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

Ichthyosis Focus

Winter 2018 A Quarterly Journal for Friends of FIRST Volume 37, No.1

Tune Into the National Conference in Nashville,TN

We don't want you to miss a beat this conference! Meet our conference committee, the volunteers who have worked to make the 20th biennial meeting the best one yet!

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Vol. 37 No. 1 Winter 2018

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

A Letter From Moureen Wenik

Dear FIRST Community,

Wish time away…I try not to, but I have to admit, I have been counting down the days until the National Conference in Nashville, Tennessee, this summer. I had the opportunity to re-connect and meet with so many of our members this past summer during our Patient Support Forums -- 453 to be exact. Although the meetings were held in different cities, and some were larger than others, I found they all had the same underlying theme: SUPPORT. I witnessed support from extended families coming to the meeting together, and teachers and childcare providers attending the meeting to learn more so they can support the family. Support was found among the attendees meeting for the first time, sharing stories, tears, hugs and a day of fellowship. I look forward to seeing more support in Nashville. At this writing, the number of registrations are already at an all-time high, with many people attending for the very first time. I am going to be counting on our returning families to support our new families and help them navigate their way through this life changing event. This year, we are pleased to have the support of FIRST members as our conference committee, helping to make this National Conference a wonderful event for EVERYONE attending!

I know attending the conference may not be a possibility for everyone, so remember support is always available to you from FIRST's National Office. Connecting to another family, joining one of our Facebook groups, participating in our FIRST to Know telephone calls, or attending a fundraising or awareness event in your area are other ways to get the support you may need. FIRST also offers financial assistance, such as the UFIRST Scholars Program.

As always, I welcome your phone calls 215-997-9400 and emails to mwenik@firstskinfoundation.org.

Moureen Wenik

3rd Annual Northwestern Ichthyosis Patient Picnic a BIG Hit!

In September, Dr. Amy Paller and her team from Northwestern University held their 3rd annual patient picnic in Wilmette, Illinois; over 70 individuals of all ages were in attendance, including a family who came all the way from Brazil! Everyone enjoyed a welcome and brief discussion by Dr. Paller and FIRST staff regarding updates to ichthyosis research studies, FIRST opportunities to connect and new FIRST educational resources, followed by a magic show and breakout workshops by age group. A kids game corner was set up for children under 10. It was the highest attended gathering to date and many new friendships and connections bloomed throughout the day. Stay tuned for 2018 picnic dates and details!

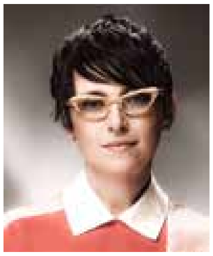
REGISTRATION OPEN for 20th Biennial FIRST National ConferenceNashville, TN - June 29 - July 1

REGISTRATION IS NOW OPEN! *As of the publishing of this newsletter, almost 60 families have registered for the 2018 FIRST National Conference! Have you?*

Not only will you meet lots of new friends and families affected with the same rare skin condition, but you will also have the opportunity to meet one-on-one with the world's most renowned medical experts in the field of ichthyosis - all while enjoying the zest and culture of America's beloved Music City. The FIRST National Conference has something for everyone. Whether you are an affected adult attending on your own, a relative or friend of someone affected, or a family coping with an affected child, the FIRST National Conference offers plenty of opportunities for education, inspiration, and education...plus so much more.

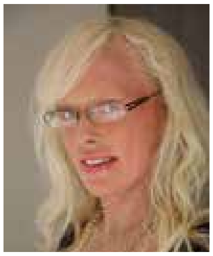
All of the information for the conference can be found on FIRST's website at firstskinfoundation.org/nashville. You'll find information about registration, childcare, hotel accommodations, conference program, keynote speakers, exhibitors and more. You can also feel free to reach out to conference director Lisa Breuning, lbreuning@firstskinfoundation.org.

Meet our 2018 Keynote Speakers;



Andrea Avery!

We are excited to announce our 2018 Keynote Speaker is musician, author and activist, Andrea Avery. Andrea is the author of Sonata: A Memoir of Pain and the Piano, which describes her experiences growing up as an aspiring pianist even after a diagnosis of rheumatoid arthritis at age 12. Her writing has appeared in Ploughshares, Real Simple, The Oxford American, and The Politics of Women's Bodies: Sexuality, Appearance, Behavior. She was the winner of Real Simple's 2010 essay contest and a finalist in Glamour magazine's essay contest. She holds a doctorate in education from Arizona State University. She teaches English at Phoenix Country Day School and is an active volunteer with the Arthritis Foundation. Don't miss her extraordinary story!



Bailey Pretak!

Bailey Pretak, a long-time member of FIRST and a motivational speaker and performer, grew up with ARCI-lamellar ichthyosis. Even with being bullied as a child, she has discovered a way to overcome insecurity with confidence and has turned her pain into a purpose. Her desire is to help others embrace what makes them beautifully unique and to find their value and worth. Part of Bailey's story has been featured on Yahoo and Allure's websites as well as a Snapchat daily story. When she's not speaking, you can find her on stage performing (playing piano, singing, dancing, acting), teaching dance, modeling, or traveling.

Meet our 2018 FIRST National Conference Volunteer committee

Denise Benedetto - A teacher, and mom to Marc Benedetto, affected with ARCI-lamellar ichthyosis, Denise has been a dedicated and passionate advocate for FIRST for the past 20 years. We are privileged and delighted that Denise has joined our 2018 conference planning team! Denise's positive energy, friendly nature, and sheer grit for "getting things done" has made her an unstoppable force for advocating for FIRST and the entire ichthyosis community. The Benedettos were honored as the 2016 recipients of the FIRST Champions Award and they have held more than a dozen fundraisers to support the mission of FIRST. Additionally, Denise has frequently contributed to FIRST's library of resources and she is a committed member of our regional support network. Denise is currently serving as Secretary on the FIRST Board of Directors. Her guidance and input into the 2018 conference development process is invaluable to the entire community!

Sean and Jolie Cina - Sean and Jolie are the proud parents of 10-year-old Portia and 7-year-old Myles, both of whom are affected with ichthyosis en confetti. 2017 officially marked their 8th annual wine tasting fundraising event for FIRST at their home in New Jersey. The Cina family have been strong advocates for FIRST and ichthyosis awareness over the years, and are also familiar faces at the FIRST National Conferences, having led skin care sessions at past conferences. Additionally they have been featured in FIRST's educational videos, including the FRAME video produced in collaboration with the Positive Exposure Foundation, and a number of online resources and communications. With the insight and dedication of members like the Cinas, the 2018 National Conference is sure to be an amazing experience for the entire family!

Abby Evans - FIRST has had the privilege of watching Abby Evans, affected with ARCI-lamellar ichthyosis, grow and blossom into the confident, intelligent self-advocate she is today. Abby is well-known for her bubbly personality and friendly, welcoming presence at FIRST events. She was featured in the FIRST FRAME video produced by FIRST and the Positive Exposure Foundation, and she is a frequent participant in FIRST teen panel discussions. Additionally, in recent years, she has participated in the Release the Butterfly Benefit Concert. We are thrilled to have Abby on our committee and privileged to have witnessed the journey of this remarkable young advocate. Her parents Mark and Rhayne have been involved with the organization since Abby was first diagnosed. Mark currently serves as Second Vice President on the FIRST Board of Directors.

Diana and James Gilbert - Diana and James Gilbert, have been impactful volunteers for the FIRST community for many years. Diana, affected with Netherton syndrome, has leant her creativity and energy to many FIRST initiatives including the IAM and RAISE fundraisers, FIRST to Know conference calls and FIRST patient support events. Their engaging and lively personalities bring a special warmth and excitement to FIRST events and they are very encouraging to the entire community. We are very appreciative of their dedication to conference committee and the success of the 2018 National Conference.

Sarah Hodgkinson - Sarah is the mother of 13-year-old Ema who is affected with ARCI-CIE. Sara has been a dedicated supporter of the FIRST mission for many years. Her creative fundraising events for FIRST, like the 2013 Dance-athon, along with her public relations savvy, bring a remarkable amount of awareness and support to the ichthyosis community. Additionally, her willingness to support and connect with other mothers has made a positive impact on families for generations to come. We are delighted that she is part of our 2018 conference planning committee.

Sarah and Jonathan Kimmelman - Sarah and Jon are an involved FIRST family. Sarah is affected with epidermolytic ichthyosis, and her son Alexander, is affected with ARCI-CIE ichthyosis. The Kimmelmans have a contagious enthusiasm for bringing community together. Their involvement in FIRST events and the regional support network has been inspiring and transformational for the whole community. They have not only participated in online FIRST fundraisers like RAISE and IAM, but also enthusiastically coordinated a FIRST Night Out for baseball fans and FIRST supporters. We are appreciative of their contributions as part of 2018 National Conference planning team.

Tune In! for the 2018 National Conference
June 29 - July 1 • Nashville Airport Marriott

Registration can be submitted by completing this form or registering online at www.firstskinfoundation.org/nashville-registration. All registrations must be received by June 5th. Registrations with missing information or payment will not be considered. Cancellations received prior to June 5th will be refunded, less a $25 per person administrative fee. No refunds issued after June 5th.

Family Registration, Contact Info, and Permissions

Family Last Name: ____________________________ Contact Person: ____________________________

Address: ____

City/Town :______________________State/Province: ________ Zip/Postal Code:______________

Country: ______________________________ Home Phone:_____________________________________

Cell: _________________________________ Email:____

Type of Ichthyosis: ____

☐ I give FIRST permission to publish names, contact, and type of ichthyosis in the conference roster, which will be distributed to attendees, vendors & faculty attending the event.

☐ I give FIRST permission to use and distribute any photos or videos taken at the conference, in which I, or my family, may be a part, including but not limited to use in newsletters, appeals, social media, website and reports.

Who's Attending?

	First Name	**Last Name**	Date of Birth	**Age**	Affected with ichthyosis or a related skin type?	**Relationship to person affected?** *(mom, brother, uncle, friend, etc.)*	Participating in Kid-a-Palooza?	Participating in FIRST's Got Talent Show?	T-Shirt Size
1)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
2)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
3)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
4)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
5)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								
6)					Yes No		Yes No	Yes No	YS YM YL S M L XL XXL
	Provide address if different than above								

Tune In! for the 2018 National Conference
June 29 - July 1 • Nashville Airport Marriott

Clinical Appointments & Ichthyosis Registry at Yale

All appointments will be scheduled for Saturday, June 30

This unique opportunity is offered to any affected member(s) and families to meet with expert dermatologists and researchers from Yale University. Please check which option you are interested in:

☐ Option 1—A 15 minute appointment with experts in ichthyosis to discuss your/your child diagnosis. This option does not involve participation in any research studies.

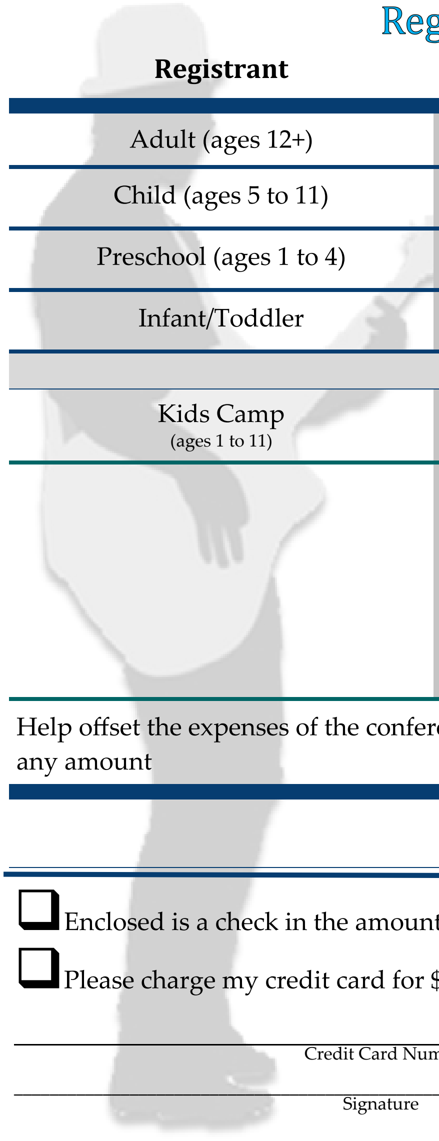
☐ Option 2—An in-depth, longer appointment to enroll in the Ichthyosis Registry at Yale for research studies. This option also includes a 15 minute appointment with expert dermatologists as well. For new enrollees, the study will involve providing a saliva sample, photographs, and completing a questionnaire.

☐ Option 3—For those already enrolled in the Ichthyosis Registry at Yale , you are encouraged to still sign up, as there will be an opportunity to update information, ask any questions, and participate in continued Registry activities.

Name	Age	Type

A packet will be mailed to you from Yale which will contain necessary paperwork and confirmation of your scheduled appointment time.

Registration & Payment



Registrant	Number		Fee Per Person		Total
Adult (ages 12+)		x	$300 per person	=	$
Child (ages 5 to 11)		x	$120 per person	=	$
Preschool (ages 1 to 4)		x	$35 per person	=	$
Infant/Toddler		x	No Charge	=	$
Optional Add-Ons					
Kids Camp (ages 1 to 11)		x	$15 per child	=	$
Help offset the expenses of the conference with an additional donation of any amount				=	$
				Grand Total	$

☐ Enclosed is a check in the amount of $__________________, payable to FIRST, Inc.

☐ Please charge my credit card for $____________(Visa, Mastercard, American Express, Discover)

Credit Card Number ______________________ Exp. Date ____________

Signature ______________________ Date ____________

Waiver

In consideration of the acceptance of this registration entry, I/we the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters, and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by the negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

____
Signature

____
Date

SEE YOU IN NASHVILLE!

2018 UFIRST Scholars Applications Deadline March 31

The UFIRST Scholars Program was established in 2010 by a seed gift from Valerie & David Scholl. Grandparents to an affected granddaughter, the Scholls wanted to provide an opportunity for affected students to advance their post-secondary education in partnership with FIRST. Their inspiration is to provide the opportunity for students affected with a form of ichthyosis or related skin type to achieve their highest educational potential. Other donors are encouraged to contribute to the fund to help grow its capacity.

How to Apply

- Applications for 2018 will be accepted from February 1 - March 31, 2018.
- Faxes and online applications will be accepted.
- Scholarship winners will be notified in May.
- Eligible candidates are individuals affected with some form of ichthyosis or a related skin type who are seeking post-secondary education at an accredited university, college, junior college, or trade school.
- Qualified applicants may apply throughout the duration of their education career; however, a new application is required every year and proven success in previous year(s) will be required to be considered for future funding.
- Funds can be used for school tuition or fees. All monies for tuition or fees are paid directly to the institution.
- Participation in FIRST activities, communication with the national office, and advocating in your local community strengthens your application.

Scholarship Selection Criteria

A committee of volunteers will evaluate each scholarship application based on the following criteria:

1. Demonstrated academic ability
2. A written essay on the topic "Describe a challenge you have overcome and how that has shaped your attitude toward life and your college choices."
3. Extracurricular activities and community activities
4. Financial need
5. Recommendation letters
6. FIRST activities

Please contact Lisa Breuning, lbreuning@firstskinfoundation.org, for more information.

...Related Skin Types.

Meet FIRST Member and Volunteer Amneet Anand, Affected with Chanarin-Dorfman Syndrome

The Skin I'm In, Touching the Feeling of Freedom

BY AMNEET ANAND

Recently I met an extremely bright and confident little boy named Isaac who has a skin condition called lamellar ichthyosis, and because of Isaac, I'm going to share with you a part of my own story. I'm finally willing to reach out of my comfort zone and share my story to the public – something I've never done before. As some of you already know, I was diagnosed with Chanarin-Dorfman syndrome – a combination of neutral lipid storage disease and ichthyosis (in my case ARCI-lamellar ichthyosis) – from birth. It affects me physically and internally, making it hard to break down lipids and fats in my body. My condition is extremely rare, with less than 10 known cases throughout the world. With that being said, you can see how difficult it might be to research and possibly find a cure to improve this condition.

Neutral lipid storage disease affects me internally – my triglycerides are always high. Lamellar ichthyosis however, has affected me both physically and medically. I was born with dry, scaly skin all over my body. This condition affected me in all sorts of ways – my skin is inconsistent and can change (for worse or for better) based on the weather or season. This can lead to my body overheating. There will be days where my skin will be amazing and there will also be not so amazing days. It has been an extremely hard journey and still is – in ways you cannot even imagine. I wake up every morning not knowing what to expect – every minute of any given day, I have to take my comfort into consideration on top of juggling my personal and academic life. My skin is an endless cycle that takes priority in my life.

I used to have extremely thick scales and patches from head to toe. While these have improved over time through constant care, I still occasionally have discoloration and an appearance of redness on my skin. I always felt and heard the passes made at me, which made me feel like an outsider that just didn't belong. I asked myself why I couldn't look "normal" like the other kids. Why did I have patches and scales? Why couldn't I just be "normal" and accepted? People only saw what I had physically, but didn't understand the types of struggles I went through.

With time my skin began improving. People who have known me my entire life have seen how I had to take things into my own hands and experiment with different remedies. I struggled a lot – both mentally and physically – and was really giving up on myself. After high school, I decided to make a 180 and told myself that it's time to work on myself and understand my body, understand the many changes it goes through and what types of environments are better or worse, and understand that I need to break out of my shell and not restrict myself from doing activities that other people participated in. I restricted myself a lot because of my skin – whether it was hanging out or playing sports. It was all because I felt insecure. I fought with myself a lot, resenting my skin and putting myself down because I could pick up on how other people judged me. I thought I couldn't strive as an individual because I was scared of doing everyday things. The constant itchiness of my skin used to be

unbearable and still is at times, but I try not to fight it as much anymore – I've learned to make it my friend.

I would constantly go to that dark place and feel like I had lost, but I realized that I had to pick myself up and not lose. And it's not that I don't find myself in that dark place sometimes even now, but at least now I realize I have to get on my own two feet, build that strength and acknowledge that I have such a great support system consisting of my family and friends.

As time went on and I learned to become comfortable with myself and I learned to make my skin condition, ichthyosis, my friend. I would not be the person I am today if I didn't have ichthyosis. I realized that I can make myself happy and feel just as good as any other person by striving to fulfill my dreams and my passions, whether it's for photography, dancing, or something else. I would like to thank my family, friends and accomplished team of doctors and nurses for constantly being huge pillars in my life and for instilling confidence and having faith in me. I would also like to thank those people who made passes at me; words can be hurtful, but my actions disproved them – I broke all odds only to come out stronger than ever. Of those passes, some of the worst were when people used to say, "I feel bad for you." Why? Pity is something I never saw as making me feel better. I am not sorry for having ichthyosis – I am thankful for it. Something I live by and tell myself is to "make your struggle your strength," and ichthyosis has taught me just that. We've all heard the quote, "Don't judge a book by its cover," which can be cliché but is true. Too many times, we are so unaware or uninterested in actually reading the pages of the book – and we do this every single time we make snap judgments. Taking a second to humble yourself, think of the person behind the picture, and understand the words of a book, only takes a little bit of extra effort.

Each day, I am growing, becoming a stronger person, and learning to love the skin I'm in. With time, I have realized that there is no such thing as normal in this world because the world is full of differences. Living and having Chanarin Dorfman syndrome doesn't define the person I am, but it is definitely a part of me. A part that, in ways, I am thankful for. I am happy to have guided Isaac in ways in which he can improve his skin, and I am thankful for meeting people who live with various types of ichthyosis and skin disorders, because they are simply beautiful and awesome. I want those kids who have ichthyosis to realize that with confidence and strength you can conquer anything. This message isn't just for people who have ichthyosis though – it's for anyone who has fear or doesn't feel confidence within themselves. It's not always going to be easy and you might face these challenges on a daily basis, but in life you have got to keep trying by taking it one step at a time. Open yourself up and make it known that, yes, you can do anything; you have the power to bring that strength to the surface and beat the odds. You are your biggest support system. You make the change. I step into the world knowing that I have to face my obstacles, but I face them with my head held up high and my faith stronger than ever. You may look at me differently after this post or you may not – it honestly won't phase me anymore, because I just touched the feeling of freedom.

Update from NORD's 2017 Rare Disease and Orphan Products Breakthrough Summit

NORD®
National Organization for Rare Disorders

FIRST staff attended the 2017 Rare Disease and Orphan Products Breakthrough Summit in Washington, DC, this past October. NORD has created a culture of conversation, education, and engagement in the debate about our nation's healthcare system, and this summit allowed FIRST to interact with leaders from the FDA, NIH, other patient advocacy groups, medical professionals, and the orphan product industry. The patient perspective is becoming the central voice in the product development space and FIRST is standing right there on the front edge, working side-by-side with our product partners and physicians. Keynote presentations were made by parent advocate, award-winning journalist, and founder/CEO of The Mighty Mike Porath; and the new Commissioner of the Food and Drug Administration Dr. Scott Gottlieb -- followed by three days of roundtable topics and ample time to meet and network with others in the rare disease community.

FIRST Board of Directors Vice President Builds Dreams, One Note at a Time

A lifelong advocate for the arts and an inspiring mentor to young musicians, FIRST Board Vice President, mother of Bailey, who is affected with ARCI-lamellar ichthyosis, Tracie Pretak has written two original songs recorded by her former voice student, Tara Hart. The songs were released November 10, worldwide and have been downloaded 11,000 times!

Pretak states, "I am a dream builder. I saw massive potential for Tara to be a recording artist, and strongly believed she was born to be on stage. For her dream to come true, she needed original songs. So I wrote some for her! The songs she released are actually the first two I had ever written. And though I created them seven years ago, the timing couldn't be more perfect. I am thrilled with Tara's vocals, and the passion she poured into them. She truly captured my intent as the songwriter in both songs. We are excited to share them with the world! This is a dream come true, for both of us!"

"Crushed Again" is a soulful pop ballad featuring Tara on both lead and back-up vocals, and Tracie Pretak on piano. The song also features FIRST Member Mikela Murphy of Baltimore on viola.

"What Are You Doin' with Him?" was co-written by FIRST member Bailey Pretak.Tracie Pretak accompanies on piano.

Season's Greetings Contest Inspires Artists Near And Far

Meet the talented winner of our Season's Greetings Art Contest, Alexandra Hanson! Alexandra's winning entry below was featured on the front of FIRST's Season's Greeting card.

"My name is Alexandra. I am 7 years old. I am an artist, I like to dance, and I love the outdoors. My favorite food is pizza. I have 2 cats. One is mean and one is fat! I'm in first grade at school. I have harlequin ichthyosis which makes beautiful pink skin. I live with Mommy, Daddy and my big brother Ben," Alex wrote with her submission. Alex and her family have been members of FIRST since 2010.

Her mother Patti recently told FIRST, "Our family has been involved with the FIRST community since Alex's birth. The support we have received through FIRST has reminded us that Alex can accomplish anything she sets her mind to!"

Clinical Trials & Patient Recruitment Opportunities

Visit firstskinfoundation.org/clinical-trials to see if there is a clinical trial or patient recruitment opportunity for you.

Have you been diagnosed with Darier-White or Hailey-Hailey disease?

FIRST held a FIRST to Know call for all those affected by Darier Disease, and was joined on the call by Dr. Carmella Evans-Molina, an endocrinologist from Indiana University Diabetes Research Center, who is the lead researcher on a Darier-White Hailey-Hailey clinical study currently underway. Dr. Evans-Molina is pursuing potential cell function discoveries, using pluripotent cells, regarding a correlation to mutations of the beta cell, calcium utilization, insulin and hormonal imbalance. The callers were able to ask Dr. Evans-Molina direct questions regarding her study. If you are interested in receiving the recording to the call or to learn more about the study, email Moureen at mwenik@firstskinfoundation.org.

If you have an interest in participating in the study, and you have been diagnosed with Darier-White or Hailey-Hailey disease, a blood sample must be taken at Indiana University. The goal of the study is to use cells isolated from the blood sample to create stem cells in a petri dish. The stem cells will be studied in our lab to understand how having Darier-White or Hailey-Hailey disease affects cell function.

To participate, you must be:

1. At least three years old
2. Diagnosed with Darier-White or Hailey-Hailey disease

Women who are currently pregnant are not eligible. Study participants will earn $25 for each blood draw and will be reimbursed for travel expenses and parking at the Indiana University Hospital. For more information about this study, please contact Dr. Evans-Molina at cevansmo@iu.edu.

New Studies

Ichthyosis Research Opportunity: Mental Health and Quality of Life in Ichthyosis

The National Registry for Ichthyosis and Related Skin Types is conducting a new study examining the effects of ichthyosis on mental health and quality of life. Your participation will help us better understand how ichthyosis impacts daily life across various ages and ichthyosis subtypes.

If you have already enrolled in the registry and would like to participate in this study, please email the Registry's Patient Coordinator - Theodore Zaki, theodore.zaki@yale.eduor call the Yale lab at (203) 737-4675. You will be asked to complete a short electronic survey assessing mental health and quality of life.

If you have not already enrolled, please email the Registry's Patient Coordinator - Theodore Zaki, theodore.zaki@yale.edu or call the Yale lab at (203) 737-4675 to enroll in the registry and to participate in this project.

IRB approved text

NEW Ichthyosis Vulgaris Study

Participate in a research study for moderate to severe ichthyosis vulgaris. This study is currently enrolling patients to investigate a topical cream. Qualified participants will be compensated for study-related time and travel.

www.superdryskinstudy.com

IRB approved text

Record Numbers Attend One-Day Meetings

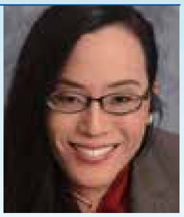
Our Patient Support Forums where a huge hit last spring and summer, a total of 453 people attended 10 one-day meetings throughout the United States. What made these meetings so impactful? The connections that were made at each meeting, the honest conversation, and the real answers to the hard questions. The medical lectures, product sharing, and special presentations were well received and informative. Ichthyosis affects the entire family, and these meetings allowed the family to learn together. FIRST is grateful for the doctors who volunteered their time to host the medical portion, and for the members who attended.

If you didn't have a chance to attend one of the 2017 meetings, there are many ways to connect with others. The 2018 National Conference will be held from June 29 to July 1 in Nashville, Tennessee. This is FIRST's signature in-person event. Knowing that travel isn't easy for everyone, FIRST offers private Facebook Groups for our members to join, as well as FIRST to Know telephone calls, connecting people by phone. We can also connect members through email. Contact the national office and we can help you find the best way to connect with others.

FIRST Board Happenings…

Dr. Moise Levy

Dr. William Rizzo



Rachel See

It is always difficult to say farewell to Board of Directors members who are ending their terms. FIRST has been extremely lucky for the guidance, and the countless number of volunteer hours from Dr. Moise Levy, Dr. William Rizzo, and Rachel See. Each have served on FIRST's Board of Directors for nine years, and during that time have been able to lend their expertise to projects, decisions, and direction for the organization. Thankfully, we will be seeing each of them in different capacities, Rachel See as a dedicated FIRST member, Dr. Levy as the Chairman of the Medical and Scientific Advisory Board, and Dr. Rizzo as a member of FIRST's Research Review Committee. The commitment to FIRST doesn't end with their board terms, and for this we are forever grateful.

Sean McTernan

We are excited to welcome Sean McTernan to the FIRST Board. He and his wife, Carolyn Straub McTernan, have three children. Their youngest daughter is affected with ARCI-lamellar ichthyosis. Sean and Carolyn have been active members of FIRST, attending support events and hosting fundraisers, as well as being wonderful supporters of other FIRST members and their events. Sean is the Director of Business Development at Penn Mutual Asset Management. We look forward to Sean bringing his expertise, passion and enthusiasm to the FIRST Board of Directors.

Member Spotlight

Tiny Bubbles, Big Results for This Ichthyosis Family

FIRST introduces mom and dad, entrepreneurs, and FIRST members Paul & Heather Lynn.

Paul is a passionate researcher, dedicated father, and loving husband. Heather is a loving mother and empathetic caregiver with a background in nursing education. They have a story to share about how they discovered the best and most cost-effective solution for their daughter's ARCI-harlequin ichthyosis. Subsequently, they developed a new medical-use device, in concert with the manufacturer, specifically designed for ichthyosis. Together, they created a company to share the device with the ichthyosis community.

"Our daughter Clarity was born with ARCI-harlequin ichthyosis, which, as many of you know, there currently is no cure or therapy for even the symptoms. Like many others with ichthyosis, Clarity has no normal skin function from head to toe and can create 20 to 30 times the usual amount of skin daily. Additionally, she cannot sweat and was born with bilateral hearing loss. The skin that she does create also has no fats, elastin or collagen," stated Paul and Heather.

As Paul and Heather began to explore treatments, they discovered that current options such as over the counter skin creams and ointments, retinoids, or bathing additives offered very little benefit for Clarity's condition. They say most made the situation worse and they avoided bathing for the first 10 months. Then they discovered a suitable treatment that they say made a real difference – tiny nanobubbles and oxygen.

Nanobubbles are tiny bubbles smaller than one millimeter in diameter that can be integrated directly into bath water, using specialized technology. This allows for better gas infusion, water mixture homogenization, and increased contact time to the treated surface area. The tiny size of these bubbles allows them to enter crevices that are unreachable by traditional methods of hydrotherapy.

According to her parents, "Our daughter's skin never looked healthier, and we felt strongly about sharing this discovery with other families and individuals affected with ichthyosis."

After hours of research, product development, specifications for filtration, and more, in early 2016 Paul and Heather brought a new product to market: the Portable Nanobubble system by The White Water Company. Learn more at www.thewhitewatercompany.com.

REF. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2889676/

This information is provided as a service to patients and parents of patients who have ichthyosis. It is not intended to supplement appropriate medical care, but instead to complement that care with guidance in practical issues facing patients and parents. Neither FIRST, its Board of Directors, Medical & Scientific Advisory Board, Board of Medical Editors, nor Foundation staff and officials endorse any treatments or products reported here. All issues pertaining to the care of patients with ichthyosis should be discussed with a dermatologist experienced in the treatment of their skin disorder.

Turkish investigators report new findings on tears in ichthyosis.

BY DR. LEONARD MILSTONE

Many people with ichthyosis suffer from watery, scratchy eyes. The usual explanation for this is that their eyelids do not close completely when they blink or when they sleep and, as a result, tears evaporate more rapidly and need to be replaced by more tear production. Work by a group in Turkey has shed new light on this problem.

Researchers compared patients who have lamellar ichthyosis with normal controls of the same age. They used standard ophthalmologic tests and showed that, on average, visual acuity and tear production were equal in both groups. However, using a new infra-red imaging technique to examine the inside of the eyelids, they found that there were fewer Meibomian glands (the oil secreting glands inside the eyelid, similar to the sebaceous glands around the hairs on your skin) in the patients with ichthyosis. They then showed that, in ichthyosis patients, tears were of poor quality, meaning that the fluid film covering the eyeball of ichthyosis patients dispersed more readily – and as a consequence tears evaporated more readily - than in the controls.

Why would fewer Meibomian glands result in poor quality tears? It is thought that the Meibomian gland contributes something, probably lipids and proteins, to tears that improves their ability to maintain a film over the eyeball. A number of conditions besides ichthyosis are associated with decreased Meibomian glands. Aging is the most important associated condition, and the "dry eyes" of aging is now thought to result primarily from reduced Meibomian gland number and secretion.

What does all this mean for patients with ichthyosis? First, generous use of artificial tears may be even more important for older individuals with ichthyosis than for children. Second, some artificial tears may work better than others for individuals with ichthyosis. Third, the recent appreciation of poor tear quality in all aging populations should stimulate development of more effective eye lubricants for aging, as well as ichthyosis patients.

Palamar, M. et al, Contact Lens and Anterior Eye (2017), http://dx.doi.org/10.1016/j.clae.2017.06.001

Asthma & Ichthyosis *Is There a Connection?*

Asthma and ichthyosis continues to be a frequent discussion within the ichthyosis community. Recently, we sat down with FIRST MSAB member *Dr. Sarah Asch and asked whether or not there is a connection and if any research has been done on this specific subject. Here's what she had to say...*

Allergic disease, such as asthma, has complicated beginnings and not all children who have asthma have impaired skin barriers. However, there are children whose impaired skin barrier likely predisposes them to allergic diseases such as asthma. The most well-studied and understood link so far is in filaggrin, an important protein located in the upper portion of the skin.

The filaggrin gene is mutated in ichthyosis vulgaris. There are a group of people who have moderate to severe eczema (atopic dermatitis) that is due to an underlying mutation in the filaggrin gene. Asthma and eczema are a well-known association. There is some data to show that an impaired barrier early in life may predispose people to more allergic disease down the road,such as asthma and allergies. There is some early data to support that emollient use early in life decreases the development of atopic dermatitis, but we do not yet have long-term data to show that this will prevent asthma.

People with Netherton syndrome are more likely to have asthma and eczema due to impaired skin barrier function. However, this condition is due to mutations in a different gene, the SPINK5 gene.

For more information visit https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3042307.

Grassroots Events

Thank You to Our Members for Organizing Events to Support FIRST.

A Clothing Swap for FIRST

FIRST member, Lisa Gigli-Smith took a creative approach to fundraising and hosted a clothing swap at her California home and donated the proceeds to FIRST. Lisa, mother to 11-year-old Massimo, who is affected with Netherton syndrome, has hosted successful events in the past and this event was just as successful raising more than $1,000. We truly appreciate the continued support and hard work of Lisa and her family and friends.

KEEP Sales Online

FIRST member Erin Edwards is the mother to 12-year-old Ethan who is affected with ARCI-CIE. Erin hosted an online KEEP jewelry sale and donated the proceeds of her sale to FIRST. The online sale was very lively with comments and posts and questions about purchases etc. One item that Erin created was an ichthyosis awarenessbracelet. Many thanks to Erin and Ethan for their continued support.

Fall Softball and Pumpkin Painting

Once again, Michelle & Chad Iott hosted their September softball tournament, raising more than $1,500. Later in the fall, the family also hosted their annual Pumpkin Paint & Bake Sale with $2,200 raised. FIRST is so appreciative to the Iott family for their continued dedication and hard work throughout a decade of hosting events for the ichthyosis community.

Volleyball Tournament a Tremendous Success!

The volleyball team at Vestal Varsity High School has once again hosted a volleyball tournament, with the proceeds benefiting FIRST. For the 5th year, athletes played volleyball at the school gym, raising more than $900. The students decided to host this tournament because one of their teachers, Nicole Ewing, has a son, Liam, who is affected with ichthyosis. Liam has joined the students in the fun each year. Many thanks to Susan Darpino who coordinates this event each year with the students.

FIRST
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Summer Camp Dates

June 17 – 23
www.csdf.org/camp-wonder

Ages 8 to 16
June 17 - Crosslake, MN
July 1 – Crosslake, MN
Aug 5 – Crosslake, MN
Aug 11 – Millville, PA
Aug 12 – Andover, CT

www.aad.org/public/kids/camp-discovery