



# FAMILY Newsletter

Fall 2020

A semi-annual publication of the Fanconi Anemia Research Fund

issue  
68



## In this issue

- Get Ready for the Holidays:
  - Easy ways to make an impact on the FA community
  - How to support loved ones during this season
  - Dealing with toxic positivity
- New Infographics: Cancer in FA, Stem Cell Transplants, Stages of Life with FA
- FA Registry Update
- Nutrition Overview
- International Support Grants
- Family Fundraising Wins
- Research Dollars at Work



## Update from HQ

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**It is hard to imagine the full extent of pain COVID-19 has caused to people worldwide. In the United States alone, we have lost over 200,000 lives. Millions of jobs have disappeared. The inequities and shortcomings in our healthcare system have been made even more visible. And the crisis is far from over.**

During the pandemic, FARF has remained committed to serving as an essential lifeline to the FA community. We are working hard to maintain the level of service you are accustomed to and are staying focused on moving the mission forward. However, like you, we have faced struggles over the last six months. COVID-19 upended our plans for the entire year and we had to pivot to a new service model. This new model required a shift in each of our organization's pillars: administration, family services, fundraising, and research. In each of these areas, we have strived to anticipate potential issues. We asked hard questions, considered worst-case scenarios, and brainstormed all the many choices and decisions we could make to maintain a high service level. During this process, the FARF staff reminded me of their resilience and the deep, shared commitment they have for individuals with FA. They have taught me what is possible when confronted with unexpected challenges and last-minute changes in direction. They worked feverishly to shift all our events in 2020 to a virtual format and created new action plans for raising money and funding research. This ability to innovate, execute, and deliver was precisely what was needed.

The pandemic clouds will eventually lift, but our community must stay close together when facing challenges like we are now. **The team here at FARF will not waiver in our support to the community.** We will remain nimble and pivot when necessary. **But we must also stay honest with the community and let you know that we need your help.** Currently, the best way to help is through a holiday appeal. We're asking you to reach out to your friends and family, to ask them to support your family and our efforts. Invite your community to help continue to fund FA research and provide the services that mean so much to your family. We rely on appeal letters every year to fund the next year's research and services. This year, we need you even more to offset the challenges faced by our organization in 2020. Gone, at least temporarily, are events, galas, and live auctions. What is left are appeals to those who want to support your families. I urge you to read the next page. Our team stands ready to assist you in this effort and will help guide you through developing an appeal, so please reach out for our help.

I wish I could provide the clarity we all want for what FARF will look like in 2021, but unfortunately, the uncertainty is present and real. However, I can promise that we will learn from any challenges, we will adapt as needed to keep us pointed in the right direction, and we will continue to grow despite the hurdles. I will not try to predict the unpredictable, but what I know is that our FA community is strong, and if we work together, we can drive our efforts forward even when things are uncomfortable. Thanks for taking this journey with us!

Mark Quinlan  
Executive Director

# SEASON OF Promise



<https://fundraise.fanconi.org/holidays>

## How you can help the FA community this holiday season

Did you know that 70% of FARF's income is generated by holiday gifts? Many of these are the result of families like yours asking your communities to make a gift in honor of your family. The median sized gift made during the holidays is \$60. If 10 of your friends or family gave that much, you would raise \$600 for research and support services. We know this year has been particularly challenging which is why we've made it easier than ever for you to invite your community to give.

### YEAR-END FUNDRAISING CHECK-LIST:

- DECIDE:** do you want to send a traditional printed letter, an email, or have a customized donate page on FARF's website? To increase your impact, do all three!
- CONNECT:** if you're sending a letter, email Julia at [julia@fanconi.org](mailto:julia@fanconi.org) and she will help you format your letter & photos, then work with you to get your mailing list, print, stuff & send your letters – no need to worry about postage!
- CREATE:** if you're going the online route, all you need to do is visit <https://fundraise.fanconi.org/holidays> and click "become a fundraiser". Add your photo and a personal message to your friends. We've already added the impact of fundraising dollars for your donors to see. All you need to do is then share your page with your community.
- CELEBRATE!** You've made a difference! We will connect with you in early 2021 with a fundraising report so you know the impact you and your community made.

### Sample email to send to your friends & family this holiday season:

Full letter template on the last page of this newsletter

Dear \_\_\_\_\_,

This year has been challenging, to say the least. The feelings of uncertainty and unease are no strangers to our family. As you know, our son/daughter(s), \_\_\_\_\_, has Fanconi anemia, so this organization is very close to our hearts. [Insert personal update about your family's experience.]

I'm writing to let you know this holiday season I'm fundraising for the Fanconi Anemia Research Fund (FARF). FARF funds research for better treatments and a cure for Fanconi anemia. They also provide support services to affected families like ours. I'll be asking pretty much everyone I know to make a donation, but I thought I'd ask my closest family and friends first. Will you help me reach my goal of \_\_\_\_\_?

You can check out my fundraising page by clicking this link: \_\_\_\_\_.

Any support you can give means so much to us. Thanks for reading and helping me support this important cause.

Thank you and happy holidays!



# LET'S TALK ABOUT CANCER IN FANCONI ANEMIA



## WHAT DOES FA HAVE TO DO WITH CANCER?

Due to the underlying DNA repair issue in people with FA, they are at a higher risk to develop squamous cell carcinoma (SCC) in the head & neck and anogenital regions (vulva, vagina, cervix, anus). SCC can also arise in other areas of the body. Risk increases with age.

## WHAT ARE THE CURRENT TREATMENT OPTIONS?

Traditional therapies such as chemotherapy are toxic for people with FA, making surgery the most viable treatment option. For surgery to be a success, it is crucial to find and remove cancers before they spread. That is why prevention & early detection are key.

## IMPORTANT TO KNOW

Not everyone with Fanconi anemia develops squamous cell carcinoma. Long-term survival after SCC in FA is feasible if it is detected early enough. In the mouth, most lesions are non-malignant. Survival correlates with stage (size of the tumor and spreading).

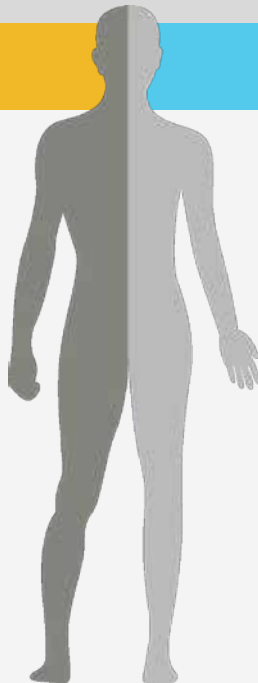
### HEAD & NECK, MOUTH, ESOPHAGUS

#### Add to your healthcare routine:

- See your dentist at least twice a year
- See your ENT doctor at least twice a year starting at age 10. Inspection of the throat should start at age 16.
- Perform monthly self-inspection and documentation, looking for any abnormal spots or changes
- Participate in oral screenings offered free at all FARF meetings (in-home visits also offered)

#### It's time to see a specialist:

- If a spot isn't healing over time (3-4 weeks)
- The color of a spot changes
- If the spot starts to bleed
- If you start to develop even slight problems with swallowing or speaking



### VULVA, VAGINA, CERVIX, ANUS

#### Add to your healthcare routine (females):

- Begin visual exams of external genitalia at age 13 with a gynecologist
- Perform self-inspections with a mirror
- Start comprehensive exams, including pap smear, at age 18, every 6-12 months
- Colposcopy of the vulva, vagina, or cervix should be performed when any abnormal spots are seen on visual inspection or if a cervical cytology test is abnormal

#### It's time to see a specialist:

- When you notice the development or change in any spots

*Though these recommendations are specific to females, it is important to note that anal cancer may develop in males as well. Screening recommendations have yet to be determined.*

## 4 PROACTIVE STEPS AGAINST CANCER



### INFORMATION

Keep yourself informed. Updates are provided at in-person meetings, on FARF's website and in newsletters.



### DOCUMENTATION

Perform self-inspections of the mouth and take photos of any spots. Mark spots on an "oral cavity map" (printable available at [fanconi.org](http://fanconi.org)), describe details and note the date.



### THE DO'S

In addition to regular screenings, maintain good oral hygiene and a healthy lifestyle, including diet and exercise. It's key to give attention to mental health, too.



### THE DON'TS

People with FA should avoid consuming alcohol and partaking in smoking, both of which cause extra damage to DNA.



# LET'S TALK ABOUT STEM CELL TRANSPLANTS

## BONE MARROW FAILURE

Bone marrow failure is one of the manifestations of the DNA repair problem in Fanconi anemia (FA), and leads to the need for a Hematopoietic Stem Cell Transplant (HSCT). This is currently the only long-term treatment for fixing bone marrow failure in FA.



## WHAT

## THE TRANSPLANT

In this process, the patient's (non-functioning) stem cells are replaced with healthy stem cells from a donor. This donor can be related or unrelated, and the cells can come from the bone marrow, cord blood or peripheral blood. When choosing donor cells, the goal is to find a donor whose cells "match" the recipient's as closely as possible. The closer the match, the more likely the transplanted cells will grow and the less risk there is for a complication known as graft-versus-host-disease (GvHD).

## WHEN

## TIMING OF TRANSPLANT

It is important to note that not every person with FA will need a transplant. Although likely, it is not a certainty. Someone needs a transplant when his/her counts are low enough to require it. Criteria may include:

- A consistent **downward trend in counts** over a few readings. This is determined by assessing blood counts every 1 to 3 months, depending on how low counts are. Infection can cause a decline in counts, so it's important to take this into consideration, looking for a consistent trend over time. Ideally, patients should be transplanted before requiring blood or platelet transfusions.

- **Leukemia or Myelodysplastic Syndrome (MDS)**
- An **abnormal clone** (changes in the chromosomal number or structure of certain bone marrow cells). Some of these clonal changes can be monitored over time and some require immediate attention.
- Diagnosis of a **BRCA2 mutation** (this presents a high risk for the quick development of leukemia without warning signs).



## WHERE

## FA COMPREHENSIVE CARE CENTERS

FA is very unique and complex, and the best chance at positive outcomes are when patients are treated at centers that have a deep understanding of and experience with treating FA. This is important for long-term follow-up as well. If a patient is unable to travel to an FA center, physician-to-physician communication and collaboration is vital. The transplant process and follow-up require a team approach to care for all aspects of the patient's needs. An effective team will include sub-specialists that are invested in FA and who approach their patients through an FA lens.

*Thank you to Dr. Margaret MacMillan (University of Minnesota) for help in developing this information*

## PROVEN FA CENTERS

- University of Minnesota Masonic Children's Hospital (Minneapolis, MN)
- Cincinnati Children's Hospital Medical Center (Cincinnati, OH)
- Memorial Sloan Kettering Cancer Center (New York, NY)

## MORE INFORMATION

Visit [www.fanconi.org](http://www.fanconi.org) for more information about transplants, including frequently asked questions, as well as specific medical guidelines about when and how to proceed with treatment.

# STAGES OF LIFE WITH FANCONI ANEMIA

This visual offers a potential progression of living with FA. Remember that every individual may progress uniquely along the FA journey.



## STAGE 1: DIAGNOSIS

AGE 1-5

Typically, children are diagnosed before age five, though not always. Diagnosis often entails feeling shocked, devastated, terrified, and unsure of how to proceed. Families are taking in a lot of new and potentially confusing information and trying to determine the best next steps for the future. It's also a time where families may feel isolated within their own communities, but are beginning to form valuable connections within the FA community.

SOURCE: STELLA DAVIES, MBBS, PHD, MRCP  
CINCINNATI CHILDREN'S HOSPITAL MEDICAL  
CENTER JUNE 2020 | FA FAMILY MEETING

## STAGE 2: WAITING

AGE 5-12

The elementary school years are often spent waiting and wondering if/when a bone marrow transplant (BMT) will happen. Not everyone will need a transplant, so the waiting and wondering can sometimes feel more stressful than actually going through the transplant process.

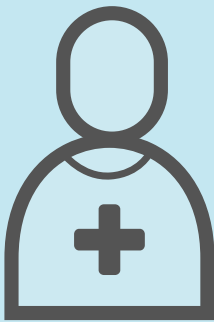
The BMT procedure involves a couple days of pre-conditioning, then after the transfer of cells and recovery, patients are usually requested to stay near the hospital for about 100 days.



## STAGE 3: WATCHING

AGE 12-18

As children enter adolescence, families begin to shift focus to watching for the development of head and neck or gynecologic cancer. All individuals with FA should begin cancer screening visits with doctors at a young age regardless of whether they have gone through a bone marrow transplant.



## STAGE 4: GROWING

AGE 19+

Entering adulthood comes with its own set of milestones, which may include moving out of the home, becoming independent, getting a job, or forming relationships. These transitions are accompanied by additional challenges, such as securing a physician who specializes in long-term care for adults with FA, and transitioning from guardian health insurance plans to new personal coverage. Regular screening for cancer is imperative in adulthood, as it becomes more prevalent with age.



For more information and specifics around each stage, visit [www.fanconi.org](http://www.fanconi.org)

# Scientist Spotlight

Name: **Agnieszka Czechowicz MD, PhD**

Institution: **Stanford University; Lucile Packard Children's Hospital**

Area of expertise: **Pediatric Stem Cell Transplant and Regenerative Medicine**



## My work:

I am a translational physician-scientist. I care for patients at Stanford Children's and specifically focus on treating bone marrow failure patients with stem cell therapies. In addition to helping diagnose, monitor and transplant patients with allogeneic stem cells from various types of donors, I have also helped design and treat Fanconi Anemia-Type A patients with promising but exploratory gene therapies.

I also oversee a basic science research lab that is aimed primarily at understanding how blood-forming stem cells work and how they interact with their environment with a goal to then alter these interactions to improve the function of the blood and immune system. We have been using these findings to try to improve bone marrow transplantation through development of new antibodies and alternative methods that can eliminate chemotherapy and irradiation from transplant protocols. We are further studying how these antibodies work in FA and how they can be combined with gene therapy, as well as exploring alternative gene-modification approaches that potentially could be used in a variety of ways for FA patients.

## What motivates me to work on FA:

I have long been passionate about developing better treatments for FA, as I see this as an unfortunate condition that really should be curable! Ever since I was a medical student and cared for FA patients in Minnesota and India, I set my heart on this goal. First and foremost I aspire to eliminate the use of known DNA-damaging agents

including chemotherapy and irradiation from treatment protocols, but ultimately, I hope to play a role in broadly changing care for FA patients in many ways. Additionally, I am motivated to work on FA as I think there is a lot that we can learn from this illness that we can then use to help in the treatment of many more patients with other diverse conditions from various genetic diseases to cancers to aging.

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

In our clinic or on our inpatient ward taking care of patients! I am also a big advocate of encouraging various broader collaborations, especially with industry, and can often be found in environments where we are brainstorming how to develop better and more innovative therapies. I also LOVE traveling and experiencing how different people enjoy life, so sometimes you can find me globe-trotting and working from afar.

## Anything else you want FA families to know?

No one has a perfect life and while FA is an unfortunate condition, we are very fortunate to have the FA family to help navigate the complexities of this disease! If there is anything I can do to help, I am always available as I truly care. Especially if you have any questions about gene-therapy or reduced conditioning protocols, please let me know. We have upcoming FA trials that I would love to talk about!

# Current **CLINICAL TRIALS** and **RESEARCH OPPORTUNITIES**

New treatments and therapies for people with FA are not possible without research. Listed below are current clinical trials and research opportunities available.

Visit the links listed to learn more about eligibility and protocol descriptions. If you're interested in participating in a clinical trial, scholarships are available from FARF in order to help offset the cost of transportation and housing.

## SOLID TUMORS

### Reducing the burden of squamous cell carcinoma in Fanconi anemia

Cancer treatment options for individuals with FA are limited due to the DNA repair defects associated with the disease. Therefore, there is an urgent need to develop early surveillance and screening modalities to reduce the burden of advanced disease.

This research project will focus on the four following aims:

- 1) Non-invasive oral brush biopsy technology, with combined cytologic evaluation, will be implemented as an early detection screening tool. This program will be available for medical professionals who will perform brush biopsy screening for people with FA.
- 2) Clinical patient data will be incorporated into a digital platform and analyzed to identify potential cancer-promoting risk factors in the FA population.
- 3) Educational programs focused on early surveillance will be developed to empower individuals with FA to manage their own care in adulthood.
- 4) Collaborative molecular research projects will focus on the analysis of clinical biological materials collected from the study to develop an understanding of the natural history of squamous cell cancers in individuals with FA.

Contact: FARF | 541-687-4658 | [suzanne@fanconi.org](mailto:suzanne@fanconi.org)

### Quercetin Chemoprevention for Squamous Cell Carcinoma in Patients with FA

Cincinnati Children's Hospital Medical Center, Cincinnati, OH | currently recruiting participants

In the lab, quercetin, a natural antioxidant, kills tumor cells in FA head and neck squamous cell carcinoma (SCC) cell lines and also prevents development of SCC tumors in non-FA mice. Based on these strong and promising data this study will look at the beneficial effects of oral quercetin treatment for 2 years, in post-transplant patients with FA. It is hoped that treatment with quercetin will result in decreased oxidative stress and ongoing DNA damage of the mucosa, leading to the prevention of, or at least delay the development of squamous cell carcinoma. <https://clinicaltrials.gov/ct2/show/NCT03476330>

Contact: Stephanie Edwards | 513-636-9292 | [StephanieL.Edwards@cchmc.org](mailto:StephanieL.Edwards@cchmc.org)

## BONE MARROW FAILURE

### Eltrombopag for People with Fanconi Anemia

National Heart, Lung, and Blood Institute (NHLBI), Bethesda, MD | currently recruiting

Objective: To find out if a new drug, eltrombopag, is effective in people with Fanconi anemia and to know how long the drug needs to be given to improve blood counts. <https://clinicaltrials.gov/ct2/show/NCT03206086>

Contact: Evette N Barranta | 301-827-4421 | [barrantae@mail.nih.gov](mailto:barrantae@mail.nih.gov)



### **Quercetin in Children with Fanconi Anemia; a Pilot Study** Children's Hospital Medical Center, Cincinnati, OH | currently recruiting participants (pre-transplant)

This is a pilot study aiming to assess feasibility, toxicity and pharmacokinetics of oral quercetin (a dietary supplement) therapy in patients with FA and is a first step towards a clinical study of the efficacy of quercetin therapy in delaying progression of bone marrow failure in FA. <https://clinicaltrials.gov/ct2/show/NCT01720147>

Contact: Stephanie Edwards | 513-636-9292 | [stephanieL.edwards@cchmc.org](mailto:stephanieL.edwards@cchmc.org)

## **NATURAL HISTORY**

### **Cancer in Inherited Bone Marrow Failure Syndromes** National Cancer Institute (NCI), Bethesda, MD | currently recruiting participants

This is a study to provide information regarding cancer rates and types in inherited bone marrow failure syndromes (IBMFS), including Fanconi anemia. It is a natural history study, with questionnaires, clinical evaluations, clinical and research laboratory tests, review of medical records, and cancer surveillance. <https://clinicaltrials.gov/ct2/show/NCT00027274>

Contact: Blanche P. Alter | 240-276-7239 | [alterb@mail.nih.gov](mailto:alterb@mail.nih.gov)

### **Natural History of FANCD1/BRCA2**

National Cancer Institute (NCI), Bethesda, MD | currently recruiting participants

We previously determined that published cases with two mutated FANCD1/BRCA2 genes appeared to have a very high risk of cancer before age 6. We are now aware of individuals with these mutations who are much older and have not had cancer. In order to determine the natural history of patients with FA associated mutations in FANCD1/BRCA2, we have created a subgroup within the **National Cancer Institute study of Cancer in Inherited Bone Marrow Failure Syndromes** (above). <http://www.marrowsfailure.cancer.gov/>

Contact IBMFS Study Team | 1-800-518-8474, or email [NCI.IBMFS@westat.com](mailto:NCI.IBMFS@westat.com)

## **GENE THERAPY**

### **Gene Therapy for Fanconi Anemia, Complementation Group A**

Stanford University, Stanford, United States | Active; currently recruiting participants

The objective of this study is to assess the therapeutic efficacy of hematopoietic cell-based gene therapy for patients with Fanconi anemia, subtype A (FA-A). Hematopoietic stem cells from mobilized peripheral blood of patients with FA-A will be transduced ex vivo (outside the body) with a lentiviral vector carrying the FANCA gene. After transduction, the corrected stem cells will be infused intravenously back to

the patient with the goal of preventing bone marrow failure. <https://www.clinicaltrials.gov/ct2/show/NCT04248439?>

Contact: Elisabeth Merkel | [scgt\\_clinical\\_trials\\_office@lists.stanford.edu](mailto:scgt_clinical_trials_office@lists.stanford.edu)

## **STUDY SPOTLIGHT**

### **NUTRITION**

#### **Nutrition & Metabolism in Fanconi Anemia**

Cincinnati Children's Hospital Medical Center, Cincinnati, OH

This study is actively recruiting and consenting participants with an anticipated start date in late June/early July. Participants must be 12+ years of age and those with diabetes or need for insulin are ineligible for the study. This clinical trial uses tracing experiments to show how efficiently and effectively individuals with FA are able to utilize glucose versus fat and protein for energy. Studies have shown that individuals with FA break down fat and muscle at a quick rate, making it difficult for them to maintain weight or build muscle. Studies have also shown that FA individuals have low levels of Carnitine, known to combat DNA damage. Poorly functioning metabolic systems influence physical appearance, immune function, host defense, and brain energy. Also to be considered are the equally significant impacts on the psychological, social, and emotional wellbeing of individuals with these metabolic challenges. The results obtained from this trial could lead to treatment options that combat body mass index (BMI) issues, including those pertaining to muscle mass, and could positively impact the general psychological and emotional resilience and wellbeing of the FA population.

Lindsey Romick-Rosendale | 513-517-0256 | [Lindsey.Romick-Rosendale@cchmc.org](mailto:Lindsey.Romick-Rosendale@cchmc.org)

## **TRIALS vs. TREATMENT**

It is critical to understand the difference between medical treatments and clinical trials. A medical treatment is a regimen specific to an individual patient and his/her condition, administered by doctors. A trial tests a potential drug, procedure, or medical device in people. Participants in trials play an integral role in determining the safety and efficacy of drugs or procedures. It is important to remember that clinical trials are meant for research, not to administer proven medical care. ■



# Nutrition in FA: an Overview

Many individuals with Fanconi anemia (FA) experience poor growth, proportionately lower weight, and have short stature. Parents of children with FA are often concerned about their child's poor weight gain and "picky eating."

This overview incorporates information shared at the FA Family Meeting in June 2020 to help families understand nutrition issues in children with FA. The full guide – including information about vitamins, supplemental feeding specifics, and a list of resources – can be found at [www.fanconi.org](http://www.fanconi.org) under "Patients and Families" → "Nutrition in FA".

## How is growth affected by FA?

Individuals with FA may be shorter than expected based upon the genetic condition itself, non-FA related genetics, hormonal abnormalities, malnutrition, malabsorption, or growth suppression due to inflammation associated with infection.

Malnutrition, whether the result of poor food intake, high energy utilization, utilization of fat and protein over glucose, or excessive stool loss, initially results in a growth curve demonstrating low weight relative to height or low body mass index (BMI) relative to age.

## What is a "normal" growth curve and what if my child's measurements do not fall within "typical" growth percentile ranges?

- Growth curves allow physicians to monitor a person's growth over time in comparison with other individuals of the same age and gender.
- Dietitians and physicians monitor trends in weight, height, weight/height comparison (BMI) in children with FA.
- Weight and height should be measured at each clinical visit and the child's measurements should be plotted on a graph called a growth curve.
- Typical growth range for a child is between 3<sup>rd</sup> and 97<sup>th</sup> percentile; however, there are conditions and diseases where children will never grow between the 3<sup>rd</sup> and 97<sup>th</sup> percentile.
- Oftentimes, the growth curve of an FA child will mimic a non-FA child's growth curve but remain significantly below the typical growth curve. This may be okay, as long as there is some growth.
- Dietitians who see children with FA look to see that the child

has established their own growth curve. They may not gain weight or height like a non-FA child, but it is important to examine whether they have established their own growth curve regardless of where that growth appears on the growth chart.

## What if my child is a picky eater?

Poor oral intake can result from many factors, including complications of anatomic gastrointestinal abnormalities (narrowing of the digestive tract or complications of repair), chronic inflammation and/or infection, medication side effects, or neurologic/behavioral problems.

Individuals who are "picky eaters" may benefit from behavioral therapies, such as family-based and cognitive-behavioral (CBT) approaches to increase the variety of foods eaten.

Dietary counseling, with or without evaluation by a feeding specialist, may be enough to improve oral intake; however, if food intake does not increase, counseling should be aimed at maximizing calories by the addition of high-calorie foods to diet and liquid or powder supplements (e.g., bananas, avocados, nut butters, hummus, cheese, oil, butter, dairy, dressing, medical-grade calorie additives, etc.).

Aggressively trying to increase the individual's food intake will not increase their height or overall health and may even encourage disordered or unhealthy eating problems.

## Healthy eating information & tips

The gold standard for healthy eating can be found on MyPlate.gov. It replaced the traditional food pyramid and was put out by the United States Department of Agriculture (USDA). These standards dictate that half of a plate of food should contain fruits and vegetables, a quarter of the plate should be protein, a quarter grains, and dairy as a supplement to the meal.

- Eat in-season fruits/vegetables
- Eat natural sugars and avoid processed sugars (e.g., eat dried fruit, fresh fruit)
- Add variety to meals by adding a new vegetable to meals
- Dips, dressings, and dairy can be a great source of extra calories
- Many processed foods contain high amounts of sodium. Choose fresh fruits and vegetables when possible. Try using spices and herbs to add flavor in place of salt.



- Purchase lean meat to stay within saturated fat limits (e.g., chicken, fresh tuna, venison, etc.).

### Supplemental feeding

Supplemental feeding via a feeding tube (enteral supplementation) may be needed to achieve a healthy nutritional status in children with FA who are persistently less than 85% of the expected weight for their height, who have a BMI that is persistently less than the 3<sup>rd</sup> percentile for their age, or who have failed to gain weight over a 3-to-6 month period and when deemed necessary by a physician. Options may include an NG tube and a G-tube.

- An NG tube is inserted into the nose, goes through the esophagus and into the stomach. These feeding tubes are typically meant to be short-term.
- G-tube requires a surgical procedure and is placed into the stomach through the abdominal wall. G-tubes are often used for long-term nutritional needs.

Pros of feeding tubes include helping to meet nutritional needs and mitigating the pressure of mealtimes. In some cases, they may assist with stretching the stomach and can be used if there

are esophageal or swallowing issues. Finally, G-tubes may also be used for medication administration. Cons of feeding tubes include discomfort with placement and the care and maintenance of the tube.

### Remember

The overall nutritional status of individuals with FA can be determined during each routine physical exam by assessing muscle mass, skin and mucus membrane health, and energy and activity levels.

Just like all of us, children with FA have different body types and needs. Your child may grow at a different rate than a non-FA child or even other children with FA; this is not necessarily a negative thing. Remember that physicians and dietitians familiar with treating FA will look at whether a child has established their own growth curve. Evaluation by a pediatric endocrinologist may be needed for children with FA who exhibit poor growth and/or stop growing and do not develop their own curve.

*Special thanks to Cynthia Taggart, RD at Cincinnati Children's Hospital for help putting this overview together. ■*



## Mealtime routine tips

The "Parents provide, kids decide" method:

- Parents serve a variety of healthy foods and children get to choose from those foods offered
- Offer new foods with favorite foods (avoid offering all new foods on the plate)
- When introducing new foods, it can take 12-20x for a child to accept that new food. This is frustrating but keep at it!
- Avoid becoming a short-order cook
- Prepare the same foods for everyone in the family
- Stick to regular meals and snack routines (every 2-4 hours). Allow 20-30 minutes for a meal and 15-20 minutes for a snack.
- Offer water between meals, avoid offering juice or milk between meals/snacks
- Have a dedicated place to eat meals and snacks and attempt to create a pleasant eating environment.
- Limit distractions during meals
- Eat together when possible and model positive eating habits
- Avoid centering conversations around how much or how little your child is eating. Expect your child's appetite to vary from day to day.

It may become a concern if your child shows a decline in eating over a week-long period or isn't eating like they previously did. If this is happening, consult a physician.



## A diagnosis of FA amidst a global pandemic –2020 has been a year we will not forget

By Chris Payne

Without a doubt, 2020 has been one of the most difficult and challenging years our family has faced. With Covid-19 changing the world as we know it, we have faced our own battle with the diagnosis of our four-year son, Elliott, with Fanconi anemia (FA).

What started as a routine blood test led to a life-changing diagnosis. I can still

recall receiving Elliott's DEB test result via email on Sunday, February 9 as we checked our email over breakfast. At the time we had no idea what a DEB test was, let alone what Fanconi anemia was. Due to Elliott's low platelet counts, his doctor told us they would monitor and send off samples for various tests to see if they could figure out what might be causing his low counts.

Unfortunately, due to the way the test result was recorded, we received notification of the positive result for FA before our doctor could call us. This left us searching for answers and doing what we all know we shouldn't do — Googling Fanconi anemia. To our shock, we were led down a path of worry and heartbreak. Since we were home with both of our

young children and the news was simply overwhelming, my wife and I had to take it in turns. We had to be alone to read as much as we could and to cry as we tried to digest the diagnosis.

In hindsight, while I wouldn't wish the way we found out about Elliott's condition on anyone, it gave us time to reflect and be prepared to fight for Elliott. Included in the test results was a link to the Fanconi Anemia Research Fund (FARF) and this gave us the starting point we needed to find valuable resources, connect with experts and rapidly expand our knowledge. I am so grateful that I was immediately able to reach out to FARF and get recommendations on specialists, the latest research and treatment options, and how to connect with other families.

During the first few weeks after Elliott's diagnosis, we threw ourselves into learning as much as possible by contacting doctors around the world for guidance and by researching trials to evaluate what care might be best for Elliott. Having had no previous health concerns or experience reaching out to specialists, I was blown away by everyone's willingness to listen to our concerns and to help in any way they could. In particular, we are so grateful that we were quickly able to connect to Dr. Wagner at the University of Minnesota. Despite my endless list of questions and emails, his willingness to be available and his reassuring voice have been invaluable to us through our journey so far.

One of the hardest parts of FA so far has been the uncertainty. As a planner and someone who is goal-driven, not knowing when Elliott's condition might deteriorate has been tough, and at times left me feeling helpless. To combat this, I have sought to identify different treatment options and trials for Elliott so that when and if the time comes, we have a clear plan of what steps we should take. However, it has also been a learning

experience in dealing with the fluidity of his condition, which has taken on another meaning for most in the context of Covid.

Back in May, Elliott's condition unfortunately deteriorated a lot faster than we or even his doctors had expected, and a bone marrow transplant was likely to be needed within a few months. We are still in the midst of this possibility, but Elliott has been responding well to intervening treatments and we are hopeful that he will continue to respond.

Like most families who are new to FA, after overcoming the initial shock, we are still adapting to this "new normal", but are fully aware that the most challenging days are yet ahead of us. One of these will be when we have to explain to Elliott that he has a life-threatening illness. This day may come sooner than we are ready for, as his medical appointments and questions increase, but for now, we are trying to enjoy the silver lining in this pandemic as we spend more together as a family.

One of the few highlights for us has been sharing our story with friends and family to raise funds for FA Month. These were not easy conversations, but giving others an opportunity to help Elliott by advancing FA research and treatment gave us all something positive to focus on.

There is so much we still need to learn and we are grateful to have met so many families, medical professionals and FARF, who are all striving to support the FA community and provide hope that Elliott and everyone with FA can lead a full and happy life.

While we are still "beginners" when it comes to FA, we did want to share a few tips from our personal experience so far, which will hopefully help new families who are coming to terms with an FA diagnosis:

- Utilize FARF resources early on and set up a time to speak to them for recommendations.
- Reach out to FA specialists for initial consultation calls. I spoke to five specialists in three countries and I was so grateful for their time and advice.
- Review clinical trials and treatment options.
- Don't be afraid to advocate for your child and reach out.
- Keep all of your doctors up-to-date and share test results regularly.
- Trust your doctor – find someone you can connect with and trust. You might not always hear what you want, and a second opinion is always useful, but it is also important to have someone who can give perspective and continuity, and who can develop a comprehensive care plan.
- Connect with other families for support and advice.
- Try to stay positive.
- Enjoy family time – especially with your other children who may feel unintentionally neglected.
- Remember that you are not alone!

I look forward to finally meeting in person at the next Family Meeting!

— Chris, Mel, Elliott and Emmett

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**“...it has also been a learning experience in dealing with the fluidity of his condition, which has taken on another meaning for most in the context of Covid.”**



Assila (second from left) and Omar (center) with their family

the only way to be able to advocate for my son and to make sure that he is getting the best care possible. We are very grateful for all the help we received from this organization. We got connected to many FA specialists around the globe and with FA families, which meant that I got answers to many of my questions. While I was busy researching FA, my little ninja was getting blood transfusions regularly; his bone marrow was shutting down and a transplant was vital.

In 2018, we managed to attend the German Fanconi Family Meeting. It was nice to meet Families and find answers to many of our questions. In Germany, it was confirmed that Omar needed a bone marrow transplant as soon as possible.

My little ninja received his new cells from his donor sister on February 14, 2019, in Oman. We started a new phase of uncertainty and worry over him, and God had other surprises waiting for us which we could never imagine! As Omar reached 259 days after transplant, I was diagnosed with stage 2 triple negative breast cancer. A

# A Ninja from the Desert

By Assila Al Marshoudi

Until September 2017, we were a happy family of six. We lived life to its maximum and had lots of hope for the future. As a believer in God, I knew that life cannot always be as perfect as it looks, and for certain we would have to overcome some emotional hurdles along its journey. Well, our lovely happy little family tripped into a very heavy hurdle that involved the health of our beloved little ninja, Omar.

It started with a high fever, then went to getting checked for leukemia and aplastic anemia. From there forward Omar went

through many tests until one geneticist noticed Omar's abnormal left thumb and connected it to his abnormal kidneys. That led her to the diagnosis of Fanconi anemia (FA). Omar was then four years old.

We were alone in Oman with no other FA families that we knew. I was searching online and discovered the Fanconi Anemia Research Fund (FARF). The information I read about FA gave me horrific nightmares and made me sick for months. Despite my fear and hesitation, I decided to register Omar with FARF. I knew that getting information from the right sources was



“ I was tougher than any chemo and my strength came from a little boy who taught me that FA, cancer, bone marrow transplant, etc., is not the end of the world. ”

mother's worst nightmare had just turned into reality, and then this. We as a family were in total shock to receive such a diagnosis while also battling FA.

We took a deep breath and decided that my treatment would not defeat our fighting souls. We were determined as a family to fight anything that came our way. My treatment started right after my diagnosis. Omar did not know I had cancer, though he did ask about my bald head. I told him mummy needed a new makeover and new lovely hair to grow as beautiful as his had following transplant. Some days we would go together to our treatments, me for my chemo and him for his pentamidine infusions.

What I felt as a mother and a caregiver was stronger than any cancer. I was tougher than any chemo and my strength came from a little boy who taught me that FA, cancer, bone marrow transplant, etc., is not the end of the world. Life continues and we need to make the best out of it.

Omar has grown so much in these past three incredible years! He has grown not only physically but emotionally and mentally. He is now seven years old. He loves playing with ninja turtles and wishes to become a police officer when he grows older. He has so much passion for life and appreciates the simplicity of everything in it. He has shown us how much a little spirit can blossom and how much a child can fight just for the sake of having a normal childhood. From him, we have learned how to become courageous and to be thankful for all the blessings that we have. I learned from Omar how to fight my cancer and how to stay strong through my darkest days. We are blessed with our little FA ninja who is keeping us undefeatable no matter what path God has hidden for us.

Omar now has many Omani FA friends who are fighting next to him at all times. I managed to create an Omani support group and include as much Omani FAmilies as I can. It hasn't been easy but surely worth the effort. We take care of each other and meet during our hospital visits. We now feel that we belong to a safe place where we talk, cry, laugh and cherish all the moments together because we are FAmily. ■

## In Loving Memory

Amanda Dellapenta  
3.4.1985 – 2.24.2020

Joanne Smith  
9.22.1965 – 4.16.2020

Jonas Ripplinger  
4.21.1996 – 4.29.2020

Chelsea Sprague  
10.9.1989 – 5.5.2020

Riley Mack  
5.29.2012 – 5.26.2020

Lucian Valor  
11.1.1987 – 6.16.2020

Amanda Gleason  
10.8.1987 – 6.18.2020

Anna Berglund  
3.17.1994 – 7.5.2020

Cora Aerianna Lyons-Wise  
6.16.2020 – 7.13.2020

Sandra Hubbard-Gonzales  
2.15.2002 – 7.14.2020

Aryan Bhatnagar  
2.12.2006 – 9.8.2020

# Our Journey to Emma

By Keith Loo



The Loo Family: Keith, Jessica, and daughters Alexis and Emma



**A few days after our daughter Alexis was born, my wife Jessica and I got a call from the hospital informing us that based on the newborn test screen results, we needed to be re-admitted for further testing.**

Something was off with our daughter's white blood cell count and they suspected she had SCIDS (aka the "bubble boy/girl" disease). Our pediatrician referred us to a leading immunologist, Dr. Jennifer Puck, and we eventually got our FA diagnosis nine months later.

After making a desperate Facebook post describing my situation and asking for help, I was lucky a former high school classmate referred me to FARF and I got plugged into the family support group on Facebook. As we learned more about Fanconi anemia, we discovered the difference between a related vs. a non-related stem cell donor and how some families successfully had another child via in-vitro fertilization (IVF) to ensure their next child was both free from FA and could be a donor for their FA-affected sibling. Through the FA community, we kept hearing of a fertility doctor named Dr. TurKaspa who is based in Chicago.

We eventually took a leap of faith and traveled to Chicago for a consultation. In our initial meeting we learned that our odds of conceiving a child were about 25%.

However, if we then screened for FA and for a specific match, our odds decreased to less than 5%. As daunting as that sounded, it was still more than 0% and gave us hope of a lower risk transplant down the road. More importantly, it would give us peace of mind that when the time came for a transplant, we would already have what we needed and wouldn't need to worry about finding a donor for Alexis.

I remember feeling excited about our first IVF cycle. We had met families who found success after their first or second cycle despite the <5% odds. However, we would not be so lucky, and the excitement quickly turned into disappointment. Still, we tried again a few months later and went through the same cycle of emotions. Excitement turned into disappointment for a second time. It happened once again for a third cycle, which was soul-crushing. After that third cycle, we had to think long and hard about how many more times we could really go through this. Not only was it emotionally draining, but it was a huge financial burden, without any help from insurance at all. We told ourselves we

would try two more times.

A few months and several self-administered fertility shots later, we found ourselves back in Chicago for a fourth attempt. I recall feeling so lost, desperate, and in such despair. That was a very tough trip. However, a few weeks later we learned that we had finally found our elusive embryo who was both free of FA and was a match for Alexis. It was such a huge weight lifted off our shoulders after a long and arduous road that involved way more lows than highs. Regardless, we got our miracle embryo. As of today, our miracle embryo has now grown to be a two-month-old baby girl named Emma. It is impossible to describe how precious she truly is. It's only by the grace of God that she is with us today.

FA is unique to every individual and every family. There are many dark moments throughout each of our journeys. However, there are bright moments as well, even during some of the darkest times. FA and the FAMily have taught us to truly appreciate and seize each of those bright moments that make time stand still. All we can do is do our best and never lose hope. As hard as that may be, signs of love, positivity, and optimism are all around us if we try hard enough to see them. ■

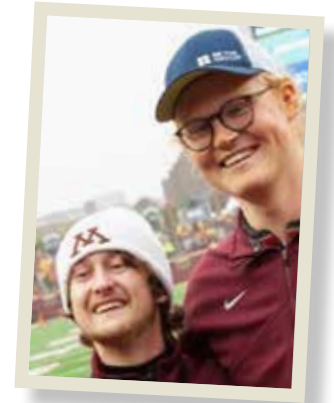


**There are many dark moments throughout each of our journeys. However, there are bright moments as well, even during some of the darkest times.**

# Interview with FA Caregiver Mary Tanner



Mary and son Kyle Tanner



Kyle and bone marrow donor  
Manuel Suilmann

Caregivers are essential to the wellbeing of their loved ones. Often, the focus is on the person with Fanconi anemia (FA), yet caregivers live their own FA journey. In an effort to hear more of these experiences, our friend Allison from [The Negative Space Blog](#), and wife to an adult with FA, interviewed another FA caregiver to learn about her experiences.

**Allison Breininger (AB):** Mary, you care for your son Kyle, who is now 25-years-old. How old was Kyle when he was diagnosed with Fanconi anemia and has he had a bone marrow transplant?

**Mary Tanner (MT):** Kyle was diagnosed at sixteen and had his transplant when he was 22. He and I relocated to Minnesota from Michigan for his transplant.

**AB:** Kyle had a number of major complications during his transplant. What was it like watching this person you love go through such a hard thing?

**MT:** I tried to stay positive on the outside the whole time for Kyle's sake. I would just keep moving forward, hoping it would get better. If there was a minor setback one day, I would tell myself and Kyle that tomorrow would be better. I tried to keep a positive outlook even though things were dreadful. I was calm and cool during it all. I couldn't let myself panic until afterwards.

**AB:** I imagine it was difficult to put on a brave face during that time. What was the hardest thing to stay calm about?

**MT:** Germs. When it comes to germs and Kyle, I am not calm and cool. I am an advocate. This was even before COVID. After transplant we avoided elevators that were crowded. I would scope out a situation before we would go into a crowd. I would even step in between him and a person who coughed or sneezed! It was like I was his bodyguard and I was taking a germ bullet. I would take a bullet for Kyle any day.

**AB:** What's that like for you, being such a super advocate and protector of your son?

**MT:** It's my job. Even before BMT I knew he was sick, but even more so now. As a mom, as a caregiver, it's my job. It's my duty. It's what moms do. I have a Mama Bear shirt. During transplant I wore it a lot. It's like my superhero uniform.

**AB:** When the time came to go home to Michigan after transplant, what emotions did you feel?

**MT:** I was scared of being so far away from the hospital and people who know us, who know FA. When we were living at the Ronald McDonald House in Minneapolis, we were so close to the hospital and clinic. One call and we could be there in five minutes. But at home we live ninety minutes from the university hospital. That made me really nervous. I was also sad to leave behind the staff at the hospital. We got to know them really well and they were so kind and provided so much support. Leaving them behind was hard.

**AB:** What is it like when Kyle has scans or tests or bone marrow biopsies coming up?

**MT:** I try to stay positive until I hear something negative, otherwise the negative consumes me. I want to stay positive as long as I can. He's had a few good biopsies in his mouth, but I know the next one might not be. I stay positive...but I also play out all the scenarios. I can't help it.

**AB:** When you get a good report, how do you feel?

**MT:** Yay! I get to exhale for a little while. Plan something. Not cancel what we have planned. But that only lasts until the next thing comes up or the next lab draw is scheduled.

**AB:** Do you have people in your day-to-day life who understand what it's like to be a caregiver for a person with FA?

**MT:** When he was younger and less sick, I was more involved in my community at home. But now I hesitate to tell new people that I meet about Kyle and FA. It's just such a long story and FA is so complicated. I have actually told people to go to [fanconi.org](#) to learn more about it because it's too much for me to explain sometimes.

**AB:** Is there anything else you want to add?

**MT:** I'm a Mama Bear. Don't get between me and my cub. ■



# MARIA ISABEL RODRÍGUEZ RIBERO

*receives the 2020*

## Amy Winn & Christopher T. Byrd Award for Adults with Fanconi Anemia

Congratulations to Maria Isabel Rodríguez Ribero! Maria is a mother, English teacher, master’s student, and community volunteer who lives in San Gil, Colombia. Now 33 years old, Maria was diagnosed at age 11. As a teenager, Maria remembers not understanding why her parents kept her inside of a bubble and away from the outside world. “I wanted to know about what made me different from my classmates and friends. There was very little information about Fanconi anemia (FA) available in Spanish. The information I did find was in English. So, what did I do? I learned English on my own.”

After taking the initiative to teach herself a new language, Maria discovered a new world of possibilities. By understanding more about FA, she could educate her doctors and get better care. Not only could she advocate for her own health, Maria was also able to connect with other people like her for the first time. She met Chris Byrd and Amy Winn at a Meeting for

Adults with FA organized by the Fanconi Anemia Research Fund (FARF). Maria describes Chris and Amy as “beautiful souls” who helped her feel normal for the first time and who inspired her to make plans and set goals for her life.

This is a life lesson she now embodies in her work as a teacher and leader in the community. “When I was little, I was told I would die young, so I was not motivated to think about my future. I wanted to be a hematologist, but my doctors told me it wouldn’t be safe to work around sick people. So, I changed direction. I got my business administration degree and I became a mother.” She strives to teach her students that a seemingly insurmountable problem may sometimes present the best opportunity to learn. Maria encourages her students to see beyond today’s obstacles and look toward their goals. She is driven by her purpose to be of service to others, to be a better mother and citizen. ■



“ I wanted to know about what made me different from my classmates and friends. There was very little information about Fanconi anemia (FA) available in Spanish. The information I did find was in English. So, what did I do? I learned English on my own. ”



# BE PRESENT FOR YOUR FRIENDS THIS HOLIDAY SEASON

By Allison Breiningner

Originally published at [www.thenegativespace.life](http://www.thenegativespace.life) (2019)

Life can be hard this time of year. While for some, twinkly lights, eggnog, and carols help lighten the mood, for others the holiday season feels like a time when mourning, struggling, or feeling anything less than “jolly” is not an option. This season can feel hard for all of the above reasons and then, in the midst of feeling the very opposite of cheer and goodwill, we are expected to attend more social gatherings than in the rest of the year combined. This year, though we may not be attending events or gatherings in person, virtual events including Zoom parties and social media sharing are more prevalent than ever.

While we are tinsel deep in “all the feels”, we find ourselves attending these virtual or distanced events filled with noise, small talk, inquiries of “How have you been?” and recitations of others’ recent triumphs.

A number of articles have been circulating lately on this very topic at this time of year. A piece I wrote entitled, “Friend, I See You This Thanksgiving” was shared and read exponentially more than anything else I’ve written. This tells me that the world is full of those who feel unseen on a good day, let alone the days when we are expected to gather with friends, relatives, and acquaintances and be nothing short of merry.

For many readers, these pieces have raised their levels of consciousness about what might be going on in the negative space of the people in their lives. By this I mean the things that are not obvious, that

are hidden behind a smile and an “I’m fine,” but that make up an integral part of who they are and how they are feeling. Now more aware, people have reached out to me asking what they should avoid saying or doing and what may be helpful as they host events this season.

## Make a list and check it twice

Let’s start with what you already do. When you are hosting an event – whether it’s a small, socially-distanced one or a virtual one – you likely look at your guest list as you prepare, think about who will be coming, what needs they may have, and what accommodations you can make to support them in having a good time. For the vegetarian, you’ll make sure there are enough non-meat dishes so that she doesn’t go hungry. For the family with a toddler, you’ll move breakable objects out of reach and haul the baby gate out from

the basement. For the aunt living abroad and nine hours ahead, you’ll make sure you host the Zoom party in the morning so she can participate.

This year as you look at the list, think about the needs that may be in your guests’ negative space. Have a quiet space available for your friend who is chronically ill to rest if needed. Have hand sanitizer around to support everyone, especially your friend who is immune compromised. Catch up on your cousin’s posts about his medical condition beforehand so that when he joins the Zoom party, you can start with, “I read your posts. Sounds like things have been really hard. I’m glad to see you,” instead of, “What’s the latest?”

These small gestures will show your friends that you see them, that you are working to meet them where they are, and that you value their presence at this event and in your life.

## **“We could not talk or talk forever, and still find things to not talk about.”**

Whether you're carrying hard things, an introvert, or just not a fan of chit chat, small talk can be painful. Or perhaps the issue for you is that at your family gatherings there are few conversations that end without a room full of tension and you long for a way to be with each other without quite so much talking. An easy way to help people be together with less pressure is to put in your space things like an already started puzzle or coloring books with colored pencils. These simple items give folks something to do with their hands and their eyes, allowing them to be around others without feeling like they have to talk. Both are activities that people can do for a few minutes or for hours at a time, alone or with others, while talking or silent, and at any age or ability level. The lack of eye contact involved often brings people together and, in the end, leads to better conversations because they feel more comfortable. They are also both activities that lower stress levels and induce the same state as meditating, which may be just what a person at a holiday party or family gathering needs.

## **See the whole picture**

Sometimes when we start paying attention to what's in the negative space of the people in our lives, we forget that it is only part of what makes up their whole picture. It's possible that your friend going through chemo doesn't want to spend all evening talking about that. Try a phrase like, "I know you're halfway through your treatments. Do you feel like talking about that tonight or would you rather talk about something else?" This acknowledges that you recognize her hard things and that she may not want to go there on this occasion. Have a friend who's a caregiver? (You do. We're everywhere.) Don't forget to ask her

how SHE is, not just how the person she cares for is doing. Try, "At some point I'd love to hear how your husband is doing, but right now I'd really love to know how you are." Don't let your awareness of that one though very important aspect of their life, create tunnel vision that ignores that they are a multi-faceted human with interests that go far beyond their hard things.

## **Twenty questions**

We often ask the same few questions to everyone we encounter. "How is work?" "Any fun plans for the weekend?" There are many scenarios in which these questions do not apply. Too often I see people avoid asking anything when they realize these won't work. Instead of giving up, get creative! Try questions like, "Are you reading/listening to/watching anything good these days?" Bonus: you will likely have more interesting conversations and learn more about the person by asking questions that are outside the box.

## **Exit stage right**

Even if you set the stage perfectly, there will likely come a time before the end of the event when people have reached their limits. If you see someone attempting to slip out early — let them. A wave is sufficient; even better is an acknowledgement that attending this

event may have been challenging and that you were glad they were there. Avoid coercing them to stay or calling the attention to their departure, making others come say goodbye. If they are slipping out — whether in-person or online — they have likely used up their social capital for the evening. Bless and release.

## **It's not about you**

There will be people who won't come to your event at all. This pandemic is not over and Zoom fatigue is real. Don't badger or lay guilt on them. As Brene Brown says, "What we don't need in the midst of struggle is shame for being human." Others may come but will stay to themselves, practice stricter distancing measures, or hide in the bathroom or start to cry for reasons that won't be obvious to you. Here's what you need to know: it's not about you. It's not about your party. People are carrying around burdens that we cannot see and sometimes those burdens are just too heavy to carry to a social event. Those people are on your guest list for a reason - because you love them, you're related to them, you value their friendship. Let that reason outweigh the importance of the event. Give your people grace and space and love. Realize that not attending your event may be the exact form of "self-care" that you are always telling them they should practice. ■

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**“ For many readers, these pieces have raised their levels of consciousness about what might be going on in the negative space of the people in their lives. By this I mean the things that are not obvious, that are hidden behind a smile and an “I’m fine,” but that make up an integral part of who they are and how they are feeling. ”**

# TOXIC POSITIVITY

## It's okay not to be okay



"In the midst of the pandemic, reminders to stay upbeat are everywhere. Mottos, memes and maxims along with Twitter hashtags and Instagram accounts are devoted to preaching optimism as an approach to manage the epic uncertainty. But for some people, the relentless focus on the bright side can go too far."

This is a quote from an article entitled "It's OK not to be OK" by Kevyn Burger of the Star Tribune in Minnesota. At the Virtual FA Family Meeting, Dr. Megan Voss shared Burger's article and shared how the current cultural pressure to maintain an upbeat and positive outlook in the face of a health crisis is 1) nothing new to FA families; and 2) can actually be detrimental to one's wellbeing. This phenomenon is known as toxic positivity.

### What is toxic positivity?

Toxic positivity is the excess and ineffective overgeneralization of a happy, optimistic state across all situations. This results in denial, minimization, and invalidation of the authentic human emotional experience.

We see manifestations of toxic positivity around us all the time. #Blessed. #Thankful. #Grateful. It's the oversimplified message that it will all be okay if we just put on a smile and get through another day. As individuals who face challenges every day, these messages – even if well-intentioned – are rarely ever helpful.

### How do you know if you are experiencing toxic positivity?

- 1) You feel that you have to hide or mask your true feelings
- 2) You try to just 'get on with it' by dismissing an emotion
- 3) You feel guilty about what you feel
- 4) Your experiences are minimized with 'feel good' quotes or statements

- 5) Perspectives like 'it could be worse' are embraced, instead of validating an emotional experience
- 6) You feel shamed or chastised for expressing frustration or anything other than positivity
- 7) Things that bother you are brushed off with an "it is what it is" type attitude

### What are the consequences of toxic positivity?

#### Shame

When in shame, you feel like you have two choices: to be brave or to pretend everything is great all the time. According to leading shame researcher Brené Brown, shame is defined as the intensely painful feeling or experience of believing that we are flawed and therefore unworthy of love and belonging – something we've experienced, done, or failed to do makes us unworthy of connection. Brown asserts that shame is neither helpful nor productive, and in fact, is much more likely to be the source of destructive, hurtful behavior than the solution or cure. Guilt and shame are often confused, but unlike guilt, which can be reflective and suggests a change in behavior, shame does not result in positive change.

#### Suppressed emotions

Studies have shown that people experience less of the physiological signs of stress in the body when they are allowed to outwardly express their emotions. This can happen through words,

facial expressions, or tears. If you cry or yell or express what feels bad or sad in a situation, you're doing your body good by getting that stress out of the body. On the contrary, if you don't express what you're truly feeling, and you're holding back words or tears, you're housing that stress in your body, which can lead to negative effects on your health.

### Isolation and other relationship problems

If you aren't free to express yourself, to be seen, to be heard, it's impossible to relate to others. Research has shown that isolation is detrimental to health and wellbeing. There is an increased risk of developing coronary heart disease and stroke, dementia, and depression.

So, how can we safely combat isolation, especially now when many of us are in lockdown?

- Find safe ways to connect using technology, barriers, and distance. In areas where it's safe to socially distance outside, connect with people in your community.
- Reach out to your health care team.
- Utilize tele-health. It's come a long way and your healthcare providers are here for you.
- Find meaning and purpose in this time of increased isolation. It doesn't have to be a new hobby or job; it could be spending more time cooking or playing games with your family.

### What can I do for myself and my family?

Dr. Voss' advice for FA families during this time is to:

- Stay safe
- Work with your health care team

- Seek support for not only your physical health, but your mental and emotional wellbeing
- Recalibrate, reassess, refocus. Listening to your body and emotions is the most important part of taking care of yourself.
- Speak up when something doesn't feel right
- Seek support within your communities that "get it". The rest of the world may not be able to understand what it's like to live with FA and now a global pandemic, but other FA families share similar experiences. Reach out in the FA Family Support Group on Facebook (or we can post your concern or question anonymously) or contact FARF Family Services Director Jordan Deines to talk about ways to get connected.

**Remember: positivity needn't be toxic**

Cultivating a positive outlook can boost immunity, decrease stress and even lengthen life spans (Burger). So, how do we embrace positivity but not end up spreading it in a toxic way to others or to ourselves?

- Cultivate real and genuine reasons to feel positive.
- Find the good in the situation. Finding positivity does not have to be this outward expression of joy, like jumping up and down. Everyone has different ways of feeling joy or 'good'. Remember that the labels of good and bad are subjective, so find what feels right for you.
- Cultivate gratitude and have an active gratitude practice. Our brains are hardwired for negativity, and gratitude is the antidote to that. It takes about 3-4 'gratitudes' or good things to combat a negative thought in our brains. You could do this by going around the dinner table each night, writing them down on slips of paper and into a gratitude jar then sharing them later, keeping a gratitude journal, or even just typing it

into the notes tab on your phone. There's no right or wrong way to keep track of your gratitude, but the key is to be consistent in your practice.

- DO NOT deny yourself negative feelings. Cultivating a positive outlook should never involve denying negative feelings. If you're feeling anger, sadness or grief, it's often hard to sit still with those feelings. Sometimes doing something movement-based (exercise, gardening, etc) or creativity-based (art, music, etc.) helps us to express those feelings and allows them to pass.
- Notice any feeling you have and allow it, listen to it, working with it and through it. Part of mindfulness is simply noticing a feeling, without placing judgment (good or bad) on that feeling.

You're not expected to not feel sad, or to just bounce out of an off mood. As Mary Jo Kreitzer, University of Minnesota, Bakken Center for Spirituality & Healing, reminds us: "Someone who is experiencing overwhelming feelings of sadness can't flip a switch or jolly their own way out of it. Toxic positivity refuses to acknowledge their challenges. If we ask others to be

inauthentic, that doesn't build resiliency and relationships."

**Tips on what to say & avoiding toxic positivity**

If you or someone you know is struggling, looking on the bright side may not be helpful. Trying to reason away negative feelings or demanding that you "Snap out of it!" likely won't do any good and may, in fact, be harmful.

Instead, when someone expresses their emotions, listen, then acknowledge and validate their feelings. Instead of assuring them that everything will be OK, say, "I'm here for you, I care for you," and ask how you can support them.

If someone feels overwhelmed, give them space to talk about their experience without judgment. You can say, "That sounds hard for you, tell me more about that." Don't tell them what you would do or feel in their place. Instead, ask them if they just need to vent or want advice.

If the negative feelings deepen or linger, don't play therapist. People with persistent depressive feelings should be encouraged to see a physician and a mental health professional. ■

Validation and Hope	Toxic Positivity
This is hard. You've done hard things before and I believe in you.	You'll get over it!
I know there's a lot that could go wrong. What could go right?	Just be positive!
All vibes are welcome here.	Good vibes only!
It's pretty normal to have some negativity in this situation.	Stop being so negative!
It's probably pretty hard to be positive right now. I'm putting out good energy into the world for you.	Think happy thoughts!
Sometimes giving up is ok. What is your ideal outcome?	Never give up!
It's never fun to feel like that. Is there something we can do today that you'd enjoy?	Just be happy!
It's probably really hard to see any good in this situation. We'll make sense of it.	See the good in everything.

# FAMILY FUNDRAISING WINS



## Team Bravery Doubles Up on Challenges in 2020

Never ones to shy away from a challenge, Team Bravery conquered not one – but two incredible physical feats this year. Comprised of FA parent and FARF board vice-president Orion Marx, his father-in-law, and brother-in-law, Team Bravery started strong in April. They took on the “calendar challenge”: running the number of miles in the day of the week (1 mile on April 1<sup>st</sup>, 2 miles on April 2<sup>nd</sup>, etc.), clocking in a whopping 465 miles during the month! They didn’t stop there, however. In September, Team Bravery traveled to North Dakota to run 144 miles in three days along the Maah Daah Hey trail. In total, Team Bravery has raised over \$146,000 from their incredible feats this year. We are **so** impressed! Thank you, Team Bravery, for constantly taking on new challenges, reaching new milestones, and making our mission possible. We are so appreciative of you!



## Norah Needs You

Last year for FA month, Zach and Rachel Gratz-Lazarus, parents of six-year-old Norah, created their first fundraising page and raised over \$4,000. This year, they took FA Month by storm and quadrupled what they raised last year! After securing their own matching donors, they raised over \$22,000 in May. Wow! Thank you so much, Gratz-Lazarus family!



## Superheroes Run Together, Separately

The 6<sup>th</sup> annual FARF Superhero Run went virtual this year! Hosted by the Robison and Graham-Anderson families of Washington, the Superhero Run was inspired by their three boys, Blake Robison, Isaac and Avery Graham-Anderson, who all bonded over their love of superheroes. This year, despite a new set of challenges 2020 brought, the superhero team pivoted their event online and raised \$9,000! The Superhero Run community proves its dedication and perseverance once again. Thank you, Robison and Graham-Anderson families, for all the hard work you put into this fun and exciting fundraiser.

**#THISHOWIFA**  
FIND ANSWERS. FIGHT ALWAYS. FANCONI ANEMIA.

## FA Month Breaks New Records Despite All Odds

Every May, FA families from around the world come together to share their stories, raise funds for research and support services, and show how they FA. This year, this campaign launched just as shelter-in-place orders became reality, completely changing many fundraising plans. Despite all of the uncertainty and stress around COVID-19, more FA families than ever stepped up to raise funds. This increased participation couldn’t have come at a better time. As other events were canceled, families raising funds online brought in over \$107,000! Thank you to everyone who gave a gift, raised funds, and shared their stories. We are so proud of this community!





### Sheltering in Place to Raise Funds

FA families are no strangers to isolating at home when needed. This year, the COVID-19 pandemic has given the rest of the world a taste of sheltering in place. It also sparked some creativity for many, like the Mitchell family. While in quarantine this summer, Tricia Mitchell, mom to 12-year-old Emily, turned sheltering in place into a fundraising idea. She started Power Up for FA, a campaign centered around playing virtual games. During the month of August, Tricia encouraged others to play games and raised over \$3,000! Thank you, Mitchell family, for your creative quarantine fundraiser!



### The Payne Family Jumps into Fundraising

Just months after their four-year-old son Elliot was diagnosed with FA, Chris and Mel Payne reached out to FARF to fundraise for FA Month. While still processing what this diagnosis means for their son and family, they graciously shared their story with their friends and family. By the end of FA Month the Payne family raised over \$6,000. Thank you, Payne family, for bravely stepping up to raise funds for a better future for Elliott and others with FA!



### Play for FA Golf Tournament

Gerard and Cynthia Vandermeys, FA parents from Virginia, hosted the 2<sup>nd</sup> annual Play for FA Golf Tournament on October 1. The socially-distanced event featured a full day of golf, prizes, delicious food, and raised over \$19,000! Thank you, Gerard and Cynthia, for continuing to raise funds on behalf of Alex, Jacqueline, and all individuals with FA. Your enthusiasm and willingness to take on new fundraising initiatives is inspiring and encouraging to all of us!



### Hoop N' Holler

The Kendall and Taylor Atkinson (KATA) Foundation, based in Denver, Colorado, is one of the top FA fundraising organizations in the United States. Each year, they host a grand, impressive event called the Hoot N' Holler. Due to COVID-19, KATA had to pivot and changed their fundraiser to the Hoop N' Holler. For this event, KATA invited donors to purchase numbered mini cowboy hats that they then dropped from a helicopter. The hats that fell the closest to the center of hula hoops won prizes. Altogether, donors gave more than \$125,000! Thank you, KATA, for all you do to raise funds for research and family support services. It's always creative and always FUN!

From September, 2019 – October, 2020, your contributions allowed FARF to award **\$1,834,176** to the following projects:

## YOUR FA RESEARCH DOLLARS AT WORK

### Correction of Fanconi Anemia Mutations using Digital Genome Engineering

**Investigators:** Branden Moriarity, PhD; Beau Webber, PhD; John Wagner, MD

**Institution:** University of Minnesota

**Issue:** Hematopoietic cell transplants for treating bone marrow failure in people with FA carry risk due to toxic preconditioning regimens.

**Project:** This project aims to apply new gene editing technologies that can efficiently correct FA mutations in hematopoietic stem cells. This preclinical study will inform eventual clinical application for gene editing as a way to cultivate healthy bone marrow in patients.

**Amount Funded:** \$250,000



Branden Moriarity, PhD



Beau Webber, PhD



John Wagner, MD

### Reducing the burden of squamous cell carcinoma in Fanconi anemia

**Investigators:** Eunike Velleuer, MD; Christine Krieg

**Institution:** Heinrich-Heine University

**Issue:** Cancer treatment options for individuals with FA are limited due to the DNA repair defects associated with FA; therefore, there is an urgent need to develop early surveillance and screening modalities to reduce the burden of advanced disease.

**Project:** Researchers will implement non-invasive oral brush biopsy technology as a widespread screening tool to be used in the FA community. Data will be analyzed to identify potential cancer-promoting risk factors, and educational programs focused on early surveillance will be developed for the FA community.

**Amount Funded:** \$732,432



Eunike Velleuer, MD



Christine Krieg

### Pathogenesis, clinical and treatment outcomes, and molecular characteristics of anogenital squamous cell carcinomas in individuals with Fanconi anemia

**Investigators:** Kathryn Pennington, MD; Agata Smogorzewska, PhD; MD

**Institution:** University of Washington, The Rockefeller University

**Issue:** Individuals with FA have an increased risk of developing cancer of the vulva, cervix, vagina, or anus. The best and safest way to treat these cancers is unknown because only a small numbers of cases have been published in the medical literature, often with incomplete information and follow-up.

**Project:** Researchers will identify individuals with FA who have been diagnosed with anogenital cancer and will collect information about their cancers and any treatment outcomes. Available tumor samples will be sequenced to identify changes that promote cancer development and progression. This information will help us understand how to best prevent and treat these cancers.

**Amount Funded:** \$150,589



Kathryn Pennington, MD



Agata Smogorzewska, PhD, MD

### A small molecule approach to overcome replication dysfunction in FA

**Investigators:** Sharon B. Cantor, PhD; Peter Kurre, MD

**Institution:** University of Massachusetts, Children's Hospital of Philadelphia

**Issue:** Bone marrow failure in FA is caused by faulty DNA replication.

**Project:** The goal of this proposal is to identify drugs that can improve DNA replication and, ultimately, hematopoietic stem cell function in FA.

**Amount Funded:** \$250,000



Sharon B. Cantor, PhD



Peter Kurre, MD

### Severe spermatogenic failure as a sentinel for early diagnosis of late-onset Fanconi Anemia

**Investigator:** Csilla Krausz, PhD; MD

**Institution:** Fundacio Puigvert (Spain)

**Issue:** Fanconi anemia can remain undiagnosed into late adulthood. As infertility is one of the issues that people with FA face, researchers wonder if spermatogenic failure (in individuals not otherwise diagnosed with FA) might indicate a need to evaluate patients for FA.

**Project:** The objective of this project is to identify if infertile men have FA, in which case these men can be given the right supervision and surveillance that other adult FA patients have.

**Amount Funded:** \$103,900



Csilla Krausz, PhD, MD

FARF Tank is a competition for young investigators to win a \$10,000 grant for an innovative and creative idea. Winners are selected by a panel of judges and the audience at the Scientific Symposium. These grants do not undergo the traditional grant review process for FARF-funded projects.

### FARF TANK WINNER: Expanding the Fanconi Anemia toolkit: Developing Alpaca nanobodies to detect Ubiquitinated FANCD2

**Investigator:** Sylvie van Twest

**Institution:** St. Vincent's Institute of Medical Research

**Issue:** Ubiquitinated FANCD2, a key marker for a functional FA pathway, is difficult to detect with current diagnostic methods. New technologies are needed to accurately detect this form of the protein for diagnosing FA and for research on the disease.

**Project:** The goal of this project is to develop an antibody that will recognize ubiquitinated FANCD2 using a new approach that will create an antibody a fraction of the size of a typical antibody (nanobody). This nanobody has a higher likelihood of recognizing ubiquitinated FANCD2 and will streamline the FA diagnostic process.

**Amount Funded:** \$10,000



Sylvie van Twest

### The Fanconi Anemia Cancer Translational

**Resource** (note: this is an extension of a grant from 2018)

**Investigator:** Raymond J. Monnat, Jr., MD

**Institution:** University of Washington

**Issue:** Individuals with FA are at exceptionally high risk of developing squamous cell cancers of the head and neck region.

**Project:** This project aims to identify features of these cancers that provide new insight into their origins, and better ways to treat them. Researchers will develop and characterize FA-deficient and control cancer cell lines to test new cancer therapies for FA patients. All cells will be available via a public cell repository to enable FA translational research.

**Amount Funded:** \$77,255



Raymond J. Monnat, Jr., MD

### FARF TANK WINNER: Cincinnati Children's Hospital Medical Center Title: HPV-associated SCC

**Investigator:** Adam Nelson, MBBS, FRACP

**Institution:** Cincinnati Children's Hospital Medical Center

**Issue:** Evidence has shown that the HPV virus may be associated with development of squamous cell carcinoma in the FA population.

**Project:** Viral Specific T cells (VSTs) have been used to treat a number of different viral infections in patients with a poor immune response, including patients with FA post bone marrow transplant. Researchers will isolate mononuclear cells from patients with FA, stimulate the cells to recognize and kill the HPV virus and place the cells back in patients to fight the viral infection and reduce the risk of squamous cell carcinoma (SCC).

**Amount Funded:** \$10,000



Adam Nelson, MBBS, FRACP

### Synthetic Lethal Approaches to Treatment of FA Gene Mutant Head and Neck Cancer

**Investigators:** Barbara Burtness, MD; Gary Kupfer, MD

**Institutions:** Yale University & Georgetown University

**Issue:** Typical treatments for cancer involve conditioning that damages DNA and can therefore be harmful for people with Fanconi anemia, who cannot repair DNA.

**Project:** Researchers are identifying drugs that may be specifically useful in FA and then, testing drugs using patient-derived xenografts (tumors from patients that are grown in mice).

**Amount Funded:** \$250,000



Barbara Burtness, MD



Gary Kupfer, MD

FARF is committed to supporting research to further treatments and a cure for Fanconi anemia. Over our 31-year history, we have funded 248 grants, 163 investigators and 67 Institutions worldwide. The total amount of research dollars awarded is more than \$25,350,000!

# 2020 International Support Grant Recipients

In 2018, the first FA International Summit took place in Newport Beach, California. Out of that meeting, FARF established an international support grant program to bolster efforts of our partners around the world. FA support organizations as well as individuals working to improve the lives of individuals with FA are invited to apply each spring.

In 2019, three projects received the first round of grants: establishing a support group in the Dominican Republic, building an FA support organization in Australia, and developing an umbrella organization in Europe of FA groups. This year, we are excited to announce three new projects to address the needs of individuals with FA in three countries:

## Group: National Research Centre

**Country:** Egypt

**Project:** *Diagnostic support and genetic characterization of subtype in FA patients.* FA patients in Egypt do not have a referral center that is easily accessible. This grant seeks to improve the clinical diagnostic process and offer carrier detection, prenatal and premarital genetic counseling, as well as help characterize FA mutations. The acquired data will improve the quality of genetic counseling and provide information about disease prognosis and future evolving genetic management modalities.

**Amount awarded:** \$10,000

## Group: Asociación Mexicana de Anemia Aplásica (Mexican Association of Aplastic Anemia)

**Country:** Mexico

**Project:** *The first meeting of patients with FA in Mexico.* The aim of this project is to hold the very first meeting for FA patients in Mexico. The opportunity for patients and families to meet in person is the first step to build a vibrant and organized FA community in Mexico. Through sharing personal stories and experiences, common needs and hardships can be identified and addressed. Concurring patient and scientific meetings allow

for experienced clinicians and researchers to be available to answer both common and individual questions and concerns. Additionally, educational sessions tailored to target patients with FA and their families will be held to provide reliable and up-to-date FA information and research participation opportunities. The meeting will take place once it is safe for participants to gather.

**Amount awarded:** \$10,000

## Group: Fundación Anemia de Fanconi (Fanconi Anemia Foundation)

**Country:** Spain

**Project:** *Digital marketing and fundraising strategy.* In order to make a greater contribution to research, The Fanconi Anemia Foundation (FAF) seeks to increase fundraising by engaging partners and donors, and mobilizing affected families as fundraisers. This grant will enable FAF to partner with a digital marketing company that will develop a fundraising and communications strategy and plan. This will allow FAF to continue building a supporter base and increasing income to support research and FA families in Spain.

**Amount awarded:** \$10,000 ■



# HAVE YOU JOINED THE FA REGISTRY? FALL 2020 UPDATE

## WHO HAS JOINED THE REGISTRY SO FAR?



**154**

people with FA  
have signed up for  
the registry



**56**

of these 146  
have filled out  
questionnaires



**21**

countries are  
represented



**50%**

about half of the  
registrants are  
minors, and half  
are adults

## WHAT DOES THIS TELL US?

We're off to a great start! Getting registered is the first step, then entering your data is **vital** to providing the critical information that clinicians and researchers need to truly make a difference.

## HOW TO JOIN THE REGISTRY



Visit  
fanconiregistry.  
iamrare.org  
to create your private  
account



Answer questions about  
your personal info and  
experience with FA.  
Come back to  
complete at any time.



Don't have  
access to all  
of your  
medical  
records?  
We can help.



Fanconi anemia is a rare disease and can be hard to diagnose and treat. Research is the key. And the key to research is you.

If you have been diagnosed with Fanconi anemia, or your child has FA, join the registry today.

JOIN THE FA REGISTRY TODAY: [HTTPS://FANCONIREGISTRY.IAMRARE.ORG](https://fanconiregistry.iamrare.org)

# FAMILY FUNDRAISING LIST

From January through August 2020, FA families have raised more than \$850,000 for the Fanconi Anemia Research Fund! 195 families raised funds with 92 raising at least \$500. Each dollar donated advances research and family support, making a difference for all those affected by FA and their families. Sincere thanks to every family and individual who worked so hard to raise funds in honor or memory of loved ones.

## \$200,000+

The Kendall and Taylor Atkinson Foundation with the Nash and Griggs Families

## \$50,000 – \$199,999

Lynn Frohnmayr  
Orion and Lisa Marx

## \$20,000 - \$49,999

Rachel and Zachary Gratz-Lazarus  
Kevin and Lorraine McQueen  
Gerard and Cynthia Vandermeys

## \$10,000 - \$19,999

Rachael Alaniz and Kevin Gatzlaff  
Mauro and Kerrie Cazzari  
Andre Hessels and Rutger Boerema  
Ian and Tricia Mitchell  
Nigel and Ann Walker

## \$5,000 - \$9,999

Brian and Carly Adel  
James and Jennifer Armentrout  
Ryan and Rebecca Brinkmann  
James and Crystal Eubank  
David and Mary Ann Fiaschetti  
John and Martina Hartmann  
Charles and Kathleen Hull  
Keith and Jessica Loo  
Kristina Mack  
Nancy Nunes  
Peggy Padden  
Chris and Mel Payne  
Rose and David Pennell  
Neil and Emily Robison  
Jessica and Jonathan Young

## \$1,000 - \$4,999

Michael and Jennifer Aggabao  
Glen and Teresa Alessandri  
Brian Anderson and Sultana Graham  
Amanda Barber  
Adam and Marissa Becker  
John and Francene Berglund  
Jennifer Bland  
David and Sarah Borden  
Chris and Jennifer Branov  
David and Kim Chew  
John and Kim Connelly

Ezat and Laila Faizyar  
Brittney Ferrin  
Erin Furr  
Patrick and Maria Gleason  
Alan and Rachel Grossman  
Owen Hall and Margaret Kasting  
Timothy and Mary Ann Lana  
Brian Horrigan and Amy Levine  
Stan and Michelle Kalemba  
Anonymous  
Stephen and Jennifer Klimkiewicz  
Chad and Lauren Kriner  
Robert and Anna Langtry  
Tyler Morrison and Rachel Altmann  
David and Stacy Ownby  
Mark and Diane Pearl  
Peter and Janice Pless  
Craig and Alisha Rushing  
Richard and Marilyn Sablosky  
Andrea and Robert Sacks  
Bryan and Karen Siebenthal  
Bradley and Darlene Starner  
Alejandra Tabar Concha & Elvin Estevez  
Robert and Julie Williams  
Jason and Joan Woodle

## Up to \$999

Peter and Donna Abramov  
Jeff and Susan Amestoy  
Marzban and Daisy Ardeshir  
Andrew Athens and Dr. Vicki Anton-Athens  
Charles Balow and Xandra Towndrow  
Faith Barbe and Shane Estelle  
Mark and Linda Baumiller  
Israel and Mary Jo Becerra  
Jasmine Bennetsen  
Domenico Bertolucci and Federica Bonati  
Tracy Biby  
Rodrigo and Junia Bires  
Randolph and Nancy Bloxom  
Jeffrey and Donna Boggs  
Richard and Tena Boson  
Sean and Allison Breininger  
Preziosa Briga  
Nathalie Britt  
Donald and Danielle Burkin  
Elizabeth and Richard Butts

Robert and Barbara Capone  
Lynn Check  
Mary Eilleen Cleary and Gleaves Whitney  
Andrew Coons and Valeen Gonzales  
Darrel and Kalani DeHaan  
Jeremy and Michelle DellaValle  
Egil Dennerline and Nanna Storm  
Marie Di Mercurio  
James and Carol Dillon  
Cleonice DiSandro  
Delbert and Linda Dotson  
Oscar Duque and Yanira Ramirez  
Chloe Eminger  
Billy Joe and Debra Estep  
Curt and Crystal Fales  
Scott and Windy Farmer  
Daryn and Carol Franzen  
Fabio and Sune Frontani  
Brian and Cindy Fuller  
Emmanuel and Dana Gallegos  
Melody Ganz  
Andrew and Jennifer Gough  
Gary and Heidi Grassi  
Eugenio Grassi and Brittany Miller  
Dr. Michael Greenberg  
Madeline and Patrick Gregg  
Shawn and Doreen Gummoe  
Rachel and Kristian Guttulrsrud  
Eric and Elisabeth Haroldsen  
Robert and Victoria Hathcock  
Patricia and Michael Hilbert  
Mark and Carol Hill  
Judith Hoffman  
Jeff and Beth Janock  
Nancy Jansen  
Mary-Beth and Ben Johnson  
John and Karilyn Kelson  
Dan Klug and Elizabeth Bertrand-Klug  
Christopher and Dana Lamb  
Mayra Lemus  
Peg LeRoux  
Todd and Kristin Levine  
Robert and Darla Lindenmayer  
Tanner and Jessica Lindsay  
Col Gregory & Lt Col Lynnette Lowrimore  
William and Jacquelyn Lucarell  
Kory and Julie MacMurray  
Daniel and Nicole McCarthy

Kevin and Barbara McKee  
Esther, Jamison, Scotty, and Declan McKellar  
Daniel and Angie McMahon  
James and Holly Miranda  
Kelly and Gerald Mlachak  
Kate and Daniel Montgomery  
John and Betty Mozisek  
Des Murnane and Mai Byrne  
Kenny and Lisa Myhan  
Louis and Virginia Napoles  
Lisa and Jack Nash  
Jack and Tammy Neal  
Philip Nelson and Candy Lindsey  
Caroline Nguyen  
Alice Nicholson  
Robert and Mary Nori  
Matthew Padgett  
Seth Parelman  
Michael and Joanna Peros  
Tim and Ashleigh Pinion  
John and Dianne Ploetz  
Lynn and Shirley Quilici  
Pedro and Marina Ravelo  
Mark Ritchie and Lisa Mingo  
Kelsey Robinson  
Kevin and Katherine Rogers  
Les and Nancy Ross  
Sean and Angela Ross  
Jennifer and Brian Sadlowe  
Ty Sanders  
Colleen Satterlee  
Sharon Saunders  
William and Marisela Schaecher  
William and Connie Schenone  
Colleen Scholl  
Sean and Talisa Sebourn  
Thomas and Brenda Seiford  
Jim Siniawski  
Jamie Slappo  
Karin Staab  
Lea Ann and Jeff Stiller  
Sharla and Josh Strickland  
Sharon Swanson  
Janice and Kenneth Sysak  
Esther Thompson  
Bruce and Loreen Timperley  
Mark and Susan Trager  
Lucian Valor  
Michael and Beth Vangel  
Theresa and Louis Viola  
Joseph and Natalie Vitrano  
Emily and Gail Webster  
Jessica and Ezekiel Werden  
Michael and Kimberly Williams  
Troy and Debra Williams  
Alex Winn  
Chad and Dawn Wood  
Kyle and Madison Wright  
Sean and Kristin Young



<https://fundraise.fanconi.org/holidays>

**Sample print letter to send to your friends & family this holiday season:**

Dear friends,

As we reflect on the past year, we are acutely aware that for many, it has been wrought with isolation, fear, global uncertainty, and personal fatigue. While challenging indeed, feelings of unease aren't limited to 2020 for a family with a child[ren] living with a rare disease.

As you know, our son/daughter/child/children \_\_\_\_\_ lives with Fanconi anemia, a rare DNA-repair disease that leads to bone marrow failure, leukemia, and cancer. There's currently no cure, but there is very promising research. That is where your support means so much. The Fanconi Anemia Research Fund (FARF) was started in 1989 to find effective treatments and a cure for FA and to provide education and support services to affected families worldwide. FA research cannot move forward without funding. Great advances in understanding this disease have been made, but more needs to be done to find a cure.

The survival of people with Fanconi anemia is in our hands. You can be part of the breakthrough. When you give to the Fanconi Anemia Research Fund,

- You help FA families navigate the FA diagnosis, connect with other FA families around the world, and feel hope for the future.
- You invest in better outcomes for everyone touched by cancer. By funding FA research, you're helping to unlock the mysteries of DNA repair problems that impact all of us.
- You support research in gene therapy, gene editing, and advances in bone marrow transplants.
- You fund clinical trials to advance therapies for kids and adults with Fanconi anemia.

We humbly ask for your support to find a cure for \_\_\_\_\_ and others with FA. You can send your tax-deductible gift back in this envelope or give online at [www.fanconi.org/donate](http://www.fanconi.org/donate).

Thank you so much for helping us spread hope and love in the community, especially this year. We wish your family a [peaceful/restful/restorative] holiday season!

The \_\_\_\_\_ Family

## Use of Logo

A reminder to our families: 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.

### DONATE WHILE YOU SHOP ON AMAZON

We are all shopping more online these days. When you buy on Amazon, you can designate FARF as your charity of choice, and we will receive a portion of the sales. Visit [smile.amazon.com](http://smile.amazon.com), select Fanconi Anemia Research Fund as your charity, and start shopping. That's it!





360 E. 10th Ave, Suite 201  
Eugene, Oregon 97401

RETURN SERVICE REQUESTED

Our mission is to find effective treatments and a cure for Fanconi anemia and to provide education and support services to affected families worldwide.

# HOW YOU CAN HELP

## Donations Online:

Donate via the Fund's website ([www.fanconi.org](http://www.fanconi.org))

## Donations by Phone:

Call us at 541-687-4658 or toll free at 888-FANCONI (USA only)

## Donations by Mail:

360 E. 10th Ave., Suite 201, Eugene, OR 97401

## Donate While Shopping on Amazon:

[www.smile.amazon.com](http://www.smile.amazon.com). Choose Fanconi Anemia Research Fund.

## Donations of Appreciated Stock:

Please contact our office at 541-687-4658 or email [info@fanconi.org](mailto:info@fanconi.org).

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