

Research Makes an Impact



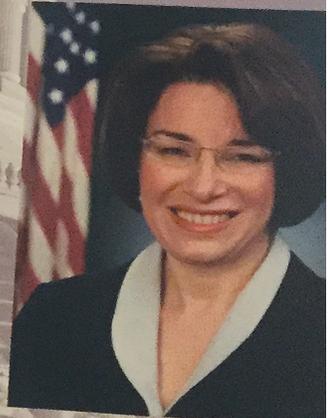
CONGRESSIONAL CAUCUS

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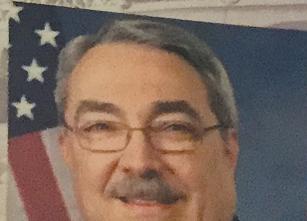
THANK YOU TO OUR CAUCUS CO-CHAIRMEN



Senator
Orrin Hatch (R-UT)



Senator
Amy Klobuchar (D-MN)



Inside This Issue:

UFIRST Scholars • Decoding Labels • The Difference Between Phenotype and Genotype
A Patient Perspective on Research • Itch Remedies • Reflecting on the 2018 National Conference
2020 National Conference • A Scout's Life • Grassroot Events • Members Support FIRST

Letter from the Executive Director

What do you do in your down time? I enjoy reading and watching movies or documentaries. In my neighborhood, the theaters are becoming more comfortable with reclining seats and even food service brought right to you; going to the movies has become an experience. Although I enjoy the movie experience, I find it just as enjoyable to stay home and watch a movie. Recently I watched *Neighborhood*, the story of Mr. Fred Rogers. I was struck by the timelessness of Fred Rogers and the messages he presented on his show. As a young child, I watched *Mr. Rogers' Neighborhood*, so this movie brought back many wonderful memories. The movie encouraged me to reflect on the impact of the many FIRST neighborhoods I am a part of.



In the FIRST neighborhood...

The staff and volunteers who work tirelessly... which was evident during the National Conference last summer. Nashville was the highest attended conference to date, and we are happy to share the highlights with you on pages 14-18. I hope you enjoy the stories from our attendees, and will consider attending the 2020 National Conference in Rhode Island on page 19.

Members of the FIRST Board of Directors have so much passion for the organization, which is evident by the number of volunteer hours they dedicate serving on committees and making sure FIRST is the best it can be. I want to thank board member Larry Silverman for his service to the board: Larry volunteered his time for six years as FIRST CFO. His service is unique because he does not have anyone in his family affected with ichthyosis, but was called to serve FIRST through his friend, and former board member and President, Mike Briggs. Larry has been instrumental in keeping FIRST's mission in all of the work we do. Thank you Larry! I welcome Sean McTernan as FIRST's CFO, as well as our six new board members. Please read more about them on page 3.

Our Medical and Scientific Advisory Board is critical to our neighborhood. Research, medical knowledge, understanding about ichthyosis, and vetting information FIRST delivers to our members is possible because of this group of dedicated physicians. This issue of *Ichthyosis Focus*, MSAB and FIRST board member, Dr. Brittany Craiglow helps us understand the difference between phenotype and genotype on page 10.

And our biggest neighborhood...you, the member. I, and the FIRST staff, work harder because we see the needs you have. We follow many of you on Facebook, and read your posts in the groups. I have met many of you in person, or we have emailed or spoken on the phone. This issue of *Ichthyosis Focus* has many stories from our members, such as Stefanos Koutsoukos, page 12 and his involvement with the NIH, I hope you enjoy reading his story, and others, while learning more about the people in your "neighborhood".

Being FIRST's Executive Director is wonderful, and leading this 38-year-old organization is "easy" because I am not doing it alone. Just like Mr. Fred Rogers, I am in a neighborhood – I thank you for being my neighbor.



Moureen Wenik

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Improve lives and seek cures for those affected with ichthyosis or a related skin type.

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The editor invites your correspondence. We welcome your comments, observations and suggestions. Please send your letters to Ichthyosis Focus at the address listed above.

 **FIRST**
Foundation for Ichthyosis & Related Skin Types®
Educate • Inspire • Connect

Meet the New FIRST Board of Directors



Brittany Craiglow, MD, practices at Dermatology Physicians of Connecticut in Fairfield, CT. Dr. Craiglow serves on FIRST's Medical and Scientific Advisory Board.

Brittany Craiglow



Bailey Pretak resides in Beaver, PA and is affected with ARCI-lamellar ichthyosis.

Bailey Pretak



Latanya Benjamin, MD, practices dermatology in Hollywood, FL. Dr. Benjamin serves on FIRST's Medical and Scientific Advisory Board.

Latanya Benjamin



Jolie Cina resides in West Caldwell, NJ and is a parent to two children affected with ichthyosis en confetti.

Jolie Cina



Brian Stern resides in Lancaster, PA and has a daughter affected with Congenital ARCI-CIE Ichthyosiform Erythroderma.

Brian Stern



Beth Hampshire resides in Fishers, IN and is affected with ARCI-lamellar ichthyosis.

Beth Hampshire

Welcome FIRST's six new Board of Directors. These dedicated individuals have served FIRST in many ways through committee work, fundraising, or as Medical and Scientific Advisory Board members. Their commitment to FIRST is exactly what made them outstanding candidates for the FIRST Board of Directors. Welcome them as they join our current board members, and create a team of volunteers who will dedicate their time and talents to support the mission of FIRST. Read about the 2019 FIRST Board of Directors at www.firstskinfoundation.org/board-of-directors.

Highlights in This Issue

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Decoding the Mystery of Product Labels

Learn how to research the wording and ingredients on your personal and household product labels to make sure they're safe.

By Margaret W. Crane

Even if you're an educated consumer, and even if you routinely shop for products that are all-natural, organic and fragrance-free, a product's claims may not be all they're cracked up to be.

What's more, finding out what's really inside the tubes, bottles and boxes we buy can be surprisingly challenging.

LEARN TO DECODE "LABEL-ESE"

Labels aren't as transparent as we'd like them to be, mainly because the Food and Drug Administration (FDA) wields limited authority over cosmetics and personal care products. The FDA requires ingredients to be listed on package labels, but very few labels list the specific ingredients within general categories, such as "fragrance," "flavor" and "inactive ingredients."

Let's consider "fragrance," a common ingredient that appears on many personal product labels. People often can have an allergy to fragrance, yet it's almost impossible to find out which fragrance-related chemical is the culprit. By listing this seemingly simple category on a label, the manufacturer can mask hundreds of potentially harmful chemicals.

Descriptive language on product labels can also be deceptive. Watch out for questionable terms, such as:

HYPOALLERGENIC – According to the FDA, this term means anything a manufacturer wants it to mean. Consumers may be led to believe that hypoallergenic products will be gentler to their skin than non-hypoallergenic ones, but dermatologists say it has very little meaning.

FRAGRANCE-FREE – A product advertising this claim may legally contain fragrance chemicals as long as they are used for a purpose other than fragrance itself.

UNSCENTED – This one doesn't mean that a product is truly fragrance-free. The term can be listed on products that use fragrance chemicals to mask strong smells. A product may have no discernable scent, but it isn't necessarily free from chemical irritants.

GREEN – There is no set definition or standards for this term. It is frequently used as code for sustainable, environmentally friendly, and possibly manufactured with recycled materials.

ORGANIC – This popular term implies that a product is made from plants grown without chemical fertilizers or pesticides. But unless you see the U.S. Department of Agriculture's "USDA Organic" logo on the product label, the word can be inaccurate or even meaningless. However, small farms and businesses that sell less than \$5,000 in organic products per year don't require USDA certification, and you should always read the label completely.

ALL-NATURAL – This term typically refers to a product that is made of minimally processed ingredients and does not contain artificial ingredients or preservatives. This is not an official label with set standards however, and even a product that contains one or more natural ingredients—aloe or lavender, for example—may contain potentially harmful preservatives or other additives.

Household product labels can be even harder to decode than those on personal products. As with cosmetics and skincare products, the household products we use all the time typically contain dozens of unregulated chemicals.

The Consumer Products Safety Commission regulates labeling for a wide range of household products, including cleaning products, car wax, battery acid and drain openers, among others. All such products are required to list their main ingredients, including those known to be hazardous.

They also need to list instructions on how to use a product, and how not to use it, along with first-aid information. But household product manufacturers suffer no legal or regulatory consequences when they fail to provide a complete list of ingredients.

If all this sounds grim, don't despair. There may be no foolproof way to see "what's in there" in every case, but there's a lot you can do to become label-literate and protect your skin and your health in the process.

HELPFUL RESOURCES AND GUIDELINES

The Environmental Working Group's Skin Deep database is a good place to start exploring the world of cosmetics and personal care products, and the Cosmetic Ingredient Review and Cosmetics Info websites are highly informative as well. Use these resources to look up a product or ingredient and see if it has known toxic effects.

And in the real world, there's a lot you can do to make sure you're buying the gentlest, most skin-friendly personal care products on the market to keep allergic reactions at bay. Just pay attention to the following guidelines:

- Keep it simple! Buy products with fewer ingredients.
- When reading a product label, look for your known triggers, and if you see any of them, cross that product off your list.
- Read and follow the directions on the product's label.
- Avoid trying new products when your skin is irritated or inflamed.

And you can also become a label-savvy consumer when it comes to household products:

- Get to know the National Library of Medicine's Household Products Database, where you can look up products and ingredients to check for toxicity.
- When shopping for "green" cleaners, read product labels carefully to make sure the ingredients are truly environmentally friendly.
- Choose products that advertise themselves as "non-toxic," "biodegradable" and "petroleum-free," and for products that list all their ingredients.
- Beware of catch-all categories such as "inactive ingredients" or "fragrance." Try to find out what's really in there.

FIRST has a Product Listing which includes an extensive list of personal products recommended by members.



Reprinted with permission by the National Eczema Organization; Fall 2018 issue.

UFIRST

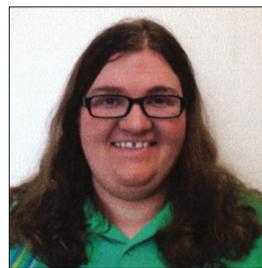
Scholars
 Education Scholarship
 Program

The UFIRST Scholars program is an opportunity for affected students to advance their post-secondary education in partnership with FIRST.

Please visit firstskinfoundation.org/ufirst for more information.

FIRST is proud to announce the 2018 and 2019 recipients from the UFIRST Scholars Program.

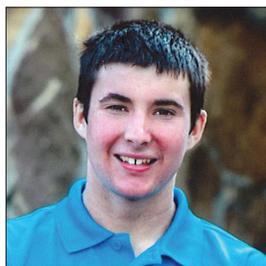
2018



Kayla Murray
 ARCI-CIE

University of North Carolina at Charlotte

Goals & Aspirations: My goal is to obtain my Bachelor's degree in Psychology next spring. I want to become a psychologist. My ultimate end goal is to have a fulfilling career in which I can help others.



Ryan Balog
 ARCI-CIE

LaRoche College

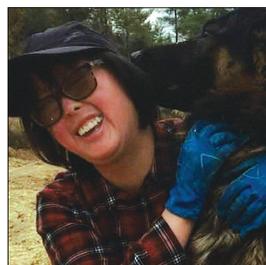
Goals & Aspirations: I want to be able to influence students lives going forward. I want to be a role model for all of my students and encourage them to be the best that they can be. I am excited to become a teacher after I graduate LaRoche College.



Alexis Rodrigues
 Netherton syndrome

University of South Carolina

Goals & Aspirations: I plan to pursue a degree in pharmaceutical sciences and upon graduating, I aspire to work as a retail pharmacist.



Tshering Choden
 ARCI-lamellar ichthyosis

Royal Thimpu College

Goals & Aspirations: To obtain a Bachelor's Degree from the Royal Thimpu College and in the future go into teaching and counseling students.



Caroline Schulze
 Netherton syndrome

Oregon Institute of TEchnology (Klamath Falls)

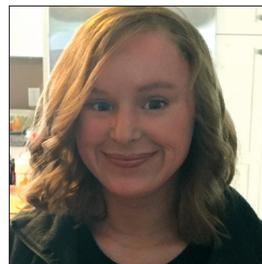
Goals & Aspirations: Become a civil engineer, building roads, bridges, sky scrapers and energy efficient buildings.



Margaret McCoy
 ARCI-CIE

Smith College

Goals & Aspirations: I hope to work in a job where I can help others with their struggles and make their days brighter. I also want to continue my volunteer work with young children.



Tatum Tierney-Osterloth
 ARCI-lamellar ichthyosis

UW Eau Claire

Goals & Aspirations: My goal is to pursue a degree in biology.



Drew Mollan
 PPK

Grand Valley State University

Goals & Aspirations: Obtain my college degree and continue playing baseball.



Alex Yoder
 ichthyosis vulgaris

Indiana Wesleyan University

Goals & Aspirations: I want to get a college degree and teach children in a public school setting. I want to have a part in raising and inspiring the next generation.

2019



Naseer Ahmed

ARCI-lamellar ichthyosis

University of Kotli Azad Jammu

Goals & Aspirations: To help mankind.



Joseph Lozenski

Netherton syndrome

University of Kansas

Goals & Aspirations: My goal is to go into the medical field. As an undergraduate, I will study chemical engineering with an emphasis on biomedical engineering-the field that my research pertains to. Then, I plan on becoming a physician so that I can continue to help others.



Rohit Mittal

X-linked ichthyosis

University of California Berkley

Goals & Aspirations: I hope to do something that is both something I am passionate about and also what the world needs. Currently, I am very passionate about the idea of doing cyber security and helping keep people's personal information safe.



Tshering Choden

ARCI-lamellar ichthyosis

Royal Thimpu College

Goals & Aspirations: To obtain a Bachelor's Degree from the Royal Thimpu College and in the future go into teaching and counseling students.



Caroline Schulze

Netherton syndrome

Oregon Institute of Technology

Goals & Aspirations: To build sustainable infrastructure.



Christina DaSilva

Palmoplantar Keratoderma

Purdue University

Goals & Aspirations: I aspire to obtain my registered dietitian certification and work as a sports dietician for a top professional or collegiate athletic team.

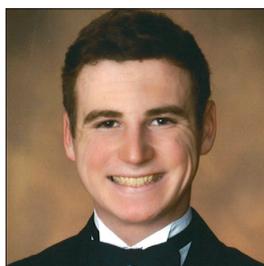


Alex Yoder

ichthyosis vulgaris

Indiana Wesleyan University

Goals & Aspirations: I want to get a college degree and teach children in a public school setting. I want to have a part in raising and inspiring the next generation.



Kyle Dowling

X-linked ichthyosis

New Jersey Institute of Technology

Goals & Aspirations: To bring new and emerging technology into the workplace for improved efficiency with plans to continue my education at the master's level.

Congratulations to everyone and we wish you the best of luck as you continue your education!



Emelia Gregor

ARCI-CIE

University of Redlands

Goals & Aspirations: My goals are to get my BA in Liberal Studies and Spanish and my MA in Education so that I may pursue my goal of becoming a high school Spanish teacher.



Rylee Iott

ARCI-CIE

University of Sioux Falls

Goals & Aspirations: A personal goal of mine that I enjoy working on is to encourage others. I love to help others, especially younger classmates, and then watch them succeed. With that, I want to keep being involved in FIRST and in people's lives with ichthyosis.



My Journey with Tazorac

BY FRANCINE MONDI

I was born with ARCI-lamellar ichthyosis in 1979. I never knew any other way to be. My parents spent a lot of time looking for information on my condition and were always there to help me understand how to care for my skin and to support me. FIRST was just beginning to come into its own but, even then, it was a great source of information. I remember growing up and looking for the newsletter to come in the mail because it always made me feel less alone. Before the Internet, it was the best way to feel connected.

In June 2018, I attended my first FIRST conference. It's perplexing that it took me almost 40 years to attend one since I've always been active in the organization. In fact, in 2012, I earned a fundraising award at the conference even though I was unable to attend. Yet, it wasn't until I adopted my son Casey in 2016 that I decided it was time to attend the conference. Casey is affected by ichthyosis and I thought it was in his best interest to know that he's not alone either. Casey was so excited to go but as it turns out I got more out of it than he did.

I signed up to participate in the Yale study and during our meeting with the doctors, I met Dr. Brittany Craiglow. Dr. Craiglow casually suggested that she had some ideas on

how to help my quality of living. While others were concerned because her office is about three hours from my home, after finding out that I travel 3 1/2 hours for Casey's dermatologist, we decided it was worth at least a meeting.

I came home feeling optimistic. I called and made an appointment. The first available appointment she had was six weeks out. Since I had already waited over 10 years to see a dermatologist what's six more weeks, right? When we finally got together, she discussed the medication Tazorac and what she believed it could do to help my ectropion eyelids. I was hesitant at first, but after listening to her explanation, decided to give it a try. After a few days, I immediately saw a difference. The skin around my eyes was less tight and I could almost close them completely. In addition to the Tazorac, I started taking a low dose of Acitretin as well. We started out low, .05% Tazorac, a few times a week and 25mg of Acitretin once a day. I did have to up my Acitretin to 50 mg for a few weeks in the beginning but now that I'm clear I was able to drop it back down to 25mg to maintain.

I was always hesitant to start drug therapy for my condition. As a teenager, I was given large doses of Accutane which over time caused serious side effects. Seeing the amazing results now, I can't believe I waited so long. Tazorac is a lotion that is very potent and if I use it more than three times a week, I find that the skin near my eyelids is very sore to the touch.

If anyone would like to talk more about Tazorac, Acitretin or what it's like living with and raising a child with ichthyosis, please feel free to email me at francinemondi@gmail.com

FIRST LAUNCHES

Pen Pal PROGRAM

In Fall 2018, FIRST launched its inaugural Pen Pal program! The Pen Pal program is for children ages 8 to 12 to become more connected with other children. We had a great response and currently have 50 families enrolled with more children requesting to participate! The goal of the Pen Pal program is for children to create lifelong friendships.

A Pen Pal kit is available to the children welcoming them to the program. It included pencils, writing paper, stickers, coloring sheets and envelopes to make the mailing process very easy.

Children will learn important life skills such as writing a letter, addressing an envelope, and using the mail system correctly—all while having fun! Writing their own address is important to help children memorize it. Neat handwriting is practiced and children will learn about geography by learning about where their pen pal lives.



If you wish to enroll your child or would like more information, please contact Christine at cwassel@firstskinfoundation.org.

TYLER

Tyler with his first letter from his new friend, Sam in Virginia.



CASEY

We are loving this!!! Here is a pic of Casey writing her first letter to Cate in Georgia. She enjoyed writing it and figuring out what she should tell her in her letter.



DAVID

David got his very first FIRST pen pal letter! Happy son happy mom. Now he wants to write to others Yay. Thanks FIRST for a great idea!!





Dr. Brittany Craiglow Breaks Down **PHENOTYPE AND GENOTYPE**

If you or someone you love is affected by ichthyosis, chances are that you have heard the words ‘genotype’ and ‘phenotype’ used at some point. These are important but confusing terms, particularly when it comes to ichthyosis.

Genotype refers to the gene or set of genes that are responsible for a particular trait, whereas phenotype refers to actual physical characteristics. In some cases, such as eye color, there is a very straightforward relationship between genotype and phenotype – for instance, if you carry 2 copies of the gene for blue eyes (genotype), then your eyes are blue (phenotype). Ichthyosis, however is generally not so cut-and-dry.

In the case of ichthyosis, when we talk about genotype we are referring to the gene that carries the mutation(s) that cause a person’s skin to be scaly, while the phenotype refers to the way the skin looks. There are many different genes that can cause ichthyosis, so there are many possible different genotypes. In some cases, there is one genotype associated with a particular phenotype, while in other cases, there are many genotypes associated with a phenotype. For instance, Netherton syndrome is always caused by mutations in the SPINK5 gene, but autosomal recessive congenital ichthyosis (ARCI, sometimes referred to as ‘lamellar ichthyosis’ or ‘congenital ichthyosiform erythroderma’ depending on the way a person’s

skin looks) can be caused by mutations in a variety of genes, including TGM1, PNPLA1, NIPAL4, CYP4F22, ALOX12B, ALOXE3, ABCA12, and CERS3.

To make things even more confusing, in some cases it is not just the gene, but rather the type of mutation that is associated with a certain phenotype. For instance, severe mutations in ABCA12 (genotype) cause harlequin ichthyosis, which is marked by very thick, armor-like scale in infancy and red, scaly skin in childhood (phenotype), whereas milder mutations in ABCA12 are associated with an ARCI phenotype, in which affected babies do not have the characteristic thick scale at birth but rather may have a collodion membrane or thinner, yellowish white scale. Another example is mutations in the gene TGM1, where most mutations cause ARCI–lamellar ichthyosis, in which all of the skin on the body is scaly, but certain other mutations can cause ‘bathing suit ichthyosis,’ in which scale is mostly limited to the trunk.

These are just a few examples, but as you can see, understanding genotype and phenotype is pretty complicated when it comes to ichthyosis. If you have questions about your or your child’s individual situation, your dermatologist will likely be able to help.

ITCH REMEDY

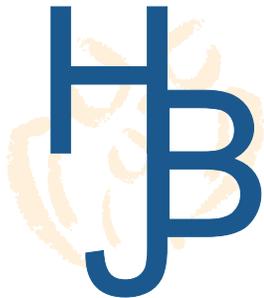
BY DENISE GASS

When my itch gets out of control, I base some of my treatment methods on a natural and holistic approach to physical and mental health known as Ayurvedic ...and I want to share these methods which have helped me. I have CIE and live in a hot humid climate and these treatments calmed my inflammation, got rid of my itch in two days, and even reduced redness.

- 1 Add coconut milk (one to two cans) to a bath. It is antimicrobial! Pour it over your skin for a real treat. It is good in hair too.
- 2 Make a calming skin mask by blending oats into a fine powder and adding honey. Thin with plain Greek yogurt. Spread the mixture all over your body. I let it stay on until it dries, then shower off.
- 3 In place of lotion or cream, try ghee. This is clarified butter—an ancient super oil -- works very well for me in place of Vaseline. Add some essential oil to mask the smell. Ghee is loaded with key vitamins and fats, and absorbs quickly. I use it from face to foot. Massage the body toward the heart (up legs and arms, down from shoulders) for better lymphatic drainage.



I am in love with all three. Give them a shot if you are looking for something soothing and deeply moisturizing. I wish I had these tricks when I lived up north for cold winters!



Jane & Henry Bukaty
Skin Care Fund

Thanks to the generosity of the Bukaty and Shahnaz-Kraybill families FIRST has established two skin care funds to help alleviate some of the financial burden that may be facing our members. This is your opportunity to apply for some financial assistance for ichthyosis treatments. Since the fund is limited, the following criteria must be met by the applicant in order to be eligible for a grant.

The applicant must be registered in our database and is required to submit an application indicating his or her need for funding. The application can be downloaded from FIRST's website and requests the specific product, treatment or device for which funds are needed, and a demonstration of financial need. Diya & Aliya Friends Fund is for anyone 17 years and younger.

Applicants are eligible to receive one award every two years. Applicants receiving funds from the Diya & Aliya Friends Fund, are not eligible to also receive funds from the Jane & Henry Bukaty Skin Care Fund.



Please download the application from www.firstskinfoundation.org/financial-aid and submit to the national office by email to lbreuning@firstskinfoundation.org, fax to 215-997-9403, or mail to the attention of:

FIRST Skin Care Fund
Attn: Lisa Breuning
2616 N. Broad St, Colmar, PA 18915

A Patient's Perspective on Basic and Applied Research in Rare Disease

BY STEFANOS KOUTSOUKOS

In the summer of 2017, I had the opportunity to join the National Human Genome Research Institute at the National Institutes of Health in Bethesda, Maryland, and participate in rare disease research. I joined a group studying two rare inborn errors of metabolism named methylmalonic and propionic acidemia. Both diseases present major challenges to patients and their caregivers. Patients with these inborn errors of metabolism are on highly restricted diets which limit protein intake. The disease, if not managed correctly, can present major complications to patients which can often lead to hospitalization.

Having the opportunity to work in rare disease research has always been an aspiration of mine as a rare disease patient myself. I was born with ichthyosis, like many now reading this article. What type of ichthyosis? Well, I have a currently undiagnosed subtype of the disease, but I'll get into more on that later.

My interest in rare disease research evolved with my education in biochemistry, as I am currently a senior at the University of Maryland, College Park. My exposure to the life sciences has inspired an interest in the underlying biology of my disease and lead me to pursue rare disease research and efforts in rare disease advocacy.

I believe it is important to discuss the definition of a rare disease before continuing my discussion and personal relationship with the topic. A rare disease, also referred to as an orphan disease, is one that affects fewer than 200,000 individuals in the United States. The definition was formalized by the 1983 Orphan Drug Act which incentivized pharmaceutical and biotechnology companies to develop treatments for rare diseases. There are more than 7,000 rare diseases, which affect about 30 million Americans, the subtypes of ichthyosis being included in that group. Rare disease is really not that rare!



So now I'd like to circle back to my ichthyosis diagnosis I mentioned earlier. Back in 2016, as I was gaining interest in studying my own rare disease, I decided to contact Dr. Keith Choate and his team at Yale University. Through FIRST's financial support and resources, Dr. Choate is constructing an ichthyosis registry, working to discover and characterize subtypes of the disease. I received my saliva kit in the mail and sent over my sample for genetic sequencing, an expensive experiment kindly provided at no cost to patients by Dr. Choate and his lab. Six months later, in December, I received a phone call from the registry coordinator and I was excited to learn that my diagnosis was novel in its discovery. My mom, brother, uncle, and maternal grandparents were asked to provide saliva samples to further study the genetic mechanism of my subtype.

Fast forward to June of 2018 and the FIRST National Conference in Nashville, Tennessee. There, I had the opportunity to meet with Dr. Choate and many other world-renowned physicians in the ichthyosis community. They delivered what I considered to be exciting news by letting me know that they had



only ever found my specific mutation in a few other families out of the many in the registry. If that isn't rare, then I don't know what is! I have yet to receive a clinical diagnosis as the Yale lab is still currently working on characterizing their novel discovery. Updates to come!

My involvement at the National Institutes of Health and journey through my own rare disease diagnosis has influenced my perspective on the patient's power in rare disease research. I have come to realize that patients hold the real command in the advancement of the knowledge of their own rare disease. Providing samples including saliva, blood and skin, in addition to clinically relevant quality of life data improves the extensiveness of information from which research scientists have the ability to study and learn. A great resource that I often use to learn more about rare disease clinical trials is the clinicaltrials.gov website. The website, administered by the National Institutes of Health, publishes past and current clinical trials, which are easily searched by keywords related to a disease. Check out the website and search for a clinical trial near you! I urge patients of any and all rare diseases, as both a patient and scientist-in-training, to participate in the betterment of the understanding of the disease that affects your life and your loved ones so closely. Future development of novel treatments and cures depend so heavily on your participation.

I would love to hear your perspective on the topic of rare disease research and any other comments or questions you may have! Please do not hesitate to email me at stefanoskoutosoukos@gmail.com.

Reflecting on the 2018 National



The energy filled the Nashville Airport Marriott last summer as FIRST members gathered to meet one another, or to reconnect! An event of this magnitude doesn't happen without an entire team such as the FIRST staff and a committee of volunteers who worked for 18 months on the planning of the National Conference.

Please join FIRST in recognizing the committee of volunteers: Denise Benedetto, Jolie and Sean Cina, Abby Evans, Diana and James Gilbert, Sarah Hodgkinson, and Sarah and Jonathan Kimmelman. They spent countless hours on conference calls, organizing and planning! FIRST is pleased to welcome Carrie McCullers and Terry Smith as additional conference planning committee members for 2020!

The meeting brought researchers and pharmaceutical industry representatives together to share how their relationship, and patient advocacy groups such as FIRST, play an integral role with clinical trials. A panel including pharma reps and researchers answered attendees' questions, and listened to feedback on how using words such as disease, rather than disorder, can be upsetting for patients.

Our keynote speakers were inspiring and brought different perspectives on living with a rare disorder. Andrea Avery, diagnosed with juvenile rheumatoid arthritis that threatened not just her musical aspirations but her ability to live a normal life, shared her experiences and why she wrote *Sonata, A Memoir of Pain and the Piano*. FIRST was thrilled to have long-time member Bailey Pretak as the other keynote speaker. Her message of choosing to be who she is, completely and unapologetically, ... was inspiring to everyone and was filled with tears, laughs and a few aha moments. FIRST was a perfect platform for Bailey to speak as she commences a motivational speaking career.

Clinical screenings and research are a staple at the conference, with many of FIRST's Medical and Scientific Advisory Board members in attendance to meet with members. The meeting allowed the dedicated group of physicians and researchers the

ial Conference

Nashville, Tennessee



opportunity to meet the members and discuss gaps in care. Often, the National Conference is the first time a person with ichthyosis has been seen by an expert dermatologist; this appointment has a tremendous impact on the affected individual.

A special Friday evening event had attendees boarding trolleys for a tour through Nashville, visiting the top sites, learning about the city's history and hearing the music the city is known for.

General and breakout sessions were led by physicians and members with vast knowledge in many areas. The moms huddled in a room to laugh, cry and support one another during their journey. Dads spent a few hours opening up and discussing how ichthyosis affects them and what this journey means. Grandparents, spouses, affected men, women and teens all had their own groups to share how they manage living with ichthyosis in their lives.

A performance by the Release the Butterfly Tour highlighted a number of FIRST members through song, dance and instrumentation, while many children took part in the traditional talent show. We had clogging, singers, gymnasts and dancers. One special moment was a dad strumming the guitar while his daughter sang. No dry eyes were in the house! The talent show isn't only about the talent, but the unending support from the audience to give the children the confidence to stand up, in front of 500 people, and perform. Bravo to all of the performers!

As the conference came to an end, hugs were exchanged and promises to keep in touch were made. Through FIRST's social media, the pen pal program, as well as a successful mom's retreat and many one-day meetings, those promises can be kept so when 2020 arrives, everyone can pick up where they left off, and welcome new families and individuals into the fold.

Thank you must go to EVERYONE for making the 2018 National Conference a wonderful and memorable event!



BETH HAMPSHIRE

I was ten years old when I went to my first National Conference in Williamsburg, Virginia in 1991. It was the best weekend of my life. I couldn't tell you anything that I learned from that conference other than I was finally seeing people who looked like me for the first time.

I have attended several conferences with my family over the years: Chicago, Philadelphia, Kansas City, Orlando, Indianapolis and, the most recent, Nashville. The conferences have always been a time for me to be with my people, to be free from worry about my skin and, as I get older, to learn about managing my skin and health on my own.

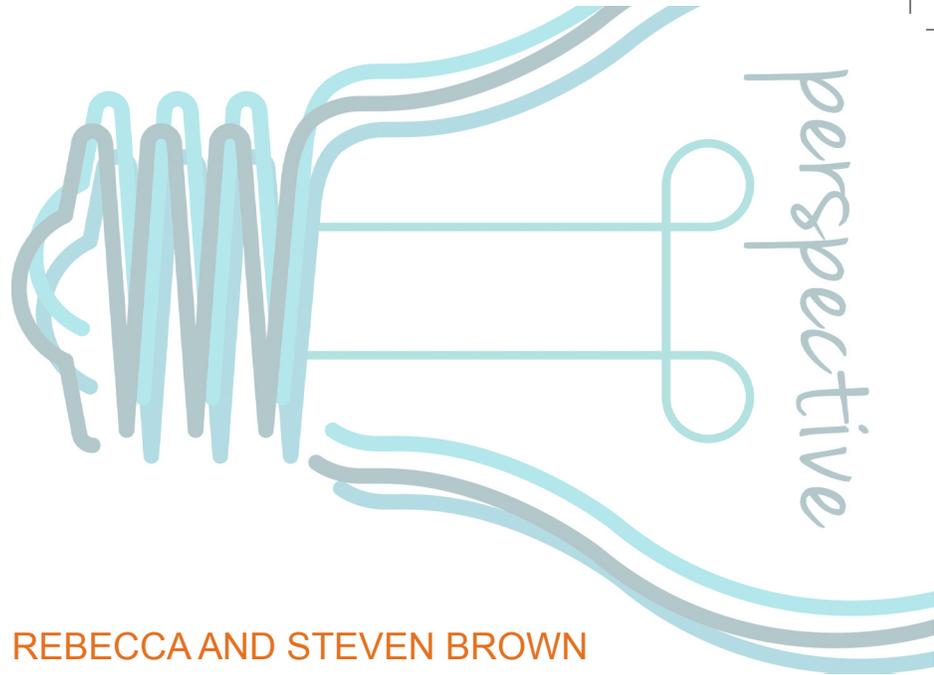
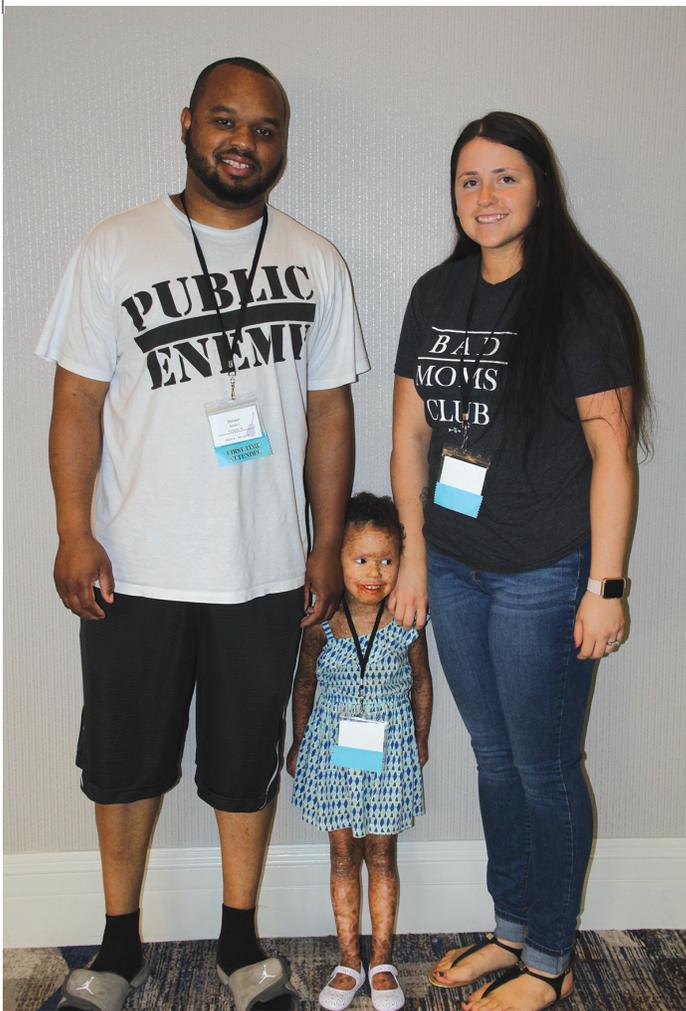
I remember going to Kansas City at age 23 with the attitude that I would wear whatever clothes I wanted and show my skin because no one there would care about the way my skin looked. I went to Orlando with my husband and 18 month old son. I wanted to introduce them to my people and have them experience the joy I have always felt while attending the conferences. The conference in Indianapolis was on my home turf and I was thrilled to have everyone in my city. It was also the first time I felt that I had something to contribute to others attending the conferences.

I ended that weekend exhausted and exhilarated at the same time. I realized that I really enjoyed sharing my experiences with a group of people that wanted to learn about my life, how I managed my skin and my social interactions. I also recognized I had something pretty amazing -- my experiences to offer parents that were scared and worried about their kids the same way my parents must have worried about me. I shared so much that I lost my voice.

I went to Nashville determined to do something that I am not very good at -- initiating new friendships. I wanted to reach out and be open to parents of children that had questions about skin care, growing up, physical activities, social interactions, relationships, "girl stuff", marriage, and having babies. I wanted to give them guidance, reassurance, and a person to listen to them. I left Nashville with new friends, invites to social media pages, cell phone numbers and email addresses. I even kept my voice because I was better prepared. I have been keeping in contact with these new friends and am continuing to provide advice and answer any questions I can.

The evolution of my experience at the FIRST National Conferences has been extraordinary. One of the greatest things that the conference provides is the opportunity to interact with people who are just like me as well as those who are raising people that are just like me. While sometimes it seems that I don't have much more to learn about my ARCI-lamellar ichthyosis, I have come to understand that sharing my knowledge with others is valuable and life changing.





REBECCA AND STEVEN BROWN

Our family attended our first National Conference because we wanted to learn more about our daughter's condition and also for her to see that she is not alone. What we got out of it was SO much more. We built life-long friendships with other families, learned different ways to help our daughter live her best life and also heard about the research going on with the ichthyosis genes right now. Seeing our daughter go from a shy child, always clinging onto mom and dad, to seeing her running around with her new friends so open and carefree was priceless! It was truly a life-changing weekend and our goal is to now attend every National Conference!

YESENIA, MATTHEW AND MIA CHAPPELL

For our family, our first time attending a FIRST conference was eye-opening, encouraging, and life-changing in varied ways. While the ichthyosis community is rare, our specific type (Sjögren-Larsson syndrome or SLS) is an even more rare sub-type. Since it involves other neurological issues related to mobility and cognition/learning, there are concerns and experiences we have that are a bit unique in the world of ichthyosis families. Twice at previous conferences we were able to meet one other family with a child who has SLS, and this kind of connection has meant a lot. Having Dr. Bill Rizzo, a leading world researcher of SLS, at the conferences has been amazing, too. Though we have been only a few patients and their families, he has always offered a dedicated SLS sit-down session each time. He also typically takes time to connect outside of conference sessions and has been a wonderful resource.

At the Nashville conference, three SLS families registered and attended, and this on its own represents a first. Again, Dr. Rizzo spent time in planned sessions and also joined our little group for meals, chatting and Q & A in the lobby, and photo sessions in which we made sure he was included. Being able to meet with the other families at a conference provides the invaluable opportunity to ask each other questions, share information and ideas, and just hold a little tighter to that often-expressed sentiment that "we are not alone."

Along with the families who attended the conference, our Sjögren-Larsson group was informally joined by a few more SLS families who worked a stop in Nashville into their summer travel plans. As we all talked, laughed, and spent time together, we agreed that the FIRST conference was a unique force that brought us together to share and support one another. At the same time, we were able to learn while exchanging our knowledge and experience with others. I have no doubt that from our SLS group, there will be more who attend the conference in the future. All of us are excited about the connections we made as well as those yet to come.

For anyone thinking of attending a FIRST conference for the first time, I will repeat what so many others say. There is so much to gain, so much to learn, so much to appreciate, and so much to enjoy from the experience. There is also so much to give, sharing one's own experience and knowledge, and simply offering strength to others through being together in a welcoming and supportive community. Friends made, knowledge gained and shared, and support given keep us coming back, and we are already looking to next year.

CARRIE AND VANCE MCCULLERS

Have you ever wondered what it would be like to be in the same room with other people and not been seen as different? I know my 10-year-old daughter has, as have many other dealing with ichthyosis. My husband and I learned that the FIRST foundation was holding their biennial national conference in Nashville and asked our daughter if she would like to attend. After a few days, she finally said yes and a mix of emotions came rushing over my husband and I. What were we getting ourselves into? How many kids would actually be there? Would she have a good time or be overwhelmed? What actually happens at these conferences and during the doctor visits? What could we possibly learn that we didn't already know from 10 years of personally dealing with ichthyosis?

From the moment we walked into the lobby of the hotel, some of our fears were washed away. FIRST staff members, as well as a few conference attendees with varying forms of ichthyosis, immediately welcomed us. It was incredible to finally be around others who just "get it." They understand how we feel as moms, dads, affected, unaffected family members and no discussion about "why is your skin different" was had throughout the entire conference. The kids! There were tons of kids! Our daughter felt right at home with them from the word go and was super excited to head to kids camp every morning to play games and hang out with her new friends so that my husband and I could attend lectures and seminars that would best fit our needs. It was the very first time in her life that she wasn't concerned that she was different from everyone else in the room (because she really wasn't!) and the first time that she was open about needing to apply lotion without being embarrassed.

There were so many seminars that we could attend. I wish we had time to attend all of them together but many times we divided and conquered. At a seminar regarding overheating, I was taken aback by one of the doctors. One of the first things the doctor said to the room was, "I am here to learn from you. Tell me what it's like, what you have experienced, what works or what does not work. I can tell you everything I have learned in a book but none of that matters. You guys are the experts." WOW. Never have I ever had a doctor actually WANT to learn from me, let alone learn from a room full of parents, grandparents and friends who deal with ichthyosis in their everyday life. It was during this seminar that I felt a 10-year weight lift off my shoulders. Listening to all of these people dealing with and managing overheating, for their type of ichthyosis, in very similar ways to what I had done for the last 10 years was liberating. Trial and error seemed to be the resounding theme of nearly every seminar or doctor group that we attended. One of the most important seminars, in my opinion, was actually a group meeting for moms (there is also one for dads). We told stories, asked questions, laughed, cried, and could have stayed in that room for days. From what I understand, the dads group had less crying and they also talked sports (naturally).

All weekend we were inundated with information – some new and useful, some we already knew, and some that didn't apply to our daughter but was interesting to learn nonetheless. It was the most incredible weekend and my only regret is that I didn't attend a FIRST conference sooner. I believe that as a family, we came away from this conference not only ready to attend the next but also with a newfound sense of family that we never knew we had.

PHOEVOS HUGHES, MAYNE PHARMA

Full disclosure – I do not have ichthyosis.

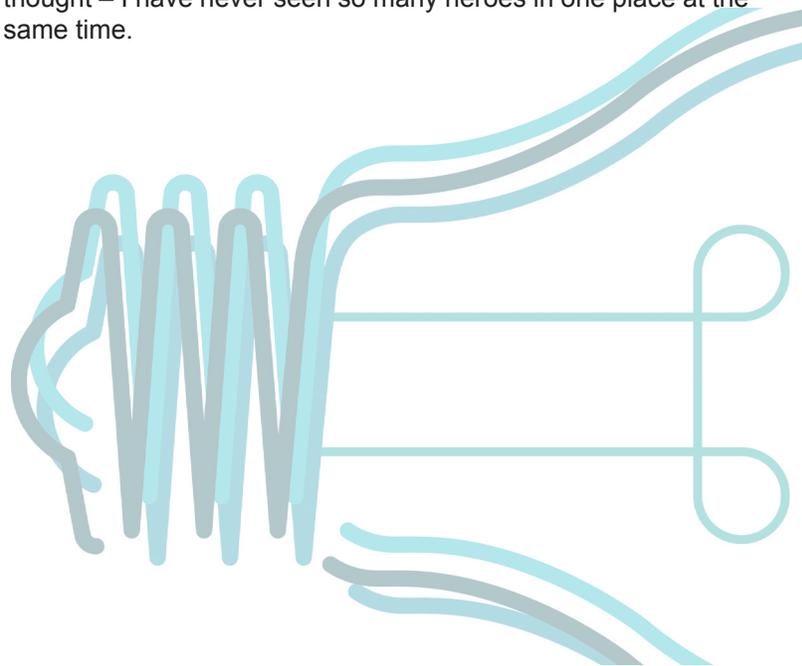
Nor does a family member of mine, and I am not a physician. In fact up until almost a year ago, it was not a condition I was familiar with. My involvement with ichthyosis came as a result of my profession, and as such my relationship with ichthyosis was professional. In June 2018 however, that relationship became personal.

Being new to the world of ichthyosis, I began to educate myself with this condition. Not only to understand ichthyosis itself, but also what it means to live with ichthyosis. As a result, my colleague and I attended the FIRST conference in Nashville last June. Neither of us have been the same since.

If there was one thing I learned from attending this conference, it was love. The love people had for their family members, the love people had for strangers from various parts of the world, the love physicians had for their patients and patients had for their physicians. I could not believe the selflessness and willingness to help that everyone involved displayed. It was truly remarkable and heartwarming.

I am extremely impressed with FIRST, and the platform they have created to help, educate and connect this amazing community. The conference was an incredible experience that left me wanting to participate in any way I could, both professionally and personally. I would like to thank everyone who participated in this conference for allowing me into your world and providing me with a new perspective.

As I left the conference in Nashville I couldn't help but have one thought – I have never seen so many heroes in one place at the same time.





2020 National Conference

FRIDAY, JUNE 26 — SUNDAY, JUNE 28

Crowne Plaza Providence-Warwick Airport • 801 Greenwich Drive • Warwick, Rhode Island 02886

We're headed to the biggest city in the smallest state! Providence is home to many historical sites and features many water activities too! You will meet lots of new friends and families affected with very same rare skin condition, but you will also have the opportunity to meet one-on-one with the world's most renowned medical experts in the field of ichthyosis - all while enjoying the place where history and hipness go hand in hand. The FIRST National Conference has something for everyone. Whether you are an affected adult attending on your own, a relative or friend of someone affected, or a family coping with an affected child, the FIRST National Conference offers plenty of opportunities for education, inspiration, and connection...plus so much more.

REGISTRATION DATES AND RATES:

Rates include all meals*, conference presentations, breakouts, panels, workshops, t-shirts for all attendees, and a generous goody bag full of skincare products. *(Friday night dinner not included in registration.) Hotel reservation is not included in conference registration and must be booked separately. Visit www.firstskinfoundation.org/providence-hotel to book your guest room.

EARLY BIRD REGISTRATION:

OCT 1, 2019 TO DEC 31, 2019

Adult (13+): \$250

Child (4-12): \$140

Pre-K(1-3): \$35

REGISTRATION:

Jan 1, 2020 to Apr 30, 2020

Adult (13+): \$300

Child (4-12): \$150

Pre-K(1-3): \$35

LATE REGISTRATION:

May 1, 2020 to May 31, 2020

Adult (13+): \$350

Child (4-12): \$175

Pre-K(1-3): \$35

Child Care: \$25

(No registrations accepted after June 1, 2020)

Registrations that need to be canceled will be refunded, less a \$25 administrative fee, until June 1, 2020. After June 1, 2020, no registration refunds will be issued.

FINANCIAL AID OPPORTUNITIES:

For more information and application visit www.firstskinfoundation.org/providence-financial-aid.

The deadline to apply for financial aid is February 1, 2020.

Stephanie Turner Conference Scholarship: Applications accepted October 1, 2019 to February 1, 2020

FIRST National Conference Scholarship; Applications accepted October 1, 2019 to February 1, 2020



A Scout's Life

BY JEFFREY "KANGA" GRIDLEY



My name is Jeffrey "Kanga" Gridley. I have ARCI-lamellar ichthyosis and live in Brisbane, Australia. I first became a Scout at the age of 10 and will always be a Scout. This is the story about how being a Scout has helped me deal with the challenges ichthyosis brings, but more importantly, how Scouting has helped me live a happy life.

For many, Scouts is where you go to learn outdoor skills such as how to camp, survive and have great adventures in the great outdoors. Like most 10-year-olds, I was keen and looking for adventure.

My first night of Scouts saw me building a teepee fire and cooking some sausages in a cast iron fry pan. The concept of cooking on a fire certainly hooked me and to this day outdoor cooking is one of the most enjoyable things I do.

My second night was a knotting night, certainly a very Scout thing to do. I was given a tangled mess of a rope and asked to untangle it so I could learn my very first Scout knot. Desperate to get involved without much delay, I started pulling at the rope like a mad man and to my dismay, I made things worse instead of better. My Scout leader came over to me, put his hand on my shoulder and told me that if I want to untangle the rope, I needed to first find an end and then work my way along the rope to untangle it. Soon enough I was all set to learn my first knot.

I really do not remember learning the knot. I assume it was a reef knot which is typically the first knot that Scouts around the world learn. What I do remember is that I learned a great life lesson. I learned that no matter what the problem we face is, you have to start somewhere and starting effectively is the hardest part of solving any problem.

That life lesson was the first of many that Scouting taught me. Scouting may be based around outdoor adventure but it is just the vehicle to teach us how to live an honorable, productive and happy life. Scouting does this by providing Scouts the opportunity to develop their full social, physical, intellectual, emotional, spiritual and character potentials while learning a lot of cool outdoor skills and enjoying our wonderful world.

So how did Scouting help me cope with ichthyosis? Scouting taught me to "Be Prepared"!



So how did Scouting help me cope with ichthyosis? Scouting taught me to "Be Prepared"!

Be prepared to cope with whatever medical issues I have. This means having all the creams, lotions and ointments I need to take care of my skin. It also means being a logistics expert to ensure that I receive the medical care I need from multiple specialists. Being prepared also means learning what I can about my medical challenges and find what treatments work for me.

Be prepared to handle adverse weather conditions. Because my work and play has taken me around the world, I have had to deal with extreme heat and cold, something that many with ichthyosis shy away from. I have done this through physical training to ensure that I am as fit and able as possible, therefore giving my body the best chance. Physical training also provides me with the knowledge about where my physical limits are so I know when to pull back and look after myself. Being prepared also means making plans to deal with hot or cold conditions easier, be that ice vests and access to shade and water, or extra warm clothes.

Be prepared to deal with the stares of being noticed and turn it into an opportunity rather than being offended by it. This is a tough one, and I won't pretend there aren't tough times, but if you develop your self-confidence and understanding of the world we live in, the ability of others to influence your state of mind reduces to almost nil. Looking different is also a fantastic opportunity as everyone notices you so why not use it to your advantage?

Be prepared to help others. This may seem like a strange concept to include when talking about dealing with ichthyosis but the founder of Scouting, Lord Baden Powell, told us in his last message to Scouts that "the real way to get happiness is by giving out happiness to other people." One of the advantages of having more challenges than some is that you develop empathy and understanding for others going through a rough patch. It would be a shame not to use these skills to help others on their journey through life.

Be prepared to live your best life. No matter what challenges we face in life, be it ichthyosis or something significantly worse, have a go at whatever makes you happy. The only thing stopping you is your fears or your unwillingness to adapt and overcome your challenges. Put the effort into life and life will respond in kind.

Being a Scout is a way of life and a true Scout uses the Scouting methodology throughout all aspects of their life. Scouting has blessed me with the opportunity and ability to travel the world, see amazing things, and make lifelong friends. In short, Scouting has helped me live a happy life, a Scout's life!

About the author: I am an active Scout as an adult and I am currently the group leader (manager) of my local Scout group and am active in the community through various organizations such as the Australian Red Cross.

A Mom's Lesson to Her Sons

BY LISA CUMMINS

I have five children -- four are boys; three have epidermolytic ichthyosis (EI). I want to share a little about my boys. My eldest son is 20 years old. He has accomplished two 50-mile hikes for Scouts; he has been to Argentina serving a walking mission for The Church of Jesus Christ of Latter-day Saints. He has had blisters but has never complained to me. Sometimes I did not know how badly until much later.

My 15-year-old son (a sophomore) wants to have something of his own. Despite my trying to protect him, he has joined the rugby team at his local high school. On his first day of tournaments, there were seven players on the field; in spring, the number of players rises to 15. He made some tackles and two field goals. Through practices and games, he has left chunks of skin on the field as pads are not allowed.

My 10-year-old son is just now testing the waters of what he can do and what he wants to do. He is watching his older brothers be independent, brave, persevering and expanding their limits.

As a mother who has ichthyosis, I cringe at what I have seen my boys experience. Call it scrape and blister memory, if you will. I know how it feels. As a young girl, I was involved in dance. Relatively safe.

I have learned to not allow my fears to get in the way. My boys want to become strong men capable of doing anything they set their mind to; most of the time they do not ask my permission. The protective side of me is always nervous about what they are experiencing by choice. "Who in their right mind brushes off being scraped and goes back for more?" Ouch! Maybe I am just a girl/mom and that is a boy thing.

Anyway, it has reinforced my teaching them that they can do hard things and that ichthyosis does not define them.

Being the parent of ichthyosis is a lot harder than being the kid with ichthyosis.



GRASSROOTS EVENTS

FIRST is so appreciative to our many members who host and organize a wide variety of grassroots fundraisers on our behalf. Some are first-time organizers, and others have continued to host events year after year. We truly appreciate ALL of the time and energy dedicated to support the mission of FIRST!

T-shirt Sales Create Awareness Across the Country

Shout out to **Denise Lewis** of Ohio, mom to Brennan who is affected with ARCI-CIE! She sold T-shirts in her community to create awareness and raise funds for FIRST. Her sale of 385 shirts raised more than \$2,400! Brennan's school also held an Ichthyosis Awareness Day celebration in May and all of the students who purchased a shirt wore it, while those who didn't purchase a shirt, wore Brennan's favorite color - green. Such a great idea for celebrating Ichthyosis Awareness Month!

Our sincere appreciation to Denise and her friends and family for their continued support of FIRST.

Chiara Marino, mom to 5-year-old Arianna who is affected with epidermolytic ichthyosis (EI), created T-shirts in three languages and sold them to family and friends to spread awareness in her community! Way to Go!

Jennie Wilklow, mom of Anna, who is affected with harlequin ichthyosis, sold T-shirts geared towards women and girls, featuring a "Rosie the Riveter"-type character. She shared on social media sites and the T-shirts were so popular that Jennie had a second sale. Combined, the sales raised almost \$2,400!





Corvette Club Open Car Show

FIRST members **Mary and Hain Swope**, grandparents of 5-year-old Andrew, who is affected with ARCI-lamellar ichthyosis, belong to the North Jersey Corvette Club. Each year, the club holds a car show and donates part of the proceeds to up to two charities. In September, the club held its 10th Annual Corvette & Open Car Show and, after a request submitted by Mary, designated a portion of the proceeds be directed to FIRST. The show was held on a beautiful day and was a terrific success. FIRST members **Sean and Jolie Cina** and their children, **Portia and Myles**, traveled to Pompton Plains, New Jersey, to support the Swopes and this fun event! The Club will be sending proceeds of more than \$1,000 to FIRST!



Lemonade Stand

Cailyn McCullers, 10 years old and affected with ARCI-lamellar ichthyosis, showed her amazing drive when she held a lemonade stand in her hometown of Lutz, Florida, to raise funds and awareness about ichthyosis last May. As part of her lemonade stand efforts, Cailyn set up a donation page on Facebook. Through her efforts, more than \$1,300 was raised for FIRST. Cailyn presented her donation directly to Moureen Wenik at the FIRST National Conference in Nashville. What a fantastic achievement for this young girl.



Wine Tasting

In June, **Jolie and Sean Cina** and their children, **Portia and Myles**, affected with ichthyosis en confetti, hosted their annual Wine Tasting event. Friends and family members joined them at their home in West Caldwell, New Jersey, to sample wines and to learn more about FIRST and ichthyosis. A highlight of the afternoon was listening to Portia play the piano and sing. This wonderful event was once again a tremendous success, raising almost \$4,000 for FIRST.



Beach Run/Walk

FIRST member, **Greg Licalzi**, affected with ARCI-lamellar ichthyosis, has been the driving force behind the Ace in the Hole Foundation's Annual Beach Run & Walk, which takes place on the second Saturday of May each year, at Lido West Beach on Long Island's South Shore. The event is in honor of Greg's twin brother, 1st Lt Michael LiCalzi who died in Iraq while serving in the United States Marine Corps 2nd Tanks Battalion. Mike died along with 3 platoon mates in 2006. Ace in the Hole Foundation was founded in 2008 to honor Mike's life and sacrifice.



Pictured, L-R Greg Licalzi, FIRST Board of Director Sean McTernan, Claire McTernan, Carolyn Straub McTernan, FIRST Board of Director Denise Benedetto, Matthew, Landon, Liana and Julie Liff.

FIRST is honored to be one of the recipients of the event, and thanks Greg and the Ace in the Hole Foundation for their generosity over the years. Their \$10,000 donation to FIRST allows for continued support to those in the ichthyosis community.

Project Change

Mui Thomas is affected with harlequin ichthyosis and lives in Hong Kong. Mui participated in Project Change, a fitness challenge contest. The contest promotes healthier living. The winner of the contest had a prize awarded to the charity of their choice. FIRST is thankful to Mui for designating our Foundation, raising more than \$200 through her workouts.



Softball Tournament

Michelle and Chad Iott, parents of Rylee, who is affected with ARCI-CIE, held their annual softball tournament in Flandreau, South Dakota. Several teams signed up to play and enjoy a beautiful September day while raising \$550 for FIRST.

Pumpkin Paint & Bake Sale

Nancy Iott, grandmother to Rylee, hosted her annual Pumpkin Paint & Bake Sale at their family-owned greenhouse. This fun fall event raised \$2,400 for FIRST.

Grassroots Fundraising Kits Available!

FIRST now offers grassroots fundraising kits, an assortment of supplies that you can use for your event. If you would like to consider hosting a grassroots fundraiser and would like some ideas, visit the FIRST website. If you have an event planned, please contact Christine Wassel at the national office, cwassel@firstskinfoundation.org or call 215-997-9400, and we will be happy to send you the kit.



Apple Festival

The **Wilklow** family have an apple orchard in Lloyd, New York. Each year they hold an apple festival and designate proceeds to a charitable organization. This year, **Jennie Wilklow**, mom to Anna, who is affected with harlequin ichthyosis, coordinated with family members to choose FIRST. Although it was a bit chilly on the October day of the festival, attendees enjoyed pony rides, face painting, music and much more! Members of the **Cina and McTernan** families traveled to support the Wilklow family with their event and enjoy the day. More than \$2,000 was raised from the event for FIRST's mission.



Release the Butterfly Tour Stops

Hunter Steinitz, affected with harlequin ichthyosis, and her father **Mark** hosted the Release the Butterfly Tour group at the Riverview Presbyterian Church in Pittsburgh, Pennsylvania, during May, in celebration of Ichthyosis Awareness Month. During October, **Julia and Brian Stern**, parents of Bella, who is affected with ARCI-CIE, hosted the tour at the Grandview United Methodist Church in their hometown of Lancaster, Pennsylvania. Bella performed with the group, which gave her the chance to share her talent with her community. This wonderful group of talented musicians always create an uplifting and memorable evening for the audiences. In April, **Betty Ann and Carlie Foulks** organized their second RTB in Greenville, TN. The tour traveled to share their talents, along with Carlie's friends who joined in the fun and performed as well. If you are interested in hosting a Release the Butterfly Tour, contact Chris Wassel at cwassel@firstskinfoundation.org.

FIRST's 2018 Nights at the Ballpark



Washington Nationals

Melissa and Jacob Beard, parents of 5-year-old Blake, who is affected with loric-rine keratoderma, once again hosted a fun evening at the Washington Nationals. The Beards and their friends and family saw the Nationals play the San Francisco Giants. More than \$2,000 was raised during this great evening.

Chicago White Sox

The Chicago White Sox battled the Kansas City Royals and FIRST was there. **Frank Osowski**, father of Ben who is affected with epidermolytic ichthyosis (EI), once again organized an evening at Guaranteed Rate Field to benefit FIRST. FIRST member families, including the **Jeff Lyngaas** and his family and **Laura Hogan** and her family, were part of the more than 250 people joining the Osowski family at the ballpark for friendship, food and fun! Frank's efforts raised more than \$6,600 for FIRST.



New York Mets

Denise Benedetto and **Brooke Saccente** teamed together again to host FIRST Night at the Mets. This annual event brought together almost 300 friends and members of both families for an evening of cheering on the Mets as they played the Chicago Cubs. In addition, families from the FIRST community came out to join the fun. **Julie and Matthew Liff** and **Eric Schweighoffer** brought friends and family for the night out. This year, our group was able to submit a 30-second video about FIRST to be played on the jumbotron. This game was a great night for everyone and raised almost \$10,000 for FIRST!



Los Angeles Dodgers

Roland and Lani Coates once again hosted a great time watching the Los Angeles Dodgers. Many members of the FIRST community were part of the more than 70 people who came out to support Ro and Lani as the Dodgers battled the Arizona Diamondbacks, raising more than \$600 for FIRST.

Facebook EVENTS

The Foundation is truly grateful to our committed community members who are using Facebook to help raise funds to support our mission.

Thank you to these fundraisers:

Enrique Ayala
Michelle Kennedy Baranoski
Alicia Kay Barber
Claudia Barillas
Jacqueline G. Barrett
Roderick Beech
Nihal Bhat
Stephanie Bodden
Kari Bohnow
Wendy Breen
Kimberly Grace Bregger
Silje Breines
Beth Bresnahan
Kaylee Brown
Paige Buade
Mel Bullen
Johnny Burt
Michele Butcher
Sonni Cee
Keith Charsha
Francze Fabiola Clodomir
Kimberly Cole
Alisha Nicole Cook
Dana Schmitt Curren
Jessica Dobzenski
Debbie Johnson East
Daryn Edgemon
Erin Edwards
Marian Egan
Missy Everett
Joe Evola
Erica Marie Farinella
Diane Fasciano
Casandra Ferrer
Steven Flury
Gary Moe
Eliza & Lacie Fredrickson
Kimberly Rose Penney Ghaney
Dennis Golberger, Jr.
Elizabeth Gray
Margaret Anne Gray

Leslie Guaranga
Crystal Rose Harrison
Amanda Hellwig
Elizabeth Hirtzinger
Laura Hogan
Stephanie Morse Hollis
Jennifer Hornsby
Vanessa Ann Hurtado
Valerie Jackson
Ada Jensen Wilson
Kylie Johnson
Leslie Jones
Kisha Jones
Marleen Jones
Ray Jubela
Lisa Kass
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