



Executive Director Report Fiscal Year End 09/30/12

Dear Members, Friends and Donors of FIRST,

Fiscal year 2012 turned out to be a good year for FIRST. Although the recovery of our economy has been slow, we experienced solid growth at FIRST in three key areas: programs/services, fundraising, and membership.

The highlight of our programs this past year featured our national conference in Denver. We had an excellent turnout in attendance. Investigators and scientists associated with the Gene Discovery Project at Yale University were able to meet with more than 80 families who contributed to finding the genetic basis of ichthyosis and understanding how mutations in specific genes (genotype) give rise to unique physical findings in each person (phenotype).

In the fundraising department, we saw our best year ever in terms of local, grassroots events around the country. Our gross revenue totaled over \$100,000! More and more members, family and their friends are joining the efforts to raise awareness and dollars for FIRST. From small bake sales to large community concerts, FIRST is reaching people far and wide. In addition to these FIRST supporters, our direct mail campaigns, corporate appeals, and grants have all seen slight increases as well. This is a sign that FIRST is important to our members and their families and reinforces that we are armed with the resources to continue to educate, inspire and connect.

Over the past eight months, our staff, key volunteers, and board members have focused their attention on how FIRST is 'getting the word out' — in essence, our public relations and marketing strategies. With today's new social media phenomenon, it is clear we can reach more and more people with less and less time and money. And in the world of a rare disease, this is a tremendous asset. Over the past four years, our membership has grown over 20%, with last year seeing the biggest jump of 8% over the previous year.

Because we now know that approximately 300 babies are born each year with some form of **moderate to severe** ichthyosis, our mission is even more important 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.

Warm regards,

Jean R. Pickford