

## 2019 Impact Report

### YOU Make Our Work Possible

#### A letter from our President

I am excited to connect with you! On behalf of the staff at FIRST, our Board of Directors, and our Medical and Scientific Advisory Board, I thank you for your engagement and support. Eight years in, I still pause every time I hear stories about our members' lives. FIRST affects change in one-on-one conversations with new parents all the way to rare disease advocacy on Capitol Hill. **Simply put, your contributions allow us to do vital work for the ichthyosis community.**

With our 39th anniversary approaching, FIRST continues to grow. Our number of affected members has doubled in the past five years—now around 8,000 and counting! The connections in our community span the globe, and our strategic plan strives to provide programs and services for in-person engagement, to facilitate social media support, and to remain a trusted resource globally.

In 2018, your gifts allowed us to subsidize 30% of the cost to attend our National Conference in Nashville—allowing it to reach more people than ever, 500 people. We are now deep into the preparations for our National Conference in Providence in 2020. We hope to see you there! As before, we'll have clinical screenings with the world's leading ichthyosis

researchers. The past year has seen great strides in genetic understanding, and conversations with these researchers demonstrate and contribute to the remarkable knowledge they gain every day.

FIRST benefits from the talents and passionate work of so many people. I thank deeply Moureen Wenik for her twelve years of service to FIRST and her tireless devotion to members. I thank our staff, our board and committee volunteers, and our dedicated researchers and clinicians. I thank each of you for believing in FIRST, and supporting affected individuals like my daughter, Alexandra.

Together, we share, we connect, and we work to achieve FIRST's mission: *To improve lives and seek cures for those affected by ichthyosis and related skin types.*

My warm regards,



Jeff Hoerle  
President, FIRST Board  
of Directors



# YOUR Gifts are Needed Now More Than Ever

With the rise in digital communication, more people than ever are finding FIRST. Though based in the United States, the reach of FIRST grows more global every year. Every affected individual and his or her family are automatically qualified as “members” of the FIRST family. Ichthyosis is extremely rare, so each new member we welcome brings the potential to contribute to our shared formal and informal understanding of the diseases. The more we grow, the more we learn. The more we learn, the more we can share.

## Total Membership



Every year, approximately:



200-400

U.S. babies are born with moderate to severe ichthyosis



10  
college  
students  
receive  
UFIRST  
Scholarships



130  
new families call  
the FIRST office

## YOU Create a Community of Kindness

Your gifts fund some of the world's only programs and services for ichthyosis and related skin types.

### Programs

- Patient Support Forums
- National Conference
- Ichthyosis Focus Newsletters and Emails
- Informational Conference Calls
- University Scholarships
- Children's Pen Pals
- Ichthyosis Registry at Yale
- Research Grants

### Services

- Physician Referral
- Tele-Ichthyosis (Coming 2020!)
- Education Cards
- New Member Support
- Genetic Diagnoses
- Educational Resources
- Clinical Trial Information
- Rare Disease Advocacy

## YOUR Gifts Change Lives and Promote Awareness

Behind every number and statistic at FIRST there are human faces and beating hearts. A new family terrified in the NICU. A young teen thinking about potential careers. A first-grader struggling to tell his class about his skin. An adult wondering how ichthyosis will affect her chemotherapy. These are the members we are honored to support with listening ears, databases of resources, and connections that might just change lives.

### FIRST on the Road

6  
Patient Support Forums in  
2019 with 116 attendees

504  
attendees at 2018  
National Conference

25  
attendees at Mom's  
Support Retreat

### FIRST in the Office



Lisa Breuning, Director of Operations, has handled the funding of more than 40 financial aid requests for 3 different programs in 2019



Chris Wassel, Director of Community Engagement, has handled more than 900 online communications in 2019

### Ichthyosis Registry at Yale University

The Registry is now the largest pooled resource of genetic information for affected ichthyosis individuals in the world! FIRST underwrites the cost of the genetic testing, providing a free definitive diagnosis for better, more targeted treatments...and eventual cures.

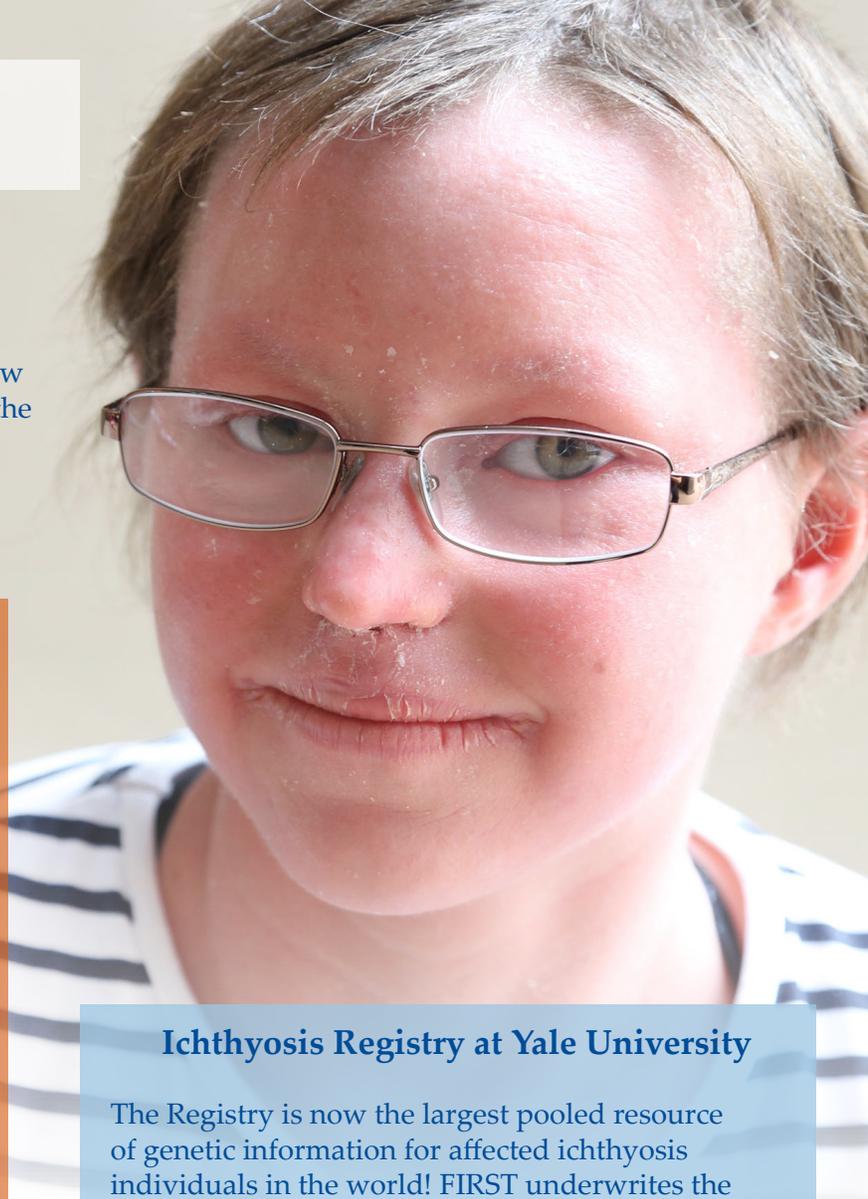
1,429  
total affected individuals  
in Registry

5  
new genetic mutations  
discovered in 5 years

7  
clinical fellows have become  
experts in ichthyosis

30  
national and international lectures

17  
papers published on ichthyosis  
treatment and management



# We Call, YOU Answer

By opening your hearts and supporting FIRST, you address the dire need for specialized ichthyosis programs, services, research, advocacy, and support. Due to the generosity of our members, staff, Board and Emeriti, I am pleased to report that FIRST is in a position of financial stability.

FIRST's full financial results can be found in our Form 990. I am excited to share below the broad categories of our financial assets and investments in our community. Your gifts improve the lives of affected individuals like my daughter, Claire.

As our membership numbers continue to grow, our donations have remained mostly flat. FIRST's continued ability to offer these important programs and services depends on expanding the support we

receive from our members and community.

My family and I hope to see you at the National Conference in Providence next summer and I look forward to reporting on our progress and status for fiscal year 2020.



Sean McTernan  
Chief Financial Officer, FIRST Board of Directors

