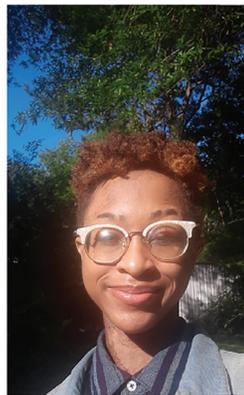


POWERFUL EVENT SHARES BLACK MEMBER STORIES



IN MY SKIN:
*music + voices
from the Black
ichthyosis
community*



Realizing Our Mission Despite Change

The year 2020 will be remembered as one that was unprecedented and full of change. Through it all, our talented staff, strong leaders and committed volunteers have proven they are adaptable and creative by finding new virtual ways to provide value and connections for our members. This issue will highlight some of those, including our powerful In My Skin event featuring music and voices from the Black ichthyosis community.

In May, our new CEO joined the staff. Christopher Boynton brings decades of experience in nonprofit management. We are excited to work with him to create strategy and vision for the future.

In September, Board President Jeff Hoerle stepped down. His leadership has left us on a positive trajectory with a strong financial position. We thank him for his dedication and service to FIRST. Jeff has trained and inspired our new Executive Committee:

- Co-Chairs of the Board – Mark Evans and Tracie Pretak (parents of affected children)
- 1st Vice Chair – Brian Stern (parent)
- 2nd Vice Chair – Beth Hampshire (affected)
- CFO – Sean McTernan (parent)
- Secretary – Denise Benedetto (parent)

While we embrace change and improvements, we are committed to keeping the heart of FIRST in our mission.

In Shared Passion,
Mark Evans (pictured below with daughter Abigail) & Tracie Pretak (pictured with daughter Bailey)



FIRST has a New Address!

As always, in order to be good stewards of your generous donations, and with FIRST staff now located in three different states, the decision was made to go fully remote. The boxes have all been packed and moved to a local storage unit, but our service to you remains the same. FIRST's phone number is still 215-997-9400 or toll-free 800-545-3286, but you may now reach us via USPS mail at:

Foundation for Ichthyosis & Related Skin Types, Inc. (FIRST)
PO Box 1067
Lansdale, PA 19446-0687

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

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Meet CEO Chris Boynton

My first months here at FIRST as your CEO have flown by with many phone calls, virtual meetings and much reading. Under normal circumstances we would be coming off another successful conference where I would have met many of you and experienced the FIRST “family” first-hand. Unfortunately, like many of you in your work, Zoom has had to replace face-to-face meetings and gatherings for the staff team.

I look forward to meeting you and hearing your stories about living with ichthyosis and how FIRST has played a role in helping you and your family. The one constant in my conversations with members is the importance of the connections made through FIRST and the opportunity to meet and talk to others with similar experiences.

I am very excited to work with the FIRST volunteer leadership, staff and the Medical and Scientific Advisory Board to advance the mission of this great organization. Although we were unable to hold the conference in June, the staff team put together an ambitious agenda of *FIRST Connects* and *FIRST To Know* Zoom and Facebook Live events in an attempt to replace some of the programming scheduled for Providence. A very active Ichthyosis Awareness Month in May provided numerous opportunities to engage and to support the organization financially.

“What do we want FIRST to look like four years from now? How can we bring more affected individuals and families under the tent?”

Along with the pandemic, major social issues have roiled our country. FIRST has confronted some of our own shortcomings and is making needed changes. Some of our efforts in these early weeks have been towards creating a more “welcoming” environment. We strive to create a culture where people from under-represented communities share equally in all the organization has to offer. The Board Development Committee is actively working to ensure our volunteer committees and leadership team represent our membership and the ichthyosis community at large. We are also working to quickly onboard new members into the organization, so they also see the value of the information, connections and programs early on. We are such a small community, there is no excuse for anyone falling through the cracks.

In the months ahead, we will be equally ambitious. As I actively become more familiar with our internal operations, programming offerings, research program and fundraising I will strive to increase efficiency, effectiveness and member value. Much of this is already underway.

We are creating policies and tools to create meaningful



partnerships more easily with the biotech and the pharmaceutical industry. FIRST supports research efforts in academic medical centers and for-profit corporations. We are experiencing increased interest from pharmaceutical companies to connect with our membership as they prepare for clinical trials in the next few months. There will be increased opportunities for you to get involved, as well.

The staff team and volunteer leadership are planning for the next several years. What do we want FIRST to look like four years from now? How can we bring more affected individuals and families under the tent and once here, how do we provide maximum value to them? How can we, with limited resources, help to accelerate research? Fundraising in a pandemic is challenging; how will FIRST sustain itself in coming years? These are critical questions we will be assessing in the coming months.

Many of you reached out with warm welcomes when my hire was first announced. Let’s keep the lines of communication open. Please reach out to me with your ideas, comments and concerns. FIRST is a volunteer organization. Your input and involvement, your time and financial support are critical to our ability to deliver on our mission: *to improve lives and seek cures for those affected by ichthyosis and related skin types.*

I am excited about the future! There are challenges ahead, but I know together we will grow and evolve FIRST into an even more successful mission-driven organization while maintaining and improving the culture that truly sets us apart.

Thank you,
Chris

Clinical Trial Participation Benefits Individuals, Science

Clinical trials are a necessary step in the approval of new therapies for ichthyosis treatments. Since clinical trials are fairly new to most FIRST members, we reached out to Jess Raiz, senior director of clinical operations at Timber Pharmaceuticals, to answer some common questions about clinical trials and participation. This is the first part of an ongoing conversation. Future issues will contain more information so that, if interested, you and your family can make an informed decision.

Why are clinical trials so important?

Clinical trials are a way to test new and improved methods of diagnosing, treating, or preventing health conditions. The goal is to determine whether something is both safe and effective. Clinical trials make it possible to apply the latest scientific and technological advances to patient care. More recently, clinical trials have been able to focus on personalized medicine to be able to target the exact reason a disease or condition has manifested in an individual and aim to treat it.

“Clinical trials are a way to test new and improved methods of diagnosing, treating, or preventing health conditions. The goal is to determine whether something is both safe and effective.”

How is clinical research in rare diseases different?

In the United States, a rare disease is defined as a disorder or condition that affects fewer than 200,000 people. In addition, each clinical trial protocol has a set of eligibility criteria (for example age, or genetic mutation) that takes that group of potential participants and shrinks it even further. Due to the scarcity of eligible participants, and their distribution across countries, finding eligible participants and effectively getting them to clinical trial sites proves to be incredibly challenging.

What does it mean to be in a clinical trial?

The decision to participate in a clinical trial is not one that should be entered into lightly. The study doctor will discuss with you all the requirements, risks, and

expectations. Participation requires commitment to attend all the study visits and communication with the study doctors throughout the trial. Many times, trials are designed to include a placebo, which will not have any beneficial effects. Participants are randomly chosen to receive either the study medication or the placebo -- and they will not know which one they receive. The placebo is required to demonstrate if the study medication is making a definitive difference. Study participants still get the same care, whether they are receiving the placebo or the study medication.

What happens when my participation in a trial is over?

There are generally four phases of clinical trials. Each phase aims to answer unique questions about the new drug or device being studied. Before the United States Food and Drug Administration (FDA), or any other countries' regulatory agencies can approve a drug for use, data from multiple studies must be collected and reviewed. The phase of study will likely determine how long it could be until the drug may be available to patients “on the market.” In some cases, patients may be able to continue taking the study medication if it has been proven to help, even after participation in the study has ended. This is usually made clear in the informed consent document, but participants should also speak with the study doctor about this.

Participating in a clinical trial means providing critical data to support not only your own journey with a disease, but those in future generations, as well. It is often seen not only as an opportunity to find a way to help yourself but as a truly altruistic act that can help in advancing research and science overall.

COVID-19 Creates Challenges for Clinical Trials

The COVID-19 pandemic has disrupted clinical trials worldwide, making it difficult for research to be conducted safely and effectively. Many trials have been suspended or stopped due to lockdown restrictions. At the same time, many resources have been redirected toward COVID-19 research. The interruption is expected to have long-lasting effects on research and results.

To read more about the effects of the pandemic on clinical trials, visit firstskinfoundation.org/news/covid-19-and-readjusting-clinical-trials.

Understanding Bullying

At first glance, many people think bullying is easy to define. Parents need to know that bullying behavior can be much more complex and varied than they expect. The Pacer Center in Minnesota provides this helpful reference:

The definition of bullying will vary by school and state. While there are significant differences between definitions, most include the following traits:

- Behavior that hurts or harms another person physically or emotionally, and
- An inability for the target to stop the behavior and defend themselves, and
- An imbalance of power that occurs when the student doing the bullying has more physical, emotional, or social power than the target, and
- Repetitive behavior; however, bullying can occur in a single incident if that incident is either very severe or arises from a pattern of behavior

Many definitions also include:

- **The types of Bullying:** The behavior can be overt and direct, with physical behaviors, such as fighting, hitting or name calling, or it can be covert, with emotional-social interactions, such as gossiping or leaving someone out on purpose. Bullying can also happen in-person, online or through smart phones and texts.
- **Intent of the student with bullying behavior:** “It is intentional, meaning the act is done willfully, knowingly, and with deliberation to hurt or harm,” but there is some controversy with this statement as some assert that not all bullying behavior is done with intent or that the individual bullying realizes that their behavior is hurting another individual.
- **The implications for all students:** It is also important to note that bullying is not just about the implications for those targeted by the behaviors, but that the behavior can impact all students in the school, including those who witness the behavior and those that engage in the behavior.
- **Additional factors:** These can include; the differentiation between bullying and harassment, enumeration of protected classes, statements around the use of technology, how the behavior impacts educational performance and the physical locations that would fall under the jurisdiction of school sanctions.

For more resources on preventing bullying, visit firstskinfoundation.org/bullying.

Kid's Corner

By Brenna Westlake, from Illinois, 8 ½

Me and my family went on a hike in Glacier National Park, and we saw three or four pretty waterfalls. I liked hearing the water crashing down. It was really cold. I had a lot of fun exploring.



Create a Facebook Fundraiser
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- Select FIRST
- Choose a personal cover photo and fill in the details and your personal story
- Click Create.



Celebrating Black Voices with Special Event

As I think about all of the things that are currently going on in our country, I pause. There are so many opinions, so many choices. There are so many topics being debated: COVID, politics, riots, protecting the police, defunding the police, shooting, looting, and rioting, oh my. Yet, in the midst of it all, people are still being heard. After hearing negativity concerning its stance pertaining to people of color, FIRST acted. They decided to set the record straight in a big way.

In the beginning, I was skeptical. I thought that FIRST would only put out a statement confirming that they also feel that the problems associated with people of color are “disturbing”. Maybe they would make a donation to one of the causes and then go back to business as usual. However, they didn’t. FIRST began preparations for an event that’s sole intent was to allow people of color to be heard. I was there for the planning of the event. I attended every meeting, so I got to see things develop. I saw how motivated people were, participants and staff alike. I saw how passionate the staff and board at FIRST are and how much they truly care about their members.

For the event, participants were given the opportunity to express themselves in whatever way they wished. It became a conglomerate of life experiences expressed through stories, songs, poems and art that told an overall story of hope, love and remaining positive when facing the struggles of life. It was an event that pertained to people of color specifically, but it also allowed everyone the ability to empathize or sympathize with the topics.

We heard the voices of Kelly Benford, Kaylee Brown, Aïcha Kandé, Brittany Mickens, Angela Lowry-Sellers, Puveri Tjikuua, Kelly Walters, Taylor White, Treasure White, Sarafina Arthur-Williams, Kim and Lowell Wright. Jeyza Gary and Denise Gass worked behind the scenes with the

Release the Butterfly team to plan, publicize and produce the event.

“Everyone involved was there to make a change, and I believe we started that path to change on the right foot.”

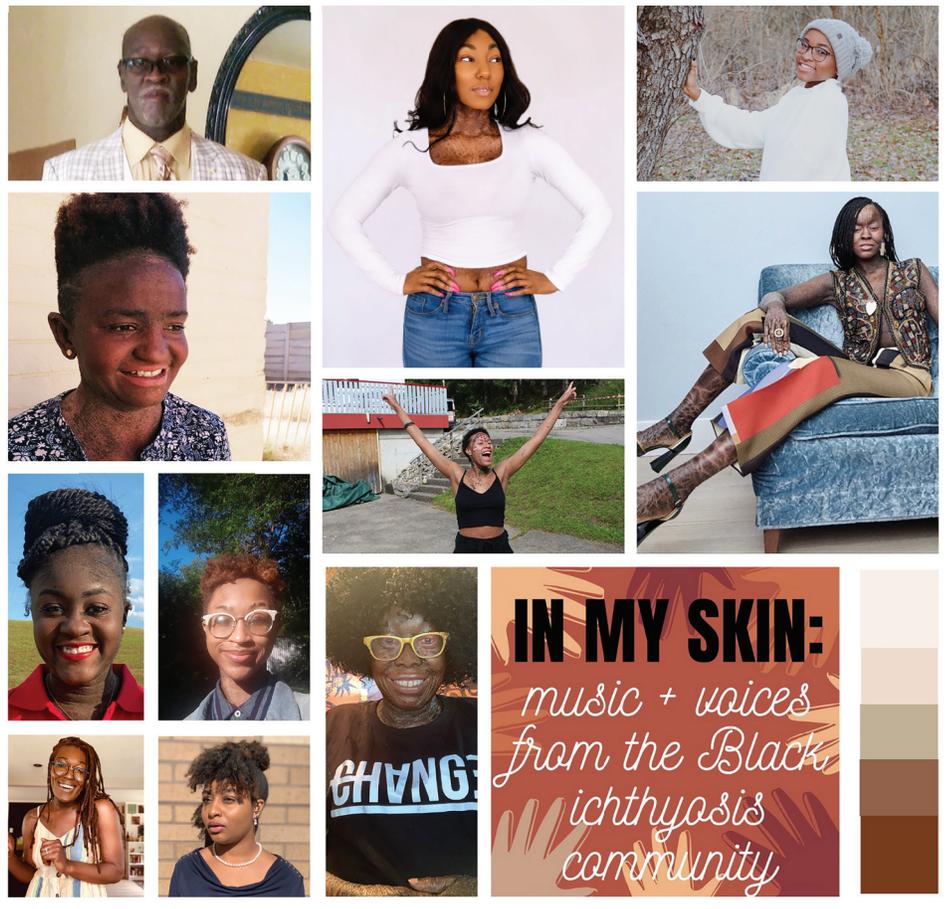
People opened up. We had fun. We got to see that even though people of color within the ichthyosis community have some distinct differences, we also share so many similarities. I remain optimistic that there will be additional events like this which focus on other groups.

I leave you with the words of Kaylee Brown because she sums up my own feelings:

“Being a part of this concert made me feel as if I wasn’t alone in this world. I made connections with people whom I had never met before. I was not aware of all the Black representation in the ichthyosis community before this. I felt as if my voice was truly being heard and understood by all races throughout the whole community. Everyone involved was there to make a change, and I believe we started that path to change on the right foot. I was honored to be a part of the beautiful event that was made.”

Editor’s note: Our work in this space continues. If you would like to be a part of ongoing diversity, equity, and inclusion efforts at FIRST, please email Denise at dgass@firstskinfoundation.org.

Submitted by Lowell Wright



Participants in the In My Skin event included:
Top Row: Lowell Wright, Brittany Mickens, Kaylee Brown
2nd Row: Puveri Tjikuua, Aïcha Kandé, Jeyza Gary
3rd Row: Kelly Benford, Treasure White, Angela Lowry-Sellers
4th Row: Sarafina Arthur-Williams, Taylor White

Release the Butterfly Goes Virtual for Ichthyosis Awareness Month

One day, a suggestion was made to take the show on the road and the Release the Butterfly Tour was born. The Release the Butterfly (RTB) team has been organizing concerts across the United States over the past 5 years. They have traveled coast-to-coast to bring a message of hope through song and dance. Their mission is to spread awareness of ichthyosis and bring to life the transformation from insecurity to confidence, all while raising money for FIRST. For many living with ichthyosis, this transformation mirrors their journey through life. The uplifting message of the concert often informs and resonates with those affected and unaffected in the community.

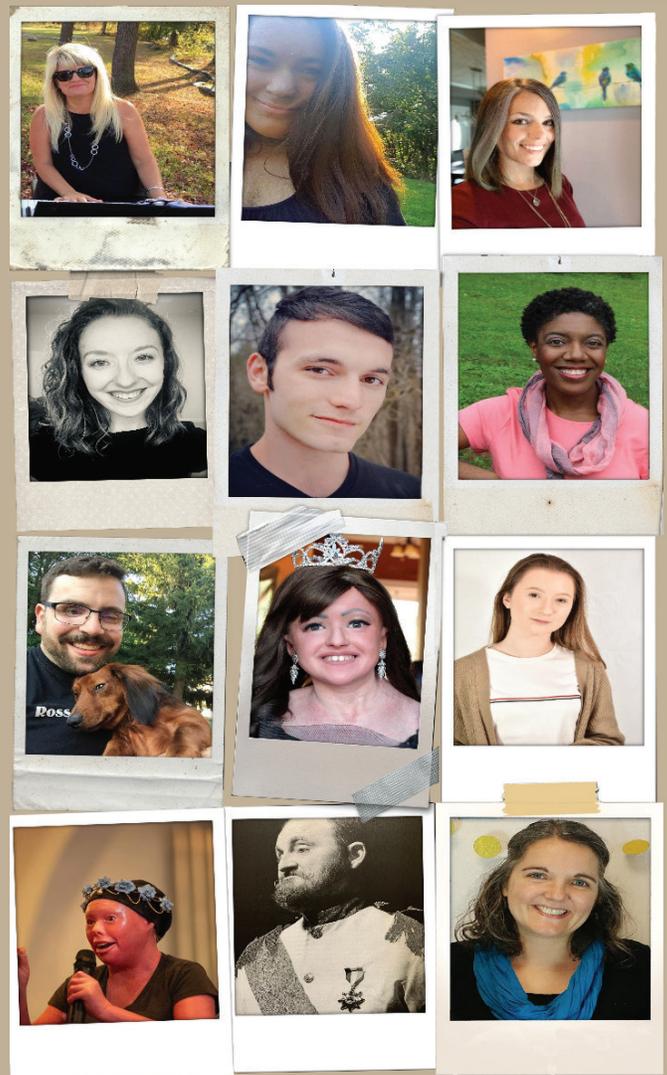
With the unprecedented challenges of 2020, the RTB team felt disconnected from their usual in-person concerts and country-wide travel. That is until May brought Ichthyosis Awareness Month, which sparked their desire to reconnect with many in the ichthyosis community. After many video meetings, the RTB team organized a virtual concert. This concert – with an expanded slate of performers -- streamed live on Facebook on May 8 and was watched by thousands around the world.

Riding the success of this concert, a second was organized and scheduled for the weekend of the 5-year anniversary of RTB's very first tour stop. To celebrate this milestone and to conclude Ichthyosis Awareness Month, the second concert was streamed live on May 31. It paid tribute to the FIRST National Conference and worked to give audience members the same feeling of community.

Throughout the month of May, the RTB concerts raised over \$7,100 for FIRST.

The RTB team sincerely thanks all who performed, watched, and supported these virtual concerts. Watch for more events this fall!

Submitted by Abigail Evans



*Performers in the Release the Butterfly concerts included:
Top Row: Tracie Pretak, Abby Evans, Lyndsey Weidow
2nd Row: Tara Hart, Will VanSlander, Tiffani McLaurin
3rd Row: Ross Bish, Carlie Foulks, Gabriella Fye
4th Row: Hunter Steinitz, Jason Phipps, Nicole Saylor*

To watch recordings of these events, please visit youtube.com/firstskinfoundation.



*Performers (cont'd):
Top Row:
Bailey Pretak,
Ceddie Conway,
Brianna Blankenship,
Mikela Murphy*

*Bottom Row:
Jacob Mosier,
Natalie Hann,
Portia Cina,
Abigail Mosier*

Research Examines Netherton, Mental Health, Alopecia

The Medical Scientific Advisory Board (MSAB) reviews recent research published in medical journals and provides summaries for members and physicians.

Read on for more information on developments in ichthyosis research.

Title: Secukinumab Therapy for Netherton Syndrome

Journal: *JAMA Dermatology*

Publication Type & Date: Case Series; May 2020

Reference: Luchsinger, Isabelle, et al.

"Secukinumab Therapy for Netherton Syndrome." *JAMA Dermatology*.

vPMID: 32459284 DOI: 10.1001/jamadermatol.2020.1019

Summary: Previous research has demonstrated increased activity of the helper T cell 17/interleukin 23 pathway in patients with Netherton Syndrome. When activated, these cells release IL-17, which stimulates skin cells (keratinocytes) to proliferate. A medication commonly used for psoriasis, secukinumab (Cosentyx®) is designed to stop this signal. This case series evaluated the efficacy of using secukinumab to treat four patients with Netherton Syndrome. Significant improvement in ichthyosis area, severity, itch, and quality of life was seen in all patients by three months and was measured using established scales (ichthyosis area and severity index, 5-D itch scale). The best results were seen in two pediatric patients with the erythrodermic subtype. Three patients were followed for 6-12 months and all chose to remain on the medication. The only side effects experienced during this time were nail fungus infection and an itchy eczema reaction on the palms. This research shows promise that this medication may be beneficial to Netherton Syndrome patients with severe erythema and itch and should be investigated further with more patients over a long period of time.

For patients with Netherton Syndrome and severe itch and diffuse redness (erythroderma), a treatment option can be considered, as noted, in the summary above.

Title: Ichthyosis affects mental health in adults and children: A cross-sectional study

Journal: *JAAD*

Publication Type & Date: Research Letter (in press); Jan 2020

Reference: Sun, Qisi, et al. "Ichthyosis affects mental health in adults and children: A cross-sectional study." *Journal of the American Academy of Dermatology* (2020).

PMID: 32006604 DOI: 10.1016/j.jaad.2020.01.052

Summary: Patients with ichthyosis face daily challenges that may include discomfort, harassment, and difficulty engaging in work or leisure activities as a result of their disorder. This study surveyed 181 patients from the National Ichthyosis Registry to investigate the psychiatric impact of the disorder. The patients were surveyed using questionnaires (PHQ-9, GAD-7) commonly utilized to screen for anxiety, depression and quality of life in patients with other medical conditions. The results showed that among adults with ichthyosis, 34% screened positive for depression, 27% positive for anxiety, and 95% experienced impairment in their quality of life. The results were similar in the pediatric population with 30% positive for depression, 38% positive for anxiety, and 85% with quality of life impairment. Most participants surveyed had the autosomal recessive congenital ichthyosis (ARCI) subtype and the results did not differ significantly between those with severe versus those with moderate disease severity. These data highlight the need for physicians to screen ichthyosis patients to detect psychologic conditions and provide appropriate care.

As known by many patients and families impacted by any type of ichthyosis, the potential impact on personal interactions and behavioral differences cannot be overlooked. While formal screening for, for instance, depression (as done in this study) can be considered, from a practical stance, such information should be sought from patients and family members when evaluating our patients.



Title: Association of the Severity of Alopecia with the Severity of Ichthyosis

Journal: *JAMA Dermatology*

Publication Type & Date: Research Letter; Sept 2019

Reference: Putterman, Elana, et al. "Association of the Severity of Alopecia With the Severity of Ichthyosis." *JAMA dermatology* 155.9 (2019): 1077-1078.

PMID: 31365037 DOI: 10.1001/jamadermatol.2019.1520

Summary: Hair loss (alopecia) is commonly reported in patients with ichthyosis, but not much is known about why this happens or if it is associated with a particular subtype or severity of ichthyosis. This small study was conducted with 86 patients from the National Registry for Ichthyosis and Related Skin Types to investigate if hair loss can be predicted based on disease severity or the genetics related to subtypes. In this study, two experts examined photographs of each patient without knowing their genetic subtype and scored the severity of hair loss and skin findings. The results showed that there was no significant relationship between the severity of skin findings and hair loss severity. However, when they separated the patients by genetic subtype, those with TGM1 and ABCA12 mutations appeared to have more severe hair loss in association with their greater skin disease severity. While previous research has shown the association of hair loss with TGM1 mutation, these results suggest that ABCA12 mutation may also be associated with hair loss in milder phenotypes in addition to the known association of severe hair loss in those with harlequin ichthyosis. Additionally, patients in these subtypes may suffer from more severe hair loss if they have severe skin symptoms than patients in these subtypes with more moderate skin findings.

While ichthyosis can, in some cases, be associated with hair loss or alopecia, there does seem to be relationship with more severe types of disease as noted by most physicians caring for these patients and by the patients, themselves. The authors seem to confirm the relationship with certain genetic mutations which can be associated with more severe disease, overall, as well as in some of the milder clinical subtypes.

FIRST Relaunches Tele-Ichthyosis

Perhaps during quarantine you've gotten to explore the benefits of telehealth.

Telehealth uses technology to link patients and care providers who are in separate locations. It can use video, text, email, or app functionality.

Thanks to members of our Medical & Scientific Advisory Board (MSAB) and a grant from the Lennox Foundation, an all-new, relaunched FIRST Tele-Ichthyosis platform will be soon available to dermatologists and other health care professionals. This allows a patient and their health care team to seek input from ichthyosis experts in other parts of the country – or the world – without the costs, time and other burdens associated with traveling.

Providers can use Tele-Ichthyosis to upload questions, documents and images for input and consultation from ichthyosis and related skin type experts. The site uses a secure, HIPAA-compliant environment to allow communication between providers in different locations.

But Tele-Ichthyosis offers more than a portal for doctors to connect and collaborate. It offers the promise that, one day, patients with ichthyosis and related skin disorders around the globe will have access to the care they need, at the time they need it the most.

Watch your email to find out when the new Tele-Ichthyosis will launch!



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Writer Finds the Words to Share About Her Life with Ichthyosis

The checkout lady's panic surged as she held the coins six inches above my hand and dropped them into my palm. They clanged until I made a fist. She ran her fingernails through her hair.

"What's wrong with you?" she asked, her voice rising to a higher pitch. I slid the money into a jeans pocket and stroked my thigh to calm down.

"Just dry skin," I murmured. That wasn't true.
(An excerpt from "Finding Refuge With the Skin I'm In")

When reading the opening of this essay from *The New York Times*, those of us living with ichthyosis can relate to this type of encounter and the feelings that often accompany it. The reason this resonates so strongly is that the essay was written by Anne Kaier, who is affected with ARCI-lamellar ichthyosis.

Anne is someone who has been writing since childhood and developed that passion into a career. She has a Ph.D. from Harvard University and taught English literature at both Arcadia University and Rosemont College. She became connected with *The New York Times* when she reached out to an editor. At that time, they were initiating a series about disabilities and the paper was looking for great writers to share their perspectives. Anne, who is a gifted writer, happened to be at the right place at the right time. In 2016, she wrote "Finding Refuge With the Skin I'm In" for that disability column. Since then, she has written another called "Learning to Sing Again".

"When writing about her ichthyosis, Anne recognized it was going to be hard to remember and face the difficulties again, and she surely didn't want people's pity"

Her essays, as well as others from the disability series of *The New York Times*, were compiled into an anthology last fall. It is entitled "About Us: Essays from the Disability Series of The New York Times" and features perspectives from various people with physical differences, viewpoints from their caretakers, politics of the disability movement, and people urging changes in public policy for disabilities. Before the pandemic hit, they were able to hold readings in several cities across the United States. Anne participated in an event in Philadelphia, where she lives. About 60 people attended, and the books sold out!

Writing about ichthyosis was not something Anne started out doing. It came with time. Growing up in the

50s and 60s, her family didn't really talk about her skin condition. Disabilities and physical differences were not something people discussed in mainstream media. And FIRST did not exist yet, so like many families back then, they didn't have anyone to help them understand ichthyosis or to navigate through the challenges of living in our skin.

Around the age of 50, Anne felt ready to begin writing about her experiences with ichthyosis. She knew it would be a challenge to strike a delicate balance – keep the skin disorder from sounding frightening or scary, without sugar-coating the struggles. She recognized it was going to be hard to remember and face the difficulties again, and she surely didn't want people's pity. Anne was able to find that balance in her essays for *The New York Times*. Her words help the non-affected better understand our daily struggles and the affected to acknowledge that sometimes it's okay to not be okay; that we face challenges daily that impact our lives immensely.

When asked what advice she would have for the next generation of people affected with ichthyosis, she said, "Be yourself. Live your life. You need to be a part of the world, but give yourself a break from it when needed. It's not always easy and don't forget, you do not have to be a poster child for ichthyosis. It's only one aspect of your life. You are so much more."

Other than writing and teaching, you can find Anne singing in her community choir in Philadelphia or tending her garden. Information about her writing, including her memoir, can be found on her website, www.annekaier.com.

Submitted by Bailey Pretak



Ichthyosis Inspires Teen's Essay to The New York Times

I entered the 7th Annual Student Editorial Contest for The New York Times. What stood out to me was the fact that there was no specific question to write from; we could write about anything that we wanted to. I thought this was a great opportunity to express myself and share my story. I've written in English class



and in school, but writing was never something I viewed myself being very strong at. Since I was writing about a topic I am very passionate about, it really motivated me to step out of my comfort zone.

Having ichthyosis and the daily inequality and struggles I face are not something I usually talk about

“I now feel much more confident in sharing my perspective and experience with others ”

with anyone. I am very comfortable with myself, and I always try to look on the bright side of things. However, I chose to write “The Unexpected Benefits of Social Distancing” because I liked the thought that perhaps two negative experiences -- society ostracizing people with disabilities and coronavirus forcing people to self-isolate -- could combine to create a more inclusive society. I was selected as a Round 3 Finalist. I also submitted my piece to a local newspaper in Singapore. As a result of participating in this competition, I now feel much more confident in sharing my perspective and experience with others and hope this can bring about a positive change in the world.

Submitted by Aliya Shahnaz-Kraybill, 14

Committee Spotlight: Advocacy, Program and Services (APS)

The APS Committee was put to the test this year due to the pandemic. All in-person meetings were cancelled, including FIRST's signature event, the National Conference. The committee needed to come up with new ways to connect and educate our members.

Fortunately, FIRST members have expertise in many different areas. Members came together to produce virtual events to keep everyone connected during Ichthyosis Awareness Month in May. More events were hosted through the summer -- and the efforts will continue for the foreseeable future.

Most of these virtual events were live and have been recorded for you to watch on FIRST's YouTube channel, including:

- *Release the Butterfly* concerts/fundraisers
- *In My Skin: Music and Voices from the Black Ichthyosis Community* (see article on p.6)
- FIRST Connects – Ichthyosis & School
- FIRST Connects – Grandparents
- FIRST Connects – Ichthyosis & Activities
- FIRST Connects – Ichthyosis & Adoption
- FIRST to Know conversations with members Pierre Brault, Brian Gass, Hunter Steinitz and Sonya Wheatcraft
- FIRST to Know – What's New in Research
- Ichthyosis Picnic, sponsored by Northwestern University

To watch recordings of FIRST's virtual events, please visit youtube.com/firstskinfoundation.

Advocacy efforts are also going virtual. Each year, FIRST staff and an affected member or family are invited to be an advocate at the American Academy of Dermatology Association Legislative Conference in Washington, D.C. The conference is an opportunity for FIRST to influence policy issues and speak directly to legislators.

This year, due to restrictions related to the pandemic, the conference was virtual. FIRST sent a request for volunteers and you responded! Nine members attended training and participated in the virtual 2020 AADA Legislative Conference. This is an amazing way to push forward ideas that will benefit everyone with ichthyosis.

More opportunities to volunteer for FIRST will become available. Stay tuned to FIRST's social media and email newsletters for more information.

The APS Committee is led by Jolie Cina and consists of Board Members Dr. Latanya Benjamin and Tracie Pretak, FIRST staff Chris Boynton and Chris Wassel, and volunteers Jackie Barrett, Sean Cina, Abby Evans, Sarah Kimmelman, Hunter Steinitz, Mark Steinitz, Lowell Wright and Sam Zavitz



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Will FIRST Be a Part of Your Legacy?

Since our founding in 1981, FIRST has been fortunate to count on significant planned gifts from dedicated donors. These gifts have been left by will, or bequest, and have ensured our long-term viability in research, support, programs and services.

Planned giving opportunities for charitable gifts to FIRST are many and varied. Gifts can be in the form of cash, securities or other property. Bequests can be a designated dollar amount, a particular asset or a fixed percentage of an estate.

FIRST recognizes that making a planned gift is a personal and private matter; all gifts are treated with strict confidence. However, with permission, the Foundation welcomes the opportunity to publicly thank donors for their generous support and commitment to our mission.

FIRST is grateful to be considered as you plan your legacy.

This information is not intended as tax, legal, or financial advice. We suggest consulting with your tax, legal, and investment advisors. Your advisors can contact FIRST directly for assistance in the giving process.

*Please email or call Denise Gass to learn more about planned giving:
dgass@firstskinfoundation.org, 215-997-9400 ext.3.*

