

Foundation for Ichthyosis & Related Skin Types, Inc.

President Report

Fiscal Year End 09/30/17



Dear FIRST Members and Friends,

FIRST had a remarkable 2017 as the foundation engaged with members all around the world while welcoming new leadership. Your foundation is vibrant and aspires to be the leading ichthyosis advocate. This past year we engaged with members at twelve patient support forums and our staff attended a number of skin-related conferences, including the World Congress of Pediatric Dermatology, where FIRST provided its vision on tele-ichthyosis and how we can improve ichthyosis diagnosis and treatment all around the world.

I welcome Moureen Wenik, Senior Director of Programs and Research and major driver of FIRST's membership programs for ten years, as FIRST's new Executive Director. I and the board are excited to see how her vision and passion provide new value for you. She has been the unsung hero of our engagement with individual members, and her leadership of Patient Support Forums has personally touched the lives of hundreds of families over the years. Jean Pickford, FIRST's long time Executive Director, left to pursue new nonprofit challenges, and we deeply thank Jean for the growth she led at FIRST during her seventeen years. We also say good bye to Larry Silverman, FIRST's chief financial officer for the past five years. Larry has been a vital member of FIRST's board and we thank him for his astute financial guidance and his warm friendship. We now welcome Sean McTernan as FIRST's new CFO and look forward to his strong capabilities and commitment. These individuals along with FIRST's board have hundreds of hours of collective discussion about FIRST and the communities we serve each year. I am privileged to work with them in helping FIRST provide value as the leading global ichthyosis patient support organization.

FIRST is in the midst of transformation and is evolving to keep up with how your lives are changing. During the year, we continued to support and build out our interaction with FIRST Facebook groups. The daily member engagement is exciting to see! Expanding programs like the global Ichthyosis Awareness Month in May—[#ichthyosisawareness](#), [#FIRST](#), [#ichthyosis](#)—we worked to educate, inspire, and connect members all around the world. The internet shrinks our world and we strive to bring all individuals affected by ichthyosis together so that we are better able to share and support one another. Digital social interaction presents many new challenges, and we strive for all of our members to be compassionate and supportive.

Genetic research is transforming healthcare and FIRST's direct connections with leading ichthyosis researchers means we are on the frontlines of new discoveries. FIRST has now provided over \$2 million in research grants, and while scientific progress requires patience, it is important to understand that an exponential increase in medical knowledge is occurring, which will lead to better therapies and better access to those therapies.

I love hearing member stories and communicating with members. I volunteer my time to help FIRST make a positive impact on individual lives, and I know there is always more, and more exciting, work to do. FIRST is privileged to have a wonderful staff, dozens of committed member volunteers, a capable and engaged board of directors, and a leading group of physicians and researchers on our Medical and Scientific Advisory Board. I deeply thank all of them for their work for FIRST in support of making a difference for each of you. We are all together in this community, and together, we all support one another.

My best regards to you,
Jeff Hoerle
President