

Redefining Beauty

How two members are succeeding as models and challenging beauty standards



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My warm hello to you. Our staff, board of directors, and FIRST Medical and Scientific Advisory Board, hope you and your families are safe.



Together, our team is working to help the ichthyosis communities through this difficult period amidst the COVID-19 pandemic. We thank you for your engagement with FIRST.

Our newsletter goes to print amid major changes at FIRST. We will soon welcome a new leader for our staff and for FIRST! Our team has been in the process of reviewing a number of highly qualified candidates. Also, in the coming months FIRST will name our next board president to guide our board comprised of passionate and capable individuals. These new leaders will make a great impact on your foundation. We look forward to communicating much more about these changes soon.

We chose to have our spring newsletter provide insight into how FIRST's board operates behind the scenes. As president of FIRST's Board of Directors and chair of FIRST's Executive Committee, I am privileged to have worked with over three dozen board members since I joined FIRST's board in 2012. As I look through this list of friends, I am humbled by the immense commitment of time, energy, and emotion each person has poured into FIRST. By my calculation, this group of volunteers—our collaborative team—has contributed more than 8,000 hours of service to FIRST since 2012. These hours have been given to help those affected by ichthyosis and to make a positive difference in your lives. Volunteering for FIRST changes lives. My volunteering has also changed my life, and I am so thankful to have had

the honor to serve you. I encourage all of you to think how you can help FIRST advocate for the ichthyosis communities. You can reach out to me directly at jhoerle@stoneruncapital.com. We are always excited to have new volunteers!

FIRST's leader and the officers of FIRST's board comprise our Executive Committee. Our current committee members are First Vice President Tracie Pretak, Second Vice President Mark Evans, Chief Financial Officer Sean McTernan, Secretary Brian Stern, and myself. Our committee meets formally once a month; every week, numerous individual conversations and countless emails address pressing member issues, foundation decisions, and strategic issues. The topics span all functional aspects of FIRST, from member engagement to research plans to event planning to fundraising to staff development to financial management. While FIRST is a small nonprofit, we have more than 20,000 members across the globe, and we have the same needs for management and oversight as the largest nonprofits in the world. Recent discussions have focused on looking forward several years and strategizing to make sure FIRST is connected with the small and large biopharma companies that are working or will be working on breakthrough therapies. There is much to be excited about and the executive committee works to make sure FIRST brings this to you.

FIRST's Board of Directors is your board. We hope you enjoy learning more about how we volunteer to serve you.

My warmest regards,

Jeff Hoerle
FIRST Board President

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Improve lives and seek cures for those affected with ichthyosis or a related skin type.

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National Conference Postponed to 2021

Due to the COVID-19 pandemic, the FIRST 2020 National Conference has been postponed to summer 2021 in Providence, Rhode Island. For 37 years, the FIRST National Conference has been a beacon of hope, health, and support. It is with great sadness we delay this year's conference.



The connections and knowledge shared within our community make FIRST vibrant and vital. Stay tuned as we launch new programs to foster member connections digitally. We hope you will join us in 2021 for an unforgettable conference!

COVID-19 & Ichthyosis

FIRST is grateful to Dr. Len Milstone, Dr. Amy Paller, and Dr. Moise Levy. Together, with the FIRST Medical and Scientific Advisory Board, these doctors have provided ichthyosis-specific interpretation of the virus data as it emerges, answered member questions, authored statements, and presented guidance through a live webinar format. Check our website for the most up-to-date information on COVID-19, and how you can connect with FIRST during this time.

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Ichthyosis Awareness Month

Every May, we celebrate Ichthyosis Awareness Month (IAM). FIRST and many of our members join together to use our voices to raise awareness about the hopes and difficulties of living with ichthyosis.

There are many ways to participate. In past years, members have hosted awareness days or fundraisers for FIRST. Others have handed out information or talked to neighbors, friends, coworkers and their communities. Some have contacted their local media and shared their story with a broader audience.

Whatever you decide to do, we want to hear about it! Share your story on social media using hashtags #IAM20 and #IchthyosisAwareness. FIRST will be posting throughout the month, as well, and you can help spread our messages further by sharing.

Let's jump in and see how, as a community, we can make a real difference this year.



Redefining Beauty

by Bailey Pretak

In a world where beauty is often confined to a predetermined mold, we have two of our own who are stretching outside of that confinement to redefine beauty and what that means. As someone who has challenged the view of beauty in my own way by competing and winning beauty pageants, I was thrilled to reach out to two members of our ichthyosis community to find out exactly how they are navigating the world's beauty standards and what it means to them.

Jeyża Gary is 21 years old and lives in North Carolina. Jeyża, who is affected with ARCI lamellar ichthyosis, has had a breakout year in modeling -- appearing in advertisements for Target and on the cover of Glamour UK. Harper Foy is a spunky 4-year-old from Washington with harlequin ichthyosis. Her mother, Angie Foy, says Harper is on a mission to show the world that beauty has no bounds.

Jeyża and Angie answered my questions about their experiences modeling with ichthyosis.

BP: I am looking forward to learning more about how these opportunities came about for both of you. Let's start with this. Have you always wanted to model? If so, when did you know?

JG: I haven't always wanted to model. Earlier in my life I had, and still have, an affinity for music. So much so, I pursued a degree in vocal performance. I realized I wanted to model in the summer of 2018.

AF: Harper has this personality that is unmatched. She is special and we knew that from the day she was born: her fight and strong will to not let people define her, but to write her own story and redefine beauty.

BP: Well, congratulations to both of you for your modeling contracts. This is so exciting for our community! Is the contract something you pursued, or did it just happen?

JG: My agency reached out after I submitted my digital photos to their site.

AF: Just happened. We have many life experiences and I was told by those close to us...she will never model. And like Harper's strong will, she said this

will not define who she was. So, as a mom, I decided that I would fight for her. I would show the world how pretty Harper is and that she can meet the necessary model standards. Even when we were told no, we fought and blessed by the Lord, good things happened.

BP: Jeyża, for those who might not know, what exactly does a modeling contract do? What are the benefits of signing one?

JG: A modeling contract affords the model opportunities to interact and work with clients (i.e. brands, stores, businesses, etc). Having a contract is a definite way to get castings and bookings. The model isn't freelance. There is an agent in place working on the model's behalf, making the job a bit easier.

BP: And what does a typical photoshoot day look like?

JG: Long, very long. Normal shoot days start early in the morning. They are anywhere from 3-4 hours long and I have multiple shoots in a day.

BP: Does Harper have any photoshoots coming up?

AF: We have one with a local photographer for Easter with



Raneyday Photography and we have a few other interviews lined up for the next few months, so we are very busy!

BP: For both of you, what do you hope comes from people seeing someone with ichthyosis in an ad?

JG: I hope a massive amount of confidence and dignity ensues. If I grew up and didn't see ichthyosis represented, I can only imagine how many others have this story. We're changing that, taking up space and being unapologetic.

“Though it makes those that have [ichthyosis] appear different, the reality is they are no different than anyone else.”

“You aren't called to fit in. Stand out.”

AF: Awareness. There are many forms of ichthyosis and though it makes those that have it appear different, the reality is they are no different than anyone else.

BP: Jeyża, your photos have made it into prominent locations like Target and Glamour UK Magazine. What was your reaction when you first saw these?

JG: I stared at the Target ad for five minutes and I asked my friend if that was really me. I didn't take time to feel the reality of what I'd just done and what it meant. I just went to California, completed my job and came back to my norm. Glamour still hasn't hit me yet. I know it happened, but I haven't processed how huge it is and the history that was made.

BP: Continuing with this, what is your dream in modeling? Any particular designer or brand you'd love to work with?

JG: My dream is to be a household name. It is my full intent to book big brand names and infiltrate the media. I'd love to walk for Marc Jacobs!

BP: For Harper, what is her favorite part of modeling and what does she want the world to know about people with ichthyosis?

AF: Harper loves the dancing and music on set. When we take pictures, she always has music and some sort of dance move going on. She wants the world to know that people with ichthyosis are no different than everyone else. They may look different or have some issues related to their skin, but deep down they are no different.

BP: What advice do you have for other moms of children with ichthyosis?

AF: One of my favorite quotes: "I've never met a strong person from an easy past."

BP: Jeyża, what advice do you have for a young girl, like Harper and countless others, growing up with ichthyosis?

JG: My advice is simple, do not apologize for who you are. You were made special and you matter. Choose your own happiness in a world that loves to push an agenda of perfection. You aren't called to fit in. Stand out.

BP: Well said! And that advice is something that anyone in our community can learn from. Are there any people or models who inspire you?



JG: Everyone that takes a chance and leads a fearless lifestyle inspires me. Bold, courageous and unapologetic people inspire me.

BP: Can both of you share a little more about yourself?

JG: I'm a Virgo and I can't go out to eat without organizing everything on the table! LOL I'm a Special Education major. I'm always smiling, even though I don't look like I smile in all my pictures.

AF: Harper enjoys playing anything with a ball...football, soccer, basketball, golf...she plays everything. Also, she likes going to the park and playing with her toys.

BP: Jeyża, any concluding remarks you'd like to share?

JG: Anyone who has ichthyosis is not required to view themselves as a victim. We are victorious. We live a life others don't understand and we aren't obligated to coddle anyone's ideas of normalcy. Walk with your head held high. You are meant to be here. Your life is not a mistake, no matter how much society tries to convince you otherwise.

BP: On behalf of FIRST and others living in our skin, thanks to both of you for being brave and going out there shining your light. The world finally sees us! I can't wait to see what the future holds.



Photos: Sophie Kietzmann

FIRST Committees in Action

In 2019, FIRST reorganized its volunteer committee structure to better meet member needs and ensure the success of the organization. Read these updates from each committee chair to understand more about their purposes and current efforts.

Finance

Sean McTernan

My name is Sean McTernan and I am a member of the FIRST Board of Directors and the CFO. Our family was introduced to FIRST shortly after the birth of our youngest child, Claire, who was born with a collodion membrane and eventually diagnosed with ARCI. Our family is grateful for the role that FIRST has played through their support, advocacy and connection they have provided to the ichthyosis community.



Consistent with what was shared in the 2019 FIRST Impact Report, we remain in a sound and healthy financial position. There is great benefit of having a strong financial position during times of uncertainty in the world and market volatility, like those we experience today. This financial strength is possible only through the generosity of our donors and those who contribute to our great cause.

This is a busy time of year for the Budget and Finance committee as we are working hard to complete our 2019 audit and IRS Form 990 – a tax form that most tax-exempt organizations are required to file annually. This form provides the IRS with an overview of our organization's activities, governance and detailed financial information.

The completion of these reports is being overseen by our committee, in conjunction with members of the Staff, our outsourced financial accounting advisor as well as our independent auditor.

Interested in Volunteer Opportunities?

Contact Denise Gass at dgass@firstskinfoundation.org

Board Development

Gabriele Richard, MD

The main goal of the Board Development Committee is to ensure that our organization has now and in the future a strong, committed, highly skilled, energetic and forward-looking Board of Directors. The committee determines what special skills the Board will need in the future (such as legal, accounting/finance, education or marketing/communication expertise), recruits and evaluates candidates, and assists them in finding their footing with a mentorship program. Recently, we are focused on planning for a transition as Jeff Hoerle's term as President comes to an end this year.

As chair of this committee, I am humbled by your trust to help shape the future of FIRST, and being able to give back to this generous organization and its members who have supported my research career on erythrokeratoderma, Netherton syndrome, and other ichthyoses.

Research

Phil Fleckman, MD

Many members of FIRST (like you!) are interested in research to help affected individuals and their families. The goal of the FIRST Research Committee is to address these interests.

We review grant proposals for potential to improve the lives of affected members – regardless of whether it addresses a basic science question or a more clinical concern. Since 2006, more than 50 grant applications have been submitted. Approximately 30 percent of the grants were funded, totaling over \$2 million towards research to support our ichthyosis community.

As more is learned about the basis of the ichthyoses, interest by the pharmaceutical industry in clinical studies has grown. The committee vets proposed studies to insure merit and helps FIRST staff interact with these companies.

Strategic Planning

Beth Hampshire

I wanted to become more involved in FIRST as an affected adult, so that I could support the organization that was so important to my family for the first years of my life. I feel extremely grateful to lead the Strategic Planning Committee and be part of such an important piece of the foundation.

This committee creates the roadmap used by the staff and other committees. It helps guide our decision-making and collect data to inform us. We work with other committees, members and the medical community to develop goals for the organization and a plan to achieve them.

The committee has developed a three-year strategic plan. The plan has three primary goals: enhance FIRST's value to members through programs, services, and communication; retain and broaden donations to the organization annually; and improve operational and financial capabilities of the organization. We are continually working to make sure that FIRST meets the needs of the membership and supports the continued success of the organization.



Advocacy, Programs & Services

Jolie Cina

Hello everyone! I am proud to be the mother to two amazing children, Portia (12) and Myles (9), who were born with ichthyosis en confetti. They inspire me every day. I became involved with FIRST soon after Portia was born. FIRST has provided amazing support to our family over the years.



I am grateful for the opportunity to give back by serving on the Board and now leading the Advocacy, Programs and Services Committee. I encourage everyone to become more involved with the organization on any level. I like to think that though our team is small, we are mighty -- together we can do a lot to meet the goals we have to support those affected and raise awareness in our communities and beyond.

The goal of the Advocacy, Programs and Services Committee is to add value to members by providing direction on programs, ensuring consistency with the mission of FIRST and its strategic initiatives. This includes developing programs related to advocacy, events and scholarships; ensuring programs provide value to members; and implementing communication, marketing and social media strategies to increase member engagement and awareness.

Fundraising

Brian Stern

My wife, Julia, and I have two daughters: Ava (13) and Bella (11). Bella has ARCI - CIE. She is an inspiration to so many with her grace, her attitude, her fight and her love of others. She is an overcomer and a difference-maker. She is a great daughter, a great sister and a great friend.



I am the Secretary of the Board of Directors at FIRST and the Chair of the Fundraising Committee. It is a great honor and a privilege to be part of shaping the future of FIRST. This committee is vital: it creates opportunities, provides scholarships and helps people get to the National Conference. It also directly supports FIRST's mission to improve lives and seek cures for those affected by ichthyosis and related skin types.

I am so excited about leading the Fundraising Committee as I think there is great opportunity for stronger member engagement -- increasing fundraising dollars at the grassroots, corporate and pharma levels -- that will result in additional funding for programs, research and events to foster a greater sense of friendship and community.

Important Information about Pharma and Fighting Rare Diseases

Biopharmaceutical research is bringing new hope to people living with ichthyosis. Industry researchers are making significant progress in rare diseases as new science has created enormous opportunities.

This is an exciting time to advance research -- and you can play a part.

FIRST promotes the advancement of research through our support of the Ichthyosis Registry at Yale, by awarding grant funding to promising studies and investigators, and by promoting clinical trials and other studies seeking member participation.

With increasing regularity, FIRST is approached by biopharma companies looking to develop treatments for ichthyosis and related skin types. FIRST can help investigators access our community of affected individuals -- who can play an essential role in research.

The FIRST Research Committee thoroughly reviews these requests before they are posted at firstskinfoundation.org/clinical-trials and shared with our members.

Researchers use trials to learn whether a new treatment works and is safe for people. It's important that participants are fully informed and aware of the risks and benefits of participation. When joining a trial, here are some important reminders:

- Participation is voluntary.
- Read all documents, ask questions and fully understand what is required (blood draws, appointments, travel, etc.) before consenting to participate.
- Some trial participants may receive placebos, which means they are not receiving real treatment. This helps ensure that study results are valid.
- Clinical trial sites are often set up across the country (or around the world) to make it more convenient for patients. Participation will likely involve several visits to the clinical trial site.
- Financial compensation may be available for a participant's time and travel.
- Participants may be asked to stop medications or amend usual treatment during the study period.

By partnering with the FIRST community, product developers and medical investigators have a more direct opportunity to accelerate research for better treatments and eventual cures. The key to their success may be you.

2616 N. Broad St
 Colmar, PA 18915



Jean O'Brien: Celebrating Life

March 2, 1931 – January 23, 2020

Jean O'Brien always sought joy. She was an extrovert, a true people person, said her husband Warren. One year, as Warren's white beard grew out, Jean convinced him to dress as Santa Claus. That one year became 25 Christmas seasons with the two of them dressing as Santa and Mrs. Claus, bringing joy to countless children.

Jean O'Brien, one of FIRST's oldest affected members, passed away in January at 88 years old.

Jean, who was born with ARCI - lamellar ichthyosis, was a fixture at FIRST events for many years and a reliable resource for members of all ages.

One of her earliest friends through FIRST was Ellen Clemmer, former president of FIRST. Ellen and Jean were often the oldest members at FIRST conferences. "Our reason for being there was not to learn about ichthyosis, because we had lived a lifetime with it," Ellen said. "We were there to provide encouragement and hope to young parents and young adults."

Ellen recalled 'crashing' a conference session for parents of affected children, and delivering a powerful message. "We stood up together and said we wanted the parents to see two collodion babies all grown up," she said. "We wanted them to know that we had lived good lives, had great jobs,

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were happily married, had families and friends, traveled, and had done everything we wanted to do."

Jean was born in Schell City, Missouri, in 1931. She met Warren while playing music at her church. The two married in 1959 and later moved to Florida. After 60 years of marriage, Jean and Warren were still very much in love, Warren said, and Jean was still bringing joy to others. Her tombstone reads "a joyful Christian" which perfectly captures her spirit, he said.

Dr. Leonard Milstone recalls meeting Jean at a FIRST conference many years ago. Instead of asking questions about herself, she wanted to know how he was doing, he recalled. She became one of his patients and traveled for annual appointments at Yale University.

"I think one reason she kept making those visits was to help young clinicians learn about ichthyosis," said Dr. Milstone, who credits Jean with encouraging the careers and research interests of other doctors – and contributing to research herself.

Jean traveled less frequently as she aged and Dr. Milstone realized how much he appreciated and anticipated her yearly visits. "We all can learn a lot from her positive attitude and cheery disposition," he said.

Added Ellen: "Jean will be so missed in the FIRST community. She was always willing to share her experience, strength, and hope with others."