

Foundation for Ichthyosis & Related Skin Types, Inc.
President Report Fiscal Year End 09/30/18

Dear FIRST Members and Friends,

FIRST works to reach, educate, inspire, and connect every single person affected by ichthyosis—in the United States, and around the world. The FIRST family includes our staff members, who are passionately committed to our thousands of members; hundreds of volunteers, who selflessly contribute their time to our foundation; and a membership from whom we are continually learning how better to serve the ichthyosis community. Together, we support one another, share knowledge, and improve lives. FIRST is a premier advocacy organization and we utilize our impressive resources—staff and volunteer time and talents, connections with the medical and scientific communities, and financial support—both prudently and diligently. On behalf of our staff, board of directors, and the members of our Medical and Scientific Advisor Board (MSAB), I sincerely thank all of FIRST's members and donors for your engagement with the foundation. FIRST's very successful and productive 2018 is a tribute to your commitment.

Our standout event for 2018 was the FIRST National Conference in Nashville, Tennessee. More than 500 people participated in three days of informative sessions, collaborative discussions, and clinical screenings with ichthyosis experts. Most importantly, members connected with other families and individuals to discuss and bond over shared issues and concerns. Led by our keynote speakers, Andrea Avery and long-time FIRST member, Bailey Pretak, the weekend was highly educational and deeply inspirational for all of us. During several days in which I was privileged to join many group discussions and personal conversations, I was moved by the consistent and sincere desire of all of our members to help one another. Making these connections is the heart and soul of FIRST; sharing in these connections is life changing. Saturday night's dance and talent show, and the performance of the *Release the Butterfly* tour, were entertaining and exhilarating, bringing us all together to recognize what we can and have achieved as individuals and as an organization. We thank all of our talented and deeply committed members for their profoundly positive contributions to FIRST. Our board of directors thanks FIRST's staff and the volunteers of the National Conference Committee for all their incredible work in making our 2018 National Conference a great success. FIRST is grateful for your support in enabling these events and we look forward to our next National Conference in 2020 in Providence, Rhode Island. We hope to see you there!

FIRST's mission statement is: "To improve lives and seek cures for those affected by ichthyosis and related skin types." We provide many established programs and services in pursuit of this goal; additionally, we communicate continually with our membership to understand your changing needs. During 2018, as part of our strategic planning process, we completed a member survey in which nearly 500 responses via email and Facebook groups offered enhanced understanding of your priorities for FIRST. Across our diverse membership, a pressing issue is the desire for increased knowledge of treatment options and more comprehensive medical information. To meet this need, our staff and volunteers use Facebook, digital communications, and traditional newsletters to integrate the research of FIRST's MSAB—the 30+ members of whom include the world's leading practicing clinicians and scientific researchers for the ichthyoses—with member experiences and insights to maintain and refine a robust source of ichthyosis knowledge. Our direct connection to these experts—and to their patients, our members, who are also experts—is unique to FIRST, and we continually review new methods for leveraging this expertise to your advantage. Every May, Ichthyosis Awareness Month provides both inspiration and detailed practical insight. This is knowledge that only *you*, our members, can contribute to FIRST's mission—as well as to our medical experts. We look forward to all of the future member interactions and future medical breakthroughs that will optimize and transform treatment regimens.

FIRST continues to grow its membership. The number of affected individuals in our database has more than doubled in the past five years and is now more than 7,300 members. We are humbled by this growth and aspire to enhance our connections with all of you. Core to this growth and to the success of FIRST is our staff. On behalf of FIRST's board and MSAB, I thank deeply Moureen (Moe) Wenik, our Executive Director; Lisa Breuning, our Director of Operations; and Chris Wassel, our Community Engagement Director. Between normal office hours, the monitoring of chat groups, the attending of evening board committee meetings, and the management of weekend patient and member meetings, they work literally around the clock. They have a combined thirty years of service to FIRST, and their talents and compassionate dedication to our membership are what make FIRST FIRST. Their work often goes unheralded, so I would like to laud their great commitment and skills here. Please join me in thanking them for their many years of service to FIRST! In 2019, we will welcome six new board members. This is the largest class of directors FIRST has ever brought in. Jolie Cina and Brian Stern are both longtime FIRST members and parents of affected children. They bring great passion for FIRST and a clear understanding of what affected families need. Beth Hampshire and Bailey Pretak are also longstanding FIRST members and each is affected with ichthyosis. They will contribute invaluable insight to help drive FIRST's strategic goals. Finally, Dr. Latanya Benjamin and Dr. Brittany Craiglow are both esteemed practicing physicians who will provide exceptional clinical perspective. I thank them all in advance for their energy and time for FIRST. I am grateful for their commitment!

FIRST is in a vibrant and ambitious stage and my letter just touches the tip of the iceberg for 2018's accomplishments. FIRST also has an ambitious set of goals for the future—from enhancing our engagement with you, our members, to functioning as a key contact for biopharmaceutical company and academic institution research and development on ichthyosis. To continue to ensure FIRST's resources to pursue these goals, I ask you to consider beginning or increasing your financial commitment to the foundation. *Every* dollar makes a difference. Truly, no donation is too small. Every contribution provides support to FIRST and demonstrates your confidence in the work we do for you.

In closing, I thank you again for your engagement with FIRST. Every single person I work with in my service to the foundation shows me the value of what we share—a love for FIRST, its mission, and the people we serve.

My warmest regards to you and your families,

Jeff Hoerle

A handwritten signature in black ink, appearing to read 'Jeff', with a stylized flourish at the end.

President, FIRST Board of Directors