DONOR Newsletter

An annual publication of the Fanconi Anemia Research Fund

2018

Your gifts, big and small, make an impact on FA families

A year ago, I was just a few months into my tenure as Executive Director of FARF, still finding my footing and getting acquainted with the Fanconi anemia community. Now, as I write this article, I am filled with amazement by the courage of our FA families, the dedication of our researchers, staff and volunteers, and the generosity of our donors. I've experienced the distinct privilege of working with devoted, compassionate, and talented people toward a most meaningful mission. Over the last year, we have paid particular attention to strategically positioning our organization to be agile and efficient in an ever-changing rare disease landscape. This means continuing to fund innovative and life-changing research, developing our infrastructure as a staff, communicating

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TWO CLINICAL TRIALS FUNDED

Many of the last 30 years have been dedicated to gene identification, improving bone marrow transplantation, and uncovering connections to breast and other cancers. Thanks to this research, FARF is now poised to create less toxic therapies and move into developing treatments tailored to people with FA. In 2018, FARF took a big step in this direction by funding two clinical trials. This would not have been possible without the support of our donors.

Pilot Study of Metformin to Treat Fanconi Anemia

While stem cell transplantation can cure the hematologic complications of Fanconi anemia (FA), transplant is associated with potential short-term and long-term risks, and has been associated with an increased risk of solid tumors. Safe and effective oral therapies to treat or prevent marrow failure and cancer are urgently needed. With this goal, collaborative laboratory studies by some of the leading FA investigators have been ongoing for over a decade. These lab studies have identified a few candidate compounds and molecular pathways that protect against DNA damage in FA models and improve blood production. The most promising of the compounds studied to date is metformin.

Metformin has been shown to be a safe oral medication widely used for many decades to treat high blood sugar. Recently, there has been renewed

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Cincinnati Children's

DANA-FARBER Boston Children's

CANCER AND BLOOD DISORDERS CENTER

Your gifts, big and small

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effectively with our stakeholders, and being excellent stewards of our resources.

In this newsletter you'll read about some of the incredible work our community has accomplished over the past year, thanks to your support. You'll read stories of struggle and triumph from people with FA and their families. For instance, Joel Walker, a remarkable young man with FA who sadly passed away in 2016, left an impactful gift to promote innovation and collaboration among FA researchers and clinicians. His family has continued to build his legacy and a few months ago, FARF held the first meeting in the Joel Walker Scientific Meeting Series, focused on improving outcomes for people with FA who develop head and neck cancer, like Joel did.

The collaborations and initiatives that came out of this meeting are much more than a pipeline of research projects and steps to developing treatments – they represent hope for kids like 5-year-old Eli Borden from Wisconsin. Last year, Eli's family learned of his FA diagnosis and quickly connected with FARF. They were able to attend the annual FA Family Meeting in Maine, meet with expert FA clinicians and connect with other FA families. For the first time since Eli's medical issues began years earlier, the Bordens didn't feel isolated and terrified – they felt supported and hopeful.

We know it's a long road before families will no longer experience the devastation and fear that come with an FA diagnosis. Treatments won't happen overnight, but we are in this for the long haul. Small steps and acts of kindness all add up to make the major advancements that we are envisioning and our families are counting on. Thank you for your support.

Mark Quinlan
Executive Director

Two Clinical Trials Funded

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interest in metformin given its anti-oxidant properties, aldehyde scavenging capability, and potential cancer-protective effects. A decreased incidence of breast cancer, lung cancer, colorectal cancer, and hepatocellular carcinoma has been observed in patients treated with metformin. There are ongoing trials testing metformin both for cancer prevention and cancer treatment in the general population. Promisingly, preclinical FA studies have demonstrated that metformin protects against DNA damage, and improves blood counts while also delaying tumor formation in mice with Fanconi anemia.

Based on these data, FARF has funded a pilot study of metformin for patients with FA which is now open at Dana-Farber/Boston Children's Cancer and Blood Disorders Center. The study will assess improvement in blood counts after six months of treatment. This pilot trial also incorporates biological studies investigating the effect of metformin on DNA damage and oral cancer risk. The results of this study will inform potential future trials investigating the long-term use of metformin for cancer prevention or marrow failure prevention, as well as combination therapies with androgens or other agents to treat marrow failure, or as adjunct therapy in combination with transplant to reduce cancer risk.

Quercetin Chemoprevention for Squamous Cell Carcinoma in Patients with FA

Excessive toxicity from chemotherapy and radiation makes treatment for squamous cell carcinoma (SCC) in FA quite challenging and leads to negative outcomes in most patients. There is clearly a need for a new approach for prevention and/or treatment that has fewer and less severe side effects. A previous study by Cincinnati Children's Hospital Medical Center showed that the naturally occurring antioxidant quercetin is safe and well tolerated in pre-transplant patients with FA. Quercetin is a plant polyphenol with multiple pharmacological properties including anti-cancer, anti-inflammatory and anti-oxidant effects in preclinical models. Additionally, there was evidence of decreased DNA damage in oral mucosa brushings from patients with FA (pre-transplant) after treatment with quercetin for one month.

Based on these promising data, this new study will examine whether quercetin treatment in post-transplant patients may prevent or delay the development of SCC. Participants in the study will take quercetin for at least six months, with the possibility to take it for up to two years. It is hoped that quercetin treatment will result in decreased oxidative stress and ongoing DNA damage of the mucosa, leading to the elimination or delay of the development of squamous cell carcinoma of the oral mucosa.

Research

The path to a cure for FA is a long and winding one, with many different routes and detours. It all starts with research. Each idea or concept builds on the others, taking us closer and closer to better treatments and a cure. Many of today's treatment protocols began 30 years ago as new research ideas funded by FARF.

1 Discovery or idea

2 Fundraising for research

3 Development of drug or protocol

4 Research is 'translated' for preclinical testing

5 Clinical trial

6 New treatments for people with FA!

Treatments

Dr. KJ Patel, FARF researcher

NO LONGER AN ORPHAN

By Sharon Schuman

My subject was born an orphan in 1927. With no known relatives and no connections to a wider community, what followed were 60 years of abandonment. In 1985, one courageous family decided that this isolation had gone on long enough, and that connections to relatives, if there were any, should be found. This family reached out for help from those who were particularly good at understanding this orphan. Investigators chipped away at the mystery and began to uncover clues. Over a 30-year period bits and pieces of information emerged about a chain of relatives who at first glance seemed distant, then turned out to be close kin. What was once considered an orphan now has an extensive family and has become a celebrity, recognized worldwide. This is the story that I want to tell you.

Fanconi Anemia

Some of you may have already figured out that the orphan I am talking about is not really a person, but a disease—Fanconi anemia—the rare genetic disorder that took the lives of all three daughters of Lynn and Dave Frohnmayer. Fanconi anemia was considered an "orphan" disease because it was so rare and so little was known about its causes, connections to other diseases, or any effective treatment. When Katie Frohnmayer was diagnosed in the 1980s, doctors could only offer palliative care. Some people might have reacted to this shock with paralysis and passivity, but the Frohnmayers responded with energy, determination, leadership and sheer grit to this unwelcome challenge. In the beginning they hoped scientists might uncover "the gene" that causes FA, then do something about it.

In 2004, not one, but eight genes had been discovered, one of which was *BRCA2*, a breast cancer gene. That one discovery linked FA to breast cancer, a disease that in 2012 affected 1.7 million women worldwide. Since then, four additional breast cancer genes have also been found to be Fanconi anemia genes. Now we know that *BRCA2* is only one of the genes in the Fanconi anemia pathway, all of which, when they function correctly, are essential to the DNA repair process that keeps us alive.

For all of us, the healthy metabolism of our cells requires an elaborate network of interconnected pathways made up of chemical reactions that involve proteins, enzymes, and the synthesis or breakdown of amino acids. When cells fail, it is because something has gone wrong in the DNA replication and repair processes that are governed by these pathways and are essential to life. In people with Fanconi anemia, one or more of these 22 genes has a mutation that makes it defective. Thus, people with FA have a tougher time than the rest of us repairing DNA damage, whether it is caused internally by normal processes of metabolism, or externally, by environmental factors like radiation therapy, chemotherapy, alcohol, tobacco, or the sun. It is important to know that none of us can avoid all DNA damage. No matter how much sun block we wear, no matter how many glasses of wine we don't sip or cigarettes we don't smoke, no matter how many carcinogens we avoid in our air, water, soil, and in the food we eat, our own bodies create DNA damage every single day, just through the normal process of staying alive.

What this means is that from the moment of conception, when cells are dividing like crazy and life is bursting forth, people with FA begin to fall behind in DNA repair. The damage accumulates at such a rapid rate that FA babies are sometimes born with missing thumbs, bones, or organs. Though some people with FA show almost no outward signs of the condition, their bodies age prematurely from all this DNA damage. As children they often fall behind on growth charts. As their blood cells struggle to keep up with demand, many kids with FA develop bone marrow failure or they get leukemia. If a way could be found to restore in people with FA

Sharon Schuman

the DNA repair processes that operate in healthy people like you and me, Fanconi anemia would become a manageable condition like diabetes or asthma. **We would not need to find a cure for FA if the disease itself could be made manageable.**

Much of the FA research over the past decades has been devoted to figuring out what it is and to coping after the fact with the physical problems it creates. In small children, surgeons fashion thumbs out of fingers and straighten out bones that are bending. Doctors prescribe growth hormones that help FA kids grow. Still, bone marrow failure remains a huge threat to children with FA. One of the best after-the-fact interventions is a bone marrow transplant that replaces the compromised ability of a person with FA to create healthy blood, with a donor's healthy bone marrow. Because of improvements in bone marrow transplant protocols between 1990, when 20% of FA patients survived the process, and now, when over 90% survive, most children with FA who need a transplant now live into adulthood. This is a remarkable accomplishment. Would that it were a cure!

But for people with FA, the DNA repair problem is not just in the bone marrow, or in the blood. It is in every single cell of the body. A bone marrow transplant can fix the blood, but the rest of the DNA damage grinds on, and the result is all too often cancer. Now that more children with FA are surviving into adulthood, what we are seeing is an epidemic of head and neck cancers in FA adults who have had successful bone marrow transplants. These cancers are particularly awful, because they are painful, disfiguring, and usually lethal. Individuals with FA get head and neck cancer at roughly 500 times the rate in the general population. By the time these cancers are detected, it is often too late. So far, the best treatments for these head and neck cancers involve detecting them at the earliest possible stage, so that they can be surgically removed before they spread. BUT, even if month-by-month and year-by-year diligent patients and doctors catch hundreds of these cancers, the DNA damage continues to pile up, and new cancers appear.

Thank You, Fanconi Anemia!

I realize that this all sounds pretty grim, but there are a number of reasons we should all be grateful to Fanconi anemia and to the research it has inspired. Discovering the link to breast cancer was just the beginning. Now that we know that Fanconi anemia is not just a blood disorder, but rather a DNA repair disorder, and that the 22 Fanconi anemia genes are essential

> “What was once an orphan disease is closely connected to a very large family of cancers.”

to the DNA repair process in healthy people, these genes turn out to be the very genes that malfunction in various forms of cancer, which is ALSO a DNA repair disorder. Uncovering the secrets of FA’s genes and pathways is a step toward uncovering the secrets of all cancers. Right now if you travel anywhere in the world to a scientific meeting that studies blood, radiation, gene therapy, immunotherapy, or various specific cancers, you will hear papers about Fanconi anemia. In this sense, FA has become a celebrity disease, known to researchers all over the world for the insights it can give them about how cancer destroys lives. What was once an orphan disease is closely connected to a very large family of cancers.

On a therapeutic level, FA research has also found a larger family that includes many people without Fanconi anemia. This is how it works. Because FA patients are extremely sensitive to DNA damage, the toxic regimens of radiation and chemotherapy that are routinely used to treat cancer in the general population can be lethal for people with FA. As researchers develop less toxic therapies to treat FA patients, these same drugs can be used in non-FA patients, avoiding levels of toxicity that otherwise kill the very sick or elderly.

Furthermore, because the accumulation of DNA damage in people with FA leads to premature aging, research into the nature of this process has given scientists insights into aging itself, which turns out to be a gradual loss of our ability to repair the damage to our DNA that accumulates day by day over many years. If we could slow that process, what would that mean for the human life span—not just of people with FA, but for us all? The most cutting-edge FA research today is devoted to trying to discover ways not just to correct bone marrow failure, remove head and neck cancer, or repair birth defects—all after-the-fact interventions—but to slow down the DNA damage that is accumulating and to restore to good health the DNA repair process that could prevent these problems from arising in the first place.

What can we hope for?

Since we can never hope to prevent all DNA damage (which is part of our natural metabolic processes), we are hoping for a breakthrough that will allow us to enable people with FA to cope with that damage as effectively as you and I do. **That would constitute a cure for Fanconi anemia!**

Fanconi anemia was once an orphan disease that no one knew anything about, except that it was rare, it affected the blood and it was fatal. Thanks to 30 years of research tirelessly promoted by the Frohnmayer family, Fanconi anemia is no longer an orphan disease. The DNA repair problem at its center turns out to be the problem that characterizes all cancers. Thus FA is deeply embedded in a huge family of conditions that touches us all. Not only that: the cutting-edge discoveries about DNA repair, bone marrow transplant protocols, immunotherapy, gene therapy, and aging, give Fanconi anemia a family so large that it embraces us all. It’s still a fatal disease, but the urgency we feel to find a cure is an urgency not felt in isolation, as it was for the Frohnmayers in 1983. It is an urgency that lies at the heart of our shared mortality. ■

Sharon Schuman, PhD, is Secretary of the Board of Directors of the Fanconi Anemia Research Fund. She was Amy Frohnmayer’s violin teacher from age 9 to 15. Sharon holds a benefit concert for FARF every year which has raised more than $330,000 over 25 years. This presentation was first delivered to the Round Table town-gown organization in Eugene, Oregon, in February, 2018.

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Zach – aka, Batman – is a 7-year-old boy from New York. He had a bone marrow transplant in 2017 and is doing well. This photo was taken last month at the FA Family Meeting in Maine, where Zach and his family spent the week with other FA families participating in educational sessions and fun activities.

LEAVING A LEGACY:

Joel Walker Inspires Scientific Meeting Series to Advance FA Research

Joel and Joanne Walker were talented students, good at sports, sociable and happy. Some of their happiest memories as children were spent visiting family and friends in England and Australia. As seemingly happy, healthy children, no one would have guessed that they both had Fanconi anemia (FA). At age 33, Joanne was diagnosed with FA a few months after she developed esophageal cancer. Following this diagnosis, she immediately began chemotherapy and radiation – standard treatment protocols for cancer but very dangerous to those with FA. These treatments caused an immediate deterioration of her bone marrow function and blood levels. After many tests to find the cause of this deterioration, she was finally diagnosed with FA in March 2013. Joel volunteered to be tested as a sibling donor match in case a bone marrow transplant became a possibility. It was then that the Walker family learned that Joel also had FA. Joanne's blood counts never recovered sufficiently from the chemotherapy. She passed away on June 24, 2013 at the age of 34.

Watching Joanne throughout her journey, Joel knew what he could potentially face and was closely monitored for bone marrow deterioration and cancers. It was devastating when Joel was diagnosed with cancer of the hypo-pharynx in August 2015. In November of that year, a radical laryngectomy was performed to remove his voice box. Joel then spoke and breathed through a hole created in his throat, and for a while, it appeared the cancer had gone. However, it returned a few months later, along with esophageal and mouth cancers. He was deemed inoperable shortly thereafter, so he started on a variety of immunotherapy treatments. Joel continued to deteriorate as the tumors grew, but insisted on trying newer experimental treatments and did not want to take hospice care. Joel passed away on November 1, 2016 at age 33.

Research into treatment for FA was a high priority for Joel, along with the hope that he could help others, so he left a large part of his estate to the Fanconi Anemia Research Fund (FARF). The Walker family worked with FARF to set up the **Joel Walker Scientific Meeting Series**, which supports focused scientific meetings on a variety of topics, beginning with head and neck cancer prevention and treatment in FA.

Joel Walker and Joanne Walker

Joel Walker Scientific Series Meeting

Head & Neck Squamous Cell Carcinoma (HNSCC): Developing Guidelines to Maximize Therapeutic Outcomes

The first Joel Walker Scientific Series Meeting took place on April 9, 2018 at the University of Pittsburgh. The meeting brought together the clinical and scientific expertise of physicians and researchers who treat people with FA or have extensive research programs focused on the disease. The goals of this meeting were to begin developing standard of care guidelines and future research objectives to maximize therapeutic outcomes for treating head and neck cancer in people with FA.

What do we know about head and neck cancer in people with Fanconi anemia?

- People with FA are at an increased risk to develop cancer (500-700 times higher than in the general population)
- Reasons for increased risk are not well understood
- Treatment options are limited

People with FA diagnosed with HNSCC have limited options for treatment because of low tolerance to adverse effects from highly toxic radiation and chemotherapy. This often leaves surgery as the only viable treatment option, which is highly problematic because FA patients are typically diagnosed at an advanced stage with highly aggressive disease. The surgical removal of tumors is currently the best treatment option, but this is usually not curative for FA patients who often acquire secondary tumors or have aggressive tumors that are difficult to remove.

Aside from surgical intervention, the current treatment guidelines for FA HNSCC include preventative measures such as (1) abstaining from carcinogens including alcohol and tobacco, (2) maintaining oral hygiene, and (3) participating in extensive oral cancer screening measures.

Researchers and clinicians are working with FARF to develop a roadmap for clinical care for FA patients diagnosed with HNSCC. Basic and clinical research is needed to develop an understanding of the molecular mechanisms driving FA HNSCC and tolerance to targeted therapies so that FA-specific treatment plans can be established.

So, what do we do?

1) Improve strategies for early detection by expanding current screening protocols and developing a brush-biopsy kit to be used by patients, families, and medical professionals.
2) Develop a biorepository so that researchers have access to tissue for study and patients have the possibility for personalized care.

JOEL WALKER
SCIENTIFIC MEETING SERIES
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3) Research the potential of immunotherapy for FA patients, beginning by characterizing their immune systems and moving into trials.
4) Develop more clinical trials specifically for people with FA to truly understand potential and efficacy of therapies.
5) Assess if treatment options in non-FA patients could be applicable for FA patients.
6) Establish FA cancer centers of excellence so that people with FA have access to expert teams of physicians and scientists. In addition, a virtual FA tumor board or advisory panel of experts could be enlisted to manage FA patients with HNSCC who would be unable to attend the centers of excellence.

What needs to happen next

The challenges of preventing, detecting, and treating HNSCC in FA patients are many. The Joel Walker meeting identified clear areas that need to be addressed from both the research and clinical treatment perspectives moving forward. FARF is poised to lead these efforts and we will focus immediate efforts on (1) developing the tissue biobank and clinical registry and (2) establishing a personalized cancer prevention/detection brush biopsy kit for all FA families and (3) developing chemoprevention clinical trials using compounds already approved by the FDA for use in other cancers.

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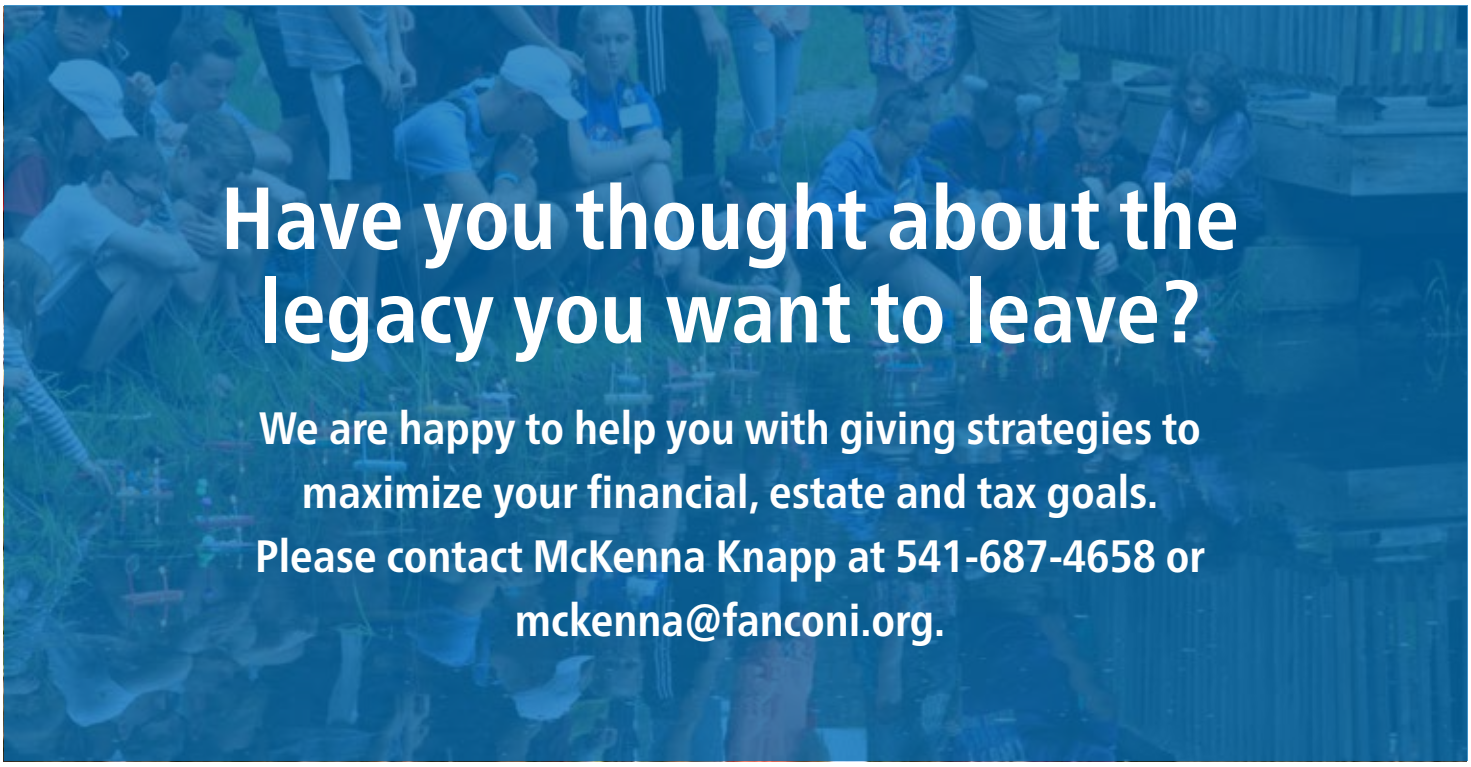
To learn more about the specifics discussed at the meeting and for a more detailed plan of action, visit **www.fanconi.org/news**.

How can you make a difference? Support the Joel Walker Scientific Meeting Series by making a gift at **https://fundraise.fanconi.org/joelandjoanne.**

Special thanks to Phil and Penny Knight for their extraordinary commitment to FA cancer research. Their instrumental gifts enable scientists to seek answers to the most pressing questions, inspire others to join the fight, and give hope to those with FA and their families. Thank you!



Scientist Spotlight

Name: Andrew Deans, PhD

Institution: St. Vincent's Institute, Australia

Area of expertise: protein chemistry and cell biology of Fanconi anemia

My work:

We are working on biochemical reconstitution of the Fanconi anemia DNA repair pathway outside of cells, using only FANC proteins. We have so far been able to use this system to find out the exact biochemical function of several of the genes that cause Fanconi anemia. We can also now see what the FANC proteins look like at the molecular level, using powerful new electron microscopy techniques. Our current major goal is to discover what the critical ubiquitination modification* does to FANCD2 and FANCI. This modification is absent in almost all FA patients, but we still don't know its normal function in protecting cells from DNA damage, and people from bone marrow failure. We also have a program searching for genetic and chemical activators of FANC proteins that might one day be able to restore FA pathway function in some FA individuals.

What motivates me to work on FA:

As a scientist, I was originally motivated to work on FA because it results from failure of a very complex system that is very interesting to understand. But meeting families and hearing their stories of heartache and triumph is now easily my biggest motivator to succeed in my work. The more I have worked on FA, the more I have realized that the work I do in the lab could have important outcomes for FA patients and families.

When I'm not in the lab, you could find me:

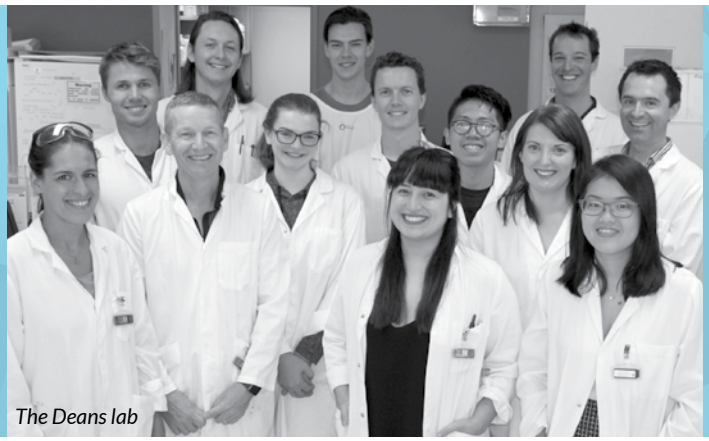
At one of Melbourne's many beautiful beaches or parks with my wife and son.

Just a note:

My research now has 13 scientists working on FA, which would never have been possible without the financial and scientific support of FARF and its network in my early days as a lab head. So, thanks!

* Ubiquitin is a small regulatory protein. It must be added to both the D2 and I proteins, a process called ubiquitination, for them to function normally and repair damage to DNA. If an FA patient is defective in any one of the core complex genes (A, B, C, E, F, etc), the protein products of the genes D2 and I cannot be ubiquitinated, resulting in the DNA repair defect. It is therefore crucial to understand this process. ■

"My research now has 13 scientists working on FA, which would never have been possible without the financial and scientific support of FARF and its network in my early days as a lab head. So, thanks!"



The Deans lab

My name is Mary-Beth Johnson. I'm 25, and I have Fanconi anemia. I climb mountains, make avocado roses, and I spend a lot of money at Target when I'm stressed. I don't generally identify as someone who is sick, because I'm healthy for the most part. I had an older brother, Danny, who died of FA over 20 years ago. Ever since then, I've balanced a great isolating act when it comes to the FA community.

If I'm being completely honest, I was peer pressured to attend the adult meeting. I went in silently, kicking and screaming, convinced that I could remain stoic and detached...that I was there for the science, and to learn how to boss my doctors around better.

But here's the thing: there's a magnetic quality to other people who share parts of your story. The anxiety, fear, the memorized blood count numbers. The feeling that you need to squeeze as much life into your years as possible. The necessity to love, love, love and rise, rise, rise and continually chase after joy in the face of uncertainty.

I won't lie to you: I had a lot of feelings about the adult meeting. I called my husband every night and started our conversations with, "I've had 37 meltdowns, but at least half of them were good." And here's why: there is no better antidote for isolation than to find your heart in other people.

YOUR GIFTS MAKE

Hi there, I'm Amelia Hawkshaw! I live in Sydney, on the east coast of Australia. I'm 25, and I found out I had Fanconi anemia less than two years ago. For many people, learning that you or your child has FA can be a daunting and frightening experience. For me, it was a relief.

It was towards the end of 2016 and I had just been through the toughest year of my life. I grew up not knowing that I had a genetic condition. I lived and laughed, read constantly, learned an instrument, traveled across the world, found my faith, studied, and had just begun a career in social research. So, when I was diagnosed with bowel cancer in January 2016, it came as a shock. Getting cancer at any age can be a kick in the guts. **At 23, I hadn't yet realized that suffering is present in all people's lives, and it would exist in mine.**

Two weeks later, I had my first major surgery to resect my bowel and get the tumor out. In April, I would undergo another major surgery. After recovery, we prepared for chemo. And if you know anything about FA, you know what I'm going to say next – chemo didn't exactly agree with me. Two days into my first cycle, I was back in the hospital. My bone marrow and immune system stopped doing their job. I spent eight weeks in the hospital as my body cycled through several issues. The doctors were bewildered by what was happening. They had no explanation for my reaction to treatment. I didn't have much capacity for being myself at this time, so I shut myself down and focused on staying alive.

Thankfully, my bone marrow kicked in again and I did get better. I transitioned to a rehab hospital and built up my strength. I began to feel like myself again, and I went home. In November of 2016, my geneticist diagnosed me with Fanconi anemia. After spending 2016 as an anomaly – a patient with an unusual cancer for my age, unexpected symptoms, unexplainable reactions, endless complications, it was comforting to finally have a reason. FA also explained other strange things about me, like how I'm the shortest in a very tall family, my hydrocephalus and endocrine problems, and the café-au-lait spots on my skin.

However, the FA diagnosis also came with more confusion. Every patient is unique. And I didn't present like a normal FA patient anyway. There are so many possible manifestations of the condition. We had a lot to learn, and very few specialists in Australia we could contact. On top of dealing with the emotional and

Maybe that sounds melodramatic (my brain operates at a base level soap opera), but when you're an adult with FA it can be hard to explain the crossroads where you live.

As an adult with FA, I want a lot of things for my life. I want to have a successful career. I want to be generous, hopeful, and life-giving for the people around me. I want a family. I want to travel the world with the love of my life. I want old age. GOSH, I want old age. Give me the wrinkles, age spots, the Velcro sneakers; I crave sassy grandma status.

And yet, as an adult with FA, I also keep a list of my symptoms. I message my doctors every other week. I force them to check and recheck for cancers. I pay way too much money just to be sure I'm still healthy. I lose sleep sometimes, imagining what it will be like when my waiting is over and I finally get a diagnosis.

So you see, when I walked into a room with 41 other adults who are thriving in their present, dreaming and working for their futures, and claiming control over their health, I felt a new part of my heart.

I am indebted to the doctors, researchers, and scientists who are fighting for us. Indebted to the parents and caretakers—lay people who became medical experts—who have fought for and championed our health. Indebted to the spouses and partners, who stepped into our stories of FA and forever changed the way we understand unconditional love. Indebted to the FARF staff and board, for taking our orphan disease and giving us hope.

But mostly, and forever, I will be indebted to the adults with FA. For creating a community of generosity and hope. For sharing the pit of feelings. And for finding the resilience to climb out of the pit, with arms reaching down to pull others up, and sit around a pool late into the night sharing life, laughing at morbid jokes, and squashing gigantic Georgia cockroaches. ■

A DIFFERENCE

physical repercussions of cancer, I was learning to live with the constant anxiety and anticipation of hardship that comes with FA. I found just one person with FA living in Sydney. After the relief I'd felt with a diagnosis, I was suddenly feeling isolated and lost. I was dealing with the unknown once again.

This began to change as I got connected to the Fanconi anemia family. Through FARF I gained advice from others dealing with FA, a handbook on the most recent research and treatments, support from fellow patients, and learned of the Adult and Family Meetings. In September 2017 I attended the Adult Meeting/Scientific Symposium. It was overwhelming and brilliant! I went from knowing one person with FA to knowing over 40! They know exactly what it's like to have a dozen different doctors and some kind of test every month or so. They know what it's like to balance living life in the moment while worrying about possible illness in the future. We spent five days sharing our experiences with FA, giving each other advice about the illness that connected us, talking about our lives, and having fun. We took advantage of every moment we had hanging out with each other, because next week, we would go back to our own lives. I left that meeting with new hope for my future, a clearer idea of how to manage my medical screenings, a lot of new friends, and a tight bond that I feel tugging me across the sea to the next meeting. **The other adults with FA inspire me, they make me laugh, they make me want to grab life while I can, because that's what they have learned to do.** It turns out there is strength in numbers, even with FA. ■

DO SOMETHING EPIC

By Orion Marx

Dream. Challenge yourself. Go for it. Do something no one thinks you can do. Set an audacious goal. Fix our DNA. Cure Fanconi anemia. Cure cancer. This is what all FA families request from the doctors, scientists, researchers and bio/pharma companies. But they aren't the only ones who can help. We can all play a part.

We can apply our ability, passion, encouragement and energy into raising funds to help the Fanconi Anemia Research Fund carry out its mission and find that cure. Our family started Team BrAvery in 2010, shortly after our daughter Avery's diagnosis. Prior to that, we were unknowingly training for future Team BrAvery events. My brother-in-law, father-in-law and I were on our way back from a double-crossing run across the Grand Canyon (called a Rim to Rim to Rim) when we received the life-changing news that Avery had been diagnosed with Fanconi anemia. We'll never forget that day in early May 2010. By the end of that same year, Avery (then age 7), received her bone marrow transplant.

Now, Team BrAvery completes challenges for an even more important reason: Avery, now 15, and all of the kids and young adults like her need our help. The team's challenges are a fantastic opportunity to bond, to accomplish the seemingly impossible, and to raise funds and awareness for FARF. In other words, do something epic.

This past May, we set our sights on running the Keys 100 – a 100-mile run from Mile Marker 100 in Key Largo to Mile Marker 0 in Key West. It was a grueling run, but we did it! We finished the 100-mile run in 31 hours and 54 minutes, just under the 32-hour cutoff. We never gave up, even with all the rain (most of the race), the blisters and the difficulty. The other part of our challenge was to raise $100,000 – $1,000 for each mile. As of early July, we have raised $70,000!

This race was a true metaphor for the struggle FA families face. The event was daunting yet inspiring with challenging weather and distance alongside beautiful scenery. Our bodies were aching yet continued to move forward. There were times that we could have given up because, frankly, it was hard. But we didn't – the team's amazing strength and endurance and our team spirit for success carried us through.

Doctors, researchers and scientists face challenges, too. Often, results may not be what they expected. Yet they continue to endure, they set audacious goals and they work to solve medical mysteries. Together with all FA families, Team BrAvery walks alongside this team of experts. We provide encouragement and support throughout their challenges, all the while knowing they will use their passion, preparation, research, and training to deliver results. The results are amazing. The results will be epic.

Do something epic. ■

Help Team BrAvery meet their $100,000 goal at www.goteambravery.com. Learn more about Team BrAvery's next crazy adventure and follow them on Facebook @goteambravery.

FROM FEAR TO FAMILY

By David Borden

I will never forget May 15, 2017. It was the day our geneticist called to tell me that my son had Fanconi anemia and what that meant for him and for our family. I was in shock. This couldn't be real. A few months earlier, our geneticist told us this test was to *rule out* FA – that she didn't think our son had this disorder. The gene came up on an exome sequencing for "unknown significance." She didn't even spend much time explaining what it was during the last appointment. She said it was a terrible disease that she didn't think Eli had, but that it would be smart to rule it out. We almost didn't take the expensive DEB test (diepoxybutane, which tests for FA).

We had spent years working through various medical issues and finally thought most of it was behind us. Our local children's hospital seemed to be baffled by Eli for years, which left us feeling terrified about our future. My mind raced as the geneticist started rattling off outdated information and figures...90% fatality by age 18 is the only number I remember. Then she instructed me to call the local hematology department and make an appointment as soon as possible. I had never felt so alone and terrified for my wife to come home from work, as I would soon share with her what I had learned.

After the call, I started frantically researching. Wherever I went searching for FA, I found the Fanconi Anemia Research Fund (FARF). Later that same evening, FARF Family Services Director Marie Sweeten returned my emails with answers to **ALL** of my questions. She provided a list of doctors who knew about FA and told us about a camp we should attend just a few weeks later. Suddenly we were not so lost. We had a plan. We were moving forward.

I tried to call our local children's hospital to set up an appointment with the doctor on the list FARF gave me, but I was told that doctor only sees patients in bone marrow failure. I told them we just were diagnosed with Fanconi anemia and that we wanted to see the FA specialist. We ended up with an appointment with a regular hematologist. This frustrated me, so we cancelled the appointment. A few weeks later, we found ourselves in Minnesota for a full FA workup to find out where we stood. Another few weeks after that, we were traveling to Camp Sunshine in Maine, our first ever family road trip.

It was at Camp Sunshine where we found the courage to face FA head on. While at times we felt very overwhelmed, we never felt alone. The outpouring of love and support from the other families made us feel welcome, gave us strength, and filled us with courage. It was at camp that we realized that this terrible, ugly, dark disease has a silver lining, if you can believe that. It comes along with some of the strongest and most caring parents and children we have ever met. You know when you meet someone like this because that person is electrifying to be around. It's one thing to meet one person like this, but we got to go to a place filled with people like this. What an incredible experience we will not soon forget! We miss our new FAmily and already look forward to next year.

The keystone to all of this was FARF. Without FARF, none of this would have been possible. We would still be lost and filled with sadness and despair. We will never forget what FARF has done for our family and the other FA families. Thank you from the bottom of our hearts.

NEWLY FUNDED RESEARCH GRANTS & CLINICAL TRIALS

From July 1, 2017 to June 30, 2018, the Fanconi Anemia Research Fund awarded $1,656,003 in research grants to the following projects:

Investigator: Agata Smogorzewska, MD, PhD

Institution: The Rockefeller University, New York City, New York

Title: Identification of Novel Therapeutic Targets against Fanconi Anemia-associated Squamous Cell Carcinoma

Amount Funded: $120,000

Investigator: Raymond Monnat Jr., MD

Institution: University of Washington, Seattle, Washington

Title: The Fanconi Anemia Cancer Translational Resource

Amount Funded: $174,987

Investigators: Kevin G. Haworth, PhD and Hans-Peter Kiem, MD

Institution: Fred Hutchinson Cancer Research Center, Seattle, Washington

Title: Direct in vivo gene correction of hematopoietic stem cell populations in Fanconi anemia

Amount Funded: $175,000

Investigator: Agnieszka Czechowicz, MD, PhD

Institution: Stanford University, Stanford, California

Title: Development of a safe, completely non-genotoxic anti-Kit antibody-based conditioning regimen for hematopoietic stem cell transplantation in Fanconi Anemia

Amount Funded: $180,000

Investigator: Jacob E. Corn, PhD

Institution: University of California Berkeley

Title: Defining tractable approaches for gene editing of Fanconi Anemia hematopoietic stem cells

Amount Funded: $121,600

Investigators: Akiko Shimamura, MD, PhD and Elissa Furutani, MD

Institution: Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Boston, Mass.

Title: Pilot Study of Metformin for Patients with Fanconi Anemia

Amount Funded: $686,848

Investigator: Parinda Mehta, MD

Institution: Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio

Title: Quercetin chemoprevention for squamous cell carcinoma in patients with FA

Amount Funded: $75,000

Investigators: Susan R. Mallery, DDS, PhD and Joerg Lahann, PhD

Institution: Ohio State University, Columbus, Ohio

Title: Field-Coverage Oral Cancer Chemoprevention via Janus Nanoparticles

Amount Funded: $122,568

The Fund is committed to supporting research to further our mission of finding new treatments and a cure for Fanconi anemia. Over our 29-year history, we have funded 230 research grants and two service grants to 152 investigators worldwide. The total amount of research dollars awarded is nearly $23 million!

FINANCIAL SNAPSHOT

We envision a future in which we can prevent and/or eliminate the primary causes of death and disability in people with FA, enabling them to live full and productive lives. The best way to do this is by funding research. That's why most of our budget is committed to research. We also support families by providing them with education and other services, like our annual family camp and our meeting for adults with FA. Thank you for making our research and support programs possible!

Have you been to the new Fanconi.org?

We're excited to share our brand new website, featuring a fresh design, easier and better options to give, a news blog, directories of funded research and supported researchers, and more. Check it out today by visiting **www.fanconi.org**.

Just a few highlights over the past year

289 children and adults with Fanconi anemia participated in oral screenings in 2017 through our oral cancer prevention project

More than $1.6 million was awarded to new FA research grants and clinical trials since July 2017.

Sixty-one FA families received support and education at the Family Meeting, including 14 new families and 12 international families.

Nine-year-old Calix went through a bone marrow transplant earlier this year at an FA center. He is doing well thanks to wonderful FA doctors and past research into bone marrow transplant protocols.

All of this is made possible because of you

Thank you

DONOR HONOR ROLL

Over $3 million raised!

We would not be able to make strides in research or provide family support services without you, our wonderful donors. Below is a list of donors who contributed $250 or more to the Fanconi Anemia Research Fund between July 1, 2017 and June 30, 2018. Although space prevents us from printing all the names of our generous supporters, please know that we appreciate every single dollar raised—gifts of $10, $20, and $50 all add up and together give us the power to make a difference through FA research and support. Thank you!

A note to our supporters: we greatly appreciate your donations to our Fund, and we want to recognize donors with 100% accuracy. If we have inadvertently made an error, please let us know by emailing info@fanconi.org. Thank you.

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