

Foundation for Ichthyosis & Related Skin Types, Inc.
Executive Director Report
Fiscal Year End 09/30/17



Dear FIRST Member,

I am thrilled to write this letter as FIRST's Executive Director. My eleven years with this well-established organization, and the experience I have in the area of programs ignites me to continue my work for all of you. We have a fantastic team at FIRST, staff, Board of Directors, and members. We work together to put our best foot forward for the entire ichthyosis community.

In 2017, the one-day meetings were the focus of our work. Bringing together over 450 people in this community, for a day of learning, sharing and fellowship was the highlight of my year! At each meeting, it seemed that a person stood and announced that this was the first time they were meeting someone with ichthyosis. How lucky I, and the other meeting attendees were to witness this. As we all know, ichthyosis can be very isolating, and knowing FIRST had a hand in bringing people together, even if for only one day, was inspiring to me and the work we do at FIRST.

Looking forward, we know our National Conference is the highlight of our "even" years and the 2018 conference in Nashville, Tennessee will not disappoint those in attendance.

How our members connect with one another, and the FIRST office, has changed since I started in 2007. We now have social media, and are proud of the closed Facebook Groups we manage to help support the community. Support is found in many forms, and the way a person needs to connect has become very personal and specialized. We help to form those connections in the way that is best for the individual, and we will continue to nurture the relationships and build a network for support.

Engagement will be a focus of our work over the next year or two. Making sure our materials are relevant, and timely; providing resources to guide the affected individual and their families through their lifetime, and creating a platform to share more about ichthyosis with someone who is learning about it for the very first time is our priority.

FIRST's role in research is also changing slightly. Our support of the Ichthyosis Registry at Yale is a priority, and the discoveries coming from this registry are most rewarding. Our families continue to enroll in the registry, and are becoming part of the future research and an eventual cure for ichthyosis.

I am glad to be a part of FIRST, and I look forward to what the future holds.

Sincerely,

Moureen Wenik
Executive Director