Fall 2014

FA Family Newsletter

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Families Gather in Maine for the 23rd Annual FA Family Meeting

Fifty-seven families, including 11 first-time families, traveled to Camp Sunshine in Casco, Maine in June for the Fanconi Anemia Research Fund's 23rd annual FA Family Meeting. Unlike recent years, there was no rain and the meeting was full of sunshine, smiles, laughter, and hugs during the five-day gathering! Educational sessions, support groups, research opportunities, and fun recreational activities filled the busy days.

Sixty-seven adults and children with Fanconi anemia, ranging in age from one to 24 years, attended with parents, siblings, and other family members. Participants traveled from seven countries: Canada, Germany, India, Pakistan, Switzerland, United Kingdom, and the United States.

Medical and educational sessions included presentations on improving nutritional behaviors, endocrinology, gastroenterology, oral health care, head and neck cancer, gynecologic issues, post-transplant effects, and the role of aldehydes in FA. New this year, a dermatologist informed attendees about skin issues associated with FA and another speaker provided updates on new potential treatments. A panel discussion, including representatives from three FA Comprehensive Care Centers, focused on stem cell transplantation issues. See reports on these

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$25 for 25!

25 YEARS

The Fanconi Anemia Research Fund is 25 years old this year! In honor of this milestone, please consider sending a donation of $25—or $250, or $2,500… Please be sure to designate your donation as "$25 for 25!" Thank you for helping us make a difference.

Potential Drug Therapies for Fanconi Anemia

Richard Gelinas, PhD

Richard Gelinas, PhD, Institute for Systems Biology, Seattle, gave an informative overview at the FA Family Meeting of current research into drug therapies that have the potential to improve the course of Fanconi anemia, possibly even provide a cure. Much of this research exists because of funding from the Fanconi Anemia Research Fund. Sufficient progress has been achieved in understanding FA during the past 25 years to be able to visualize many approaches to drug discovery by some of the best investigators in the world.

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Potential Drug Therapies for Fanconi Anemia

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Oral Cancer, Squamous Cell Carcinoma (SCC)

- Robert Sclafani, PhD, University of Colorado, Denver, tested the drug resveratrol on cell lines derived from SCC and found that it kills some of the SCC cell lines, but not normal cells. The next step is to study drugs that could work in a complementary and synergistic way with resveratrol to prevent or control SCC.
- Michael Spiotto, MD, PhD, University of Chicago, knowing that many SCC oral tumors in the general population show signs of the HPV virus, tested two drugs, Rapamycin and Imatinib, in a mouse that develops HPV-positive oral tumors. Both drugs are FDA approved to treat other cancers. He has shown that, in combination, these drugs significantly delay the emergence and growth of HPV-positive SCC tumors.
- Joel Greenberger, MD, University of Pittsburgh, is testing a drug (GS-nitroxide) on Fancd2-deficient mice to show that treatment with this drug protects non-cancerous cells from a therapeutic dose of radiation but still allows SCC tumors to die.

Marrow Health

- Michael Garbati, PhD, Oregon Health & Science University, Portland, is testing a variety of clinical compounds, some of which are in Phase I clinical trials for other indications like ovarian cancer, to determine the possibility of intervening in the pathway of aldehyde damage to FA cells by modulating cytokine levels. Cytokines are small proteins that are important in cell signaling.
- Markus Grompe, MD, Oregon Health & Science University, Portland, and his collaborators, have found several compounds that may be effective in promoting blood stem cell survival. They are now investigating the positive effect that Tremulacin, cysteamine, STAC, and oxymetholone have on FA stem cells.
- Ray Monnat, MD, University of Washington, Seattle, is testing two potent yet safe aldehyde "scavengers" that could protect blood stem cells from damage by aldehydes. One could chemically inactivate aldehydes and is widely approved for other purposes.

Novel Drugs

- Andrew Deans, PhD, University of Melbourne, Australia, found a way to isolate FA proteins and has suggested a method to use these functional proteins to screen drugs that will restore the pathway. He will continue to investigate whether this method, which has had some success in cystic fibrosis, is viable for FA.
- John Postlethwaite, PhD, University of Oregon, Eugene, is screening drugs using FA zebrafish to identify pathways and gene targets to protect stem cells.
- Elizabeth Eklund, MD, Northwestern University, Chicago, is investigating how the FA pathway prevents bone marrow failure during emergency blood cell formation caused by an acute infectious or inflammatory challenge.

Clinical Trials

- A clinical trial for N-acetyl cysteine (NAC) coordinated by Rabin Tirouvanziam, PhD, Emory University, Atlanta, is in the planning stages.
- Aldea Pharmaceuticals is in the pre-clinical stages of a compound to promote the breakdown of aldehydes in the body.
- Major pharmaceutical companies are researching SCC immunotherapy with drugs that unleash the body's natural defense against a tumor by activating T-cells to kill the tumor.
- Single patient studies can be done when: 1) a physician creates a study for one patient to use an approved drug for an off-label use or 2) a physician creates a study of an investigational drug if a drug company agrees to supply the drug and it is sanctioned by the FDA.

Twenty-five years ago, FARF was funding research into finding the FA genes. The genes led us to the pathway; the pathway is helping us understand the function of FA proteins and how FA affects the whole body and its physiology. Now we can identify possible drugs that will be beneficial and predict their effect, especially those drugs that already have FDA approval. With basic research translating into drug therapies, families will have to decide which clinical trials to participate in as these trials become available.

A video of Dr. Gelinas' presentation that further elaborates on these topics can be found at the FARF website, www.fanconi.org, Family Support Tab, Annual Family Meeting Link. This presentation also includes a helpful "Glossary of Small Molecule Terms."

Reducing Aldehyde Toxicity as a Therapy for FA

Alan D'Andrea, MD

Alan D'Andrea, MD, Dana-Farber Cancer Institute, Boston, explained the research from many labs suggesting that highly reactive organic substances called aldehydes play a key role in Fanconi anemia bone marrow failure and fetal development. (Specifics of this research have been detailed in recent issues of this newsletter.)

Dr. D'Andrea described how the findings on aldehyde toxicity and FA point to several therapies that have the potential to reduce the overall aldehyde burden on individuals with FA. The following areas are considered: 1) avoiding aldehydes; 2) drugs which can "sponge up" aldehydes from the blood; and 3) drugs which stimulate the body's production of enzymes that normally convert aldehydes into non-toxic substances.

Avoiding Aldehydes:

Our bodies are exposed to toxic aldehydes both externally and internally as a result of their formation from normal body processes. Figure 1 provides examples. While it is impossible to avoid all aldehydes, alcohol has been particularly linked to problems in FA, so it is recommended that individuals with FA and mothers pregnant with an FA fetus not drink alcohol.

Drugs to "Sponge up" Aldehydes:

Substances called thiols can react with aldehydes in the blood and facilitate their removal. A multi-center clinical trial is currently being developed for the thiol, N-acetyl cysteine (NAC). Scientists are researching another thiol, cysteamine, with a view to bringing it to clinical trial in the future.

Drugs to Increase Aldehyde Breakdown:

A family of enzymes called "aldehyde dehydrogenases" break down aldehydes in the body. One important enzyme in this family is ALDH2. Figure 2 shows the role of ALDH2 in the breakdown of alcohol in the body. A pharmaceutical company plans a clinical trial of a drug that stimulates ALDH2. The trial will determine the safety and efficacy of this drug to promote the removal of aldehydes from the blood for acute alcohol toxicity in the general population. If this trial is successful, the company plans to study the drug's potential for use in FA. Other research labs are studying different aldehyde dehydrogenases, such as ALDH3 and ADH5, as potential therapies.

Future Studies

Dr. D'Andrea listed some important questions that require more research into aldehydes' effect on Fanconi anemia:

- Why are the blood stem cells so sensitive to loss of ALDH2 and the FA gene? Why do some FA cell lines have more ALDH2 than others?
- Is there a relationship between low ALDH2/ALDH3 levels and squamous cell carcinoma of the head and neck?
- Can mice with ALDH2/FA deficiency or ADH5/FA deficiency be a helpful experimental model since they present with spontaneous bone marrow failure?
- Can we suppress the production, accumulation, and dietary effects of aldehydes?
- Are some aldehydes more toxic than others to FA patients?
- Should aldehyde levels be monitored in a patient's blood?

The Fanconi Anemia Research Fund encourages and directly funds research into aldehydes. Answers to these and related questions have the potential to translate into better outcomes for those with FA.

Figure 1. Examples of Aldehyde Sources

External

Environmental

- In the air (phytochemical degradation and automobiles)
- Cooking fumes
- Cigarette smoke
- Cosmetics, perfumes, hair salons

Dietary

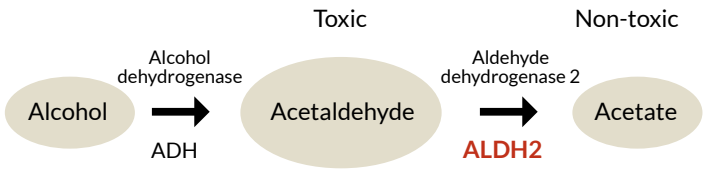
- Alcoholic beverages

Internal

Normal Metabolism

- Acetaldehyde formed from the breakdown of alcoholic beverages
- Formaldehyde produced close to DNA
- 4-hydroxynonenal (4-HNE)
- Malondialdehyde (MDA)

Figure 2. Acetaldehyde metabolism in our body



Oral and Dental Health Care in Fanconi Anemia

Flavia Teles, DDS, DMSc

Flavia Teles, DDS, MS, DMSc, Harvard School of Dental Medicine, Boston, discussed oral and dental healthcare in the context of Fanconi anemia. She stressed that the best ways to avoid oral diseases include regular plaque control and diligent monitoring by a dentist.

The human mouth is normally colonized by many different microorganisms, some of which can be pathogenic. These microorganisms are present on oral surfaces as part of a biofilm, a bacterial growth that enables their attachment to such surfaces. Most common oral diseases (such as gingivitis, caries, periodontitis, periapical abscess, and peri-implantitis) are caused by oral bacteria.

Oral diseases can be diagnosed by a clinical dental exam and/or dental x-rays. X-rays for FA individuals should be done only when necessary since FA tissue is more susceptible to DNA damage from x-rays. Radiation exposure can be reduced with the use of digital x-rays, which are recommended for FA individuals. Dr. Teles also discussed the controversy over fillings made of amalgam versus composites, noting that there is no clear answer whether either is harmful.

Prevention of oral disease can occur through proper oral hygiene, regular dental visits, and sealants. Proper oral hygiene is a patient responsibility and includes:

Individuals with FA can avoid oral diseases and be much healthier if they practice good oral care, which is particularly essential in FA.

- Tooth brushing. No method or design of toothbrush seems superior, but good technique is important. Brush a minimum of twice a day for two minutes. Toothpastes that contain fluoride are recommended. Toothbrushes should be replaced every two to three months and used with care to not cause trauma while brushing.
- Interproximal cleaning. The interproximal area is the gap that exists between teeth and is hard to clean by tooth brushing. Proper cleaning with dental floss is important. Interdental brushes can also be helpful and can be used for other tight spots such as root concavities. Use a gentle in and out stroke.
- Tongue cleaning. A coated tongue might contribute to bacterial accumulation, can alter the taste of food, and can cause bad breath. A tongue scraper is a good way to remove this coating and promote health.
- Chemical plaque control. The use of a mouthwash can help to achieve and maintain oral health. It is important that FA individuals not use mouthwashes containing alcohol as this could be harmful to FA mouth tissue. Furthermore, toothpastes and mouthwashes may contain antimicrobials such as triclosan. It has been suggested that triclosan may alter hormone regulation and may favor the emergence of triclosan-resistant bacteria. Although the potential detrimental effects of triclosan remain inconclusive, patients with FA are advised to avoid products containing triclosan due to their predisposition to endocrine disorders.

Individuals with FA may face specific oral issues in the context of bone marrow transplantation (BMT). Some drugs and procedures used in BMT can compromise patients' ability to fight infections and lead to gingival overgrowth and mucositis, all of which can be exacerbated in the presence of poor oral hygiene.

Another area of concern to individuals with FA is oral cancer. Signs of oral cancer might include ulcerations, petechiae (small spots of bleeding under the tissues), spontaneous gingival bleeding, and gingival tissues that are red to pinkish/white. The dentist can look for irregularities during the clinical exam. Prior to therapy for oral cancer, the dentist would try to restore oral health and eliminate sources of infection. If tooth extractions or therapy on the tissue surrounding the teeth is required, it should be completed prior to radiation or chemotherapy. Head and neck radiation therapy that may be used to treat the cancer can cause such mouth issues as mucositis, infections, osteoradionecrosis, and xerostomia. The dental treatment should be coordinated with the medical team treating the cancer and should include frequent dental maintenance visits.

Individuals with FA can avoid oral diseases and be much healthier if they practice good oral care, which is particularly essential in view of the challenges of Fanconi anemia.

Improving Nutritional Behaviors

Susana Patton, PhD, CDE, University of Kansas, Lawrence, addressed mealtime challenges and strategies, issues that concern many parents of FA children. She noted that eating is a complex set of skills that children learn gradually over time, particularly during the first two years. Common feeding challenges include neophobia (fear of new foods), limited food variety, variable food intake, limited attention span, and disruptive behaviors.

For those with neophobia, it's important to realize that it can take up to 15 tasting experiences of a new food to develop a preference for it. Just looking at the food doesn't work! However, most families give up after three to five introductions of a new food. Not surprisingly, this can lead to limited food variety. Dr. Patton recommended choosing the least-challenging meal when introducing a new food. Present a small amount early in the meal, and praise even incremental changes like picking it up, smelling it, and tasting it.

Limited food intake is also a common concern for parents. Interestingly, kids will eat the majority of their calories in the first half of a meal. You can maximize the number of calories eaten in each bite by choosing healthy, high-fat foods like avocados, nuts, and dairy products. Spread calorie intake goals over the whole day instead of each meal.

Challenging mealtime behaviors that members of the audience raised included leaving the table, playing, refusing to eat, spitting out food, crying, and talking. Dr. Patton suggested some specific strategies to address these issues. Praise behavior you want to see repeated such as coming to the table, taking bites of food, and trying new foods. Ignore undesirable behaviors such as complaining about food, not eating, and attempts to draw your attention away from the meal. It's easy to attend to these frustrating behaviors, but it's more effective to ignore them. Ignoring a behavior can initially result in an escalation of the behavior, but with consistent ignoring, the behavior will change over time.

A different type of strategy is to set and reward specific goals. The best goals focus on behavior instead of outcomes (for example, trying one new food at dinner for two weeks, instead of gaining a certain amount of weight). Goals are most effective when they are specific, measurable, realistic, and time-specific. It also helps if the parent and child can choose the goals together.

Parents can also encourage positive mealtime behaviors by limiting distractions, eating along with their children, and keeping mealtimes relatively short.

Proposed NAC Trial for FA Patients Progressing

Rabin Tirouvanziam, PhD

Rabin Tirouvanziam, PhD, Emory University, Atlanta, updated attendees at Camp Sunshine on an upcoming Phase I/II trial of NAC (N-acetylcysteine) in FA patients. The multi-center, multi-national nature of this trial has led to delays in implementation. Medical centers in four countries (Canada, the US, Italy, and Germany) plan to participate. The Fanconi Anemia Research Fund has approved funding for the trial; researchers hope to initiate it in early 2015.

Dr. Tirouvanziam noted that FA patients have a high level of oxidative stress in their cells, which causes DNA damage and bone marrow failure. NAC passes through cell membranes, is transformed to cysteamine in the liver, and stimulates the production and distribution of an endogenous antioxidant called glutathione which inhibits oxidative damage and inflammation.

This study has three aims: 1) Determine safety of NAC; 2) evaluate ability of NAC to improve hematopoiesis; and 3) evaluate the effect of NAC on genome stability and oxidative stress.

The trial will enroll 10 patients in Phase I, followed by 30 patients in Phase II.

All enrolled patients will receive the same dosage of NAC through a pharmaceutical company. Dr. Tirouvanziam cautions against obtaining NAC over-the-counter, since some formulations may be unsafe and ineffective.

This first trial will exclude patients who are post-transplant, have a history of myelodysplasia or malignancy, or those who have been on other investigational drugs within 90 days of participating in this trial.

The Fund will update families on study sites and patient enrollment as the trial date approaches.

Managing Endocrine Concerns in Fanconi Anemia

Susan Rose, MD

Susan Rose, MD, Cincinnati Children's Hospital Medical Center, Ohio, discussed endocrine issues for individuals with Fanconi anemia. Hormones are the foundation of the endocrine system. They control childhood growth, energy, stamina, blood sugar, bone minerals, sexuality, and fertility.

Dr. Rose stressed the importance of tracking a person's body mass index (BMI), not just weight. While weights in people with FA are often below average, the BMI tends to be normal or low-normal. About one-third of individuals with FA have low BMIs and about one-tenth are considered overweight.

Weight can be affected by low appetite, malabsorption, increased caloric needs during illness, and low insulin secretion. The body's ability to use nutrition depends on insulin secretion. Insulin should rise after sugar consumption, but people with FA often have a "lazy" insulin response. This can worsen with androgen or steroid therapy and after transplant.

Height can also be a concern and can be affected by birth size, genetic mutations, parental heights, nutrition, hormones, transplant status, and medications. Dr. Rose proposes developing growth charts specifically for FA, based on heights and weights from children with FA during periods when they are healthy.

Thyroid levels are often mildly abnormal in FA. Research supported by the Fanconi Anemia Research Fund studied the effect of supplemental thyroid hormones on growth rate in children with FA who had mild thyroid-stimulating hormone (TSH) elevation. The study concluded that for children with FA who have borderline thyroid function tests, T4 therapy may be beneficial in improving their growth.

Growth hormone deficiency can also lead to low growth rates, but this is rare in patients with FA, and unfortunately test results can be misleading. Use of growth hormones in the absence of growth hormone deficiency is controversial because of the potential cancer risk.

For some people with FA puberty starts early, for others it is delayed. Early onset of puberty decreases the amount of time for the child to grow taller; delayed puberty leaves more time to grow, but has the potential for decreasing the marrow.

Infertility can be an issue for men and women with FA, and early menopause can be an issue for women. Both may be due to FA or to transplant. Low testosterone or low estradiol levels can lead to lower sex drive and low bone mineral levels. Bone mineral development is also controlled by nutrition, weight-bearing exercise, vitamin D, and growth hormones. Bone mineral density is often tested with a DEXA scan, which can give inaccurate results in someone with small bones. For people with FA, DEXA results should be corrected for height. Dr. Rose suggested that the test be done at about 15 years of age, and then not again for at least 5 years if the results (corrected for height) are normal.

Recommended annual evaluations:

- accurate height measurement
- TSH, T4, FT4, cortisol
- glucose and insulin after eating (fasting glucose is *not* needed for FA patients)
- GH stimulation test and bone age if on thyroid therapy and growth is slow
- MRI of head if multiple pituitary hormone deficiencies
- LH, FSH, estradiol or testosterone, AMH, inhibin B if delayed puberty (last two are new test recommendations)

Diet recommendations:

- adequate calories and regular exercise
- sufficient calcium and vitamin D; milk or other dairy for calcium and milk or supplements for vitamin D
- avoid concentrated sweets to avoid rapid glucose rise; choose complex carbohydrates instead of simple sugars (e.g., if you're going eat candy, have something with nuts)

Help Advance FA Research!

Researchers are working hard to find effective treatments and a cure for Fanconi anemia, but they can't do it alone. **FA researchers need you.** Please consider donating tumor tissue for FA research.

Contact Teresa Kennedy at teresa@fanconi.org or 888-FANCONI.

Monitoring Gynecologic Health in Women with FA

Rahel Ghebre, MD

It is important for young women with FA to develop a trusted relationship with a healthcare provider, starting at age 16, or with the onset of sexual activity (whichever comes first). Rahel Ghebre, MD, University of Minnesota, Minneapolis, recommends that the doctor understand adolescent health, and that the first visit not include a Pap test unless medically indicated. Parents can help their daughter gradually take on more ownership of the patient-doctor relationship.

Preventative care should include a Pap test and careful examinations of the cervix, vulva, and vagina. The doctor should also discuss sexual activity, contraception, and sexually transmitted diseases. Although FA usually causes a decrease in fertility, contraception should still be used to prevent unwanted pregnancies.

Common gynecological concerns with FA include delayed puberty and other menstrual abnormalities. Contributing factors include hormonal imbalance, low body weight, low platelets, chronic illness, and medications.

Women with FA have a higher rate of squamous cell cancer of the cervix, vagina, and vulva, and cancer tends to occur at a younger age than in the general population. Dr. Ghebre recommends the HPV vaccine and annual screenings. Women should regularly perform self-exams and report any new vulvar lesions. If a biopsy is needed, she suggests that light sedation can be helpful in avoiding the trauma that some women may feel. Talk with your doctor and consider consultation with a specialist about appropriate treatment options for FA women, including the use of Aldara cream (Imiquimod).

Ovarian function is another concern for women with FA. Early menopause can be a result of FA generally or brought on by stem cell transplant or cancer therapies. Ovarian failure is more likely if the transplant occurs at an older age, and less likely if it occurs prior to menarche. Even if women are fertile after cancer treatment, the duration of their fertility may be shortened. Women (and parents of girls) should discuss the impact of transplant and/or cancer therapy on ovarian function with their doctors prior to starting treatments. Preserving ovarian function applies to more than fertility as the ovaries have many other functions.

Despite these challenges, women with FA, including those who have and haven't undergone transplant, have had successful pregnancies. The majority have experienced normal deliveries with limited maternal and fetal complications. But it's important for a woman's oncologist, transplant team, and a maternal fetal medicine specialist to work together.

Dr. Ghebre discussed some potential options for fertility preservation such as in vitro fertilization (IVF) with embryo cryopreservation, oocyte cryopreservation, ovarian tissue cryopreservation, and suppressive and surgical therapies. The viability of each option depends on the woman's age, diagnosis, type of treatment, partner status, time available before treatments begin, and overall health status. Dr. Ghebre encourages early and open conversations about fertility options between parents and young women with FA, and their doctors.

Gene Therapy Trial Now Approved for Pediatric and Adult Patients

A clinical trial of gene therapy for individuals in the *FANCA* (FA-A) complementation group recently received approval from the FDA to enroll pediatric patients. The trial, conducted by Hans-Peter Kiem, MD, Fred Hutchinson Cancer Research Center, and Pamela Becker, MD, PhD, University of Washington, both in Seattle, was initially approved for FA-A adults only. The trial is the first lentiviral vector-based gene therapy study for patients with FA. It incorporates novel gene delivery by a safety-modified lentivirus using newly improved techniques. The trial is now open to individuals with FA-A, ages four years and older. Enrolled patients are expected to be in Seattle for 6-8 weeks.

For more information, please contact:
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For information about FARF's clinical trials scholarships, please contact:
Teresa Kennedy, Director of Family Support Services
phone: 888-FANCONI, email: teresa@fanconi.org

Ask the FA Experts

At this year's Family Meeting, participants enjoyed an open forum with two veterans in the field of FA research, Blanche Alter, MD, MPH, FAAP, National Cancer Institute, Bethesda, Md. and Rich Gelinas, PhD, Institute for Systems Biology, Seattle. The two have over 50 years of combined experience. Below is a sampling of some of the questions posed during the forum:

Q: How many post-transplant women have had successful pregnancies?

A: There has been one paper published on this topic. The study looked at 101 post-transplant women who were at least 16 years old. All of them had had aplastic anemia. They ranged from 4-17 years post-transplant. Five of the women had ovarian failure. There were 14 births, three of which were premature, but all infants were healthy.

Q: What can be done to bring up low ANC (neutrophils)?

A: Androgens focus on improving hemoglobin counts, though in some people platelets will respond, too. Neupogen is effective in raising ANC, but because it's an injection it's not often used as a long-term treatment.

Q: What can you say about the occurrence of Sweet's syndrome with FA?

A: There are published reports of twelve FA patients presenting with Sweet's syndrome (among more than 2,000 reported cases of FA), so it is relatively rare. It has been associated with MDS or AML. People should be aware of it and seek appropriate treatment as necessary.

Q: Is there a chart with guidelines of recommended tests that should be done year by year?

A: Recommended tests are based on individual conditions. FARF can help you find doctors near you with FA experience, who will be most able to tailor care to your or your child's needs. Contact the Fund for copies of the current edition of *Fanconi Anemia: Guidelines for Diagnosis and Management*.

Managing Gastrointestinal, Hepatic, and Nutritional Challenges in FA

Sarah Jane Schwarzenberg, MD, University of Minnesota, Minneapolis, noted that the majority of gastrointestinal (GI) problems in people with Fanconi anemia are common in the general population, but are a little worse due to FA. GI specialists should be able to treat these issues, even if they aren't familiar with FA. A pediatrician or hematologist can provide routine care with referral to a GI specialist as needed.

Creating a symptom diary for one to three months prior to a visit can help you and your doctor pinpoint issues. Make note of the time of any symptoms (such as pain, nausea or diarrhea) and any patterns you notice.

One common issue, gastroesophageal reflux, is characterized by heartburn, abdominal pain, excessive burping, and poor appetite. It can be treated with acid suppressors (but avoid H2-antagonists because of bone marrow suppression), a slight elevation of the head of the bed, and reduction of food intake two hours before bedtime.

Small bowel overgrowth can occur after antibiotic therapy or previous GI surgery. It is characterized by diarrhea, abdominal pain, greasy orange stools, and B12 deficiency. It is treated with metronidazole (Flagyl) or rifaximin (Xifaxin). Probiotics aren't effective because the problematic bacteria are usually too numerous.

Seek medical attention for any of these symptoms: involuntary weight loss, deceleration of linear growth, gastrointestinal blood loss, significant vomiting, chronic severe diarrhea or persistent right-side abdominal pain.

Endocrine abnormalities account for 80% of the short stature that characterizes many with FA. When evaluating poor growth, it's important to look at the body mass index (BMI), not just weight. Low BMI can be attributed to poor intake and/or diarrhea. Keep a food diary and see a good dietician. Supplemental feeding through an NG-tube (short-term) or G-tube (long-term) is sometimes needed.

Individuals with FA using androgens should be aware of the potential of hepatic complications such as adenoma, peliosis, and intrahepatic bleeding. Patients should have liver enzymes tested every three months, a liver ultrasound every six months, and seek immediate care if they experience pain.

If possible, arrange for a GI evaluation approximately one year prior to transplant. To support the liver before transplant, complete necessary immunizations, avoid alcohol, and have a liver evaluation to check for disease and adenomas. Post-transplant GI/liver concerns include graft-versus-host disease and iron overload (from repeated red cell transfusions).

Important Dermatology Issues Noted for FA

Vinod Nambudiri, MD

Vinod Nambudiri, MD, Brigham and Women's Hospital, Boston, gave a helpful overview of dermatology problems that can affect individuals with FA. The following issues can have serious health implications, and need prompt diagnosis and treatment:

- Sweet's syndrome (SS) is a skin disorder characterized by painful red sores on the arms, legs, and head or in the lungs. One retrospective study of seven FA patients with SS noted that six of the seven had progression of hematologic disease at the time of the SS diagnosis (MDS in two cases; AML in four). Appearance of this complication should compel an immediate hematological evaluation.
- Ultraviolet radiation from the sun has different subtypes: UVA causes premature aging and wrinkling of the skin; UVB mutates DNA and is the major source of skin cancer. Individuals with FA have an inability to repair DNA damage and are therefore highly vulnerable to the damaging effects of UVB.
- The most common type of skin cancer in the general population (80% of cases) is basal cell carcinoma (BCC). BCCs can look like shiny, waxy, pearly red or pink bumps, but can have other appearances. They almost never metastasize but grow locally, can be disfiguring, and must be removed.
- Actinic keratoses present as flat pink or red scaly patches that sometimes progress to squamous cell carcinoma (SCC).
- SCC is more aggressive than BCC and can metastasize, especially when on the head and neck. It appears as red, thick, scaly, tender patches of skin. Individuals who are immunocompromised are at greatly increased risk of SCCs.
- Melanomas are the most dangerous form of common skin cancer. The majority are black or brown, often multicolored, have irregular edges, and are asymmetrical. They are highly aggressive, and must be removed immediately before they metastasize.

Prevention and Treatment of FA Skin Cancers

- Dr. Nambudiri stressed the importance of prevention. Sunscreens are effective. The SPF must be at least 30 (50 or higher is often recommended in immunocompromised patients), and should be reapplied every 1-2 hours. He recommended products that provide broad-spectrum UV coverage. Examples include Neutrogena (helioplex), La Roche-Posay and Blue Lizard (zinc oxide). Sun avoidance and protective hats and clothing are helpful. Skin is the sole source of vitamin D synthesis and sunscreen prevents this process. Diet and vitamin D supplements can provide adequate amounts of vitamin D.
- Dermatologists usually remove skin cancers surgically. In addition, photodynamic therapy (PDT) can be used to treat BCCs, actinic keratosis, and SCCs. PDT uses a drug called a photosensitizing agent and a specific type of light to kill cancer cells. Other therapies include use of a topical chemotherapy such as 5FU to kill cancer cells, and topical drugs that stimulate the immune system to kill cancer and precancerous lesions.
- Dr. Nambudiri cautioned that the anti-fungal drug voriconazole can increase the skin's sensitivity to sunlight. Voriconazole has been implicated in SCC in transplant patients in the general population when used for over 12 months.
- For any changing or concerning skin lesion in individuals with FA, involve a dermatologist in evaluation and treatment.

Editors' note: Individuals with FA have reported the diagnosis of both BCCs and SCCs, some patients needing multiple medical interventions. This suggests the need for greater understanding of the incidence of these cancers in FA, and more focus on prevention.

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 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.

Long Term Follow-Up after Stem Cell Transplant

Farid Boulad, MD

Patients who survive one year post-transplant have a 90% chance of doing well long-term, said Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center, New York. Dr. Boulad's study of 22 patients who passed the one-year mark post-transplant revealed the following:

- None of the 22 survivors of T-cell-depleted transplants suffered from chronic GvHD.
- All had normal blood counts and normal T-cell function.
- Nine patients with fewer than 20 transfusions pre-transplant had low ferritin (iron) levels post-transplant.
- Seven patients with more than 20 transfusions pre-transplant had high ferritin levels. Iron accumulation in different organs can lead to cirrhosis of the liver. Dr. Boulad recommended removing iron from the blood by one of two methods: (1) Phlebotomy, or withdrawing a small volume of blood every two weeks. Some iron is removed along with the blood. (2) Chelation with an oral agent called deferasirox, which can be effective and is generally well-tolerated. Use of deferasirox requires monitoring of kidney and liver side effects.
- Twelve patients had normal thyroidism post-transplant.
- Five had hypothyroidism both pre- and post-transplant.
- Five had high levels of triglycerides post-transplant.
- Eight of 12 males evaluated and four of five females evaluated had gonadal dysfunction post-transplant.

All FA patients need close follow-up post-transplant to monitor overall health status, including iron level, endocrine and gonadal function, and psychological well-being. Patients also need to be screened for secondary malignancies.

Dr. Boulad stated that patients are at risk for long-term complications due to the underlying disease and to the transplant itself. It is too early to draw any conclusions about the late effects caused by specific transplant protocols. However, there are some indications that there may be fewer late effects after regimens containing busulfan than those with total body irradiation.

Head and Neck Cancer in Fanconi Anemia

David Kutler, MD, Weill Cornell Medical College, New York, gave an overview of head and neck squamous cell carcinoma (HNSCC) in the FA population. While this cancer is detected in only 0.08% of the general population, it affects 21% of individuals with FA by age 40, a risk increase of 500- to 700-fold. In the non-FA population, smoking and drinking, chewing betel nut (common in some countries), and viruses such as HPV cause this cancer. **Individuals with FA should not drink or smoke, should avoid second-hand smoke, should not chew betel nuts, and should be immunized against HPV.**

Sixty-five percent of FA HNSCCs occur in the oral cavity. They appear as irregular ulcers (sometimes with raised margins), can look lumpy or wart-like, and can be painful and hard. Most are found on the lips, gums, tongue, and floor of the mouth. In FA, HNSCC is aggressive. Of 19 FA HNSCC patients studied, half had a recurrence in 10 months. Even when the first cancer was treated at an early stage, recurrence was common.

A qualified examiner, such as an ear, nose and throat specialist, should screen individuals with FA every six months. Age of cancer onset can be as young as 12 years, so screening should begin before age 12. Dr. Kutler prefers inserting a scope through a nostril (instead of using a mirror in the throat) to view the voice box area. Screening should increase to at least every three months if a premalignant lesion is detected or after surgery to remove cancer.

Surgery is the best treatment for FA HNSCCs. Robotic surgery is increasingly common and can be minimally invasive. FA patients do not tolerate chemotherapy or radiation well. Erbitux is less toxic and more targeted than traditional chemotherapies, and can be considered in selected FA patients.

Dr. Kutler described a study of 12 FA patients with advanced HNSCC who underwent radiation therapy. A total of eight patients died, four during the therapy. Side effects of radiation were more extensive than in the general population, but radiation can be used successfully in selected FA patients with advanced cancers of the head and neck. Individuals who had not received a stem cell transplant fared worse than post-transplant patients, due to the fragility of their stem cells.

New therapies are badly needed to treat this severe complication of FA.

Major Transplant Centers Share Protocols, Outcomes, and New Directions

Transplant experts from three major FA Comprehensive Care Centers updated Family Meeting attendees on conditioning protocols, transplant outcomes, and future directions at their centers. A spirited question and answer session followed.

Farid Boulad, MD, Memorial Sloan-Kettering Cancer Center (MSKCC), New York, noted that in the non-FA population, radiation is associated with a significantly higher risk of cancer post-transplant. He hypothesizes that eliminating radiation would reduce a host of late effects and lead to fewer secondary tumors. Dr. Boulad and Parinda Mehta, MD, Cincinnati Children's Hospital Medical Center, Ohio, are the principal investigators of a multi-center study to determine if busulfan (which, Dr. Boulad noted, has its own toxicities) could be substituted for radiation with equally good survival outcomes. This study has just ended and investigators are analyzing the data from 45 patients (27 younger than 10; 13 ages 10-18, and five older than 18). Disease status and donor match varied considerably. Overall survival is 81%, with 78% surviving disease-free; chronic GvHD was less than 7%. Eight patients died: five from infection; three from toxicity. Of note, four of five patients older than 18 did not survive transplant.

Dr. Boulad stated that future directions include a second trial (see Dr. Stella Davies' update below), and a new approach to treat (and soon prevent) high risk infections using T-cells.

Stella Davies, MD, Cincinnati Children's Hospital Medical Center, Ohio, described a new study at her institution and MSKCC. This trial, entitled "Risk-adapted Radiation-free Study," will modify the dose of busulfan depending on patients' age and disease status. Older patients will get a lower dosage due to toxicity concerns, and patients with myelodysplastic syndrome (MDS) or acute myeloid leukemia (AML) will receive more conditioning to eliminate disease. Three patients have enrolled to date.

Since 1976, the University of Minnesota, Minneapolis, has transplanted 226 FA patients, continually modifying the protocol to obtain better outcomes. John Wagner, MD, now finds a similar survival rate between FA patients with matched sibling donors and those with alternate donors (over 90% in both categories), if patients in each group are "standard risk" (defined as absence of MDS/AML or renal failure). Because alternate donor outcomes are so good, Dr. Wagner suggested that preimplantation genetic diagnosis to create a matched sibling donor might not be needed. Two subgroups, those over age 18 (eight patients) and those with advanced MDS/AML (21 patients), have poorer survival (approximately 50% in both categories).

New directions at this center include protecting ovaries to preserve ovarian function, eliminating cyclophosphamide, and expanding cord blood prior to transplantation, to hasten engraftment and greatly improve the likelihood that patients will find an acceptable donor.

The University of Minnesota uses 300 rads of radiation as part of the conditioning protocol. Dr. Wagner sought to determine if radiation increased the risk of cancer in post-transplant FA patients. He received surveys from 95 patients transplanted at Minnesota between 1990 and 2012. Four patients developed a malignancy post-transplant (at ages 41, 28.6, 19.4, and 16.8), similar to what one would expect in the non-transplanted FA population. Dr. Wagner concludes that the increased risk of cancer observed in earlier studies in Europe was due to a higher incidence of GvHD and not due to use of radiation. Minnesota's results, as well as updated reports from Europe, support this conclusion.

Future directions include a second trial and a new approach to treat (and soon prevent) high risk infections.

Oral Cancer Fact Sheets Available

Regular screenings for oral cancer are critically important for people with FA. The Fund has 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.** The fact sheets—in English, Spanish, Afrikaans, Dutch, French, German, Hebrew, and Italian—are available on our website or by calling our office.

Record Attendance at Meeting for Adults with FA

The fifth Meeting for Adults with FA was held March 21-24 in Baltimore, Md. A record 42 adults with FA ages 18 to 61—including two grandparents—and their guests attended from 11 countries. This was a significant increase from the previous meeting in October 2012 in which 24 adults with FA participated. The Fanconi Anemia Research Fund allocated more than $27,000 for travel assistance to adults with FA who otherwise would not have been able to attend.

Presentations at the meeting included Fanconi Anemia 101; Personal Relationships: Genetics and Fertility; Aldehydes; Empowering Wellness with Dynamic Food Therapy; Head and Neck Squamous Cell Carcinoma in FA; and Gynecologic Considerations for Women with FA. In addition, the meeting offered support groups for adults with FA and their parents, spouses, and partners, as well as opportunities to participate in four FA research projects.

Planning is underway for the next Meeting for Adults with FA.

"Thank you for this amazing opportunity. I especially want to thank everyone who has ever donated to FARF. Without donations and fundraising events, FARF wouldn't be here. I know a lot of us wouldn't have been able to attend the meeting if not for the travel scholarships FARF offered us."

"It was a blessing to be given the opportunity to learn more about Fanconi anemia and to meet the incredible people who attended this meeting."

"I don't feel alone anymore. I am so glad to know about the wonderful support system of FARF."

Empowering Wellness with Dynamic Food Therapy

Christine Dionese, LAc, MSTOM, integrative health care specialist and food writer, gave a spirited presentation on "food therapy" at the Meeting for Adults with FA. She described her "eat for life" philosophy, which embraces the idea that food should be flavorful and delicious, but also promote good health. She believes that the entire family should get involved in choosing a wide range of healthy foods, incorporating the following concepts:

1. Whole foods are plant-based and contain high levels of usable nutrients.
2. A whole food diet, full of variety, should serve as the cornerstone of a successful food therapy plan.
3. Superfoods contain an unusually high amount of beneficial nutrients. Superfoods include blueberries, kale, raw almonds, coconut oil, kefir, camu camu, mulberries, maca, and goji berry. Superfood powders such as "Amazing Grass" and "Navitas," found in health food stores, can be used to fortify a favorite dish.
4. Fats rich in omega-3 are necessary for support of the immune system. These include fish and other seafood, nuts, eggs, seeds, olives, avocados, and seed and nut oils.
5. Choose organic foods. They are not grown with pesticides which can cause cancer and other health concerns when consumed in large quantities. Seek the advice of experts to rule out food allergies.
6. Get calcium from green, leafy foods rather than calcium supplements.
7. Avoid sugar.
8. Many varieties of mushrooms such as shiitake, cordyceps, enoki, maitake, reishi, lion's mane, and turkey tail are good for your health. Mushrooms primarily elicit their medicinal effects when used as dried powders or sautéed.
9. Many spices and herbs sold to flavor food have been irradiated and stored with preservatives for several years. Choose organic whenever possible. Spices such as turmeric ("You can't overdo turmeric!"), rosemary, thyme, oregano, and basil are immune enhancers.

Ms. Dionese shared this philosophy: "Your immune system is already dancing along delicately—why give it a reason to have to fight harder?"

How Fanconi Anemia Made the World Look Different

By Kyle Tanner

When I was first diagnosed with Fanconi anemia at the age of 16, I really didn't know what to think. I had never heard of the disease and at the time didn't know of the seriousness behind it. I could tell by my parents' reaction and the doctor's tone of voice that this disease had to be devastating for the people who had it and their families.

I abstained from doing any research on the disease for many months after being diagnosed, in fear of learning things that I would rather not know about my condition. However, through discussions with my doctor, I had learned about the shortened life-span of those living with Fanconi anemia and this had really scared me. I often thought about why this had to happen to me and why my parents made it seem like everything was normal with me when I was growing up, even though I was much smaller and sicker than the kids around me. After finally giving into temptation, I looked up more about the disease online. This only sunk me into a deeper depression and made me feel somewhat helpless.

It wasn't until I went to the Family Meeting at Camp Sunshine for people with Fanconi anemia that I realized the positive outcome such a tragic thing would have on my life. At the meeting, I was able to meet and socialize with other people who had FA, many of them my age. It gave me a new hope, and I no longer felt like I was the only one who was different in the room. The experience also gave me a renewed strength. I no longer fear the outcome of my disease, but value the time that I have been given to make the best out of my situation.

I believe that the diagnosis has made me a better person in many ways. Not to say that I'm done improving, but what I have learned through something that seemed so tragic has actually been a blessing in disguise. I don't look at the world the same way anymore. I stopped taking so many things for granted, and realized that the way I was previously living my life was detrimental to my well-being. Like so many other kids at that age, I was stuck in a cycle of media-driven interests and a selfish need to fulfill my desires, and it didn't matter at whose expense. I lacked empathy. I didn't value relationships and didn't see the affect that one's mood and outlook had on the others around them. My life was right in front of me and I never stopped to look at it through any other point of view. If it weren't for FA, I might still be stuck in that selfish lifestyle. Fanconi anemia will always be a part of me, but never will it define me. I thank those around me and the people striving each and every day for a cure, but never will I say that FA didn't affect my life in a positive way. I am proof that even in the deepest depths of adversity, a rose can bloom.

Families Gather in Maine for the 23rd Annual FA Family Meeting

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presentations in this issue. In addition, a workshop for teens and young adults addressed the logistics of transitioning to adult health care, the risks of drinking alcohol and how to avoid it in social situations, the importance of sunscreen, and other topics pertinent to this age group. To complete the program, there were updates on gene therapy and NAC trials and an "Ask an FA Expert" session.

Thanks to the dedication of the amazing staff and energetic camp volunteers, including some FA family members, the meeting was a smooth-running success. Lasting memories were sure to have been made during the full, but fulfilling, five-day meeting.

"Exciting, educational, knowledgeable, creates power and sense of belonging for kids. Good to feel at home where everyone else knows how you feel."

"It was a thorough learning experience and it will help us a lot in the management of the disease."

"Each time we come away from camp we feel more empowered and excited to come back! Thank you so, so much for this opportunity and ALL that you do!"

—from participant evaluations

The Unexpected Journey

By Reshma Shahid Usmani

It was winter 2012. I was waiting restlessly in my office. Three cups of coffee already finished, and the fourth was in my hand when the mobile rang. I hurriedly came out in the lobby and answered,"Yes, Doctor," knowing very well that our doctor in New Delhi would be on the other end. I still remember her words, "Reshma, the reports are ready… I am afraid the reports are positive." I asked, "Are you sure, doctor? Maybe there is some mistake, somewhere." She replied, "I am sorry, but the reports were well checked by a doctor who has been doing this a long time, and it's a simple test with mitomycin C."

I was devastated. My words remained inside my throat as there was a huge lump which stopped them from coming out. I felt very weak and vulnerable, like there was a vacuum inside. The rest of the doctor's words are very hazy in my memory. I think she said, "Don't worry, it is not that something will happen to him immediately, but it is the beginning of many new challenges." Needless to say, before the test everything was discussed with the doctor and I had already searched all the sites which gave information on Fanconi anemia, the two words I had never heard before.

I must say that the test result, however painful, gave answers to a series of my earlier queries, like why my son Yahya had a low birth weight, why his left thumb was rudimentary, why we had to go through two immediate surgeries after his birth in 2006, why feeding him was like a battle won, and why weighing him always baffled me. I was quite sure that the scale had some mechanical problem, as it never made me smile.

I almost decided to quit my job as I thought it would be very difficult to manage everything. I called my husband, who is a civil engineer involved in road constructions and always posted in far-off places of our country, and announced that he must either leave his job or change his work profile. I cried and cried for a long time. But it is so, that when we come face to face with difficulties, we also get the strength to fight back. I understood that I had no time for mourning. I knew that if I grieve, I will grieve alone but if I smile, the world will smile with me. I wanted my world to smile. I wanted Yahya to smile.

I often think of disclosing Yahya's illness to him, but stop myself when I see him singing, dancing, learning, and enjoying every moment of his childhood. Maybe one day I will be able to tell him, and he will be able to understand.

We have come a long way since then. Yahya, our only child, is now settled with his periodic blood tests and the frequent days off from school when he is not well or the counts are very low. The options—going for another child, BMT, androgen therapy—were discussed with the doctors and family and friends. The risks of the first two options led us to take the safer path of androgens, although this too had its side effects. At first, androgens could not prevent the transfusions of haemoglobin and platelets but luckily, the androgens started working and now Yahya is stable with no transfusions. A doctor at the premier transplant centre in India helped me find a fully matched donor (unrelated). I am still struggling with the issue of whether or not to undergo a stem cell transplant.

This summer, after attending the Fanconi Anemia Research Fund's Family Meeting at Camp Sunshine and meeting so many families with one or more child with FA, one thought crept into my mind: that diseases are impartial, they come to us irrespective of our creed, caste, color, religion, and country. It hardly matters whether we are rich or poor, big or small. Yahya had a great time at the camp. There was no fear, just love and affection; the whole mood at the camp was one of jubilation and celebration. We all were one, unique Family, bonded at the meeting. I got an inner strength. Now, I know that I, too, have a role to play in this journey. I have to give meaning to this new role and work towards its achievement.

In the end, I would say that FA gave me a difficult path indeed but, at the same time, it bestowed me with a challenge, made me count my blessings, acquainted me to a strength which I never thought existed in me, helped my husband quit smoking, and reminds me to enjoy each passing day with my loving son. It also taught me to be organized, hopeful, optimistic, and live with the certainty of uncertainty, although, I must say… the journey is quite unexpected.

Sophia's Story

By Sabine Mohr

Sophia was born in January 1997 with a beautiful head of black hair and a loud voice. We were surprised to see a bifid left and a hypoplastic right thumb. That raised the doctor's concern, and further tests showed that she had a horseshoe kidney and two congenital heart defects that were of no concern. In addition, she had a patent ductus arteriosus which was repaired when she was five weeks old. We were given several differential diagnoses, VACTERL and Fanconi anemia being among them. At that time, medical genetics was my hobby and I had the Ohio State University medical library at my disposal, so I was pretty sure the diagnosis of Fanconi anemia was correct. Sophia's thumbs were operated on when she was 10 months old. At the same time, Dr. Arleen Auerbach did the chromosome breakage test and diagnosed Fanconi anemia. Later on, we did more specific testing (she is FancA) and considered a savior sibling, but decided against it because of my age.

Sophia was a beautiful baby, developed normally, and was joined by her sister, Isabelle, two and a half years later. Thankfully, we learned that Isabelle was unaffected. Both girls attended a wonderful preschool and elementary school, and both were accepted into a selective magnet middle and high school, for which we are very grateful.

When she was six years old, Sophia learned to play the cello, and she has been playing with various orchestras and with the Austin Chamber Music Center ever since. At the beginning, we designed many different contraptions to help her hold the bow, but over the years her hand adapted and she is playing with a regular bow now. The teachers had to accommodate for her uniqueness, and some of them seemed at a loss what to do.

Sophia's counts declined slowly and were at 8.3 for hemoglobin and 17,000 platelets in 2009. We were in contact with both the University of Minnesota and Cincinnati Children's Hospital. We were advised to consider a transplant and were looking for a donor. Unfortunately, Isabelle's HLA markers are just the opposite of Sophia's. I looked into steroids and we decided to try oxandrolone. The hemoglobin went up to normal levels within two months, and the platelet count climbed to 60,000 within a couple of months, and that's where the counts are today. Her liver enzymes are a little bit elevated. We monitor the blood counts every month and the bone marrow every year and do a cancer screening and a liver ultrasound. In addition, I am a firm believer in good nutrition, and we make sure everybody is eating well.

The oxandrolone made a huge difference. We hike in Big Bend National Park most Thanksgivings, and I usually hiked back in the group with Sophia because she could barely keep up and had to rest frequently. After taking oxandrolone, Sophia was at the front of the group! She has no virilization effects and has grown up to be a smart and beautiful (and very opinionated) young lady. Now she is entering her senior year of high school and we will have to think about college, a scary thought for all of us! We have been lucky so far and are grateful that Sophia is now making the transition to a FA adult!

In Favor of Androgens

By Sophia Mohr

My name is Sophia, and I am 17 years old. I have been taking androgens since middle school.

Androgens are male hormones, such as testosterone, that can affect the production of blood platelets and help push back the onset of bone marrow failure. I take oxandrolone, which is fairly rare because only 50% of people who try it react at all. However, oxandrolone has much milder side effects than most other androgens.

Androgens can affect the liver, heart, and kidneys, and the influx of male hormones can occasionally cause girls to develop more masculine features. I personally haven't had these kinds of problems with oxandrolone, but we still check every year to make sure something isn't going wrong.

Personally, I like taking androgens, because they keep me healthy and give me a little boost in developing muscles, which I appreciate now that I'm in color guard. The longer I can put off a transplant, the better, because I am not actually sure what to expect if I ever have to go through one. I've heard they're not the most comfortable experiences and I'd like to avoid that. In addition, taking androgens can push back onset of bone marrow failure enough to ensure a higher chance of a successful transplant. When I was born, transplant success rates were a lot lower than they are even now, and I'm sure with the leaps science is making the rate will keep getting higher every year.

A Journey of Love, Fear, and Hope

By Eben Marais

At the age of 23, I was newly engaged and looking forward to settling in with the love of my life. The last thing on my mind was being told that I was suffering from an incurable illness.

In September 2009, I got engaged to Joline and we were planning to spend our lives together. Our wedding was booked for the following April, and we were on the verge of buying our first house.

After carrying some furniture around, I noticed bruising all over my body. My dad advised me to go to the doctor the very next day as he feared it might be leukaemia. My doctor ran a full blood count and results showed that I was anaemic and needed to go to the hospital immediately. At the hospital, the doctor did a bone marrow aspiration and said that the results would be available the next day. That night I asked Jo if she would marry me sooner if we got bad news.

Wednesday, November 4, 2009, was the day my doctor told me that I had Fanconi anemia. My prognosis wasn't good; I had 5% working bone marrow left and to survive I had to undergo a bone marrow transplant within four months. I looked to Jo and asked, "So I take it we are getting married this Saturday?"

That Saturday we got married and I experienced overwhelming love for my new wife. I had to be kept isolated because my immune system was compromised. Our family friends treated us to a homemade three-course meal and decorated my mom's living room for the wedding reception.

They served us and catered to all our needs, and even cleaned up afterwards.

I had my bone marrow transplant in March 2010 from an unrelated 100% matched donor. After three different types of chemotherapy treatment, the transplant, and five days in ICU with a lung infection, I was on my way home to my new wife on day 22.

Three months before I got sick, I applied for medical aid and got it for the first time in my life. If I didn't have the medical aid I might not be here today. My medical aid covered most of my medical expenses, but there was still a large balance that I had to cover myself and through the grace of God we were provided with the funds. When we met Vincent Barrington he was a very brave 16-year-old boy. He suffered from aplastic anemia and did not have medical aid. He could only have a bone marrow transplant after raising funds to pay for it. Sadly, he lost his battle with aplastic anaemia in February 2010. On his death bed, he said that he wanted me to have the remainder of his funds—exactly the amount we owed!

On December 31, 2010 we had our big white wedding on Jo's family farm. What a way to start the New Year—with a new life, a new wife and a brand new future!

I am living a healthy, normal life in a beautiful house with my wife. We are planning to start a family next year. After the bone marrow transplant and chemotherapy, an expert determined that I have maintained fertility. I am very fortunate to be able to have children normally.

Being diagnosed with FA was the scariest time of my life, and although I would never wish it upon anybody else, I would not want anybody to take this experience away from me.

New! Donate While You Shop on Amazon

The Fanconi Anemia Research Fund is now a participating charity in the AmazonSmile program which donates 0.5% of the purchase price of eligible products to selected charities. Simply visit smile.amazon.com, select the Fanconi Anemia Research Fund as your charity, and start shopping! You'll find the same prices, selection, and shopping experience that you are used to on Amazon.com. You can use your existing Amazon account on AmazonSmile, and once you select your charity on your first visit it is retained with your account. So, just remember to do your Amazon shopping at AmazonSmile. It's that easy!

FA Family Support Group Started in Denmark

For the first time ever a FAmily support group meeting was held in Denmark! Five families from all around Denmark and even northern Germany attended this first union in April. The need for connecting families was obvious and bonds were made instantly. Ralf Dietrich, Executive Director, German FA Support Group and Eunike Velleuer, MD, Heinrich Heine University, Duesseldorf, also attended and gave valuable feedback on their research into FA head and neck cancer as well as Fanconi 101 information. The second meeting is already in the planning phase. Until then the families "meet" and offer support via their Facebook group, Fanconi Anemia Denmark.

Your FA Research Dollars at Work

From March to August 2014, the Fanconi Anemia Research Fund awarded $218,200 in research grants to the following projects:

Investigator: Agata Smogorzewska, MD, PhD, The Rockefeller University, New York, N.Y.
Title: *Genomic and functional analysis of the anogenital and head and neck squamous cell carcinomas (SCCs) in patients with Fanconi anemia*
Amount: $148,200

Investigator: Robert Sclafani, PhD, University of Colorado, Denver, Colo.
Title: *Potential therapeutic use of resveratrol for head and neck carcinogenesis in Fanconi anemia (supplement)*
Amount: $70,000

The Fund is committed to supporting research to further our mission to find new treatments and a cure for Fanconi anemia. Over our 25-year history, we have funded 198 research grants and one service grant to 103 investigators at 56 institutions worldwide. Research dollars awarded total almost $17 million!

Congratulations!

Egil Dennerline (FA) and Nanna Storm, married June 7, 2014

facebook Find us on Facebook at www.facebook.com/fanconianemiaresearchfund

In Loving Memory

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

Jessica Carvalho ..... *7/4/86 - 1/31/14*
Amnah Alyammahi ..... *5/21/03 - 3/10/14*
Michelle Ploetz ..... *10/11/93 - 4/18/14*
Constanza Mulet Goldberg ..... *1/23/89 - 5/26/14*
Lisa Kinsella ..... *5/18/81 - 7/4/14*
Hesmé Rossouw ..... *12/2/97 - 7/22/14*
Cooper DeHaan ..... *1/16/09 - 8/17/14*
Benjamin Silverston ..... *3/26/81 - 9/20/14*
Jocelyn Montero ..... *8/10/02 - 9/22/14*

Chris Hull Memorial Sigma Pi Open: Raising Funds for 15 Years

By George Hoffmaster

At The Pennsylvania State University, each fraternity and sorority is required to host a philanthropic event of its choosing. For the brotherhood of the Sigma Pi Fraternity, a golf tournament raised money over the years, yet there was no consistent focus on why or how a beneficiary was selected. That all changed when Sigma Pi brother, Chris Hull, passed away in 1999 due to complications from Fanconi anemia. For the past 15 years, Chris' friends and family have joined the brothers of the Sigma Pi Fraternity at Penn State for the Chris Hull Memorial Sigma Pi Open, with all proceeds going to the Fanconi Anemia Research Fund.

Tom Harner, Sigma Pi brother and longtime fraternity house advisor, was the first to recognize how natural this transition would be. "We wanted to honor Chris and at the same time raise money for a charitable organization which had meaning to the brotherhood." The event was transformed into a private, invitation-only tournament where Chris' two families, the Hulls and the Sigma Pi Fraternity, could come together to enjoy a weekend in beautiful State College, Pa., and remember the bright, kind, and caring person that Chris was.

Chris' parents, Dr. Charles and Katy Hull, are significant donors to the Fund and the driving force behind participation from the "Hull friends and family" contingent. As Sigma Pi Open Chairman, I work with Tom Harner to secure attendance from both alumni and undergraduate brothers, bringing about 60 participants to the event each year. Sigma Pi brother and perennial tournament participant, Scott Bennett, says, "The Sigma Pi Open is my reason to return to Penn State every year and now my kids are old enough that I bring them for the weekend, too."

Dr. Charles and the Miller Girls

The Kennedy Foursome

In its 15 years, the Chris Hull Memorial Sigma Pi Open has raised more than $200,000 for Fanconi anemia research and family support. Planning has already begun for next year's tournament. Geoff Joerg, a recent tournament champion, is looking forward to more fun with the tournament players and their families. "It's a wonderful, well-run event and I'll be back year after year. It's a great way to remember Chris as well as have a fun time with good friends."

Scrambling for Research and a Cure

By Peg Padden

The 11th Annual Fanconi Anemia Golf Scramble/Silent Auction/BBQ/Raffle held this July in Brush Prairie, Wash., was a success once again! We are so, so lucky to have such loyal and wonderful family and friends who continue year after year to show their support by volunteering, golfing, donating and buying auction items and raffle tickets to Maui, mulligans, entries to the putting contest, and more.

Yes, we take their money wherever we can, and they very generously continue to give it. Why? In memory of our beloved son Jake, for our son Spencer, for all those with FA, and for millions in the general population as well. They know that FA research is progressing, and that improved therapies are getting closer and closer. They know their donations

are used carefully and wisely, with less than 12% going to administrative costs. It's a fun event and SUCH a good cause. They know all this and because of their kindness and generosity, the Fanconi Anemia Golf Scramble has raised close to $450,000 these last 11 years. FAntastic!

An Amazing 250 Miles for FA

By Emily Robison

Grandpa Bob and Blake

Anyone who meets Blake immediately sees a happy two-year-old who loves trains and cars. They would never guess that in September 2013 he was diagnosed with Fanconi anemia. Besides being born with an extra thumb, which was removed at a year old, and a slight hearing loss in one ear, Blake was relatively healthy. We were shocked when the doctor called and said what no parent ever wants to hear. Our lives changed forever on that day. The days and months that followed were filled with doctor appointments and learning all we could about a disease that we had never heard of before.

With so much daunting information online we were very grateful to find the Fanconi Anemia Research Fund and the community of FAmilies. Connecting with other families gave us a ray of hope and comfort. We were fortunate enough to attend the Fund's FA Family Meeting at Camp Sunshine in June. This experience was invaluable to us. We were able to learn so much and meet so many different people in the same situation as our family.

Fortunately, Blake remains relatively healthy. We monitor him very closely and every medical appointment is nerve-racking. How we hope that his counts remain stable and that doctors don't find anything concerning. While we continue to watch Blake's health, we try to live as much of a "normal" life as possible. But we decided that we couldn't just sit back and wait, we needed to actively do what we could to fight this disease.

My father, Bob Satko, approached me with a fundraising idea. Along with the rest of our family, he was devastated by the news of Blake's diagnosis and wanted to help. Bob is a marathon maniac and an ultra trail runner. He wanted to run 250 miles in 72 hours to raise money for FARF. We thought he was crazy, but in 2012 he had run a 200-mile race, so Bob thought he could do it again, adding a "few" extra miles for Blake. We started planning for the big event. It takes a lot of behind-the-scenes work to run 250 miles. Bob was obviously training hard, and we created a video and fundraising page to ask anyone and everyone to donate to FARF. Bob's group of running friends put together a support team so that he would almost never be running alone. These friends and family were life savers, helping Bob at each rest station along the run. They helped him change his socks and made sure he was eating enough calories to keep going.

Neil, Emily, and Blake

We brought Blake to see his grandpa any time that we could during the 72 hours. Every time that Bob saw Blake he lit up. Seeing Blake renewed his energy and reminded him why he was running and why he needed to finish. After 72 hours, Bob finished his 250 miles. He could not have done it without the help and support from so many different people. We were all very humbled and amazed as each donation poured in, some from people we didn't even know. After our fundraiser closed we had raised more than $11,000 for FARF, money that we hope will make a difference not only for Blake, but all children with FA.

A day will never go by that we don't think about FA, but with the help and support from other FAmilies and the FARF we are so optimistic. We plan to never stop fighting and fundraising so that Blake will have the best future possible.

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!

Katie Kits: Made with Care, Sent with Love

By Sandra Dunn

Katie Kits was started in 2013 soon after our daughter Katie passed away from complications after her bone marrow transplant (BMT). Before and after she lost her hair, she loved animal hats and other hair accessories. Katie embraced her baldness and was such a fighter, right up to the end.

In her memory, I began making "Katie Kits," care packages sent to adults and children with Fanconi anemia who are ill, in the hospital, or going through BMTs. The kits contain animal hats for fun or when chemotherapy steals their hair, a Kit Kat candy bar (Katie's favorite), a stuffed animal or elephant (another favorite), and games or other activities. Each kit includes something specific to the recipient's likes and is sent with love.

As I write this, nine kits have been sent, one as far as Ireland. Each one is as special as the person receiving it. If you or your child is going through BMT or in the hospital, please contact me so I can send a special kit to you. You can reach me at katiekits@yahoo.com or 425-356-7877. A portion of my donations go to the Fanconi Anemia Research Fund to help find a cure.

Katie left behind her loving family, friends, and her legacy, her son Bentley, now two years old. My daughter was always helping others and she would have loved this project.

Fundraising and Howe!

By Jeanne Atkinson

The force behind the Art Howe Scramble for the Kendall and Taylor Atkinson (KATA) Foundation is Dan Adair, an old childhood friend of my husband, Ken. Rocked by the deaths of our two children due to Fanconi anemia, Dan has always wanted to help in any way he could. What could be a better way to remember Kendall and Taylor than raising money to fight the disease that took their lives at ages 20 and 18? Dan and some of his golfing buddies decided, with no tournament experience, that they could have some fun by holding a golf tournament while raising money for FA. Art Howe, a close friend of Dan's and a former professional baseball player, came on board as the tournament "face." Although Art lives in Houston, he and his wife, Betty, travel to Denver each year to play in the tournament. The three spots in Art's foursome are auctioned off at the KATA Foundation's annual Hoot 'n' Holler fundraiser. Art and Betty are also the presenting tournament sponsors.

Since its first year in 2012, the Art Howe Scramble has grown from 80 players to 136 players this year. With a goal of FUNdraising in mind, the tournament includes:

- A Marshmallow Shoot: Participants try to hit a marshmallow the farthest at hole #1 to win a smoked turkey.
- Pro Drive: Players can elect to pay $20 to have a pro hit their ball across a lake onto the green.

Art Howe's Foursome

- Speed Hole: A timed hole where each foursome tries to get its ball onto the green and into the hole in the fastest time—this leads to some hilarious moments and should be videotaped!

The event wouldn't be possible without the dedication of Dan and his committee who recruit players and do all the planning and preparation, as well as the many others who volunteer on tournament day. We are enormously grateful to all of them, and to Art and Betty Howe for their generosity and commitment to the cause.

The Scramble raises money through tournament registrations, hole and other sponsorships, golf contests, donations, and a raffle. This year, the third Art Howe Scramble raised nearly $19,000!

Family Fundraising Efforts January through September

From January 1 through September 30, 2014, Fanconi anemia families raised $858,970 for the Fanconi Anemia Research Fund. Almost 89 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!

$132,000 - $186,000
Dave, Lynn and Amy Frohnmayer
Kendall & Taylor Atkinson Foundation with the Nash and Atkinson Families

$74,000 - $98,000
Kevin and Lorraine McQueen
Peg Padden
Glen Shearer

$20,000 - $56,000
Robert and Barbara Capone
Mark DeGroot and Hanneke Takkenberg
Steve and Jennifer Klimkiewicz
Dan and Nikki McCarthy

$11,000 - $19,999
Kerrie and Mauro Cazzari
Orion and Lisa Marx
Pedro and Marina Ravelo
Neil and Emily Robison
Gerard and Cynthia Vandermeys

$5,000 - $9,999
Jimmy and Jenny Armentrout
Chris and Jennifer Branov
Ryan and Becky Brinkmann
Patti and Mike Hilbert
Brian Horrigan and Amy Levine
Charles and Katy Hull
Deane Marchbein and Stuart Cohen
Jack and Lisa Nash
Peter and Janice Pless

$1,000 - $4,999
Rachel Altmann and Tyler Morrison
Ron and Juanita Arroyo
Mark and Linda Baumiller
Israel and Mary Jo Becerra
Randy and Nancy Bloxom
Rutger Boerema and Andre Hessels
Jeffrey and Donna Boggs
Richard and Tena Boson
Donald and Danielle Burkin
David and Kim Chew
Daniel and Melinda Coleman
John and Kim Connelly
Darrel and Kalani DeHaan
David and Kelly Dunnock
Justin and Britteny Ferrin
David and Mary Ann Fiaschetti
Ben and Stephanie Griggs
Alan and Rachel Grossman
Owen Hall and Margaret Kasting
Kaps for Kendall
Mark and Angela Lamm
Tim and Mary Ann Lana
Todd and Kristin Levine
Gregory and Lynnette Lowrimore
Sheila Meehan
Tony and Lina Nahas
Ron and Fredi Norris
Susan Ortiz
Mark and Diane Pearl
Bob and Andrea Sacks
Ron and Elesa Schaefer
Bryan and Karen Siebenthal
William and Mary Underriner
Mike and Beth Vangel
Louis and Theresa Viola
Nigel and Ann Walker

Up to $999
Peter and Donna Abramov
Ken and Jeanne Atkinson
Cherie Bank
Gerald Barbier
Julie Barbier
Jasmine Bennetsen
John and Francene Berglund
Charles and Marie-Pierre Bichet
Richard Briga
Christopher Byrd
Jeanette Clark
Tom and Mary Eilleen Cleary
Natalie Curry
Bill and Pat Danks
Joseph and Tracey DeMarco
Egil Dennerline
Antonino and Marie DiMercurio
David and Kari Doctor
Brian and Jennifer Dorman
Ed and Janice Duffy
Lindsay and Sandra Dunn
Gene and Lynn Eddy
Mir Saleem and Umber Ellahi
Sharon Ellis
Billy Jo and Debbie Estep
Curt and Crystal Fales
Liz Funk
Mitch and Erin Furr
Anthony Glavac and Sabrina Bowmer
Pat and Maria Gleason
Andrew and Jennifer Gough
Shawn and Doreen Gummoe
Abdul Hameed
Lisa and John Hayden
Greg and Diane Hayes
Peter and Tara Himmelreich
Jeff Hoffman
Shane and Colleen Irvin
Jeff and Beth Janock
Lester and Nancy Jansen
Kayla Lackey
Christopher and Dana Lamb
Eddie and Maly Lee
Tanner and Jessica Lindsay
Joey Linsenmann
Bill and Jackie Lucarell
Kevin and Barbara McKee
Catherine McKeon
Henry and Gwen McNutt
Zachary and Shannon Mekker
Jim and Holly Mirenda
Ian and Tricia Mitchell
George and Sabine Mohr
Sydney and Betsy Moore
John and Betty Mozisek
Jack and Tammy Neal
Bob and Alice Nicholson
Robert and Mary Nori
Michael and Katharine Ormond
Steve Perkins and Karen Magrath
Michael and Joanna Peros
John and Dianne Ploetz
Michael and Kay Proctor
Lynn and Shirley Quilici
George and Kathryn Reardon
Leonard and Jan Riley
Paul and Catherine Rodwell
Stanley and Lisa Routh
Rick and Lynn Sablosky
Mike Sanders
Richard and Dolores Satterlee
Sharon Saunders
Bill and Connie Schenone
Severt and Beatrice Score
Thomas and Brenda Seiford
Matt and Diane Senatore
Lorne Shelson and Annette Waxberg
Alain Silverston
Mokrane Simoussi
Jim and Carol Siniawski
Debby Slater
Alfons and Karin Staab
Mary Tanner
Abid and Reshma Shahid Usmani
Joe and Wendy Vitiritto
Elizabeth and Graham Walker
Marc Weiner
Michael and Kim Williams
Sean and Kristin Young

Donor's Gifts Total $100,000

Anna Gould, co-founder of Camp Sunshine in Casco, Maine, has generously donated $100,000 over the past several years to the Fanconi Anemia Research Fund! The Fund has held its annual FA Family Meeting at Camp Sunshine since 2002. Anna co-founded Camp Sunshine in 1984 to provide respite, support, joy, and hope to children with life-threatening illnesses and their immediate families from around the world free of charge. The Fund is extremely grateful for Anna's vision, her most generous personal donations, and her commitment to FA families through her work at Camp Sunshine.

PayPal Giving Fund

Do you want a simple way to increase giving to the Fanconi Anemia Research Fund? Welcome to the PayPal Giving Fund.

EBay sellers are encouraged to give a percentage of their proceeds to a nonprofit certified by PayPal Giving Fund each time they list an item for sale. Participating sellers are rewarded for their generosity with special eBay Giving Works features. The nonprofit receives recognition in the listing and benefits from the seller's success. PayPal Giving Fund and eBay collects and distributes the donation, and handles the tax receipt.

EBay members can also choose to make an online gift with PayPal. The Donate Now tab lets anyone with a PayPal account donate. For more information, see www.paypalgivingfund.org/index.html.

Family Camp Souvenir Sales

Donna and Spencer Boggs championed sales at the Fund's annual FA Family Meeting this year at Camp Sunshine. Donna greeted all comers with smiles and hugs, while managing the sales of everything from t-shirts and car magnets to jewelry, umbrellas, and woven key chains. It was the best-ever selection of items, according to several buyers. Thanks to those who donated items and Donna and Spencer's management skills, sales totaled more than $2,200 for FA research and family support!

Game, Set, Match against Fanconi Anemia

Trinity-St. John Lutheran School in Nashville, Ill., held a volleyball fundraiser, Spike Out Fanconi Anemia, in February. Two of their students, Sydney and Zach Brinkmann, have FA. All of the admissions and concessions from the game were earmarked for the Fanconi Anemia Research Fund. In between games, fans and players could participate in fun activities for a $1 donation. Spike Out Fanconi Anemia t-shirts were sold, and parents coordinated a silent auction, sucker raffle, and bake sale. The girls on the volleyball team made special hair bows, which they sold to other teams to wear to raise awareness of FA. At school, students paid a dollar to wear pajamas for a day. All told, the school-wide effort raised $4,200!

Sam's FAns 5K for FA Shines

The first-ever Sam's FAns 5K for FA was a HUGE success, thanks to the efforts of the McCarthy family, who lost their daughter, Samantha, in 2009 following a bone marrow transplant. The June race in Columbus, Ohio, attracted more than 300 participants and raised more than $20,000 for the Fanconi Anemia Research Fund! Many helped, including Sam's friend, Anna Mattes, who organized a bake sale at her school that raised starter funds for the event. Many thanks to the McCarthys and their friends and family who made this event an amazing success!

Top of the World Fundraising

After a climbing accident on Mt. Rainier that nearly claimed his life, Bill McCorey founded Your Rope Team with twin goals of reaching the top of Rainier and helping a special boy with his life-threatening challenge. Bill is a friend of Kevin McQueen, whose son, Sean, 15, has FA.

Since its inception, Your Rope Team has climbed five mountains—Mt. Rainier, Mt. Washington (twice), Old Rag Mountain, and Mount Shasta—raising more than $127,000 to fight FA. Along the way the team has included many FA patients, parents, and researchers.

This year the team, including Bill's sons, Bill and Drew, returned to where it all began, Mt. Rainier, for a second summit attempt on June 29. Although weather conditions did not allow the team to reach the top, they had a wonderful experience climbing for a cause.

Austin's House of Mouse

The 1st Annual Rock-n-Mouse Race? Who knew that mouse racing existed? Patti Carter Hilbert, whose grandson, Austin, lost his battle with Fanconi anemia in 2013, created this unique fundraising idea. The event included mouse races, a 50/50 mouse roulette, a lottery board, prizes, silent auction, a raffle basket, and dancing. In its first year, the Rock-n-Mouse Race raised nearly $7,000! Thanks to Patti and Mike Hilbert, Marti Pearl, and all their friends and family who made this great event possible.

Fund Welcomes New Board Members

Sharon Schuman, PhD

Elizabeth Swisher, MD

The Fanconi Anemia Research Fund recently welcomed Sharon Schuman, PhD, Eugene, Ore., to its Board of Directors. Dr. Schuman is a long-time volunteer and supporter of the Fund, and has organized a highly successful annual chamber music benefit concert and auction for the past 15 years. About her membership, Dr. Schuman says, "I wanted to join the FARF board to do more to help push forward the path-breaking medical research that has already extended many lives. As a friend of Amy Frohnmayer, I have a very personal interest in this project and in the Fund's ability to help families with this challenge. I also think FA research is important for the connections it uncovers to other illnesses, such as cancer, that it can help understand and treat."

The Fund is also happy to announce that Elizabeth Swisher, MD, University of Washington, Seattle, has joined the Scientific Advisory Board. Dr. Swisher is an associate professor of obstetrics and gynecology and an adjunct associate professor of medical genetics. She is also the Medical Director of the Breast and Ovarian Cancer Prevention Program at the Seattle Cancer Care Alliance. Dr. Swisher says, "As a gynecologic oncologist, I have a longstanding interest in the genetics of ovarian cancer. I have been studying how Fanconi anemia genes impact risk of ovarian and breast cancer and how changes in these genes affect how cancers respond to various treatments. Serving on the Scientific Advisory Board is an exciting opportunity to get to know and learn from the leading world experts in the Fanconi anemia field, while serving families impacted by Fanconi anemia and others who carry Fanconi anemia mutations."

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

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