



## President Report Fiscal Year 2007

Greetings to all Members and Friends of F.I.R.S.T.:

In my previous Annual Report message, I spoke of *Soaring to New Heights*, a theme that was used for the Foundation's 2006 Family Conference in Atlanta, Georgia. For all F.I.R.S.T. Board Members, our Executive Director and our extremely talented staff, this theme has provided a continual reminder that sustaining organizational growth, providing enhanced and effective service to those affected with ichthyosis and related skin types, and developing even better ways to actively engage more people in F.I.R.S.T. are indeed lofty goals.

With these summary goals of continued growth, service and engagement, a sub-committee of the board and staff worked during much of 2007, and with great care and diligence, to reflect on our progress against the previous strategic plan. We also sought ways to leverage our past successes and programs into even more success and progress over the next four years.

Indeed, in my short time as president, an undeniable strength of F.I.R.S.T. is our rich history of dedication and commitment of so many volunteers for over 25 years. Clearly, the wonderful people associated with our Foundation, including staff, members and volunteers, are its most important asset.

Therefore, as we conducted a nine-month strategic review and planning process, performing in-depth interviews of founders and past presidents, medical advisors, volunteers of F.I.R.S.T., members and current board and staff leadership was fundamental to our evaluation and establishing the proper future direction and actions upon which F.I.R.S.T. should embark. Additionally, we sought the outside counsel of a third party to help facilitate the effort – the Nonprofit Center at LaSalle University, a group that specializes in counseling and advising non-profit organizations in such matters.

In the end, reliance on this type of dedication from our past and current members, volunteers and the professional guidance from LaSalle, made our work gel quite nicely. From among all whom participated in the process of reviewing our past goals, brainstorming and setting the course for the next four years, our mission has never been clearer, and the effort to accomplish our mission never more resolute - everyone felt very strongly about, and emotionally embraced, the following statement:

*Our mission is to educate, inspire, and connect  
those touched by ichthyosis and related disorders  
through emotional support, information, advocacy, and research funding  
for better treatments and eventual cures.*

Perhaps you have seen this statement already on recent newsletters. You will surely begin to see the consensus message of *Educate, Inspire & Connect* on future publications, informational tools, marketing pieces, and on literature and shirts at our upcoming marquee organizational event, the 2008 Family Conference in Chicago (June 27-29).

Importantly, our mission at F.I.R.S.T. is authentic, and genuinely defines who we are and what we are about. From an organization perspective, this clarity is a key to gaining the confidence and collective, yet focused, efforts of our members, staff, and volunteers. Equally important, our mission statement presents us to others in a clearly differentiated way to drive future awareness campaigns.

In acting on this mission, our goal is to continue forging bonds among us and other stakeholders that last a lifetime, and so the board is committed to the development of a solid, long-term marketing plan that takes our numerous assets and focuses them towards those that we want to reach and influence.

In this plan, we challenge ourselves to develop new and expanded approaches that continue to reach out and provide our *current members of ALL AGES* with continued support, much-needed information, advocacy and research funding and information about better treatments within the ichthyoses and related skin types, while also offering those *new to our organization* a welcome mat to meet and learn about our organization, some for the very first time. This marketing plan will be the cornerstone from which we talk about ourselves and which spurs continued interest of major benefactors in our organization.

Our updated strategic plan also calls for the aggressive development and use of technology infrastructure to enable us to “reach out” in additional, innovative ways to more people in need and prospective stakeholders. One example is a key investment in computer software that can efficiently be utilized to manage our ever-growing database of members and stakeholders.

An equally powerful way to leverage technology for our goals is through a tele-medicine initiative that we will try to form through collaboration with professional societies like the American Academy of Dermatology and with the use of restricted grant resources to F.I.R.S.T and/or unrestricted funds raised through grassroots and staff-driven efforts.

Your board of directors believes these infrastructural initiatives are simply too important to let them sit on the back burner for much longer! Having lived in a rural area for over 30 years, I personally believe that current and prospective members that just live too far away from those expert in treating ichthyosis, and their rural physicians, will find tremendous benefit from such an important and timely investment.

Developing internet connectivity without developing the outstanding young professionals that are so very important to better treatments and management for our members would be shortsighted. Thus, we have joined forces with our Medical and Scientific Advisory Board members and will develop a plan to jointly identify gifted, young dermatologists as clinical experts and nurture them in our direction with organizational support.

Connecting our members to the knowledge, engagement and inspirational support of research and clinical professionals represents hope to all affected by ichthyosis and the related skin types. We must do everything we can to strengthen those relationships and find new ones. Thus, be assured that F.I.R.S.T remains committed to finding sources of financial support for dedicated research, and will

make every effort to get these funds into the hands of the most qualified research experts that may make for better treatments and eventually lead to cures.

From the reports of Jean (Executive Director) and John (Chief Financial Officer) included in this Newsletter, together we are accomplishing a great deal and the organization is growing and on sound financial footing. This is strong testimony to those that have led us in the past, and provides a glimpse of what the current leadership needs to embellish.

So, I would ask you to consider providing further support of this good progress in the following two tangible ways:

- One of the best ways you can help support our mission statement is to attend our upcoming family conference in Chicago, and the fundraiser at Harry Caray's the evening before, if possible. If the number of early bird registrants is an indicator, 2008 promises to be a record attendance for our family conference. If you have not signed up yet, get on it right away – with more than ten clinicians doing consulting at the conference, Chicago will provide you the best way to become *connected, educated, and inspired!*
- Please join with so many other members and volunteers and get engaged in our organization – both through your continued or future financial commitment to F.I.R.S.T. and our mission, but to each other as well.

In closing, the goals of F.I.R.S.T. certainly remain lofty and our 2008 – 2011 Strategic Plan is ambitious. Nonetheless, with your continued support of our excellent staff, the Directors, and your fellow members and the many grassroots volunteers that work tirelessly throughout the year, we expect to accomplish all of our strategic goals and continue making a positive difference – please reach out and help us when you can, by answering our call when we reach out to you.

Most sincerely,

David R. Scholl, Ph.D.  
President