



FA FAMILY NEWSLETTER

#44

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Fall 2008

New Insights Gained by Your Editors at Camp Sunshine, 2008

Most of the presentations at Camp Sunshine were new to the many first timers at camp, and a helpful reminder to those of us who have attended Family Meetings for years. Here we highlight observations that your editors heard for the first time:

Sarah Jane Schwarzenberg, MD, University of Minnesota, noted that there is no evidence in non-FA patients that high doses of vitamin supplements reduce the risk of cancer. Studies have, in fact, shown toxicities with high doses of some vitamins. In response to a parent's question, however, Schwarzenberg noted that she has been surprised at

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Annual FA Family Meeting

Fifty-two families from the United States, Canada, Israel, Germany, France, Australia, and Colombia traveled to Sebago Lake in Maine to attend the Fund's Annual Family Meeting at Camp Sunshine. They were greeted by a beautifully renovated and enlarged building that clearly has been designed to be kid and family friendly! And, of course, parents and children were greeted by the wonderful staff, volunteers, and other FA families.

Thirteen families attended the Family Meeting for the first time this year. Most were understandably anxious about how they would fit in and, within hours, began to realize that their time at Camp Sunshine would be a pivotal experience for them in dealing with FA. Many parents,

FA patients and their siblings met their counterparts for the first time—an experience of immeasurable value.

Returning FA families delighted in renewing acquaintances with old friends. Many have kept up with each other since last year via the Fund's e-group or through Caring Bridge sites, and many know each other well enough now to be close friends who keep in touch throughout the year.

Best of all, ten FA adults attended, ranging in age from 18 to 38! With advances in treatment of FA, the population of young adults with FA is increasing, which is heartening to all.

Once again, FA families and FA adults were blessed by the presence

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Transplant Update from Minnesota

John Wagner, MD, University of Minnesota Transplant Center, updated attendees at Camp Sunshine on transplant results from his center. Wagner and his transplant team have now transplanted 17 patients with matched sibling donors who had aplastic anemia but not advanced myelodysplastic syndrome (MDS) or leukemia. Radiation was eliminated from this protocol. All patients engrafted; none had acute or chronic graft-versus-host disease. No patient experienced toxicity from the transplant protocol. Two years post-transplant, survival was 100%.

Unrelated donor transplants have presented a far greater challenge. Wagner has now used five different protocols to improve outcomes in this population. With the exception of a trial in the mid-1990s which had only one survivor out of 8 patients (increasing radiation to 600 rads in the hope of improving engraftment) trials have progressively benefited from previous efforts and have led to significantly better outcomes.

Wagner's most recent effort has been an attempt to lower radiation from 450 rads to the lowest level that

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John Wagner, MD

Update of Transplant Results in Berlin

Wolfram Ebell, MD, Charité Hospital, Berlin, stated that the German registry now includes 113 patients who have not been transplanted and 70 who have undergone transplant. Non-transplanted patients continue to live longer than transplanted patients but improvements in transplant outcomes should narrow this difference. Ebell noted that a significant number of FA patients will never need a transplant.

Transplant outcomes for FA patients have improved dramatically over the past 10 years. Ebell attributes this improvement to fludarabine, better matching of donors, enlargement of the donor pool, early diagnosis of abnormal clones, aggressive treatment of infections, and competent follow-up of patients.

Ebell has transplanted 21 FA patients with alternate donors during

the past 10 years. Of this number, 17 were on androgens, 13 had been transfused, 9 had myelodysplastic syndrome and 2 had leukemia. Ebell uses very low dose busulfan but no irradiation in his protocol.

Survival of patients presenting with aplastic anemia or myelodysplasia is excellent at 80% (15 of 19 patients). One of two patients with leukemia survived.

Ebell believes that two specific abnormal clones are associated with a poor outcome if the patient does not go to transplant: those involving a gain of the long arm of chromosome 3, and those involving a loss of chromosome 7. He strongly advises transplant for patients with these abnormal clones.

A history of prior transfusions or use of androgens were not risk factors in these transplants. A critical

challenge for the future remains finding ways to treat reactivation of a viral infection, especially an adenoviral infection. ♦



Wolfram Ebell, MD

Cancer Epidemiology in FA Patients

Blanche Alter, MD, MPH, National Cancer Institute (NCI) presented an overview of cancer in the FA population. Her findings are based on the literature and on four different sources: The North American Survey (NAS), German FA Registry (GEFA), Israeli FA Registry and NCI cohort.

The literature describes 324 FA cancers out of a total of 1,865 reported FA cases. The most frequent type of cancer was leukemia (139 cases), followed by liver cancer (43), head and neck cancer without transplant (36), head and neck cancer after

transplant (18), esophageal cancer (12), brain cancer (23), vulvar cancer (17) and cervical cancer (6). Alter also noted that FA patients are at increased risk for breast cancer.

Median age depended on the type of cancer, but overall was far younger than in the general population. In the NAS and GEFA studies, the risk for any type of cancer was between 52 and 44 times that in the general population.

Studies further suggest that bone marrow transplantation has been a risk factor for cancer. Transplanters are hopeful that improved protocols,

which reduce or eliminate radiation and greatly decrease incidence of graft-versus-host disease, could reduce the early presentation of head and neck cancer. The human papilloma virus (HPV) is implicated in gynecologic cancers and in 25% of the head and neck cancers in the general population. Vaccination against this virus could prevent some of these malignancies in FA patients.

Alter's Powerpoint presentation is available on the Fund's website (www.fanconi.org). ♦

Gynecologic Issues for Girls with FA

Dr. Jill Huppert from Cincinnati Children's Hospital Medical Center presented information about typical adolescent gynecologic (GYN) issues and reproductive health that relates to all girls. She identified factors that could specifically concern FA females, such as the impact of androgen therapy, thyroid problems, and weight issues. If a girl is underweight, suffers from a chronic illness or is on androgen therapy, puberty might be delayed and/or menses may be irregular. For all females, family history also influences the onset of puberty. In some cases of anemia, a physician may recommend suppression of menstruation.

Additional concerns arise for FA females after the adolescent years. Due to decreased fertility, a variety of family planning options may be desirable, including advanced assisted reproductive technology strategies. Because premature ovarian failure is a concern, FA females who want to become pregnant should not delay

childbearing. Women should be evaluated earlier for infertility treatments than would be recommended for someone without FA.

Prevention of and surveillance for GYN cancer is crucial. Dr. Alter has reported that FA females have an earlier onset of GYN cancers (vulva, anus, cervix) compared to non-FA females. The mean age of onset in the FA female population is age 22-27, while the mean age of onset in the non-FA population is age 47 for cervical cancer and age 72 for vulvar cancer.

All females should avoid infection from certain types of the human papillomavirus (HPV). HPV is recognized as the major cause of cervical cancer, and studies also suggest that HPV may play a role in cancers of the anus, vulva, vagina, and some cancers of the head and neck. An HPV vaccine (Gardasil) is now available and recommended for females age 9 to 26. Other HPV prevention measures are to avoid smoking and



Jill Huppert, MD

to practice safer sexual behaviors such as abstinence, monogamy and condom use.

Three gynecologists met at the April 2008 Clinical Care Conference in Chicago and contributed to

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Head and Neck Cancer – Prevention, Surveillance, Treatment

The risk of Head and Neck Squamous Cell Carcinoma is high in FA patients

Dr. Bhuvanesh Singh, Memorial Sloan-Kettering Cancer Center, New York, noted that head and neck squamous cell carcinoma (HNSCC) occurs in FA patients about 500 times more often than in the general population, according to a study of the International Fanconi Anemia Registry. No other known genetic disorder is so closely associated with this particular type of cancer. The age of onset in FA patients ranged from 15 to 49 years (with a median of 31 years) versus 50 to 60 years (with a median of 53 years) in the general population. By age 40 there is a 21% incidence of HNSCC in FA patients.

The development of HNSCC is not associated with any particular type of Fanconi anemia mutation. The location of HNSCC was most frequent in the oral cavity (65%) versus the larynx, hypopharynx and oropharynx (each at 10%). This is a different pattern of occurrence than in the general population.

Prevention Tools

Dr. Singh emphasized the following ways to address the risk of HNSCC:

- **Do not use tobacco.**

It takes 30 years to eliminate most of the damage to mouth tissues caused by chronic exposure; tissues are never completely free of damage caused by smoking. In the general population, smoking is closely associated with head and neck cancer.



Bhuvanesh Singh, MD

- **Do not drink alcohol.**

In laboratory studies, alcohol causes damage to the epithelial tissues of the mouth. FA patients have an inability to repair certain types of DNA damage. Thus, even a little exposure to alcohol could increase the risk for head and neck cancer. *At the most, patients should limit alcohol intake to no more than one drink a month. Anything more puts FA patients at unnecessary risk.*

- **Avoid second-hand smoke exposure.**

- **Do not use mouthwashes containing alcohol.**

- **Maintain good oral hygiene.**

The HPV vaccine may prevent certain HNSCC's. This vaccine is extremely effective in preventing HPV and is extremely safe. HPV is a virus that has been associated with approximately 25% of HNSCC's in the general population. This vaccination may help reduce the risk in FA patients. While many insurance companies will pay for the HPV vaccine in females ages 9 to 26 because of the role HPV plays in cervical cancer, it may be more difficult to get coverage if you fall outside this definition. *Dr. Singh has written a letter explaining the need for this vaccine in FA males as well as females*, which may persuade insurance companies to cover this cost. The Fund can provide families with this letter.

Detection of problem areas early while they are treatable

A qualified examiner should do a routine head and neck screening of an FA patient twice a year in order to detect lesions before they become aggressive. The health care professional performing the screening could be an ear, nose and throat specialist, an oral surgeon or other doctor experienced in head and neck cancer detection and treatment. Screening should include a regular endoscopy (a flexible fibre optic examination of the voice box).

Treatment of Head and Neck Cancer in FA patients

Surgery is well tolerated and remains the mainstay of treatment because patients with FA are especially vulnerable to radiation therapy and chemotherapy. Ideally, the patient should be treated at a highly experienced center, since the initial surgical treatment is so crucially important. If radiation or chemotherapy is indicated, a doctor extremely experienced with Fanconi anemia treatment must administer it in order to address the patient's sensitivity to DNA-damaging agents.

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Treating Precancerous Lesions of the Vulva with Topical Imiquimod

A study appearing in the April 3, 2008 issue of the *New England Journal of Medicine* suggests that a topical drug, imiquimod, can be helpful in treating vulvar neoplasia in non-FA diagnosed patients. Your editors submit a summary of these findings to encourage discussion between FA patients suffering from this complication and their physicians. This drug has never been in clinical trial in FA patients; therefore, we do not presume to recommend its use at this time.

In an article entitled "Treatment of Vulvar Intraepithelial Neoplasia with Topical Imiquimod," researchers describe a study that accrued patients from the Academic Medical Center of the University of Amsterdam and the Erasmus University Medical Center of Rotterdam, The Netherlands, between April 2001 and July 2003. Fifty-two patients with grade 2 or 3 vulvar neoplasia (47 had grade 3) were randomly assigned to receive either imiquimod or a placebo, applied twice weekly for 16 weeks. Most of these patients had already undergone surgery (almost half had had repeated surgeries) to remove vulvar lesions.

At 20 weeks, lesion size was reduced by more than 25% in 21 of the 26 patients (81%) treated with imiquimod and in none of those treated with placebo. The lesions completely disappeared in nine of 26 imiquimod-treated patients and were reduced by more than 75% in five. All patients with a complete response after treatment with imiquimod at 20 weeks remained free of disease at 12 months.

Almost all of the patients in this study were positive for HPV before treatment began (50 of 52 patients or 96%). HPV cleared from the lesion in 15 patients in the imiquimod group as compared with 2 in

the placebo group. Imiquimod acts by stimulating an immune response against HPV.

Side effects were considerable. Twenty-four of 26 patients on imiquimod reported vulvar pain, compared to 7 patients on placebo. Physicians noted increased redness, skin abrasion and fluid accumulation in approximately half of patients on imiquimod, whereas only 2 non-treated patients experienced redness. However, imiquimod appeared to improve quality of life following treatment. Severe itching and pain were lower among treated patients

than those on placebo, both right after treatment and one year later.

Your editors know of no study or of any anecdotal cases of FA patients using imiquimod or any other topical therapy for vulvar neoplasia. We have no data on how FA patients would respond to this medication. Laser surgery (for more superficial lesions) and surgical excision (to remove a deeper neoplasia) are commonly used for this complication. Recurrences can occur, because surgery may not eliminate all precancerous cells and does not eliminate HPV, which causes many of these cancers. ♦



Participants at the Consensus Conference

Consensus Conference to Update *Fanconi Anemia: Guidelines for Clinical Care*

On April 10 and 11, 2008, physicians expert in the care of Fanconi anemia patients met in Chicago, IL to arrive at consensus on the optimal guidelines for the medical care of FA patients. This conference will result in the publication of the third edition of the handbook, *Fanconi Anemia: Guidelines for Clinical Care*. The first edition (in 1999) and the second edition (in 2003) were prepared through similar consensus conferences. Eva Guinan, MD, Dana-Farber Cancer Institute, expertly chaired all three meetings. The updated edition, printed in English and Spanish, will be available to all FA patients and their physicians worldwide by the end of the year. ♦



Darryl Blecher and Bob Sacks

Dealing with Health Insurance: Helpful Suggestions by Two FA Parents

Darryl Blecher and Bob Sacks are health insurance consultants and parents of FA children. They spoke to FA families at Camp Sunshine, shared helpful tips on dealing with insurance providers, and answered families' questions.

Several years ago, Darryl prepared a booklet entitled *Communicating with Health Care Providers*, which he distributed this summer to families in attendance. Bob also distributed copies of a slide presentation on "7 Steps to a Paid Claim."

Darryl's booklet is a concise primer on progressive steps to take when one faces a claim denial. Bob's slides illustrated the steps taken by various experts and other FA families in getting a child's treatment covered by insurance or negotiating a large discount from health care providers. These steps are rarely taken by denied claimants despite the fact that they are successful about 50% of the time in getting a denied claim paid.

Families were given time to ask questions. Issues raised included getting an insurer, a claims processor of a self-insured plan, or a public official

in charge of state Medicaid to understand the medical necessity of certain procedures for a rare disease like FA, or to pay for specialty care that might be outside an HMO or PPO network of participating providers.

One parent asked a Family Medical Leave (FMLA) question during the session. Darryl observed that rather than take unpaid FMLA days it might be more beneficial to ask your employer to allow fellow employees to donate their paid time off days to you. This would allow you time off on a paid basis.

You may request copies of the booklet and slide presentation by emailing teresa@fanconi.org or by calling 1-888-FANCONI or by downloading them at www.fanconi.org. Click on Family Services in the left "Site Navigation" column. Then click on "Annual Family Meeting" in the pull down menu. You may also contact Bob Sacks with your questions at 800-638-1134, ext. 309, or Darryl Blecher at 412-874-8103, who will either answer them or direct you to the right resource. ♦

Study Finds Ashkenazi Jewish Carriers of *FANCC* Not at Increased Cancer Risk

An article in the December 2007 issue of the *Israel Medical Association Journal* concluded that Ashkenazi Jewish Carriers of *FANCC* were not at increased risk for cancer. The paper, entitled "Prevalence of Breast and Colorectal Cancer in Ashkenazi Jewish Carriers of Fanconi Anemia and Bloom Syndrome," was the result of a collaborative study involving seven researchers, six from Israel and one from Nova Scotia, Canada.

The aim of this study was to estimate the cancer rate, particularly for breast and colon cancer, among Ashkenazi Jewish *FANCC* and *BLM* carriers and their families over three previous generations. Researchers studied 42 *FANCC* carriers, 28 Bloom Syndrome (*BLM*) carriers, and 43 controls, all of Ashkenazi Jewish ancestry. Controls were participants in a prenatal genetic screening program who tested negative for *FANCC* and *BLM*. Participants filled out a questionnaire regarding their own and a three-generation family history of cancer. In addition to the carriers, the study included 463 relatives of *FANCC* carriers, 326 relatives of *BLM* carriers, and 503 family members of the control subjects.

The researchers found no significantly increased prevalence of malignancies among carriers and three generations of their relatives compared to the controls. ♦



Susan Rose, MD

New Insights Gained

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the number of FA patients who are deficient in vitamin D. She advised that FA patients be tested for blood levels of this vitamin and, if deficient, that they work with their physician to arrive at the appropriate supplement level.

Dr. Schwarzenberg noted that 27% of FA patients are overweight or obese. This condition is associated with abnormal blood fat (lipid) accumulation and a higher risk of diabetes. Careful attention to diet and exercise and special monitoring by a physician are essential.

Some FA patients have had their own bone marrow harvested and frozen, hoping that these cells could be used at a later date to rescue advanced aplastic anemia or perhaps be used for gene therapy. A few anecdotal reports at our family meetings have suggested that bone marrow cells have not been viable after long periods of cryopreservation. However, Dr. Wolfram Ebell, Charité Hospital, Berlin, reported the successful use of harvested cells with two FA patients. In both cases, patients

were given back their own bone marrow cells when they became severely aplastic (one following chemotherapy for leukemia). These cells engrafted, boosted cell counts, and enabled both patients to proceed to a successful bone marrow transplant.

Susan Rose, MD, Cincinnati Children's Hospital, has found that FA patients with abnormal thyroid levels grow "significantly better" on thyroid hormone than on a placebo. *Children age 3 and younger benefit most from this therapy*, suggesting the value of early endocrine testing and subsequent thyroid hormone therapy for this population.

We reported previously that FA patients appear to be at high risk for osteopenia or osteoporosis at a very premature age. However, Dr. Rose cautions that the DEXA scan, which tests for bone density, must take into account a patient's *height*, not just *age*, or the results can be misleading. FA patients are often quite short for their age, and may appear to have more bone loss than they actually have if compared to their taller age mates. A DEXA scan looks at bones as if they were flat, so taller people with bigger bones appear to have greater bone density. Rose evaluated the DEXA scans of 21 FA patients between the ages of 8 and 23 (average age was 13 years). When compared to their age mates, 6 of 21 were found to have bone density below the 5th percentile for age. However, when bone density was adjusted for height, all but one (who had received prolonged steroids after transplant) were in the normal range.

Dr. Rose emphasized that all FA patients should be placed on a healthful diet that avoids concentrated sweets and excessive sugar intake, following the guidelines of the American Diabetes Association. This recommendation applies only to concentrated sweets like juices, soda pop and candy and not all forms

of carbohydrate. It is important to ensure adequate caloric consumption and regular exercise.

John Wagner, MD, University of Minnesota, described post-transplant complications in FA children, including poor thyroid function after radiation, cataracts in some patients, and fertility failure. Some patients experience high cholesterol post-transplant and should be placed on cholesterol-lowering medication in order to prevent later heart disease. Some FA patients absorb iron inappropriately even without having had a single transfusion, so iron levels must be evaluated in all patients. Liver function abnormalities are common post-transplant. Patients should undergo DEXA scans to evaluate bone density and be placed on calcium plus vitamin D-25, if deficient. Wagner stated that three patients transplanted at his center have developed cancer post-transplant. Cancers were laryngeal cancer, small cell lung carcinoma and salivary gland carcinoma. ♦

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.*

Medical Care Tips and Updates

Participants at Camp Sunshine heard presentations by numerous medical care specialists. For those wishing more specific information on a presentation, the editors refer you to the Fanconi Anemia Research Fund website (www.fanconi.org), where we have posted PowerPoint presentations or summaries of talks submitted by the presenters below. In addition, the office can mail you their summaries or copies of PowerPoint presentations.

***Fanconi Anemia 101* by Blanche Alter, MD, MPH, National Cancer Institute, Bethesda, Maryland**

Alter provided a thorough summary of medical literature findings about FA and related disorders; characteristics of FA; recent discoveries at the basic science and clinical levels; and an overview of care and treatment choices for patients. Alter concluded with basic information about enrollment in the NIH Inherited Bone Marrow Failure Syndromes study of which she is a leader (marrowfailure.cancer.gov).

***Fanconi Anemia: Treatment and Management Considerations* by Akiko Shimamura, MD, PhD, of the Fred Hutchinson Cancer Research Center and Children's Hospital, University of Washington**

Shimamura gave detailed information on how to measure and monitor the numerous complications experienced by FA patients, and analyzed the most recent data on treatment options. Her expertly informed overview is highly useful for treating physicians and families.

***Gastrointestinal Tract and Fanconi Anemia* by Sarah Jane Schwarzenberg, MD, University of Minnesota Children's Hospital, Fairview, Minneapolis, Minnesota**

Schwarzenberg appeared by interactive videoconference and presented a comprehensive overview of symptoms, tests and treatments that are relevant to FA patients who experience gastrointestinal (GI) problems or distress. While approximately 7% of the FA patient population have inborn anomalies of the GI tract, far larger numbers suffer from appetite issues, poor oral intake, pain, reflux, nausea or "failure to thrive." Schwarzenberg explored appropriate methods to test and evaluate symptoms, treatment options, growth issues and supplemental feedings. She also reviewed GI issues stemming from androgen use and post bone marrow transplant management issues.



Akiko Shimamura, MD, PhD

***Endocrine Status in Fanconi Anemia* by Susan R. Rose, MD, Cincinnati Children's Medical Center, Cincinnati, Ohio**

Rose noted the startling statistic that, in her study, *over 80% of children and adults with FA have at least one abnormal endocrine test result.* Rose believes that the endocrine status of FA patients should be monitored on an annual basis. A significant number of FA patients have small stature (about 50%), low growth hormone test response, mildly abnormal thyroid levels, and slow insulin release with some insulin resistance. Many patients may develop high blood sugar or diabetes mellitus. Based on her thyroid study of 8 FA patients, Rose believes that FA patients with abnormal thyroid levels (about 67% in her study) grow better on thyroid hormone therapy.

***Preimplantation Genetic Diagnosis (PGD)* by Dana Pauling, MS, CGC, Reproductive Genetics Institute (RGI), Chicago**

PGD makes it possible to diagnose genetic diseases and HLA status in fertilized eggs, before a pregnancy occurs. Twelve FA families have worked with RGI to achieve a healthy pregnancy. These families experienced 42 *in vitro* fertilization cycles. In total 24 embryos were transferred to the mother, resulting in 7 pregnancies. Six healthy babies have been born (including one set of twins) and two pregnancies resulted in miscarriage. Based on this very small sample, chances of achieving a successful birth were 16% per cycle (~29% if an embryo was transferred). Success depends on the age and fertility characteristics of each couple and if they are doing additional testing like HLA matching and screening for other conditions (such as Down Syndrome). Preimplantation genetic diagnosis is expensive, and insurance is unlikely to cover the cost. The total cost is \$20,000–\$25,000 for each reproductive cycle, plus additional start-up fees.

Our Journey with Fanconi Anemia

by Donny Burkin

Our journey with Fanconi anemia started when our daughter, Hope, was born on May 9, 2000. Although she was not diagnosed with FA for eight months, we knew there were major problems with her health.

The first four years seemed like a blur. Hope had had numerous operations and procedures done to her body to help her survive: from the simplest of procedures like removing an extra thumb on her right hand to life-threatening surgeries like repairing two holes in her heart. As I look back now, how did she (and we) make it through all of that?

Hope has recently been pretty healthy. We haven't had any emergency runs or surgeries in a few years and have felt pretty lucky. The only issues that we have are related to her food intake and her body size. Hope does not eat much during meals, so she has nourishment provided to her through her gastric tube. Each night when we hook her up to her pump, I curse Fanconi anemia for what she was born with. However, each morning when she wakes up and we unhook her from the pump, I am very grateful that the pump has given her one more day of life. She does get tired quickly, both at school and at play. Her school and teachers have been very accommodating.

As a 37-year-old man, I have learned many life lessons from my 8-year-old. I can count on one hand how many times Hope has been in a bad mood. We are fortunate to have a child who doesn't let things bother her and who thinks of other people before herself. One quick example was when we were at my

uncle's funeral. A woman was crying and Hope walked up to her, tugged on her dress, and said "If you pick me up, I'll hug you and make you feel better." What else can I ask of a child? She has this aura about her that she is put on this earth to heal us and make our lives better.

Last summer we gave Hope the choice of where she wanted to go for vacation. She has been to Camp Sunshine a few times, with her 5-year-old sister Grace. Without hesitation Hope chose to go back to Camp Sunshine. Her reason was simple: her 3-year-old twin siblings (Clara and Isaac) have not been there yet.

So we drove the whole family to Maine this past summer. This trip, by far, was the best experience my family has ever had. All four of my children cried when we left. Camp Sunshine is a truly special place.

Attending Camp Sunshine is great for parents as well. It feels like a "reunion." People look forward to seeing each other each summer, as if it is a need in their life. For those families who have lost a child to FA and still attend Camp Sunshine, God bless you! I find it helpful to talk with others who have gone through experiences that I may go through in the future. It is such a nice feeling when people want to share their personal experiences with FA, as if they were a mentor for me.

I am scared to death about what the future holds for Hope. Even though we were working with hospice when she was born, and she was life-flighted to Michigan when she was five, nothing will compare to the emotions and fears that we will



Hope Burkin

probably go through in the future. I don't even know if Hope completely understands Fanconi anemia and all that comes with it. If she does understand it, she doesn't care about it. I have had many people tell me how Hope has touched their lives, from giving hugs to cute little smiles. I truly believe that God put her in my life to make my life more meaningful.

To raise funds for FA research, our family has held many functions, from a Cow Plop to a Casino Night, and we are so grateful for all the contributions from our friends and family for research into FA. ♦

My FA Journey

by *Christophe Bichet*

Hello, my name is Christophe Bichet. I'm French, 23 years old, and have worked for two years as a rock-climbing instructor. Some may think that my small size (4.92 feet) might be a problem for such an activity, but I'm rather fond of everything which looks like crawling on a non-horizontal surface, including canyoning and mountaineering. And, sometimes I hop off a plane with a chute luckily attached to my back, just to experience what falling for 50 seconds really means.

Unluckily, you cannot escape bad weather when you live in France, so I've found other hobbies to avoid my fingers getting bored. I've been playing piano and violin for 15 years. Music has become a kind of a therapy when I have to face difficulties in my life—and happy moments too—and allows me to let my feelings come out more easily.

Another hobby is close-up magic. I'm not specialized on the disappearance of big objects (Eiffel tower or gorgeous women) or mind-reading, but I might be able to make you smile with much more interesting objects, such as cards, coins, rubber bands, pens, pills, wedding rings (extra price for disappearance!). I like the idea of being able to do something I really enjoy wherever I am—except for the piano, which is a bit more complicated to carry when trekking on Indonesia's volcanoes. When I manage to bring people to forget their daily preoccupations, I think that's already not so bad.

Whoops! I forgot to tell that I also have quite a few health difficulties because of FA, which was diagnosed when I was four years old. To sum up:

From 5 to 11 years old, I had many transfusions and took androgens, which made me run much



Christophe Bichet with FA friends Jo Box and Maria Ribero-Rodriguez at Camp Sunshine.

faster than everybody else in my school. My two brothers were not compatible to be donors for my bone marrow transplant, but eventually a matched donor was found in 1997 in Greece when I was 11. Alleluia! It was just about time, as I could no longer walk up more than three stairs. I faced a few complications but finally, considering I had had many transfusions, the transplant was an incredible success, all the more so because I never took cyclosporine due to low kidney function and had nearly no GvHD. After 8 months, I went on with my studies until the baccalaureate. During this period, I don't remember any major health problem.

That being said, I still had to deal with the fact that I constantly felt a huge gap between other people of the same age and myself. It was definitely hard to cope with, and to accept and understand why was really tough, particularly because for about 10 years after the transplant, my life was as normal as you could dream of. I, indeed, managed to totally forget the

fact that I had a disease! Or, at least, that's what I thought!

In my innermost thoughts I think I was actually trying to hide the fact that I was different. It slowly, but surely, became impossible to keep inside me. I believe that, beyond medical considerations, this may be one of the reasons why my mouth cancers appeared in June 2007. For sure, I was psychologically somewhat in trouble, even if my skills as a magician made concealing it a bit easier. Ahah! I thought I'd be able to deal with this problem alone, without asking for help. Big mistake! Concealing your thoughts is really a bad thing to do. Your body will remind you one day or another. We do have to express our thoughts, especially us, FA extraordinary people!

The appearance of mouth cancers shocked me. I was forced to look at reality. This woke me up and helped me start really adjusting my approach to people and life and, thus, to myself. I realized that the idea of sharing feelings with other

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Life with Fanconi Anemia

by Brooke Miles

February 1, 2007, started out as one of the most exciting days in our house. Our 3½-year-old son, Jasper, was to start kindergarten. He was beside himself, and I was a very anxious mother! To stop my suffering from separation anxiety, my mum and I went shopping. All was well until I got THAT phone call.

Jasper's birth was induced four weeks early as he was not growing *in utero*. He was 4 pounds (1.8 kg) when he was born and later really struggled to put on weight. He had a thumb that was just not "normal" and another rare physical anomaly.

After many blood tests and negative results over the early years of Jasper's life, we received the phone call that changed our lives forever. Fanconi anemia was introduced into our lives.

Frantic searches of the Web left my husband, Paul, and me scared and very frustrated. All the usual questions raced through our minds: "Why him?" and "What next?"

Our first meeting with the oncology specialist left us feeling a lot better and relaxed. We were told that, if there was something to worry about, we would be the first to know about it and, in the meantime, just live a normal life. I don't know what "normal" is for other people but, for us, it is frequent blood tests, annual bone marrow biopsies, and spending a lot of time explaining to Jasper's school, doctors and dentists why we are asking for things that are not "standard."

Some of our other "normals" include changes to work conditions. Previously I worked full-time, and my husband Paul was based in Perth (where we live) and only needed to fly on business when it was absolutely required. Since the FA diagnosis, I have left my job, and Paul is away every workweek and only home on

the weekends. This means that he misses out on the little things you treasure, like Jasper learning to recognise letters and numbers or telling a new joke, and the cuddles and kisses. He also misses out on the blood tests and biopsies. But, like a lot of FA families, sacrifices have to be made, whether we like it or not.

The hospital visits get easier for all of us each time we go. The hard part is when Jasper says that he does not want his "Fanconi bugs" and wants to be like the other kids in his class. He does not like being the small-

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Jasper Miles

My FA Journey

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people helps us a lot. I used to listen to what other people had to say, but didn't express myself. I also understood that helping other people was the most rewarding feeling I've ever had.

Quick information about the cancer interlude: First, double mouth cancer on the tongue and palate (one is not enough, two is much more impressive!) in June 2007, both handled by surgery. Note that I had unconsciously delayed the testing of a strange-looking spot on my tongue, in spite of warnings from my parents. Do not make that mistake; test early!

Second, mouth cancer on the tongue (only one that time, but much bigger—ahah!) in October 2007, handled too by scissors and compresses. I still could eat and talk almost normally, after some initial worries. By the way, I unexpectedly became more talkative than I've ever been!

Third, the last cancer on the palate in January 2008. Getting nervous

about the next step, we embarked in February 2008 into a light chemotherapy, although it is really untested on FA patients. I asked for the chemo to be stopped in August, as I felt that my body could not take it any longer and needed a rest, but the fact is that, combined with a better psychological balance, I did not need another surgery over that period.

My message to you all would be that having as "normal" a life as possible is extremely important. Stay in touch with your friends, FA friends, family, work colleagues, etc. Ask them to help you when needed and listen to what they try to tell you. See that whatever problem you have, there's always either a worst potential problem or someone who is worse off than you. Listen to your body, help it cope with FA, with the help of your mind, and with the help of sound nutrition, some exercise, and so on.

And most important of all, I wish all of you to always try to keep your hopes up and stay positive. Life is so fleeting that we are already lucky to be here, and we do have to enjoy every minute we spend down here. ♦

Stuart Kasting

by Meg Kasting

I remember returning from Disneyland in 2005 and, while looking at Stuart, thinking how tired he appeared. During the vacation, Stuart often needed to be carried and we were frustrated with his unwillingness to eat. We had a busy couple of weeks coming up in preparation for school, including getting a new set of ear tubes for Stuart. We did not realize how drastically our lives would change in the upcoming month.

Stuart's health issues, some normal and some kind of weird, were always manageable. In hindsight, several of them were clearly related to Fanconi anemia: small size, limited appetite and middle ear hearing loss. The blood counts for the pre-op for the ear tube surgery were low across the board and quickly led to the Fanconi anemia diagnosis.

Dr. Yoav Messinger at Children's Hospital in St. Paul was wonderful. He took a detailed history, examined Stuart and said it was clear to him that Stuart was going to need a bone marrow transplant and, while he could be wrong, he suspected that Stuart had Fanconi anemia. I guess we were stunned. I listened to the doctor and understood we needed to get a bone marrow aspiration to check for leukemia and chromosome breakage and plan from there. Yet, I was happy for Stuart and his brother that we were still able to take a planned extended weekend vacation before the aspiration. But, when Dr. Messinger gave us warnings to come straight home if Stuart started bleeding from the ears, mouth, and nose, I was dumbfounded. I really thought Stuart was just fine, perhaps a bit anemic from not eating well, but we could shape him up with help from a dietician. We were in the denial and stunned stage of diagnosis.

It was hard to learn more about the disease. I am grateful we had the book, *Fanconi Anemia: Standards of Clinical Care*, which Dr. Messinger happened to have, and the Fund's website to educate us. I also came to appreciate that we were fortunate to be in Minnesota for treatment. In pretty short order, Stuart had been referred to Margaret MacMillan, another great physician with a wonderful bone marrow transplant team.

Transplant came quickly for Stuart, almost one year from the date of diagnosis. He had an 8/8 unrelated donor match. One cool thing is that when Stuart was in the hospital, he got to meet Lance Armstrong, and he still talks about that today. Stuart's transplant journey was a marathon (Dr. MacMillan gave that analogy, and she was right), but everything became manageable if we just broke it down into tasks to be done. A spreadsheet with everything listed was our personal equivalent of a to-do list, with satisfaction gained by filling in the squares. We celebrated notable events along the way: transplant day, engraftment, getting out of the room, release from the hospital, getting off insulin, getting off TPN, getting to 100 days post-transplant, finishing drugs, one year post-transplant, return to school, and removal of the Hickman line, etc.

Stuart is now two years post-transplant and doing great—fifth grade, a busy social calendar and having fun with his fantastic big brother, Ian. Stuart and the rest of the family are mindful that Fanconi anemia is forever. We cannot be complacent



Stuart Kasting

and are mindful of following prevention recommendations and doing appropriate and timely medical follow-up. Still, Stuart lives and enjoys life to the fullest.

The quote we wrote in our personal journal before going to transplant is from *The Lord of the Rings* (the context is certainly different, but the feeling is appropriate). Gandalf the Grey is comforting the fearful hobbit Frodo and he explains, "... and so to all who live to see such times. But that is not for them to decide. All we have to decide is what to do with the time we are given." ♦

Letter from the Proulx Family

by Benoît and Danielle Proulx, Québec City, Canada

For the second consecutive year, we went to Camp Sunshine for the Fanconi yearly meeting. Contrary to last year when we couldn't wait to have this new experience and to make new relationships, this year our participation was based on our daughter Maude. She wanted to return to Camp Sunshine because she wanted to see again her own "FA family" and to give her cousin Andréanne the chance to understand a little more about her situation.

Benoît and I had much less enthusiasm than Maude to attend this year. The experience at Camp last year was very extraordinary but also very difficult on our emotions. It was like all our effort to forget the tough reality of having a kid with FA was suddenly swept away.

Our goal this year was quite different than last year. This time, we wanted to make more contacts with other people (in spite of the barrier that we speak French) and to talk more with other parents about their lives. The parents at the Camp are tremendously supportive.

After the four days at Camp, we can say now: Maude loves Camp Sunshine and the friends she meets there. She really feels at home there. She likes the activities, the atmosphere and the respect that other people have for her. The volunteers are **exceptional** and contribute to the success of the Camp. As last year, Maude came back with new questions that show us that she is conscientious about her condition. We appreciate seeing the information taking form in her head, at her rhythm, slowly but surely!!

On our side, we realize that the week at Camp Sunshine is a balm. For a few days we don't have any chore to do like meals, no activities to plan, no phone calls or email, and

no concern for Maude's well-being. It's a week that we can be only parents, nothing else! God knows that we don't usually have so much time to think about our parental role!

The conferences are very accessible and rich for us. We attended many presentations and, for some, for the second time. We realized that we caught some more and new information.

Both of us find the "Coping with FA" meetings with Nancy very hard but necessary. Crying about our mourning, laughing about our reactions, thinking about our attitudes, discussing our roles: everything is well appreciated! And, the exchange with the others families and young FA adults is very nourish-

ing and priceless, and encouraging but realistic!

Finally, our participation at the yearly FA Family Meeting at Camp Sunshine gives us the HOPE that helps us and Maude to have, for the rest of the year, a kind of life closer to a normal one. ♦



The Proulx family

Life with Fanconi Anemia

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est and wants to be bigger like his friends. We sit with him and explain things (as well as you can to a now five year old). He knows he is different, but he can still do everything the other kids can do. The best thing about being small and skinny is that he can run faster than anyone in his class!! Jasper also knows that his Poppie says, "You can't fatten a thoroughbred" and the old one of "Good things come in small packages."

At the moment, we are just very grateful that Jasper's blood counts are

so stable and that he is really healthy. We don't know what tomorrow holds but, you know, we will deal with that IF we come to it.

The diagnosis of FA has changed our family forever. It is not all bad news, though. We have such a loving and supportive family, both at home in Australia and in our new extended FA family. No matter what the future holds, we know we are not alone and can deal with whatever comes our way. ♦

Fanconi Anemia, My Beast of Burden

by Francesca Hutchins

In February of 1981 my 9-year-old sister Tara was diagnosed with Fanconi anemia after visiting an optometrist for headaches, which resulted in a blood test. Tara was a beautiful, funny, and a very talented young actress whose life was shortened but by no means unfulfilled. Tara's spirit was undaunted and contagious. She filled those she met with joy and an appreciation for the life that she would not have the opportunity to fulfill completely. She was my inspiration and my hero. At age 21, she passed from our world due to a cerebral hemorrhage.

Fast forward to April 12, 2006. As I was purchasing cat food in Wal-Mart in Las Vegas, I received a phone call telling me that "Ms. Hutchins, you were right; you do indeed have Fanconi anemia." Laughingly, I said "Great! At least this means I'm not a hypochondriac." For some, this diagnosis would have struck fear in their hearts but, for me, it was the confirmation of a fact I had suspected most of my life.

Let me rewind. Life was good and very busy. I had left an abusive relationship that had taxed my immune system to the breaking point and was starting a new life in a new state. I was a first year teacher, enjoying the rush of a third grade classroom in the wild, woolly city of Las Vegas. I was going to be the best teacher that LV had ever seen. Unbeknownst to me, the carpets in my beloved classroom had been shampooed, but were not completely dried. At this same time, the air conditioner in my condo was leaking like a sieve. As an FA patient who is highly allergic to mold, I became very lethargic, was sleeping anytime I was not working, and just could not kick flu-like symptoms. I knew that something was severely

wrong and began the craziness of trying to convince my doctor that something was desperately wrong. After numerous tests, a number of doctors, and little to no assistance from the medical staff, I decided to take matters into my own hands by returning to California and contacting the FA Research Fund. I also wanted to contact my good friend Roc (Youngming Roc Doo), a Doctor of Osteopathy.

Earlier, in 1995, my blood counts had started to drop slowly, and my doctor had no suggestions for me other than recommending a regimen of steroids. With his blessing, I signed up to take an herbal remedies class taught by Dr. Doo. What the heck; I had nothing to lose and everything to gain. After a month of intense study of Eastern Medicine, I decided to experiment with the process myself. Rocky, as I call him, asked me many questions, such as whether I preferred cold or hot drinks, was temperature sensitive or had bubbles in my urine. Roc made a concoction of ingredients tailored specifically to my body. No one else could take this exact prescription and have it work effectively. Within four months of three doses a day, my blood counts had climbed to mid-normal range, which was amazing. I followed this treatment for almost a year but, due to financial stresses, I stopped prior to finishing the formulary. Roc warned that I must



Francesca Hutchins and her husband, Shawn

complete the cycle or later in life this anemia would come back with a vengeance, and he did not know if he could correct it the next time. Being the brilliant and impervious young adult I was, I knew full well that I would be just fine! Living in denial is a wonderful thing.

So, by the time I reached California in 2006, I was completely exhausted, sheet white, and was having problems communicating coherently. I visited Roc with my latest blood test results, and the first comment from his mouth was, "My God, are you going to die?" We started the process over, but at a much higher dose and intensity. Within four days

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Fanconi Anemia, My Beast of Burden

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my color was back, and some normalcy was brought back to my life.

I so wanted to live simply thinking that this had been Tara's disorder and not mine. After all, I had been tested for FA. Roc and I talked and decided it was time to contact the Fund. Knowing the answers before they came, I contacted them. They were so helpful and immediately put me in touch with Dr. Blanche Alter's office at the National Cancer Institute. She took over from there and scheduled both my mother and me to travel to Bethesda for a comprehensive evaluation. As many of you have also experienced, I didn't know it was possible to measure, poke, and prod so many parts of one's body. It was exhausting, but so very educational, and I highly recommend participating in Dr. Alter's study.

At this point I decided to live life with purpose. Shawn and I met last year at our 20th class reunion. At age 39, we married this May, I left my current career, and I now live in Warren, Ohio. I am no longer able to teach due to exhaustion, but I do tutor the neighborhood kids when I can. I realize that I am lucky and thank God every day for the grace to live another healthy day. Not everyone is this fortunate.

I attended Camp Sunshine in August and was introduced to some of the most amazing and loving people I have ever met. My family is indebted to each and every one of you. I once wished that I had passed instead of Tara, but I now understand that I have been given the opportunity to honor my sister and those who have passed before me. For those of us who remain, we must do as much as we can to fund the research to fight and cure this crazy disease. ♦

Two in a Million

Two in a Million, a book written by Irish student and FA patient Ben Murnane, was launched at the Royal Marine Hotel, Dun Laoghaire, Dublin, Ireland, on September 26, 2008. The book tells the story of Ben's battle with Fanconi anemia, from his diagnosis at age nine to his bone marrow transplant nearly eight years later, and beyond. At sixteen, Ben became the first person in Ireland to have a transplant involving the immunosuppressant fludarabine. During three months in hospital, along with unending diarrhea and constant pain, he suffered a psychotic episode which made him unable to recognize his doctors and his parents. And, before the transplant even began, he had to tell the girl he loved that he only had a fifty percent chance of survival.

Two in a Million describes what it's like to live with a life-threatening illness, to undergo a life-saving procedure, to recover slowly and try to live normally as a student in Dublin. It will be available from publishers A. & A. Farmar (www.aafarmar.ie) and through www.amazon.co.uk. For more information, see www.bebo.com/benmurnane. ♦

TWO IN A MILLION

A TRUE STORY ABOUT
ILLNESS AND LOVE



BEN MURNANE

In Loving Memory

Jess Alexander
5/16/97 ~ 8/1/08

Chuck Benshoff
6/25/82 ~ 6/5/08

Jeanie Heflin
8/6/97 ~ 3/6/08

Peter Herman
12/26/71 ~ 5/15/08

Alecia Morgan
2/23/99 ~ 5/3/08

Kiara Tyler
2/9/02 ~ 6/11/08



Enjoying the 2008 Family Meeting at Camp Sunshine

Annual FA Family Meeting

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of medical experts who gave of their time to travel to Camp to update our knowledge of endocrinology, bone marrow transplantation, gynecology, and other aspects of Fanconi anemia. Because Sarah Jane Schwarzenberg, MD, University of Minnesota, could not travel to Maine this year, her presentation was made via interactive videotape, which worked out very well.

As always, the Fund and all FA families are extremely grateful to Camp Sunshine for the use of their facility, their volunteers, and their wonderful staff (including Camp doctor Andy Eichenfeld and social worker Nancy Cincotta). To express our appreciation, Dave Frohnmayer presented the Camp with a check from the Fund for \$15,000. ♦



FA families picnicking at Camp



Camp Sunshine volunteers and happy campers



FA adults singing karaoke: John Hanna, Delia Horrigan, Zach Blecher, Lindsey Sablosky, Francesca Hutchins, Amy Frohnmayer, Jo Box, and Maria Ribero-Rodriguez

Nobody is a stranger here: come in cold and be warmed.

We love Camp Sunshine, and we are truly indebted to FARF for the miraculous progress in treating our children.

This time will be unforgettable for us.

Our daughter was so excited to finally meet “kids like me” with “hands like mine.”

Many counselors and others affiliated with Camp Sunshine say that the FA week here is special. At first, I didn't understand why it was considered so different. Now, after being here for seven sessions, this is becoming true for me as well. There is a sophistication, comfort and drive uniting this group that is rare and very powerful.

Camp Sunshine has changed our lives.



A furry welcome to Camp

FUNDRAISING

Our Journey with Fanconi Anemia

by Marina Ravelo

Our journey with Fanconi anemia started on July 25, 2001, when Ivan was born. He was our first child, and we were so young and very private people to be thrown into a very foreign world of doctors and hospitals. When Ivan was formally diagnosed in 2002, the only people we told were close family and friends.

Ivan continued to grow normally and never looked sick. We were in a state of shock and disbelief. How could this be happening to us? We didn't know how to tell people or even how to explain what FA was. As years went by, we finally accepted that this was our life, and we would try our hardest to make it the best for Ivan. In 2005, we underwent

pre-implantation genetic diagnosis and had Fabian, who would be Ivan's cord blood donor. Ivan underwent a cord blood transplant at the University of Minnesota the summer of 2007 and did exceptionally well. We now look back at how far we have come in seven years.

We are now doing our part to spread the word about FA. The hardest part (transplant) is over, and it seems like we can breathe a bit more easily. Transplant always loomed over us like a dark cloud; finally, it seems like we can actually see the sun! We will always worry about Ivan's health and what may lie ahead for him but, for now, we will live for today. We are concentrating on educating people

about Fanconi anemia and raising much-needed funds.

We have done several "mini" fundraisers through the years. Since many were not aware of what my family was going through, I could never really reach out to them. But, now, we are going full force, and people have been so supportive. We are doing our very first "formal" fundraiser, called "Raffling for a Cure." I had 1,000 raffle tickets printed and have been selling them for \$25. We will pay out around \$5,000 in prize money. I asked all my family and friends to sell tickets to their friends and co-workers. We have been very successful, and people have taken more than 10 tickets and have sold them. I reserved a pizzeria near us to serve food and drinks, and Ivan will be the one to pull out the winners. So far, we have managed to pull this off in a non-stressful manner. The final numbers are not in yet, but we are hoping for a great night, sharing FA with family and friends. ♦



Fabian and Ivan Ravelo

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.

Coley

by Kristin and Todd Levine

Our Nicole (“Coley”) was diagnosed with Fanconi anemia in December 2003, at five and a half years old. The circumstances leading to the discovery that she had FA were unfortunate, uncommon and hopefully less likely to occur in the future as a result of the ongoing work of FARF and so many FA families.

In early December, we noticed some unusual bruising on Coley’s legs. When it didn’t go away, we took her to the pediatrician who ordered a complete blood count. Later that day, while waiting for family members to arrive for a Hanukkah dinner, we received the call that changed our lives forever. The pediatrician reported that Coley’s blood work showed an unusually low platelet count and recommended we head to Children’s Hospital, Boston.

A few hours later, the mother of all bombs was dropped when a soft-spoken oncology resident told us that Nicole had leukemia. I remember saying, “Aren’t there good kinds and bad kinds of leukemia, and aren’t the good kinds getting easy to cure?” I was presuming, of course, that Nicole had the “good kind.” Unfortunately, her response was that there are different kinds, but that Nicole had acute *myeloid* leukemia (AML), rare in children and tough to cure.

This is where the heart-wrenching part of the story comes into play. The resident asked us to explain the history behind Nicole’s hypoplastic thumb. We were frustrated that, after just telling us about the leukemia, she would care about her silly little thumb. She went on to inform us that thumb deformity is characteristic of Fanconi anemia and, because of the implications on the AML treatment, they needed to test for FA. Of course, the full comprehension of

what FA was *really* all about would only hit us when we researched it via the FARF website.

Reading the literature, we were overwhelmed by the number of FA symptoms, physical traits and ailments Nicole had exhibited in her short life. Her thumb deformity, failure to thrive, kidney deformities, *café-au-lait* spot, small head circumference, metabolic issues, surgery to repair a heart defect, etc., came straight at us like a freight train screaming “How could you have missed this?” As much as we questioned and beat ourselves up over how we could have missed the diagnosis, we were that much more upset with the hoards of physicians within the same hospital system who examined, analyzed, treated and managed Nicole through the years. Geneticists, cardiologists, orthopedic surgeons, gastroenterologists, metabolic specialists, endocrinologists, neurologists,

urologists, otolaryngologists—you name it, she saw them! Adding to the frustration was that all of her care took place in Boston, Massachusetts, in perhaps the most highly regarded pediatric hospital in the world. And, just for good measure, the hospital is located directly across the street from a pre-eminent Fanconi anemia research laboratory. How these “dots” were not connected in this epicenter of professional medical care baffled us then and continues to haunt us to this day. To add insult to injury, a week after the diagnosis, while waiting for a clinic visit in that same Boston hospital, a little girl whom we had never met walked up to Nicole, took one look at her and said “She has Fanconi anemia, right?”

Without a choice but to focus our energies on the future, in January 2004 we brought Nicole to Memorial Sloan-Kettering Cancer Center

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Todd, Coley and Kristin Levine

Fifth Annual FA Golf Tournament

by Peg Padden

On July 12, the Fifth Annual Fanconi Anemia Golf Tournament, Silent Auction and Raffle in Battle Ground, WA took place. Once again, because of the tremendous support of the family and friends of the Padden-Shearer Family, it not only was a huge success, but great fun as well! We raised over \$24,000 for research for better treatments and—who knows?!—maybe a cure. We will continue to put on this event and others until there IS a cure. To quote Olympic gold medalist Michael Phelps: “Nothing is impossible. If you dream as big as you can dream, anything is possible.” ♦



Golfers David Chow, Jeff Folen, Ed Vranizan, and Dave Sherrett

Coley

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to undergo a bone marrow transplant with Dr. Farid Boulad and his transplant team. Unfortunately, the odds were stacked against Nicole heading into the process. Her FA complementation group was the rare *FANCD1/BRCA2*, she had a cellular structure that was curiously mosaic, was highly blasted with leukemic cells, and had an un-matched related marrow donor.

Notwithstanding the circumstances, her signature personality, courage, spunk and determination were on full display as she endured two transplants, fully engrafting both times. She amazed family, friends and medical staff alike as she took on this epic life battle—always maintaining her sense of humor and pride that she was “getting better.” Tragically, just ten short months after that

fateful phone call, Coley’s body succumbed to the effects of this horrible disease. Ironically, she passed away in that same Boston hospital, with the soft-spoken resident (now an attending oncologist) by her bedside.

We often think of how different Nicole’s prognosis would have been had we and all of the physicians been aware of Fanconi anemia, its symptoms and implications. Increasing FA awareness is a central goal of *Coley’s Cause* (www.coleyscause.com), a non-profit foundation established in Nicole’s memory. Each year since Coley’s passing, we have hosted the highly successful Coley’s Cause Golf Tournament aimed at raising much-needed funds for the advancement of Fanconi anemia research and treatment. In just four years, the event has contributed over \$100,000 to the Fund. As pleased as we are with the financial results of *Coley’s Cause*, we are even more proud of the

undeniable increase in community awareness it has generated. At each event, several FA families are in attendance to share their personal stories about how FA has affected their lives. The powerful effect of seeing the precious faces of FA in person and hearing first-hand about the progress that has been made in recent years in the areas of research, treatment methods and prognosis is amazing to witness. We can only hope that all of the attendees share their newfound knowledge with friends and family to spur an exponential wave of awareness.

As long as there is a need to make a difference, our family looks forward to continuing this event in Coley’s memory and in honor of the many FA families suffering from the physical and emotional effects of this unfortunate and uncommon genetic disorder. ♦

Upcoming Fundraisers for FA Research

2008

October 10: Play for FA Golf Tournament, Independence Golf Course, Midlothian, VA. Golf tournament. Contact Lorraine McQueen at lmqueen01@comcast.net or 804-247-1459.

October 10: Raffling for a Cure, Chicago, IL. Food, drinks, and raffle. Contact Marina Ravelo at navi725@yahoo.com.

November 9: Play for FA Wine Dinner, Bookbinder's Grill, Midlothian, VA. Dinner, wine tasting, and auction. Contact Lorraine McQueen at lmqueen01@comcast.net or 804-247-1459.

November 17–18: San Diego Tee-Off and Tip-Off, San Diego, CA. Presented by the AGIA Foundation. Kick-Off: Cocktail hour, live and silent auctions, dinner, and entertainment by "Sign Boy" at Fairbanks Ranch Country Club. Tee-Off: Golf tournament at La Costa Resort and Spa. Tip-Off: San Diego Toreros vs. University of Nevada at the University of San Diego. Contact teeandtip@gmail.com or 619-881-8608.

November 22: Brave Hearts 2008 Hoot 'N' Holler, Denver, CO. Great grub, dancin' and entertainment, Texas Hold 'Em, and a silent and live auction! Contact Ken & Jeanne Atkinson at 303-349-1309 and Jack & Lisa Nash at 303-773-6228.

2009

February 8: Fifth Annual Valentine Fanconi Anemia 5K Run/Walk, Portland, OR. Contact: Peg Padden at pegpadpad@hotmail.com.

May 10: Fanconi Anemia Research Fund Benefit Concert and Dessert, Eugene, OR. Contact: Lynn Frohnmayer at lfrohn@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, Campbell Town, PA (5 miles east of Hershey), 9 am–5 pm. Contact Brad Martin at 717-599-4576 or bandatresures@comcast.net.

July 18: 6th Annual FA Golf Tournament, Cedars on Salmon Creek Golf Course, Battle Ground, WA. Contact: Peg Padden at pegpadpad@hotmail.com.

Ongoing

Kaps for Kendall: Donate \$25 to the Fanconi Anemia Research Fund through Kaps for Kendall and a knitted hat will be donated to a patient who has lost her hair from chemo and radiation treatments. If you are a knitter, you can help by supplying a hat. Contact: Allison and Whitney Atkinson at www.kapsforkendall.com.

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.

Our Rope Team

by Kevin McQueen

In the pre-dawn hours of August 16, 2007, my good friend, Bill McC Corey, was leaping across a four-foot crevasse at 12,500 feet in an attempt to summit Mount Rainier. He reached the other side, but fell backwards into the abyss. Thankfully, he was attached via rope to four other people who two days before had been complete strangers. As Bill's life passed before his eyes, his rope team instantly dove into the snow with their ice axes and got into the "team arrest" position, stopping Bill's fall. Bill dangled by rope for twenty-five minutes in complete darkness while his rope team worked to get him out. Without the strength, courage and quick action of his rope team, Bill would not have survived.

While Bill hung suspended, wondering if he would see another day, he thought of family, friends and special moments. Since his rescue, Bill has learned to treasure his second chance at life and has realized that having the right team around you makes all the difference in the world. In some cases, it can mean the difference between life and death.

Bill has run over 33 marathons and does not like to leave things unfinished. He decided to return to the mountain in 2008 to finish what he started. Inspired by how his rope team had saved his life, he decided that this year's effort would try to help save the lives of others. He chose to make the climb a fundraiser for the FA Research Fund and dedicated the climb to our son Sean, who has FA. Inspired by Bill's courage and effort, I decided to accompany him. With that, the "Your Rope Team" was born. Bill invited two other friends, Bob Counoyer and Todd Stormes, to join the team and we started making plans.

We set an ambitious fundraising



Kevin McQueen (far right) with Rope Team members at summit of Mount Rainier

goal of raising \$10 for every foot of the 14,410 foot elevation of Mount Rainier: \$144,000! After designing a web site and sending sponsorship letters to friends and family, my challenge was to get in shape. I met with a personal trainer who developed a six-month program that included seemingly endless amounts of interval runs, sprints up hills and mountain hiking while wearing my 40-lb pack. After months of anticipation, the team flew to Seattle to start our three-day adventure.

Day one was spent learning mountaineering skills such as walking with crampons, hiking while roped together, and stopping your fall with an ice axe called "self arrest." Our summit attempt began on the morning of August 17 at Camp Paradise at 5,400 feet. The hike started through beautiful mountain meadows with incredibly colorful mountain flowers. After an hour or two, the meadows gave way to expansive snowfields and rock. The weather was cool and overcast, but the clouds did not hide the huge mountain looming above. After another 4 hours of hiking up

the slushy snowfield, we finally made it to Camp Muir at just over 10,000 feet. Our shelter was a large mouse-infested plywood box with stacked wooden platforms for sleeping. We had an early dinner and crawled into our sleeping bags at around 6 pm to try to get some sleep.

During the night a violent thunderstorm rolled through. I could see the lightning flashes through the shelter door. I was very concerned that we would not be able to try for the summit because of the weather. Just as I fell back to sleep, our lead guide switched on the lights and told everyone to get ready. It was 11:30 pm. We anxiously put on all of our gear, ate breakfast, and assembled in our rope team. We started hiking up the glaciers and rock in darkness, with only the light from our headlamps. As I climbed, I could see the tiny headlamps of other teams below. It was all very surreal.

After about two hours, we reached the toughest part of the trip, a very steep rocky ridge called Disappointment Cleaver. It was incredibly

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Our Rope Team

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difficult climbing up through the steep rocky ridge while wearing metal crampons on our feet. Occasionally I could catch a glimpse of the ledge and drops-offs we were passing. I was thankful that it was dark and I could not really see how scary our route was. Finally, after almost two hours of grueling climbing, we reach the top of the cleaver. Despite being a little tired, I felt strong and had no signs of nausea or headache that often affects people at altitude.

The rest of the climb to the summit was up steep, expansive glaciers, which took another two and a half hours of steady hiking, picking our way around crevasses. The highlight was walking across a seven-foot wide crevasse on a metal ladder. At about 6:15 am, we finally made it into the summit crater. As I walked into the snow-filled crater, I was overcome with emotion on having made it to

the summit. I was elated, relieved and proud that we had made it to the top for all the kids and families that suffer from FA. Everyone's well wishes, thoughts, prayers and support had meant so much to me, and I was so happy that we had come through. As we dropped our packs and everyone congratulated each other, I made a futile attempt to hold back the tears. After a few embarrassing minutes, I regained my composure. We snapped some pictures, dropped our packs and made the short hike to the very top of the crater rim.

As the expression goes, it was all down hill from there—easier, but a lot scarier. In the daylight I could see all the crevasses, cliffs, and steep drops-offs which we had passed a few hours earlier in the darkness. Right before we reached Disappointment Cleaver, a fast-moving storm engulfed us. We were pelted with hail as lightning flashed and thunder boomed all around us. This was the scariest part of the whole trip. I

thought for sure that one of us was going to be struck by lightning as we stood on an exposed mountainside holding metal ice axes and wearing metal crampons. Fortunately, it quickly passed and we were able to make it down to the safety of Camp Muir. After a quick break, we packed our remaining gear and then hiked and slid our way down the Muir to Paradise to board the bus back to base camp where cold beers, a nice dinner, and warm beds awaited.

The trip was an incredible experience for me. Through the amazing generosity of our "Rope Team" members, we raised over \$50,000 to fight Fanconi anemia. I am so grateful for their support. Although we have not quite reached our fundraising goal, we aren't done yet. We are currently discussing plans for future climbs for FA. If anyone is interested in joining me, let me know.

Visit www.yourropeteam.com for more information on the team and the climb. ♦

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 rider on the family's homeowners insurance policy or through "special events" insurance, both relatively inexpensive. 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.

The Chris Hull Sigma Pi Open

by George Hoffmaster

WOW! What an AMAZING day! The 9th Annual Chris Hull Memorial Sigma Pi Open was a fabulous success, with an unprecedented number of players and fourteen foursomes enjoying the round at the Penn State Blue Course!

The day started at the clubhouse with breakfast from Panera Bread Company. When the golfers got to their carts, they were treated to tee gifts including a ball cap with an Open logo as well as a \$25 gift card from the PGA Superstore online. Sweet!

We hold this golf open each year in memory of our fraternity brother, Chris Hull, who died at age 33 in 1999 as a result of Fanconi anemia. Chris brought us another beautiful sunny day, but the temperatures quickly climbed into the 90's. Fortunately, there was a mild breeze that kept players cool and on their games. At the turn, we all enjoyed lunch from Penn State's Java Catering Company. This year, empty stomachs were no excuse for poor play! At the par-three hole number 14, each player tried his luck at scoring an ace to win a 2008 Pontiac Solstice roadster. Unfortunately, the closest anyone came to driving it home was fifteen feet. Better luck next year, guys!

After the round, everyone gathered for happy hour on the porch at 303 Fraternity Row where beer and soda quenched our abundant thirst. We enjoyed the camaraderie of old friends and took a tour of the newly renovated house. From there it was off to the Days Inn for our traditional banquet and awards presentation. Prizes were awarded for longest drive, closest-to-the-pin and, of course, our tournament champions and runners-up. Congratulations to Tom Hoff and Brian Hutton, winners of the 2008 Sigma Pi Open!



Sigma Pi fraternity brothers

After all was said and done, the final win for everyone involved was the \$8,000 donation we were able to make to the Fanconi Anemia Research Fund, a very impressive amount for an event of our size and the largest figure that the Sigma Pi Open has raised in the Chris Hull Memorial era. Thank you to all the players, donors, and sponsors who contributed to this milestone.

If you missed this year's Open, you missed out on a lot of fun. Please hold the dates June 5–7, 2009 and make a point to join the returning players for the 10th Annual Chris Hull Memorial Sigma Pi Open. I'm certain that it will be a weekend you'll enjoy and, with your participation, we can reach our goal to raise a \$10,000 donation! ♦

Gynecologic Issues

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the new *FA Clinical Care Guidelines* chapter. Based on this meeting, these experts recommend that FA girls should have an annual GYN consultation with thorough external exams starting at age 13. An internal pelvic exam with pap smear should be performed once the patient becomes sexually active or at age 18, whichever comes first. Any visible changes on the vulva or cervix should lead to further testing (such as vulvoscopy, colposcopy and biopsies) and twice yearly exams. FA women should be vaccinated against HPV and have confidential discussions with their physicians concerning sexual behavior. ♦

Your FA Research Dollars at Work in 2008

In 2008 thus far, the Fanconi Anemia Research Fund has awarded \$461,796 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: David Strayer, MD, PhD, Jefferson Medical College, Philadelphia, PA
Title: Bone Marrow-directed Gene Transfer for Fanconi Anemia
Amount: \$155,817
- Investigator: K. J. Patel, PhD, Cambridge University, Cambridge, UK
Title: Reconstituting and Dissecting Monoubiquitination in the FA Tumour Suppressor Pathway
Amount: \$160,000

Head and Neck Cancer

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After the cancer is cured, the patient is at high risk for secondary cancers. Aggressive monitoring by the surgeon is an absolute must. In the Registry, the cumulative incidence of relapse for this cancer by the age of 40 years was 50%.

Future

The Fanconi Anemia Research Fund continues to encourage and fund research into Head and Neck Squamous Cell Carcinoma and in 2006 held a workshop on this topic in Bethesda, Maryland. Science is continuously changing to improve outcomes, but currently a patient's most potent tools are rigorous screening and prevention. ♦



Talent contest at Camp Sunshine

Transplant Update from Minnesota

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still allowed patients to engraft. At the present time, it appears that 300 rads gives a high rate of engraftment while reducing toxicity associated with increased radiation. Lowering the radiation exposure to 150 rads resulted in late graft failure in two patients, so this dose was subsequently abandoned. Nineteen patients have now been treated on the 300 rad protocol, and 16 survive.

Patients presenting with advanced MDS or leukemia undergo a different protocol, which includes busulfan. Seven patients have undergone this transplant with four surviving.

Two major factors influence transplant outcomes in the unrelated donor setting: the use of fludarabine greatly improves survival, while more than 20 exposures to different transfusion donors decreases survival. **Wagner emphasized that one single transfusion can come from several different donors and it is the number of donor exposures, not the actual number of transfusions, which influences the outcome.** Wagner advises that patients use single donor transfusions instead of a transfusion from multiple donors. He further emphasized that every single transfusion makes a difference, and having no transfusions is best. Other factors are also significant, such as degree of HLA match, serious infection prior to transplant, and cell dose when using cord blood. Factors that used to appear significant in the pre-fludarabine era, such as prior use of androgens or multiple physical anomalies, were not factors in this small population of patients. ♦

Family Fundraising Efforts

From January 1 through August 31, 2008, FA families raised \$975,136 for Fanconi anemia research. The Fund also received donations of \$1,577 through the United Way and \$5,218 through the Combined Federal Campaign, for a combined total of \$981,931. We extend our sincere thanks to all FA families who worked so hard to raise these much-needed funds. One family has already raised close to \$300,000 this year, and another has raised close to \$200,000. Three others have raised over \$50,000 each, and 45 families account for donations of \$1,000 or more. We are so grateful to all of you for your help.

As you know, the challenge will continue until we find a cure for Fanconi anemia. Our mutual fundraising goal this year is \$2.3 million. Members of our staff are eager to help you with your fundraising efforts—especially now, during the holiday season.

\$100,000 and Up

Dave and Lynn Frohnmayer
Kevin and Katie Rogers

\$50,000 to \$99,999

John and Kim Connelly
Dan and Niki McCarthy
Glen Shearer and Peg Padden

\$25,000 to \$49,999

Todd and Kristin Levine
Kevin and Lorraine McQueen

\$15,000 to \$24,999

Steve and Jennifer Klimkiewicz
Joey Linsenmann

\$10,000 to \$14,999

Brian Horrigan and Amy Levine
Charles and Katy Hull

\$5,000 to \$9,999

John and Audrey Barrow
Chris and Susan Collins
Mark De Groot
Ed and Janice Duffy
Jack and Lisa Nash
Marcia Reardon

\$1,000 to \$4,999

Ken and Jeanne Atkinson
Mark and Linda Baumiller
James and Tracy Biby
Darryl Blecher and Diana Fitch
Mike and Kerrie Brannock
Donald and Danielle Burkin
David and Paula Ceresa
David and Kim Chew
Tyler and Teresa Clifton
Antonino and Marie DiMercurio

David and Mary Ann Fiaschetti
Stephen and Doreen Flynn
Andrew and Jennifer Gough
Alan and Rachel Grossman
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William and Mary Underriner
Mike and Beth Vangel
Michael and Kim Williams

Up to \$999

Andrew and Vicki Athens
Larry and Janice AuCoin
Gerald Barbier
Tyren and Kelly Bennett
John and Francene Berglund
Randy and Nancy Bloxom
Jeffrey and Donna Boggs
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Jeff and Judy Hoffman
Bonnie and Robert Hutchins
Christie and Randy Kelley
John and Karilyn Kelson
Kristina King
Joseph Konikowski
William and Carol Kuell
Kayla Lackey

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* or *Network for Good* buttons in the *Donations* section of our web page (www.fanconi.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.

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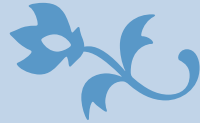
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The Twenty-first Annual Fanconi Anemia Scientific Symposium

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Fanconi
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