

Executive Director Report Fiscal Year End 09/30/14



Dear Members, Friends and Donors of FIRST:

In many ways 2014 was a very memorable year. However, for me, it marked a particularly special milestone as I celebrated my 15th anniversary at FIRST. And, as each year has been filled with great passion for supporting our families and the privilege of collaborating with the world's leading medical and science experts, I am continually inspired by the hope for a better future for all those affected. Thanks to science, technology, and many dedicated people, the horizon is filled with even more hope than ever before! In fact, if I had to sum up the journey, there is one single word that comes to mind: *flourish*.

After months of collaborating with a unique and talented team of individuals, comprised of not only FIRST staff, but affected family members, ichthyosis investigators, and FIRST Board members, I am delighted to announce the completion of our next four-year strategic plan, (2015-2018). There are many exciting initiatives that will be unveiled over the next few weeks, months and years. Members will note that our overall strategy greatly aligns with the evolving landscape of communications, outreach, and medical research.

Due to our enhanced communication efforts this year, and our overall embracement of technology and social media, 2014 will no doubt also be remembered as the year of connection. We hit our highest reach on Facebook with our inspiring "IAM selfie campaign" – empowering members to use their voices, photos and messages to share their stories and raise awareness. We also produced the highest attended National Family Conference to date, with 407 attendees in Indianapolis. We are looking forward to moving the conference to the West Coast for 2016 - San Diego! In the interim, we have planned many opportunities for in-person connection and support at our Regional Patient Support Forums in Toronto, Minneapolis, Phoenix and Miami.

In 2014, the FIRST Research Grant Program awarded \$50,000 to Dr. Brittany Craiglow of Yale University for her collaborative study of newborn and early childhood complications and comorbidities that accompany the ichthyoses. FIRST anticipates that the results will be particularly helpful in counseling newly diagnosed families, which represents a significant part of FIRST's work as a patient support organization. Additionally, Dr. Ryan O'Shaughnessy received \$50,000 from the grant program to continue his work in targeting the scaling pathways in ichthyosis. This research specifically focuses on understanding the mechanisms that cause scaling, and subsequently increasing the options for treatment.

As we move into the next phase of our journey with the ichthyosis community, we are inspired and motivated by this extraordinary group. On behalf of Moe, Mo, Chris, Lisa and myself, the depth of our gratitude for each and every one of the members is truly bottomless, and we would like to extend a warm thank you to everyone (members, physicians, investigators, staff, Board members) for their continued commitment to FIRST.

All the best,

Jean Pickford