



FA FAMILY NEWSLETTER

#36

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

Fall 2004



FA families launch their "wish boats" at Camp Sunshine.

Annual FA Family Meeting

Camp Sunshine seemed more welcoming than ever this year. The weather included rain, but no one cared because of the warmth of the staff, the volunteers, the delight in reconnecting with FA families last seen a year ago, and meeting FA families new to the Family Meeting. Forty-three FA families with 63 children attended this year, from the United States, Canada, Germany, Argentina, and Israel. Four adult FA patients also attended. The attendees included newly-diagnosed families, those who had lost a child to FA, those who have had a successful

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Fanconi Anemia Gene Therapy Trial Opens

Medical scientists at Cincinnati Children's Hospital Medical Center are now enrolling patients in the FA-A complementation group for a gene therapy trial. In reports to Camp Sunshine participants and to your editors, Franklin O. Smith, M.D., described the progress of this trial and the anticipation of subsequent clinical trials for patients in the FA-C and FA-G complementation groups. The Cincinnati studies are led by Patrick Kelly, MD, and involve a team of collaborating scientists and clinicians in the United States and Germany with specific expertise in Fanconi anemia and gene therapy.

Smith noted great advances in understanding gene therapy following both successes and setbacks in France with efforts to cure patients with severe combined immune deficiency (SCID). As is true of FA, SCID is caused by a single-gene defect and lends itself to correction by using a newly constructed virus to introduce a correct copy of the gene into the patient's defective cells. Ten of twelve patients were cured of SCID following gene therapy. While two other patients in the French study developed a leukemia-like illness, both these children survive after further treatment. Smith reports

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Fanconi Anemia Cytogenetics Workshop

On June 11 and 12, 2004, the Fund sponsored a workshop on the laboratory diagnosis of Fanconi anemia and on bone marrow studies of FA patients.

Christopher Mathew, PhD, Guy's Hospital, London, chaired the session on *Laboratory Diagnosis*. Susan Olson, MD, Oregon Health & Science University, Arleen Auerbach, PhD, The Rockefeller University, Akiko Shimamura, MD, PhD, Dana-Farber Cancer Institute, and Hans Joenje, PhD, Free University, Amsterdam presented their individual diagnostic protocols, including DEB, MMC, and FANCD2-L. They also addressed mosaicism, including distinguishing lymphocyte mosaicism from true stem cell hematopoietic mosaicism.

The participants discussed the determination of FA complementation groups and mutations, with

specific presentations by David Williams, MD, Cincinnati Children's Hospital Medical Center, Hans Joenje, PhD, and Gerard Pals, PhD, Free University, and Helmut Hanenberg, MD, Heinrich Heine University.

Grover Bagby, Jr., MD, Oregon Health & Science University, chaired the session on *Bone Marrow Studies*. The highlights of this session were the presentations by Heidemarie Neitzel, PhD, Charité Hospital, Berlin, and Betsy Hirsch, PhD, University of Minnesota School of Medicine, on the frequency and meaning of clonal chromosomal abnormalities in FA patients.

This meeting was attended by 27 diagnosticians, researchers, and physicians from the United States, Italy, Germany, The Netherlands, England, France, Spain, Brazil, and South Africa. The sharing of information by these participants and the



David Williams, MD, Cincinnati Children's Hospital Medical Center, leads a discussion on determination of complementation groups.

ongoing collaborations set up at the meeting will be invaluable in improving diagnostic and bone marrow studies for FA patients. ♦

Educational Considerations for FA Patients

At the annual FA Family Meeting, Mary Dasovich, PhD, an educator from Saint Louis University, presented information on the learning issues that may face some FA patients. Dasovich emphasized that it is important to note that learning can be impacted by many factors, not just a learning disability. For example, fatigue because of the disease can cause a significant educational performance deficit. She noted that, because FA is a rare condition, it can be difficult to ensure a coordinated approach to the child's learning disability in particular school districts. Dasovich noted the importance of identifying patterns of strengths and weaknesses and building upon strengths to compensate.

Dasovich reported that her program has funds to provide educational consultation and support on behalf of an FA child anywhere in the United States. The consultation includes the provision of training and support to teachers and the development of professional links between the school, family and agencies dealing with learning disability or other learning issues affecting the school performance of a student with FA. For further information, contact Dr. Dasovich through Suzanne Lauck, Family Support Coordinator, at the FA Research Fund. ♦



Dr. Dasovich discusses educational options for FA patients.

Recurring Clonal Chromosomal Abnormalities

Betsy Hirsch, PhD, University of Minnesota School of Medicine, presented data on the frequency, types, and clinical associations of clonal chromosome abnormalities in FA patients. The data were based on 99 FA patients, of whom 80% were evaluated during assessment for bone marrow transplant. Fifty-six percent of the patients had normal chromosome findings; 44% had one or more clonal abnormalities. The probability of having a chromosome abnormality increased with patients' age: the mean age of those with normal chromosome findings was 9.2 years compared to 14.4 years for those with abnormalities. Seventy percent of those patients 20 years or older had an abnormal clone.

Chromosome abnormalities were identified by standard techniques utilizing G-banding. Fluorescence *in situ* hybridization (FISH) was often

used to supplement the G-banded study to confirm the exact characterization of the abnormality. The vast majority of abnormalities found were structural chromosomal abnormalities resulting in either a net gain or a net loss of chromosome material.

The most frequently seen abnormalities were a gain (i.e., an extra copy) of material from the long arm of chromosome 3, loss of most of the long arm of chromosome 7 or loss of one entire copy of chromosome 7, and gain of material from the long arm of chromosome 1. Of the 44% of patients with clonal abnormalities, 77% involved these chromosome 1, 3, and/or 7 abnormalities.

There was a significant correlation between the hematopathology findings (evaluated by a hematopathologist) and the presence of clonal abnormalities. Two-thirds of patients with abnormal clones were diagnosed



Betsy Hirsch, PhD

with myelodysplastic syndrome (MDS) or acute myeloid leukemia (AML) based on the abnormal appearance (morphology) of the bone marrow cells. One-third of patients with abnormalities had no apparent MDS or AML. Follow-up

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Clone with Chromosome 3 Abnormality Predicts Poor Outcome

The Fall 2002 issue of the *FA Family Newsletter* reported on findings from Germany that a subtle chromosomal abnormality on chromosome 3 was associated with a high incidence of myelodysplastic syndrome (MDS) and acute myelogenous leukemia (AML) in FA patients. At our April 2004 Cytogenetics Workshop, Heidemarie Neitzel, PhD, Institute for Human Genetics, Charité, Berlin, updated participants on the earlier findings.

In the original study, 18 patients had the same subtle abnormality on chromosome 3 (gains of the chromosomal segment 3q26q29); 35 did not. As of June 2004, only 5 patients with this abnormality were alive; 33 of 35 without this clone were living. Neitzel repeated her earlier concerns:

- This particular clone represents an ominous finding in FA patients.
- It does not disappear from the marrow, but becomes more dominant.
- It is often associated with other ominous clones, especially monosomy 7 (8 of the 18 patients also had monosomy 7).
- Patients with this clone should strongly consider a bone marrow transplant.

Routine cytogenetics analysis is usually insufficient to diagnose this abnormal clone. Neitzel stated that FISH (fluorescence *in situ* hybridization) is often necessary for accurate diagnosis. Using FISH with peripheral blood can also detect this clone, but the procedure is too new to use blood alone; one must also examine the bone marrow. ♦



Heidemarie Neitzel, PhD



Frank Smith, MD

FA Gene Therapy Trial Opens

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that scientists now better understand the use of viruses to target the correct cells. The goals of FA gene therapy are to transfer normal copies of the FA-A gene into patients' blood stem cells, with the hope that corrected cells replicate more rapidly than defective FA cells in the bone marrow.

In the case of FA patients, stem cells are first harvested from bone marrow or peripheral blood. A viral vector carries a normal FA gene into the FA stem cells. Corrected cells are

then returned to the patient. **Important note: Smith emphasized the need to collect and freeze stem cells from FA patients before marrow failure.** Otherwise, there may be too few stem cells to allow gene therapy to work with enough efficiency. Cincinnati and other centers are now urging patients and their physicians to consider the advisability of an early stem cell harvest to preserve the option of a later gene therapy procedure.

The Cincinnati gene therapy study has three stated objectives: first, to explore the feasibility of collecting stem cells and securing gene transfer into them; second, to establish the safety of stem cell collection, re-infusion of corrected cells, and the use of competent retroviruses which target appropriate cells; and third, to detect corrected peripheral blood and bone marrow cells in the patient over a substantial period of time.

FA-A patients have been invited to apply to participate in the trial. Patients must have normal bone marrow cytogenetics (within a recent testing period); must weigh greater than 10 kg; must be between ages one and 35; and must have an adequate unrelated donor identified (in the event of a need for a BMT "rescue"). Sufficient CD34⁺ cells (a type of stem cell) must be collected for the trial to proceed.

Prospective patients are excluded if they have a matched sibling donor; if they are currently on another experimental therapeutic agent; if they have a malignancy, clonal cytogenetics or MDS; if they have no identified unrelated donor; or if they are pregnant or lactating.

For additional information, contact Robin Mueller, RN, at robin.mueller@cchmc.org or at 513-636-3218. The entire FA community will be watching for these investigative results with enormous hope and interest. ♦

Your FA Research Dollars at Work in 2004

Through the end of September, 2004, the Fanconi Anemia Research Fund awarded \$567,952 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: \$43,500

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 Lakshmipathy, PhD, and Catherine Verfaillie, MD, University of Minnesota School of Medicine

Title: *FANCC Gene Correction Mediated by PhiC31 Integrase*

Amount: \$86,400

Ear and Hearing Problems in Fanconi Anemia

Jeffrey Kim, MD, National Institutes on Deafness and Other Communication Disorders, NIH, presented information at the FA Family Meeting on the ear and hearing problems that may affect patients with Fanconi anemia. Kim noted that, while the life-threatening problems that affect FA patients require much attention, a complete hearing assessment often is overlooked. Such an assessment is necessary to ensure that the FA patient has adequate hearing.

Kim cited a study of 69 FA patients, of whom 12% had a narrow

external auditory canal; 6% had a small or abnormal outer ear; 3% had low-set ears; and 1% had abnormal bones in the middle ear space which transmit sounds from the air to the fluid-filled labyrinth part of the ear. Although there have been few studies of hearing problems in FA patients, Kim estimated the incidence of hearing loss caused by narrow ear canals or other ear abnormalities in FA patients is higher than reported and noted that these problems can often be treated with hearing aids, and/or surgery. ♦



Jeffrey Kim, MD, presents information on hearing problems in FA patients.

Physician Responds to Medication Concerns

Blanche Alter, MD, MPH, responded to questions about medications posed by FA parents on our FA listserv:

Use of Folic Acid

Many physicians suggest 1 mg. per day, because folic acid is a vitamin that is needed for production of blood cells. It comes from many foods, but is not stored in the body, so that if someone is not eating well, there may be a folic acid deficiency. To my knowledge, there are no side effects at this dose. I have seen a slight improvement in blood counts in some patients. There is NO STUDY of it, so I cannot prove that it is beneficial. However, since folic acid is harmless and might help, I tend to recommend it. Each of you must discuss this with your own physician, and let him or her guide you. Folic acid is inexpensive and can be purchased over the counter (OTC). You may ask for a prescription for it, but some drug plans will not reimburse you for OTC medications.

Fever and Pain Medications

Most physicians recommend acetaminophen (Tylenol) almost exclusively. Drugs such as aspirin and other non-steroidal anti-inflammatories (including ibuprofen), as well as some antihistamines, may cause bleeding. Stomach bleeding can be from irritation of the stomach lining. Bruising, nosebleeds, and other bleeding, including stomach bleeding, may occur because these drugs interfere with the function of platelets in making blood clot. Since many FA patients have low platelet counts, it is best to make sure that the platelets that are present are able to function fully.

Some FA patients have normal platelet counts. In these patients it may be possible to use drugs which we do not use in patients with low platelet counts. However, even people who do not have FA and have

normal platelet counts may bleed when given some of the drugs that I mentioned previously. If this occurs, that drug should not be used. Page 34 of the *2003 Standards for Clinical Care* discussed some of these points.

Our thanks to Dr. Alter for her helpful advice! ♦

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.

The Sun Will Come Out Tomorrow

by Kristin Young

I have to admit that I was a little apprehensive, a little scared. My son had been diagnosed with Fanconi anemia a few months earlier, and we were on our way to Camp Sunshine for the Family Meeting. It's hard to explain why I was afraid. I guess it was knowing that reality was about to rear its ugly head. The reality that my baby was among the other children who had been diagnosed with this awful disease. Knowing that I was about to hear stories of triumph and loss from people I knew were now part of my family, even though we had never met. Realizing that the beginning of a heavy heart burdened with worry for them was about to become a routine part of my life. It scared me.

Yet, it was so wonderful to meet people who understand like no one

else ever could. And although I cried a lot, it was wonderful. It was amazing to see how happy and beautiful all the children were. It was inspiring to see how positive and strong the parents were. I met people who will forever be a part of my life, and I gained a family that I would do anything for. I know they feel the same.

A special part of the Family Meeting was to be able to learn about all the recent discoveries and statistics from experts in the field, yet to combine this activity with talent shows and masquerade parties. My children had the time of their lives, and I know I heard the same from many other families. It was a wonderful experience.

So yes, I still cry for all the children who have to endure things no one should have to go through in



Wesley Young

life, but I'm also so thankful for the chance to have those four days at Camp Sunshine. The chance to meet other families is so important in helping the heart to heal. I know we'll never have to fight this alone. ♦

Attending the Annual Family Meeting is "a Must" for All FA Families

by Mary Ann Fiaschetti

We just attended our very first Family Meeting at Camp Sunshine. Although our five-year-old son, Peter, was diagnosed with Fanconi anemia in February 2000, we couldn't attend previous meetings due to busy schedules. We felt no urgency to attend. Our child is relatively healthy, he has a matched sibling donor, and during the past four years he did not have a social or emotional need to interact with other FA children due to his young age. We read all the newsletters, reviewed the scientific literature and kept abreast of anything that will help us when it is time for a bone marrow transplant. To be completely

honest, attending the previous Family Meetings was not a priority for us. How stupid and naïve we were!

This year was different. Peter started noticing this spring that he is different. He has only four fingers on each hand and everyone he knows has five fingers (except the characters at Disney World!). Peter decided he'd have five fingers too and refused to count the number four. His preschool teacher was bewildered when, all of a sudden, he began counting "1-2-3-5." And, he now asks why, if he is not sick, does he have to have CBCs every three to six months and an annual bone marrow

aspirate? No one else in the family does this. Whenever Peter has a doctor's appointment, he puts his hands on his hips and shouts "I AM NOT SICK!" So, when the invitation arrived to attend the Family Meeting this year, and we learned that school schedules would not conflict, we decided to attend. We packed up ourselves, the two boys, and their paternal grandparents and off we headed to Camp Sunshine in Maine.

What a jam-packed four days it was for all of us! We marveled at how cohesively the agenda for presentations, counseling sessions, and

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Karly's Story

by Nancy Ross

Our daughter Karly was first diagnosed with idiopathic thrombocytopenia purpura at her pre-kindergarten physical when her platelets came back a low 86k. We spent the next 2 years watching her platelets and then her white and red counts decline. Finally in October 2002 she had a series of tests that revealed the shocking result: Fanconi anemia. All of the little symptoms Karly displayed over the years now made sense and fit into the package called FA.

Things moved quickly from there. At age 7, Karly's counts were all low, so my husband and I decided a bone marrow transplant was our best option. We were referred to the Kaiser's bone marrow transplant specialist, Peter Falk, MD, in Los Angeles. Although nobody in our family was a match for Karly, among her 500 registry matches we found the perfect match in a 23-year-old Marine. On March 26, 2003, Karly was transplanted. She did very well and now has excellent blood counts.

We got our first chance to attend the Fanconi Anemia Family Meeting in the summer of 2004. We flew from our home near San Diego, California to the other side of the continent in Maine. This was the first time Karly got to meet kids "like her." It was a wonderful (if draining at times) experience. We were a bit nervous at being first time attendees, but the families were welcoming and supportive. I learned so much and feel more empowered to be Karly's advocate. From Karly's perspective, Camp Sunshine was a blast!! She enjoyed all the activities and made new friends. We are looking forward to going back next year, this time with Karly's dad Les and brother Kyle.

Being 18 months post-transplant, life has gotten back to "normal." Karly is off all medication and remains strong and healthy. Although we know nothing is guaranteed, we feel we've been given the gift of time with her. We

appreciate life so much more now. We spend more quality and quantity time together. We thank God every day for the gift of our precious little girl. ♦



Karly enjoying herself thoroughly with Sully at the Family Meeting.

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.*

*"Each day comes bearing its own gifts.
Untie the ribbon."*

~ Ruth Ann Schabacker

Johnathan Eckstadt

by Ann Eckstadt

We found out that Johnathan had Fanconi anemia when he was three years old in 1993. It was the worst news any mother could ever hear and very hard to accept. Johnathan's counts remained stable until the year 2000 when his hemoglobin dropped down to 5.2, and he had to have his first red blood cell transfusion. We had to choose at that time between a bone marrow transplant or starting Johnathan on the steroid Anadrol to stimulate his red blood cells. We chose to put Johnathan on the

steroid rather than undergo a bone marrow transplant, to buy some more time. We knew that the Fairview Hospital in Minnesota was making rapid progress in unrelated donor transplants and felt it would be better to wait for that reason.

Johnathan responded well to Anadrol for about three years. The side effects of Anadrol include adenomas or tumors of the liver. In August of 2003 an ultrasound and CT scan showed that he had a mass in his liver, and he had to have surgery to



Johnathan Eckstadt



FA families and patients listen to medical presentations at Regional Meeting.

FA Regional Meeting Held in Los Angeles Area

Thirty-two FA patients and their families from the West Coast met on Saturday, May 22, 2004, in Monrovia, CA, for an FA Regional Meeting. Blanche Alter, MD, MPH, National Cancer Institute, provided information on the basics of Fanconi anemia and on the risks of FA patients acquiring solid tumors. David Kutler, MD, New York University, provided specific information on the squamous cell cancers of the head and neck that affect FA patients, and Susan Rose, MD, Cincinnati Children's Medical Center, spoke on diabetes and hormonal problems in FA. Josef Rosenthal, MD, City of Hope, discussed bone marrow transplants for Fanconi anemia patients and provided a tour of the City of Hope Comprehensive Cancer Center. As always, a highlight of the meeting was that FA families had the opportunity to meet each other and share their experiences in dealing with FA. Our thanks to the physicians who gave their time and expertise to the FA families at this meeting. ♦

have it removed. The surgeons found another small tumor of the same nature while in surgery and removed that one as well. Johnathan came through his surgery with flying colors and was back on the basketball court in no time, although he had to stop taking Anadrol for fear he would get more tumors. His blood counts began dropping, especially his red blood cells. Eventually, he had to have monthly red blood cell transfusions.

Johnathan's bone marrow transplant in Minnesota was on July 7, 2004. I asked Johnathan if he was nervous, because God knows that I was! He told me that he was not that nervous and was glad there was a procedure out there that could take his disease away. When the small bag of the new bone marrow was brought into the room, it was a very emotional moment. I thought that the donor had a very big heart to want to donate bone marrow so that my son could live. I remember it described on someone's *Caringbridge* site as a bag of gold. The procedure took only 30 minutes and, then, a new journey had begun. Johnathan hit some rough patches along the way, but he always came through them with a

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Our Experience with PGD

by Katie

We've done eight PGD-IVF cycles, and we're still gung ho and trying. Chloe's counts are OK—not great but not terrible—and we're just praying we'll have the time and money to keep trying until we're successful. As many of you know, PGD-IVF stands for pre-implantation genetic diagnosis in conjunction with *in vitro* fertilization. Chloe was diagnosed with FA at thirteen months and, when we learned of her condition, we were already trying to have another child. We were so grateful to hear there was a way to have another child who we could be assured wouldn't inherit this awful disease. And we were floored to hear that through that process we could help Chloe. Although the process is difficult mentally, inconvenient logistically, uncomfortable physically, and expensive, the potential rewards—a healthy baby and help for Chloe—are priceless.

We didn't know much about the process our first time through, which made it a little harder. Now that we're fully familiar, it has become routine and much easier. The protocols differ from doctor-to-doctor and patient-to-patient, but I'll share our experience in case it's helpful. An IVF cycle takes about six weeks. We did injections of hormones every day during this time. Some of the injections are subcutaneous, and I could do them myself in my stomach. Some of them are intramuscular and Kevin did these for me in my hip. The intramuscular shots are uncomfortable, particularly the progesterone ones, but not really painful.

We typically begin a cycle with two weeks on a drug called Lupron, which simulates menopause and turns your body "off" so that your IVF specialist can manage your reproductive system. Then we begin

two weeks of drugs to stimulate the development of eggs. During these two weeks, I visit our IVF center almost every morning for blood work to check my hormone levels and an ultrasound to check my egg/follicle production. Every night, based on the results of the blood tests and ultrasound, I am told how much of each stimulating drug to inject (there are usually three shots nightly). It is time-consuming for Kevin to mix the medications and prepare the injections. He says he feels like he's back in chemistry class. I don't know if it is a side effect of the medications or the stress of wanting so badly for this to work, but I am pretty irritable during this time. We just try to maintain a sense of humor. After these two weeks of stimulation, my doctor retrieves mature eggs. This is an outpatient procedure done under a mild sleep anesthetic. This is when the hard part begins, mentally. Physically, I take a few Tylenol, rest that day, and take it easy for the next few days.

In five days we know if we have an embryo that does not have Fanconi anemia and is an HLA match for Chloe. The waiting is maddening, as are the bits of information we receive, because the numbers and, therefore, the odds of success just keep going down. Immediately following the retrieval, we learn how many eggs were harvested; the day after the retrieval we learn how many of those eggs were mature and fertilized into embryos. Three days after the retrieval, we learn how many of those embryos are still viable and able to be biopsied for genetic testing (only one cell from the embryo is sent for testing). If there's a healthy embryo that is a match and, if that



Chloe

embryo is still growing in culture at the IVF center, we feel like we've won the lottery. We jump in the car, race to the hospital, and implant the embryo in a painless procedure done fully awake. Then we hold our breath for another 10 days until we have a pregnancy test. During these two weeks of hoping and waiting we're doing progesterone injections nightly and doctor visits occasionally. We find strength in the love and caring of our family and friends.

On our last cycle, we had our first positive pregnancy test result and were elated, euphoric, and ecstatic. Chloe's been asking for a sibling for a year now, and we've been praying and trying for over two. We continued with progesterone injections for three more weeks after the pregnancy test, until we had our first ultrasound. Unfortunately, there was no heartbeat, and our hearts broke again. But you know how strong all of our FA family hearts are, and that there's nothing we can do but glue the pieces back together and keep on going.

Zev Rosenwaks, MD, and his team at Cornell and Mark Hughes, MD, Genesis Genetics Institute, Detroit, have been so good to us. We

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Attending the Annual Family Meeting is “a Must”

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evening activities flowed together. How dimwitted we were to think that we had so little to gain by attending the Family Meeting! It was truly an educational experience.

The presenters were excellent. Each professional was also willing to talk with us outside the lecture to answer specific questions about our child. They were gracious with their time and truly cared for the well-being of Fanconi anemia patients. We were surprised and grateful to gain something medically for our son from the lectures. For instance, after listening to Dr. Jeffrey Kim, we learned that Peter has a slightly defective ear drum that is causing his difficulty in pronouncing certain sounds. We also are trying several ways to increase his caloric and nutritional intake as well as boosting the fiber in his diet, thanks to some suggestions from Dr. Sarah Jane Schwarzenberg. Although Peter has been seen previously by several ENT, audiology, and gastrointestinal professionals, they had not treated other Fanconi anemia patients and were not able so immediately to identify and remedy situations. We extend our deep gratitude to all the presenters who attended this year’s Family Meeting. Thank you.

Enough cannot be said about the “Coping with FA” sessions with Nancy Cincotta. Where on this planet can one sit in a room full of adults who have had to or will have to make life and death decisions about the health of their FA child? Only at the Family Meeting! We sat in awe of the journey many have taken, are undertaking, and are just beginning. How inspiring it was to have adults with Fanconi anemia present also! It doesn’t matter where we are on the journey, we can all provide emotional support for one



The Fiaschetti family having a great time at the Family Meeting.

another. The difficulties we face can only be truly understood by one another. Thank you for providing this forum as well as for all the chocolate, Nancy! It was therapeutic.

The planned activities for the families were memorable. Whenever there was an emotional, heartfelt event (e.g., balloon release and wish boat launch), there was something fun and uplifting following (e.g., costume party and talent show). Although we felt battle-weary by the end of each day from the emotionality of the day’s events, we were ready again the next day for the thrilling roller coaster ride.

As a family, we were truly humbled by the Camp Sunshine staff. The volunteers were so genuinely caring and kind. What remarkable men and women took such loving care of our children and us! The children had a wonderful time on the playground, using the paddle boats on the lake, swimming in the pool, rock climbing, and playing miniature golf, shuffleboard, and volleyball with the camp counselors. Our family will never forget the generosity of

the volunteers. And, the facility itself was perfect.

Every participant contributed to the success of the meeting. However, the most cherished moments we have from our four-day excursion would have to be of the FA children and adults. Each and every one of them is beautiful. They humanize this dreadful, awful disease. And, they empower and inspire us to achieve the unimaginable. The Fiaschettis are proud to be members of the Fanconi Anemia Family.

We were and always will be grateful and thankful to those who contribute to the success of FARE. It is because of your dedication, devotion, and generosity that our loved ones are able to enjoy the successes today that were impossible yesterday. We have now learned as a family how significant an impact the Family Meeting can be to an FA family. Thank you for making it a wonderful experience for which we will be forever indebted. Our advice to any FA family that has not attended a Family Meeting: mark your calendar for next August and make it a priority! ♦

The Long Journey

by Esmat and Rehman Saleem

Ameera Saleem was born in 1985 with an extra finger. At the age of 7 she was diagnosed with Fanconi anemia. We were not aware of this disease and were very thankful to the Fanconi organization and the Family Support Coordinator; they helped us in every step. Ameera was a brave girl and was a big fighter against this disease. She was very active and lively, always smiling, and she never showed that she was suffering from a chronic disease. We went to Singapore in 2000 for her bone marrow transplant, with her older brother as a perfect match, but it was very sad news for us when we learned that he too had Fanconi anemia. His disease is stable.

We came to Canada in 2003, and Ameera had a bone marrow transplant on March 26, 2004, with my husband, a 4/6 match, as the donor. The transplant was done at The Hospital for Sick Children in Toronto. Her first transplant did not engraft, and at day 28 the cells were infused again, but again, she didn't engraft. On June 8, 2004, she contracted pneumonia and her left lung collapsed. On June 21, 2004 she passed away and went to the peaceful world.

We always pray that medical science will find a solution for this disease and that no other family should suffer such a big loss. We pray for Fanconi patients everywhere, that God will bless them, and that they get well soon. ♦



Ameera Saleem

Johnathan Eckstadt

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fighting spirit. He is determined to beat this and get better so that he can do all the normal things he likes to do again, like playing basketball with all his friends and riding his bike to a friend's house.

Johnathan had a lot of faith and determination before and during the transplant. That was, and still is, a big factor for him making it this far. As a mother, it has been hard to see him have to go through all that pain and suffering. I cried a lot of tears and prayed a lot of prayers to get me through it. All I can say to the parents who will have to go through a BMT with your child is stay positive and take one day at a time. My faith in God really helped me through everything as well. I prepared myself either way, and I am thankful that Johnathan has made it this far. He is still not out of the woods, and we have hit a few bumps along the way. He is doing well at this point. Each day that I have with Johnathan is a blessing from God. ♦

In Loving Memory

Kendall Atkinson
5/4/83 – 3/14/04

Emile Kriegler
2/2/92 – 9/12/04

Matthew Lindenmayer
7/3/90 – 4/22/04

Randall McNutt
7/3/84 – 3/3/04

Benjamin Platte
4/29/93 – 2/22/04

Janelle Redekop
4/25/90 – 6/9/04

Glen Russo
11/15/53 – 9/13/04

Ameera Saleem
9/19/85 – 6/21/04

Reid Trager
1/18/88 – 2/27/04

Annual FA Family Meeting

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transplant, and those facing transplant. Some families had attended the Family Meeting since its inception and others were attending—with trepidation that quickly turned into gratitude—for the first time.

As always, FA families were awed by the presentation of experts in all aspects of FA who also gave freely of their time on this special long weekend. The Fund was honored that Blanche Alter, MD, MPH, National Cancer Institute; Akiko Shimamura, MD, PhD, Dana-Farber Cancer Institute; Wolfram Ebell, MD, Charité Hospital, Berlin; Mark Hughes, MD, The Genesis Genetics Institute, Detroit; Franklin Smith, MD, and Richard Harris, MD, Cincinnati Children's Hospital Medical Center; and Sarah Jane Schwarzenberg, MD, University of Minnesota, attended again this year. New presenters included Mary Dasovich, PhD, St. Louis University, who discussed educational considerations for FA patients; Jeffrey Kim, MD, NIH, who made a presentation on



The Nash family enjoying Camp Sunshine.

ear and hearing problems; Thomas Hart, DDS, PhD, NIH, who described an FA Facial Imaging project for possible participation by FA families, and Carter van Waes, MD, NIH, who discussed head and neck cancer.

Families sometimes felt overwhelmed with the wealth of data,

much of it complicated. Yet all were grateful for knowledge that will help them deal with FA. As always, families deeply appreciated the listening ear provided by Nancy Cincotta, MSW, who facilitated many “coping with FA” sessions for parents and children.

The children had a tremendous time. Camp Sunshine volunteers kept them occupied with one activity after another, and the kids delighted in getting to know others like themselves, whether they were FA patients or the siblings of FA patients. Parents and children alike dressed up for the Masquerade Ball, all trooped down to the pond in the rain to sail their “wish boats”—with the fervent hope that their wishes would come true—and the (quite talented!) children performed at the talent show.

The Family Meeting ended all too soon, but families left buoyed by the experience and rich with new friendships. ♦



Performing in the Talent Show.



The Frock kids dressed for the Masquerade Ball.



Showing off their Wish Boats.

Enjoying the FA Family Meeting



The Lauzier family ready for the Masquerade Ball.



FA teens Zach Blecher, Amanda Gleason, and Amy Frohnmayer ready for the Ball.

Honoring the Beloved Memory of Our Fallen Diamond

by Derek Persson

We knew early on that there were going to be some complications with Diamond Ashley's birth. However, we could never imagine the fears and horrors that we would have to live through in her short life. Shortly after Diamond was born on October 16, 2001, the doctors told us that Diamond had a disease called Fanconi anemia. They explained to us that FA is a very rare genetic disorder and that Diamond would ultimately have bone marrow failure and die before she reached adulthood. This news about my first and only child was devastating. While we sat there and watched her those first 30 days in the NICU, we thought that we would never be able to bring her

home. We were very lucky to have a great medical support staff at the hospital. They helped prepare us to bring Diamond home 30 days after her birth, still weighing only approximately 5 lbs.

The geneticist at the hospital referred us to the website for the Fanconi Anemia Research Fund. Our hopes for the future started to change. We realized that we were not the only family out there facing this horrible fight. We went to regional meetings and joined the e-mail group. Words cannot express the support and love that we received from the other families dealing with



Derek and Diamond Ashley Persson

our same problems and concerns.

We planned a dinner/dance benefit in Diamond's honor in the summer of 2002. This was Diamond's "coming out" party. We had kept her secluded from the outside world before this, because of so many unknown fears. This was the first chance for a lot of family and friends to meet her. Looking back, it was one of our best events. We had a DJ play some music and speakers talk about the need for bone marrow donors. We also had a raffle and silent auction. We raised over \$7,000 that night.

Those funds paid medical bills and helped pay for trips to Cincinnati to see Dr. Harris, to Minnesota to see Dr. Wagner, to New York to see Dr. Auerbach, and then to the FA Family meeting in Maine. The knowledge and friendships that we gained through these trips were just amazing. We finally thought that we were on top of the disease and had a good plan for the future.

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Fundraising Assistance

Almost all of the donations (85%) to the FA Research Fund are raised by FA families. If you are not now involved in raising funds for FA research, we very much need your help. The staff of the Fund will be happy to assist you. 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. This insurance 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.

Why Our Family Decided To Raise Funds For FA Research

by Peg Padden

Less than a year and a half ago, our 21-year-old son, Jake, was diagnosed with FA. Our two younger sons, Conor (18) and Spencer (15), were tested to see if they were a bone marrow match for Spencer's transplant. We were so happy when Spencer was found to be a match, only to find out he also had FA. Last July, Jake had a transplant, using a partially matched unrelated donor.

Tragically, Jake did not make it, and he passed away last October. I figured I had a choice. I could lie in bed and cry all day (which would have been very easy to do) or I could force myself to take some action and do something to help Spencer and others with this difficult disease. I e-mailed our doctor (John Wagner) in Minneapolis and asked him if he thought the majority of my time would be better spent working with the Red Cross to get more people on the bone marrow registry, since we still don't have a complete match for Spencer, or to raise funds for FA research. Dr. Wagner said that, although both are obviously important, the most important thing we can do right now is to make transplants safer by funding research.

So I thought, O.K., we'll have an auction. I knew absolutely nothing about putting on an auction, but figured anything we made would be better than nothing. If we made \$1,000, that would be \$1,000 that the Fanconi Anemia Research Fund otherwise would not have. We put the auction on in three months and were absolutely stunned when we made \$106,000.

The money we made was tremendous, but something else happened that we had not expected. Having the auction started a chain reaction with our family and friends. My cousin's



Jake, Spencer and Conor Shearer

son (whom we see maybe once every two years) convinced the company he works for to have their golf tournament raise money for a charity this year. And, of course, that charity was the Fanconi Anemia Research Fund. They made approximately \$2,500. My husband's old friend from law school (whom we see once or twice a year) had a golf tournament, BBQ, and raffle a couple weeks ago and raised \$6,000. Jake's good childhood friend who, at the age of 21 directed a play in New York this summer, is planning on directing another play and having all the money go for FA research. Our niece came up with the idea to get as many people as possible to run or walk the *Las Vegas Marathon* in honor of Jake and, at the same time, get sponsors for Fanconi research. Just yesterday, our 14-year-old niece called to tell us that the club she belongs to had \$106 left over in its treasury, and they decided to give it to the Fanconi Anemia

Research Fund. I'm thinking of putting on a 5K run/walk specifically for Fanconi anemia sometime this spring.

The point is, if you can do anything to raise money for research, do it! It doesn't have to be big. Every bit helps. Obviously, the more people involved, the more it adds up. And, who knows? If you do something, people you know might get the idea to do something. Any amount you raise will go for research, and it is research that can save our children's lives. It does not get any bigger than that. Warren Buffet said it well: "It is not necessary to do extraordinary things to get extraordinary results." ♦

Fundraising Myths

At the FA Family Meeting at Camp Sunshine, FA parent and co-founder of the FA Research Fund, Dave Frohnmayer, discussed the myths and rationalizations that families sometimes use **not** to raise funds. Dave identified such myths as:

- *I can't raise enough money to make a difference.*
- *My friends don't want to help.*
- *I would be embarrassed to ask someone for funds.*
- *It would devastate me if my neighbors (relatives or friends) did not donate if I asked.*
- *It would embarrass my FA child if I were to ask others for funds for FA research.*
- *I need to focus my efforts on bone marrow drives.*
- *I don't know how to raise money.*
- *I don't have the time.*
- *We really need to find a Hollywood celebrity (or athlete) to raise funds for us.*
- *The benefits from research are too far away, so why should I waste my time raising funds?*

Dave pointed out that every dime raised makes a difference, especially since no one else is going to raise funds for FA research if parents do not do it. Foundations and other donors are impressed with a broad donor base, even if individual donations are small. He noted that, just as no one is embarrassed to ask a doctor for help, there is no stigma attached to raising funds for research that can benefit all those with FA.

Dave observed that friends, in fact, do want to help and are eager to donate. While everyone has had the experience of having friends or relatives who do not donate, it is important not to personalize their response as a rejection. These individuals may choose to help in a different way or have their own problems.

Contrary to the myth that fundraising embarrasses a child, Dave and others find that children are encouraged that their parents are trying to advance FA research and pleased to know that others are pitching in to help.

Dave, as a founding member of the National Marrow Donor Program, acknowledged the importance of bone marrow drives. However, many in the general population are conducting those drives whereas few in the general population are raising funds for FA research. If there is a choice between doing one or the other, funding FA research would seem to be more important to our group. Dave encourages FA families to find the time to do both if they can.

When will we ever have “time”? It depends on what we choose as priorities. Dave notes that he and Lynn simply have had to make time in their extremely busy schedules to raise funds. They literally spend days during Christmas vacation writing personal thank you notes to their donors. They make this a priority, as the best use of their limited time.

Dave observed that it is easy, and completely ineffective, to defer one's own responsibility for fundraising to the elusive “Hollywood celebrity.”



Dave Frohnmayer discusses fundraising myths at Family Meeting.

The Fund has benefited from donations from celebrities and billionaires but, even if a celebrity raised funds for us, we would still need the efforts of all FA families, given the high cost of advancing FA research rapidly.

The last myth, regarding the futility of raising funds because the benefits from research are so far away, is not true. The Fanconi Anemia Research Fund may be the single most effective rare disease fundraising group in the world. Since 1989, fifteen short years, FA science has advanced rapidly, simply because of the funds raised by FA parents. Had it not been for their efforts, researchers would not be financially able to study FA, no genes would have been identified, and bone marrow transplant success rates would be extremely poor.

Myths notwithstanding, fundraising by FA families has made **all** the difference. ♦

Family Fundraising Efforts

From January 1 through June 30, 2004, FA families raised \$553,828 for Fanconi anemia research. The Fund also received donations of \$4,154 through the United Way and \$5,057 through the Combined Federal Campaign. Our thanks to all of you who have worked so hard to raise critically-needed research dollars.

\$200,000 and up

Dave & Lynn Frohnmayer

\$100,000 and up

Glen and Peggy Shearer

\$60,000 and up

John and Kim Connelly

\$20,000 - \$60,000

Deane Marchbein and Stuart Cohen

\$10,000 - \$19,999

Andrew and Vicki Athens

Brian Horrigan and Amy Levine

Fred and Nancy Nunes

Mark and Diane Pearl

\$5,000 - \$9,999

Claire Ashurst

Ken and Jeanne Atkinson

Randy and Nancy Bloxom

Donald and Danielle Burkin

Beth and Jeff Janock

Bob and Andrea Sacks

\$1,000 - \$4,999

John and Audrey Barrow

Darryl Blecher and Diana Fitch

Antonino and Marie DiMercurio

Ed and Janice Duffy

Allan Goldberg and Laurie Strongin

Charles and Katy Hull

Erik Kjos-Hanssen and Turid Frislid

Gregory and Lynette Lowrimore

Lorraine and Kevin McQueen

Virginia Napoles

Jack and Lisa Nash

Derek and Ginger Persson

Adam and Laurie Platte

Peter and Janice Pless

Shirley Quilici

Marcia Reardon

Lynn and Rick Sablosky

Bill and Connie Schenone

William and Mary Underriner
Marge Zaborney

Up to \$999

Cherie Bank

Mark and Linda Baumiller

John and Francene Berglund

Diane Bradley

Roel and Diane Brand

Richard Briga

Lynnette Chandler

Floyd and Susan Clark

Tyler and Teresa Clifton

Richard Day

Joseph and Tracey DeMarco

Carol Dillon

Pat and Mary DiMarino

Nathan and Ann Eckstadt

Paige Ellis

David and Mary Ann Fiaschetti

Stephen and Doreen Flynn

Gary and Melody Ganz

Maria and Josh Godwin

Todd and Robin Gray

Alan and Rachel Grossman

Mitchell and Tirzah Haik

John and Martina Hartmann

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Christie and Randy Kelley

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Sheila Muhlen

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Kim and Michael Williams

*“You may have the
loftiest goals, the highest
ideals, the noblest
dreams, but remember
this, nothing works
unless you do.”*

~ Nido Qubein

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).

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

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



Kevin McQueen, team leader, and other FA families plan fundraising efforts at Camp Sunshine.

Fundraising for FA Research: Join the Winning Team!!

In an effort to increase fundraising by FA families, the FA Research Fund has developed regional fundraising teams. Kevin McQueen, Mark Pearl, and Mike Vangel, who are all FA parents and members of the Fund's Board of Directors, have volunteered to develop these teams to provide support to families in their fundraising efforts. Kevin, Mark, and Mike are aided by fundraising team leaders Peg Padden, Lisa and Jack Nash, Kim and John Connelly, Rachel Grossman, Brian Horrigan, Donny Burkin, Patrick Gleason, and Randy Bloxom. The team leaders will be contacting FA parents in their respective geographical areas to assist them with their fundraising plans. ♦

Our Experience with PGD

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truly feel their support and know they're rooting for us as much as our family and friends. For half of our attempts, we haven't had a healthy, matched embryo to transfer, and we know they share our frustration. Statistically, 3 out of every 4 embryos (75%) will not be affected with FA, and 1 out of every 4 embryos (25%) will be an HLA match. Therefore, 25% of the 75% (which equals 19%) will achieve both and be an unaffected match. Since not all of the eggs

retrieved will be mature and will fertilize into embryos, these are tough hurdles. But we truly believe it HAS to work eventually, and we know we'll be successful if we're given the time to try. When the three of us hold that baby in our arms, all of the effort and disappointments will be forgotten and replaced with pure joy. ♦

Recurring Clonal Chromosomal Abnormalities

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studies will be important to determine the time frame between the occurrence of a chromosome abnormality and the development of abnormal morphology. Only 6% of patients with normal cytogenetics had MDS or AML.

G-banded chromosome analysis currently represents the best method for identifying all types of chromosome abnormalities. However, the finding that abnormalities of chromosomes 1, 3, and 7 comprise the bulk of abnormalities seen in the bone marrow of FA patients presents possibilities for supplementing and increasing the sensitivity of screening strategies. For example, if G-banded studies are normal, FISH can be used to rapidly screen additional cells for the presence of 1, 3, and 7 abnormalities. Further, peripheral blood FISH studies might provide a means of screening in between annual bone marrow examinations.

At the University of Minnesota, the following clinical strategy is followed: bone marrow chromosomes are analyzed once per year by G-banding. If an abnormal clone is detected, the finding is discussed with the hematopathologist and treating physician. If there is no MDS or AML present, the bone marrow is then monitored every four months. If there is evidence of MDS or AML, treatment options are discussed. In general, the treating physician considers the presence or absence of abnormal clones, the appearance of the cells of the bone marrow, the availability of a matched bone marrow donor, and the clinical condition of the patient in making treatment decisions. ♦

Honoring the Beloved Memory of Our Fallen Diamond

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We decided to attempt to reconnect Diamond's esophagus, one of her birth defects associated with FA. We thought that we had done all the research and had complete confidence in Diamond's medical team. They advised us that this was a tricky procedure, but was not life-threatening. Unfortunately for my little Diamond, she did not do well post-surgery and passed away on March 29, 2003, before my very eyes.

At this point I thought my life had ended. I believed that I no longer wanted to be a part of the FA family. I wanted to get as far away from Fanconi anemia as I could. But as time went by and we got closer to the one-year anniversary of Diamond's passing, we started to think how we could use Diamond's life story to help others who are facing the same battles. We realized we missed our FA family and wondered how the families that we had met at the regional meetings and the FA Family meeting in Maine were doing. I began again to follow the e-mail group and the newsletters. I realized that, even though my daughter's fight with this horrible disease had ended, we could honor Diamond's memory by raising funds for the FA Research Fund.

So we planned a dinner/dance fundraiser. Our goals were very small, because we knew this fundraiser would be very tough on us following the one-year anniversary of Diamond's passing. A small group of family and friends helped greatly. We brought in a local band and received donations from local businesses. Even with some costs we can reduce next year, we exceeded our goals and were able to donate \$1,500 to the Fund. We developed a scholarship in Diamond's memory that was

presented to a graduating senior from the local high school who intends to pursue a degree in the medical field.

The fundraiser was a big step for us in the healing process. We used Diamond's life story to help educate others on the needs for organ and bone marrow donors. It also helped us to stay connected to another family that was very important to us

during Diamond's life, and that was the FA family. We know our donation was small, but we hope that we can build on this year's success. Every little bit helps and, if each family can just do a little, maybe someday we will find that cure that will save the lives of all of our wonderful children. My heart, thoughts, and prayers continue to be with all of you as you fight this battle. ♦

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. 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: Families who have lost a loved one may ask that a donation to the FA Research Fund be made in memory of the deceased individual.

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 (w)

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 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%, 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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