



FA FAMILY NEWSLETTER

#45

A Semi-annual Publication of the Fanconi Anemia Research Fund, Inc.

Spring 2009

FA Scientific Symposium

This year marked the 20th year of the FA Annual Scientific Symposium. In honor of this milestone, the Symposium was held in Eugene, OR, the home of the Fund.

Dave Frohnmayer, co-founder, made an excellent presentation entitled *The Fanconi Anemia Research Fund Story: Building Something from Nothing*. He noted that the first meeting, in 1989, was held in the donated conference room of Oregon businessman and philanthropist Earl Chiles. Eighteen researchers attended, a number of whom are still doing FA research today.

Remarkable advances have been made in FA science and in the growth of the meeting since 1989.

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Mary Ellen Eiler

Mary Ellen Eiler Receives *Distinguished Service Award*

On behalf of the Board of Directors of the Fanconi Anemia Research Fund, Barry Rubenstein, Board President, and Lynn Frohnmayer, Advisor to the Board, presented the Fund's *Distinguished Service Award* to Mary Ellen Eiler at the Scientific Symposium Dinner on October 5, 2008.

Mary Ellen served as Board President for two years and Executive Director of the Fund for eight and a half years until her retirement on December 31, 2008.

In making this presentation, Lynn noted Mary Ellen's extraordinary dedication to our cause. Her

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An Amazing Story: Small Gifts Lead to Huge Bequest

For many years, Lynn and Dave Frohnmayer sent their fundraising letter to an elderly couple living in Gladstone, Oregon. From 1999 through 2005, this couple gave annual gifts of \$25, for a grand total of \$175. Last spring, the FA Research Fund was informed that both were deceased, and that FARF and The Nature Conservancy had been named in their will.

In June 2008, we received \$15,000 from their Estate. In January of 2009, we received the staggering amount of **\$708,288.59!!!**

This bequest comes at a very good time, given the state of our economy and our urgent need to continue to fund promising research. This story is an example of the importance of reaching out to a large number of potential donors. It particularly demonstrates the value of persistence in writing donors annually, updating them on our progress and informing them of our urgent need. We can never know when a simple request for help will yield a transformative gift!

Squamous Cell Carcinoma in FA Patients – Keynote Address



Jennifer R. Grandis, MD

Jennifer R. Grandis, MD, Director of the Head and Neck Cancer Program, University of Pittsburgh Cancer Institute, delivered a keynote address on squamous cell carcinoma (SCC) in FA patients to attendees at the 20th Annual FARF Scientific Symposium. She outlined the increased incidence of these cancers in FA patients and the challenge of treating patients who are highly sensitive to radiation and chemotherapy. Targeted, less toxic therapies are desperately needed for FA patients suffering from SCC.

Dr. Grandis recommended the centralized collection and study of tumors that develop in FA patients, so that FA cancers can be examined for their unique properties. If certain proteins are overexpressed on the surface of cancer cells, this could suggest that therapies targeting those specific proteins might be effective.

Dr. Grandis described a number of new therapies that are now in clinical trials for patients suffering from head and neck cancer in the general population. One new compound, cetuximab (™Erbix), which targets the epidermal growth factor receptor, is highly effective in some patients with sporadic tumors but not in others, and is most effective when combined with standard therapies including radiation and chemotherapy. Different pathways contribute to the growth of tumors, suggesting that a combination of compounds might be needed to arrest tumor growth. Dr. Grandis emphasized the need to study the effectiveness of various new compounds on a centralized collection of FA tumor samples and cell lines developed from FA-associated cancers. ♦

New Efforts for the Treatment of FA by Gene Therapy

Juan Bueren, PhD, Hematopoiesis and Gene Therapy Division, CIEMAT, and the Institute of Rare Diseases, Madrid, Spain, discussed a new gene therapy approach for FA patients at our 20th Annual Scientific Symposium. He is hopeful that new methodologies will be successful in improving engraftment of corrected cells in FA patients.

Dr. Bueren presented new preclinical data demonstrating the genetic correction of bone marrow cells from FA-A patients using lentiviral vectors. Previous studies had already shown the improved efficacy and safety properties of lentiviral vectors, compared to retroviral vectors already used in gene therapy trials. He showed that the lentiviral-mediated transduction of red cell-depleted bone marrow samples (instead of purified CD34+ cells) from FA patients not only facilitated the correction of hematopoietic progenitor cells, but also corrected stromal cells present in the bone marrow. Dr. Bueren believes that the added infusion of corrected stromal cells may improve engraftment in FA patients.

The biotechnology company Genethon is beginning production of the first preclinical batches of the therapeutic vector. Dr. Bueren is hopeful that that a new gene therapy trial for FA patients could begin in approximately two years. ♦



Juan Bueren, PhD

FA Scientific Symposium

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This year, 185 researchers from 14 countries attended the three-day conference, which featured 44 oral and 53 poster presentations on subjects ranging from DNA repair to cancer in FA patients. Ian Hickson, PhD, Oxford University, Oxford, UK, and Jennifer Rubin Grandis, MD, University of Pittsburgh Cancer Institute, Pittsburgh, PA, each made extremely well-received keynote addresses. Participants uniformly evaluated the meeting as exceptional, with many researchers commenting that the annual Symposium is consistently the best meeting they attend.

Three researchers received awards for their poster presentations. Suhasini Avvaru, PhD, National Institute on Aging, NIH, Baltimore, MD, received the Best Basic Science Award; Frederic Guenard, Laval University, Quebec, Canada, received the Best Clinical Award; and Paula Rio, PhD, CIEMAT, Madrid, Spain, received the Best Translational Award. ♦



Suhasini Avvaru receives her Best Basic Science Poster Award from Dave Frohnmayer.

Satellite Meeting on Transplantation for Bone Marrow Failure and Acute Myeloid Leukemia in FA

by Frank Smith, Cincinnati Children's Hospital

Forty-eight medical scientists participated in a Satellite Meeting on FA stem cell transplantation and acute myeloid leukemia in Eugene, Oregon on October 3rd and 4th, 2008. This important gathering of experts was held in conjunction with the 20th Annual FA Scientific Symposium. Attendees came from fifteen nations including Turkey, Saudi Arabia, Israel, Brazil, India, Japan and Australia.

Participants identified the progress achieved over the past several decades and the challenges that remain. Physicians have improved results dramatically for matched sibling donor transplants. When performed at experienced centers, outcomes are outstanding.

In the past, FA patients who were transplanted with alternate donors had a poor outcome, due in part to both graft rejection and toxicity from the procedure. The recent addition of fludarabine to the transplant preparative regimen decreases the probability of graft rejection without increasing toxicity. Preliminary results suggest greatly improved outcomes for these patients.

Fludarabine has clearly improved transplant outcomes, but other aspects of the transplant process can vary from one transplant center to another with considerable success. These different approaches include the choice of stem cells (bone marrow, peripheral blood or cord blood),

the choice and doses of chemotherapy and radiation used in the transplant preparative regimens, the choice of drugs used for graft-versus-host disease (GVHD) prophylaxis and how stem cells are processed (e.g., T-cell depletion or not). The challenge is no longer whether any of these transplant methods is right or wrong, but rather how to optimize their use to achieve the best outcome. Collaborative studies conducted at experienced FA transplant centers around the world are needed to determine the best protocol.

One exciting area for future study is the potential to personalize therapy for FA patients. For example,

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Mutant Zebrafish Might Help Identify New Therapeutic Compounds for FA

The laboratory of John Postlethwait, PhD, Institute of Neuroscience, University of Oregon, has developed a *fancc* zebrafish mutant that is totally lacking a functional *fancc* gene. These mutant zebrafish are sensitive to DNA crosslinking agents and showed other cellular similarities to FA patients. At two and three days post-fertilization, mutants display a marked reduction in red blood production. Most die as juvenile fish between 12 and 14 days post-fertilization; zebrafish that survive 70 days are much smaller and misshapen compared to their normal siblings.

The zebrafish *fancc* mutant model is now being used in efforts to develop a small molecule screen for compounds that might correct the FA phenotype. This mutant is unable to produce adequate hemoglobin shortly after fertilization. This deficiency

suggests that the model may be an ideal way to identify compounds that might correct this defect. ♦



John Postlethwait, PhD

Multi-Center Collaboration to Identify Small Molecule Compounds to Treat FA

In October 2008, the FA Research Fund gave a large grant to four collaborating laboratories seeking to identify compounds for treating Fanconi anemia. Researchers at the University of Oregon and University of Pennsylvania School of Medicine will incubate *fancc* mutant zebrafish embryos and zebrafish deficient in the *fancd2* protein with thousands of FDA-approved small molecule compounds, to establish if one or several could correct or improve the FA phenotype in these small animals. A third laboratory at Harvard Medical School will study the mechanisms underlying the effectiveness of the identified compounds. Finally, a fourth laboratory at the Dana-Farber Cancer Institute, Boston, Massachusetts will test promising compounds in FA mice and FA human cell lines.

Years of research have now made it possible to determine if a specific compound can overcome or bypass the harmful effects of the loss of the FA pathway. Researchers are hopeful that approximately four potential compounds will be identified each year, and that one or more will prove effective in treating FA. ♦

FA Patients Who Reach Adulthood

by Kornelia Neveling, PhD, University of Würzburg, Germany

Fanconi anemia is usually described as a disorder that manifests during childhood, with congenital malformations and hematological problems. However, there are a growing number of adult patients. What factors pave the way for FA patients to reach age 20 and older?

We analyzed the life histories of 134 adult FA patients (92 from our own cohort; 42 from the literature). Among these 134 patients, 74 are ages 20-29; 46 are 30-39; eight are ages 40-49; and six patients are older than 50.

There are twice as many females as males older than 20. The majority of adult FA patients belong to subgroups FA-A and FA-C, but individuals in subgroups FA-D2, -G, -I, and FA-J were also found. All patients older than 50 belong to FA-A.

Most of the adult patients display few congenital abnormalities. We identified four main factors contributing to relative longevity in FA patients: hematopoietic stem cell transplantation, androgen therapy, "mild" mutations, and somatic mosaicism.

A number of individuals were diagnosed with FA during adulthood due to leukemia or solid tumors. Two adult male patients had no major clinical signs of FA except infertility, making infertility a new important criterion for ruling out FA in young adults. Clearly, improved medical care and increasing awareness of the highly variable manifestations of FA contribute to the impressive extension of the lifespan of these patients. ♦

FANCM Puzzles Researchers at Scientific Symposium

Sietske Bakker, graduate student, Netherlands Cancer Institute, Amsterdam, gave a provocative presentation on *FANCM*, a gene identified in 2005 and thought to belong to the FA core complex. Bakker identified unusual characteristics of *FANCM*, leading some to question its designation as a bona fide FA gene.

At present, only one mildly affected FA patient has been assigned to the FA-M complementation group. Surprisingly, this patient also has two mutations in *FANCA*. Her brother, who has typical FA anomalies, has only one mutation in *FANCM*, but like his sister, has two mutations in *FANCA*. This might suggest that both patients are in the FA-A complementation group, and that *FANCM* is not really an FA gene.

However, when efforts were made to correct the FA-M patient's cell line by restoring the *FANCA* protein, the correction was only partial.

To study *FANCM* function, the researchers made a mouse model that lacked *FANCM* expression. The researchers observed that this mouse model showed FA features, but also suggested that *FANCM* may have an additional function independent of the FA core complex.

Ruhikanta Meetei, PhD, Cincinnati Children's Hospital Medical Center, elaborated further on the atypical findings of the only FA patient assigned to FA-M, who also has biallelic mutations in *FANCA*. Efforts to correct her cell line by introducing either the *FANCM* or the *FANCA* protein resulted in only partial correction. Introducing both



Ruhikanta Meetei, PhD

the *FANCM* and *FANCA* proteins resulted in complete correction. These perplexing findings further illustrate the variability in the FA genes. ♦

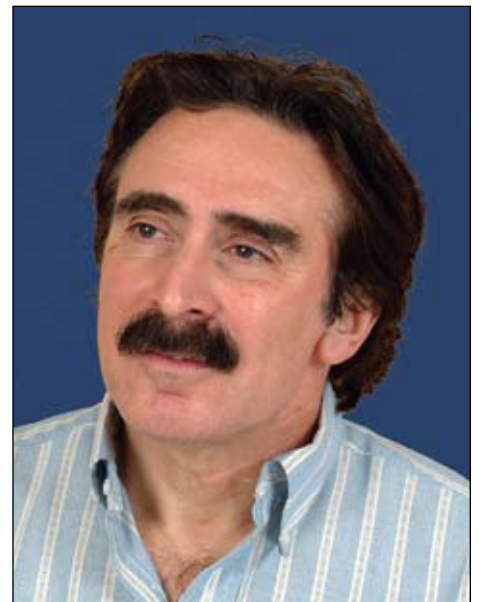
In Vivo Gene Delivery Method Leads to Gene Expression in Epithelial Cells

At our 19th annual Scientific Symposium, researchers from Thomas Jefferson University, Philadelphia, described a gene therapy method whereby a special vector (recombinant SV40-derived vector) is injected directly (*in vivo*) into the femurs of rabbits. These vectors transduce both resting and dividing cells efficiently and are not attacked by the immune system. Thirteen months after inoculation, marker genes were detectable in high numbers of different blood lineages (see *Family Newsletter* #43).

David Strayer, MD, PhD, Jefferson Medical College, updated attendees on the results of his ongoing research at our 20th Annual Scientific Symposium. He has now

determined that more than a year after injecting rabbit femurs with this vector, the transgene is detectable in cells of the spleen, as well as in the epithelial cells of the lungs, brain and liver, and in endothelial cells of the vascular system. The percentage of peripheral blood cells expressing the transgene varied from 15% to 40%, depending on the cell type. The level of gene expression among epithelial cells in the several organs varied, but increased dramatically following organ damage.

Strayer concluded that gene transfer by direct intrafemoral inoculation might eventually lead to widespread gene modification of epithelial cells of diverse organs. This approach



David Strayer, MD, PhD

could be of special relevance to an illness that affects multiple body systems such as FA. ♦

Parental “Weariness” Expressed in Online Survey

In January 2008, members of the FARF Board of Directors and Scientific Advisors met at Skamania Lodge, Washington, to plan the next year’s activities. A physician in attendance suggested that valuable treatment insights might be gleaned from parents’ anecdotal reports concerning what has worked and what has failed in treating FA patients.

Between June 24 and August 15, 2008, FARF conducted an on-line poll to elicit feedback from parents on the above subject, and received 71 responses. Eva Guinan, MD, Dana-Farber Cancer Institute and member of our Scientific Advisory Board, summarized results from this survey at our October Scientific Symposium.

Poll responses did not address medical insights as much as they revealed areas of parental concern and the continuing stress of living with FA. Mentioned most frequently as a worry were the numerous GI problems their children face, followed by concerns about short stature, medications (troublesome side effects and compliance issues with teenagers), and the lack of provider expertise in the local community.

Dr. Guinan’s most striking impression from the responses was that dealing with this rare, genetic, complex, chronic, and malignancy-prone disorder is extremely demanding psychologically, not just on patients, as expected, but on parents. Many described their lives as “watchful stressful waiting,” and communicated a nearly overwhelming overall sense of weariness in dealing with the multiple problems of FA. Scientists, treating physicians and parents in the audience were all deeply moved by Dr. Guinan’s summation, which has broad implications for patient care and family support. ♦



Eva Guinan, MD

Diagnosing and Treating Esophageal Cancer

On December 2, 2008, an article by Jane E. Brody, Personal Health Columnist, appeared in *The New York Times* entitled “Finding, and Treating, Esophageal Cancer.” Brody states that esophageal cancer is the fastest-growing cancer in the United States, with over 16,000 new cases diagnosed annually. For 90 percent of these patients, diagnosis and therapy come too late, and the outcome is fatal.

Brody notes that the esophagus is difficult to monitor as it is not readily accessible. In the traditional diagnostic exam, the patient is heavily sedated and a scope is inserted

through the mouth into the esophagus. If a biopsy indicates cancer, the usual treatment is removal of all or part of the esophagus and the upper part of the stomach, and reattaching the remaining parts of the digestive tract. Survival improves dramatically when cancer can be detected before it reaches an advanced stage.

Brody describes a technique called TransNasal Esophagoscopy, which came into use in the mid-1990s and can be done safely and effectively in a doctor’s office. Patients are completely awake, and sit upright in a chair. A thin flexible scope is placed via the patient’s numbed nose past

the throat and into the esophagus, thereby avoiding the gag reflex in the mouth. This procedure is fast, usually well tolerated, and reduces costs.

Brody’s article suggests that the esophagus can be monitored more effectively with this approach. Relevance for FA patients, who experience an unusually high incidence of esophageal cancer, is unknown. TransNasal Esophagoscopy uses a thin scope, but one that is larger than the scope used to screen patients for head and neck cancer, and thus may be inappropriate for some FA patients. ♦

Study Reveals that FA Patients do *Not* Undergo Regular Screening for Malignant or Pre-malignant Lesions of the Head and Neck

Eunike Velleuer, MD, Department of Pediatric Oncology, Hematology and Immunology, Heinrich Heine University of Düsseldorf, and Ralf Dietrich, FA parent and Executive Director of the FA Patient Support Group of Germany, are meeting with large numbers of FA patients in their homes or at family meetings, in an effort to educate them about the prevalence of head and neck squamous cell carcinoma (SCC) and to encourage regular monitoring of the head and neck by a qualified physician. Velleuer and Dietrich obtain brush samples of seven locations in the oral cavity for later analysis. At the October 2008 Annual Scientific Symposium, Dr. Velleuer reported on interviews and brush sample results from 100 FA patients.

Of 100 FA patients, only 10 were visiting a head and neck physician on a regular basis for monitoring, and six of these 10 had already been diagnosed with head and neck cancer. Thirty-two patients had a total of 74 visible oral lesions; 25 of these patients were not undergoing regular screening. Eight of the 74 lesions were suspicious for malignancy by cytology analysis, and four were confirmed as malignant.

Velleuer concluded that FA patients are not well informed about the high risk of SCC. Many transplanted patients believe that they are cured of FA. Others are fearful of cancer, so they avoid screening by head and neck physicians. But frequent surveillance and early intervention are crucial for the management of this all too common and life-threatening complication. ♦

Satellite Meeting on Transplantation

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different gene mutations may determine the optimal timing of a transplant. It may also be possible to personalize the doses of chemotherapy used in the transplant preparative regimen based upon data from each individual patient. This personalized dosing of chemotherapy might allow for more effective use of drugs while reducing side effects.

More FA patients are now surviving transplantation. It is important that transplant physicians better understand problems (such as secondary cancers) that these survivors may encounter and how to prevent and treat them. There is a great need to understand squamous cell carcinoma (SCC) and its relationship to FA, GVHD, radiation and human papillomavirus. Finally, research should explore the relationship of mixed chimerism (i.e., a mixture of donor and host blood cells after transplantation) as it relates to the risk of developing AML, and how best to measure and improve the rate of immune recovery post-transplant.



Frank Smith welcomes participants to the conference.

For FA patients with AML, data presented at the meeting suggested that transplantation clearly has the potential to be curative. However, very little is currently known about the biology of AML in patients with FA, how to use AML chemotherapy in these patients and how to optimize the transplant procedure to achieve better outcomes.

Participants agreed that important next steps include a cohort study to understand the long-term effects of transplantation in FA patients and better ways to provide tissue samples to scientists who study AML and SCC. Highly collaborative clinical trials will be essential for FA physicians and scientists to be able to ask and answer important questions. ♦

New Clinical Trial for Preventing Head and Neck Cancer for FA Patients

The most recent issue of the *FA Courier* includes a Phase II study for the prevention of head and neck squamous cell cancer (HNSCC). This trial includes the use of cetuximab (TMErbitux) a low risk toxicity agent that is effective in invasive head and neck cancer. Some Fanconi anemia patients with head and neck cancer have used cetuximab to treat HNSCC. This trial seeks patients with oral pre-malignant upper aerodigestive lesions. It includes both a study and control group; however, patients in the control group (i.e., the no treatment group) have the option to receive the treatment after the conclusion of the study. To learn more about this trial, contact Dr. Joseph Califano, MD, Johns Hopkins Medical Institutions, at 410-955-6420; Zubair Khan, MD, MPH, Johns Hopkins Medical Institutions, at (410) 955-3157; or Teresa Kennedy, Family Support Coordinator, at the Fund (541) 687-4658. ♦

Meet the Staff Members of FARF

Jeanne Negley, MBA, joined the Fund as its director in November 2008. Jeanne previously managed Children's Array of Psychiatric Programs (CHARPP), an association of children's psychiatric residential treatment programs based in Oregon. She is excited to work with the Board of Directors in leading the Fund to accomplish its mission to find effective treatments and a cure for FA and to provide education and support services worldwide.

Teresa Kennedy, MA is the Family Support Coordinator and has been with the Fund since April 2008. Prior to that, she worked in the field of infant adoptions, family counseling, and with children with disabilities. She provides information and support to families worldwide. Teresa loves hearing from FA families, so please contact her anytime with questions, comments, or even just to say "hi."

Melanie Fee has worked at the Fund since March of 2008. Before relocating to Oregon, she worked in arts programming for a PBS affiliate in Kentucky. As Publications Coordinator for FARF, she is involved with the publishing of the *FA Courier*, newsletters, and the upcoming *Clinical Care* handbook. Families can contact her for help with fundraising materials including personalized brochures and letters.



Left to right: FARF Staff Members Teresa Kennedy, Jeanne Negley, Melanie Fee, Kim Larsen, and Kristi Keller

Kristi Keller has been with the Fund since November 2005. She is the Fund's Bookkeeper and Administrative Assistant. She handles the daily financial operations of the Fund and keeps track of all donations. She also works with families to keep them informed of donations and to provide help with fundraisers.

Kim Larsen has been working part-time with the Fund since 2004. She is the Fund's grant writer and coordinates conferences and events including the Annual Scientific Symposia. She has a BA in Anthropology and Geography from the University of Oregon. ♦

Learning to Love and Live to the Fullest

by Pilar Goñi, pgoni@terra.cl

My son Alejandro was born with serious health problems, but he lived for 40 years despite that fact. He grew and lived, a little giant of love and energy. Alejandro's small stature, as well as his small face, eyes, and mouth were always noticed, as well as his extra finger on his right hand, which was later removed.

When Alejandro was nine, he fell ill with the chicken pox. He was so gravely sick that a blood analysis was done and what came back was a diagnosis that shook the entire family like an earthquake. He had Fanconi anemia, a progressive disease with a bad prognosis: he would be lucky if he lived until his 15th birthday. It was not long after this that we had further devastating news: Constanza, our daughter, also had Fanconi anemia.

Living with this disease in our family was an incredibly harsh experience for all of the children. The healthy children resented the sick ones because they felt as if they were pushed aside for their extra care. The sick ones felt diminished and different, since their siblings, though younger, were taller and heavier.

Thankfully, both Alejandro and Constanza had childhood and



Four siblings: Alejandro (FA), Macarena, Constanza (FA), and Andrés

teenage years free from any significant health problems. The problems they did have emerged through their emotions. At fifteen, Alejandro, having lived with the stigma of premature death, found solace in drugs and alcohol. It was his way of escaping from his pain and fear. Nevertheless, Alejandro's health did not start to

decline until he was around thirty. First he had repeated respiratory infections and he also began to experience problems with his skin and liver. At the end of 2007, only 5% of his bone marrow was active and cancer had appeared in his mouth.

Despite having such a difficult life, in his later years he met a wonderful woman, with whom he fell profoundly in love. With her he formed a family. He started a small company of his own and they bought a house where they were able to live a few very happy years.

Constanza, his sister, lived through her brother's experiences with a lot of sorrow and I imagine with a lot of fear. She is a wonderful

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Positive Growth for French FA Support Group

The Fanconi anemia support group located in France, Association Française de la Maladie de Fanconi (AFMF), had its annual meeting in January of this year. At this meeting, a new seven-member board of directors was chosen. The new president of AFMF is Marie-Pierre Bichet (mpcbichet@hotmail.com) and you may find her, and other members' contact information on their new web site, www.fanconi.com. Former president of 19 years, Sylvette Silverston will maintain an active role in the organization. ♦

The Story of Jess

by Samantha and David McDowell

Our gorgeous Jess was born on May 16, 1997. She seemed healthy, other than two thumbs on her right hand. We were assured that surgery would rectify this and give her normal movement and appearance. We were extremely happy and Ash was excited about her lovely little sister. On day two, however, Jess became hypoglycemic, hypothermic, and jaundiced and was rushed to the Special Care Baby Unit. After months of uncertainty in the hospital, she was diagnosed with a malfunctioning pituitary gland. There was NO mention of FA, despite her early symptoms—*café au lait* spots and abnormal blood counts.

For years, Jess had frequent hospital admissions and growth hormone injections. Our definition of “normal” had changed and Jess became accustomed to hospitals, taking everything in stride, including surgery. At age one, Jess had a feeding tube inserted, which she had for two years. She had three operations for her thumb abnormality. At age six, Jess started bruising badly when injected and experienced nosebleeds. In November 2006, she was hospitalized with low blood counts; still, she was not diagnosed with FA until January 2007, at age nine.

During April 2007, Jess had frequent hospital visits for blood tests, scans, blood transfusions, and the insertion of a central line. She became blood transfusion dependent, so we had no choice, and in May 2008, she underwent a bone marrow transplant from a half-matched donor. She was not terribly sick during chemo, but she was unable to eat much and had terrible stomach pain and some bleeding. She developed graft-versus-host disease (GvHD). Jess coped well. She was a remarkable



David, Samantha, Ashleigh (top), and Jessica McDowell

young lady—brave and composed, full of decorum, always polite, constantly putting others first.

For a brief time, we were allowed to leave the hospital. We were nervous but excited, and Jess didn't want to return to the hospital. But she deteriorated and was admitted to the Paediatric Intensive Care Unit (PICU) to control her breathing. Jess was intubated and had transfusions, which stabilized her. Her breathing improved but her GvHD spread. She was discharged from intensive care, but her GvHD spread so badly that she had total skin failure and could not be touched. The pain was unbearable.

Jess returned to PICU, where she was sedated and intubated again. Up to that point, we always thought that she would pull through, but now, we were not so sure. We stayed at a hotel next to the hospital to be close; generally, one of us stayed with Jess. Staff convinced us to go to the hotel and rest, promising to call us immediately

if anything changed. We couldn't settle down, feeling that at least one of us should be there with Jess.

Around midnight, PICU called, saying that we should return to the hospital because Jess was not getting enough oxygen and they wanted to change the ventilator to an oscillator (the most powerful breathing machine). This was Jess's last chance and we agreed there was no other choice. Jess did not respond and we had to make a dreadful decision: to switch the machine off and let her go. She was heavily sedated and we were assured that she could not feel anything and was totally unaware. David lifted Jess from her bed and cradled her in his arms, with Samantha at one side and Ash at the other. We felt her life leave her. No words can describe how horrific this IS, definitely the worst time in our lives. Our angel, Jess, has gone. ♦

In Loving Memory

Jessica McDowell
5/16/97 ~ 8/1/08

Alejandro Leontic
7/3/68 ~ 9/30/08

Stacy Fuller
3/19/87 ~ 10/8/08

Lilly Irvin
4/25/06 ~ 11/21/08

Phylis Ann Resh
8/16/81 ~ 12/18/08

Mai Yer Xiong Lee
3/5/80 ~ 3/9/09



E-Group Offers More Features than Just E-mail

As many of you know, through Yahoo, the Fund has an online support group for parents of children with FA and for adults with FA. We currently have 325 people on our E-Group. You can visit the Group page of the FA General E-Group online at <http://health.groups.yahoo.com/group/Fanconi/>.

If you visit the group page, you will see a number of features available. On the left side of the group page, options include Home, Messages, Files, Photos, and Calendar. Some families have uploaded pictures there. You can easily send a message to the group by clicking on Messages and then on Post. You can also view the recent posts, and you can scroll back through the older posts (all the way back to 1999!).

Another great feature is the Search box. By utilizing this feature, you can search various topics posted and the responses received by simply typing in the keywords of any topic that interests you (fundraising, feeding, bullying, PGD, androgens, etc). With over 13,750 messages posted, you can find a wealth of information within our E-Group.

The Fund also has an E-Group for Adults with FA, Teens with FA, and a Bereavement E-Group. If you are registered with us and would like to be added to one of our E-Groups, please contact Teresa Kennedy, Family Support Coordinator, at our office (teresa@fanconi.org or by phone at 1-888-FANCONI or [541] 687-4658). ♦

SuperSibs! Lends Great Support to Siblings

SuperSibs! is a non-profit organization that offers support to siblings (in the USA and Canada, ages 4–18) of patients with pediatric cancer and FA. The program is based on the understanding that siblings need healing support throughout the journey, too, so that they may face the future with strength, courage, and hope. Because stem cell transplants are a treatment for cancer and FA, SuperSibs! will now accept referrals from FA families, ideally about the time of transplant.

SuperSibs! will send age-appropriate comfort and care packages to siblings (approximately ten times the first year, eight times in years two and three, four times the fourth year, and twice yearly after that). Some of the items include courage trophies, beads, tee shirts, relaxation CDs, sweet dream pillowcases, and more. They also offer grief support, newsletters, a scholarship program, and summer camps for siblings.

You can learn more at <http://supersibs.org>. If you would like more information or assistance with registering, please contact Teresa Kennedy at the Fund. ♦

Embracing My Identity

by Amy Frohnmayer

People always tell you that “time flies.” In early childhood, you picture small clocks with wings and ignore the meaning of the statement because to you, life is an endless mystery. As you grow older, this concept begins to make sense, and the rapid succession of moments that constitute life becomes increasingly real.

I notice that mindfulness of time passing is enhanced in many FA patients. We don't always squeeze meaning out of every minute consciously, but I do believe that in the midst of the pain and fear we experience as a result of living with FA, we are also blessed strangely with rare insight into the fragility of life.

Each of us has a unique life story. We find ways to cope with our diagnosis that are influenced heavily by personal characteristics, family dynamics, and major life experiences, and these may fluctuate dramatically throughout our lifetimes. For me, dealing with FA has meant learning to accept it as a core part of who I am, and although not easy by any means, this has proven to be one of the most empowering decisions I have ever made.

When I left for college, I contemplated a new beginning where no one knew my life story. I came from a relatively small town where nearly everyone in my high school knew I had an illness and I was curious about how my life might be different without an identity colored by FA. I went to school, made new friends, and, inevitably, by the time I was hospitalized in February for shingles, all of my close friends knew not only that I had FA, but also that I had lost two sisters to the same illness and that I was considering a bone

marrow transplant in the not-so-distant future.

I was surprised with my own relief in sharing that I had FA. For the first time, I felt I had control over who knew, and disclosing this information made me feel more connected to myself. I was finally taking ownership of a condition responsible for profound sadness, anxiety, and fear throughout my life, and this was unexpectedly reaffirming. Regardless of how much I have been hurt by FA, it has shaped me in countless ways. To push it away was to deny an important part of my identity. To embrace it was to gain more control through a greater sense of comfort with myself.

An effect of accepting FA has been a growing enthusiasm to fund research geared towards finding a cure. For the last two years, I have written my family's fundraising letter and flown to southern California and to Denver to speak at fundraising events. As a patient with FA, I have felt deeply disempowered at times, even paralyzed by the profound uncertainty inherent in this disorder. But when I channel energy into supporting this cause, I feel as though I turn a dark burden into a source of sincere meaning in my life, and there is nothing more gratifying.

As a senior, I struggle with what it means to take the next step in life. I sometimes wonder why I'm still here while other FA patients are not, and I think often about the significance of my age in terms of my prognosis. I realize, however, that uncertainty is part of every life, and although I am by no means



Amy Frohnmayer at Camp Sunshine

free from anxiety or sadness, I am grateful just to be here and to have formed important relationships with so many other FA patients.

Each of us with FA forges a distinct trail through life, but our paths often converge somewhere along the way. FA has allowed many of us to meet as perfect strangers, some from separate cultures. We have bonded across the strongest barriers of difference. Because of the positive impact fundraising has had on my life and the way it has empowered other patients, I encourage everyone to support research in whatever way he or she can. A growing awareness of the passage of time gives me a sense of urgency. We are all in this together, a team made up of strong, spirited, and yes, often-times short, participants in this race against the clock. ♦

New Daughter Overcomes Remarkable Odds

by Nancy and Ernie Landwehr, nancy_landwehr@msn.com

When we adopted Maddie from India, she was two years old. The adoption agency told us the horror of how her life began. Born to an unwed mother in the southern part of the country, Maddie was literally thrown away moments after her birth and left to die. As she lay alone, a wild dog attacked her, destroying part of her right leg and hip. She was near death when a police officer heard her crying and took her to a hospital, where she was given a mere 1% chance of survival. But survive she did.

Maddie joined our family in Iowa in 2002. She has had many surgeries to her hip and right leg, including a very successful leg lengthening surgery in 2007. But soon after the surgery we started to notice her low blood counts. Maddie's doctor performed a bone marrow biopsy

to check for leukemia. Those results came back normal.

However, her medical condition began to worsen. This led us to meet with doctors at the University of Minnesota who, after more testing, returned with the unfamiliar words: Fanconi anemia. We looked at each other and said (almost in sync) "What in the world is that?" Dr. MacMillan explained much of what we needed to know about FA, and last May Maddie underwent an unrelated donor cord blood transplant.

Maddie has had her ups and downs after transplant, but she is doing well. Maddie is our miracle daughter. With her strong spirit, there is no disease that will stop her from following her dreams to become a doctor. As parents, we have learned so much about FA. We feel that someday there will be a cure,



Maddie Landwehr

but we also recognize that the road ahead will be bumpy. Maddie's determination to keep fighting will ensure that she overcomes any obstacle that stands in her way. ♦

Congratulations!

We would like to extend our best wishes to Maria Rodriguez-Ribero (FA, 22) and her husband Sergio Martinez-Hernandez on the birth of their healthy son Samuel, born on January 5th, 2009.

We also offer our congratulations to Josie Proctor Keyes (FANCA, 28) and her husband Josh Keyes of Portland, Oregon, on the arrival of their first child, Penelope Clover Keyes, born January 30th, 2009.

Congratulations to Glen and Teresa Alessandri (FA, 37). Their beautiful daughter, Maria Eve, born March 31, 2008, joined their family through adoption on November 20, 2008. ♦



Maria Rodriguez-Ribero with son Samuel

Carrying a *BRCA2* Mutation: Issues to Consider

by Rachel Altmann

The day my daughter was diagnosed with Fanconi anemia is one I won't ever forget. Her geneticist handed us his card with "fanconi.org" handwritten on the back. It was the beginning of our education about all things FA. Four months later, when we received confirmation that she had mutations in the *FANCD1/BRCA2* gene, my husband and I started another journey, learning about all the issues that we faced as *BRCA2* mutation carriers.

Our family is enrolled in Dr. Blanche Alter's study, and through that study we have received genetic testing (for ourselves and our parents) and counseling about the many decisions that *BRCA2* carriers face. We have also received support and information from a group called FORCE (Facing Our Risk of Cancer Empowered), a group for *BRCA* mutation carriers and others with a high risk of breast and ovarian cancer.

We both have a slightly increased risk of skin cancer. My husband faces a somewhat increased risk of



Rachel Altmann with daughter Nina

prostate cancer. The biggest concerns for *BRCA2* carriers, however, are the ones that female carriers face. Both men and women face an increased risk of breast cancer, but the risk for men is still quite low. The risk for women can be as high as 80%. Women also carry a high risk of ovarian cancer, a cancer that remains extremely difficult to detect and treat.

For me this has meant having to make difficult decisions about whether to follow the path of surveillance or prophylactic (preventative) surgeries for both my ovaries and my breasts. With surveillance there are choices about what types of screening to use and on what schedule. Different doctors have different recommendations, and even these change as advances are made in screening technology.

Because *BRCA2* carriers face risks that most other FA carriers don't,

it is important for extended family members to consider testing as well. Those who test positive who are of childbearing age should have their spouse tested as well. Several of my husband's family members tested positive for a *BRCA2* mutation. One of them, who was ready to start a family, then had his wife tested so they knew whether they risked having a child with FA.

Although my mutation is one of the classic Ashkenazi Jewish mutations, my husband's is not (and as far as we know he has no Jewish relatives), so we've learned that it's important not to assume that one's spouse is not a carrier just because of ancestry.

It can be hard to focus on your own health when your children's medical needs are all consuming. But it's important. They need you. ♦

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.*

FUNDRAISING

Annual Hoot 'N' Holler Rounds up Fun for All

by Jeanne Atkinson and Linda Wurtzbacher

Rumor has it that hootin' and hollerin' could be heard far and wide last November as over 300 people in Denver gathered for Brave Hearts 2008...Hoot 'N' Holler. This is the second year the Kendall and Taylor Atkinson Foundation (KATA), along with Jack and Lisa Nash, have put together this western themed event to raise money for Fanconi anemia research. KATA was started after the deaths of Kendall and Taylor Atkinson from Fanconi anemia. It is in their memory and in the hope of a cure for Molly Nash and all others who courageously battle FA that money is raised.

Throughout the evening, guests enjoyed buying a mud slide or frosting shot for a chance at a diamond, the roaming Pony Up corral, wrangling up silent auction items, the entertaining live auction, dancing, casino games, prize giveaways, and

just good fun. Toby Munroe, World Champion Country Swing dancer who had just returned from dancing at the CMA Awards, and his partner Emily Wurtzbacher, lassoed in the crowd with their engaging country swing performance.

Special guest Amy Frohn-mayer, a senior at Stanford University and Fanconi anemia patient, was the highlight of the program as she shared pieces of her heart, paths in her journey, and educated everyone on some of the encouraging FA research findings.

Because of the dedication of our many volunteers and the wonderful generosity of our event guests, sponsors, auction donors, and the Hilton Garden Inn, KATA was able to send a check to FARF for \$107,000!

We are ever grateful for the

continuing support of both old and new friends of FA and hope to be hootin' and hollerin' with everyone again this year on November 21! ♦



Molly and Jack Nash

Another Busy Year for Play for FA!

by Lorraine McQueen

After our ten-year old son Sean was diagnosed with FA in 1999, Kevin and I vowed to do everything we could to help him overcome the disease. We felt the best way to do this was to raise money to fund medical research. Fortunately, we are blessed to have a fantastic group of friends who graciously jumped in to help. We quickly formed the "Friends for Sean" committee and brainstormed ideas for raising funds. Our first event was the Play for FA Casino Night, an auction held way back in the fall of 2000. Since then,

the committee has planned and organized a variety of different Play for FA events including golf tournaments, formal dinners, and a wine tasting. The committee has done a phenomenal job of making the events a lot of fun for attendees while raising significant amounts of money for FARF. Our two events this past year were no exception.

This past October we held the 6th Annual Play for FA Golf Tournament at Independence Golf Course in Midlothian, Virginia. The event was generously underwritten by

CapTech and sponsored by numerous local companies. Over 110 golfers participated in the captain's choice tournament on a beautiful, sunny fall day. New this year, we hosted a bone marrow drive in conjunction with the tournament. Free mulligans were offered to those who agreed to be tested. It was a huge success—32 people signed up for the registry. Sean was thrilled to be able to "play hooky" from school and join in the fun. Although the McQueen foursome did not win the coveted

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Kaps for Kendall: A Successful and Heartwarming Legacy of a Sister

by Whitney Atkinson

The CT scan confirmed our worst fears and there was nothing more we could do. Grenades had gone off, one in my heart and the other in Kendall's body. The mucositis had ravaged Kendall's body and it would take her life. Allison, my dad and I got on the next flight from Denver to Minneapolis to join my mom and Kendall for her final days. When I walked into Kendall's room that night I was expecting the worst. Instead, Kendall had a beautiful peaceful glow. Her skin looked an olive tan. She was wearing her pink shades from the "pink party" we gave her to celebrate transplant day. On her soft bald head was a hand knitted purple hat from my mom. As Kendall quietly and painlessly slipped away from this life a few days later, I couldn't help but think back to a few weeks ago, the last time I saw Kendall awake. She had tears in her eyes and a look that

said, "I'm not ready for you to go yet." Now it was my turn to tell her that I wasn't ready.

This March will mark the five year anniversary of Kendall's death. Kendall was diagnosed with Fanconi anemia along with her brother Taylor in September of 1990. For many years Kendall was able to embrace life and not let the disease slow her down. In 2003, at the age of 20, her health began to fail and she was faced with transplant as her only hope for a future. It was a very difficult decision for Kendall, but like everything else in her life Kendall went to transplant bravely and with much determination to face her illness head on.

It is these attributes of Kendall that inspired Allison and me to start "Kaps for Kendall" in honor of our sister. We have been going strong now for 5 years with each year reaching more and more people. Our



Allison Adams with Jeane, Whitney, and Kendall Atkinson on Transplant Day, February 19th, 2004

goal is 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 while others sponsor the hats with a \$25.00 donation to FARE.

This past year, despite economic concerns we were able to raise over

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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!

FA Family Fundraising Teams now exist on a regional level to assist our families with fundraising. If you are unsure how to contact your team leader, contact the FA Research Fund.

The staff of the Fund is 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.

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

Please ask your donors to write their donation check to the "Fanconi Anemia Research Fund." When a donation is received, we will generate 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.

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

New Fundraising Endeavor Shows Promise for the Future

by John Hanna, jrhanna2000@sbcglobal.net

I wanted to give my whole FA family an update on my journey with this disease. As I write this, I am about three weeks away from surgery on my left ear. Like many other FA patients, I had many ear infections as a child and numerous sets of tubes, along with the occasional bursting ear drum. The many years of infections have caused my eardrum to retract and form a cholesteatoma. I will have surgery—hopefully my last—to alleviate this problem. As for other health issues, I am pretty much in the clear for now. No cancer recurrence as of yet, knock on wood.

I miss all of the friends I've made at Camp Sunshine and am anxious for August to arrive so I can see all of you again. To anyone who has not attended a Camp session yet: What are you waiting for? It is a great opportunity to meet and talk with some of the top doctors that specialize in FA and a fantastic way to connect with others going through similar trials with FA. You will definitely not feel alone while at Camp!

As some of you know, my wife and I put on our first fundraising event in February 2008 and it was

somewhat of a success. Putting an event together can be difficult and typically the first attempts are not as successful as future ones. Because of my ear issues and my wife's back issues, we decided not to hold an event this year, but still wanted to do something to raise at least a little bit of money. My wife and I have gotten into the dog breeding business and we're breeding labradoodles and possibly some standard poodles. The initial expense of setting up our first litter meant that there was as not much to donate to FARE as we had hoped, but with future litters we'll be expecting more profits to go to FARE. Though we live in a very small town in Oklahoma and don't have access to a large number of people, we are still able to find a way to help. Hopefully this message will resonate with some of you who have not yet attempted to raise funds. Try to think outside the box a bit and give it a shot. You might be surprised with the results.

I hope to see you all at Camp!

John Hanna
Almost 37 years old! ♦



John Hanna

Mary Ellen Eiler

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vision concerning future directions, her stellar organizational skills and her selfless devotion of personal time to the work of the Fund have greatly advanced research progress.

Mary Ellen organized a series of workshops on issues of great concern to FA patients, such as cancer, therapeutic potential of small molecule compounds, bone marrow transplantation and bone marrow clonal abnormalities. She has focused efforts on recruiting outstanding head and neck cancer experts to our Board of Scientific Advisors. Making knowledge available to parents has been a strong priority. Mary Ellen has planned annual international family meetings, regional meetings in cities throughout the US, and workshops to develop clinical care guidelines for physicians and families. This prestigious award, given on only rare occasions, reflects Mary Ellen Eiler's extraordinary contributions to FA science and family support. ♦

Raffle Proves to be a Simple and Successful Fundraiser

by Marina Ravelo

Our October 10, 2008 "Raffling for a Cure" was a great success. We were able to raise over \$15,000 for FARE. In the beginning, raising that amount seemed daunting, but with the help and involvement of family and friends (including FARE families), our goal became more easily attainable. In total we sold about 750 tickets at \$25 each, for a grand total of \$18,750. We used money that we raised to pay for the raffle prizes (about \$5,000). My sister was able to get a matching gift from her company for her portion (\$3000), an added bonus. We are pleased with how our raffle turned out and hope to do this again, as it was a pretty simple way to raise money for FARE. ♦

Family Fundraising Efforts

In 2008, FA families raised an astonishing \$2,439,349 for the Fanconi Anemia Research Fund, an especially impressive total when taking into account the year's turbulent economic crisis. Families worked hard to accomplish this goal by sending out fundraising letters and holding a variety of fundraising events.

An impressive one hundred ninety FA families raised funds this year and, of those, ninety-two families raised \$500 or more and six raised over \$50,000. Late in 2008, the Fund received an unexpected \$708,288 bequest from a Frohnmayer donor, which is detailed elsewhere in this newsletter. Without the addition of this large bequest, the Frohnmayers raised 35% of funds, compared to 65% for all other families. We are grateful to everyone who worked so hard to raise funds so that the urgent work of the Fund can continue to move forward at a fast pace.

FA families who raised funds in 2008 are the following:

Over \$500,000

Dave and Lynn Frohnmayer

\$190,000 to \$499,999

Kevin and Katie Rogers

\$100,000 to \$189,999

Glen Shearer and Peggy Padden

\$50,000 to \$99,999

John and Kim Connelly
Dan and Nikki McCarthy
Kevin and Lorraine McQueen

\$25,000 to \$49,999

Mark De Groot
Peter and Tara Himmelreich
Steve and Jennifer Klimkiewicz
Todd and Kristin Levine

\$15,000 to \$24,999

Brian Horrigan and Amy Levine
Joey Linsenmann

\$10,000 to \$14,999

Ken and Jeanne Atkinson
Mike and Kerrie Brannock
Stuart Cohen and Deane Marchbein
Carol Felmy and Michael Glas
Charles and Katy Hull
Pedro and Marina Ravelo

\$5,000 to \$9,999

John and Audrey Barrow
Joseph and Nancy Chou
Chris and Susan Collins
Ed and Janice Duffy
David and Mary Ann Fiaschetti
Jim and Holly Mirenda

Tyler Morrison and Rachel Altmann

Jack and Lisa Nash

Marcia Reardon

Bob and Andrea Sacks

Kim and Michael Williams

\$1,000 to \$4,999

Yavin Atzmon and Sharon Harari

Mark and Linda Baumiller

James and Tracy Biby

Darryl Blecher and Diana Fitch

Randy and Nancy Bloxom

Chris and Jennifer Branov

Donald and Danielle Burkin

David and Paula Ceresa

David and Kim Chew

Jeanette Clark

Tyler and Teresa Clifton

Antonino and Marie DiMercurio

Doreen Flynn

Andrew and Jennifer Gough

Alan and Rachel Grossman

Owen Hall and Margaret Kasting

Bob and Victoria Hathcock

Roger and Eleanor Herman

Jeff and Beth Janock

Christie and Randy Kelley

John and Karilyn Kelson

Erik Kjos-Hanssen and Turid Frislid

Sejin and Jee-ai Kim Kwon

Lynette Lowrimore

Gianna and Lauren Megna

Sydney and Betsy Moore

Robert and Mary Nori

Mark and Diane Pearl

Peter and Janice Pless

John and Dianne Ploetz

Lynn and Rick Sablosky

Richard and Dolores Satterlee

Ron & Elesa Schaefer

Bill and Connie Schenone

Matt & Diane Senatore

Bryan and Karen Siebenthal

William and Mary Underriner

Mike and Beth Vangel

Marc and Sandi Weiner

Up to \$999

Chris and Ellen Allums

Andrew and Vicki Athens

Larry and Janice AuCoin

Gerald and Julie Barbier

Tyren and Kelly Bennett

John and Francene Berglund

Jeffrey and Donna Boggs

David and Carole Boudreau

Roel and Diane Brand

Ed and Barbara Brookover

Jeff and Darlene Brunson

Matt and Lisa Buglehall

DeeDee and Tad Burzynski

Merry Cable

Pattie Carter

Lezlie Chesler

Floyd and Susan Clark

Ray and Diane Cronin

Brian and Margaret Curtis

Richard Day

Tony and Phyllis Dellapenta

Donna DellaRatta

John and Wendy Delzell

James and Carol Dillon

Kim and Stephanie Dillow

Pat and Mary DiMarino

Frank and Susan Dixon

Brian and Jennifer Dorman

Delbert and Linda Dotson

Sandra and Lindsay Dunn

Peter and Tami Dunstan-Adams
 Gene and Lynn Eddy
 Sharon Ellis
 Billy Jo and Debbie Estep
 Kay Eubanks
 Ezat and Laila Faizyar
 Curt and Crystal Fales
 Justin & Britteny Ferrin
 Danielle Folkes
 Nanette Vannostran Foster
 Sue Fulton
 Susan Gannon
 Lisa and Brian Gillott
 Pat & Maria Gleason
 Maria and Josh Godwin
 Allen Goldberg and Laurie Strongin
 Young Ju and Kwang Sick Ha
 Mitchell and Tirzah Haik
 John and Raquel Hanna
 Milton and Jackie Hardy
 John and Martina Hartmann
 Sean and Helen Healey
 Mary and Larry Heath
 Jeff and Judy Hoffman
 Bonnie and Robert Hutchins
 Shane and Colleen Irvin
 Lila Keleher
 Kristina King
 Joseph Konikowski
 William and Carol Kuell
 Kayla Lackey
 Eugene and Renee Lemmon
 Peg LeRoux
 Larry and Gayle Licari
 Tanner and Jessica Lindsay
 Keith and Heidi Littleton
 Eric and Beth Losekamp
 John and Theresa Maimone
 Steve and Allison McClay
 Leighsa McCommon
 Kevin and Barbara McKee
 Charles and Cecelia Meloling
 Greg and Marguerite Meyer
 Paul and Brooke Miles
 Adam and Olivia Mindle
 Mark Ritchie and Lisa Mingo
 Griff and Cecilia Morgan
 John and Betty Mozisek
 Ilja Mracek and Liana Mrackova
 Sheila Muhlen
 Tony and Lina Nahas
 Louis and Virginia Napoles

Mark Your Calendar

Adult FA Meeting

Hilton Garden Inn

Denver Tech Center, Denver, Colorado

Friday, July 17–Sunday, July 19, 2009

All adult FA patients are welcome! Scholarships are available (application deadline is June 1). Please contact Teresa Kennedy at teresa@fanconi.org or 1-888-FANCONI if you are interested in attending.

Annual FA Family Meeting

Camp Sunshine

Sebago Lake, Casco, Maine

Friday, August 7–Tuesday, August 11, 2009

All FA families and adult FA patients are welcome! Camp Sunshine applications are available at http://campsunshine.org/pdfs/2009_Fanconi.pdf or by telephone at 207-655-3800. Acceptance to the meeting is on a first-come, first-served basis of completed, accepted applications. Scholarships are available through the Fund (application deadline is July 1). Contact Teresa Kennedy at teresa@fanconi.org or at 1-888-FANCONI.

Elvarro and Alicia Navarro
 Jack and Tammy Neal
 Bob & Alice Nicholson
 Ron and Fredi Norris
 Fred and Nancy Nunes
 Kevin and Lorraine O'Connor
 Steve Perkins and Karen Magrath
 Derek and Ginger Persson
 Lori Peterson
 Freddy and Kathy Pharris
 Vicki Phillips
 Tom and Tera Plummer
 Michael and Kay Proctor
 Lynn and Shirley Quilici
 Mario and Yolanda Ramirez
 Jack and Tannis Redekop
 Paul and Rena Rice
 Gail Richardson
 Ben and Shirley Ricker
 Jan and Leonard Riley

Paul and Catherine Rodwell
 Dov Rom
 Les and Nancy Ross
 Steph and Chantel Rossouw
 Rehman and Esmat Saleem
 Chris Scaff
 Severt and Beatrice Score
 Thomas and Brenda Seiford
 Lorne Shelson and Annette Waxberg
 Debby Slater
 Mitzi Speelman
 Greg and Brandi Stuart
 Richard and Janice Thomas
 Mark and Susan Trager
 Steve and Melissa Turner
 Tom and Kathy Uno
 Joe and Wendy Vitiritto
 Sean and Kristin Young
 Marge Zaborney

Your FA Research Dollars at Work in 2008

In 2008, the Fanconi Anemia Research Fund awarded \$1,188,299 in research grants to the following projects:

Investigator: Hans Joenje, PhD and Josephine Dorsman, PhD,
Vrije Universiteit Medical Center, Amsterdam, The Netherlands

Title: *Expression Profiling of Human Cells under Oxidative Stress: Relevance for FA*

Amount: \$145,979

Investigator: Qishen Pang, PhD, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio

Title: *Role of NPM in FA*

Amount: \$80,000

Investigator: KJ Patel, PhD, MRCP, University of Cambridge, Cambridge, United Kingdom

Title: *Reconstituting and Dissecting Monoubiquitination in the FA Tumour Suppressor Pathway*

Amount: \$160,000

Investigator: John Postlethwait, PhD, University of Oregon, Eugene, Oregon; Michael A. Pack, MD, University of Pennsylvania, Philadelphia, Pennsylvania; Alan D'Andrea, MD, A. Thomas Look, MD, and John Kanki, PhD, Dana-Farber Cancer Institute, Boston, Massachusetts

Title: *Screening for Therapeutics in Fanconi Anemia*

Amount: Postlethwait, \$179,128; Pack, \$167,792; D'Andrea, \$150,000; Look/Kanki, \$150,000

Investigator: Weidong Wang, PhD, National Institute on Aging, National Institutes of Health, Bethesda, Maryland

Title: *Identification of New FA-associated Genes and Understanding the Disease Mechanism through Protein Association, Part 3*

Amount: \$55,400

Investigator: Li Zhong, MD, University of Florida College of Medicine, Gainesville, Florida

Title: *Recombinant Adeno-associated Vectors for in vivo Gene Therapy of FA*

Amount: \$100,000

Another Busy Year for Play for FA!

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"Green Jackets," Sean's putting skills were a wonderful asset to the team. There were some fantastic scores posted, but none more amazing than the 18 under par turned in by the winning team from UDIG Technologies. Thanks to the generosity of the sponsors and attendees, we were able to raise over \$11,960 for FARE.

After wrapping up the golf tournament, we planned the Play for FA Wine Tasting and Auction which was held at Bookbinders Grill in Midlothian, Virginia, on November 9, 2008. This year's event included fantastic food and a live and silent auction. The atmosphere at Bookbinders was wonderful and perfectly accommodating for our 80 guests. The restaurant provided a plethora of delicious food and was wonderful to work with. As always, the highlight of the evening was the exciting live auction with a number of great packages, including a trip to Costa Rica, fishing trips, beach houses, and use of the McQueen RV! Thanks to the generosity of the attendees, auction donors, and Bookbinders we were able to raise an additional \$31,772 for FARE.

These events and all the previous ones would not have been possible without the amazing work and dedication of the "Friends for Sean" committee. We would like to thank all the committee members who have helped through the years, but especially want to recognize Pam Watson, Susan Brizzolara, Sandy Kasch, Molly McAleer, Eileen Pilc, Susan Roever, John and Mary Helen Willett, and Danielle Dehmler-Buckley.

Not yet sure what 2009 will hold for Play for FA, but we will keep you posted.... ♦

Heppner Family Foods Asks Patrons to “Have a Heart”

Heppner Family Foods owners, Bert and Kim Houweling, in collaboration with FA parent Kay Proctor of eastern Oregon, supported fundraising for FAREF by selling pink, red, and white hearts that were displayed in their grocery store. Donors wrote their names or messages on the hearts. The campaign ran until right after Valentine’s Day 2009. ♦



Kay Proctor poses with FA Hearts.

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. As the genetic basis of Fanconi anemia continues to be deciphered, your donations are also having an impact on the lives of millions in the general population. We continue to move to the mainstream of scientific interest. To help us in this 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 event, consider asking that donations be made to the Fund in lieu of a gift.

Gifts to commemorate a loved one: Families who have lost a loved one may ask that a donation to the FA Research Fund be made in their memory. The Fund has received many thousands of dollars from caring people who have commemorated loved ones in this way.

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

Matching Gifts: Many employers match the charitable gift of an employee. Ask if employers have taken this initiative to encourage philanthropy. This is an excellent way to double your donation.

Gifts of Appreciated Property: Donors who have property that has gained greatly in value (stock, vacation homes, art items, etc.) can avoid tax liabilities and provide enormous support by donating this property to the Fund. Please contact us for advice and suggestions.

Sales on eBay or Purchases through iGive: If you sell an item on eBay, you can designate that all or a portion of the proceeds be given to the Fund through their non-profit MissionFish program [see www.missionfish.org]. You can also donate to the Fund by shopping online through iGive [www.igive.com].

United Way or Combined Federal Campaign: If you work for an organization that participates in either of these campaigns, consider making a donation and asking your colleagues to do the same.

Donations Online: You can donate via the *PayPal* button in the *Donations* section of our web page (www.fanconi.org) or through www.networkforgood.org.

Donations by Telephone: Call us at (541) 687-4658 or toll free at 888-FANCONI.

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

Technology Lends Success to Fundraising Letter

What does it really take to raise funds successfully? It must take a commitment of time, money, and an extensive network of people. It is certainly not something a person can do alone! Or is it?

FA mother Sharon Harari dispelled all of the aforementioned fundraising myths with her 2008 fundraising letter. Sent out as an email to encourage friends and family to donate to the Fund in honor of her birthday, Sharon's letter was an amazing success. By sending her letter as an email, the cost of materials, printing, and postage was eliminated, and her message was able to reach a large number of people in a short amount of time.

If you think of an electronic letter as impersonal, remember that you can customize it with photos, creative fonts, borders, and any other images that are meaningful to you. Another benefit of distributing your fundraising letter by email is the ability to link to the Fund's "Donate" web page, making it easy for your donors to get in touch with the Fund, and to donate online. Sharon's letter was sent out internationally, but its scope ended up being more far-reaching than she expected. The interconnectedness afforded to us by computers allows us to share information easily, and that's just what some of the recipients of Sharon's letter did. Forwarding takes only a moment's time and effort, and drastically increased Sharon's mailing list. As of March 2009, Sharon's letter raised almost \$9,500, an unexpected and impressive amount!

For those short on time, resources, or anyone who wants to save a tree and try something new, take Sharon's example; you never know what kind of success you may have! ♦

Upcoming Fundraisers for FA Research

2009

April 25: 3rd Annual Croppin' for A Cure, De Pere, WI.

Contact John or Kim Connelly at kimjohnconns@aol.com.

May 10: Fanconi Anemia Research Fund Benefit Concert and Dessert, Eugene, OR.

Contact Lynn Frohnmayer at lfrohnm@uoregon.edu.

June 5-7: 10th Annual Chris Hull Memorial Sigma Pi Open, State College, PA.

Golf scramble. Contact George Hoffmaster at hoffie@comcast.net or (770) 864-6473.

June 6: "Down on the Farm" Arts and Crafts Fair, Campbeltown, PA (5 miles east of Hershey).

9:00am–5:00pm. More info to follow. Contact Brad Martin at bandatreasures@comcast.net or (717) 599-4576.

June 26: 5th Annual Coley's Cause Memorial Golf Tournament, Lakeville, MA.

For more information, please visit www.coleyscause.com.

July 18: 6th Annual FA Golf Tournament, Cedars on Salmon Creek Golf Course, Battle Ground, WA.

Contact: Peg Padden at pegpadpad@hotmail.com.

August 11: Climb for a Cure, Mt. Washington, NH.

Ten-mile hike up the tallest peak in New England. For more information, contact Kevin McQueen at kmcqueen@captechventures.com.

Ongoing

Kaps for Kendall: In memory of Kendall Atkinson, donate to the Fund by sponsoring a volunteer to knit hats for children and adults who lose their hair to chemotherapy and radiation. Contact: Allison and Whitney Atkinson at www.kapsforkendall.org.

Caddy for a Cure: Caddy for a Cure, Inc, generates charitable funds for designated organizations while offering the opportunity to be "inside the ropes" as a caddy for a Tour player at a PGA Tour event. This perfect gift for a golf fanatic offers a one-of-a-kind professional sports fantasy while contributing to genetic disease research. 25% of the proceeds from Caddy for a Cure are donated to the Fanconi Anemia Research Fund. Contact Russ Holden at www.caddyforacure.com.



Volunteers Spencer Shearer, Joe Nelson, Conor Shearer, and Rose Wilson at the 5th Annual Valentine Fanconi Anemia 5K Run/Walk

Annual Valentine Run a Sizzling Fundraiser, Despite Cold Temperatures

The 5th Annual Valentine Fanconi Anemia 5K Run/Walk was held on February 8, 2009 in downtown Portland, OR. Even though it was bitterly cold, there were 700 participants and \$38,000 raised for the Fanconi Anemia Research Fund!

There was sprinting, running, jogging, speed walking, strolling, chatting, eating and shivering... and all for a VERY good cause! The 5K not only raises money for much needed FA research, but also brings awareness of FA to the general public.

There also were 26 people tested and now on the National Marrow Donor Registry! Who knows who out of those 26 might be a match for someone some day?!

We are very thankful to our sponsors: Pediatric Hematology/Oncology - Doernbecher Children's Hospital and Harley Marine.

The following quote from Helen Keller pretty much sums things up: "Alone we can do so little. Together we can do so much."

This event will continue until there IS a cure! Hope to see some of you at the 6th Annual Run: Valentine's Day, 2010! ♦

Learning to Love and Live to the Fullest

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36-year-old woman with few health problems. Contrary to Alejandro, her emotional evolution was very positive; she studied theology and works actively with the church and the community. She is very careful with her body and doesn't smoke or drink alcohol. She also has a very happy marriage with a husband who adores her.

Living with Fanconi anemia in the family has been an experience that has taught me to experience every minute with the most possible joy and to live day by day enjoying every instant. ♦

Kaps for Kendall

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\$12,000 bringing our project total to over \$60,000 and 2,400 hats donated to treatment centers all over the country. Behind these numbers are many amazing people. Donations come faithfully every year so that those still fighting have hope, and many wonderful knitters rally each year to make hats that provide comfort to the sick. We were incredibly honored to be named the beneficiary of the Colorado Avalanche's annual "Sticks n' Stitches" this past January. Knitters gathered at the hockey game while knitting hats for Kaps for Kendall.

Five years since Kendall's death and words cannot describe how I miss her. I feel an incredible ache in my heart to be able to spend time with her. There are days when it is still very hard for me to reconcile to her death. But I remain inspired by her heart and her determination to put up a good fight against Fanconi anemia. Kendall hated her disease yet loved to comfort others. She fought FA as hard as she could, but the fight did not end with her life. Kaps for Kendall will continue to be a legacy of our sister in the hope that we will someday find a cure. ♦

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 step 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.



The Twenty-first Annual Fanconi Anemia Scientific Symposium

OCTOBER 1-4, 2009

Marriott Waterfront Hotel
Baltimore, Maryland



Fanconi
Anemia

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