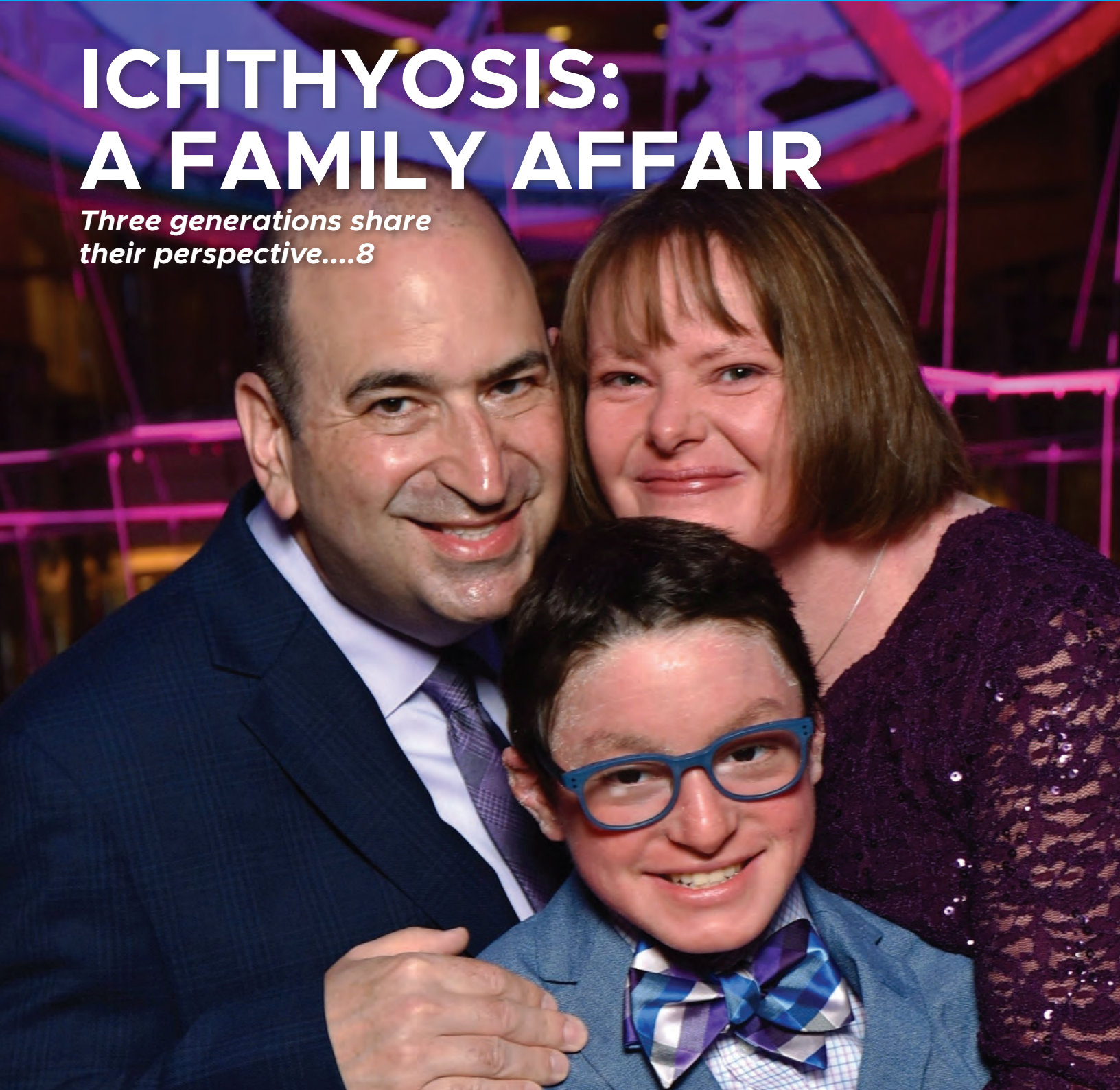


ICHTHYOSIS: A FAMILY AFFAIR

*Three generations share
their perspective....8*



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Preview....4*

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Research Reviews....7

Dear Members,

Staff and volunteers working for you at FIRST already have a busy 2022 underway with the best still to come. The organization's three-year strategic plan continues with work to improve the quality and quantity of resources available to our community. In-person events will return as the pandemic seems to be winding down. I know many of you are excited to see each other for the first time since 2018.

Our schedule of virtual events will continue because they have become so popular. The option to stream the session live and participate in real time appeals to many. Others are viewing recordings of the sessions later, at their leisure. Our YouTube channel, accessible through youtube.com/firstskinfoundation, is the fastest-growing way people are accessing our information. Our virtual programs and other videos on our channel yielded just under half a million views last year.

Important updates are also underway for our printed guides and our website. New information will be developed for more skin types and increased resources for managing ichthyosis will be online by September. The firstskinfoundation.org website is an important front door to our organization and the greater community. We strive to be the most comprehensive place for all information related to ichthyosis, its treatment and important resources for those living with the condition and their families.

We are "full steam ahead" for the in-person National Conference in Providence, RI, in June. Many interesting workshops and informative information sessions will be offered. There will be free time and fun activities planned so attendees can network, socialize, meet members of our Medical and Scientific Advisory Board and other researchers. Don't miss the conference June 24-26!

Many thanks to our volunteers who give of their time and our generous donors for making this all possible.



Chris Boynton

A handwritten signature in black ink that reads "Chris Boynton". The signature is fluid and cursive.

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 HAS A NEW ADDRESS!

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

The logo for the Foundation for Ichthyosis & Related Skin Types, Inc. (FIRST). The word "first" is written in a lowercase, bold, blue sans-serif font. The letters are closely spaced, with the "i" and "r" being particularly prominent.

Foundation for Ichthyosis & Related Skin Types

Use Your Voice This IAM

May is Ichthyosis Awareness Month (IAM). During May, families and friends around the world join together, use their voices, and raise awareness about the challenges and hopes of the ichthyosis community.

Educating your local community about ichthyosis is important as it can make day-to-day life much easier for those affected. Whether you share educational information with neighbors and coworkers, post on social media or host an event to bring friends together, your efforts to raise awareness contribute to a better experience for people with ichthyosis.

There are many ways to raise awareness all month long. Try posting on social media, sharing a photo or writing about a new topic each week -- or even every day. Reach out to local newspapers, television and radio to open up about how ichthyosis affects your life.

Fundraisers can be a great way to organize the power of your community to give back to FIRST. A virtual fundraiser on Facebook can be started in a few simple steps. FIRST members have shared many ideas for fundraising events that they had success with. Visit www.firstskinfoundation.org/grassroots-fundraising for inspiration!

When posting on social media, be sure to use IAM hashtags to amplify your voice. Tag posts with #ichthyosisawareness #FIRST #ichthyosis and #IAM22.



Thanks to the lott family for hosting a pumpkin painting fundraiser in 2021 – and raising more than \$2,500 for FIRST. Let us know about your event! Share your photos with the FIRST office to be featured in a future newsletter or email.

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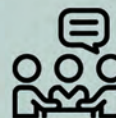


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To learn more, please contact
Denise Gass at
dgass@firstskinfoundation.org
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Shine Your Light: Register Now for National Conference

FIRST's National Conference is back this summer featuring three tracks for personalized sessions and connections. Members will gather in Providence, RI, June 24-26 for three days of information, sharing and friendship.

Register on the FIRST website through June 1 at firstskinfoundation.org/providence-registration. Childcare registration is available for children ages 1-12 for a small additional fee.

Program At-A-Glance

THURSDAY, JUNE 23

Evening Welcome Reception

FRIDAY, JUNE 24

Breakfast

First-Timers Welcome

Clinical Appointments and Research Studies (by appointment)

Opening Keynote

Distinguished Service Awards

Lunch

Sessions for Families with Children, Young Adults and Affected Adults

Scenic Bus Tour

(separate registration required)

Content throughout the conference is geared toward families with children, young adults and affected adults – with keynotes, care and treatment workshops, and social events to bring our full community together. The conference will also offer insights into current research and information about participating in clinical trials.

SATURDAY, JUNE 25

Breakfast

Keynote Session

Care & Treatment Workshops

Lunch

Types of Ichthyosis Sessions

Groups for Families with Children, Young Adults and Affected Adults

Celebration Dinner featuring Karaoke Sing Off
Mixology Class

SUNDAY, JUNE 26

Breakfast

Research Update

Clinical Trials Panel

Closing Keynote

Farewell Lunch

Top 10 Reasons to Attend

1. Meet medical experts
2. Feel understood
3. Make friends
4. Get ideas
5. Stay informed
6. See your future
7. Inspire others
8. Have fun
9. Meet the staff
10. Score free samples



Friday, June 24, 2022 -
Sunday, June 26, 2022
#FIRSTNC22

Crowne Plaza Providence-Warwick Airport
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401-732-6000

Keynote speaker Shawn Harper

With 25 years of experience, Shawn Harper has impacted youth development in schools and churches with high-energy keynote speeches that activate winners.



Shawn translates the life principles and life lessons that he learned on and off the field into understandable concepts leadership, teamwork and personal growth that his audiences can use to move from complacency to high-powered thinkers and doers.

Shawn knows what it feels like to encounter failures, road blocks and disappointments. Growing up on the south side of Columbus, Ohio, Shawn had to overcome failure, adversity, and learning disabilities. But he discovered the secrets to unlocking “The Winning Edge”.

Hear his powerful and challenging messages on relevant topics such as:

- Overcoming adversity
- Winning
- Effective leadership

Audiences are captivated by his wisdom, authority, and energy as he relates real issues to major life lessons. Humorous anecdotes also help the audience easily connect with him.

Shawn is certain to provide a powerful and positive start to the conference with his inspirational stories.

Member Keynote: Hunter Steinitz

Hunter is from Pittsburgh, PA, and was born with harlequin ichthyosis.

She is one of the oldest people with HI in the United States and is about to graduate with her Masters of Divinity. Hunter has been a part of the ichthyosis community for over 20 years and she is excited to be with everyone in Providence!

Hunter was selected from among members who entered a contest to choose a conference speaker. We look forward to hearing Hunter’s story!



Need to register? Want to see more details about the conference program? Scan the QR code at right!



FIRST Members Appeal to FDA for Treatment Options

By Abby Evans

Earlier this fall, a team of affected individuals and family members caught the attention of representatives of the Food and Drug Administration during the FIRST FDA Listening Session. The purpose of the session was for those affected with ichthyosis to directly inform the work of the FDA, by educating FDA employees about what types of outcomes would improve the lives of those living with ichthyosis. The group focused on ways in which the FDA can work to improve treatment options for ichthyosis and related skin types.

The session began with a chronological account of what it is like to live with ichthyosis, as told by parents and affected individuals representing a spectrum of ages. Dr. Mary Williams gave a brief overview of ichthyosis in preparation for each speaker to share their story. Evan Westlake shared his account of the birth of his daughter Brenna, which allowed the FDA to see just how important neonatal care is for

the ichthyosis community. Jennie Riley followed, sharing about her daughter Anna's journey through childhood. She illustrated to the FDA all of the care and support family members provide.



Abby Evans, an affected young adult, discussed the impact of ichthyosis on the body, including how the condition affects the eyes, ears, and mobility. These details shed a light on how treatment outcomes can not only be measured through improvements in the skin, but for the person as a whole. Beth Hampshire, an affected adult, shared current treatment options that are popular among the ichthyosis community. Drawing on her expertise as a health professional and her personal experience as an affected adult, Dr. Mary Ashley Mercer shared how many with ichthyosis cope with mental health and self-image issues. Again, allowing the FDA to adopt a holistic

understanding of a condition commonly thought to only affect the skin.

To complete the hour-long session, Lowell Wright expressed his hopes for the future. Measurable improvements for the treatment of ichthyosis is crucial. Dr. Keith Choate explained what is currently taking place in the research sphere and the challenges that lie ahead.

If you are interested in learning more about these sessions, you can visit the FIRST website and FIRST's YouTube channel, youtube.com/firstskinfoundation to view a prerecorded video of each presenter. The FDA Listening Session gave affected individuals, parents of affected children, and doctors the opportunity to share the ways in which ichthyosis has impacted their lives and how the FDA can work to improve treatment options with measurable impacts.

Learn more at firstskinfoundation.org/fda-listening-session-ichthyosis.



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Studies Examine Use of Ultrasounds, Collodion Scoring System and Observable Characteristics for Ichthyosis Diagnosis

Prenatal diagnosis of a rare variant of harlequin ichthyosis with literature review

BMC Medical Imaging; case report and review of the literature, March 2021; Zhou Y, Liang L, Wang L, Zhang C.

Review: The authors reviewed the published literature over the past 20 years and found 10 cases of harlequin ichthyosis (HI) diagnosed through ultrasound. Three were identified during the second trimester and seven during the third trimester.

Summary: Fetal characteristics of HI appreciated on ultrasound include ectropion, abnormal double auricles, flattened nasal ridge, persistent open mouth, limb contractures and decreased movement. Additionally, the authors comment that particles floating in the amniotic fluid can be seen. Both 2D and 3D ultrasound performed together later in pregnancy are most likely to identify these features.

Leslie Potter Lawley, MD, and Kerrie Satcher, MD, of Emory University summarize recent ichthyosis research



Dr. Leslie Potter Lawley



Dr. Kerrie Satcher

Collodion babies: A 15-year retrospective multicenter study in The Netherlands-Evaluation of severity scores to predict the underlying disease

Journal of the American Academy of Dermatology; research letter, April 2021; Cuperus E, Bolling M, Graaf M, et al.

Review: The authors used a collodion severity scoring system to evaluate 23 babies at three academic sites in the Netherlands. Genetic studies were completed on all babies and they were grouped into non-syndromic ichthyosis, syndromic ichthyosis, and self-healing collodion baby/unspecified congenital ichthyosis. The authors found no significant difference in the scores of the syndromic and non-syndromic ichthyosis groups.

Summary: A scoring system has been proposed as a way to measure severity of collodion and predict the underlying ichthyosis type. This scoring system has not been proven to reliably predict type of ichthyosis, although, lower scores have been seen in syndromic ichthyosis and higher scores in non-syndromic ichthyosis. It is possible that the small number of study patients contributed to the inability to assess the validity of the scoring system.

The Genomic and Phenotypic Landscape of Ichthyosis: An Analysis of 1,000 Kindreds

Journal of the American Medical Association Dermatology; original investigation, December 2021; Sun Q, Burgren N, Cheraghlou S, et al.

Review: Over a 10-year period, the authors recruited 1,000 patient participants from around the world. Patients completed a questionnaire, genetic testing on blood or saliva, and standardized clinical photographs. Pathogenic variants of genetic material were identified in 869 participants. The authors identified 266 unique disease-associated variants in 32 genes.

Thirty-five percent of patients with a genetic diagnosis completed the questionnaire. Itching, decreased sweating, skin pain, eye problems, skin odor and infections were the most commonly reported features. Findings related to specific genetic causes include:

- Collodion membrane at birth, skin odor, hearing problems, eye problems and alopecia were associated with patients who had TGM1 variant.
- Collodion membrane at birth was associated with patients who had ALOX12B variant.
- Skin pain, skin odor and skin infections were associated with patients who had KRT10 variant.
- Collodion membrane at birth and skin odor were associated with patients who had FLG variant.
- Collodion membrane at birth, skin pain, skin odor, skin infections, and hypohidrosis were associated with patients with STS variant.

Summary: This study helps us expand the genetic causes of ichthyosis, along with the clinical features of different types of ichthyoses. The authors report specific clinical features of ichthyosis which are significantly associated with particular genetic causes. This can help doctors with diagnosis, and guide treatment plans for patients moving forward.

Read more research reviews at
firstskinfoundation.org/quarterly-research-literature-review



Helen (second from left) with daughter Sarah, husband David, and sons John and Patrick.

A Mother's Love

Helen Ryding, Mum and Grandmum

My daughter Sarah was born on June 6 at 3:33 in the afternoon. We still celebrate her birth by talking to each other by phone at that time on that date each year.

I was shocked and frightened when the doctor came to my room shortly after her birth to say that she, the doctor, was concerned about a skin condition that had shown up with bullae, or blisters, on Sarah's right foot and ankle. We learned she was born with a form of ichthyosis.

No one could tell me much about this condition. It was difficult learning how to care for Sarah as an infant and toddler. As she grew and could talk with me, Sarah could tell me where and when she was hurting, which made it easier to help.

One dermatologist who examined her said, "You'll have to reconcile yourself to the fact that this child may never crawl or walk." He didn't even use Sarah's name. As I drove home crying and looking at the beautiful little face looking up at me, I told her that she would crawl. She did. And then she learned to walk, swim, ride a bike, and do many other things some doctors believed she would not do.

There were times when Sarah was bullied because of her skin and my heart ached for her. Sometimes I was quite abrupt, perhaps rude, to people who asked me why I hadn't taken my child to a doctor. Sarah tried to comfort me by tugging at my skirt or sleeve while saying: "It's all right Mum, it's all right".

Sarah was a good achiever at school and made some lovely friends who are still her close to her. She had some teachers who were impatient with her at times, and some teachers who greatly admired her.

After graduating from university, Sarah met and married a wonderful man. They later adopted a little boy, Alex, who also has ichthyosis – though not the same type as Sarah's.

It was joyous to see how well she understood Alex's condition and how well she could look after him. When unthinking people comment on Alex's skin condition Sarah is patient and polite as she responds to their comments.

Sarah's achievements and then her care for Alex helped to heal the heartaches that I had experienced when people made hurtful comments about my beautiful little girl. I could see she had grown up into a beautiful woman physically, mentally and spiritually.

The First in the Family

Sarah Kimmelman, Daughter, Wife, and Mum

My name is Sarah. I'm a mum, a wife, a daughter, a sister, a friend, and many other things. I also have epidermolytic ichthyosis.

I grew up in a harsh, cold Canadian climate with parents that have a high level of medical know-how. I credit them, particularly my mum, with figuring out how to keep infections at bay, how to make me more comfortable, and how to respond to being visibly different. I used to be embarrassed of my mum going "mama bear" when people were rude, as most preteens and teens are of their parents. Now, I feel myself doing the same thing and I am proud that I'm as strong and protective as my own mum.

There were definitely hurdles growing up. Some had to do with my skin condition and some were normal growing pains. Occasionally, it is hard to tell the difference. Looking different and dealing with pain, itchiness, and infections has an impact on how a child develops. Ichthyosis seasoned every experience I had as I grew up, so it is a part of me that I would not change since I like who I am. That, of course, took decades to learn.

“ I hope that, someday, [Alex] feels the level of love from us that I do from my family ”

The first time I saw another person with skin that looked like mine was at my first FIRST National Conference in Chicago, as a full grown and married adult. I cannot describe the feeling that washed over me and then stayed for the whole weekend – and beyond. I hadn't even realized how alone I had felt, even surrounded by those who love me. FIRST gave me that and, ever since, I've tried to give back and be that person for someone else.

In 2012, that dream was fully realized when my husband, Jon, and I were graced with the addition of Alex, our son, in our lives. The fact that we were considered to be ichthyosis experts by the country he lived in made his adoption possible and incredibly fast. Even though Alex's ichthyosis type is ARCI and mine is EI I've learned enough from friends at FIRST that we were able to jump into caring for his skin. Then we just had to love him.

I hope that, someday, he feels the level of love from us that I do from my family. My brothers that never blinked an eye at me being different and treated me just as any pesky, annoying little sister should be treated. My friends that only showed genuine curiosity so they could know me better and we could celebrate our differences. My parents that never let me use my skin for an excuse to

not do something and raised me to care, to love, to enjoy and play music, to work hard.

Alex went to his first FIRST conference when he was 5 years old. After the weekend of busy travel, while we were creaming up after a bath I asked him, "What was it like to meet other kids that look like you?"

He looked at me, confused, for a moment before replying, "They didn't look like me. Their eyes and their hair are different than mine. Just our skin is a little the same." With that I realized that he would never feel the isolation that I had, never having seen anyone else with the same condition. I can't convey how pleased that makes me feel.

Now, at 13, Alex looks forward to the conference because he knows no one will ask him what is wrong with him. I look forward to the conference because it's fun, I get to see my friends, and I hopefully can make a small difference for someone else out there.

I was the first, a spontaneous genetic mutation, in my family. Now, my circle is bigger and better and includes a bunch of awesome, inspiring, funny, and just plain cool people that I've met through FIRST.

Going to the conference in Chicago was the best decision ever. Many years later, when my mum was able to join us in Nashville, it changed how she thought of herself as a mother toward me.

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*Baden, H.P. Management of Scaly Skin with Epilyt. Seminars in Dermatology, 6:55-57, March 1987.

Knowing What I Need

Alex Kimmelman, Son and Grandson

Hello, it's me, Alex. This is the story of my life when I was little. When I was born from my first mother, I had ichthyosis. They looked at me and they thought I wasn't normal. They didn't know how to take care of me so I lived in a place with lots of other kids.

They didn't know what food to give me or how much I could eat. They thought that water was bad for me so I never even got a bath. They didn't know what cream I needed until, one day, they showed me two people named Jon and Sarah. I didn't like them because they were strangers and I felt shy.

They took me home and they knew what I needed. I learned a new language, I ate lots of awesome food, and I learned that water is good for me. I even learned how to swim! I learned that lots of people love me and that I'm part of a big family.

Now I am 13 years old and I can mostly take care of my skin on my own. I take baths and scrub and have huge tubs of white cream and Aquaphor.

My mum and dad knew what I needed when no one else did. Since that day I learned to love my skin and to love who I am.



Alex Kimmelman

FIRST has several member stories regarding adoption posted on its website. Search "adoption" to locate them. If you'd like to connect with another family who has adopted, please contact the FIRST office.



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GCCA 2015 GCCA Cleantech Top 10 Best in Class Award

From Surviving to Thriving: 2021 Annual Report

As I write this, our global community is slowly emerging from unprecedented times. The pandemic has changed how we as a society work, celebrate, educate and operate. It has also changed FIRST. I have been CEO for a little less than two years and have only met a few board members in person. The Cina family alone (with two affected children) makes up a little less than 50 percent of the affected people I have met in person! I am really looking forward to meeting as many of you as possible. We are planning a great conference in Providence and hope you will join us!

As you can see in the graphics in this report – and throughout this issue – FIRST has continued to provide the information and resources needed by our members. Your Board of Directors approved an aggressive strategic plan about 18 months ago and implementation of that plan did not slow down over the past year. The number of research proposals reviewed by our committee grew sharply, with two proposals ultimately being funded. Virtual programming became a necessary substitute for in-person forums. Even when members couldn't catch the live-stream, they accessed programming on-demand – views on our YouTube channel grew dramatically.

The primary front door to FIRST is our website, www.firstskinfoundation.org. Thousands of visitors and page views tell us this is an important source of information, one not found anywhere else on the internet. This coming year we will be making further improvements to the site to provide more in-depth information about some of the rarer skin types, and enhancing our skin management pages. Stay tuned.

We also know that many seek us out for referrals to dermatologists who understand ichthyosis and related skin types. While our number of requests grew in 2021, the database of available physicians only grew by two. We are working to expand this list in the coming year.

Research by pharmaceutical and biotech companies interested in ichthyosis is ramping up. Part of our mission is to support research no matter where it takes place and FIRST is working with several companies on exciting projects that will improve treatment options. Clinical trials are a critical part of the drug development process. We encourage you to keep an eye on trials that are recruiting and assess if you are able to participate. It is one of the most important ways you can support this community.

Speaking of support, I want to give a very special thank you to our donors! Your commitment to support FIRST enables us to provide the information, resources, access to expert clinical recommendations and community not found anywhere else in the world. We simply could not exist without you.

Thank you all for being a part of this very special organization. Let's make 2022 even greater!



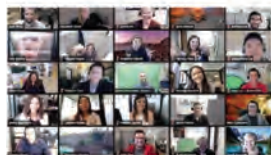
Christopher Boynton
Chief Executive Officer



Physician Referral—
Made **280** referrals to physicians who understand Ichthyosis



Financial Support—
provided grants for skin-care or scholarships to **37** members



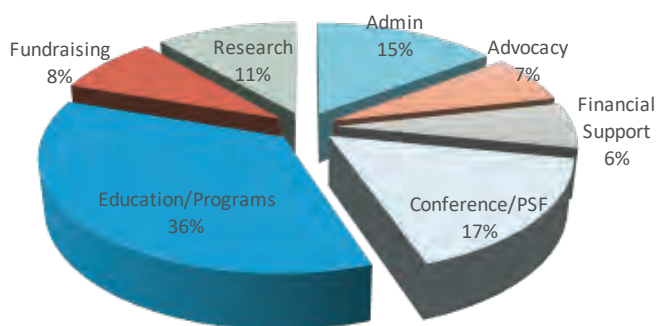
Virtual Programs—
FIRST hosted **15** virtual programs and workshops



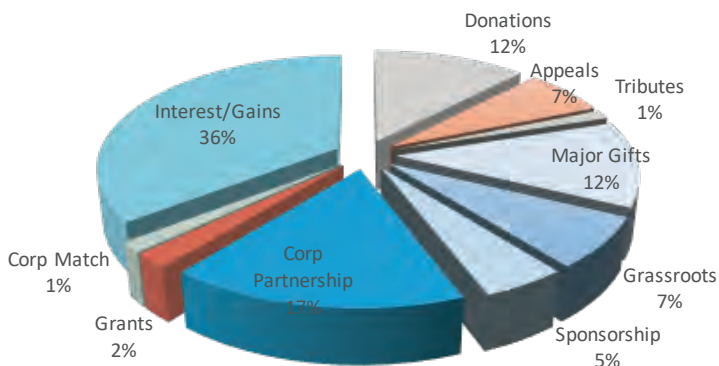
Patient Support Forum—hosted **22** members at a forum in Rehoboth Beach, Delaware

Financial Highlights September 30, 2021

Fiscal Year 2021 Expenses - \$603,844



Fiscal Year 2021 Income - \$933,641



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College Graduate Excited About His Future

Jelani Hedley has his eyes on an exciting future in bioengineering. Jelani, a UFIRST scholarship recipient in 2017, recently graduated from North Carolina Agricultural and Technical State University’s well-known engineering school.

Jelani, who is 23 years old, wants to learn more about human biology, and perhaps contribute to advancing medical treatment for ichthyosis patients and others. He was diagnosed at an early age with keratitis ichthyosis deafness (KID) syndrome.

Read more about Jelani’s story on the FIRST website at firstskinfoundation.org/jelani-h-2022. The UFIRST Scholars Program supports affected post-secondary students with grants to offset the costs of tuition. Learn more at firstskinfoundation.org/ufirst.



New Frontiers in KID Research



2022 marks the beginning of a new research effort generously funded by FIRST member Patti Brennan. Patti’s grandson, Logan Hovanetz, is a 12-year-old from Minnesota who has KID syndrome. KID is a related skin type with very little research to date.

The Brennan funding will allow FIRST to: conduct research among KID members, spur academic research into KID, and share summaries and de-identified information with pharmaceutical and academic investigators.

“ **FIRST staffer Denise Gass says, “The KID community needs this! It’s an exciting and fresh approach only possible with collaboration from FIRST members and medical advisors.”** ”