



EMPOWERING IN ALBUQUERQUE

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A new strategic plan set to guide the priorities of FIRST for the next four years is nearing completion. The key word for this plan is IMPACT. Participants in the process were asked “How can FIRST make more impact in the future?” In other words, “What can FIRST accomplish that will make the biggest difference in the lives of our members and those that care for them?” Answers were varied but some common themes emerged. Those themes were distilled into about 30 priorities, and voting took place to narrow the focus into several key areas that became the roadmap for the near future.



Chris Boynton

Here are the objectives laid out by the newest strategic plan.

Website Upgrade – FIRST’s website is now well over 10 years old, a dinosaur in technology years. Improvements will include the overall appearance of the site, functionality, user experience and content. We have improved site-specific information over recent years and will continue to add resources important to our visitors.

Patient Empowerment – FIRST will provide tools, resources, and educational opportunities to increase confidence and a sense of control over the decisions and actions that affect skin health. This will include mental health and wellness resources, improving communication with your healthcare team, and increasing understanding of health insurance issues.

Access to Experts – The physician referral network will be enhanced to include physicians not already listed and provide training to others to increase their “ichthyosis literacy.” We will also build upon the EDVYCE system of communication between dermatologists, giving those with less familiarity with ichthyosis a direct connection to the experts. We will also encourage more connection with informal experts among our community.

Professional Development – FIRST will work closely with medical schools, continuing medical education providers, dermatology nurses, NICU nurses, medical schools, and other key groups to increase ichthyosis literacy and encourage students to pursue a career in dermatology research.

Accelerating and Approving New Treatments – FIRST will continue its efforts to familiarize the FDA with ichthyosis’ nuances and increase communications with the NIH with the goal of accelerating the path to new treatments and their eventual approval.

Many thanks to those that participated in the survey and prioritization process that helped shape this new plan.



Chris Boynton
CEO

FIRST exists to improve lives and seek cures for those affected with ichthyosis or a related skin type.

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FIRST introduces Captain's Council



Designation recognizes those who name FIRST in their estate plans

Joseph Galluccio's love of boats began when he was 12 years old. His first after-school job was scrubbing tour boats, for which he earned 50 cents per boat. Within a few years, he worked as a mate on charter boats during the summer. In 1957, at the age of 19, he earned his captain's license. "Captain Joe" purchased his first party boat in 1964 and took happy customers on fishing tours and dinner cruises until his retirement in 2002.

Captain Joe, of Jensen Beach, FL, also had ichthyosis. FIRST could count on him for small annual donations. However, when it came time to do his estate planning, he had something much larger in mind.

Captain Joe, who passed away on July 6, 2023, at the age of 85, included FIRST in his will. That simple gesture will be transformative for FIRST. His legacy is a gift of over \$750,000 to help improve lives and seek cures for people living with ichthyosis.

FIRST is grateful and moved. Earlier this year, FIRST established the Captain's Council, named in honor of Captain Joe, to recognize individuals who include FIRST in their estate planning.

A gift to FIRST leaves a legacy of caring for and championing the ichthyosis community. Planned giving can be accomplished in many ways, including through a will, bequest or gift of stock.

Have you included FIRST in your estate plans? Please let us know so we can add your name to the Captain's Council. Email Denise at dgass@firstskinfoundation.org.

Scan here to make a will for free online, at freewill.com:



Captain's Council Featured Member

Jim Griffin
Computer Science Teacher
Santa Cruz, CA
ARCI - Lamellar

What does FIRST mean to you? To me, FIRST is an example of how the interactions of a few individuals – in this case Dr. Mary Williams, Barbara Landwehr, and Mary Householder – can grow from a small support group to a national organization with international influence. With innumerable points of possible failure, the organization was born, grows and continues to thrive. It's a remarkable story that reflects the same determination, perseverance, and resilience that its members demonstrate.

Why is FIRST a part of your legacy planning? My skin condition significantly impacted the direction my life took, as did my education and the inspiration and support I received. With their motto of "Educate, Inspire, Connect," I am honored to contribute and know that FIRST will continue its mission into a more distant future than I will see.

“Legacy, to me, is keeping the inertia of one's own life going in the same direction as when one leaves it.”

- Jim Griffin

Our FIRST trip to the Grand Canyon

Submitted by Matt Kocher

FIRST returned to the Grand Canyon in May, when four members and the CEO of FIRST completed a one-day rim-to-rim challenge to raise ichthyosis awareness and funds for FIRST. The trek covered 18 miles and 5,000 feet of elevation gain.

Together, the hikers raised \$30,000 for FIRST.

Matt Kocher of Pittsburgh, PA, who completed the hike with his affected son Calvin, shares his story.

When my wife Lauren asked me if I wanted to hike the Grand Canyon with my 12-year-old son Calvin, it took less than five seconds to answer “Yes!” Calvin and I both wanted to do something challenging and experience something new. The chance to help FIRST and spread awareness for ichthyosis was the cherry on top.

But was it irresponsible to take our child with ichthyosis into the desert heat to hike the Grand Canyon? This would be an incredible challenge for any child or adult, but Calvin’s skin is dry and cracked – and he is unable to sweat.

Friends warned us not to go. An internet search result listed the South Kaibab to Bright Angel Trail – the route we planned to take – as one of the most challenging hikes in the U.S. The hike covers more than 18 miles with a mile of elevation gain. The National Parks website even recommends against it. Unsettling to say the least.

But Calvin has been showing us he is capable of incredible things since the day he was born with his “special skin” and we vowed never to let his skin be a reason he couldn’t do something. We had to try.

Lauren researched the hike and ordered backpacks, water bottles, inflatable sleeping pads, body glide for chaffing, shorts with zippered pockets, headlamps, electrolyte powders, camping pillows, a packable shade umbrella, and much more.

Once our supplies arrived, we started writing in our newly purchased hiking journals. One of our assignments was to write mantras to help us on our journey. Calvin came up with “smell the cactus,” a play on “smell the roses,” to remind us to take it all in and enjoy the grandeur, and “suck it up, buttercup” to push through the challenges we would encounter. My addition was “W.I.T.,” or “whatever it takes,” knowing that, ultimately, I had to ensure the safe return of myself and my son.

I hoped that the accomplishment of completing the hike would give Calvin the perspective that the normal things in his life like middle school math class were not that hard and that he was capable of anything.

Joining us on the hike were FIRST CEO Chris Boynton, fellow ichthyosis dads Adam Schlitt and Ben Aughenbaugh, and guides Colt and Ryan. The day before the hike, we set up camp and I got my first glimpse of the Grand Canyon. I have no words to describe the view. My human brain could not comprehend the depth, width, or size. The canyon is so massive that you can’t see the bottom from the top. It was incredible!



Director of Development Denise Gass and hikers Adam Schlitt, FIRST CEO Christopher Boynton, Matt Kocher, Calvin Kocher, and Ben Aughenbaugh pose at the Grand Canyon.

After sleeping on the ground, our alarms went off at 4 a.m. I was happy to start early as my biggest concern for Calvin was the heat. We were briefed to drink a mix of water and electrolytes frequently, not to drink too much water as it could create a very serious electrolyte imbalance, snack regularly, and apply sunscreen every hour.

Because Calvin was the only member of our hiking group affected by ichthyosis, he was chosen for the honor of carrying the FIRST flag through the canyon. Up to this point the most Calvin had ever hiked in a day was 11 miles at Cedar Point amusement park with a lemonade and a pulled pork sandwich. Sixteen years ago, I was an elite Division I athlete in peak physical condition. Fast forward 30 pounds, a missing ACL, and a head of grey hair later, and I’m about to descend a mile into the earth. We got this!

I feel bad for those hiking later in the day. The sunrise in the Grand Canyon was a religious experience and the best part of the day. The sun beams piercing through the clouds and the golden hues on the rocks were otherworldly. If you are ever at the Grand Canyon, you owe it to yourself to hike at least to Ooh-Ah Point at sunrise. The hike down was all about taking in the sights. It was dark and cold, but I didn’t care. I was witnessing the most natural beauty I had ever seen.

At the bottom, we crossed the Colorado River and hiked to Phantom Ranch. We wrote some post cards to be carried out by mule mail, made a collect call on a payphone to Lauren, and cooled ourselves with a dip in the Colorado River. Then we were ready to hike the 10 miles back up the canyon. This is where our hike turned from a sightseeing tour to a slow race to the finish.

After a particularly sunny uphill climb, Calvin was feeling the heat, and we were both fatigued. We stopped taking pictures and instead focused on putting one foot in front of the other. Calvin and I were in this together. Ryan dropped back to stay with us and encouraged us every step of the way, letting us move at our own pace.

Calvin said “I was tired. I thought it would never end. Like a never-ending staircase”

As we approached one of the last switchbacks, we spotted Ben making his way back down the trail to lift our spirits! The rest of the group joined us for the last 100 yards as Calvin raised the FIRST flag and trudged towards the crest of the canyon. What a proud moment!

I liked seeing the river for the first time because I knew we were close to Phantom Ranch and a break point. We also saw mules so I was excited to see them up close as we kept going.

- Calvin

Every time Calvin accomplishes something, I feel a flood of emotion. I remember all of the worry we had as first-time parents, magnified by the uncertainty of his skin condition and what his future would hold - it all comes rushing back. Watching Calvin walk the final steps out of the Grand Canyon, embodying all that is possible for a child with ichthyosis, was a powerful moment.

Calvin held my hand as we walked across the parking lot. At breakfast we dreamed about possible next adventures – hiking mountains or whitewater rafting.

By talking about the trip and connecting with people on social media, we were able to spread awareness and raise money for FIRST, an organization that has been a



Matt and Calvin Kocher on the trail

support system for us since Day 1. FIRST has provided us with information, taught us how to care for our child, and connected us with parents and other people with ichthyosis who showed us our child would be able to live an exceptional life.

Thank you, FIRST, and everyone who supported us in this once-in-a-lifetime experience. The amount of love and support we felt was truly humbling. Through all who donated, we were able to raise nearly \$10,000 for research, treatments, and the betterment of life with ichthyosis and other rare skin types. We know the funding will help people like Calvin and bring comfort to families who are entering the ichthyosis community. With the support of FIRST, I feel confident these kids are going to continue to amaze us all. Ichthyosis is a superpower.

**Interested in joining FIRST's
2025 Grand Canyon challenge?
Email Denise at
dgass@firstskinfoundation.org
by Nov. 15.**

FIRST mission on display at National Conference

FIRST was thrilled to welcome more than 300 people to the National Conference in Albuquerque, NM. The weekend, June 28 to 30, was filled with educational sessions, events to promote connections, and opportunities for clinical appointments or to participate in medical research.

Keynote speakers delivered powerful messages of self-advocacy, finding happiness, embracing differences, and the importance of representation. Sessions hosted by medical experts and FIRST members provided forums to discuss skin care, accommodations, and the unique needs of affected individuals by life stage or type of ichthyosis.

The following pages recap some of the conference highlights, including yoga sessions led by and for members, research presented, and awards for grassroots fundraisers and volunteers.

Planning for the 2026 conference is underway. Watch for announcements on the FIRST website, through our e-newsletter, and in future issues of this magazine!



Thank you to our sponsors for supporting activities throughout the conference:



Yoga improves mental, physical, and dermatological health



Mui Thomas, certified yoga instructor from Hong Kong, and Sacha Schenker, certified trauma sensitive yoga therapist from British Columbia, Canada.

Have you ever had a period of intense stress followed by a skin flare up? Rash, itch, sensitivity, and other symptoms can make it feel like your body is betraying you at the worst possible time. If this sounds familiar, then you already know firsthand the mind-skin connection.

Meditation and movement can help ease stress, calm anxiety, and regulate mood. Physically, yoga can improve strength, flexibility, and – important for many people with ichthyosis – joint mobility. These mental and physical benefits reinforce one another. That is, calming the nervous system can help calm the inflammation in the body driving ichthyosis. This means, in short, yoga can be helpful for reducing the intensity and occurrence of skin flare ups.

Regardless of your ichthyosis, age, skill, fitness, time, and budget, yoga can offer you a chance for meditation and movement. Yoga is truly for everyone in the ichthyosis community!

A pair of yoga teachers with ichthyosis have been volunteering their expertise

to make yoga accessible for FIRST members!

Sacha Schenker and Mui Thomas began hosting live virtual classes for the ichthyosis community in 2022. Later, they began recording classes on video for the FIRST website. Then, after much planning, both Sacha and Mui attended the 2024 National Conference in Albuquerque and led attendees in morning yoga sessions. Generous funding by Beiersdorf, the makers of Eucerin and Aquaphor, allowed for every participant to get a free mat and blocks.

Said Mui, “There’s something special about doing yoga with people like you. You can come as you are, and you get proof you’re not alone. Representation is important for building self-acceptance.”



Mui Thomas guides participants through a variety of pose adaptations



Sarah Kimmelman and son Alex practice from chairs



Laura de Shields relaxes into a pose

Classes with these teachers are accessible for all body types and accommodating if you have no prior knowledge of yoga. They encourage participation by people who prefer to be seated or lying down the whole time, and those with mobility concerns. Customizing classes just for you is the passion of these teachers!

Together with FIRST staff, the two teachers are committed to creating even more yoga content for the ichthyosis community! Check the website and FIRST's YouTube channel for updates. Please email Denise at dgass@firstskinfoundation.org if you have questions, suggestions, or want to get involved!

INTERESTED IN YOGA?

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Capturing the conference





Poster session prompts connection, curiosity

Submitted by Stefanos Koutsoukos, predoctoral trainee, University of Colorado Anschutz Medical Campus, Denver, CO

Poster sessions are events that allow researchers to share research conducted in the lab or clinic. As an affected individual with autosomal dominant lamellar ichthyosis and graduate student at the University of Colorado Anschutz Medical Campus, I thought a poster session at the FIRST National Conference would encourage affected individuals to interact with researchers and learn more about studies that could impact their lives.

The research presented during the poster session was diverse and included presentations from academics and industry. Topics presented by researchers from Northwestern University included quality of life, stigma and mental health; current ongoing studies; and skin ceramide and lipid changes. Yale University researchers shared posters on cytokine profiling of ichthyosis with confetti and the reliability of the Ichthyosis Scoring System in skin of color. I brought a poster highlighting my work in the generation of a gene editing strategy for autosomal dominant lamellar ichthyosis.



Stefanos Koutsoukos

Timber Pharmaceuticals shared research on the efficacy, safety, and pharmacokinetics of topical isotretinoin. Boehringer Ingelheim brought three posters overviewing Netherton syndrome treatments and natural history.

I strongly believe that individuals living with ichthyosis and the researchers leading the effort to improve their quality of life should communicate. I am happy that the poster session was able to facilitate that goal. I am looking forward to organizing another poster session at the next conference!

Poster session presenters:

- Stefanos Koutsoukos, University of Colorado
- Angela J. Luo, Yale University
- Mariana McCune, Northwestern University
- Alan Mendelsohn, Timber Pharmaceuticals
- Ryland Mortlock, Yale University
- Mara O'Connor, Northwestern University
- Dr. Amy Paller, Northwestern University
- Angela Yang, Northwestern University
- Lynna Yang, Northwestern University



Abstracts from the National Conference

In a new offering, post-doctoral fellows from Northwestern University presented research posters at the FIRST National Conference. This was an engaging way for attendees to learn more about recent developments and opportunities to participate in research

Here are abstracts from the research shared.

The Impact of Stigma on Children with Ichthyosis

Authors: Yang A¹, Rabbaa L¹, Rangel S¹, Paller AS¹

Child-reported Surveys Have Weak Correlation with Proxy Reports

Authors: Yang L¹, Cheng B¹, Yang E¹, Rangel S¹, Griffith J¹, Lara-Corrales I², O'Haver J³, Rehmus W⁴, Paller AS¹

¹Northwestern University; ²University of Toronto; ³Phoenix Children's Hospital, and ⁴University of British Columbia

A recent survey sheds light on the profound effects of stigma on children and adolescents living with ichthyosis. The research, conducted across 19 sites in the U.S. and Canada with 34 child-parent pairs, revealed that the impact of this condition goes far beyond physical symptoms and significantly affects mental health and quality of life. The findings show that internal stigma (self-perceived) has a stronger correlation with anxiety, depression, poor peer relationships, and reduced quality of life compared to external stigma (experienced through bullying or social exclusion), suggesting that a child's perception of the condition may be more influential on well-being than actual negative experiences with others.

Another crucial finding is the weak to moderate correlation between child-reported and parent-reported experiences of stigma and its effects. This discrepancy highlights the importance of directly engaging with children about their experiences rather than relying solely on parental observations – and that parents should be discussing experiences and feelings with their children with ichthyosis. Overall, these results emphasize the need for comprehensive care that addresses both the physical and psychological aspects of ichthyosis.

If you have not completed the survey from the FIRST conference, please contact lydia.rabbaakhabbaz@northwestern.edu or 312-227-6817 to participate.

The ichthyosis frequency and time burden (IFTB) scale:

A supplemental ichthyosis family quality of life measure

Authors: McCune M, Cheng B, Yang L, Kwon A, Rabbaa L, Ren Z, Paller AS

Northwestern University

Quality of life (QoL) scales often neglect disease time burden, despite its importance. In a recent ichthyosis study, patient assessment of improvement failed to correlate with improved QoL. Time burden was a key difference. The Ichthyosis Frequency and Time Burden tool was developed, a supplement to adult quality of life scales. This survey was adapted for the caregiver (proxy) to report time burden associated with a child with ichthyosis. Initial validation compared results to the Children's Dermatology Life Quality Index (CDLQI), which is commonly used in clinical trials to study skin disorders and is self-reported by the child.

We studied 12 children with congenital ichthyosis, between 6 and 13 years old. Each child had a physician score for severity (Ichthyosis Scoring System/ISS) and a self-assessed severity (SAS). We compared the IFTB-Proxy with the CDLQI scores at two time points - baseline and 7 months after starting biologic medication called ustekinumab. The mean baseline SAS and ISS score measured moderate severity. The mean IFTB-Proxy and CDLQI were also moderate. IFTB-Proxy questions addressing moisturization and skincare burden, clothing choice and lifespan, cleaning scales from bedding, and hot weather had the highest mean scores.

At 7 months, ISS, SAS, and IFTB-Proxy were significantly reduced (by 36.1%, 52.2% and 15.5%, respectively). In contrast, CDLQI was not reduced. IFTB-Proxy (parent-reported) and CDLQI (child-reported) were both moderately correlated with ISS. These data suggest that IFTB-Proxy captures short-term ichthyosis family QoL improvement better than CDLQI and complements CDLQI with time burden data.

Characterizing Joint Pain in Ichthyosis Patients

Authors: O'Connor M¹, Soltani H¹, Echeandia-Francis C², Rustad A¹, Ren Z¹, Choate K², Paller AS¹

¹Northwestern University and ²Yale University

The goal of our study is to better understand the relationship between joint pain and ichthyosis. We asked patients with a variety of ichthyosis subtypes to complete a survey about whether they had joint pain and the features of the joint pain, including the areas of the body that are affected, when the pain began, and how this pain impacts their life. Thus far, 76 adults and 21 parents of children with ichthyosis completed the survey. We found that 77.6% of adults and 47.6% of children experienced joint pain – well above the rate of occurrence in the general population. Of this population, only 26% of adults had seen a rheumatologist, with 36.1% not receiving any sort of treatment for their joint pain. The most common treatment regimen was over-the-counter pain medications, such as ibuprofen.

We also asked patients to score certain qualities of their joint pain. Children with joint pain reported moderate pain intensity. In contrast, adults with joint pain rated their pain and its interference on daily activities as mild, while their physical function remained in the normal range. Our results suggest that joint pain may be a common issue in ichthyosis, although it is unclear what percentage is true arthritis. We are continuing to study the frequency, characteristics, and impact of joint pain in ichthyosis. If you have ichthyosis or have a child with ichthyosis, **please scan the QR code to complete the survey.** You do not need to experience joint pain to participate.



Fundraisers, volunteers honored at National Conference

The awards ceremony at the National Conference celebrates members who have raised funds or donated their time to support the mission. FIRST is pleased to congratulate the following members!



Evan Mayone Award

This award recognizes the top fundraiser under the age of 18. Evan was FIRST's leading young fundraiser in 2020 and 2021, before he passed away in 2022 at age 17. FIRST is proud to name this award in Evan's memory to honor his life, spirit, and commitment to others.

The 2023 recipient was **Brenna Westlake**, who raised \$4,676 with a Facebook birthday fundraiser.

Frances Bernstiel Award

Grassroot fundraisers reflect the very core of what we do at FIRST—come together to make a difference, in any way we can. The Bernstiel Award is presented to the member(s) whose outstanding grassroots fundraising efforts surpassed all others to contribute to the financial strength of FIRST.



The recipients for 2022 were **Michelle and Rylee Iott**, who raised \$3,036 at their annual pumpkin painting event. This is a special event because the Iotts have been running it for 17 years! The pumpkins are grown by the family and baked goods are sold by the family.



There was a tie for 2023 with two recipients. First, **Samantha and Adam Schlitt**, whose first attempt at fundraising was a cornhole tournament. Not only did they meet new folks with ichthyosis, they blew us away raising more than \$15,000!



Also recognized was **Sarah Aughenbaugh**, who climbed 20 miles in our first Grand Canyon challenge and raised \$16,635 from supporters!

As this issue went to press, the Schlitts, whose 4-year-old son Logan has ARCI lamellar ichthyosis, were gearing up to repeat their cornhole event in Livonia, MI. This year, they have teamed up with Jane and James Goff, who have two children, Annie and Theo, with ichthyosis. Together, they are hoping for an even larger outcome.

“We know how important and pivotal FIRST is to people's lives and wanted to give back to the foundation that gave so much to us, especially in the first few months of Logan's life,” Adam Schlitt said.

He said his family was motivated to host the event to drive awareness of ichthyosis in their community. “I want people to hear that word and know exactly what we are talking about,” he said. “We want the community to get to know Logan, along with the other individuals who attended with ichthyosis, and see that these are people who live happy and healthy lives.”

Volunteer of the Year

This award is presented to the member who has made the most compelling contribution to FIRST. As a rare disease organization, we rely on our volunteer Board of Directors, Medical & Scientific Advisory Board, and our members at large to answer the call day in and day out.



The recipient for 2022 was **Laura Hogan**. Laura is steadfast and loving, the sort of person who treats anyone in the room like they are immediately family. She's a volunteer willing to go the extra mile. Laura has helped arrange the Chicago Ichthyosis Picnic with Dr. Amy Paller, has volunteered at several conferences, and spends time every year presenting her patient experience to medical students.



The 2023 recipient was **Kim Cole**. Kim served on the FIRST's Board of Directors for several years, where she offered priceless guidance on several projects. After her time on the board, Kim has stayed on in a different capacity – as editor of everyone's favorite print magazine, Ichthyosis Focus. Kim is a master of details, layout and grammar but has also helped steer FIRST strategy and long-term planning. We are so grateful for her time, expertise and contributions!

Winter tips: A few essentials

Winter can be particularly challenging for individuals living with ichthyosis. The cold, dry air can exacerbate symptoms like dryness, scaling, and discomfort. However, with the right care and a few practical strategies, you can protect your skin and maintain comfort throughout the season. In this guide, we'll share some helpful tips on managing your skin during the winter months, so you can feel your best even in the coldest weather.

- **Everyone experiences weather differently.** Some with ichthyosis have expressed that winter can leave their skin feeling extra dry, with the potential for fissures and additional irritation. Some may switch their daily skin care routine to thicker, more emollient creams. And some even use aids to help the lotion soak in, such as wearing gloves after applying lotion to their hands. Everyone has their own preference. To learn more about options that work for others, visit the FIRST social media pages and website. Interested in trying something new? Consider applying for FIRST-Aid, financial support to assist with the cost of skin care needs. Learn more at <https://www.firstskinfoundation.org/first-aid>.
- **Hydration is key.** During the winter, staying hydrated is especially important for people with ichthyosis, as the cold, dry air can worsen skin dryness and scaling. Adequate hydration helps maintain skin moisture from the inside out, making your skin more resilient against the harsh winter elements. Using a humidifier in your home can also add moisture to the air, further supporting

your skin's hydration and helping reduce discomfort throughout the season.

- **Dress in layers.** Many people with ichthyosis have difficulty tolerating the heat. Likewise, some have mentioned having similar challenges staying warm in cold temperatures. Dressing in layers may help to cope with these conditions.
- **Advocate for yourself in every season.** Your voice is a powerful tool. Advocating for your needs in uncomfortable temperatures is important no matter the season. Overactive heating systems or brutally cold outdoor temperatures can present challenges in the winter. Prioritize your well-being by speaking up and ensuring you have the environment and support necessary to stay safe and comfortable.

When speaking up for your needs you may find it helpful to take a deep breath and ground yourself. A good mantra to keep you grounded could be something like: "My well-being is worth speaking up for, and I deserve to be heard" or "I am a great advocate, and my needs are valid." Additionally, you may find it beneficial to practice communicating your needs by practicing with a supportive friend or family member.

FIRST is excited to introduce Mikela Murphy, who will be contributing regular columns on mental health topics.

Hi! My name is Mikela, and I have ARCI ichthyosis. I grew up in Baltimore, MD, and currently live in New York City. I am starting my third year in a clinical psychology doctoral program at Fordham University. I'm thrilled to be working with FIRST member Christine Brush to gather mental health resources to share on a dedicated page on FIRST's website (sponsored by Beiersdorf, the makers of Eucerin and Aquaphor). I wanted to share some of what I've gone through with the hopes that it could possibly help others.

I have struggled with anxiety my whole life, beginning when I was about 6 (I'm 29 now). My anxiety likes to keep me on my toes by shifting around and finding new targets. Sometimes I feel like I'm playing a game of whack a mole! I've dealt with intense performance anxiety (did I mention I majored in violin performance?), fear of flying, and panic attacks.

I am immensely grateful to have



Mikela Murphy

worked with therapists who have changed my life and improved my quality of life significantly. To give an example: I had an intense fear of flying which made traveling by plane very difficult for me for about 10 years. In 2021, I had the opportunity to work with a therapist who specialized in this fear. I'm happy to report that now I can fly with much more manageable levels of anxiety. Traveling to New Mexico for the FIRST conference was just one way therapy has allowed me to live my life to the fullest!

Though my anxiety isn't about my skin condition, I believe that they are linked. My anxiety began when I was being bullied in school because of my skin. My anxiety is still a part of me, but I feel that I have been able to change my relationship with it and see it as having less power over me.

My lifelong journey with anxiety and my experiences living with ichthyosis are some of the reasons I became interested in psychology. My goal is to help others through therapy, since therapy was so meaningful to me, and to help at the intersection of medical conditions and mental health, since I have lived experience with both.

In the meantime, I hope to lend my knowledge and support as a graduate student in clinical psychology to the FIRST community. **I would love to know what topics related to mental health you would like to see featured! Please consider sending me an email, info@firstskinfoundation.org, with your ideas for future articles.**

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Netherton Syndrome Study with Azitra

Clinical research study of a topical investigational medicine for adult patients with Netherton syndrome

Netherton syndrome is a rare disorder that affects skin, hair, and the immune system. Common manifestations include scaling skin, often in a pattern known as ichthyosis linearis circumflexa, and skin inflammation.

The investigational medicine, known as ATR12-351, is a topical ointment containing a modified bacterial strain that produces a critical part of the protein missing in Netherton syndrome.

If you have been diagnosed with Netherton syndrome and want to participate in this clinical study, you must meet these eligibility conditions:

- Male or female 18 years and older with skin changes consistent with Netherton syndrome, without large areas of open wounds or scratched areas
- Avoid certain kinds of medicines and therapies before and during the study
- Able to come to the study site for 2 weeks for twice daily application of the study drug; travel, hotel, and related expenses will be paid by the study sponsor
- Additional inclusion and exclusion criteria, which will be described by the study staff

When participating in a clinical trial, you are expected to follow study instructions. You will need to attend regularly scheduled visits, have examinations and lab tests, and answer questionnaires. This process aims to gather more information about you, your medical condition, and your experience in the study.

Participation in a clinical trial is **voluntary**, with study related examinations and tests performed at no cost to you or your medical insurer. **You may withdraw from the study at any time** with or without any given reason. You can read more about the study in the material provided to you during your screening visit.

Azitra Inc is sponsoring this clinical study with the guidance of FDA. Additional information is available at <https://clinicaltrials.gov/study/NCT06137157>, including current study site contact details.

Safety and effectiveness have not been established.

Study Contact

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This study has 1 location

United States

New Haven, Connecticut,

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Recruiting

Yale University

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Shared experiences helped preserve member's health

Submitted by Eileen Uthuppan



After discovering the Foundation for Ichthyosis and Related Skin Types in high school, I gained a new perspective that truly changed my life. By reading the various FIRST stories, I had a sense of belonging and comfort for the very first time.

However, a skin story that stood out to me the most was about a girl who had Chanarin-Dorfman syndrome (CDS), a rare combination of ARCI-lamellar ichthyosis and nonalcoholic fatty liver disease. Witnessing her mental strength left a lasting impression, as managing a single condition can already significantly impact a patient's life.

Coincidentally, I later discovered that I too had CDS when my distant relative, who was unaware of having CDS, advised me to undergo lab tests at the age of 16.

Reflecting on my relative's journey, I realized the importance of early awareness when he only discovered he had CDS when facing the need for a liver transplant. His lack of knowledge about the condition led to a decline in liver health which emphasized the critical role of proactive measures such as a low-fat diet and abstinence from alcohol. I wish there was someone that told my relative to take precaution when he was my age, but thankfully, he was able to find a match and is doing well today. There is not a single day that goes by without me thanking him as he truly saved me.

Read more of Eileen's story online at firstskinfoundation.org/eileen-u-2024.