



President's Report Fiscal Year 2011

Greetings to all Members and Friends of FIRST:

Educate, Inspire, and Connect; these three words were first adopted at the November 2007 board of directors retreat in Philadelphia as our organizations branded "tagline," or guiding light.

For all stakeholders of FIRST, we eye these three words as goal posts to fuel the passion and commitment for FIRST that each of us shares. These three words serve to unite all of us around our singular mission of best serving individuals and families affected by ichthyosis. In the end, these three words explain why we do - what we do.

And how we do it is important too. Our board members, Jean, and FIRST staff are challenged to invest wisely, deliver results, make a positive difference, and leverage our investments into larger, more sustainable outcomes over time. After all, precious resources are ... well, precious!

Be assured that at FIRST, your financial support is crucial and used with direction and oversight that drives our fundamental, daily operations and multiple strategic priorities. In 2011, we focused on building greater program depth with key initiatives. We will amplify and expand on those achievements during our next planning period (2012-2014) and beyond.

Good listening and strong volunteerism underpins all of FIRST's successes. What we invest in is driven largely by what we hear members say is critically important to them and most beneficial to their membership. Further, these programs don't happen on their own, they represent substantial commitments of innumerable volunteer hours by hundreds of members and an extraordinary core of expert medical professionals to achieve.

For certain, a strong investment of time, treasure, and talent is essential to our sustainability as a premier advocacy organization. Below are a few illustrations of the type of results, impact, and leverage we have all produced by supporting each other:

- ***We seek a cure.*** Financial commitment, exceptional researchers, and member engagement add to create hope that new scientific knowledge in skin biology, genetic mutations, and stem cells will address key questions and provide important answers. Since 2006, our peer reviewed research grant program has motivated world class scientists to submit 34 applications for funding. FIRST has made 13 awards totaling more than \$1.4 million to explore novel approaches and new therapies to find a cure for ichthyosis. We must do more research!
- ***We support young clinical researchers.*** Ichthyosis is rare, with around 250 births per year. Even rarer are clinical dermatology experts that focus their research on ichthyosis. Without exceptional young clinical dermatologists focused on advancing research relevant to FIRST,

we will fall further behind. In 2008, we awarded our inaugural Clinical Scholar Award to Dr. Keith Choate of Yale University. Dr. Choate's research provided free genetic testing to 85 members at the 2010 Family Conference in Orlando, Florida. His laboratory obtained significant funding from the National Institutes of Health (NIH) valued at \$1.86 MM over 5 years, and his major scientific article appeared in the prestigious journal called *Science* (co-authored with mentor and colleague Dr. Leonard Milstone and other scientists at major research institutions).

- ***We help our members.*** Members cope best with ichthyosis through a strong support system. Ours is truly a difference maker. Since 2011, our office staff has provided much needed information and network support to 160 new contacts. Further, seven regional conferences have brought 30 dermatologists directly to 248 individuals and 118 families at a cost of ~\$160 per person. Direct interaction by skilled, knowledgeable professionals, or face-to-face engagement, has changed the lives of more than 400 people, an estimated 75% of whom are new to FIRST and its services and programs! We do not stop there. Through the Jane & Henry Bukaty Skin Care Fund, we provided 11 grants for members to purchase much needed skin care products to vastly improve their skin condition; 42 individuals received travel scholarships to attend the 2012 Family Conference; and 7 young students became UFIRST Scholars via our partial scholarship program to attend a four year college/university of their choice.
- ***We make technology work for us.*** Our website undergoes constant review, and our tele-medicine program, launched in 2009, promises to link rural physicians with ichthyosis experts. We have successfully registered 60 physicians and 22 cases have been submitted and reviewed by 11 experts through tele-medicine. Not surprisingly, a smart phone "app" is being piloted in Texas as part of our involvement with the Coalition of Skin Diseases (CSD), a consortium of skin disease non-profit organizations.

Our aggregate investments and volunteerism embody each of the words **Educate, Inspire and Connect** in clear and substantive ways.

So how do we accomplish more? We must secure greater funding from a wider variety of sources, continue to invest in research, provide a stronger network of support by building leadership groups within our Ambassador Program, extend the skin care assistance program to more individuals, and use internet technology and social media in savvy ways to broadcast our story wider, promote stronger connections with members, and do so cost-effectively.

Such an aggressive agenda requires strong leadership. You will soon see evidence of our Board-level succession planning. Mike Briggs will transition to president of FIRST starting in 2013 as I complete my sixth year as president. Many of you know Mike. For those who do not, we could not have found a more passionate, competent, and generous individual with his time and resources to lead FIRST. Mike, congratulations on assuming this leadership position; thank you!

I wish to close this year's letter with a story that reflects well on why what we do matters.

Called *The Story of Emma Klima and Bassett Elementary School*, you will read later in this issue about the wonderful staff and students at Bassett Elementary school. You will be left inspired by how Bassett Elementary School planned a month-long awareness and fundraising campaign for FIRST, by the generous commitment of school staff and parents alike with their time, talents, and resources, and how they ultimately connected FIRST to Westlake, Ohio, a very generous and caring community. Imagine my distinct pleasure of attending their school assembly on Valentine's Day, seeing the excitement of over 300 students from K-4 celebrating their hard work at fundraising, and recognizing Emma with huge cheers for over 20 minutes.

All of the activities at Bassett Elementary School created a sense of love and caring that was quite powerful. This type of story is "told" repeatedly throughout the year by so many dedicated and active members. *Emma's Story* is a great example of how FIRST transforms ideas into a vision, weaves a broader dream of what can be for our members, and educates, inspires and connects skillful participation and support from all stakeholders that will take those dreams and make them real.

Please keep FIRST uppermost in your mind – as the premier advocacy group for those affected by ichthyosis. And see you soon in Denver. We have an awesome set of events planned for you!

Dave