



Executive Director Report Fiscal Year 2009

Dear Members, Donors and Friends of FIRST:

This past year has been one of many accomplishments for FIRST. I am privileged to be working with such a talented group of committed board members and volunteers, along with our dedicated staff who work tirelessly to advance our mission. As we continue moving forward with our four-year strategic plan, 2009 added another year of tremendous growth for the ichthyosis community:

- **Regional meetings**
By creating smaller, geographically diverse meetings, in addition to the national biennial conference, more affected individuals and families were provided the opportunity to connect with one another in person and to learn about the latest ichthyosis news, treatments and research updates.
- **Tele-Ichthyosis Website**
This site allows dermatologists and primary care physicians to have access to a panel of leading experts in ichthyosis to assist them with the care of their patients, by working with the doctors to determine the proper diagnosis and to suggest possible treatments.
- **Marketing Plan**
The volunteer and hard-working marketing committee, developed and is executing a comprehensive marketing plan to:
 - 1) create and grow awareness of ichthyosis and FIRST,
 - 2) re-energize active and inactive FIRST members to participate in our cause and be ambassadors for the Foundation, and
 - 3) engage both current and new donors that their contributions are a worthwhile “investment” for them and FIRST.

The old adage, “Success breeds success,” certainly applies to FIRST, particularly over the past five years. Our membership and donors are part of a successful organization whose careful stewardship of donated funds and thoughtful planning of current needs and future goals set us on a winning course. Some of the most notable accomplishments over these past five years include:

- **FIRST’s Research Program** – In 2005, FIRST developed its own research funding program and has been accepting grant applications since its inception, funding a total of 13 worthy projects to date, focused on Lamellar/CIE, EHK, and ichthyosis-related research.
- **Strengthening our membership and donor base** – Our membership is the lifeline of FIRST. It’s how and why we exist. With increased attention to member’s needs and a more sophisticated donor management system, FIRST is serving more members every day and reaching out to new families to join our special community.

- Staff, Board of Directors, Medical & Scientific Advisory Board and key volunteers – Under the governance of our board and guided by our medical board, FIRST continues to recruit the most talented people who volunteer countless hours and who want to make a difference. With our expanding programs and services, adding two additional staff members to manage and implement these programs has taken our effectiveness to new heights and helps us reach even higher goals.
- Information Dissemination – With the use of new technologies, FIRST continues to expand our website, and will be making even more impactful changes this summer. Over the past five years, we have also added several new resources to our arsenal of information, including two online educational modules for the diagnosis and management of ichthyosis in newborns, a video featuring affected teenagers and how ichthyosis impacts their life, and an even newer video that features everything you need to know about FIRST, ichthyosis, the family conference, and why you should invest in our future.

These important highlights are just a few of the many services we have achieved to educate, inspire and connect those affected by ichthyosis. As I enter my 11th year of service to the organization, I am proud of what we have accomplished and look forward to even greater accomplishments in the future.

As always, I encourage you to contact our office with any questions, concerns, or ideas you may have. We are a strong and successful organization because of you, our members, friends and donors. Thank you for all you do to make us FIRST!

Sincerely yours,

Jean R. Pickford
Executive Director