

# FA FAMILY NEWSLETTER

#37

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Spring 2005

## Fanconi Anemia Scientific Symposium

The Sixteenth Annual Fanconi Anemia Research Fund's Scientific Symposium was held from October 14-17, 2004, at the Hyatt Regency Hotel in Cambridge, MA. One hundred ninety-four researchers from 61 research institutions and universities attended this meeting. Scientists came from Brazil, Canada, Costa Rica, France, Germany, India, Israel, Italy, Japan, Spain, Switzerland, The Netherlands, Turkey, the United Kingdom, and the United States. Ten FA family members also attended this meeting.

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*Kevin Hiom listens to Steve Meyn respond to his question in the FANCD2 Session Forum.*

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## FA Gene Discovered; Unusual Characteristics Described

At our recent Scientific Symposium, Marieke Levitus, Vrije Universiteit Medical Center, Amsterdam, announced that her laboratory, in collaboration with other centers, has cloned yet another FA gene, *FANCB*. To date, scientists have isolated 9 FA genes (A, B, C, D1, D2, E, F, G, and L). There are at least three additional complementation groups for which the FA gene has not yet been isolated.

FA-B is a rare complementation group; only 4 FA-B patients have been identified to date. The function of this gene is not known. What makes this gene unusual is its location and mode of inheritance.

*FANCB* is on the short arm of the X chromosome. All known patients are males. FA-B patients receive their disease-causing chromosome from their mother; the father (unless he is also an FA patient) plays no role in the inheritance of *FANCB*. Each son of a carrier mother has a 50% chance of inheriting this disease; each daughter has a 50% chance of being a carrier. Genetic counseling is of particular importance to FA patients and their families in FA-B. For example, all females in the family should be tested for carrier status, due to the 50% chance that their male offspring will inherit this disease. ♦

## Zebrafish as a Model for Understanding FA

Tom Titus, PhD, University of Oregon, discussed the zebrafish as a model for understanding and testing therapies for FA. In several ways, zebrafish appear to be an ideal animal model. The zebrafish genome is very similar to the human genome. Zebrafish offspring become sexually mature in only three months; they produce a large number of offspring, and zebrafish embryos are transparent. Titus's lab has identified 8 FA genes and several associated genes in zebrafish. Comparison of zebrafish FA proteins to those of humans reveals tremendous similarity. Data strongly support the hypothesis that major components of the zebrafish FA gene network have been conserved for the 450 million years since the divergence of the zebrafish and human beings. Titus believes that zebrafish may prove a useful model for testing the therapeutic potential of small molecule compounds. ♦



Tom Titus, PhD

## Progress in Assigning Patients to Specific Complementation Groups

Helmut Hanenberg, MD, Children's Hospital, Düsseldorf, Germany, reported on his five-year effort to place 378 FA patients in their appropriate complementation groups. To date, his laboratory has determined the complementation group for 333 FA patients. Twenty are "in progress," and 25 patients (6%) cannot yet be assigned to a known complementation group. Hanenberg is exploring different candidate genes to determine if they account for FA in these unclassified cell lines. ♦

## Can the FA Pathway Work in the Absence of Functioning Genes?

Two researchers are exploring the hypothesis that it might be possible to restore function to the FA pathway even in the absence of normal or functioning FA proteins. Both stated that their work might suggest a novel therapeutic approach to FA.

Researchers have established that a group of FA proteins works in a common pathway and that this pathway functions to repair damage to DNA. Upstream FA proteins (FANCA, FANCB, FANCC, FANCE, FANCF, FANCG and FANCL) are all necessary to activate a downstream FA gene, *FANCD2*, and to complete a process called "monoubiquitination." Once activated, *FANCD2* plays a role in

DNA repair.

Akiko Shimamura, MD, PhD, Dana-Farber Cancer Institute, Boston, constructed a fusion protein (D2-ubi) that mimicked the process of "turning on" *FANCD2* and discovered that D2-ubi was able to protect cells from chromosomal damage, even when an upstream FA protein was not working. This fusion protein is less efficient than the protein formed when *D2* is functioning normally, but it restores at least partial function to the FA pathway.

Toshiyasu Taniguchi, MD, PhD, Fred Hutchinson Cancer Research Center, Seattle, reported that he is beginning to test small molecule compounds to determine if one or



Toshiyasu Taniguchi, MD, PhD

more of them can activate the FA pathway, even in the absence of one of the FA proteins. ♦

## Memorial Sloan-Kettering Performs High Risk FA Transplants

Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, reported on sixteen FA transplants done at his center between 5/98 and 8/04. Nine patients had related mismatched donors and 7 had unrelated donors, with varying degrees of mismatch. High-risk features for these patients were as follows: Four patients were older than 20. Eleven were previously heavily transfused, and 12 had received oxymetholone prior to transplant. Five patients had myelodysplastic syndrome, and 5 had leukemia at

### Patients with *BRCA2* (*FANCD1*) Mutations Have Poor Prognosis

Margaret MacMillan, MD, University of Minnesota, reported on the status of 14 FA patients with mutations in *BRCA2* (*FANCD1*). Of these 14, six developed leukemia at an average age of only 2.2 years (compared to age 13 for all FA patients). Five died at early ages from brain tumors (medulloblastoma), and three had a Wilms tumor, a cancer of the kidney.

Six of the *BRCA2* patients underwent a bone marrow transplant. All were very young at the time of transplant. Five had leukemia: three had acute myelogenous leukemia (AML); two acute lymphoblastic leukemia (ALL). Only two patients survived transplant; both were treated with busulfan instead of total body irradiation and both had ALL at the time of transplant.

Dr. MacMillan advises that patients with *BRCA2* mutations need to be transplanted very early in the course of this disease and prior to the onset of leukemia. All must be screened for malignant tumors prior to transplant. ♦

the time of transplant, including 6 patients with chromosome 7 abnormalities. Two were severely infected at the time of transplant, and ten had a history of infections pre-transplant.

Preparation for the transplants included irradiation, fludarabine, cyclophosphamide, anti-thymocyte globulin and tacrolimus (FK506). Transplants were all T-cell depleted. Stem cells were derived from peripheral blood stem cells (PBSC) for 13 patients and bone marrow for 3 patients.

Twelve of 16 patients (75%) were alive an average of two years post-transplant; 11 of 16 (69%) are alive and disease-free. Patients experienced little to no graft-versus-host disease. Complete immunologic recovery was 6-11 months for 6 patients who received mismatched PBSC grafts and 9-15 months for recipients of



Farid Boulad, MD

marrow grafts. Two patients died from recurring infection, and 2 died from relapse of leukemia. ♦

### Antibodies Now Available Against Eight FA Proteins

To encourage research into FA, the Fund has sponsored the development of antibodies against eight of the FA proteins. Ray Monnat, Jr., MD, University of Washington School of Medicine and a member of the Fund's Scientific Advisory Board, spearheaded this effort.

The antibodies were developed with a commercial partner, Open Biosystems in Huntsville Alabama. Antibodies against six of these proteins (FANCC; FANCD1/*BRCA2*; FANCD2; FANCE; FANCF; and FANCG) are now available for distribution to all qualified investigators to further our understanding of Fanconi anemia biology. We anticipate antibodies for FANCA and FANCL will be available shortly.

The Fund has contracted with Oregon Health and Science University through the laboratory of Markus Grompe, MD, to manage the FA Antibody Project, in conjunction with the FA Cell Repository already housed at OHSU. Sean Baker, PhD, is in charge of this project.

The antibodies listed above are available to all qualified non-commercial Fanconi anemia investigators at no charge, except for shipping. Commercial users may also arrange to purchase the antibodies through a distribution agreement with Open Biosystems. Information about the FA Antibody Project is available at <http://www.ohsu.edu/genetics/fa>. ♦



*Wolfram Ebell, MD*

## Minnesota Reports on Unrelated Donor Transplants

Margaret MacMillan, MD, reported on the outcomes of 45 unrelated donor transplants performed at the University of Minnesota Transplant Center. Almost all engrafted and very few experienced acute or chronic graft-versus-host-disease. Fourteen patients were considered “high risk” prior to transplant. These patients had experienced a gram negative or fungal infection, had acute myelogenous

leukemia, or were over the age of 18. Only 18% of these patients survive. Of the 31 patients considered “standard risk,” survival was 65%.

Transplanters are now enrolling FA patients in a new protocol that includes shielding of the thymus during irradiation. They are hopeful this procedure will hasten reconstitution of the immune system, giving patients an earlier defense against infections. ♦

## Transplant Results in Germany

Wolfram Ebell, MD, Charité Hospital, Berlin, reported on 16 unrelated donor transplants performed at his center using fludarabine, low-dose busulfan, and a non-irradiation protocol. Of 16 patients, 10 survive. Survival was better in younger patients (<10 years), in patients prior to onset of leukemia, and in those receiving non T-cell depleted bone marrow (compared to peripheral blood stem cells). The presence of abnormal clones without acute myelogenous leukemia (AML), transfusions or use of androgens did not affect outcomes. Ebell concludes that his protocol enables approximately 60-65% of patients to survive an unrelated donor transplant. ♦

## All Patients with Matched Sibling Donors Survive Transplant Protocol

Margaret MacMillan, MD reported on the outcomes of 14 matched sibling donor transplants at the University of Minnesota. Transplanters eliminated irradiation as part of the conditioning protocol and used cyclophosphamide, fludarabine and T-cell depletion. All patients engrafted; none suffered any toxicity; and 100% survive an average of two years post transplant. These stunningly good results suggest that irradiation may not be necessary when performing matched sibling donor transplants. ♦

## Outcomes of Matched Sibling Donor Transplants at Cincinnati Children’s Hospital Medical Center

Richard Harris, MD, Cincinnati Children’s Hospital Medical Center (CCHMC), Cincinnati, reported on 36 matched sibling donor transplants performed at CCHMC, with a median follow-up of 6.4 years. The Cincinnati group used thoraco-abdominal irradiation and low dose cyclophosphamide in this population of children. Thirty-five of 36 patients engrafted, with survival in 29 patients. Five patients developed significant acute GVHD (grades II-IV); four patients had chronic GVHD

(three extensive). Two patients developed squamous cell carcinoma 6 and 15 years following transplantation. One patient developed acute myeloid leukemia twelve years post-transplant and died following a second transplant.

These results demonstrate a high degree of donor engraftment and long-term survival. Future plans include the investigation of preparative regimens without radiation for patients receiving matched sibling donor transplants. ♦

## Outstanding FA Transplant Results Reported from Japan

Hiromasa Yabe, MD, Tokai University School of Medicine, Japan, reported on the outcomes of 29 FA transplants performed in Japan from August 2000 to February 2004. Many different variables make it difficult to compare these results with those reported elsewhere. Nonetheless, it is impressive that of 29 patients, 28 survive.

Several Japanese hospitals performed these transplants. Five patients had matched related donors (4 siblings, 1 mother); 24 had alternate donors (2 mismatched relatives,

13 unrelated matched donors, and 9 unrelated mismatched donors). Patients with alternate donors were given irradiation; those with matched sibling donors were not. Twenty-two patients had aplastic anemia; 7 had more advanced disease.

One patient died of infection. Seven developed acute graft-versus-host disease (GVHD); eight had chronic GVHD. Survivors are disease-free 4 to 46 months post-transplantation. ♦



*Hiromasa Yabe, MD*

## Physician Responds to Parent's Questions

Blanche Alter, MD, MPH, responded to a parent's questions posed on our FA listserv:

- 1) *If an FA patient has a successful bone marrow transplant, is he or she still at risk of developing malignancies in early adulthood?*

The high risk of early malignancies (solid tumors) in FA will not be decreased by transplant. Our analysis of transplanted patients (using the older regimens including irradiation and cyclophosphamide) indicated an increased risk of oral cancers following transplant. This was in patients who had graft-versus-host disease (GVHD). It is hoped that newer transplant methods where there is less GVHD may not have this higher risk of oral cancer. However, the best one might imagine is that the risk following BMT is the same as in untransplanted FA patients, not a lower risk.

- 2) *Is there a correlation between the severity of birth defects of an FA child and the severity of his or her bone marrow failure?*

We have found a correlation between severity of birth defects and early onset of bone marrow failure. This is a statistical relationship, not a guarantee. The handbook, *Fanconi Anemia: Standards for Clinical Care*, provides guidelines for monitoring, and most of us think these should be followed for all FA patients. Lack of birth defects is clearly NOT a guarantee that the bone marrow function will be normal. Statistics provide probabilities for large groups, but cannot be used to make guarantees for individuals.

- 3) *Is it always possible to do PGD (Preimplantation Genetic Diagnosis) for FA?*

PGD can be done if the FA gene (complementation group) is known in the family. It is easiest and most reliable if the exact mutation has been identified, although there are some other approaches that may be possible in sophisticated laboratories, if the gene is known but the mutation cannot be proven. ♦

## Monnat, Joenje, Surralles, and Bueren Receive Awards

At the Presenters' Dinner at the FA Scientific Symposium in October 2004, Dave Frohnmayer, vice-president of the Board of Directors of the Fund, presented the *Distinguished Service Award* to Ray Monnat, Jr., MD, University of Washington School of Medicine.

In presenting the award, Frohnmayer highlighted the immense contribution made by Monnat through his leadership of the FA Antibody Project. Because of Monnat's work on this project, antibodies are now available without cost to researchers studying FA. Frohnmayer expressed the gratitude of the Board of Directors of the Fund for Monnat's tireless work on the Fund's Scientific Advisory Board, noting that Monnat clearly sees his membership on the Board as a call to do what he can, as rapidly as he can, to find a cure for the patients who are in the grip of this deadly disease.

Frohnmayer also bestowed *Awards of Appreciation* on Hans

Joenje, PhD, Free University Medical Center, Amsterdam, and Jordi Surralles, PhD, University Autònoma de Barcelona, Spain, for their leadership in organizing the *Juan Marche Molecular Cross Talk among Chromosome Fragility Syndromes* conference in Madrid in February 2004. Because of their initiative, worldwide experts in DNA repair came together at this meeting to share the results of their research and to collaborate with one another, thereby advancing the progress of FA research.

Finally, Frohnmayer bestowed *Awards of Appreciation* on Jordi Surralles and Juan Bueren, PhD, CIEMAT/Marcelino Botin Foundation, Madrid, for their initiative in organizing the second annual *Spanish Symposium on Fanconi Anemia* in



Dave Frohnmayer presenting the *Distinguished Service Award* to Ray Monnat, Jr., MD

November 2004 in Barcelona. This meeting provided a venue for over 100 clinicians and researchers to collaborate and share the results of their research with one another. Of equal importance, the *Symposium* provided an opportunity for over 40 Spanish FA families to learn more about FA and to get to know one another. ♦

### 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.*

## A Novel Method of Gene Therapy

Meenakshi Noll, PhD, of Oregon Health Sciences University, discussed research into a new, non-viral approach to gene therapy. She noted that while gene therapy has been successful in the mouse model, its use in FA patients has been complicated by the scarcity of hematopoietic stem cells and the need to manipulate these fragile cells outside of the body (*ex vivo*).

Using a special method called the "Sleeping Beauty" transposon system to carry normal genes into early blood cells, researchers were able to

get normal genes into bone marrow cells of mutant mice by 1) electroporation into whole bone marrow and 2) direct injection into the femur cavity of the mice. After one week, a single dose of cyclophosphamide (CPA) was given to provide a selective advantage to the corrected cells. Four weeks after CPA administration, all animals were strongly positive for the corrected gene, and remained so for at least nine months.

Additional studies will further determine the usefulness of this method for FA patients. ♦



Wade Clapp, MD

## Gene Therapy Study Shows Early Success

Wade Clapp, MD, Indiana University School of Medicine, and Helmut Hanenberg, Düsseldorf, Germany, are collaborating on a gene therapy study which utilizes a “helper-free human foamy virus” (HFV) to deliver a normal gene into early progenitor cells. Extensive manipulation of FA cells outside of the body leads to cytogenetic abnormalities and a propensity to develop leukemia. The advantage of the HFV is that this virus can transduce mouse cells in the absence of pre-stimulation outside the body. Following a single overnight HFV

infection, 40-80% of mouse progenitor cells were transduced with the normal gene. Four months after transplantation, bone marrow cells functioned like normal cells. These data show that HFV is an efficient vehicle for achieving gene correction in mice. ♦

### Use of Logo

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 and helps to avoid legal complications. We are happy to collaborate on fundraisers and mailings.

## Emotional Needs of the Healthy Sibling

Sadie Hutson, PhD, RN, National Cancer Institute, interviewed seven siblings of FA patients, in an effort to understand the special emotional burdens experienced by this population. She concluded that the siblings’ experience was defined by four major dimensions:

### 1) Containment

Parents are given a great deal of information about this illness, but siblings are often left out of this process. They experience isolation and withdrawal instead of inclusion and understanding.

### 2) Invisibility

Siblings stay busy, get involved in caretaking and protecting, and engage in “people-pleasing” as a way to avoid conflict and gain approval, but their own feelings and issues go unrecognized; their self-identity is compromised.

### 3) Worry

Siblings worry about how their friends perceive the family’s problems; they worry about the health of their sibling and the future of the family.

### 4) Despair

Siblings experience sadness, jealousy, loneliness, abandonment and uncertainty.

Hutson concluded that siblings may experience significant emotional consequences due to their brother’s or sister’s illness. More attention should be given to the emotional needs of this largely unnoticed special population. ♦

## Gene Therapy Trial Begins in Cincinnati

David Williams, MD, Cincinnati Children’s Hospital Medical Center, provided an update on the gene therapy trial that opened in Cincinnati in November 2004 (see *FA Family Newsletter* #36 for details concerning this trial). One FA-A patient has been treated to date. This patient has experienced no toxicity, but it is still too early to evaluate the effectiveness of the therapy.

Cincinnati continues to enroll FA-A patients in this trial and hopes to open a trial for FA-G patients by this summer. Williams believes that it is likely to be 18 months to two years before his center is able to offer a trial to FA-C patients.

If you have questions about this trial, call Dr. Williams at 513-636-0364. ♦

## Your FA Research Dollars at Work in 2004

In 2004, the Fanconi Anemia Research Fund awarded \$854,157 in research grants to the following projects:

Investigator: Jakub Tolar, PhD, and Bruce Blazar, MD, University of Minnesota School of Medicine

Title: *In Vivo Human Hematopoietic Stem Cell Transgenesis by Transposition*

Amount: \$98,622

Investigator: Maureen Hoatlin, PhD, Oregon Health & Science University

Title: *Functional Analysis of FA Pathway*

Amount: \$152,000

Investigator: Anna Petryk, MD, University of Minnesota School of Medicine

Title: *Glucose and Insulin Abnormalities in FA*

Amount: \$12,371

Investigator: Patrick Kelly, MD, Cincinnati Children's Hospital Medical Center

Title: *Hematopoietic Cells from Patients with FA for Future Autologous Reinfusion and Research*

Amount: \$50,000

Investigator: Madeleine Carreau, PhD, Laval University, Quebec

Title: *Characterization of FANCC Proteolytic Fragments*

Amount: \$21,750 [Fanconi Canada matched this amount.]

Investigator: John Postlethwait, PhD, University of Oregon

Title: *A Zebrafish Model for FA*

Amount: \$88,242

Investigator: Johnson Liu, MD, Mount Sinai School of Medicine

Title: *Supplemental Funding*

Amount: \$36,817

Investigator: Uma Lakshmiathy, PhD, and Catherine Verfaillie, MD, University of Minnesota School of Medicine

Title: *FANCC Gene Correction Mediated by PhiC31 Integrase*

Amount: \$86,400

Investigator: Hans Joenje, PhD, Vrije Universiteit, Amsterdam, The Netherlands

Title: *Cloning and Partial Characterization of FANCI and FANCI*

Amount: \$129,597

Investigator: K. J. Patel, PhD, University of Cambridge, United Kingdom

Title: *A Proteomic Genetic Approach to Defining the Precise Enzymatic Function of the FA Nuclear Complex in DNA Repair*

Amount: \$118,022

Investigator: Luca Pellegrini, PhD, University of Cambridge, United Kingdom

Title: *The Structural Basis for the Biological Role of FANCG in Homologous Recombination*

Amount: \$60,336

## Fanconi Anemia Scientific Symposium

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Highlights of the Symposium included the presentation of the X-linked inheritance of the *FANCB* gene by the laboratories of Hans Joenje, PhD, Free University, Amsterdam; Weidong Wang, PhD, National Institute on Aging; and Maureen Hoatlin, PhD, Oregon Health and Science University.

Forty-six researchers made oral presentations on the topics of *Apoptosis; FANCD2; Model Organisms and Systems; DNA Damage Responses and Repair; Complementation Groups; Bone Marrow Transplantation; and Experimental Therapeutics*. Additionally, 58 researchers presented their research results during poster presentations.

At the conclusion of the meeting, Grover Bagby, Jr., MD, Oregon Health and Science University and the chair of the Fund's Scientific Advisory Board, chaired a general session entitled *Planning for the Future*, based on the research presented at the meeting.

The evaluations of the Symposium, which are used by the Fund's Board of Directors and Scientific Advisory Board to plan the next Symposium, were uniformly excellent, with many researchers citing this Symposium as "the best ever." ♦



# FAMILY NEWS



*Kira Janock with her "lock of love."*

## A Sister's Love

Kira Janock's older sister, Carrie, died of Fanconi anemia at age eight in 1999. During Carrie's short life, Kira saw her endure the medical treatment involved with this disease, including a bone marrow transplant during which Carrie lost her hair. Shortly thereafter, Kira decided that when her hair grew long enough, she was going to donate her hair in honor of Carrie to an organization called Locks of Love, a Lake Worth, FL, organization which provides wigs for patients who have lost their hair. Finally, when Kira reached eleven, her beautiful hair was long enough that she could donate ten inches of it to Locks of Love.

As reported in *The Palm Beach Post* by Michelle Mundy, "Kira... hasn't forgotten how much Carrie meant to her. 'She was nice,' Kira said through tears. 'She was my closest friend. Sometimes we'd fight, but then we'd always get along... I miss her so much.' Kira's mom stood by her beaming with pride and tears. 'This is probably the biggest and best thing she's ever done in her life, and she's done a lot of good things,' she said. Kira thinks of her sister, and it doesn't take her long to imagine what Carrie would think of her deed. 'She would say you are doing such a good thing and to keep up the good work.'" ♦

## Celebrating Reid

*by Susan and Mark Trager*

On January 16, 2005, our children Lauren and Drew, ages 12 and 14, threw a birthday party for their brother Reid. Reid passed away February 27, 2004. In the spring, as we were mourning Reid's loss, we realized that his birthday was never going to be the same. Reid loved holidays and, especially, his birthday. The kids thought it would be great if we continued his tradition of throwing a bowling party to celebrate his birthday and raise money for Fanconi anemia. That was the inception of Reid's Bowling Bash, Strike Out Fanconi Anemia.

Lauren and Drew began the process of the fundraiser by meeting with the bowling alley event planner, who was very willing to help. They sent letters to family and friends, asking for event sponsors and lane spon-

sors. A bowling committee was formed by our friends to help with their efforts. It did not take long for each lane to be sponsored, and the bowling party to be sold out. Red and yellow T-shirts, Reid's favorite colors, were designed with a logo and list of sponsors.

On Sunday, January 16, 250 birthday guests celebrated Reid's birthday. The bowling alley was a sea of red and yellow T-shirts, and everyone had a wonderful time. During the party we showed a video of all sixteen of Reid's birthday parties. The video showed a child who loved life and enjoyed every one of his birthdays.

The event was a great success in more ways than one. It allowed us to celebrate Reid's 17th birthday with our family and friends, helped our



*Reid Trager at the bowling alley*

family get through a difficult day with a positive outcome, and raised funds to aid in finding a cure for Fanconi anemia. Lauren and Drew say, "This is one bowling party Reid would be proud of!" The kids hope to make this a yearly event. ♦

# Life as an Adult FA Patient

by John Hanna

I am 32 years old, living with FA. I was born with the usual birth defects associated with FA: short stature, absence of thumbs, etc. I was diagnosed at the age of seven through the chromosomal breakage test. Growing up with FA was difficult, to say the least. It was tough being the shortest kid in school, as everyone wanted to be a bully. I began Tae Kwon Do. I developed a lot of self confidence and the ability to defend myself when picked on. I didn't need it a lot, but I'm glad I had Tae Kwon Do on the occasions when I did. I earned my black belt at the age of twelve.

At age ten my platelets gradually got lower and lower until they bottomed out at around 30,000. If they had plunged any lower, I would have needed transfusions. Without treatment, they began slowly to start climbing back up.

At age 15, I was told by a hematologist not to expect my increase in platelets to last and that, realistically,

I'd be dead by the age of 21. I know it's hard to believe that a doctor actually would tell a patient that, especially a teenager, but that's exactly what he told me and my folks. The next couple of years were tough for me, as I was always thinking in the back of my mind that I was going to die soon, so I wondered why things like school even mattered. And girls? Forget about it. I was a shrimp. I had virtually no self confidence when it came to girls. During my senior year in high school, I was only 4'6" tall and had such low self esteem that I didn't go to the Prom, didn't have senior pictures made or do much of anything that normal kids did.

I'd like to fast forward to now. I'm almost 33 years old. I'm married with a ten-year-old stepdaughter and a

two-year-old biological daughter. As an adult, I have changed a lot in my thinking and in how I deal with FA. I'm one of the lucky ones who has not had a lot of medical problems associated with FA. I've never had a

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*John Hanna and family*



*Aaron and Sarah Shelson*

## Living with FA as a Sibling

by Sarah Shelson

My brother, Aaron, was diagnosed with Fanconi anemia soon after he was born. I don't remember how my parents told me about the disease. It was just something that was always there. When I was younger, I don't think I understood how severe the disease was. We had to be careful around Aaron, but he was still fun to be around.

I learned about the disease over the years from my parents and from going to Camp Sunshine. I think the hardest part is when we hear that another person has died of FA. That brings it right home and reminds us

how lucky we were that Aaron survived his transplant. It was tough seeing him during his transplant when he was hooked up to the IV, with all those bags and his central line, and so many ways for it to go wrong.

My parents are great. They always answer any question I have truthfully. They explain things so I understand. They don't come to me to talk about it, but I don't feel afraid if I have to talk with them. I know that whatever happens, they will always be there. Having Aaron in our family and seeing other FA kids makes me appreciate how special life is. ♦

# Nine Years After Bone Marrow Transplant, Ed Brookover is Ready to Graduate from College

by Ed and Barb Brookover

After receiving our son Ed's initial diagnosis of Fanconi anemia, our reaction was likely the same as most parents: Can he live a normal life? How can we possibly deal with this? What is the real prognosis?

That was January 1988. Fast forward to 2005. Ed is a senior at James Madison University. He will graduate in May with a degree in Marketing/Information Systems. More importantly, he is on no medications, his blood counts are normal, and he currently has no health problems.

Ed was diagnosed when he had a low platelet count at his physical at age five. We then started weekly trips, that would continue for seven years, to our hematologist. His counts did not begin to drop until he contracted chicken pox in second grade. Shortly after the chicken pox, he began taking oxymetholone to improve counts.

The oxymetholone worked well for just over four years. We kept an eye on his liver and manipulated his dosage a few times to avoid liver damage. But eventually the steroid treatment stopped working, and his counts once again began to drop.

Other treatments did nothing to improve Ed's counts. We had decided that, once treatments stopped working, we would move quickly toward a bone marrow transplant. Ed had received only one transfusion, and we wanted to transplant before he became transfusion dependent.

We started looking for a match in the fall of 1995. No matches were found in any of the registries in the United States. However, one match was found in an overseas registry. (Ed met his donor in Germany in

1999, but that is a whole other story.)

In March of 1996, we headed to the University of Minnesota for his transplant, staying in the Ronald McDonald House during Ed's stay in the hospital and his outpatient treatments. Ed has virtually none of the physical problems often associated with Fanconi patients. Except for his low counts, you would not have known he was facing such a deadly disease. In fact, he played in a basketball game the day we left for Minnesota. Looking back on it, Ed's transplant was relatively problem-free. He received his transplant on March 28, 1996. Blood counts began appearing on about day 11. He was out of the hospital for the first time 21 days after his transplant.

Ed did have to go back into the hospital two times for low-level graft vs. host disease and, later, for an infection. However, his counts progressed well, and we left Minnesota on July 4, 100 days after transplant. He progressed amazingly well. His counts increased quickly toward the normal range. By January 1, 1997, Ed was ready to go back to school full time and, amazingly, was off all his medications.

We know how fortunate Ed has been every step of the way—in how he responded to steroid treatments while progress was made with unrelated BMTs; how he remained relatively healthy even while fighting this disease; how smoothly his transplant went; and how he is now leading a life almost exactly like any other college senior. We all know Ed has to keep an eye on his health as he moves forward with his life.



*Ed Brookover*

The research provided by the Fanconi Anemia Research Fund was an important part of each of the decisions we made throughout Ed's ordeal. The support we received from the staff at the Fund and the families in the Fanconi group provided us with strength and sustained us during many of our dark days.

We count our blessings every day. We hope Ed's story will help others as we all continue the fight against this evil disease. If anyone would like to talk more about our experiences, please give us a call. And, most of all, keep searching for answers and fighting for your child's health. ♦

# Fanconi Life is a Special Life

by *Miriam Behers*

I am 38 years old and have been married almost 14 years, with a seven-year-old son and a precious four-month-old preemie angel who passed away December 26, 2003.

I was diagnosed with Fanconi anemia at age four, the only one to have FA in my family. I have three sisters and one brother. One sister is a perfect bone marrow match for me. I have been stable for so long that a bone marrow transplant is out of the question.

I take oxymetholone, 50 mg., every other day; prednisone, 5 mg., every day; and just started Fosamax, 70 mg., once a week. I also have avascular necrosis of my left hip and will require a hip replacement in the near future.

I see my doctor about every three months, depending on my blood counts, which have been stable. My

platelets are about 127,000. I don't have restrictions on what I can do, other than what my leg allows due to pain and limited mobility. I also see the gynecologist frequently, due to having a procedure done to remove a portion of my cervix. I had a condition which could have led to cervical cancer.

I like to shop and watch HGTV, along with interior design shows. I would like to have my own home interiors store one day. I don't think of my FA on a daily basis until my leg is in pain. I don't let it keep me down because I know that, even though I have FA, I have a purpose in life. I was especially chosen to live with FA. My life on earth is a special one with a significant meaning that I may not understand, but God does. So, I have to keep my faith, as hard as it may be sometimes, and trust in



*Miriam Behers*

Him. Because of FA, I am who I have become, someone who is special and full of compassion. I am grateful just to be here. ♦

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## Life as an Adult FA Patient

*continued from page 10*

transplant and never been on any medications for bone marrow problems.

I wish I had my childhood and teenage years to do over again in some aspects. I would go back and tell myself not to let what other people think get to me. It's okay to be short and to look a little different. As long as you are yourself, eventually people will come to accept you for who you are. I wish I could go back and tell myself at age 15 that I needed to remain hopeful. When that doctor gave me my grim prognosis, I lost all hope and all faith and just kind of gave up on life and crawled into a shell. The fact is that nobody knows

what's going to happen or what the future holds. Not even doctors.

I have so many other concerns now as my main focus shifts from bone marrow failure to cancers of the head and neck. I've got two kids that I'm trying to raise, and I want to see my two-year-old grow up. I've got a wonderful wife whom I love very much, and I'm constantly worrying about getting sick and leaving her alone with two kids to raise. And, the thought of me not being there to watch my kids grow up, get married, and have kids of their own is almost more than I can take sometimes.

But the bottom line is that tomorrow is not promised to anyone, even those not afflicted with FA. Whether we are kids or adults with FA, we still have to live life to the

fullest and with as few regrets as possible. Somehow you still have to find a little bit of hope and faith that things will be okay. ♦

## Donations

Donations may be made to the Fanconi Anemia Research Fund, a 501(c)(3) organization, as follows:

**Online:** Look for the Donations link on our home page ([www.fanconi.org](http://www.fanconi.org)).

**Telephone:** Call us at (541) 687-4658 or toll free (800) 828-4891.

**Mail:** 1801 Willamette Street, Suite 200, Eugene, OR 97401.

# Eulogy for Nicole Levine

by Todd Levine

In her six short years, Coley became what every parent dreams of, and yet, in some ways she became what no child should ever be. She was an energetic little girl who enjoyed all of the precious gifts of life. Though short in stature, she was long in attitude and spunk. She had a doting older sister, Marissa, who patiently coddled and protected her—no matter how much Nicole battled her for the title of Sibling-in-Charge. She had a handsome baby brother, Travis, who, despite their two years age difference, became like her twin as she deviously molded him to be her partner-in-crime. Her beautiful smile and cute little voice warmed the souls of all who knew her. As a gymnast, soccer and T-ball player, she danced and played aimlessly with a beautiful innocence. She jumped with reckless abandon on her trampoline, teaching the older kids how to do front-flips. She loved to sing and dance around the house. She rooted for her beloved Red Sox and Patriots teams. Coley was always at her happiest when playing in the yard with siblings and friends, riding her toy Harley Davidson, enjoying weekends in New Hampshire on the beach and in the boat and, above all, holidays and special occasions spent with her many cousins.

These are the images and memories that all parents cherish as they watch their child grow. This is what every parent dreams of, what every parent expects. Along with the joys of her childhood, however, came the burden of her illness, becoming wise beyond her years, and playing an inspirational role to us grown-ups. What no child should ever have to be.

Nicole, you were burdened with the Perfect Storm of medical misfortunes. Any adult, much less a child, would have been justified in wishing for the rough waters to mercifully and quickly take their toll. You, however, smirked at the storm, reached for a surfboard, and rode the wave of your life. Along the way, you taught so many people the truest meaning of courage, bravery, resilience, humility and, indeed, life. Instead of being a little girl in search of heroes, you became a hero to so many.

In life, you were given a bucket of lemons and, with your spirit, you manufactured a lifetime supply of sweet lemonade for all of us to drink from each time we remember your smiling face and silly ways. Faced with living away from home for 9 months to fight your leukemia, you took New York by storm. You turned the Ronald McDonald house into our own little playland, making up silly games to make your chores fun. Central Park became your backyard, with the ducks your personal pets. At the hospital, where weeks of continuous isolation in your room were no big deal, you stole the hearts of all the nurses, doctors, and volunteers with your humor and commanding presence. In another example of role reversal, it seemed the volunteers came to see you so THEY could laugh, and doctors and nurses visited more often than was required so that THEY could feel a little better about their day. In times when you and your sick body needed so much from them, your spirit gave back so much more. How it used to make us smile during your chemo treatments when we'd ask you "How are you feeling" and your response



Nicole "Coley" Levine

would be "Good. How are YOU doing?" Or when we'd cringe when telling you that the blood work today was going to be a finger-stick instead of drawing off your lines, you'd say "that's okay, it'll be over in a snap-and-a-clap."

Rare is it in this world that those who would be students become the teacher. Yet, for those of us privileged to have watched you gracefully navigate this lifelong storm, and for those who followed you through your journals, we cannot help but be better, stronger, and more compassionate people from your lessons. With your magnetic personality and courageous spirit, hundreds of people became "hooked on Coley" during your fight. Not because your journal was a good read. Rather, it was because the girl behind the story was so wonderfully brave and inspirational. We can safely say that no child has touched the hearts of so many in such a short period of time. We are ever so proud to proclaim you as OUR daughter.

*continued on page 14*

# Charlotte Lynn Fecteau

by Carol Fecteau

Charlotte Lynn Fecteau was diagnosed with Fanconi anemia at the age of five in March 2000. She went through her first bone marrow transplant (unrelated donor) at the Hospital for Sick Children in Toronto in April 2003. She did not engraft. She went through her second transplant (same donor) in August 2003. The second transplant was considered successful in that 90% of her bone marrow (or blood) cells were from her donor. However, for unknown reasons, the bone marrow did not work much better than her own did before transplant. She was dependent on G-CSF to keep her counts from dropping too low.

The most devastating part of this whole ordeal, though, was the brain injury she suffered two months after her second transplant (October 2003). The doctors never determined what caused it, but there were a

number of possibilities—infection, drugs, late effects of radiation, and late effects of chemotherapy. When we left Toronto by air ambulance for the IWK Children's Hospital in Halifax in December 2003, Charlotte was no longer able to talk, walk, stand, sit, hug, kiss, smile...nothing. That was the first time we lost Charlotte.

However, we loved the new Charlotte just as much. With a lot of therapy, she learned how to walk again in January 2004. When we first saw her smile again later in January, it was overwhelming. We returned home to Moncton, New Brunswick, in February 2004, and she had a team of therapists working with her every day to help her regain whatever she could. Charlotte never did talk again and, oh, how I missed that.

Charlotte went back to IWK on October 28, 2004 and never came out. She had pneumatosis in her gut,



Charlotte Lynn Fecteau

shingles which she couldn't get rid of, lung problems, and was now transfusion dependent. It was all too much for her little body.

Charlotte passed away peacefully in our arms on Wednesday, January 5, 2005. She will forever be in our hearts. ♦

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## Eulogy for Nicole Levine

*continued from page 13*

In your time with us here on earth, you were deprived of much happiness that you so rightly deserved. It is hard for us to believe that God had a purpose in leaving you with us for so short a time, breaking our hearts. But if we think—real hard—it is so clear that He had a lot of work to do quickly, and sent His strongest Angel. One so cute that we had to watch, one so loud that we had to listen, and one so strong-willed that we couldn't help but learn.

Grueling as it is to let you go, we are comforted that you are safe and at peace, and back by God's side. There you are sure to serve as

heaven's nurse, firefighter, and balloon-maker. More importantly, you will be free of the pain and suffering of the diseases that you fought so valiantly to beat.

So, no more pokes, no more central lines, no more dressing changes, no more G-tube, and no more medicines. You go have fun with the other kids now. Bounce on the clouds, swing on the stars, and slide down the moon—over and over again.

And we will know that you are watching over us always:

- When the wind blows against our faces, we will feel your kiss.
- When the sun shines upon us, we will feel your happiness.

- When the treetops sway, we will see you waving.
- When the stars twinkle above, we will see your smile.
- And when the Yankees trip and fall, we will see your outstretched foot.

Coley, know always that Mommy and Daddy, Marissa and Travis, Papa and GG, Bubbie and Zadie, and all your aunts, uncles and cousins will love you forever and ever. Take care of Lamby. Give Gramma a hug and a kiss—and, please, don't be fresh with God. ♦

## Maria's Journey with Fanconi Anemia

by Miriam Duran

My sister Maria Duran was born on October 9, 1968. At the age of 7 she was diagnosed with Fanconi anemia (FA). My parents were not familiar with FA and were told that there was no cure for this chronic disease and that Maria would probably only live to 13 or 14 years of age. Maria passed away at the age of 35. The length of her life was a gift and a true miracle.

Maria became severely ill on October 2002 when her bone marrow presented signs of pre-leukemia. She received her first bone marrow transplant on January 29, 2003, donated to her by her younger sister

Alejandra, an HLA match. Maria underwent her transplant at Memorial Sloan-Kettering Cancer Center in New York City under the care of Farid Boulad, MD. Her condition was stable for 18 months after the transplant.

On August 4, 2004 Maria developed lung problems and was hospitalized. On August 5, 2004 she had a biopsy done to diagnose the problem. During the procedure her left lung collapsed, her pulmonary condition worsened, and she was placed on a respirator. Maria fought her last battle and on October 3, 2004, she passed away and was liberated from her illness forever.

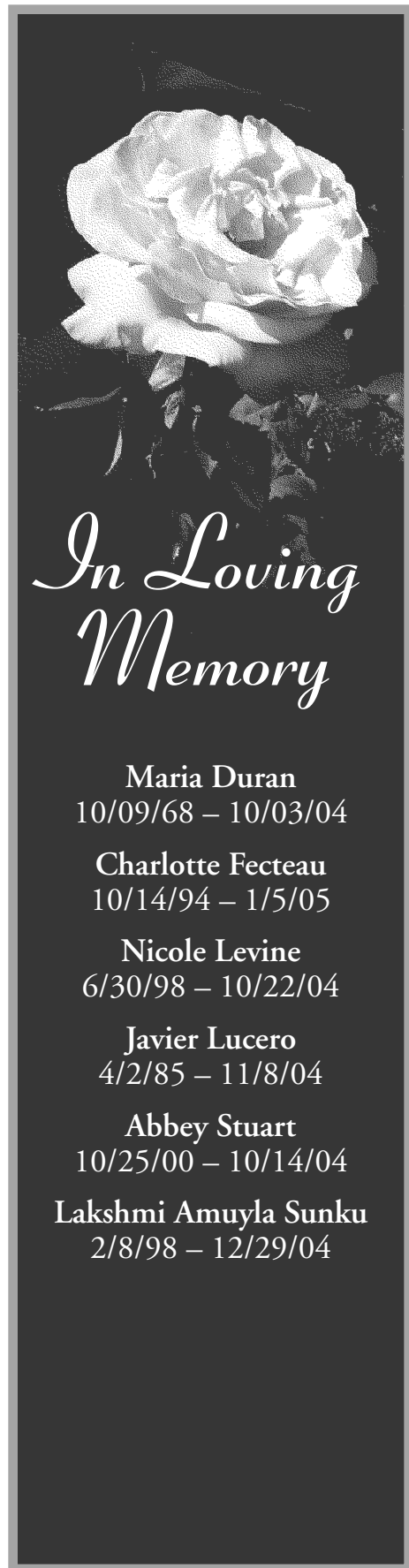
Maria was strong and optimistic about life. She ventured into many different things. Maria was always proud of her accomplishments and passionate about her activities. She was outgoing, friendly, and loved meeting people and making friends. Everyone who knew Maria enjoyed her and her unique sense of humor.

I believe that God gives difficult tasks to those who have extraordinary strength and courage to deal with difficulties such as FA. Maria lived with her illness as God expected her to do, with courage, strength, expectance, and humility. With great pride, I admired my sister's strength, courage and optimism in life. It was a difficult journey for Maria and a painful experience for us. The only comfort we have left is knowing that she is no longer suffering. We are all truly grateful that we had Maria with us for as long as we did.

To all who suffer from Fanconi anemia and to their family members, we hope that wherever you seek guidance you find support, strength, hope, and encouragement. ♦



Maria Duran



# FUNDRAISING

## Kaps for Kendall

by Allison Adams and Whitney Atkinson

When Kendall Atkinson was asked, “What are you most afraid of when you think about going for your bone marrow transplant?” her answer was “losing my hair.” For Kendall, losing her hair was more than a physical loss; it meant losing a part of her identity. Hair is one of our most defining physical features. When asked to describe someone, one of the first characteristics mentioned is his or her hair. What color is it? Is it straight, curly, wavy, long or short? Because the loss of her hair was inevitable, Kendall learned to knit and made hats for herself. She loved the colors, softness, and creativity in the hats.

Kendall lost her battle with Fanconi anemia on March 14, 2004, 34 days post-transplant and at the age

of 20. In memory of our sister, we launched “Kaps for Kendall” to raise money for FA and to provide special hats for kids and adults who have lost their hair from chemotherapy and radiation. Many wonderful people volunteer to make the hats and then someone sponsors a hat by making a \$25 donation to the Fanconi Anemia Research Fund. Over \$4,000 has been raised for FAREF by Kaps for Kendall and over 160 hats have been sponsored. A “hat tree” has been set up in memory of Kendall in the clinic at Fairview Hospital at the University of Minnesota where Kendall had her bone



Kendall Atkinson. Photograph taken by Katie Tartakof

marrow transplant. We continue to collect special handmade hats and get them sponsored. Our website is [www.kapsforkendall.com](http://www.kapsforkendall.com) ♦



Taylor Atkinson and David Wurtzbacher

## A Pink Flamingo Affair

by David Wurtzbacher

It was the best kept secret, for a while.

Flamingo Alice and her flock started to land in the neighborhood on October 13th, 2004, the 17th birthday of my best friend Taylor Atkinson, who is an FA patient. The flamingos were a birthday present to Taylor and, soon, unbeknown to the Atkinson family, a financial gift to the Fanconi Anemia Research Fund.

Each family in the neighborhood not already aware of Fanconi anemia was introduced to the disease and the hardship it has caused the Atkinsons. Each family was asked for a donation, large or small, to the Fund. The response was overwhelming, with donations totaling \$12,000 from neighbors whose hearts were filled with compassion for the Atkinson family. Every family received a pink flamingo of its own. The fundraiser concluded on a cool fall evening, when families carried their flamingos to the Atkinsons and placed them in their yard, leaving a sea of discernable pink.

Taylor and his family could not quite come up with the words to thank the literally hundreds of people who generously gave to FA. Because of their help, the flock has landed, and donations have flown in to the Fanconi Anemia Research Fund to fund the research that provides hope to FA families. ♦



# How to Heat Things Up in Colorado

by Lisa Nash

Well, the Avalanche team isn't playing due to a strike, the Nuggets might as well not be playing, and the Broncos aren't doing so hot either. So, what do you do on a Saturday night in Denver, Colorado? The members of FA Colorado, which consists of three families—the Atkinsons, Nashs, and Salos—decided to have a HUGE fundraiser. We decided on a casino night and silent auction. What we thought might be a little affair for the first of many events to come, snowballed into an amazing event still being talked about in Colorado.

We asked family and friends back in August (not enough time to plan a fundraiser!) to help in any way that they could. People offered space, food, time, and printing. We asked friends to ask their friends for auction and silent auction items. Well, to make a long story short, it turned into an awesome evening.

Over 400 people attended, four restaurants donated food for the event, and the silent auction had over 200 items—ranging from spa packages, movie tickets, and restaurant certificates, up to major things like a satellite TV system. The live auction raised five thousand dollars, from items like a suite at the Pepsi Center, a pre-prohibition bottle of whiskey, a weekend in New York and—the main attraction—a cap that Kendall Atkinson knitted during her transplant. The person who purchased the cap for two thousand dollars then returned it to the Atkinson family. The event was highlighted by the video produced by Steve Feld of Imagine That! Entertainment that was taped at FA camp this past summer. There wasn't a dry eye in the place. The casino

games were too much fun and, when you weren't trying your hand at a card game, you could be dipping into a chocolate fountain. The night was magical and ended way too soon.

Now, for the big outcome of the evening! After paying all of our expenses, we made over \$72,000 at this, our first ever silent auction/casino night! We are still indebted to everyone who worked tirelessly to help us make this evening such a huge success. We hope and pray that

everyone will come back full steam next year to make the 2nd Annual Come Play for FA Casino Night and Silent Auction another huge success.

As a sidelight, if you want a copy of the video for your fundraising event, Suzanne in the FA office has a copy. It would make us all very happy if it helped raise lots more money at other families' FA fundraisers. We are more than happy to answer any questions you might have if you are interested in holding this type of fundraiser. ♦

## Fundraising Assistance

Did you know that 85 percent of the donations to the FA Research Fund are raised by FA families? Obviously, we need the efforts of everyone who reads this newsletter!

The staff of the Fund stands ready to assist you with your fundraising efforts. We'll help you write or edit your fundraising letter; photocopy it; provide the postage; and mail it from our office, using your mailing list. If you're going to hold a fundraising event, we'll provide similar help. Fundraising help is also available through the FA Fundraising Team leader in your area.

The FA Research Fund asks FA parents to make certain that any event they hold is covered by liability insurance. Coverage for a one-time event is often available through a family's homeowners insurance as a relatively inexpensive insurance rider. Please contact the Fund if you need assistance obtaining or paying for this required insurance.

When a donation is received, we'll send a letter of thanks from the Fund with a tax receipt, and we'll notify you that a donation has been made in your name. One request: Please ask your donors to write their donation check to the "Fanconi Anemia Research Fund."

Our sincere thanks go to all of you for your efforts to raise funds to combat this devastating disease.

## Family Fundraising Efforts

In 2004, FA families raised \$1,323,620 for Fanconi anemia research, the most ever raised by FA families. Of that amount, Lynn and Dave Frohnmayer raised a total of \$609,774, another first-rate effort by the founders of the Fund. Almost as impressive, 159 FA families stepped forward to send fundraising letters or hold a fundraising event in 2004, an astonishing increase over the 114 who did so in 2003.

The FA Research Fund is exceedingly grateful for the efforts of FA families who somehow found the time and the energy to raise funds while, at the same time, deal with the ramifications of Fanconi anemia. As we all know, since FA is such a rare disease, if FA families do not raise money for FA, no one else will.

**We must continue this momentum to meet our 2005 fundraising goal of \$2.2 million. We're confident that, with your help, we can do so.** Members of the staff of the Fund will be happy to help you with your fundraising efforts, as will the leaders of the FA Fundraising Teams.

Our sincere thanks to all of you who have worked so hard to raise these critically-needed research dollars.

### \$200,000 and up

Dave & Lynn Frohnmayer

### \$100,000 - \$199,999

Glen Shearer and Peggy Padden

### \$60,000 - \$99,999

John and Kim Connelly  
Lorraine and Kevin McQueen  
Jack and Lisa Nash

### \$45,000 - \$59,999

Ken and Jeanne Atkinson

### \$20,000 - \$44,999

Pat and Mary DiMarino  
Brian Horrigan and Amy Levine  
Deane Marchbein and Stuart Cohen  
Fred and Nancy Nunes

### \$15,000 - \$19,999

Vicki and Andrew Athens  
Mark and Diane Pearl  
Bob and Andrea Sacks  
Mike and Beth Vangel

### \$10,000 - \$14,999

Donald and Danielle Burkin  
Charles and Katy Hull  
Beth and Jeff Janock  
Todd and Kristin Levine  
Tanner and Jessica Lindsay

### \$5,000 - \$9,999

Claire Ashurst and Allan Wright  
John and Audrey Barrow  
Randy and Nancy Bloxom

Joseph and Nancy Chou  
Andrew and Jennifer Gough  
Mark and Susan Trager  
Sean and Kristin Young

### \$1,000 - \$4,999

Mark and Linda Baumiller  
John and Francene Berglund  
Annette and Roger Bevelhymmer  
James and Tracy Biby  
Darryl Blecher and Diana Fitch  
Kerrie and Mike Brannock  
Tyler and Teresa Clifton  
Chris and Susan Collins  
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Stephen and Doreen Flynn  
Nanette Vannostran Foster  
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Alan and Rachel Grossman  
Leardon Keleher  
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John and Karilyn Kelson  
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Sheila Muhlen  
Tony and Lina Nahas  
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Marcia Reardon  
Lynn and Rick Sablosky  
Erik and Lori Salo  
Bill and Connie Schenone  
Connie Simpson  
William and Mary Underriner  
Marc and Sandi Weiner  
Kim and Michael Williams  
Marge Zaborney

### Up to \$999

Peter and Donna Abramov  
Glen and Teresa Alessandri  
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Wesley and Sue Wycoff ♦

## How You Can Help

Your donations have helped move this fatal disease from an orphaned status in 1989 to a disease with treatments that now buy precious time for FA patients. The genetic basis of Fanconi anemia (FA) continues to be deciphered. The relationship between FA and cancer in the general population becomes more apparent each day. Your donations therefore have an impact on the lives of millions in the general population. To help us continue the fight, consider these ways to donate:

**Gifts to celebrate an occasion:** If you are celebrating a birth, a birthday, an anniversary, a graduation, a marriage or other gift-worthy event, consider asking that donations be made to the Fund in honor of the reason for the event.

**Gifts to commemorate a loved one:** Many families who have lost a loved one have asked that a donation to the FA Research Fund be made in memory of the deceased individual. Writers of newspaper obituaries routinely include these requests.

**Bequests:** If you are preparing or reviewing your Last Will and Testament, consider making a bequest to the Fund.

**Matching Gifts:** Many employers will match the charitable gift of an employee. This is an excellent way to double your donation.

**United Way or Combined Federal Campaign:** If you work for an organization covered by either of these organizations, consider making a donation via your workplace and asking your colleagues to do the same.

**Donations Online:** Look for the PayPal button in the Donations section of our web page ([www.fanconi.org](http://www.fanconi.org))

**Donations by Telephone:** Call us at (541) 687-4658 or toll free at (800) 828-4891.

**Donations by Mail:** 1801 Willamette Street, Suite 200, Eugene, OR 97401.

The FA Research Fund has an outstanding record of fiscal responsibility. Administrative costs of the Fund have consistently been far below average for similar organizations. Our most recent annual audit, completed by the accounting firm of Moss Adams, documented that the Fund's 2003 administrative costs were 3.80% and the fundraising costs were 2.10%, for a combined total of 5.90%. These results are exemplary by any standard.



# The Seventeenth Annual International FA Scientific Symposium

SEPTEMBER 29 –  
OCTOBER 2, 2005

Intercontinental Hotel Geneve  
Geneva, Switzerland



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Anemia**  
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1801 Willamette St., #200  
Eugene, OR 97401  
phone: (541) 687-4658  
(800) 828-4891 (USA only)  
FAX: (541) 687-0548  
e-mail: [info@fanconi.org](mailto:info@fanconi.org)  
web site: [www.fanconi.org](http://www.fanconi.org)

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Mary Ellen Eiler  
Joyce Owen, PhD

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Tanya Harvey, Wild Iris Design

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