



President's Report Fiscal Year 2012

Dear FIRST Friends and Members:

This year, I begin my sixth Annual Letter with a pop quiz – *what are the fundamental tenets that explain our behavior and propel our mission at FIRST?*

You know, like those credit card commercials, those three words that no family or friend of FIRST “should leave home without.”

Think about them; I will return for your answer. In the meantime, and in the midst of a painfully slow economic recovery worldwide, I am excited to share with you some terrific news. FIRST has continued to thrive in 2012 and exert its major impact on the lives of our members. Through expanded service and communication programs, creative research oriented toward translating discoveries from the laboratory *bench to bedside*, growing financial strength, and continued outstanding leadership, FIRST is positioned to be a strong point of pride to individuals, and members with ichthyosis and related skin types now and for years to come. The ingredients for future successes are surely in place, and I wish to thank you for your continued and persistent support of YOUR organization.

Shifting back to my question about mission, one of the three words is to *educate*. Of the three, it is perhaps my favorite. A call to education implies a sense of knowing about something and teaching it to others. For example, we know ichthyosis is a family of rare genetic disorders, and it causes dry, red, scaly skin. In check-out lines, at school, restaurants, anywhere for that matter, we patiently educate those who are open to learning by teaching them about ichthyosis. The need to educate certainly takes on a compelling urgency when we serve as an educational resource to new parents of a child born with ichthyosis. We want to be there, we need to be there, we will be there, *and beyond* to educate!

What do we really know about fixing the “real problems” underlying the disorder? We know quite a bit, but not nearly enough. To overcome this, we must remain steadfast in our emotional and financial support of those “teachers” who can better educate us. The clinical researchers and skilled scientists who are heavily associated with FIRST are our partners to help us solve the problem. They are real heroes in so many ways. These extraordinary professionals hold out tremendous hope for us. Their knowledge of dermatology, genetics and metabolism, and their enthusiasm for finding solutions to problems converge in a very positive way for our organization. For rare disorders, these wonderful people are pivotal to all hope, and we must support them!

Later this year, FIRST will announce a new, exciting, and multi-year fundraising campaign that will establish a research endowment as part of a major effort to strengthen these relationships. As the FIRST Research Program enters its seventh year, the experiment has been a big success and akin to a start-up small business, ready for expansion. The time has come to stabilize and expand our commitment to ongoing research of innovative and creative solutions to problems that affect our members.

Noted essayist and poet Ralph Waldo Emerson described the basis for success when he wrote, “*Every great achievement is the victory of a flaming heart.*” Victory for FIRST’s Research Program is not hard to define, but more difficult to imagine. Yet we must imagine a future defined by the discovery of new and effective treatments and cures for ichthyosis.

There is no greater imperative. Affiliated researchers are doing their part. In fact, we are turning several interested researchers away for lack of sufficient funds. All are extremely passionate about what they are doing on our behalf. Effectively, they are dedicating their professional lives to changing ours!

So, how do we complement their passion the best? By *inspiring* philanthropy and generosity from FIRST members, friends, family, and corporate sponsors, we *connect* dollars to answers and fulfill our supportive role in the march to that victory! In the future, and as we reach out to our members and ask for your thoughtful support throughout the campaign, please consider ways that you can contribute in meaningful ways to this special campaign achievement and the ultimate victory ahead. In fact, we are searching for the most descriptive and inspirational title for the campaign—*please write to Jean at FIRST with your suggestions*. Your “inspiration” could be selected as the moniker to lead us forward for generations to come.

In closing, and upon completing my sixth year as president of FIRST, I look forward to supporting the three fundamental principles that bind us all: FIRST’s never-ending mission to *educate, inspire and connect* our members with each other and to a thriving future. Have a prosperous and healthy 2013. Together, we will board the *Fast Track to Indy* and produce a record-breaking attendance at our 2014 National Family Conference!

Sincerely,

Dave Scholl