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

Ichthyosis Focus

Summer 2017 *A Quarterly Journal for Friends of FIRST* *Volume 36, No. 3*

Pics, Positivity & Making Things Happen

By Rochelle New

When I published my blog post for Ichthyosis Awareness Month I was simply setting out to accomplish a long overdue goal while sharing a story I was proud to tell.

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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.

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FIRST Announces Leadership Change

With a mix of sadness and gratitude, the Foundation for Ichthyosis and Related Skin Types, Inc., announces that Jean Pickford recently resigned as Chief Executive Officer to pursue a career goal of starting her own consultant service. In more than 18 years with FIRST, Jean oversaw the growth of the organization into the premier resource for families affected by ichthyosis. Jean has played a pivotal role in establishing the FIRST Research Grant Program, which has funded over $1.7 million in ichthyosis research grants since 2006. Jean was also instrumental in developing FIRST's Tele-Ichthyosis Portal, an online service connecting healthcare practitioners with a world-renowned team of ichthyosis medical experts. We are all grateful for Jean's passion, enthusiasm and leadership. We wish her success in her new endeavor.

We are pleased to announce that Moureen Wenik, FIRST Senior Director of Programs and Research, has been promoted to Acting Executive Director. Moureen has been with FIRST since 2007, and we are confident that her unique ability to connect, educate and build long-lasting relationships with members of the FIRST community will serve her as she embraces this new leadership position. Please join us in congratulating Moureen on her new role at FIRST!

A Letter From Moureen Wenik

Fall is upon us, and this has always been one of my favorite seasons. The warmer weather in the Northeast is turning cooler, the leaves are changing into vibrant colors, and it is the mark of a new school year, a fresh start, new beginnings and goals for success. On page 7, you can meet FIRST member Rochelle and read what her goals were and how she learned that clear vision is key to her success. Just as the new school year brought the feeling of excitement, this is an exciting and transformative time for FIRST, one of both reflection and rejuvenation. This issue of the Ichthyosis Focus shares tips for students heading back to school, and a kids corner for the littles to learn more about ichthyosis. There are opportunities for learning in the lab, with clinical studies available throughout the United States, see page 5, learning never ends! As mentioned in our recent Ichthyosis Focus newsletter, we are engaged in many initiatives, including the development of the Life Cycle Modules and WebEx Product series; an all-inclusive approach to our Research Grant Program; the production of three more Patient Support Forums; and of course, the planning for the 2018 FIRST National Conference in Nashville. With that in mind, we are never too busy to provide support and friendship to the ichthyosis community! Please feel free to contact me directly with any comments or questions (mwenik@firstskinfoundation.org). I look forward to continuing my work of educating, inspiring and connecting the ichthyosis community.

Correspondence Corner

"We are so grateful that FIRST exists. The kids love to look through the magazines we get and they love knowing they aren't the only ones to battle these conditions."
Brandi Wanstrom

"My first FIRST conference was at San Diego in 1995. A truly dramatic turning point for me. First time I had actually met others with ichthyosis. Thanks again for all you do, FIRST, and the passion you bring to supporting ichthyosis community."
Rich Graham

"Our Little Lincoln is two today! Thank you FIRST family for helping us navigate so much these first two years."
Kaysie Berry

Will you help us support the work we do for the ichthyosis community?
Find out how to help us reach our National Fundraising goal on page 14.

Diya & Aliya's Friends (DAF) Fund

Thanks to the generosity of the Shahnaz Kraybill family (Aliya, affected with ichthyosis, her sister, Diya, and their parents Durreen and Robert), and their family and friends, FIRST has established the Diya & Aliya's Friends (DAF) Fund to help alleviate some of the financial burden that may be facing families with affected children. This special fund is available for children around the world affected with ichthyosis and is intended to provide financial assistance to purchase lotions, medicine, and treatment necessities.

To apply for an award, please complete the DAF application form. All forms must be completed in English and submitted to the FIRST office. Individual awards will not exceed $250.00. Applications will be awarded two times per year; all applications must be received by April 30 or October 31 each year to be considered for each cycle. For non-US residents, the grant award will be sent via Western Union; it is the applicant's responsibility to locate the nearest Western Union office to receive the award. Applicants will be eligible to receive one award every two years.

This fund is available to affected children from around the world. Two-thirds of the fund disbursements have been designated for non-US families; the other one-third is designated, but not limited, to US families. You will be contacted by the FIRST office if you have been awarded funding.

The application can be downloaded from FIRST's website at www.firstskinfoundation.org and emailed to the national office at LBreuning@firstskinfoundation.org, faxed to 215.997.9403, or mailed to the attention of:

Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST)
Diya & Aliya's Friends (DAF) Fund
2616 N. Broad Street, Colmar, PA 18915 USA

The deadline to apply for funds is October 1, 2017

Donations to Diya & Aliya's Friends (DAF) Fund are always appreciated and enable FIRST to make this fund available to more deserving families. Donations can be made at www.firstskinfoundation.org.

FIRST Attends 13th World Congress of Pediatric Dermatologists

The World Congress of Pediatric Dermatology is held every four years around the globe, and was last in the US in 1976. The meeting was held July 6-9, 2017, in Chicago, IL, and Moureen Wenik, FIRST's Acting Executive Director, attended this global event. A Patient Advocacy Village was built in the center of the exhibit hall, and all meeting attendees were invited to visit the patient advocacy organizations and learn more about the communities they represent. Through the involvement in the Patient Advocacy Village, Moureen met pediatric dermatologists from all over the world, including Germany, Honduras, Brazil, Bangladesh, and Turkey. These physicians are caring for children with ichthyosis, and both the physicians and the families are in need of more resources and information about the condition itself.The challenges that families face with an ichthyosis diagnosis are universal - they are very similar, no matter what part of the globe a person lives. FIRST offers Tele-ichthyosis as a tool to assist physicians with the treatment and diagnosis of patients with ichthyosis and related skin types. During a poster presentation session, FIRST's Tele-ichthyosis program was presented, and viewed by the meeting attendees. This is an important and meaningful way in which FIRST has a global reach, and can actively educate those around the world.

National Registry for Ichthyosis and Related Skin Types Plays Key Role in Yale Genetic Discovery & Development of Severity Index

The National Registry for Ichthyosis and Related Skin Types, supported by FIRST, allows investigators working in the field of ichthyosis access to the patient data they need to achieve medical breakthroughs. Without patient registries, the process of scientific discovery in rare disorders can be slowed or even halted. Studies of these conditions may take years to finish, but registries provide power in numbers. This power is especially important for studies of genetics and treatments for ichthyosis.

In a recent study, researchers from Dr. Keith Choate's laboratory at Yale University took a unique approach to examining genetic data provided by patients enrolled in the Ichthyosis Registry. The outcome was the identification of the genetic cause for a rare subtype of Progressive Symmetric Erythrokeratoderma (PSEK) and discovery that a commonly used acne medication, isotretinoin (formerly available under the brand name Accutane), could almost entirely eliminate the skin disease. The study results also highlight the central role of ceramides in skin health, and their value as common ingredients in many moisturizers.

Lead author Dr. Lynn Boyden states: "It was the power of the Registry which really enabled us to make this discovery. Without identifying multiple people with the same skin condition and mutation in the same gene, we really can't be sure that mutations in a given gene cause disease."

In another recent study, also from Yale University, the National Registry for Ichthyosis played a key role in developing the Severity of Scale index - a tool for clinical phenotyping and assessment of therapeutic response for many disorders of keratinization (DOK).

Individuals with ichthyosis are encouraged to enroll in the the National Registry for Icthysosis & Related Skin Types to enable continued progress in ichthyosis research.

Read Full Paper: www.firstskinfoundation.org/news/national-registry-for-ichthyosis-supports-genetic-discovery

Read Full Paper: www.firstskinfoundation.org/news/the-national-registry-severity-index

Learn more about the National Registry for Ichthyosis and Related Skin Types - http://www.firstskinfoundation.org/registry-faqs

Clinical Trials & Patient Recruitment Opportunities

1 A Trial of a New Therapy to Target the Redness and Scaling of Congenital Ichthyosis

This study has thus far identified that all evaluated ichthyosis subtypes (lamellar ichthyosis (LI), congenital ichthyosiform erythroderma (CIE), epidermolytic ichthyosis (EI) and Netherton syndrome), were tightly linked to increases in the same arm of the immune system that is activated in psoriasis, a common skin issue characterized by skin redness and scaling. The initial trial phase is to test whether a new, commercially available psoriasis medication, which specifically targets the arm of the immune system that is overactive in ichthyosis, will reduce redness and scaling. It is only open to adults 18 years and older, with one of the following conditions: lamellar ichthyosis (LI), congenital ichthyosiform erythroderma (CIE), epidermolytic ichthyosis (EI) and Netherton syndrome. An extension to children will be pursued if results are favorable. FIRST members who are interested in participating in the year-long trial (to be held in Chicago and New York City) should contact Dr. Amy Paller at apaller@northwestern.edu or 312.227.6486 for more information.

2 Congenital Ichthyosis Research Study

A medical research study at five sites will evaluate an investigational topical drug for ichthyosis. Researchers are looking for participants who meet the following criteria:

- Male or female (not pregnant or breastfeeding)
- 12 years of age or older
- Diagnosis of congenital ichthyosis (ARCI-lamellar or X-linked type)

- Qualified participants receive:
- Study-related skin examinations by a physician
- All study visits and study drugs
- Compensation for time and participation

For more information about enrolling, please contact the research study location nearest you.

Therapeutics Clinical Research
9025 Balboa Avenue, Suite 105,
San Diego, CA 92123
Contact: Christina West, Recruitment Supervisor
cwest@therapeuticsresearch.com
619.512.3376

John Browning, MD
Texas Dermatology and Laser Specialists
3320 Oakwell Court, San Antonio, TX 78218
Contact: Gabe Leal, Site Director
gabe@texasdls.com
210.660.2949

Christopher Bunick, MD, PhD
Yale Center for Clinical Investigation
2 Church Street South, Suite 401,
New Haven, CT 06519
Contact: Rebecca M. Chawarski
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203.737.8830

Amy Paller, MD
Northwestern University/Lurie Children's Hospital
676 N. St. Clair, Suite 1600, Chicago 60611
Contact: Benny Wu
Benny.wu@northwestern.edu
949.463.0946

Lawrence C. Parish, MD
Paddington Testing Co., Inc.
1845 Walnut Street, Suite 1650,
Philadelphia, PA 19103
Contact: hirakbrouth@yahoo.com
215.563.7330

continued

3 *Phenotyping itch in atopic eczema, psoriasis, and ichthyosis*

The purpose of this research study is to examine the genetic differences involved with itch in atopic eczema, psoriasis, and ichthyosis patients. Participants with the symptom of itch and without the symptom of itch are both needed. Participants must be willing to undergo a blood draw and 2 skin biopsies.

Researchers are currently recruiting patients who meet these criteria:

- 18-65 years old
- Have psoriasis, atopic eczema, or ichthyosis (must have genetic diagnosis)
- Have intense itch for more than 2 months or no itch
- Willing to undergo a blood draw and 2 skin biopsies
- Able to speak English
- NOT pregnant or nursing
- NOT involved in another research study

For more information, please contact:

Miami Itch Center Department of Dermatology
University of Miami Miami Itch Center Clinic: The Lennar Foundation Medical Center
5555 Ponce de Leon Boulevard Coral Gables, FL 33146
305.243.6704 (for appointments)
Study is sponsored by the Leo Foundation.

Pics, Positivity & Making Things Happen!

By Rochelle New

When I published my blog post for Ichthyosis Awareness Month I was simply setting out to accomplish a long overdue goal while sharing a story I was proud to tell. I never imagined the impact or the reach it would have and the opportunities it would bring. So here I am today, sharing the first of many posts as guest contributor to the Focus newsletter, elaborating on a question I was asked following the success of my essay: "Why Now?"

Though many people discovered me for the first time through my IAM story, I've been sharing a lot about myself since 2012 on my craft blog, Lucky Lucille. The internet knows me as a designer, a seamstress, and a knitter, and though I have mentioned my skin casually a few times on my blog I've never talked about Ichthyosis in full. As I gained more and more blog readers and social media followers the more it felt slightly dishonest not to talk about my skin in depth. It's such a massive part of my life and it influences so much of what I do and create, and yet so many people who know me know so little about Ichthyosis.

For the past three years I thought about writing something for IAM, but every time May rolled around I found myself feeling rushed, scared, lacking confidence, and generally not ready to launch such an intimate story for the World Wide Web to see. Quite simply, I hadn't actually planned to reach this goal. I had an idea in my head of what I wanted my IAM post to be, and it was clear it was going to take dedication to pull it off. The "why now?" was equal parts gut-instinct and calculated steps.

This year, I planned the post and it felt right.

You can't reach a goal without having a clear vision of the goal first, so I actually sat down and asked myself what I wanted to achieve by writing such a blog post. Obviously I wanted to raise awareness for ichthyosis, but it was equally important to me to present my skin, and myself, in a way that was full of unique beauty and inspiration. The gut-instinct sparked the goal and it was up to me to achieve it after that.

I started keeping notes on my phone of facts I wanted to include in the post, and I quickly realized I didn't want to share just facts. So much of what is already on the internet about Ichthyosis is "textbook" and clinical. I wanted my take on ichthyosis to be as inspiring and positive as it was personal, so I started crafting a story instead of a checklist.

I planned the story, and it felt right.

Because I'm a blogger I have all the camera equipment to take my own photos. I have a tripod and a remote timer which allows me to take excellent selfies so that wasn't necessarily a challenge for me. The challenge was capturing my skin in a way that came off as visually striking, not shocking. I wanted to portray enough mystery to invite readers to investigate my story. I aimed to capture myself in positions that were graceful, artful, and full of light. I wanted contrast, both literally and metaphorically. I wanted the tone of the photos to be soft even when my skin was not.

I planned the photos and they felt right.

The point I want to make is that any success in life, no matter how small, is equal parts gut-instinct and calculated planning. When something feels right you should pursue that feeling, but you can't stop there. You have to develop a plan, put in the work and follow through. Take charge of your instincts and make things happen. Map out all the steps, make several drafts, make changes, pivot your direction if you have to, and keep nurturing that gut feeling as you work toward your goal. This process is your head and your heart working together. This process is where confidence is born. The best version of yourself lives and thrives in the moment you trust your gut and make a plan to follow it.

What feels right to you today? Make a plan and make it happen!

Mind Over Matter – How Meditation Works & Why You Should Know About It

Dr. Mamta Jhavari

Dr. Mamta Jhaveri is an assistant professor of dermatology at Johns Hopkins University. Encouraged by her father, she grew up practicing yoga, which includes a component of meditation through breathing control. She has seen improvement in her asthma control, especially during flares, with deep breathing. She was more formally introduced to meditation and other integrative medicine practices during her master's degree in Complementary and Alternative Medicine at Georgetown University. She is motivated to incorporate eastern and western medicine practices to help her patients achieve the best control of their skin condition, as well as improve their quality of life. We sat down with Dr. Jhaveri to ask her a few questions about how meditation might benefit the ichthyosis community.

What is meditation and where did the practice of meditation originate?

Meditation refers to a broad variety of practices that focus on retraining the mind. The word meditation is derived from two Latin words: meditari (to apply oneself to study) and mederi (to attend). Meditation helps us step away from our normal thought processes and reconnect with our mind. By focusing on a single point of reference - such as your breathing, a mantra, walking or visualizations - the practice of meditation heightens your awareness of your thoughts, body sensations and surroundings without projecting judgment or resistance.

Meditation dates back to antiquity as part of numerous religious traditions and cultural practices, including rhythmic chants as part of prehistoric religions. Earliest written records document the practice of meditation to Taoist China and the Vedas in ancient India. Meditation today can be completed in many ways – it can be done sitting or in an active way. Commonly practiced forms of meditation include concentration meditation, mindfulness meditation, compassion based meditation and walking meditation.

What are the benefits?

Meditation can help improve focus and attention and has been shown to increase the grey matter in our brain. It decreases stress, anxiety and depression and increases our immune function. In previous studies, meditation has been shown to decrease levels of stress hormones, such as cortisol, interleukin 6 and total stress distress scores. Studies have shown improvement in control of asthma, high blood pressure, rheumatoid arthritis, chronic anxiety, depression and chronic back pain with meditation practice. In many studies, results are more pronounced after six months of meditation use.

How might the practice of mediation directly benefit those affected with ichthyosis?

The scaling, itching, pain and chronic inflammation of ichthyosis have a significant impact on the quality of life of children and adults affected with ichthyosis. A Swedish study also showed a significant impact on the quality of life in parents of children with congenital ichthyosis. The dry, itchy, painful skin of ichthyosis can interfere with sleep and normal day-to-day activities resulting in anxiety, depression and sleep deprivation. Chronic itch has been shown to activate areas of the brain similar to chronic stress and pain. Using MRI, previous studies have shown that meditation can de-activate these areas of the brain. Based off these studies, I believe that meditation could help decrease stress levels, decrease inflammatory markers and help better cope with symptoms of ichthyosis. Meditation has also been found to help decrease stress and anxiety in relationships and may also help the families of people with ichthyosis.

Do other rare skin disorders (or rare disease communities) benefit as well?

We conducted a small pilot study in subjects with chronic itch. Meditation helped improve their quality of sleep and their ability to cope with the stress of having a chronic skin condition and chronic itching. They reported that they were better able to recognize stressful triggers and use their breathing to prevent the sensation of itching from becoming overwhelming. They found that although meditation did not change their skin disease, they felt more in control of their skin by the end of the course. One of our participants commented that the "feeling of teeth clenching anger towards my itch has improved; and now when that sensation comes I don't feel as angry and can let the itch pass faster." Using our quality of life questionnaire, we found that the meditation class dampened the emotional impact of itch, which I believe would be similar for people with ichthyosis. A few examples of questions that showed significant improvement include: I am embarrassed by my skin condition; my skin often makes it difficult to concentration; and my skin condition makes me angry or irritable.

What are the instructions to begin a meditation practice? One of the most commonly available meditation courses in the United States is called Mindfulness Based Stress Reduction (MBSR). MBSR is a mindfulness-based meditation program that was developed by Jon Kabat-Zinn at the University of Massachusetts. Classes are offered throughout the country. Headspace is a popular mobile app that guides you through meditation sessions, which gives flexibility of time and location.

Although meditation is easily accessible, it is also easy to get frustrated. The most common roadblock to the practice of meditation is usually our mind and our own judgment – "I don't know how to meditate! I have too many thoughts! I will never be able to do this." Additionally physical discomfort, including low back pain, skin itching, and skin dryness, can interfere with your meditation practice. I encourage you to wear comfortable clothing and moisturize your skin before your meditation practice. Remember that the goal of your meditation practice is not to reach a state of thoughtlessness, but rather to enjoy being in the present moment. You won't see the benefits of meditation listed above immediately, but try to give your mind a break and enjoy the present moment.

References & resources:

The New York Times article on how to meditate and free resources for guided meditation, body scans and walking meditation.
https://www.nytimes.com/well/guides/how-to-meditate

Free online websites:

Free Guided meditations through UCLA: http://marc.ucla.edu/body.cfm?id=22

MBSR Practice Audio Files: http://health.ucsd.edu/specialties/mindfulness/programs/mbsr/Pages/audio.aspx

National Institute of Integrative Medicine Intro to Meditation: https://nccih.nih.gov/health/meditation/overview.htm

Have You Been on a FIRST to Know Call?

Here's what one FIRST to Know conference caller has to say...

"The call was particularly helpful in understanding the wide range of experiences that other members have had with X-linked ichthyosis. Every person's experience is different and people can respond differently to various types of treatment and care. I benefited from hearing what others have tried and discovered some new things that I can try myself. I deal with X-linked ichthyosis personally and while I do my best to find the right treatment and care, I don't really spend much time worrying about it. But I have never had to think about it from the perspective of a new or expecting parent and this call gave me an entirely different perspective and empathy for someone in that position; someone who might have grave concerns and worries without sufficient information to address their concerns."

-Scott Sorensen

FIRST to Know Call Schedule

September 24 – National Conference: What Are the Benefits of Attending?

October 29 – Darier Disease: Sharing Information

November 12 – ARCI-CIE: Sharing Information

2017 Patient Support Forum Calendar

September 16, 2017 -
Denver, Colorado

September 23, 2017 -
Las Vegas, Nevada

Register at firstskinfoundation.org/patient-support-forums

It’s Back to School Time!

Understanding Children’s Rights in School (Components of Section 504 and IDEA Protections)

--Dr. Diane Haggis

Navigating the school system and understanding what protections exist for children with special needs can be a daunting task. But understanding those protections is critical for parents who must advocate for their children – ensuring that the child is receiving every protection he is entitled to under the law.

Two specific protections for students with disabilities are included in federal law: Section 504 and IDEA (Individuals with Disabilities Education Act). Both provide protections and a free and appropriate education for all disabled students. Both are mandated in all states. State law can mandate moreprotection than the federal law requires but the states cannot provide less. IDEA is overseen by the U.S. Department of Education – specifically the Bureau of Special Education and Section 504 is an anti-discrimination law directed by the Office of Civil Rights.

IDEA was created in 1990 and reauthorized in 2004. This is an extension of the Education for All Handicapped Children’s Act which was enacted by the U.S.Congress in 1975. The law ensures that special needs children receive their education under FAPE (Free and Appropriate Public Education). These children are entitled to receive this free public education in the least restrictive environment necessary to meet their individual needs. This is a federal law binding in all states. IDEA guarantees that children with disabilities receive their education at no cost to the families; that this education be in the least restrictive environment possible to meet their needs; that they are provided with an appropriate assessment to determine the child’s needs – and with parental informed written consent; and that they receive supplementary aids and services including any support services that assist them in benefiting from their educational program. This includes an Individualized Education Program (IEP) which must be written annually for all children with disabilities. According to Peter Wright, who wrote the book “Special Education Law” (2016), “IDEA 2004 requires schools to use proven methods of teaching and learning based on replicable research…. The most important statute in IDEA is to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for future education, employment and independent living.” Wright goes on to explain that if a child’s disability adversely affects educational performance, this child would be covered under IDEA protections.

IDEA lists 13 different disability categories under which 3 to 21 year olds may be eligible for services including: autism; deafness; intellectual disability; orthopedic impairment; specific learning disability; and an Other Health Impaired category. Other Health Impaired means having limited strength, vitality or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, and that is due to continuing or severe health problems that unfavorably affects a child’s learning. Additionally, all qualified children from preschool through age 21 are eligible for services specific to their individual needs.

Additionally, under IDEA, a process exists that allows for a system to address any disagreements between guardians and the school district; specifically, a due process hearing. These hearings ensure that there are no changes made to a child’s program without prior notice to the parents and also provides a mechanism to resolve disagreement and disputes. The law requires that the school district try to resolve disputes prior to going to the state department of education for a due process hearing but there are special timelines that are required for action from the school district. IDEA requires that the school district set up a resolution meeting within 15 days of receiving notice that a parent has filed a due process complaint. There is then a 45-day timeline to reach a decision in the hearing. If unresolved, the matter goes to the department of education for resolution.

Section 504 is a civil rights law. The law applies to students and other individuals with disabilities. In his book, Wright reports that Section 504, however, does not have the same legal protections as defined in the special education law under IDEA. Although all special education students are automatically covered under Section 504, students with a 504 plan are not automatically covered under IDEA. Plans developed under Section 504 are developed to allow accessibility to buildings, modifications and accommodations in testing situations, and protects against discrimination these protections would include exclusion from school activities – for example not allowing children with disabilities to participate in school field trips. Section 504 requires the school to develop an evaluation that draws from a variety of sources including observations and parent and teacher input. This evaluation does not have to be written. 504 does not require written prior notice or a meeting before any changes of placement, only parental notification, and it does not provide for an Individualized Education Plan. The Office of Civil Rights has interpreted Section 504 to require districts to obtain parental permission for initial evaluations but again, those evaluations do not have to be written. There is a complaint process with Section 504 but it is through the Office of Civil Rights and not through the local education system. OCR has the authority to investigate complaints claiming a covered entity was discriminated based on: race, color, national origin, ethnicity, or ancestry; sex or gender; or disability. A parent or guardian may file a complaint with the school district’s 504 Coordinator. If unresolved, a complaint may be filed with the Office of Civil Rights in Washington, D.C.

Therefore, a child with a disability has specific protections under the law. Both Section 504 and Special Education law, IDEA, provide for individual protection and services for students with disabilities. Understanding those rights is paramount to helping to provide a strong program for a child in order for him to benefit from educational programs that specifically meet their individual needs.

References:

A Parent Guide to Special Education, the IEP Process and School Success (2016). Retrieved from:www.understandingspecialeducation.com

National Dissemination Center for Children with Disabilities. Categories of Disability Under IDEA (2012). Retrieved from: http://www.parentcenterhub.org/wp-content/uploads/repo_items/gr3.pdf

US Department of Education.(2016). Parent and Public Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools. Retrieved from: http://www.wrightslaw.com/images/inhouse/ocr.parent.guide.504.png

US Department of Education (2016). Retrieved from: https://www2.ed.gov/about/offices/list/ocr/complaintprocess.html

Wright, P. (2016). Special Education Law. Hartfield, VA: Harbor House Law Press, Inc.

Diane E. Haggis, Ed.D, is an Education Consultant with BHB Education Consulting. She can be contacted at www.BHBeducationconsulting.com and BHB.Educationconsulting@outlook.com.

Dr. Diane Haggis, author of the BHB Theory (Bonding, High Expectations and Belief in Success) has over thirty six years of experience in education, twenty of which was spent with special education populations and troubled youth. As an administrator in three institutional settings for at risk youth, the BHB theory was developed, identifying what teachers of troubled youth do to create a positive environment for their students. The theory offers a valuable guide in how to strengthen teacher practice for enhancing student skill sets necessary for academic success in alternative education programs. Dr. Haggis's work includes workshops on both her BHB theory and on Children's Rights Under the Law.

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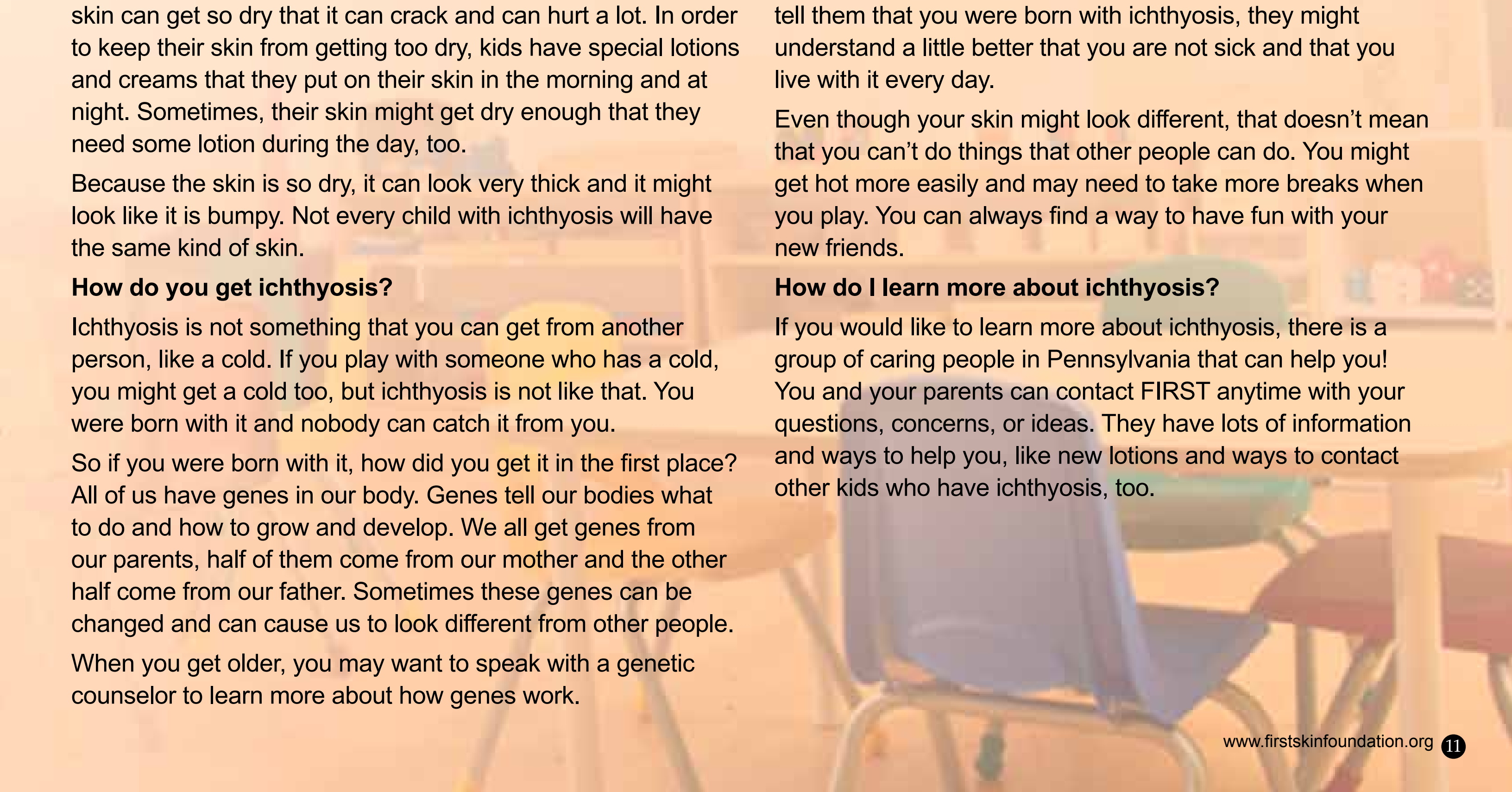
Just for Kids

Starting a New School?

Here are some easy ways to explain ichthyosis to new friends



Have your parents told you that you were born with ichthyosis (Ick – thee – oh – sis)? Have you wondered what that is? Have kids been asking you about your skin? Does it make you feel embarrassed sometimes? If you answered "yes" to any of these questions, this page will help you learn more about Ichthyosis and how you can talk to other kids about it, too.

What is ichthyosis?

Kids who have ichthyosis have very dry skin. Sometimes their skin can get so dry that it can crack and can hurt a lot. In order to keep their skin from getting too dry, kids have special lotions and creams that they put on their skin in the morning and at night. Sometimes, their skin might get dry enough that they need some lotion during the day, too.

Because the skin is so dry, it can look very thick and it might look like it is bumpy. Not every child with ichthyosis will have the same kind of skin.

How do you get ichthyosis?

Ichthyosis is not something that you can get from another person, like a cold. If you play with someone who has a cold, you might get a cold too, but ichthyosis is not like that. You were born with it and nobody can catch it from you.

So if you were born with it, how did you get it in the first place? All of us have genes in our body. Genes tell our bodies what to do and how to grow and develop. We all get genes from our parents, half of them come from our mother and the other half come from our father. Sometimes these genes can be changed and can cause us to look different from other people.

When you get older, you may want to speak with a genetic counselor to learn more about how genes work.

How do I talk to other kids about ichthyosis?

Sometimes other kids might ask you questions about ichthyosis. If you can talk to them about ichthyosis, it will make them feel better about talking to you and playing with you. They might be wondering if they can get ichthyosis by being around you. If you tell them they cannot get ichthyosis from you, they might feel better.

They might also wonder how you got ichthyosis. If you tell them that you were born with ichthyosis, they might understand a little better that you are not sick and that you live with it every day.

Even though your skin might look different, that doesn't mean that you can't do things that other people can do. You might get hot more easily and may need to take more breaks when you play. You can always find a way to have fun with your new friends.

How do I learn more about ichthyosis?

If you would like to learn more about ichthyosis, there is a group of caring people in Pennsylvania that can help you! You and your parents can contact FIRST anytime with your questions, concerns, or ideas. They have lots of information and ways to help you, like new lotions and ways to contact other kids who have ichthyosis, too.

2018 FIRST National Conference FAQs

Will we see you at the 2018 FIRST National Conference in Nashville, Tennessee?

It's the biggest ichthyosis support meeting you'll find! Medical professionals, FIRST staff, affected individuals and families from around the world gather together to learn, share information, have fun and build friendships for a lifetime. Here are some quick conference FAQs so you'll know what to expect. More details about the conference program, registration and hotel group discount coming soon!

When and where is the 2018 FIRST National Conference?

Friday, June 29 - Sunday, July 1
Nashville Airport Marriott
600 Marriott Drive
Nashville, TN 37214

What can I expect at the conference?
Members of FIRST come from all over the world to attend this three-day event. Lectures, breakout sessions, research initiatives and special events are designed to provide education and inspiration for all ages living with ichthyosis or a related skin type, as well as the physicians that care for them. Thus far, sessions include: skin care tips for your specific type of ichthyosis; caring for eyes, ears and scalp; a panel discussion with ichthyosis "teens in the know;" private breakout sessions for moms, dads, and grandparents to share stories and find support; research updates from world-renowned ichthyosis medical experts; and how to develop a 504 plan for your child with special needs…to name a few. Plus, there will be an exciting Saturday night talent show and dance party, a Nashville group excursion (TBD) and, as always, attendees will have the unique opportunity to schedule a clinical visit and meet one-on-one with our ichthyosis medical experts. There is no doubt you will leave the conference with many new friends and many tools for coping with ichthyosis. The 2018 FIRST National Conference program will be available later this fall. Learn more about past FIRST conferences at www.firstskinfoundation.org/national-conferences.

Who should attend the conference?
The conference is beneficial to those affected with ichthyosis or a related skin type, as well as their families or support network, and medical professionals interested in learning more about ichthyosis and related skin types. Many of our members find it beneficial to bring relatives and close friends to come and learn about ichthyosis. Additionally, the conference is a unique opportunity for product developers, pharmaceutical companies and researchers to engage with patients one-on-one and learn more about their specific needs and challenges.

When can I register for the conference?
An opportunity to register with early-bird rates will be available on our website October 1. The 2018 winter and spring issues of the Ichthyosis Focus newsletter will also include a registration form that can be filled out and mailed to FIRST.

How much does it cost?
Registration Rate: January 1 to June 1, 2018
Adult $300 per person
Child $120 per person (age 5-12)
Toddler $35 per person (age 2-4)

What is conference registration deadline?
June 1, 2018.

When can I reserve my hotel room?
A discounted group rate will be available at the Nashville Airport Marriott beginning on November 1, 2017. The rate for FIRST's block of rooms will be $159 ++ per night. The conference room rate is available from June 27 to July 1, 2018.

There will be complimentary WiFi in guest rooms, and complimentary self-parking.

Reservations must be made by 5:00 pm CST on Tuesday, June 5.

Room reservations are separate from the conference registration fees.

Is there transportation from the airport to the hotel?
Yes, the hotel offers free shuttle service from the airport.

Is there childcare provided at the conference?
Yes. Childcare is $15 per child for the entire conference. A professional child care company has been contracted.

What is the dress code during the conference?
Come as you are! Wear comfortable clothing and shoes.

What type of medical research will be conducted at the conference?
Dr. Keith Choate and his team from Yale University will be conducting free genetic testing as a part of the National Ichthyosis Registry, partially-funded by FIRST.

What is a clinical appointment?

Scheduling a clinical appointment at the conference is a unique opportunity to meet one-on-one with our ichthyosis medical expertsor the opportunity to play a key role in the advancement of ichthyosis research. There are three opportunities for clinical visits:

1. 15-minute brief visit with a group of knowledgeable dermatologists.
2. 1-hour visit to enroll in the Ichthyosis Registry, which will also include an opportunity to meet with knowledgeable dermatologists.
3. A visit for those who have already enrolled in the registry This is an opportunity for patients to update their information in the National Ichthyosis Registry, managed by Dr. Keith Choate's lab at Yale University.

How do I schedule my clinical appointment?
If you are interested in participating in a clinical visit, check the appropriate box on your registration form. The staff will assign appointment times. You will be notified of your appointment time by June 15, 2018.

Is there financial aid available?
Yes, there are conference scholarships available. Applications will be available November 1. Application deadline will be February 1, 2018.

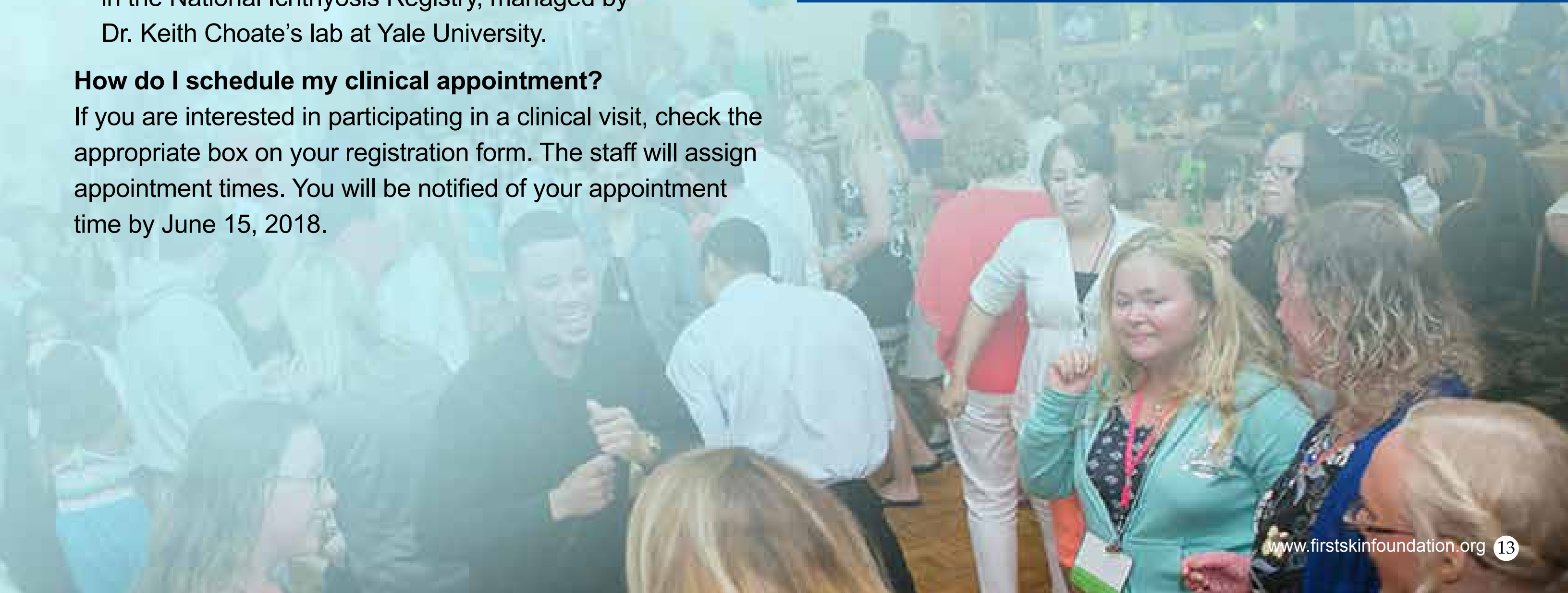
Who can I contact for more information?
Lisa Breuning is FIRST's conference director and she is happy to assist.Email Lisa at lbreuning@firstskinfoundation.org or call the national office at 215.997.9400.

Announcing Stephanie Turner National Conference Scholarship Award

In honor of our beloved friend Stephanie Turner, a beacon of hope and inspiration to all those in the ichthyosis community, a scholarship,sponsored by a generous and compassionate family in the FIRST community, will be awarded for $1000. The scholarship may be used toward conference costs of travel, registration and hotel for one family or individual. More information about applying for the Stephanie Turner National Conference Scholarship will be available online this fall.

Don't miss FIRST to Know Call!

September 24 – National Conference: What Are the Benefits of Attending?



GRASSROOTS ARE GROWING!

Ichthyosis Awareness Month (IAM) National Fundraiser Was a BIG Success!

This past May, FIRST hosted an IAM FIRST national online fundraiser. We are delighted to report that our IAM partners answered this fundraising challenge in many creative and inspiring ways! Some shared their stories on their personal fundraising pages, others hosted unique and fun events, while yet others ran 5k races! We even had a mom and daughter celebrating Cinco de Mayo with a fundraising tea party! While the events and awareness raising differed from partner to partner, one thing remained the same: These fundraisers were more excited than ever before to share their personal story of living with ichthyosis or a related skin type and how FIRST has impacted their lives.

Thanks to the following 20 IAM FIRST partners, over $40,528.60* was raised during the IAM FIRST fundraiser to support FIRST operations, the backbone of FIRST. FIRST operations includes all of FIRST events, like support forums and FIRST to Know conference calls, and of course, our biennial National Conference. Plus, operations includes the production of the Ichthyosis Focus newsletter and the maintenance and growth of our vast library of online resources for all stages of life with ichthyosis. We'd like to recognize and thank our compassionate IAM FIRST partners including:

Sarah Carroll
Lauren Gaffin
Bridget Pettitt
Kisha Jones
De Fasciano
Roland Coates
Julia Stern
Kathleen Patterson
Marcia Richmond
Hunter Hornback
Kelly Robinson
Landon Liff
Suzanne Phelps
Gina St Lawrence
Amneet Anand
Yesenia Hornback
Mackenzie Tober
Ethan Edwards
Kimberly Cole
Jesse Medina

A special thank you to the Scholl and Briggs families for their generous IAM match day sponsorships!

**** Will you help us raise $24,472 and reach our National Fundraising Goal of $65,000? Every dollar counts towards FIRST operations, including events like the Patient Support Forums, the National Conference and the Ichthyosis Focus Newsletter. (Did you know it costs $17,200 to print and mail 4 issues of the newsletter each year?). You can donate at firstskinfoundation.org, mail a check or call the office at 215-997-9400. We'd love to hear from you!***

Ichthyosis Awareness is Officially Raised!

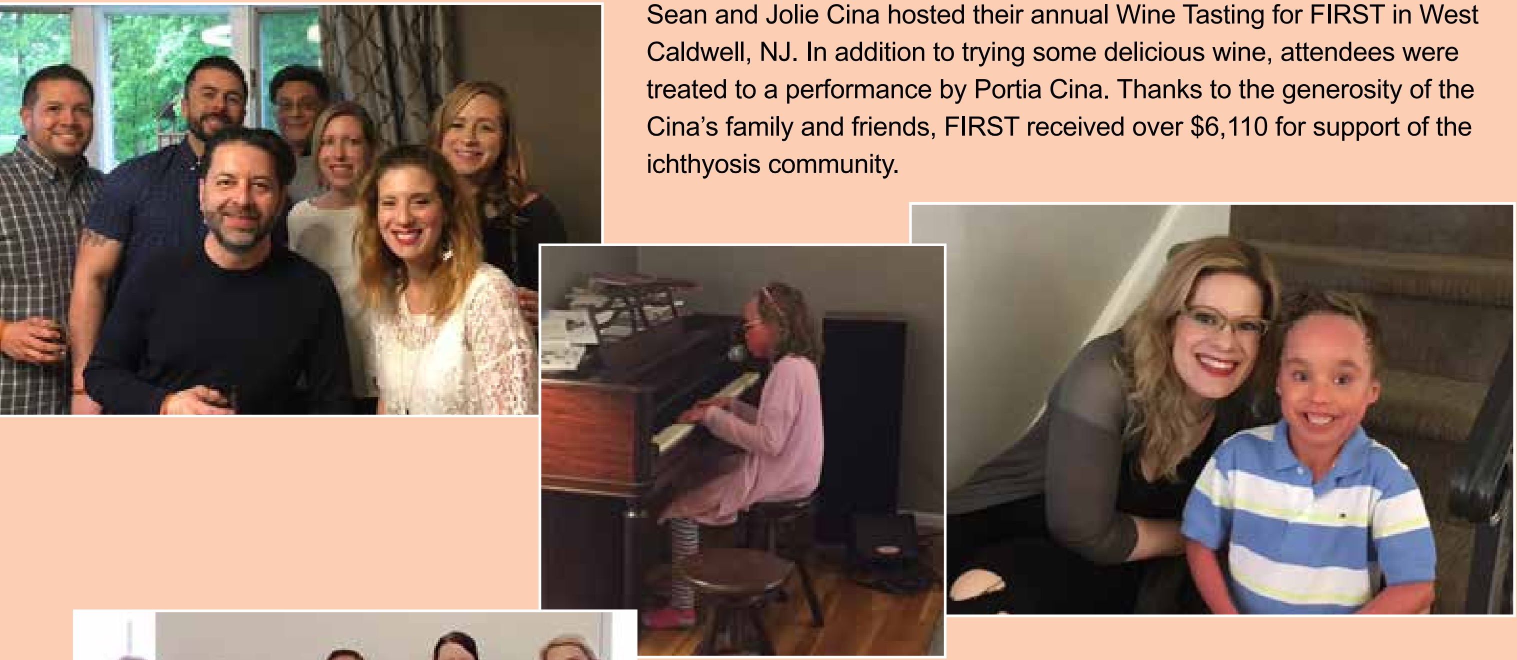
In addition to I AM FIRST, members all over the United States hosted events in celebration of Ichthyosis Awareness Month.

On Friday, May 5, Tracie & Bailey Pretak brought their Release the Butterfly Tour to Philadelphia and performed the night before the Philadelphia Patient Support Forum. Not only was it fantastic to see Nicole Saylor, Tracie and Bailey Pretak and friends perform, but it also created a fun time for FIRST families to mingle prior to the Patient Support Forum. A big thank you the McTernan Family for gathering items for a raffle. Thanks to all the effort of the McTernans and Pretaks, FIRST received $1,405 in funding!

The Ace in the Hole Foundation held their annual Beach Run and Walk in Lido Beach on Saturday, May 13. This event and the Ace in the Hole Foundation, run by FIRST member Greg LiCalzi, has supported FIRST for several years.

April Johnson hosted an ichthyosis awareness event at Launchpad Brewery in Aurora, CO. The event featured a percentage of Launchpad's sales benefitting FIRST and a silent auction. Children also had the chance to explore a Flack Ambulance, which was on display at the event. This event raised over $1,000 for FIRST's programs and services. Thanks, Johnson Family!

Sean and Jolie Cina hosted their annual Wine Tasting for FIRST in West Caldwell, NJ. In addition to trying some delicious wine, attendees were treated to a performance by Portia Cina. Thanks to the generosity of the Cina's family and friends, FIRST received over $6,110 for support of the ichthyosis community.



Priority Health in Michigan hosted a Jeans Day for FIRSTon April 28 and raised $590 for FIRST. Thanks to Kristen Wilson, who organized this event in honor of her wife, Chelsea who has epidermolytic ichthyosis.

FIRST Night Out

Baseball fans across the country have been coming together to root for their favorite sports team and support FIRST. Kicking of the baseball season, the Matt and Lauren Kocher hosted their annual FIRST Night Out with the Pittsburgh Pirates on May 21. Thanks to the generosity of the Kocher's family and friends, FIRST raised over $8,500.

Also that month, the Beard Family hosted a night out with Washington Nationals on June 24. The Nationals had a big victory over the Cincinnati Reds. Thanks to the hard work of the Beard Family, FIRST raised over $2,600.·

On June 16, Marc and Denise Benedetto and the Saccente family joined together to hold the FIRST Night Out with the New York Mets. The Mets may have lost to the Nationals, but FIRST was the big winner of that game! Thanks to the efforts of the Benedettos and Saccentes, FIRST received over $20,000 from the game.

FIRST
Foundation for Ichthyosis & Related Skin Types®
Educate • Inspire • Connect
2616 N. Broad Street • Colmar, PA 18915

Third Annual Patient Picnic in Chicago, September 23

Date: 09/23/2017
Time: 1:30pm – 4:30pm
Location Information:
Mallinckrodt Center
1041 Ridge Rd • Building "A"
Wilmette, IL 60091
Phone: 847-256-9623

Please join Dr. Amy Paller and her team from Northwestern and Lurie Children's for a fun and educational get-together! This is a great opportunity to build a local support network, and connect one-to-one with leading ichthyosis medical experts. The afternoon will include three facilitated discussion groups from 3:00-4:00: Parents; Teenagers; and Adults with Ichthyosis. You'll also enjoy a magician and balloon artist!

RSVP by September 15 by emailing Patricia.Folliard@nm.org