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FA Family Newsletter

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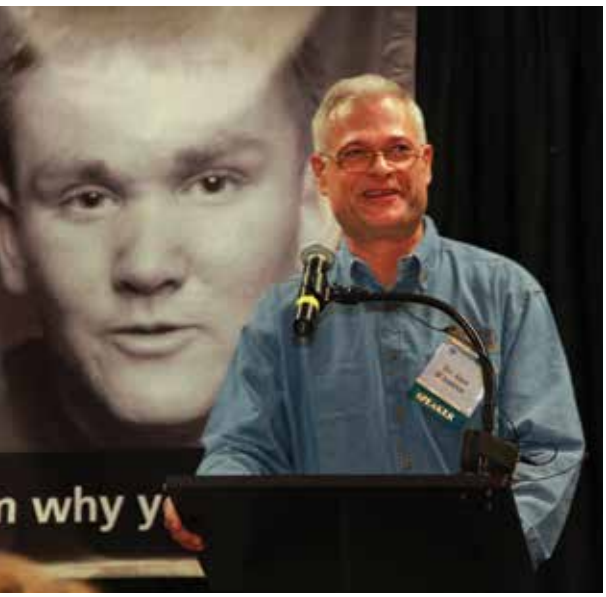
Aldehydes Inspire New Treatment Research



Alan D'Andrea, MD, Dana-Farber Cancer Institute, Boston, gave a thought-provoking presentation at this summer's FA Family Meeting on aldehydes, their connection to Fanconi anemia and how recent research suggests new treatment possibilities.

Aldehydes are reactive chemicals. They either are formed within the body during normal metabolism, like formaldehyde, or they enter from outside the body, like acetaldehyde from alcoholic beverages. In the bloodstream, aldehydes are broken down and removed by a family of enzymes, one of which is called ALDH2. Any aldehydes left over can damage a cell's DNA, and an FA cell cannot repair DNA crosslink damage like a normal cell can.

Dr. D'Andrea summarized the research regarding aldehyde toxicity in FA cells, which points to the potential for drugs that could detoxify or "sponge up" aldehydes in the blood, such as N-acetylcysteine (NAC) or cysteamine. A clinical trial for NAC in FA patients is currently being designed (see article below).

Next, Dr. D'Andrea explained research presented at the 2012 Fanconi Anemia Research Fund Scientific Symposium regarding the role aldehydes play in bone marrow failure, developmental defects, and cancer in relation to FA. This research suggests the need to investigate drug treatments which can stimulate the enzymes that remove aldehydes from the blood, such as the small molecule Alda-1, which stimulates ALDH2 production. Such a study is being planned. Ongoing research into aldehydes and FA might provide even more possibilities for developing treatments.

On a cautionary note, the research suggests that where possible, FA patients and mothers pregnant with a fetus that has FA should avoid aldehyde exposure as much as possible by not drinking alcohol and staying away from tobacco smoke.

Fanconi Anemia Clinical Trials Progressing

At the Fanconi Anemia Research Fund's FA Family Meeting, three researchers described the following ongoing or upcoming clinical trials for individuals with FA. The numbers of patients in the two open trials are very small and it is far too early to determine effectiveness. Nonetheless, it is encouraging that research efforts are moving to apply scientific knowledge of Fanconi anemia to trials that may directly inform and benefit patients.

Danazol Trial

Colin Sieff, MB, BCh, Boston Children's Hospital, described the rationale for his center's ongoing danazol trial. Danazol is a male hormone that is less virilizing than oxymetholone. While some individuals with FA have used danazol to stimulate blood production, this drug has never been studied for efficacy or safety.

This is a 24-week dose escalation trial. Researchers carefully monitor side effects, determine hematopoietic responses, and conduct gene expression studies of bone marrow cells to determine the effects of danazol. The study will enroll 20 patients with Fanconi anemia or Dyskeratosis congenita.

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Fanconi Anemia Clinical Trials Progressing

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Five patients have enrolled in this trial to date. Four patients were evaluated for hematological responses: one had an increase in hemoglobin, one in hemoglobin and platelets, and two patients saw an increase in both platelets and ANC. Danazol was well-tolerated, with patients showing minor endocrine or central nervous system effects. One patient had a serious dermatologic side effect and left the trial.

Early data suggest that this trial is worth completing. Contact Dr. Sieff at colin.sieff@childrens.harvard.edu with questions or for information on enrollment criteria.

Quercetin Trial for Fanconi Anemia

Quercetin, a flavonoid, is a naturally occurring antioxidant (free radical scavenger) found in apples, onions, berries, tea, and other foods. Parinda Mehta, MD, Cincinnati Children's Hospital Medical Center, described the rationale for this trial in patients with FA, and the progress made to date in implementing this study.

Cincinnati researchers have shown that in FA mice, reactive oxygen species (ROS) appear to play a major role in progressive bone marrow failure. They also showed that quercetin reduces ROS, prevents marrow failure and leukemia, and improves the stem cell compartment in these mice. Prediabetic mice show an improvement in glucose tolerance and insulin sensitivity after administration of quercetin. In laboratory studies, blood and marrow cells from FA patients also showed increased ROS at baseline that was reduced to near normal levels when treated with quercetin. Based on these preclinical data, Dr. Mehta and her team designed a clinical trial of quercetin for individuals with FA that is open and enrolling patients. The FDA has approved and is monitoring this trial. Based on the FDA's recommendation, the first three patients enrolled in the study were >12 years of age. The study is now open to all ages. The trial will evaluate safety, feasibility, and quercetin blood levels in patients with FA. This product is administered in liquid form twice a day for four months. It may be possible to take quercetin for a longer period of time.

> Research efforts are moving to apply scientific knowledge of Fanconi anemia to trials that may directly inform and benefit patients.

The first three patients enrolled showed good tolerance to quercetin and had no side effects. Dr. Mehta noted an improvement in the colony count of baby blood cells, and a slight improvement in glucose tolerance. She believes that early results are encouraging. Contact Dr. Mehta at parinda.mehta@cchmc.org for additional information about this trial.

N-acetylcysteine (NAC) Trial for Fanconi Anemia

Rabin Tirouvanziam, PhD, Emory University, Atlanta, described an upcoming multi-center study of N-acetylcysteine (NAC) in FA patients. Eleven researchers from three countries (Canada, Italy, and the US) are collaborating on this trial.

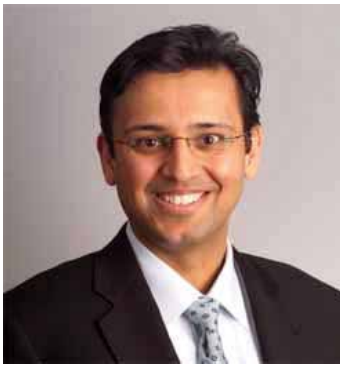
NAC is a molecule found naturally in the body that stimulates the production of glutathione. Glutathione is the body's primary antioxidant and prevents damage to cells caused by oxidants. Oxidative damage contributes to a variety of severe inflammatory diseases such as cystic fibrosis, chronic obstructive pulmonary disease, and autism. A compound such as NAC that inhibits oxidative damage and inflammation can thus be therapeutic for a variety of disorders.

Oxidative damage is a hallmark of FA. Recent research demonstrates that aldehydes, a particular type of reactive chemicals, are especially toxic to the cells of FA patients. NAC binds and detoxifies aldehydes, and helps to prevent damage caused by these toxins. NAC is efficient and safe, as demonstrated by a series of trials in other disorders. It does not leak into plasma in humans and, Dr. Tirouvanziam believes, it is virtually impossible to overdose on this naturally occurring compound.

Many formulations of NAC sold over-the-counter are not effective because of poor quality control. These products are not well protected against NAC oxidation, a stability issue that makes them inactive. The FA clinical trial will use a specific formulation that has overcome this issue. The new formulation that will be used in the FA trial also eliminates an additive that may have caused slight nausea in a small percentage of patients in previous trials.

Researchers anticipate that this trial will begin in the spring of 2014. They plan to enroll 40 FA patients from all complementation groups; transplanted patients will not be eligible for this initial NAC trial. Outcome measures will be safety and efficacy of NAC in improving hematological anomalies characteristic of FA.

Head and Neck Cancer in FA: Risks, Prevention, Screenings, and Treatment Options



Bhuvanesh Singh, MD, PhD, Memorial Sloan-Kettering Cancer Center, New York, reminded the FA Family Meeting attendees why we have to worry about head and neck cancer: the risk is 500-fold higher than in the general population. Risk increases with age, and cancers appear at much earlier ages in individuals with Fanconi anemia. Not everyone with FA gets cancer but the risk is high, so prevention is extremely important.

Environmental factors such as tobacco and alcohol cause head and neck cancers in the general population. Individuals with FA should avoid both. The risk of both smoking AND drinking is not just additive, but dramatically increases the likelihood of getting cancer. Second-hand smoke is equivalent to smoking—parents should never smoke around their children. It takes a long time for the risk from these carcinogens to go away completely. Long-term smokers who quit need 30 years for the risk to disappear; regular drinkers need >18 years of abstinence for the risk to go away. While an occasional drink is not a problem, long-term, repetitive, chronic alcohol use clearly is.

The human papillomavirus (HPV) has been implicated in head and neck cancers in the general population. All FA patients should be vaccinated against HPV.

Head and neck cancer surveillance should begin at age 10, and should continue on a twice-yearly basis. The mouths of post-transplant patients are challenging because worrisome areas come and go. Diffuse changes require the examining physician to have a high level of experience and expertise.

Surgery by an experienced treatment team remains the best therapy for head and neck cancers. Physicians have become increasingly expert in performing these surgeries, which no longer have to be disfiguring. Even extensive surgeries can leave no visible trace. Radiation and chemotherapy have serious side effects and should be avoided whenever possible.

After surgery, follow-up should occur every three months. There is a high risk for secondary cancers in the FA population.

Several areas offer hope for the future:

1. Identifying causative factors for FA cancers to better prevent and treat these malignancies.
2. Treatment with drugs such as Erbitux that bind to specific gene products in cancer cells (EGFR in the case of Erbitux) and cause those cancer cells to die.
3. Novel therapies: Dr. Singh described his work on a novel oncogene (*SCCRO*) that plays a role in the pathogenesis of head and neck cancer and other cancers as well. Turning off this gene inhibits the growth of cancer cells.

Testing Service for FA Patients

Testing for Potentially Beneficial Cancer Therapy

The Knight Diagnostic Laboratories at Oregon Health & Science University have recently made available new molecular tumor tissue tests designed to identify potential treatment targets in cancer and to predict the likelihood of benefit for patients treated with the latest therapeutics.

This new testing is available at NO CHARGE to FA patients.

For more information, contact:
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Phone: 541-687-4658 or
1-888-FANCONI (888-326-2664)
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Or contact:
Christopher Corless, MD, PhD, Medical Director
OHSU Dept. of Pathology (mailcode L113)
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Five Transplant Centers Report Protocols and Outcomes

Five transplant experts from major treatment centers presented results and engaged in a lively question and answer session at the FA Family Meeting.

Wolfram Ebell, MD, Charité Hospital, Berlin, reported on 39 alternate donor transplants using two separate protocols, GEFA 02 and GEFA 03. Patients ranged in age from two to 25. Patient characteristics suggest that many on both protocols were high-risk: 16 had a cytogenetic clone; 23 were multiply transfused; 29 were on androgens, and nine had liver adenomas. None of these factors seemed to affect transplant outcome.

The GEFA 02 protocol included fludarabine, busulfan (2 mg/kg/day orally), ATG, and OKT3. Ten of 18 patients survive. Causes of death were AML (1), squamous cell carcinoma (1), and viral infections (6). The GEFA 03 protocol, initiated in 2003, was a modification of GEFA 02. Both protocols used fludarabine and busulfan; in GEFA 03 cyclophosphamide and MabCampath were added, and ATG and OKT3 were eliminated. Of 21 patients transplanted on GEFA 03, 19 survive. Causes of death were AML (1) and viral infection (1).

Dr. Ebell concludes that alternate donor transplants are now almost equivalent to matched related donor transplants. The GEFA 03 protocol seems to offer more stable engraftment with similar toxicity, and perhaps fewer viral infections. Since 1995, transplanted FA patients are living longer than those never transplanted.

Parinda Mehta, MD, Cincinnati Children's Hospital Medical Center, reported on the multi-institutional unrelated donor transplant for FA study, which substitutes busulfan for radiation in the conditioning protocol, and also omits steroids to prevent associated side effects. In addition, cyclosporine is weaned after 100 days instead of 6 months with the goal of reducing kidney side effects and to expedite early immune reconstitution.

Four of five participating centers have transplanted 33 patients: Cincinnati Children's (23), Memorial Sloan-Kettering Cancer Center, New York (7), Boston Children's Hospital (2), and Children's Hospital of Wisconsin, Milwaukee (1). Ages range from four to 44, with a median age of eight. Four were over age 18. Twenty-four patients had marrow failure and nine patients had myelodysplastic syndrome (MDS). The conditioning protocol included fludarabine, busulfan, cyclophosphamide, and ATG.

The first 25 patients received a busulfan dose of 0.8-1.0 mg/kg. One of the initial three patients developed veno-occlusive disease (VOD) of the liver, which responded to treatment. However, the patient later died of infection. Busulfan dosage was lowered for the rest of the cohort. Dr. Mehta noted that final dosage was not identical for all patients, but was adjusted based on busulfan blood levels. Patients did well with this regimen, but experienced some delay in complete resolution of mild to moderate mucositis. Twenty of the 25 on this protocol survive. Causes of death were severe pulmonary hypertension (1) and infection (4).

To further reduce toxicity, the next eight patients received 0.6-0.8mg/kg busulfan. None has experienced VOD and mucositis was mild for most. Six of eight patients survive. Causes of death were relapse of MDS/progression to AML (1) and fungal infection (1).

Dr. Mehta concludes that radiation is not necessary for good survival outcomes.

Leslie Lehmann, MD, Boston Children's Hospital, stated that her center recently joined the FA multi-center study. Boston Children's Hospital has transplanted two patients with alternate donors on the fludarabine, busulfan, ATG, and cyclophosphamide protocol. Both patients are doing well over a year post-transplant.

Busulfan may be less toxic than radiation, but is an alkylating agent that causes cellular damage. Dr. Lehmann hopes that her center can eventually eliminate alkylating agents from transplant protocols and use only immune suppressing agents. Both

Experts suggest a prominent transplant center providing a large range of services, and a multi-disciplinary team approach. Transplant is only part of the care.

campath and fludarabine suppress the immune system, and are less toxic to patients' cells. Boston Children's initiated a transplant study of Dyskeratosis congenita patients using only immunosuppression for the conditioning regimen. Three patients with matched unrelated donors are now one year post-transplant, have had no GvHD, and have over 90% engraftment. At present, the implications of this approach for FA transplants are unknown.

Joseph Rosenthal, MD, City of Hope Cancer Center, Duarte, Calif., reported on 18 FA patients transplanted at his center: Eleven were Hispanic, five Caucasian, one Asian, and one African American. Seven were matched sibling donor transplants; 11 were alternate donor transplants. The transplant protocol includes cyclophosphamide, total body irradiation (200 rads), fludarabine, and ATG. Dr. Rosenthal does not believe that busulfan provides an advantage to this small dose of radiation, and his outcomes compare favorably to those seen with busulfan.

Long-term survival rates for patients receiving *marrow* from matched siblings and matched unrelated donors were excellent: 14 of 15 patients survive (93%). No major toxicities or severe acute or chronic GvHD were recorded. Three patients who received *cord blood* and one patient transplanted with leukemia did not survive. The center no longer uses cord blood in FA transplants.

Margaret MacMillan, MD, University of Minnesota, Minneapolis, reported on her center's extensive experience in transplanting FA patients. Since 1976, Minnesota has transplanted more than 200 FA patients on ten different trials. Protocols and outcomes vary depending upon patient characteristics. Dr. MacMillan discussed the results of the most recent trials.

Matched sibling donor transplants: 28 patients received a non-radiation conditioning protocol of cyclophosphamide, fludarabine, and ATG. Twenty-seven survive.

Alternate donor transplants, standard risk: 47 patients received a conditioning protocol of cyclophosphamide, fludarabine, ATG, 300 rads of radiation, and thymic shielding. Survival rate is 87%. Five patients were over age 18; two were ages 33 and 34 (both survive). Dr. MacMillan no longer believes that age is a risk factor.

High-risk transplants: Patients with advanced MDS (5% blasts in marrow), leukemia, or renal failure are considered high-risk. Of six patients transplanted with the protocol described above, four survive.

BRCA2: Patients with *BRCA2* are treated with a busulfan-based protocol as they appear to need higher dose therapy for successful outcomes.

Dr. MacMillan encouraged families to contact a transplant center early in the disease process. While cord blood donations can be obtained in a few weeks, locating an unrelated donor and completing the work-up process can take two to four months. The search must begin well before the patient is in crisis.

Minnesota transplant physicians continue to modify the protocol for FA patients. ATG was recently eliminated as fludarabine sufficiently suppresses the immune system. New approaches are under consideration to speed immune recovery and lessen the risk of infections after transplantation.

Questions & Answers

1. *Are there differences in how busulfan is used in Germany and in the multi-center study?*
   The primary difference is that busulfan is given orally in Germany and by IV in the multi-center study. Dr. Ebell prefers oral administration to achieve high blood levels and prolong presence of busulfan in the liver. Dr. Mehta prefers IV administration to collect blood levels, regulate dosage, and correlate blood levels with toxicity.
2. *In the general population, radiation is associated with an increased risk of post-transplant malignancies. Is busulfan less toxic than radiation?*
   Dr. MacMillan stated that there is no evidence that the risk for malignancies in FA patients is higher after transplant. High cancer rates have been associated with GvHD, not radiation, stressing the importance of reducing GvHD. Radiation and busulfan have different toxicities. Minnesota observed higher rates of severe toxicities after busulfan-based regimens.
3. *Would the elimination of radiation and busulfan, and use of bone marrow suppressants alone (such as campath and fludarabine), be effective in FA transplants?*
   Dr. Ebell stated it would be "great" if this would work; his experience suggests that FA patients might not engraft with immunosuppressants alone.
4. *What factors should be considered when choosing a transplant center?*
   Experts suggest a prominent transplant center providing a large range of services, and a multi-disciplinary team approach. Transplant is only part of the care.
5. *What future directions will improve patient outcomes?*
   Dr. MacMillan stated that speeding immune recovery and better treatment for severe infections are future goals. Use of regulatory T-cells to speed immune recovery and manufactured cells to combat certain viruses both hold promise for improved outcomes.

Late Effects of Transplant Require Monitoring

Margaret MacMillan, MD, University of Minnesota, Minneapolis, emphasizes that all Fanconi anemia patients need careful monitoring following a bone marrow transplant, because early identification of problems leads to better outcomes. The physician who best knows the patient is most able to provide post-transplant care. The transplant center should determine the necessary follow-up examinations, and provide direct care and consultation when appropriate.

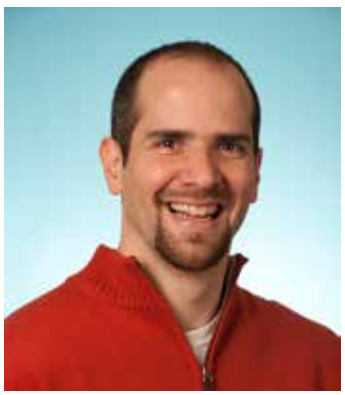
Dr. MacMillan recommends extensive screening at one year post-transplant. If the screening suggests nothing worrisome, she recommends extensive follow-up at five-year intervals. The underlying FA diagnosis—plus treatment and transplant-related complications—contribute to late effects. Appropriate experts should monitor patients for head and neck cancer, skin cancer, gynecological issues, and endocrine problems. (See *Fanconi Anemia: Guidelines for Diagnosis and Management, 2008* for timing and frequency of surveillance).

Patients can usually return home around 100 days post-transplant, but immune recovery is not complete for one year. Patients need to wear masks to filter out fungus from the air and reduce exposure to viral infections from others until at least 100 days after the transplant. Recipients of matched sibling donor transplants can usually return to school three months post-transplant, but those receiving alternate donor transplants should wait at least six months. Active GvHD and delayed immune recovery can postpone return to school. Patients who have no active GvHD and have been successfully weaned off immunosuppressive drugs can receive inactive vaccines one year post-transplant, but must wait two years for live virus vaccines. All patients and household members need an annual flu shot, but should NOT get a viral mist that entails live bacteria.

FA patients are at high risk of cancer. In the past, acute GvHD and use of azathioprine were associated with increased cancer post-transplant. A study of 169 patients transplanted at the University of Minnesota identified only three patients who developed cancer post-transplant. Cancers occurred relatively soon after transplant. Dr. MacMillan does not believe that transplant increases the natural risk of malignancy in this population.

Dr. MacMillan concluded that many FA patients now enjoy a better quality of life post-transplant than prior to transplant. Careful surveillance and follow-up care will contribute significantly to one's quality of life.

Gastroenterology Disorders in FA Patients Have Many Causes



Jose Garza, MD, Cincinnati Children's Hospital, discussed how Fanconi anemia patients experience many gastrointestinal (GI), liver, and nutritional problems due to FA and its treatments. He cautioned that diagnostic tests, particularly those involving radiation, should be used sparingly.

Approximately 7% of people with FA have GI tract anatomic abnormalities, most commonly treated in infancy by surgery. An assessment for growth should be done at each clinical visit to evaluate a patient's weight in relation to height, body mass index, and possible slowing growth rate. Poor growth may not be caused by GI problems, but by other FA issues, for example, genetic short stature or endocrine concerns. Paradoxically, overweight and obesity may also be a difficulty with FA.

Often, parents describe their children with FA as being picky eaters, but that may have nothing to do with poor growth. Poor growth may be due to three factors: 1) greater than normal need for calories and nutrition; 2) reduced ability to absorb and utilize food; and 3) less than normal oral intake. Dr. Garza described specific problems that cause these factors, along with various associated treatments such as dietary counseling, appetite stimulants or other medications, and enteral alimentation (a way to provide food through a tube placed in the nose, stomach or small intestine).

Patients with FA may also have deficiencies or increased need for specific vitamins and minerals; supplements, as well as vitamin D screening, should be discussed with a physician. Dr. Garza cautioned against complementary/alternative nutritional regimes that can be unnecessary, expensive, and sometimes harmful, including antioxidants and probiotics.

Endocrine Hormone Irregularities Common in FA

Constantine Stratakis, MD, DSc, National Institute of Child Health and Human Development, Bethesda, Md., spoke about the functions of the body's endocrine hormones and the common irregularities of these hormones in individuals with FA. He also gave an overview of the diagnostic tests and treatments recommended. Dr. Stratakis particularly stressed the importance of involving an endocrinologist to evaluate and closely monitor all people with FA.

Dr. Stratakis emphasized the following aspects of the endocrine problems in FA:

Hormones Control	Common Irregularities in FA	Key Recommendations
Growth	• Short stature • Low birth weight • Poor weight gain or overweight	• Annual height and weight measurement • Further evaluation if patient is less than the third percentile on the growth chart or displays poor growth velocity
Metabolism and Blood Sugar	• Insulin resistance • Insulin secretion defects • Glucose intolerance • Diabetes • Too little thyroid hormone (hypothyroidism) • High cholesterol and triglycerides (hyperlipidemia)	• Annual blood test screening including: – sugar level after a meal (post prandial glucose) – fasting glucose – insulin level – thyroid hormone levels (T4 and TSH)
Puberty and Fertility	• Delayed puberty • Early puberty • Reduced sperm count • Premature ovarian failure and early menopause • Infertility	• Careful physical examination for pubertal changes and progression • More research is necessary to understand infertility issues in FA
Bone Health	• Low bone mineral density (osteopenia) • Fragile bones which break easily (osteoporosis)	• Bone mineral density test prior to bone marrow transplant and annually thereafter

25th Annual Fanconi Anemia Scientific Symposium

The Fund's 25th Annual Fanconi Anemia Scientific Symposium, held in Houston in October, attracted 190 participants from a record 19 countries—US, Canada, Mexico, Brazil, Colombia, United Kingdom, Italy, Netherlands, Spain, France, Germany, Portugal, Turkey, Lebanon, Pakistan, Australia, Singapore, China, and Japan.

By all accounts, this year's meeting was exceptionally inspiring and interactive. Watch for details and reports on the scientific and medical presentations to be featured in the spring edition of the FA Family Newsletter.

For More Information...

Slides from many of the FA Family Meeting medical presentations may be viewed on our website. Go to "family support," and select "annual family meeting." Additional information on specific topics may also be included in *Fanconi Anemia: Guidelines for Diagnosis and Management* found on our website under "publications."

Promoting Gynecologic Health for Females with FA

Mercedes Castiel, MD, Memorial Sloan-Kettering Cancer Center, New York, discussed a wide range of issues concerning gynecologic care of women and girls with Fanconi anemia. She emphasized that screening and treatment recommendations for the general population are often different for females with FA.

FA and gynecological cancers

FA is associated with a very high rate of squamous cell carcinoma of the anogenital tract. The increased risk is several hundred-fold for cervical cancer and several thousand-fold for vulvar cancer. The median ages of cervical or vulvar cancer diagnosis in FA women (25 and 27 respectively) are significantly younger than expected in the general population.

The possible role of HPV and need for HPV vaccination

HPV has long been associated with cervical and other gynecological cancers in the general population and has been found in a subset of FA vulvar cancers. The HPV vaccine, Gardasil, protects against HPV types 6 and 11, which are found in 90% of genital warts, and types 16 and 18, which are present in 70% of cervical cancers. Dr. Castiel recommends vaccination for females and males with FA beginning at age nine. This vaccination protects individuals in the general population for at least five years following vaccination. The need for boosters is still uncertain.

Screening recommendations for anogenital cancers

Dr. Castiel recommends that females with FA establish a relationship with a gynecologist around age 13. This promotes a trusting relationship, allows for evaluation of the patient's pubertal status, and could include a vulvar exam. Dr. Castiel recommends Pap smear testing, as well as visual vulvar examinations, every six months beginning at age 18. Colposcopy, or visualizing tissue with magnification, is crucial if a visual exam reveals suspicious areas. The gynecologist should biopsy lesions if suspicion remains during colposcopy. Several drugs such as topical Aldara (imiquimod), topical 5-fluorouracil, and injectable alpha interferon are effective in treating precancerous lesions. Laser surgery is effective against more extensive disease. Gynecological dysplasia in FA requires early detection and aggressive therapy.

Screening recommendations for breast cancer

Are guidelines for women with *BRCA* mutations in the general population appropriate for females with FA? Physicians recommend that individuals with *BRCA* mutations should begin self-exams at age 18, clinical exams at age 25, and semi-annual mammography alternating with MRI beginning between ages 25 and 30. Mammography entails radiation, raising the concern that this diagnostic test might increase breast cancer risk. MRI does not use radiation, but premenopausal women can have higher breast density, which leads to more false positives and more biopsies. The FA population is predisposed to early menopause. MRI might be particularly useful after the onset of menopause, when breast tissue becomes less dense, thus avoiding the longer-term radiation exposure in this population. Experts have not yet reached a clear consensus on how best to screen for breast cancer in women with FA.

Reproductive life of women with FA

Females with FA often experience late onset of menses and early menopause. Periods can be unusually light or very heavy. Heavy periods might result from low platelets and can present a dangerous bleeding problem. Low-dose birth control pills or, in more serious situations, IV premarin can control this complication. Lupron can be used for long-term control of bleeding as well.

FA women have a fertility rate of 15-29%. Most pregnancies occur by the mid-20s, with very few pregnancies known to occur after age 30. Stem cell transplantation further reduces, but does not completely eliminate, the chance to become pregnant. In one study, ten FA patients out of 285 became pregnant post-transplant, and four conceived twice.

Pregnancies in the FA population are high-risk, and should be managed closely by an experienced team. Possible complications include pre-term delivery, preeclampsia, miscarriage, need for transfusions, and Caesarean section.

Fertility preservation

Physicians should address the possibility of fertility preservation with females with FA. Both embryo and oocyte (egg) cryopreservation are now options, although they entail an invasive procedure. In the non-FA population, 14 live births worldwide have resulted from freezing of ovarian tissue. Lupron may protect the ovaries from the toxic effects of chemotherapy and radiation, and may help preserve fertility. However, this is not considered a first-line fertility preservation method. It is still experimental.

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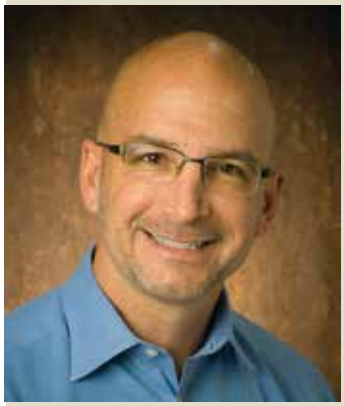
Effects and treatment of menopause

After onset of menopause, bone density should be monitored every two years due to increased risk of osteoporosis. Patients can experience hot flashes and vaginal dryness. Dr. Castiel recommends birth control pills rather than hormone replacement therapy to alleviate these symptoms. She stated that some over-the-counter products, such as black cohosh or St. John's wort, contain hormones and are effective against some menopausal side effects.

New and better therapies will lead to longer survival. Physicians and their patients need to discuss these health issues early and often in order to maximize quality of life.

Treating Arm and Hand Differences in Children with FA



Scott Kozin, MD, Shriners Hospital for Children, Philadelphia, presented his approach to treating arm and hand differences in children with Fanconi anemia. Dr. Kozin finds that if children are challenged to accomplish a task, they will resolve it regardless of the form of their arms and hands, saying "Where there's a will, there's a way." Treatment is chosen to improve function or appearance.

Dr. Kozin also discussed the emotional impact on children with an arm or hand difference, and how children can view treatment. Many young children hope that the treatments will restore their arm and hand to normalcy regardless of how the facts of the treatment are presented to them. When they are old enough to appreciate they have lost their "perfect body image," but are too young to express this idea, sometimes this appears as regressive behavior or pain. Dr. Kozin suggests parents talk directly and honestly to their children about their feelings regarding their limbs, and seek professional help if their children still seem to be struggling emotionally.

Since arm and hand differences are common irregularities found at birth for an FA patient, surgeons should consider an FA diagnosis whenever they see a thumb or radial anomaly.

See a summary of Dr. Kozin's treatment approach in the Family Newsletter, Issue 52, on our website under "publications." A videotaped interview with Dr. Kozin speaking to the mother of a child who had pollicisation surgery may also be found on our website. Go to "family support," select "annual family meeting," then "Interview by Scott Kozin."

Early Detection of Hearing Loss Important

Chris Zalewski, PhD, National Institute on Deafness and Other Communication Disorders, Bethesda, Md., believes that hearing loss and congenital ear abnormalities are more common in individuals with Fanconi anemia than previously reported. Most studies investigating hearing loss and ear-related abnormalities have found a prevalence of about 15% in FA patients. However, work done at the NIH shows that 52% of patients with FA have associated hearing loss, and ear-related abnormalities are as high as 57%. Dr. Zalewski presented the NIH study results, which showed that the most common type of hearing loss in FA is due to abnormal middle ear function and is conductive in nature. Dr. Zalewski recommends that all newly diagnosed FA patients and all FA patients with identified hearing loss receive comprehensive ear, nose, and throat (ENT) and audiologic evaluations every year.

Dr. Zalewski emphasized the importance of early detection of hearing loss. Children with unmanaged slight to moderate hearing loss have trouble hearing certain sounds which makes language learning difficult. He noted that even very young patients can undergo an audiologic evaluation.

Conventional hearing aids continue to be an excellent management option and come in a variety of styles. An FM auditory trainer is strongly recommended for the classroom, as this device helps all children to hear the teacher better, not just those with hearing loss. Patients with conductive hearing loss might benefit from surgery, while those with sensory hearing loss probably will not. In either situation, surgery should be discussed on a case-by-case basis with an otologist. An implantable bone anchoring hearing device (BAHA) can help when a patient has an absent ear canal.

Attention to Oral Health Especially Important for People with FA

Mark Schubert, DDS, MSD, Seattle Cancer Care Alliance, observed that the most frequent dental problems for Fanconi anemia patients are dental decay, gingivitis, and periodontal disease. These complications are very common in medically compromised patients and can result in oral infections and pain. Routine oral hygiene and care is effective, and can prevent many of these problems.

Dr. Schubert strongly recommends DAILY care. This includes brushing twice a day with either a hand or an electric toothbrush, and flossing once a day. Proper technique, taught by dentists and hygienists, is absolutely critical. Training must be customized to an individual's age and ability. Young children need assistance until they can completely carry out self-care. Dr. Schubert also noted that 90% of bad breath comes from poor dental hygiene.

Inappropriate diet can lead to dental problems. Sugar produces bacteria, and carbonated beverages like soft drinks can cause bacterial plaque. Parents don't have to restrict all sweets and carbonated drinks, but should greatly limit their use. Dental treatment is expensive—prevention is key.

Individuals with FA are at high risk for oral cancers, and these occur at much younger ages than in the general population. Patients need to be *alert* and *aware.* Patients and their families often have to educate dentists and hygienists about the cancer risk so that these professionals can be actively involved in regular oral surveillance. (The FA Research Fund has fact sheets on oral cancer to share with doctors, and recommends bringing one to every appointment. Find the fact sheets on the Fund's website or call the office.) Everyone must be alert to abnormal non-healing lesions.

No one single clinical appearance characterizes all oral cancers. They can be red, white, or both. They can appear as a lump, a bump, an ulcer or a growth. Some are firm or painful, some are not. There may be a single lesion or multiple lesions. The single characteristic of oral cancers is that *the lesion does not heal or go away*. An ear, nose and throat specialist must examine any lesion that does not heal in 21 days. In many cases, these lesions should be biopsied. Screening with toluidine blue or examination by Velscope are not diagnostic, but may direct an expert's attention to the part of the lesion that should be biopsied.

Finally, there can be a number of acute and chronic problems associated with stem cell transplant. Prior to transplant, significant active dental problems should be stabilized. During transplant, patients can encounter mucositis, dry mouth, and taste dysfunction, which can affect quality of life and oral function. Following transplant, patients may experience significant problems such as oral GvHD, persistent oral dryness, dental decay caused by oral dryness, and oral cancers. These complicated health care issues require follow-up with dental specialists and experts in oral health care.

Editors' note: In response to a participant's question, Dr. Schubert advised against using Total Colgate toothpaste which contains triclosan. While triclosan is an antibacterial and antifungal agent that has anti-gingivitis effects, it has also been implicated in endocrine dysfunction. Triclosan is currently under review by the US FDA and Health Canada.

SCC Fact Sheets Available

Regular screenings for oral cancer are critically important for FA patients. The Fund produced fact sheets about squamous cell carcinoma to share with your dentist and ear, nose and throat doctor (ENT). **FA patients and families are encouraged to take a fact sheet to every dentist and ENT visit.** Fact sheets—in English, Spanish, Afrikaans, Dutch, French, German, Hebrew and Italian—are available on our website or by calling our office.

Study Underway to Detect Oral Cancer in FA

If you or someone in your family is diagnosed with oral cancer, please consider participating in a new research study funded by FARF to determine if saliva can be an early detection tool for oral cancer. Contact Teresa Kennedy as soon as possible after diagnosis and before treatment at teresa@fanconi.org or 888-FANCONI. Teresa will coordinate your participation with David Wong, DMD, DMSc, the study's principal investigator. For more information, visit Research Highlights on our website.

Fanconi Canada and FARF Partner on Research Project

In 2012, the Fanconi Anemia Research Fund approved the research project of Madeleine Carreau, PhD, Laval University, Quebec, Canada, entitled *Exploring the Role of FANCC in the Development of Cell Death*. Fanconi Canada committed its efforts to providing the funds for this project. After successful fundraising by many Canadian FA families in 2012 and 2013, Fanconi Canada reimbursed the Fund $93,644, the full amount of the grant. Many thanks to the Canadian donors who contributed the funds necessary to make this partnership possible!

New FA Gene Identified: *FANCQ*

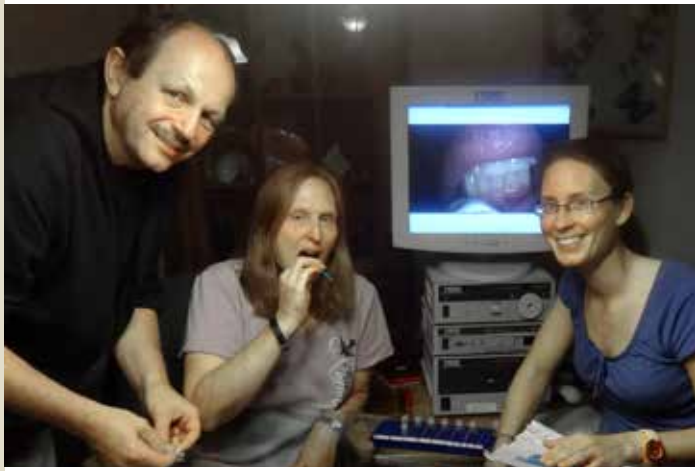
Two research groups, led by Jordi Surralles, PhD, Barcelona, Spain, and Tomoo Ogi, PhD, Nagasaki, Japan, recently identified the 16th Fanconi anemia gene, *FANCQ*. Their findings were published in two separate articles in the May 2013 edition of the *American Journal of Human Genetics.* Drs. Surralles and Ogi were joined on their publications by scientists from Germany, Italy, Japan, the Netherlands, Spain, the United Kingdom, and the United States.

FANCQ has two different cellular functions: to repair DNA damage caused by sunlight and to repair DNA damage caused by other cellular processes, called crosslinks. If the DNA mutation in *FANCQ* is in the part of the gene that repairs crosslinks, it causes FA. However, if it is in the part of the gene that repairs sunlight-induced DNA damage, it causes the rare diseases xeroderma pigmentosa and Cockayne syndrome. Both of these diseases are characterized by extreme sensitivity to sunlight.

Dr. Surralles and his collaborators, Johan de Winter, PhD, and Detlev Schindler, PhD, have previously been awarded research grants from the Fanconi Anemia Research Fund.

Continuing Progress in Gene Therapy for FA

The Fourth International Fanconi Anemia Gene Therapy Working Group Meeting was held in September in Boston, sponsored by both the Fanconi Anemia Research Fund and Fanconi Hope, United Kingdom, and hosted by David Williams, MD, and the Boston Children's Hospital. Eighteen scientists and clinicians from six countries, including Italy, Spain, and Germany, attended the productive meeting. Four additional participants joined by videoconference from the United States, United Kingdom, and France. The meeting was expertly moderated by Jakub Tolar, MD, PhD, University of Minnesota, Minneapolis, who believes that significant progress continues to be made.



Ralf and Eunike (right) meet with an adult with FA.

Fund Sponsors Oral Cancer Screening Project

The Fund awarded Eunike Velleuer, MD, Heinrich Heine University, and Ralf Dietrich, Executive Director and Family Support Coordinator, German Fanconi Anemia Support Group, both from Duesseldorf, Germany, two years of funding for their research and service project entitled, *Reducing the Burden of Squamous Cell Carcinoma in Fanconi Anemia.* For this project, Eunike and Ralf visit individuals with FA to provide information about the importance of oral health care, coordinate oral brushings that may help to identify early cancers, and collect saliva and other tissue for collaborations with scientists in Germany, Netherlands, and the US.

The project brought the pair to the US four times this year—to the FA Family Meeting in Maine, the Pacific Northwest (Oregon and Washington), the Midwest (including Ohio, Pennsylvania, and Indiana), and the South (including Texas, Louisiana, Mississippi, Georgia, Tennessee, and Alabama). They traveled over 6,000 miles and visited more than 50 young adults with FA and their families. Eunike and Ralf hope to reach other areas of the United States in the near future. Their work is valuable to people with FA and the Fund's efforts to reduce oral cancer.

> "They are truly two of the kindest people I have ever met and what they are doing is so inspiring!" —Facebook comment

Memories Made at the 22nd Annual FA Family Meeting

Sixty-six families, including 20 first-time families, gathered in June at Camp Sunshine in Casco, Maine, for the Fund's 22nd annual FA Family Meeting. Busy days were filled with educational sessions, support groups, research opportunities, and fun recreational activities. Although it rained frequently, it could not dampen the warmth of spirit generated by laughter, smiles, and hugs during the five-day gathering!

> To see the true FAmily connection in person is absolutely amazing! —participant evaluation

Seventeen adults and 54 children with FA, pictured above, ranging in age from one to 47 years, attended the Family Meeting along with parents, siblings, and other family members. Attendees traveled from all over the world, including Australia, Canada, Colombia, Germany, the Netherlands, and the United Kingdom. Families attended from 25 US states from Oregon to Florida.

A diverse range of educational and medical topics was presented at the meeting, highlighted by talks on oral health care, head and neck cancer, gynecologic issues, hearing, hand differences, post-transplant effects, gastroenterology, and endocrine disorders. Attendees learned more about aldehydes and why they should be avoided. In addition, there were three panels focused on stem cell transplantation, clinical trials, and topics specific to teens and adults. In the latter session, Amy Frohnmayer and Chris Byrd, both adults with FA, FA Research Fund board members, and long-time Family Meeting attendees, shared tips and answered questions.

The dedicated staff and the boisterous camp volunteers, including some FA family members, made sure that this meeting ran smoothly and was full of compassion and affection. Without a doubt, many fond and lasting memories were made.

In Loving Memory

"For some moments in life there are no words."

Tom Templeton ..... *8/31/81 - 4/25/13*
Kaylee LaFore ..... *2/3/10 - 5/8/13*
Terri-Lee Peters ..... *8/28/85 - 5/12/13*
Janet Graham ..... *7/21/69 - 5/18/13*
Francesca Hutchins-Huff ..... *3/21/69 - 5/23/13*
Shreya S. Kashyap ..... *11/9/09 - 6/7/13*
Joanne Hamilton ..... *10/28/78 - 6/24/13*
Kari Doctor ..... *1/15/77 - 7/4/13*
Katie Lynne Criss ..... *9/4/90 - 7/25/13*
Laurea Sherman ..... *3/16/89 - 8/3/13*
Marcia Reardon ..... *7/9/70 - 8/24/13*
Mary Grabher ..... *2/12/60 - 9/3/13*
Lucy Irvin ..... *11/17/10 - 9/17/13*
Drake Mitchell ..... *7/29/02 - 10/23/13*

Towards Open Dialogue

By Nancy Cincotta, MSW, MPhil
Psychosocial Director, Camp Sunshine

What is it like to live with an illness that promises to be complex? One that is so rare that most have never heard of it, and that requires a lengthy explanation for those who want to know more? Fanconi anemia (FA) carries with it unique challenges and a future that is filled with questions. Answers emerge from an ever-growing body of knowledge, and no matter what is known today, tomorrow will invariably be different. What is making tomorrow different? The Fanconi Anemia Research Fund (FARF), a cohort of devoted professionals, adults with FA, and parents of people with FA who all share an ongoing commitment to positively impact the course of FA.

There is wisdom, strength, and an unrelenting connection that exists in the FA community. This community endeavors to learn from the combined strength, energy, and experience of each person with FA. And within the cohort of adults successfully living their lives with FA, amidst the hope and promise, there is still ambiguity.

There is a quality of honesty in the FA community that seems unequalled. It comes from a sense of understanding and of being understood, a real connection among people in the "fight" together. Strangers brought together by FA become like family. That sense of family is not limited to the length of time people know each other, but rather how people know each other. Among the greatest strengths, and also the greatest challenges, in the FA community are those strong connections. When anything happens to someone with FA, it is not a statistic, it is often about someone you know—and everything matters. The context of the illness changes; gains and setbacks are very real.

Embracing some emotional complexities of FA

To understand, and to be understood.
To speak about your FA experience, and to be heard.
To live, understanding that life is not infinite.
To embrace life, not to be held back by life's limitations.
To recognize the uniqueness of the situation, even among others with FA.
To look forward with FA, not back.
To be honest, to be able to express fear, and to have that honesty embraced.
To be connected to the FA community, but not to be defined by FA.

The discussion of "lifespan" emerged as a theme during this year's FA Family Meeting, and was met with inquiry, confusion, and honesty. The question emerged, because it could. The FA pendulum is swinging in a positive direction, and there are no limitations on the open dialogue among family members about what was, what is, and what could be.

When you live with FA and you hear a life expectancy number that you have surpassed, what are you supposed to think? How does it challenge what you do in life, or with whom you choose to be in a relationship? It can all be a bit daunting. Numbers provide a context, a framework, a parameter, but not an answer. It is clear that an ever-sophisticated FA population, with FARF in the lead, is pushing to move science forward. The concerns of the FA population are changing, because people with FA are getting older, because relationships, jobs, marriages, children, and challenges to everyday living have entered the discussion.

Along with that intense sense of connection in the FA community comes a deep sense of loss when someone with FA dies, which adds to the apprehensions individuals and their family members carry with them. In June, it was nothing less than remarkable to hear the honesty and strength of people with FA, as they spoke about how they live their lives, the importance of their connections with each other, and how they struggle and deal with difficult considerations. The ongoing message was to listen, embrace, and be inspired by them. This is a generation of FA adults taking on the world, one challenge at a time. It is better to challenge and change the future, than to sit back and anticipate it.

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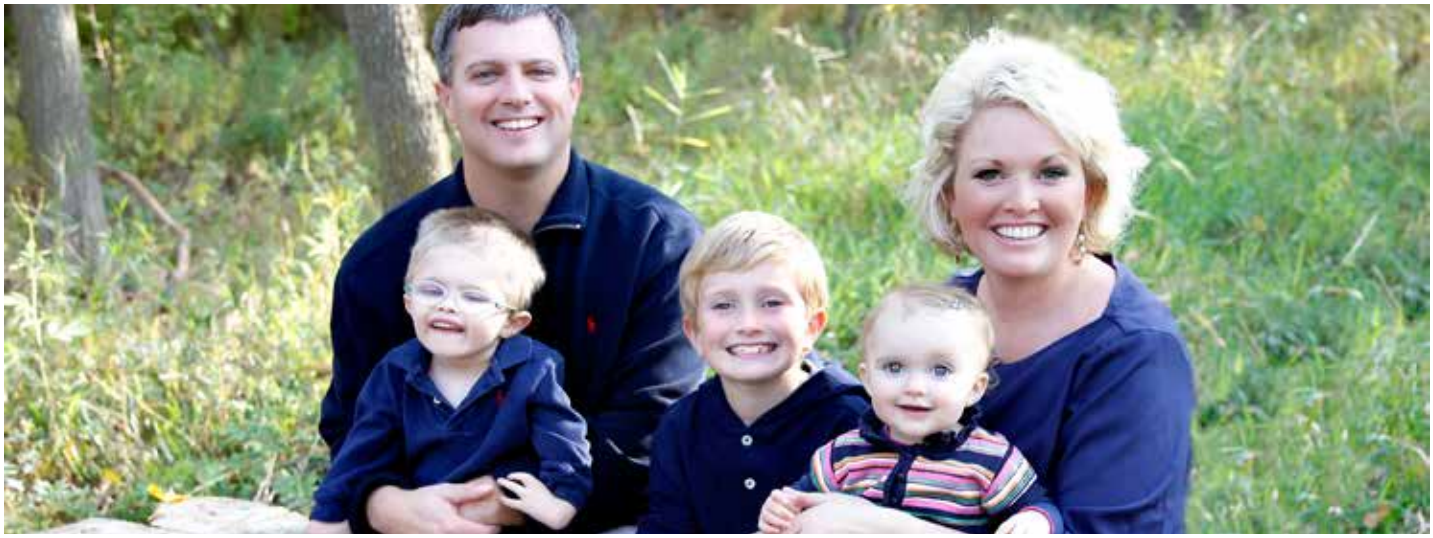


Meet Cale Ferrin, Age Six

By Britteny Ferrin

We would love for you to meet our son, Cale. He is our second child, and was born at 38 weeks on September 14, 2006. At 20 weeks in utero, Cale was diagnosed with hydrocephalus (fluid on the brain), and was closely monitored for other related serious health problems. His brain cavities were so full of fluid, that it was very hard to tell if he would have any normal brain activity at all. At delivery, the doctors were stunned to see his abnormal growth in arms, missing bones, and other anomalies. It turned out that his hydrocephalus diagnosis was a symptom of Fanconi anemia, and Cale was diagnosed when he was 10 days old. That was when we learned what FA really meant for Cale and our family. Since then, our lives have been turned upside down.

Because of FA, Cale has many organ and system abnormalities that require constant medical attention. He has a missing bone in each forearm, missing thumbs, malformations of the kidney, heart, bladder, and other organs, strabismus of the eye, and low growth rate. Cale also suffers from severe ataxia. Ataxia causes a lack of muscle coordination, and severely affects balance and coordination. Cale didn't start to walk until he was 4 years old, due to a tethered spinal cord. Now, at the age of six, Cale only weighs 25 pounds, and has had more than 26 surgical procedures and nearly 100 hospital visits.

As we struggle with the complexities that FA brings, we continue to plan for Cale's future. Knowing that he will eventually need a bone marrow transplant, we went through preimplantation genetic diagnosis (PGD), an in vitro process to find a perfect sibling bone marrow match. After three failed attempts, we had success! Our fourth attempt led to identical twins, each of whom would be an identical bone marrow match for Cale. Our joy quickly turned to total sadness, when one of the twins, Avery, died from complications of twin-to-twin transfusion syndrome (another rare syndrome to affect our family). Our surviving twin, Anna, was seven weeks premature, but we were able to save her umbilical cord blood for when Cale needs his bone marrow transplant.

As parents, we are constantly trying to help Cale lead a "normal" life while continually monitoring his health with his team of medical specialists. Cale works daily with fine and gross motor skills, but he gets so tired working on things like writing or eating. His occupational therapy team helps him with writing skills, using a zipper, dressing himself, eating, and other essential life skills. His physical therapy team works on his balance, sitting on a chair, using stairs, and walking and running—all without getting hurt. Most things we take for granted have to be adapted to help Cale function. He just learned to button a shirt using his teeth, he takes his socks off with his toes, and he eats pizza upside down so he can balance it between his pinky and ring finger. If there is a will, Cale will find a way!

Despite his daily struggles, Cale is determined to bring warmth and kindness to everyone he meets. He truly lights up a room with his sweet little voice, his smile, and BIG hugs. His doctors call him "Rock Star," and we couldn't agree more. He is meant to bring people together for a common cause. That is what makes him unique, makes him Cale, and I am so proud to be his mom.

Living Fully with Fanconi Anemia

By Sean Breininger

My name is Sean Breininger. I am 35 years old. I have Fanconi anemia. This is part of my introduction to most people I encounter nowadays.

In June 2011, I was in Honduras leading a mission group to an orphanage when I received this email from my doctor:

> **"Attached is a handbook of more info re: Fanconi anemia.… There is a Fanconi anemia expert at the National Institute of Health who you should probably see at some point in the future.**
>
> **All this being said...there is nothing you can do about this while in Honduras and you should try your best to completely put this news in the back of your head if you can."**

Obviously, putting this in the back of my head was not an option. I quickly began to download the Fanconi Anemia Research Fund (FARF) handbook. Being in Honduras, my Internet connection seemed excruciatingly slow as I waited for each chapter to reveal what the rest of my life would entail.

There was so much information to digest, but this is what stuck in my mind:

> **"Fanconi anemia (FA) is one of the inherited anemias that leads to bone marrow failure. The current median lifespan for a patient with FA is 29 years. Patients who have had a successful bone marrow transplant still must have regular examinations to watch for signs of cancer."**

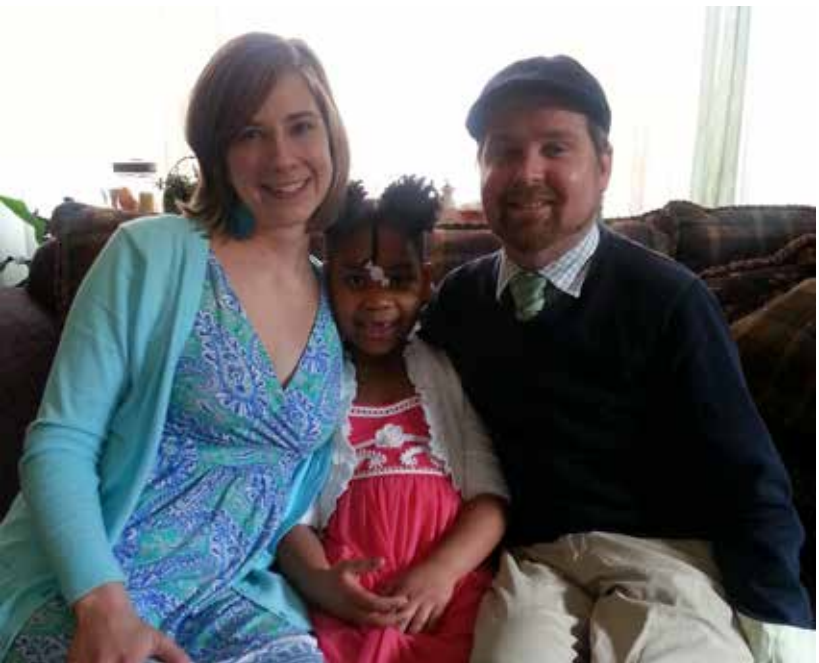
With my wife, Allison, and daughter, Maya, thousands of miles away, I sat with this news for over a week. Fast forward six months and I was at the University of Minnesota receiving a bone marrow transplant with donor cells from my brother.

Even now, when I write this, it seems surreal. The "why me?" ruminates in my mind until I exhaust myself from thinking.

However, what's more remarkable is that I have an unwavering feeling of gratitude and hope. I believe it is the blessing that we, who have known deep grief, tragedy, and sorrow are given. It has focused my life in ways I never could have imagined or planned myself. Through the compassionate work of FARF, I was able to meet people with FA from all over the world at the FA Family Meeting this summer.

I now have purpose. I want to live for those I met. To be living with FA as an adult, and as a husband and father, I want to be an example of hope for all those with FA. One such person is Theo. I was able to share a few moments with Theo at Camp Sunshine, and saw myself in him. A nine-year-old boy with FA who loves baseball and drawing. He has a whole life ahead of him. It is powerful that by my living, he can see his future. His family can dream of him growing up and living with purpose.

My deepest gratitude to all FA families, researchers, and to FARF for showing me purpose and giving me hope! It is because of you all that I have changed my introduction to people I meet. My name is Sean Breininger. I am 35 years old. I *live fully* with Fanconi anemia.



Fund Keeps Administration Costs Low

The Fanconi Anemia Research Fund strives to put its generous donations to the best possible use. As a result, our combined administrative costs for 2012 were only 7.5% of total expenses. This means that **almost 93 cents of every dollar donated goes directly to furthering our mission** to both find effective treatments and a cure for Fanconi anemia and to provide family support services.

Facing FA with Knowledge and Hope

By Lisa Mingo

Our family's experience with Fanconi anemia began when I was 20 weeks pregnant with our youngest son, Dylan. The radiologist noticed that Dylan was missing a radius bone and thumb on his left hand, but couldn't explain the cause. At my 36-week scan, they found that Dylan's kidneys were fused on one side. Then came the amniocentesis, which showed no chromosomal abnormalities. At 39 weeks, our obstetrician cautiously opted to deliver Dylan via an elective Caesarean section since no one was sure what was going on. It wasn't until a follow-up visit to the geneticist when Dylan was five-months old—when testing was suggested for a "very rare blood disease" that they were "sure he didn't have"—that we discovered that Dylan had Fanconi anemia.

It was a devastating diagnosis, and we couldn't believe that Mark and I (who happen to come from opposite ends of the earth) were both carriers of this rare genetic disease. But after the initial shock wore off, we quickly moved from thinking "why us?" to "why NOT us?" We realized that we weren't the only family with issues, so if this was our reality, then we would face it head on and learn as much as we could about the disease, its treatment protocols, and how best to support Dylan and our family in the future. Thank goodness for the Internet, because within days of Dylan's diagnosis we had located the FA Research Fund, signed up for their email support group, and immediately received a flood of supportive messages and commenced our learning process.

The knowledge we've gained (and continue to gain) has been instrumental in helping us to feel like we have some control over something that is otherwise out of our control. We have found fundraising (via community garage sales) similarly helpful because it has felt good to raise awareness and money for FA research and support, and has allowed our family to feel like we're making a difference. In 2012, we discovered the FA Family Meeting at Camp Sunshine in Maine. Camp was a lot of things for us. It was emotional, as we found ourselves forced to confront the reality of our situation and listen to sometimes heartbreaking stories from other families. It was educational, as we learned from doctors, scientists, and families about the disease, new treatments, research efforts currently underway, and where our fundraising dollars go. And it was supportive, as we had an opportunity to meet other families who are also walking in our footsteps and understand exactly what we're going through.

At age six, Dylan is becoming very aware of his differences. He knows he might need a bone marrow transplant one day (although he doesn't yet understand what this means), and has already expressed a desire to be "like all the other kids." But at Camp Sunshine, he discovered (much to his delight!) that he isn't the only four-fingered kid on the playground. And last, but not least, Camp left us with a sense of hope. The future is always uncertain, and any family dealing with FA knows this to be especially true. But given the pace of change in the medical field, and the dedication and perseverance of people like the Frohnmayers and our amazing FAmily, we are very hopeful that there are exciting times ahead in the world of FA.

PGD Study Aims to Assist Families

Do you have a child or children born using preimplantation genetic diagnosis (PGD)? If so, please consider participating in a study conducted by Heather Zierhut, PhD, University of Minnesota, Minneapolis, to assess the long-term outcomes of the procedure. Dr. Zierhut hopes to learn about families' experiences to help healthcare providers and future families understand the personal, family, societal, and medical implications of using PGD. Participation includes the completion of a 1-hour phone interview and, if you are willing, the release of medical records related to PGD. For more information or to participate, please contact Dr. Zierhut at 612-626-6743 or zier0034@umn.

Finding Support Along the Way

By Joanne Smith

My name is Joanne Smith, and I live in the city of Preston in the northwest of England. I am 48 years old, and have always known that I had Fanconi anemia, but am unsure at what age I was diagnosed and do not know my complementation group.

Between 2003 and 2010, I was living in Munich with my husband Kevin. In 2009, I was diagnosed with Type 1 diabetes and the specialist suggested I see a hematologist. Thus began my monthly blood tests and first endoscopy. When we returned to England, I insisted on being referred to a hematologist and found Dr. Meyer, a pediatric hematologist at Christie's Hospital in Manchester with a special interest in FA.

I did not know about the FA Research Fund until Dr. Meyer met Teresa Kennedy, FARF's Family Support Services Director at a meeting and told her about me. He later phoned me and said that I had been invited to attend the October 2012 Adults with FA meeting in Austin, Texas, and to contact Teresa if my husband and I wished to attend. We called Teresa and so had our first trip to America.

Although we lived abroad in Munich and have visited many other European countries on holidays, we never expected to go to the United States. So the visit to Texas was an experience of visiting a new country and, of course, meeting others with FA. This was the first time I had met anyone else with FA, and it was a great inspiration to share our experiences. Even though we are all FA warriors, we all have different characteristics. I was born without thumbs, with dislocated hips, and an ectopic anus but, fortunately, have not had any transplants. Both my kidneys are on one side, but I appreciate that I am lucky compared to other warriors. We met some wonderful people with whom we still keep in contact.

The conference was also educational for Kevin. He has known since we first met that I have FA, and has supported me throughout our 27 years of marriage.

In Austin, we learned about the FA Family Meeting at Camp Sunshine. We attended this year and had an enjoyable time catching up with old friends and making new ones.

Now I have an every three month blood test, an annual bone marrow biopsy, endoscopy, audiologist appointments, and MRI scans. I am on the National Health Service waiting list for an MR mammogram. I have also had a skin biopsy to determine my FA category; I am still waiting for the final results. I met Dr Schindler, from Wuerzburg, Germany, at Camp Sunshine who is analyzing my biopsy and was more than happy to speak to us. Although I now wear hearing aids, there is one advantage. When Kevin is watching soccer or cricket on the TV, I can switch off the hearing aids when he is shouting at the players!

With the help of FARF, I feel like I have an extended family and great support. Being with FARF reminds me of the famous English soccer song, "You'll Never Walk Alone."

Meeting for Adults with FA

March 21-24, 2014 • Baltimore, Maryland

Questions or need financial assistance for travel?
Please contact Teresa Kennedy at
teresa@fanconi.org or 1-888-FANCONI.

Preparing with Optimism for Challenges Ahead

By Darrel and Kalani DeHaan

Fanconi anemia changed our world before Cooper was even born. Having scheduled a routine ultrasound at 20 weeks of pregnancy, we were excited to find out the gender of our baby. Instead, we were devastated to learn the long list of anomalies already affecting our little boy. This was extremely overwhelming news, as nine years earlier we had a daughter, Abigail, who was stillborn with unexplained anomalies. After meeting with a genetic counselor and undergoing testing, we learned that Cooper had Fanconi anemia. Abigail would also later be diagnosed with FA. Thankfully, our two other daughters tested negative for FA. When Cooper finally arrived, he was a sweet little boy with an extensive list of health issues.

As we watched Cooper slowly grow, our time spent in surgery waiting rooms also grew. From our first time at the FA Family Meeting at Camp Sunshine, we speculated that Cooper was a unique case of FA, yet we didn't have a complementation group confirmation to verify our hunch. He just had so much going on that it was difficult to categorize him with other "normal" FA children. We knew that every case of FA was different, but struggled to make sense of Cooper's exceptional medical history and continuing challenges. Cooper has come a long way in his short life, beating the expectations of many. He is resilient. Approaching five years old and weighing barely 19 pounds, Cooper makes up for his small stature with an overflowing spirit, an ever-present smile on his small face, and the most notable giggle in a room.

Through Cooper, our fight against FA has taught us things about ourselves we likely wouldn't have known otherwise. Once the complementation group testing was complete, our hunch was confirmed when we learned that he was type FANCD1/BRCA2. While this helped explain his history and a brain tumor that had been removed, our world quickly became even more complex. Our outlook for Cooper changed as we learned more about others with FANCD1/BRCA2 and that children with FANCD1 commonly develop leukemia by two-and-a-half years of age. Additionally, the knowledge of Kalani's family medical history with several battles against breast cancer compounded our fears. Through genetic counseling, we learned that each of us was a carrier of BRCA2, a breast cancer susceptibility gene. Given this information, Kalani will have to consider a possible prophylactic mastectomy and hysterectomy, while we evaluate Cooper's next steps and a looming bone marrow transplant.

After many weeks of information gathering, soul searching, and praying, we made the difficult decision to schedule a bone marrow transplant for Cooper. In early 2014, he will receive a BMT at the University of Minnesota Amplatz Children's Hospital. The chance of a successful transplant increases greatly if Cooper is transplanted when he is healthy. His blood health is currently stable, but is susceptible to rapid decline at any time.

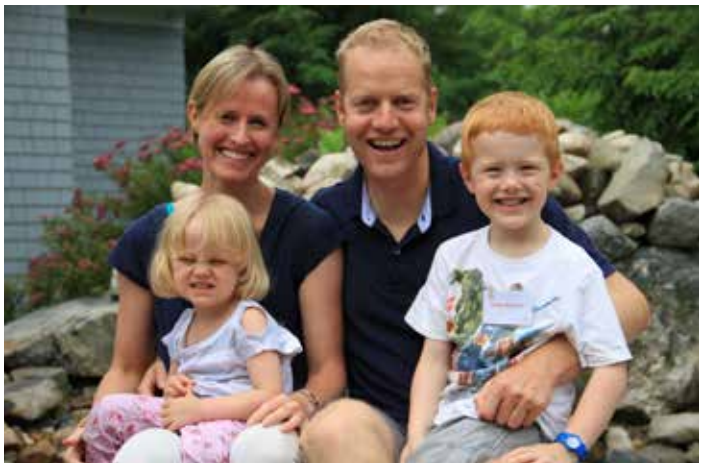
As the BMT approaches, we await further donor testing; unfortunately, neither of Cooper's sisters is a match. Planning for the many difficulties that we'll face during transplant is our current focus—keeping Cooper healthy, maintaining a long-distance family, and strengthening our support network. Mindful of our own newly-discovered health risks, we now have routine cancer screenings and make healthier lifestyle choices. Cooper doesn't let us feel down too often about his difficulties. He is always happy, energetic, and a constant reminder of what is important in life. Through Cooper, we've learned to live for each day and optimistically prepare for the challenges that lie ahead.

Congratulations!

Proud parents Michelle Ploetz (FA) and Tim Hendricks welcome their son, Timothy John "T.J." Hendricks, born August 12, 2013.

Family Hits the Ground Running to Fundraise for FA

By André Hessels and Rutger Boerema



In November 2012, our son, Dylan, six, had pain in his hip. His doctor ordered a blood test to rule out a possible bacterial cause. The doctor noticed that his mean cell volume was unusually high and encouraged us to see a hematologist. Lots of tests were performed, all with a negative outcome. To be on the safe side, the hematologist also wanted to test Dylan for a very rare disease, telling us "I will not give you the name of the disease, otherwise you will search the Internet and you will get worried." We enjoyed a peaceful Christmas, and then on January 4 we heard the devastating news that Dylan was affected with Fanconi anemia.

We had never heard of this disease before. Fanconi what? Unfortunately, the news only got worse for us as Dylan's three-year-old sister, Joy, was tested and we got the heartbreaking news that she also has FA. It was the darkest day of our lives so far. How were we going to cope with this? From being your normal average family, we went to lots of hospital visits, blood counts, bone marrow biopsies, and lots of uncertainty. We did not plan this and, like all parents, we only want the best for our children.

Although we were and are in a sad situation, we were immediately in a good place. We had moved to New York last year for André's job, coincidentally 10 streets away from the Memorial Sloan-Kettering Cancer Center (MSKCC). We received our children's diagnoses from Dr. Boulad at MSKCC. We only found out later that Dr. Boulad is regarded as one of the top doctors regarding FA and bone marrow transplantation.

The first weeks after diagnosis were hard. Digesting the news that both our children were afflicted with a disease with no cure found yet was very difficult. It was hard to explain this disease to our family, friends, and colleagues. We wrote a letter to explain, but it is still difficult to get the right message across. For example, some thought Dylan now immediately had to go to bone marrow transplant or they expected a BMT would solve all problems.

The response from André's colleagues was great. In June, his employer, Rabobank, joined the annual J.P. Morgan Corporate Challenge. For every employee who joined the race, $50 was donated to FARF. A total of 200 colleagues joined the run! Also, some colleagues in The Netherlands raised funds for FARF. In total about $15,000 was collected!

André also decided to enter the New York City marathon to raise money and awareness for FA. First, we tried to enter FARF as a charity with the marathon, but apparently it is hard for a new charity to get accepted. André then joined a team from MSKCC. Money raised from the marathon will go directly to Dr. Boulad, and he will designate from there. This will benefit FA research and patient care.

We attended the FARF's FA Family Meeting last summer which was such a great experience on so many levels. It also made us more aware of how important it is to raise funds for this orphan disease. We have a lot of ideas, and we are very willing to contribute in the coming years with new fundraisers.

For now, Joy's blood counts are fine, but unfortunately Dylan's blood counts have already dropped to critically low levels. His neutrophils are the main concern; his absolute neutrophil count (ANC) dropped a few times, but slowly recovered again. We are thinking of joining the quercetin clinical trial at Cincinnati Children's Hospital Medical Center, which may help to increase his ANC levels.

Whatever happens, we want to be there for our children in their journey. We do not have a choice about what life throws at us, but we do have a choice how we respond. And therefore, we will not give up hope, we will enjoy every moment together, and we will fight.

Online Fundraising Tools Available

Qgiv and Hobnob are online fundraising tools available through the Fanconi Anemia Research Fund. Through Qgiv, we can accept online donations directly on our website. Hobnob offers people a customizable fundraising page for events, enabling online registrations and donations in advance and at the event. Contact FARF for details on how Qgiv and Hobnob can enhance your fundraising!

Siblings Inspire Outpouring of Support

By Nigel and Ann Walker and Jim Hamilton

Joel and Joanne

The Walker and Hamilton families have recently joined the Fanconi Anemia Research Fund community as both families have been and continue to be impacted by Fanconi anemia. Nigel and Ann Walker's daughter Joanne, 34, and their son Joel, 30, were both diagnosed with FA last spring. Their supporters helped raise more than $31,000 for the Fund in a very short amount of time—truly a testament to how much Joanne and Joel mean to so many people!

As we discovered is often the case, Joanne's FA was only diagnosed after she developed esophageal cancer last December and started chemotherapy as part of the treatment. After many tests to find the cause of her sudden bone marrow deterioration, we received the FA diagnosis in March. Joel was then tested as a potential sibling donor match, but was also confirmed as FA positive. He is now monitored closely by doctors at the University of Minnesota, Minneapolis, who have told him that he will need a bone marrow transplant sometime in the future.

Sadly, Joanne passed on June 24, after a brave fight. She leaves behind her loving husband and high school sweetheart, Jim Hamilton, and their adorable two-year-old son, James. The donations to FARF were the result of the Celebration of Life service and our wish to receive donations in lieu of flowers and have come from four continents; Joanne and Joel were born in England. Her supporters also organized a bone marrow drive in conjunction with Be The Match on September 8, both in Joanne's memory and to show support for Joel. The event was quite a success and added many new and diverse donors to the registry.

Although we grieve for Joanne, we believe research on her blood donated to the tissue bank will ultimately help with the solution of the FA riddle. Other than small stature, Joanne had no other outward signs of FA and also gave birth to a very healthy son.

We look forward to meeting and seeing all of you at the next gathering and are continuing our fundraising and awareness activities.

FARF Can Help You Fundraise

More than 90% of the Fanconi Anemia Research Fund's annual budget comes from family fundraising. We're here to help make your events a success. We can:

- Provide sample fundraising letters and help you edit your letter
- Use your photos to personalize your letter, event invitation or brochure
- Use your mailing list to send your letter or invitation from our office
- Provide ideas, information, and display materials for events
- Provide a PowerPoint or video presentation to use at your event
- List your event on our website
- Send a thank-you letter and tax receipt to your donors

We ask that all fundraising events be covered by liability insurance. Insurance for a one-time event is often available through a family's homeowner's insurance policy as a relatively inexpensive insurance rider. Please contact the Fund if you need assistance obtaining or paying for this required insurance.

Please ask your donors to make checks payable to the Fanconi Anemia Research Fund. When a donation is received, we'll generate a letter of thanks with a tax receipt, and we'll notify you that a donation has been made in your name.

We appreciate all your efforts to raise funds for FA research and family support. You are making a difference!

Family Fundraising Efforts January through September

From January 1 through September 30, 2013, Fanconi anemia families raised $1,005,355 for the Fanconi Anemia Research Fund. Almost 93 cents of every dollar donated goes directly to research and family support to make a difference in the lives of individuals and families affected by FA. Thank you for your outstanding fundraising efforts so far this year!

$153,000 and up
Steve and Jennifer Klimkiewicz

$102,000 – $116,999
Dave, Lynn and Amy Frohnmayer
Kendall And Taylor Atkinson Foundation with the Nash and Atkinson families
Kevin and Lorraine McQueen

$66,000 – $86,999
Shawn Huff and Francesca Hutchins-Huff
Peg Padden
Glen Shearer

$23,000 - $49,999
John and Kim Connelly
Jim Hamilton
Todd and Kristin Levine
Nigel and Ann Walker

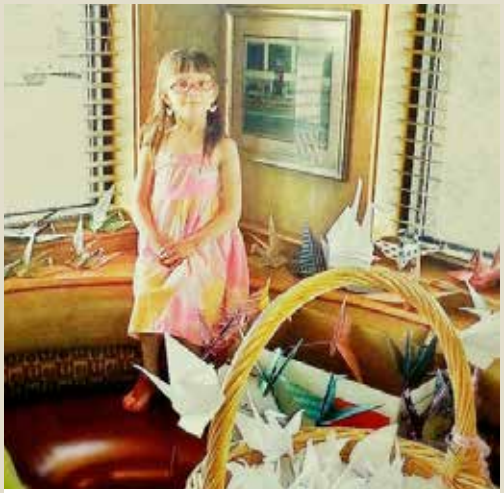
$10,000 - $19,999
Mike and Tracey Brannock
Robert and Barbara Capone
Kerrie and Mauro Cazzari
David and Mary Ann Fiaschetti
André Hessels and Rutger Boerema
Charles and Katy Hull
Orion and Lisa Marx
Susan Ortiz
Mark and Diane Pearl
Peter and Janice Pless

$5,000 - $8,999
Jimmy and Jenny Armentrout
Ryan and Becky Brinkmann
Brian Horrigan and Amy Levine
Kaps for Kendall
Jack and Lisa Nash
Gerard and Cynthia Vandermeys

$1,000 - $4,999
Michael and Jennifer Aggabao
Ron and Juanita Arroyo
Mark and Linda Baumiller
Israel and Mary Jo Becerra
Richard and Tena Boson
Chris and Jennifer Branov
Donald and Danielle Burkin
David and Kim Chew
Daniel and Melinda Coleman
Chris and Susan Collins
David and Kari Doctor
Brian and Jennifer Dorman
Mitch and Erin Furr
Ben and Stephanie Griggs
Alan and Rachel Grossman
Owen Hall and Margaret Kasting
John and Lisa Hayden
Mike and Patti Hilbert
Jeff and Beth Janock
Mark and Angela Lamm
Tim and Mary Ann Lana
Tanner and Jessica Lindsay
Gregory and Lynnette Lowrimore
Bill and Jackie Lucarell
Tue Marker and Kirstine la Cour Rasmussen
Dan and Nikki McCarthy
Adam and Olivia Mindle
Jim and Holly Mirenda
Tyler Morrison and Rachel Altmann
Marcia Reardon
Mark Ritchie and Lisa Mingo
Rick and Lynn Sablosky
Bob and Andrea Sacks
Bryan and Karen Siebenthal
William and Mary Underriner

Up to $999
Dorian Adams
Kelly Adams
Ken and Jeanne Atkinson
Cherie Bank
John and Audrey Barrow
Willie and Jeanette Beetge
Conrad and Joan Bender
Domenico Bertolucci and Federica Bonat
Randy and Nancy Bloxom
Jeffrey and Donna Boggs
Michael and Diane Bradley
Jeanette Clark
Natalie Curry
Brian and Margaret Curtis
Bill and Pat Danks
Darrel and Kalani DeHaan
Pat and Mary DiMarino
Antonino and Marie DiMercurio
Lindsay and Sandra Dunn
David and Kelly Dunnock
Ginger Eggers
Sharon Ellis
Billy Jo and Debbie Estep
Curt and Crystal Fales
Justin and Britteny Ferrin
Nancy Finnegan
Doreen Flynn
Liz Funk
Skip and Susan Gannon-Longstaff
Thomas Germann and Jennifer Bland
Stan Gilbert and Chris Brunner
Maria and Josh Godwin
Allen Goldberg and Laurie Strongin
Andrew and Jennifer Gough
David and Paula Guidara
Mitchell and Tirzah Haik
Abdul Hameed
Eric and Elisabeth Haroldsen
Shane and Colleen Irvin
Lila Keleher
Christopher and Dana Lamb
Eugene and Renee Lemmon
Eric and Beth Losekamp
Donnie and Jerri Lott
Deane Marchbein and Stuart Cohen
Steve and Alison McClay
David and Samantha McDowell
Kevin and Barbara McKee
Catherine McKeon
Gianna and Lauren Megna
Michael Menna
Ian and Tricia Mitchell
George and Sabine Mohr
Des Murnane and Mai Byrne
Kenny and Lisa Myhan
Tony and Lina Nahas
Jack and Tammy Neal
David and Catherine Newmann
Robert and Mary Nori
Ron and Fredi Norris
Fred and Nancy Nunes
Michael and Katharine Ormond
John and Dianne Ploetz
Michael and Kay Proctor
Lynn and Shirley Quilici
Jack and Tannis Redekop
Leonard and Jan Riley
Kevin and Katie Rogers
Stanley and Lisa Routh
Mike Sanders
Richard and Dolores Satterlee
Bill and Connie Schenone
Thomas and Brenda Seiford
Jim and Carol Siniawski
Kevin and Joanne Smith
Alfons and Karin Staab
Greg and Brandi Stuart
Mary Tanner
Peggy Templeton
Bruce and Loreen Timperley
Charles and Doris Trotta
Mike and Beth Vangel
Ronald and Sharon Van't Hof
Louis and Theresa Viola
Matt and Barbara Violassi
Joe and Wendy Vitiritto
Mike and Wendy Wade
Marc Weiner
Lynn Welfare
Michael and Kim Williams
Jian Yang and Jing Nie
Sean and Kristin Young

For the fundraising events calendar and helpful fundraising materials and tools, visit www.fanconi.org



1,000 Cranes for Lily

An old Japanese legend says that if you fold 1,000 paper cranes, you will be granted one wish of good health or longevity of life. The legend inspired Erin Furr to start the 1,000 Cranes for Lily fundraiser. Erin and her seven-year-old daughter, Lily (FA), folded paper cranes to benefit Fanconi anemia research.

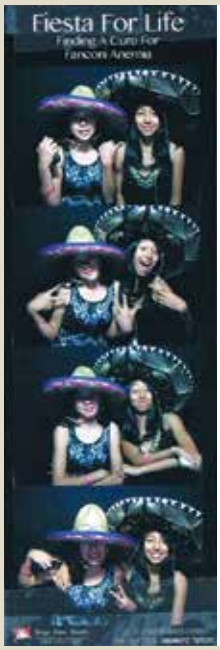
Erin then organized a "Dining to Donate" dinner complete with live music. The beautiful and lovingly folded cranes were sold with Lily on hand to personally autograph them. The event inspired the servers and bartenders to donate a portion of their tips. More than 1,000 cranes were sold, raising a total of $4,200 for FA research! Thank you, Erin and Lily, for bringing us all closer to our wish of good health and long life for all affected by FA.

A Latte for FA

For many, a cup of coffee is the way to start the day. But Daniel and Mindy Coleman, parents of Isaac, age two, turned it into a great way to help fight FA, by raising funds with a coffee-themed online raffle called A Latte for FA.

"It was a really easy fundraiser for us to do," says Mindy. "A lot of people we know wanted to be able to help in some way, so this seemed to be a small way for people to be able to do that."

Participants donated $5 for a chance to win a package of great prizes including a Chemex coffeemaker, coffee beans, two 12-ounce travel mugs, and a year's subscription to *Kinfolk* magazine. Each person who donated over $25 also received an art print of his or her choice. There were four different prints to choose from, each donated by local artists. A Latte for FA raised some cups—and more than $3,000!



Fiesta for Life

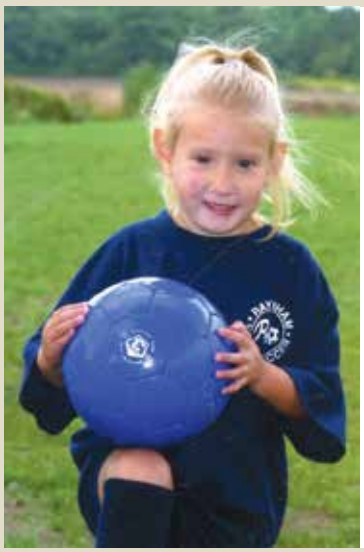
Ron and Juanita Arroyo hosted their first fundraiser this year, called Fiesta for Life. Members of their community came out in droves to enjoy a taco buffet, finger foods, and dancing. There was even a photo booth in which attendees donned traditional Mexican costumes and props to pose for portraits.

The venue was packed to near maximum capacity, as attendees danced the night away. Most guests were still present when the event officially ended at midnight!

The Arroyo family raised more than $5,000 with Fiesta for Life, and helped spread awareness of FA to the greater community.

"A good friend and our son, Anthony, 15, were our emcees. They did a great job in providing information about our cause," Juanita said. "It was lots of fun planning it, and we all had a great time at the event."

Fiesta for Life was a resounding success for the Arroyo family's first foray into fundraising. When asked if they would do it again, Juanita simply replied, "Definitely."



Coley's Cause

They say you don't have to be good at golf in order to enjoy it. Whether or not that's true, participants at the Ninth Annual Coley's Cause Memorial Golf Tournament certainly enjoyed playing golf for a good cause last June.

"It was a great success," said Todd Levine. Todd and his wife, Kristin, organize the event in memory of their daughter, Nicole "Coley," who passed away at age six due to complications of FA. This year's event, held in Lakeville, Mass., was highlighted by the attendance of several other FA families including the Flynns, the Vangels, the Youngs, and the McDowells. The fundraiser drew so many tournament participants that the entire golf course was sold out. David McDowell, Amy Vangel, and Jordan Flynn addressed the crowd during the post-tournament dinner. "They absolutely floored them all with their beautiful stories and expressions of thanks," said Todd Levine.

The hugely successful benefit raised $23,000 this year. With the goal "to raise funds desperately needed for research aimed at improving the prognosis and life expectancy of the many innocent children afflicted with the disease," the nine annual Coley's Cause Memorial Golf Tournaments have raised a phenomenal total of $203,000 for the Fanconi Anemia Research Fund.

Michael's Army's Spirited Auction

Tennessee is well known for the great music coming out of Nashville, and for the high quality of the state's namesake whiskeys. This year, Barb Capone showcased Tennnesee's finest spirits to help raise money for FA research by holding an online auction through Michael's Army.

In May, four one-of-a-kind baskets were auctioned off, each based on a theme of classic beverages from Tennessee and Kentucky, and containing some very rare bottles of premium Kentucky bourbon or Tennessee whiskey.

Bidding started at $50 per basket and quickly shot up from there. When the bidding ended, the four spirited baskets sold for an amazing total of more than $17,000!

Barb and Robert Capone started Michael's Army to fundraise for a cure for FA in honor of their son, now 15. In just a few years, their Army's efforts have had great success. A toast to the Capone family and Michael's Army!

A Few of Nina's Favorite Things

Music, dancing, and desserts were three of Nina Morrison's favorite things. The favorites made a sweet and suitable combination as the theme of a fundraiser in Nina's memory for what would have been her tenth birthday. Nina's Sweet Soiree was lovingly planned by Nina's mother, Rachel Altmann. Nina died at three years old due to complications from Fanconi anemia.

Participants packed the Vintner's Cellar in Portland, Ore. They sampled delectable desserts, tasted a variety of wines, and danced to the sweet melodies of a jazz duo. Raffle prizes were a big hit, and guests remembered Nina with a slideshow of her photos.

"It was just amazing to be in the company of so many supportive friends," Rachel said.

Nina's Soiree was a sweet success and raised more than $2,500 for FA research in her memory. Sweet.

NINA'S Sweet Soirée

Your FA Research Dollars at Work

From March to August 2013, the Fanconi Anemia Research Fund awarded $630,096 in research grants to the following projects:

Investigator: Alan D'Andrea, MD, Dana-Farber Cancer Institute/Harvard University, Boston
Title: *Novel therapeutic agents for the treatment of bone marrow failure in Fanconi anemia*
Amount: $200,000

Investigator: Ian Mackenzie BDS, FDSRCS, PhD, University of London, London
Title: *The effects of loss of Fanconi gene function on the behavior and therapeutic responses of head and neck cancers*
Amount: $185,441

Investigator: Jason Taylor, MD, PhD, Oregon Health & Science University, Portland, Ore.
Title: *HPV-associated immune defects in Fanconi anemia*
Amount: $100,985

Investigator: Flavia Teles, DDS, MS, DMSc, The Forsyth Institute, Cambridge, Mass.
Title: *Identification of microbial and host-derived determinants of oral carcinogenesis in Fanconi anemia*
Amount: $143,670

The Fund is committed to supporting research that furthers our mission to find both a cure and new treatments for individuals with FA. Over our 25-year history, we have funded 192 projects from 101 investigators at 55 institutions. The total amount of research dollars awarded is over 16 million dollars!

Board of Directors Elects New Secretary/Treasurer

The Fanconi Anemia Research Fund's board of directors recently elected Brian Matthews, PhD, to secretary/treasurer of the board. Dr. Matthews, Emeritus Professor of Chemistry at the University of Oregon in Eugene, has been an insightful and valuable member of the board since 2011. In his new role on the board, he replaces Ruby Brockett who retired from the board earlier this year after serving as secretary/treasurer since 1998.

Fanconi Anemia
RESEARCH FUND, INC.

1801 Willamette St, Suite 200
Eugene, Oregon 97401

RETURN SERVICE REQUESTED

Mission: To find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

Use of Logo

A reminder to our families with FA: Please use our logo or letterhead only after you have consulted staff at the Fanconi Anemia Research Fund and received approval. This step is necessary to be sure our messages are accurate and consistent, and it helps avoid legal complications. We are happy to collaborate on fundraisers and mailings.

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.*

HOW YOU CAN HELP

Donations Online:	Donate via the heart button on the Fund's website (www.fanconi.org) or through www.networkforgood.org or www.paypal.com
Donations by Phone:	Call us at 541-687-4658 or toll free at 888-FANCONI (888-326-2664) (USA only)
Donations by Mail:	1801 Willamette St., Suite 200, Eugene, OR 97401

Please go to www.fanconi.org to learn about other ways to donate.

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