



President Report Fiscal Year 2009

Greetings to all Members and Friends of FIRST:

From all of the staff, board members and medical and scientific advisors of FIRST, I wish to express our deep gratitude for your continued support during the past year. Thank you for your broad interest, volunteer support, and service to our organizational mission and goals to *Educate, Inspire, and Connect* those affected by ichthyosis.

Further, I hope this note finds you and your family doing well. Depending on where you live, coping with this year's "upside-down" winter weather conditions that beset much of the country over the past several months may have been difficult. When the snow piled up in January and February, the drive-way needed to be cleared often in sub-freezing temperatures. And in the southern US, they were often in sub-freezing temperatures. So, imagining the warm weather of Florida in June seemed a pipe dream, a distant illusion.

The good news is spring and warmer weather is here and June is not that far away. For FIRST members and our organization, that means our bi-annual Family Conference is right around the corner. We invite and encourage all of our members, family and friends to join us in warm and sunny Orlando, Florida. The Family Conference, our signature event, is a stellar opportunity to see folks that you may not have seen since the last conference, or longer.

There is no better way to plan a family get-away than combining the FIRST Family Conference and vacation with a famous mouse named Mickey - all in a single trip! So please join us at the Orlando 2010 Family Conference by registering on-line, by mail, or by calling the office directly. I hope you can take advantage of the opportunity to spend some extra time at Disney World, or any of the wonderful attractions and vacation spots in Florida as part of your trip. Just thinking about the warmth and positive energy from renewing long-standing acquaintances and creating new friendships is a strong antidote for any cold weather scenario! With an expected attendance of over 450 people, we definitely plan to ***Rock the House in Orlando!***

Since the organizations inception 29 years ago, the bi-annual Family Conference has clearly served as an incredibly valuable vehicle to *Educate, Inspire and Connect*. This year in Orlando, however, we are going one strategic and very exciting step further!

FIRST is convening an important, two-day scientific and medical research mini-conference in Orlando prior to the start of the 2010 Family Conference. The mini conference was the brain-child of our extremely dedicated Medical and Scientific Advisory Board. With partial funding awarded to FIRST through a grant application submitted by our talented leadership and staff, "*The Frontiers in Ichthyosis Research Conference*" represents a first-of-its-kind, seminal opportunity to gather an exclusive group of select experts from around the world to openly discuss and communicate the most recent research findings and clinical knowledge about the ichthyoses.

Beyond the exchange of critical knowledge, this scientific meeting will serve to further promote the dire need for more research funds targeting ichthyosis. We also expect to inspire greater awareness and participation of FIRST members in various research-related activities that will ultimately make clinical research studies more numerous and productive. I believe that the benefits from connecting the scientific community with our organization and member's needs will be extraordinary. We look forward to sharing the key findings discussed at the Frontiers Conference during a summary presentation by Dr. Leonard Milstone to attendees of the Family Conference.

Supporting research dedicated to ichthyosis has been a major goal of our strategic plan, and focus for the past several years. The progress is impressive! In 2009, several FIRST-sponsored research projects were underway in laboratories around the world, and have continued to make good progress towards meeting their goals. Additionally, FIRST received a greater number of grant applications requesting financial support than ever before. And lastly, the upcoming Frontiers Conference in Orlando will surely bring greater awareness about our keen interest in driving more research activity, and greater leverage within the basic and clinical research community.

With such outstanding progress on building the Research Program from scratch, and with other key strategic initiatives to financially support, FIRST welcomed its first dedicated development director in 2009. **Greg Wilson** brings a strong track record in creating, supporting and managing successful fundraising relationships and activities for similar non-profits. We are extremely excited to have this critical strategic need met through the addition of Greg, and we look forward to your meeting him in Orlando!

Additionally, the decision and commitment to add a full-time development director at FIRST provided our Executive Director, Jean Pickford, the opening to grow our current staff and organizational capability. In consultation with the board and in planning exercises with all staff members, Jean re-organized the focus of her very talented staff to provide more dedicated effort and support to key operational areas – a decision primarily motivated by our goal to provide our members a more personalized and fulfilling *FIRST Experience*, and not just the first time!

As configured now, the organization is much better positioned to serve our members with strong, sustainable support and program effectiveness *via* dedicated programmatic responsibility to key strategic initiatives.

The Regional Support Network, a new Ambassadors Program, and the Research Program, all managed by **Moureen Wenik**, have placed FIRST as a front runner in ichthyosis support. Thanks to **Lisa Breuning**, our outreach initiatives of website management/redesign and public information dissemination is on the cutting-edge of using the latest technology and reporting the most up-to-date information about FIRST and ichthyosis. Just as important is connecting with our members and making sure FIRST's services are provided to each and every member. Thanks to **Donna Wiggins**, our Membership Services Coordinator, we continue to reach out to our current members and welcome new members on a regular basis.

Through this approach, we believe you will find engagement with our organization easier to do, support from our staff plentiful when needed, and the experience more meaningful.

I wish to wrap-up this year's annual letter by recognizing the **tremendous volunteerism** displayed by so many members of FIRST.

The strength of any organization is resident in the amount of time, passion, and financial support people place on the importance of achieving the mission of the organization. The organization's development success, and one's involvement in it, has to matter to gain the strongest commitment and engagement from its volunteers.

At FIRST, you find very strong evidence of people making it happen through volunteerism in all forms, including offering of professional talents, time commitment, and financial support, that displays a fundamental passion for our organization and its members.

Just a few examples of the many I could cite are:

- Numerous grassroots fundraising efforts by our members which are the basic staple of any Foundation
- Medical talent donated to the development and recent launch of our telemedicine project, to provide clinical consults at our Family Conferences, and be guest speakers at our Regional meetings
- Technology talent that assisted us with making the right choice for our new database management system
- Professional marketing talent that formulated our new marketing plan
- A creative team that is directing our new branding campaign to give our organization a fresh new look intended to extend a compelling message of warmth, caring and support for those members and families affected by ichthyosis.
- Substantial gifting program that underpins the Research Program commitment and serves as the focal point of our future research endowment campaign

What an impressive list! For all of those volunteers that were engaged in the past and in 2009, I wish to extend a sincere and hearty thank you. Because of your service to FIRST, we have accomplished a great deal in 2009 and the future looks very bright.

For members that are considering a more active role in FIRST, I would strongly encourage you to reach out to Jean, her staff, a board member and members to ask how you can help. The organization needs and welcomes your energy, your talents, and your engagement. The timing has never been better to have a positive impact on YOUR organization and start friendships and new relationships – for life!

Let's join together to make 2010 the best year ever. See you soon in Orlando!

Warmly,

David R. Scholl, Ph.D.
President