We tried different types of medication, but none maintained his counts. A month after stopping the steroid treatment, his liver spot disappeared.

By the fall of 1995 all of his counts were dropping. He began epogen and neupogen treatment. He received his second transfusion, this time of whole blood.

We contacted the University of Minnesota Hospital about transplant procedures and locating potential donors. This was probably the best decision we made. Dr. John Wagner was patient with our questions, and direct in describing possible complications of the BMT procedure. He became a full partner with us as Ed endured his BMT.

Ed's counts responded to epogen and neupogen. He was out of immediate danger, but we knew it would only be a short time until we had to made a decision on a BMT.

Ed's counts held up through Christmas, but in January they began to fade again. It was obvious we now had to decide whether to go through with a BMT or take the route of transfusions.

This was not an easy decision. Ed's counts, while dropping, were not as low as those experienced by other FA patients. He was otherwise in good health (in fact he played in a county basketball tournament the day he left for his BMT). He had never been in the hospital for an overnight stay.

Our decision to move forward was based on our belief that any other action would delay the inevitable. Ed had only received two transfusions and we had always heard that it was good to minimize transfusions for BMT patients. Ed had no other complicating health problems. In fact, we believe his good health played a major role in his surviving the BMT procedure.

The National Marrow Donor Program identified a 6/6 match for Ed. We chose the University of

continued on page 10

Ed's Bone Marrow Transplant

continued from page 9

Minnesota Hospital because of their recent successes with elutriation and FA patients. We left for Minnesota on March 12, 1996.

In Minnesota we had just over a week of pre-transplant tests. We moved into the Ronald McDonald House for our 4 month stay (a great experience, maybe worth another article!)

Ed entered the hospital on March 20. He underwent radiation and chemotherapy to kill his own marrow. He received his transplant on March 28. And on day 11, Ed began to get a white cell count. Ed left the hospital on day 21 post transplant, about the earliest he could have been released. While he was in the hospital, we religiously followed the prescribed procedures, especially concerning cleanliness. We learned all we could about each of his medications. The BMT staff was excellent.

After moving back to the Ronald McDonald House, Ed was physically weak and still very vulnerable to disease and infection. We went to the BMT Clinic every day for blood counts and daily transfusions of platelets. He received red cells less frequently.

In late April, Ed developed a fever. He was readmitted and immediately put on a series of infection fighting medications. He developed a very slight case of graft-versus-host disease. The fevers lasted just over a week. He was released again from the hospital.

While in the hospital Ed suffered from high glucose in his bloodstream. He took insulin (just as in diabetes) for about a month. This was probably the most surprising side effect of the transplant procedure.

While an out-patient Ed was on a variety of medications. Many were to combat possible complications from the transplant, but some were to prevent side effects of the medications. Keeping up with this was a very laborious process.

In late June, Ed developed another fever and returned to the hospital. Tests failed to reveal the cause of this infection. On July 1 he was discharged. We left Minnesota on July 5, exactly 100 days post-transplant.

Upon our return to Virginia we expected constant trips to the doctor and continued transfusions. In fact, Ed needed no transfusions as his counts climbed rapidly. He had regular blood counts and remained on various medications, but was doing very well. Within a month he was able to have his line removed.

Ed started back to school part-time in early November. He was off all medications by December 31. He was playing basketball again in March. We will always remember the tremendous welcome he received from his teammates and their parents when he walked back on the court. Less than a year before they had sent him off to Minnesota to an unknown outcome.

Is there ever the perfect time to go for a BMT? No, but our plan worked for Ed. You need to trust your instincts and follow a plan best for your child. We had always managed Ed's care with an eye toward a bone marrow transplant. We were fortunate that his health remained good throughout his pre-transplant years. But we believed eventually we would be facing a decision about when, not whether, to pursue a BMT.

We are always told to learn everything about treatments and procedures. We could not agree more, especially with all that happens during the transplant process. Risks are inherent with any treatment for FA patients. You must be able to make rational, though very difficult decisions.

Finally, we believe Ed would not have survived if he faced these problems when he was first diagnosed in 1988. At that time there was a much lower success rate for unrelated transplants. Without the advances in research over an eight year period, Ed's chances for survival would have been bleak.

We welcome talking to families as you go through your decision-making process. We will talk about anything from the Ronald McDonald House to why we chose to go to Minnesota. Please feel free to call either of us at 703-690-1735. ◆

Carol Siniawski Honored

Carol Siniawski was nominated and selected to serve a two year term on the Patient Advocacy Committee for the National Marrow Donor Program. Carol writes "I have enlarged my circle of influence and want to help the families as much as I can. Give me a call or an e-mail with your ideas for how the NMDP can improve patient family education and services. Thanks." Our heartiest congratulations to Carol!

telephone: (513) 574-6518

e-mail: the3skis@aol.com

Samuel Boudreau

continued from page 6

gus to his stomach. They placed a gastrostomy tube through his stomach so we could feed him. Samuel survived all of his surgeries and was discharged from the hospital in March 1997. When Samuel was at home, I still could not accept the fact that he had Fanconi anemia. I hoped and prayed that it was a mistake.

Later in May, Samuel had to be seen for a check-up and that is when they confirmed his diagnosis. Dr. Auerbach had talked to my hematologist and told her that the DEB test showed that it was Fanconi anemia. I felt as if our life were coming to an end.

After I accepted Samuel's illness, I decided to learn as much as I could about this disorder so I could make sure he would receive the best care possible. I want to thank the Fanconi Anemia Research Fund and all the families who have information on the internet. The internet gave me all the resources to help me better understand this illness. Contacting other families through e-mail helped me realize that I was not alone in this ordeal.

Samuel is now one year old and loves playing and laughing. He recently had his gastrostomy tube taken out and periodically returns for blood tests. I think the best way to get through this illness is to live each day to its fullest and hope and pray for a cure. I sometimes feel depressed when I think about the future, but most of the time, I savor every precious moment I have with Samuel, Sylvain and my husband David.

For the time being, I try to be optimistic and I pray my older son will be a perfect bone marrow donor when it becomes necessary.

I can be reached at the following e-mail address or by telephone if anyone has any questions.

e-mail: boudrd@nbnet.nb.ca
tel: 506-743-5841

A Prayer for Compassion

by Susan Collins

To the researcher working tirelessly on our behalf do we say, "It is not enough because you have not yet cured my loved one"?

To the parent who has a matched sibling donor do we say, "Do you know how lucky you are?" as if they could somehow not know?

To the newly diagnosed family who is already frightened beyond words, do we share with them our own FA horror stories?

To the adult FA patients and their families do we talk only about saving our children, as if FA is not affecting their lives, too?

To the family of a successful transplant patient are we compelled to remind them that they may still face other complications rather than letting them enjoy their blessing?

To the family of a severely affected child who is doing poorly do we say, "Well, there are adults with FA", as if all FA patients are in the same category?

To the Frohnmayer family who has done so much for us all do we say, "Thank you, I don't know how you do it", without even asking what we can do to help?

To the family who has lost a loved one, what do we say?

Dear Lord,

Please give us compassion and understanding to guide us in dealing with each other. Please help us to remember that this dreadful disease impacts each of us differently, and help us to see through others' eyes not just our own. Please give us wisdom to offer words of comfort when they are needed, and give us restraint to offer our opinions and advice only when they are asked for. Please give us strength to rejoice in victories even if they are not our own. And dear Lord, most of all please give us love for you, love for each other and hope for the future.

Amen.

Love and Faith Sustain McDaniel Family

Karen and Gene McDaniel are the parents of three children. Their first son, Jacob, was born in April 1990, and lived for only fourteen days. He had very serious birth defects. The family learned later that Fanconi anemia was responsible for the anomalies that led to his early death. After Jacob's death, the McDaniels contacted our support group and learned all they could about this disorder. Karen's warm, loving outreach and unwavering faith are apparent to all with whom she has contact.

Katie McDaniel was born in June 1994. This delightful, caring child is "the joy of our lives." Karen stated that they named their healthy daughter after Katie Frohnmayer, "because of her bravery; she was such a beacon of courage."

In September, 1995, Joey McDaniel was born. Like his brother, he had many serious birth defects all associated with his diagnosis of Fanconi anemia. In his two and a half years, he has undergone eighteen surgeries and lived much of his life in the hospital. Karen stated that because of the many medical procedures he has had to endure, his lungs have become very weak and tired. Breathing problems eventually led to a tracheostomy and home ventilator, which he requires constantly for oxygen support. Given Joey's deteriorating health, Karen does not believe that he has too much longer to live.

In spite of the burdens they have had to bear, the McDaniels maintain a positive outlook. Karen states "These children are so special for whatever length of time God has chosen to let them be on this earth. They are incredible; they teach us so much about the quality of life. Our boys have touched so many lives; Joey's beautiful smiles are worth everything. People can't understand what a privilege it is to be the mother of such beautiful kids. Everything in this life is so fragile; we try to make each day count."

The McDaniels are sustained by their firm faith in God. Karen stated that there is no doubt in her mind that there is something much better than the short life we experience on earth. "We hold onto that hope. It's what keeps me going."

Dear Readers:

Karen McDaniel called on February 13 to let us know that Joey had gone to heaven on February 12.

The Healing Poem

by Becky Birtha

There is a healing power in the sky
For times when you cannot weep ~
travel on foot
a morning's measure; find
a vast unbounded field of sky
then, spend the whole of a day
beneath it.
In your house
keep one window free
panes shining full with blue or gray ~
you must never stray far from the sky.

There is a healing power in the land.
When what you would change
you cannot change,
take tool to hand and
work the earth:
spade deep and turn it over,
let it crumble, sift out every stone.
Near your home,
set off a stretch of ground;
feed it, keep it
growing.
If you must leave the land,
do not leave for long.

There is a healing power in you
when reason fails ~
you cannot overcome the problem
with your mind.
It is in your fingers
that lace and mend
in the bend of your back when you
swing the axe,
shovel coal or snow.
It is in your voice
singing, released
when your feet pick up
the pound of a beat, leap and whirl ~
turn full around;
return to yourself.
Do not forget to
keep your powers alive.

The healing is in these words ~
When you want very much
something you cannot have
you must begin again.

Nose Bleed Management
continued from page 6

after he had lost a great deal of blood, we had to red cell transfuse him.

After the transfusion, we decided to visit an Ear, Nose and Throat specialist who had treated patients with blood disorders. I was so glad once we started seeing him and was sorry we had not gone before needing a transfusion. This doctor saw nothing in Jake's nasal cavity that would suggest cauterizing. It would do more harm than good, based on what he saw. Jake's problem appeared to be dry tissue. His tissues were so dry that once a wound was created, it had a hard time healing.

Jake was put on a high moisturizing home treatment plan. We continued vaseline twice a day, but added non-medicated Saline solution spritz, 3-5 times a day. More is better while using NON-medicated Saline. We covered Jake's nose and mouth while outside in freezing temperatures. A winter head band (ear warmers) worked well to cover Jake's nose. The doctor did not recommend allergy medication, as most are drying agents. He also said 4 squirts of Afrin in the bleeding nostril was O.K. (we had used 2). He also recommended applying pressure to the side of the nose that was bleeding versus pinching both sides. He did not believe we could eliminate the nose bleeds, but was hopeful we could minimize their frequency and severity.

Today if Jake has a nose bleed, we give him squirts of Afrin then apply pressure to the outside of the bleeding nostril. The trick is to find the right point to apply pressure. If we don't hit it right, Jake will tell us that the blood is going down his throat. We release the pressure and let the excess out into the toilet. After a few minutes, we apply pressure again, using a single finger. This technique has minimized the time to stop the bleeding (less than one hour) and amount of blood loss, and has eliminated throwing up blood. Utilizing moisturizing techniques has also decreased the frequency and severity of Jake's nose bleeds.

One other incident especially upset all of us. During one nose bleed, Jake's eye started to tear blood. That was very frightful. Apparently the tear ducts are connected to the nasal cavity and when the cavity backs up with blood, it takes the path of least resistance which can be the tear duct. I was grateful that it was not another medical condition, but instead a spin off of the nose bleed. It was scary, nonetheless.

Some steroids can thin the nasal mucus membranes. One of Jake's meds does just that. After weighing the benefits of this drug, the low dosage and the current nose bleed status we decided to keep him on the medication.

Jake is protective of his nose during playtime but is not so afraid that he has stopped playing. Because we have more control of this problem, Jake is more comfortable and less irritated and agitated. I hope that some of this information will help those currently battling nose bleeds. It is my bigger hope that very few of you need this information. Please feel free to call us if you have anything you'd like to discuss.

Carol Siniawski
(513) 574-6518

We Welcome New Families Who Have Joined Our Support Group

Katrina Jenkinson
M/S 264 Sully & Dowdings Rd.
Pine Creek, Bundaberg
Queensland, Australia 4660
011 71 579638
18 years old

Greg & Gail King
140 "B" Hastings Ave.
Rutherford, NJ 07070
(201) 438-5380
Laurel ~ DOB 5/6/89

Andy and Kristie McCauley
22124 Cedar Street
Hillsboro, Wisconsin 54634
Alexander ~ DOB 3/21/96

Chi Sin & My Ngo
260 Chalmette Rd.
Livermore, CA 94550
Justin ~ DOB 11-1-97

Alexander and Valentine Samosiuk
Brest
Kievskaya Street, 108/1
Belarus 224020
Anastasia ~ DOB 5/19/92

Gerald & Elizabeth Wisz
34 Cottage Place
Garfield, NJ 07026
(973) 546-5113
Zachary ~ DOB 3/6/97

Paper Clip Fundraiser Wins Hearts, Raises Funds

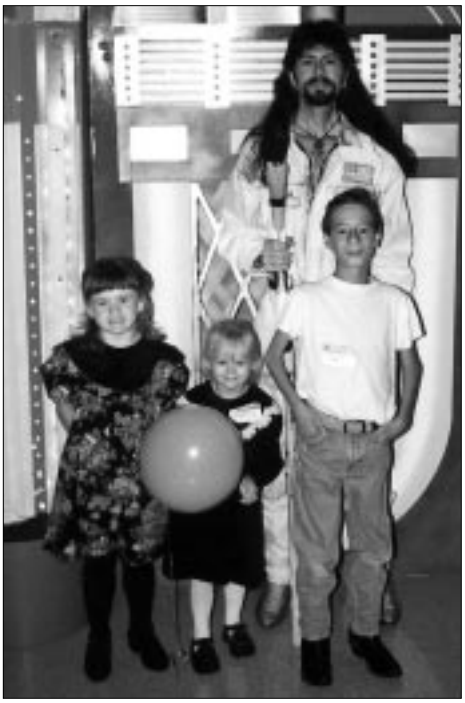
Residents of Unna, a town in Germany, have heard much about Fanconi anemia. The latest fundraising effort of Ralf and Cornelia Dietrich, parents of Sarah Ninja and Valeska, touched local hearts, informed the community about genetic disease, and inspired a generous outpouring of Deutschmarks.

The Dietrichs challenged their local community to build a paper clip chain in two weeks, from the town hall to the market place, a distance of 500 meters, requiring 20,000 paper clips. Each clip sold for one Deutschmark. Ralf Dietrich spent two weeks stringing the chain together. Local interest was intense, as residents followed progress and contributed to the chain. Children were intrigued and added to the chain. Target date for completion was Christmas Eve.

Flyers discussing Fanconi anemia and this fundraiser, newspaper articles and constant radio coverage informed the community. In addition, the Dietrichs mailed letters to over 2,000 potential donors, and children attending Sarah Ninja and Valeska's schools took appeals home to their parents. This multi-pronged effort raised 40,000 Marks (approximately $25,000), over twice the original goal and enough to build another chain from the market place back to the town hall!

A group of twenty students constructed a replica of the FA-A gene out of four colors of paper clips. Five of these students were picked by lottery to travel to The Netherlands with Ralf Dietrich to present the paper clip gene to Hans Joenje's laboratory. Because of interest generated by this fundraiser, Fanconi anemia may be chosen as the model genetic disorder for a German biology textbook.

The Dietrichs accomplished this effort while attending to the constant medical needs of Sarah Ninja, who requires two platelet transfusions a week. "If we can do this others can, too", Ralf stated. ◆



Rear: Nick Finazzo, front, L to R: Alexandria and Jessica Gallagher and Andrew Athens enjoy the Athens' Fundraiser.

Athens' Efforts Inspire Friends and Community to Give

by Shelly Tracy

Grosse Ile is the small town in Michigan which the Athens family calls home. This small town is located in an area better known as Downriver. Downriver consists of many small towns, which are tied together both geographically and emotionally. When a call for help goes out, family, friends and neighbors within the Downriver area respond. Fortunately, many have answered the calls for help from the family of Andrew Athens, and have responded in the past year with hard work and donations, donations, donations!

Following the picnics and barbeques which occured on Memorial Day, friends, family and neighbors rallied for our first fundraiser by collecting returnable pop and beer cans. We had two drop off sites, one at a local landmark, the other at a local hockey arena. As the rains poured all day, we collected bottles and cans. Some of us sorted, others made constant runs to local grocery stores to return the cans. By day's end, we had collected $4,000! And people laugh off the value of a little dime.

Our next fundraiser was hosted and directed by our local Rotary.

continued on page 17

Family Fundraising Efforts

From July 1, 1997 through December 31, 1997, seventy-eight families raised funds or made individual contributions for a total of $403,000. Miscellaneous donations through United Way and the Combined Federal Campaign, which we were unable to attribute to a specific family, totaled $11,221. This is the largest amount we have ever raised in a six month period! We should all be proud of how far we have come; our efforts will continue to speed scientific progress. Yet as long as children and adults are threatened by this awful disorder, we must continue our hard work. Each check written, each letter-writing campaign, each event big or small brings us closer to our goals of understanding, treating and curing this disease.

We thank all families who gave hours to organizing and executing events, risked public exposure and gave generously to this urgent cause we share.

$100,000+

Dave & Lynn Frohnmayer

$60,000 - 85,000

Vicki & Andrew Athens
Laurie Strongin & Allen Goldberg

$30,000 - 35,000

Carol & Jim Siniawski

$12,000 - 20,000

Deane Marchbein & Stuart Cohen
Beth & Eric Losekamp
Chris Scaff

$6,000 - 10,000

Chris & Susan Collins
Steve & Alison McClay

$2,000 - 4,000

Ken & Jeanne Atkinson
Rene LeRoux
Jeff & Debby Slater
Melissa & Steve Turner
Mike & Beth Vangel
Marc & Sandy Weiner

$1,000 - 2,000

Mark & Linda Baumiller
Greg & Diane Hayes
Roger & Eleanor Herman
Lila & Leardon Keleher
John & Karilyn Kelson
Robert & Jennifer Kiesel
Tim & Jeanne Kucera
Gil & Peggy McDaniel
Jack & Lisa Nash
Kevin & Lorraine O'Connor
Randy & Lisa Bourgeois
Matt & Diane Senatore
Bryan & Karen Siebenthal

$500 - $1,000

Joeffe & Joaquim Carvalho
Elizabeth Claypool
Brian & Margaret Curtis
Griff & Cecelia Morgan
Terry & Therese Robertson
Glen & Maureen Russo
Rick & Lynn Sablosky
Bill & Connie Schenone
Erik & Lori Salo

Up to $500

Richard & Sharon Atwood
Serge & Brenda Arsenault
Alexis Ayers
Ed & Barb Brookover
John & Elaine Beyer
Ceresa Family
Susan Combs
Susan & Derek DaRosa
Rick Day
Dottie Day & Darla Patrick
Joseph & Tracey DeMarco
James & Carol Dillon
Nick Finazzo
Darryl Blecher & Diana Fitch
Neil & Iris Frank
Gary & Melody Ganz
Dave & Paula Guidara
Ousama & Souha Halteh
Chris Hull
Jeff & Beth Janock
Lynette Lowrimore
Bill & Jackie Lucarell
Teddi Matlack
Jack & Pamela McCarty
Cecilia Meloling
John & Barbara Miller
Lynda & Skyleigh Moureau
Bob & Alice Nicholson
Ron & Fredi Norris
Robin Paulson
Michelle Petty
Hal & Bobbie Porter
Ben & Shirley Ricker
Dan & Bonnie Rosen
Bob & Andrea Sacks
Robert & Linda Scullin
My Ngo & Chi Sin
Karen Steingarten
Richard & Janice Thomas
Mark & Susan Trager
Lynn Welfare

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

~ Pablo Casals

Dinner Parties Raise Awareness and Funds

Allen Goldberg and Laurie Strongin deserve our highest praise and gratitude for their most successful "Hope for Henry '97" night, which raised $70,000 for FA research. Allen and Laurie asked friends and relatives in their Washington, D.C. community and throughout the country to host dinner parties for friends on October 18, 1997, in celebration of their son Henry's second birthday. Fifty families agreed to host an event! Each host family showed a videotape about Henry which was dubbed to precede the FARF fundraising video. Guests were asked to make a contribution to the FA Research Fund. After dinner, 500 Washington, D.C. area guests met at Temple Sinai for donated dessert, drinks and great live music.

In addition to the dinner parties, a neighbor held a New Year's Eve "Hope for Henry" party at a local restaurant and bar, and raised $1,700. An employee of *Seventeen* magazine held a fundraiser where they sold donated promotional products and raised about $700. Friends who could not host or attend a dinner were asked to contribute to our Fund. At least 700 donors have contributed already.

Allen and Laurie's fundraiser was promoted on two local TV stations and in numerous local newspapers. Their website got numerous visits due to the coverage. Our heartfelt thanks to this wonderful family, who have done so much to inform the community about Fanconi anemia and who have worked tirelessly on behalf of our cause. ◆

Creative Fundraisers

The three elementary schools in the district where Lynn Sablosky works participated in a "Dress Down Day". Funds for FA research were raised from employees choosing to take part in the relaxed dress code. We appreciate Lynn's willingness to inform her fellow employees about our mission!

Debby Slater added chocolate holiday houses and sleighs to her 1997 Christmas fundraising projects, along with the annual Christmas tree skirt raffle. Debby and her sister, Bev made 52 houses and sold them for $25 each. Each house required 6-7 hours to assemble. This was no easy task, because Debby does in-home childcare with toddlers. While children were napping, Debby prepared chocolate molds and let them setup in her freezer for 2-3 days. Debby's mother contributed her talents to making the Christmas skirt. We appreciate Debby and her family's hard work to raise funds for FA research.

Pat and Maria Gleason and their friends have undertaken an innovative fundraising project with Precision Telecom Systems, Inc. The project involves selling 20-minute long distance calling cards for $10 with $4 going to FARF. When the 20 minutes are used, the card holder may add additional minutes to the card for $.25 per minute and FARF receives $.05 for every minute added. In addition, every time the card holder uses the card, he will hear a message thanking him for supporting the FA Research Fund and to continue supporting this cause by adding time to the card.

If other families are interested in learning more about Precision Telecom's fundraising program, feel free to contact Leslie Roy at the FARF office for additional details. ◆

Chocolate Houses wrapped with Holiday Cheer

Athens' Efforts
continued from page 14

Trenton, one of the small towns, hosts an annual boat race, Roar on the River. Boat races take place over a weekend. As an opening to the event, the Rotary hosts an outside dinner party and raffle, and this year donated the profits to our cause. During the course of the weekend, the Rotary, Riverside Hospital and Loving Care Home Health Care furthered our cause by hosting a Show and Shine Car Show, complete with trophies. Those wishing to view the cars paid a donation to FA. This weekend was not only a lot of fun, we raised $6,000.

The Interact club, a teenage arm of the Rotary also worked for the cause and spent the weekend at the Roar on the River. Club members collected admission to the boat races, and donated the full $1,000 of their profits. And there are those who disparagingly question what has become of our youth!

In August, we were "Cruising' for a Cure" and having a great time. The evening attire was poodle skirts and saddle shoes for the women, and their dates aspired to be either the Fonz or Richie. We had local celebrities and community leaders in attendance, as well as all those family, friends and neighbors who've attended all the other events. We danced the night away, to the donated talents of DJ Erin Jurvis. When we weren't dancing, we were bidding on magnificent auction items which ranged from restaurant and golf certificates to an antique oil painting larger than many walls. The event was catered and the bar was manned. By the end of the evening, profits from the auction and admission totaled $25,000. Happy Days are Here Again!!

The restored Fox Theater in downtown Detroit is a jewel in the city and in our eyes as well, especially after all the assistance it has given FA. In December, the Fox theater hosted the Radio City Music Hall Rockettes. The Rockettes are much more than long legs and pretty faces, they also have big hearts. They gave us reduced rates on 200 tickets to use as a fundraiser. The Fox theater allowed us to host a pre-show party for the ticket holders. They helped to organize a catered meal with soda and wine. Once again, we had a fantastic time while we raised awareness and $10,000.

Our most recent fundraiser involved those creatures which are sought after by young and old alike, the elusive Beanie Babies. Vicki's brother, George Anton, owns a business which handles those desirable animals. As a carrier of this merchandise, he obtained ten of the coveted Princess Diana bears. As many merchants donated the profits to charities, he, too, donated the profits, and chose his nephew's cause, FA. Those purchasing the animals were asked to pay the retail cost of $5.95, and then to write a check to Fanconi Anemia for $500. You can either do the math or we'll just tell you: $5,000.

We have also received donations from family, friends and neighbors. Our fundraising totals have reached $83,000. Special thanks to coordinators Renee Mackay and Karen Mazo. God Bless!

And God Bless you, too, Vicki and Andy Athens!! ◆

Families Exceed the Tiger Challenge

Congratulations all Tiger Challengers! In May of 1997 the Tiger Foundation of New York again 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. Thirty-five FA families and hundreds of their friends contributed a total of $123,843, between June and December, meeting the challenge five months ahead of the deadline. That brings the total to $198,873! With this latest award, Tiger Challenge contributions over the last six years now total $678,843.

FA research has moved rapidly since 1991 with the help of the Tiger Foundation's outstanding philanthropy. See p. 3 for a summary of research projects supported by FARF in 1997. ◆

Editors' Note and Disclaimer

Statements and opinions expressed in this Newsletter are those of the authors and not necessarily those of the editors or the Fanconi Anemia Research Fund. Information provided in this Newsletter about medications, treatments or products should not be construed as medical instruction or scientific endorsement. Always consult your physician before taking any action based on this information.

Joyce Owen Completes Service as Board President

Joyce Owen, PhD, was a founding member of the Board of Directors of the FA Research Fund in 1989. In the fall of 1994, she became Board President, and provided gifted leadership in that capacity for three terms, until she resigned in January 1998.

A molecular biologist by training, Joyce has provided our organization and families with invaluable help. She co-edited the *FA Family Newsletter* and provided editorship and layout design of the *FA Science Letter*. She was a major editor for both editions of *Fanconi Anemia: A Handbook for Families & Their Physicians*, and did the layout for each edition of the *Handbook*. Long before many organizations understood the power and benefit of internet communications, Joyce Owen single-handedly developed and maintained our FA Research Fund Website. She has put our *Handbook*, recent newsletters and science letters on the web. Joyce has edited all our grant proposals, and has been instrumental in obtaining several significant grants.

We hope our readers appreciate the importance of credible connections to the FA research community. Joyce served as liaison between scientists and our organization by arranging countless peer reviews of grant proposals, by her attendance at scientific meetings and by her assistance in interpreting complicated scientific issues to her fellow Board members. She helped plan and organize early FA Scientific Symposia, and has recruited many of the researchers who have served on our Board of Scientific Advisors.

Joyce Owen has demonstrated exemplary service and a selfless devotion to the advancement of FA science. In honor of Dr. Owen's outstanding efforts, the Board formally has named her the first-ever Director Emeritus. Thanks to you, Joyce, for the gift of your abundant talents. ◆

FARF Welcomes New Board Members

We are pleased to welcome Mary Ellen Eiler, Peter von Hippel, Barry Rubenstein, and Ruby Brockett to our Board of Directors. Each brings a wealth of expertise to the Fund and has a strong personal commitment to our mission.

Managing and Editing: Mary Ellen Eiler, 1998 Board President, brings over 25 years of senior level management experience, including her work as a Regional Administrator for Oregon's Services to Children and Families. Most recently, Mary Ellen has served as Superintendent for the Hillcrest Youth Correctional Facility, operated by the Oregon Youth Authority. Trained as a journalist, she has edited university yearbooks and authored several training manuals and guidebooks for lay and professional readers.

Scientific Review: Peter von Hippel is a Professor of Chemistry at the Institute of Molecular Biology and Department of Chemistry, University of Oregon. Dr. von Hippel is a nationally reknowned researcher of protein structure and function. He serves on a variety of top-level peer review boards and program grant committees. We are deeply honored that he is willing to review incoming FA project grant proposals "through the eye of a microscope."

Legal Review and Resource Development: Barry Rubenstein is a law partner in the Oregon firm of Watkinson Laird Rubenstein Lashway & Baldwin. Barry assisted with the original incorporation of the FA Research Fund, and continues to deal with non-profit organizations on a day-to-day business level. Barry is well-versed in the details of how to structure charitable gifts to the advantage of both the client and the organization.

Fund Development: Ruby Brockett is co-owner and a real estate broker for Prudential Preferred Properties in Eugene, Oregon. A winner of many civic and professional awards, including American Business Woman of the Year and Eugene Realtor of the Year, Ruby brings indepth knowledge of the art of successful business development. She is a widely recognized contributor to arts, cultural, and health organizations, holding memberships on the boards of the Eugene Symphony Association, the Boy Scouts of America, the Eugene Education Fund, and the Sacred Heart (Hospital) Foundation.

We Honor Our Benefactors

Central Distributors, Romulus, Michigan
Friends at Charter National Bank, Trenton, Michigan
Damiani and Young, Dearborn Heights, Michigan
Drusilla Farwell Foundation, Michigan
G.D. Searle & Co., Michigan
J. D. Hunter Associates, Gibraltar, MI
Loving Health Home Health Care, Trenton, Michigan
MI Construction, Grosse Ile, Michigan
Monsanta Working Fund, Trenton, MI
Personal Health Care, Taylor, Michigan
SI of Trenton, Trenton, Michigan
Scuba Centers of Michigan
Suburban Services, Inc., Trenton, MI
The Andrew Athens Clinic, Taylor MI
The Branch, Inc., Highland Park, Illinois
Venus Laboratories, WoodDale, Illinois
Ancala Marketing, Inc., Scottsdale AZ
Big Sur Waterbeds, Inc., Englewood, CO
Coosemans-Denver, Inc., Denver, CO
Enron Corporation, Houston, Texas
Leeded Operating Co., Englewood, CO
South Denver Cardiology Associates, Denver, Colorado
Trinity United Methodist Church, McMurray, Pennsylvania
Blue Cross Blue Shield of Oregon
Patricia & William Smullin Foundation, Oregon
The Skanner Foundation, Oregon
Alvino Paving, Boca Raton, Florida
Bowery Lighting & Imports, Inc., Lauderhill, Florida
Children's Orthopedic Surgery Foundation, Massachusetts
Daisey Stable, Inc., Florida
Phoenix Business Systems, Inc., FL
Five Star Travel, Inc., Florida
Bruhall International, Florida
Madison Tire Co., Inc., New Jersey
Platinum Gold Entertainment, Inc., FL
Savetax Accounting, Inc., Florida
Sterling Foster Foundation, New York
O'Sullivan Children Foundation, Inc.
Woodmen of the World, Lodge 78, FL
Curtis Management Corporation, MA
Chittenden Bank, Vermont
Dominion Contracting Company, VA
Amalgamated Transit Union, Oregon
Andersen Construction, Oregon
Asante Health System, Oregon
Associate Oregon Industries, Oregon
Beaverton Toyota Co., Oregon
Capital Chevrolet, Oregon
Centennial Bank, Oregon
Century Designs, Inc., Oregon
Dynamix, Inc., Washington
First American Fund Board, Oregon
Fluhrer Properties, Oregon
Fred Meyer, Inc., Oregon
Freres Foundation, Oregon
Great Western Chemical Company, OR
Hermiston Rotary Club, Oregon
Hilton Hotels Corporation
Hyundai Semiconductor America
Jewish Community Federation, CA
Knecht's Auto Parts, Oregon
Nike, Inc., Oregon
Matrix Development Corporation, OR
Moore Information, Inc., Oregon
Pepsi-Cola Bottling Co., Oregon
National Marrow Donor Program, MN
Neste Resins Corporation, Oregon
Northwest Natural Gas Co., Oregon
Oregon Electric Station, Eugene
Oregon Jewish Community Foundation, Portland
Oregon Medical Association Auxiliary, Portland
Peace Health, Washington
Philip Morris Companies - Employee Matching Gifts
The Roberts Foundation, Oregon
Romania Chevrolet, Oregon
South Umpqua State Bank, Oregon
Spyglass Associates, Oregon
Anthony Stiles Trust, Kansas
Swain Motors, Inc., Oregon
TCI West, Inc., Washington
TMT Development Co., Inc., Oregon
The Hostetter Foundation, Massachusetts
The Marrow Foundation, Washington, D.C.
The Pape Group, Oregon
The St. Paul Companies, Minnesota
The Woodard Foundation, Oregon
Tiger Foundation, New York
Timber Products Sales Co., Oregon
U-Lane-O Credit Union, Oregon
U.S. West Foundation, Oregon
Vic Alfonso Cadillac-Oldsmobile, OR
Wildish Land Company, Oregon
Yost Grube Hall, Architects, Oregon
Saint Timothy School, Pennsylvania
FHCHS, Virginia
Helen Rees Literary Agency, MA
Relevant Knowledge, Georgia
Collins Medical Trust, Oregon
Georgia-Pacific Foundation, Georgia
Louisiana Pacific Foundation, Oregon
Meyer Memorial Trust,Oregon
The Oregon Commmunity Foundation
R. B. Pamplin Corporation, Oregon
Rose E. Tucker Charitable Trust, Oregon
Sandoz Foundation, New York
Donald R. Barker Foundation, CA
Samuel S. Johnson Foundation, Oregon
All Souls Unitarian Church, Oklahoma
Jay Rambo Co., Oklahoma
Huff Ranch, Oregon
Taylor Winfield Foundation, Ohio
The Swig Foundation, California
Maurices Incorporated, Minnesota
Kids Connecton Daycare Center, NY
Albank, New York
Nancy's Hallmark Shop, Ohio
Ethicon Endo Surgery, New Jersey
Mason Entex Activities Committee, Ohio
Seasons Retirement Community, Ohio
Visicon, Inc., Ohio
The Colorado Lottery
Frank Haberle Corporation
Playschool Cooperative Nursery, Inc., NJ
Woodbridge PBA Local #38, NJ
Current Biology Ltd., London
Students of the Lieberman School, NY
The Alex Benjamin Norris Memorial Fund, NY
Tiger Management Corporation, NY
New Hope Services, Indiana
EDS, Texas
McNeil Consumer Products Co., PA
West Alleghany Lions Club, PA
Maspeth Roofing, Inc., New York
Susquehanna Valley Country Club, PA
Charitable Gift Fund, Massachusetts
Flagstar Bank, Michigan
Northern Westchester Center for the Arts/NY

Charitable Air Transport Available

The Alliance of Genetic Support Groups informs us of Mercy Medical Alert, a non-profit charity that offers medical transport programs for patients in the United States.

Through the National Patient Air Transport Hotline (NPATH) patients can be referred to over 45 sources of long-distance air medical transport help. Patients can be flown to and from research or experimental testing programs. Mercy Medical Alert works with Air Care Alliance, an organization of volunteer pilot groups that provides air medical transport for needy outpatients. To contact the NPATH Hotline, call 1-800-296-1217.

We thank the editors of *Alliance Alert* for publishing this helpful information in their September 1997 Newsletter. ◆

New Location for Family Meeting

continued from front page

a picturesque beach on beautiful Lake Geneva, complete with swimming pier and sailboats. The campus has an 18-hole golf course, tennis courts, a full-size gymnasium, shuffleboard, nature trails, and campfire sites. It seems an ideal location offering many of the features we enjoyed at Camp Sunshine, plus a few more.

We will meet from dinner on Tuesday, August 25 through breakfast Sunday, August 30. The program will include a variety of speakers over our four-day stay, along with a children's program during the parents' sessions. Afternoons will be free for family fun and relaxation. We will provide some of our favorite evening activities such as the talent show, masquerade party and possibly Karaoke. Registration forms have been sent to families in our family support group and must be returned by March 15, 1998.

We hope all families will join us this coming August in Wisconsin! ◆

Legal Help for Insurance Problems

Have you experienced problems in securing insurance coverage for a marrow transplant? The November 1997 issue of the *Blood & Marrow Transplant Newsletter* describes the successful battle by Chicago lawyer Art Gorov to obtain insurance coverage for a cancer patient awaiting a stem cell transplant after her insurance company had denied approval for the procedure.

Skilled attorneys who are experienced in handling insurance problems can be reached through the *Blood and Marrow Transplant Newsletter's* attorney referral service. Phone 847-831-1913, or access the service through the Internet at: <http://www.bmtnews.org>.

We thank the BMT Newsletter for this information and service. ◆

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 fund-raisers and mailings.

FANCONI ANEMIA
RESEARCH FUND, INC.

1902 Jefferson St., #2
Eugene, OR 97405
phone: (541) 687-4658
(800) 828-4891 (USA only)
FAX: (541) 687-0548
e-mail: fafund@rio.com
website: http://www.rio.com/~fafund

Newsletter Editors
Lynn & Dave Frohnmayer

Layout and Design
Tanya Harvey, Wild Iris Design

WE THANK THE FOLLOWING DONORS:

Printing
Image Masters Printers
Unisource Paper Co.

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