



President's Report Fiscal Year 2010

Greetings to all Members and Friends of FIRST:

In spite of the challenging economic environment beginning in October 2008, FIRST has continued to sustain the absolute highest level of service and attention to all of its strategic and operational goals. This is very good news indeed, and remains possible in only one way; through the continued and committed generosity of time, talents, and financial support by so many who care about FIRST and its growth.

On behalf of the staff, board members, and medical and scientific advisors of FIRST, I wish to sincerely recognize all of our members, friends of FIRST, and the many corporate and charitable foundation sponsors who favor our organization. The combined and continued confidence in **YOUR** organization, and strong support and engagement with FIRST throughout 2010, was much-needed, and I request you stay the course with us for 2011, and beyond.

Fulfillment of the FIRST mission and goals to *Educate, Inspire, and Connect* those affected by ichthyosis never ends. From the board of director's perspective, we periodically identify activities that we believe will matter the most. We then make the investment of time and resources to drive them to successful completion.

As my fifth year as president of FIRST gets started, and we are celebrating our 30th anniversary, it is my honor and privilege to extol the highest level of respect, regard, and praise on a truly exceptional leader, our executive director Jean Pickford, and her equally driven, dedicated, and highly motivated staff comprised of Moureen Wenik (Program Director), Lisa Breuning (Public Relations Coordinator), Donna Wiggins (Membership Services Coordinator), and our newest member, Chris Wassel (Development Coordinator).

Moe, Lisa and Donna are very skilled, compassionate, and knowledgeable, and they provide personalized support and service to our members second to none in the non-profit world. For certain, their professionalism and work ethic would allow them to excel in the commercial world. But for board members, Jean, and you, they provide consistency, familiarity, and a relationship quality that our stakeholders can count on each and every time. To all three of you, a heartfelt thank you for all that you do in service at every level within FIRST!

I would be remiss if I failed to mention the recent addition of Chris Wassel to our staff as our new Development Coordinator. She has already demonstrated a commitment to our mission and a very strong work ethic. Chris, welcome to the organization; we wish you the best as you begin to get to know our members, and you build on the successes of your fellow FIRST colleagues.

What type of leadership does Jean provide FIRST? She displays a tremendous energy and vibrancy. In June 2010, Jean celebrated her 11th anniversary with FIRST, an astounding sign of loyalty to any organization. Jean is always focused on advocating for our members and FIRST's mission. Her leadership role with the Coalition of Skin Diseases (of which, FIRST is a member), her participation on the expert panel of the NIAMS Advisory Council, articulating the needs of our organization to benefactors and foundations, and her interactions with renowned dermatologists and scientists from around the world to request their active engagement in FIRST, are just a few examples of her commitment and dedication.

Jean, we all wish to thank you for your excellent leadership of FIRST for one-third of its life, and look forward to supporting your team's efforts to continue to exceed our goals and grow our organization for years to come. To all members and friends of the organization, please join me and my fellow board members in congratulating Jean on reaching her 11th anniversary, and taking us into 2011 with great momentum and vision for further growth of FIRST!

A connection with FIRST often starts with a concerned, anxious phone call. The questions include, What is happening? How can I learn about ichthyosis? What materials are available? Where can I find an expert clinician? FIRST provides a vast library of educationally sound literature to answer these questions. Substantial resources have been invested to develop a new infrastructure that allows broader and easier access to our resources electronically.

Execution of our key strategic initiatives continued along several veins in 2010, and included the following examples of progress:

- Re-design of our marketing materials and website to make our message clearer, materials more attractive, and our website robust, informative and navigable
- Development of a FIRST fanpage on Facebook, and Twitter feed to enhance connections to our organization through the new phenomenon of social networking
- Selection and implementation of computer software that more efficiently allows our executive director and staff to keep pace and stay in-touch with our growing list of members/friends
- Initiation of a tele-medicine offering that has grown in utility for clinicians who wish to be linked to our panel of dermatologists who are clinical and/or research experts in the field of ichthyosis. This program effectively assures that anyone in the US can find expert help, and we look forward to broadening access to this important program beyond the US in the future.
- Continued funding of select research projects administered through the FIRST Research Program
- Development of the FIRST Ambassador Program
- Establishment of a new educational scholarship program for college-bound members

What is your role in our organization? Multi-dimensional, I hope. The number one thing to consider is to get involved. It has never been easier. Also, it would be great to see you and your family at our bi-ennial National Family Conference in June 2012 in Denver, Colorado, or attending one of the several Regional Meetings that are planned for 2011, better yet **COME TO BOTH!** Please strongly consider making the commitment to attend at least one of these functions, you will see first-hand how valuable these “get together” opportunities are for you and your family.

Orlando was a blast! If you can visualize a Conga line of children, parents, FIRST staff members and expert, world class dermatologists all led by Mickey Mouse dancing, weaving, stepping and laughing through the ballroom of a resort hotel in Orlando – then you get the picture. Each FIRST conference has its own aura of fun and enjoyment, but one element that never changes is the sense of “common bond and caring” that by the end of the conference is emotionally overwhelming.

We also are forging bonds through our newly developed Ambassadors Program. FIRST coordinates a team of ambassadors, who reach out to physicians and clinicians in their area to ensure that information is readily available at medical institutions about ichthyosis and FIRST. To each individual that has committed to being a FIRST Ambassador, thank you! Your dedication of time and talents to your organization is having a measureable impact on the growth of programs and the benefits to our members.

Of course, a meaningful way to show your support and confidence in our organization is to contribute what you can financially. Your donations go a long way to make the programs and commitments to our members meaningful and helpful. They are absolutely essential to the strength and vitality of any non-profit organization. In advance, thank you for your collective generosity to FIRST.

Lastly, I wish to recognize three truly outstanding board members that have left our Board of Directors after many years of service. All have been staunch advocates and tireless workers for FIRST; Dr. Phil Fleckman and Elena Levitan for over a 9 year period of dedicated service to the board membership, and Dr. Terry Melton after two terms during which she headed up our Board Development Committee. All promise to stay involved going forward, and Dr. Fleckman will continue working directly with the FIRST board as an emeritus member. To all three, we wish only the very best, and bravo for a job well done!

In closing, please continue to help FIRST in any way you can and consider increasing your financial support to FIRST, your funds will be used wisely. I wish each and every one of you and your families the very best in 2011.

Warm regards,



David R. Scholl, Ph.D.
President