

From Surviving to Thriving: 2021 Annual Report

As I write this, our global community is slowly emerging from unprecedented times. The pandemic has changed how we as a society work, celebrate, educate and operate. It has also changed FIRST. I have been CEO for a little less than two years and have only met a few board members in person. The Cina family alone (with two affected children) makes up a little less than 50 percent of the affected people I have met in person! I am really looking forward to meeting as many of you as possible. We are planning a great conference in Providence and hope you will join us!

As you can see in the graphics in this report – and throughout this issue – FIRST has continued to provide the information and resources needed by our members. Your Board of Directors approved an aggressive strategic plan about 18 months ago and implementation of that plan did not slow down over the past year. The number of research proposals reviewed by our committee grew sharply, with two proposals ultimately being funded. Virtual programming became a necessary substitute for in-person forums. Even when members couldn't catch the live-stream, they accessed programming on-demand – views on our YouTube channel grew dramatically.

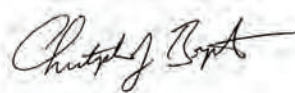
The primary front door to FIRST is our website, www.firstskinfoundation.org. Thousands of visitors and page views tell us this is an important source of information, one not found anywhere else on the internet. This coming year we will be making further improvements to the site to provide more in-depth information about some of the rarer skin types, and enhancing our skin management pages. Stay tuned.

We also know that many seek us out for referrals to dermatologists who understand ichthyosis and related skin types. While our number of requests grew in 2021, the database of available physicians only grew by two. We are working to expand this list in the coming year.

Research by pharmaceutical and biotech companies interested in ichthyosis is ramping up. Part of our mission is to support research no matter where it takes place and FIRST is working with several companies on exciting projects that will improve treatment options. Clinical trials are a critical part of the drug development process. We encourage you to keep an eye on trials that are recruiting and assess if you are able to participate. It is one of the most important ways you can support this community.

Speaking of support, I want to give a very special thank you to our donors! Your commitment to support FIRST enables us to provide the information, resources, access to expert clinical recommendations and community not found anywhere else in the world. We simply could not exist without you.

Thank you all for being a part of this very special organization. Let's make 2022 even greater!



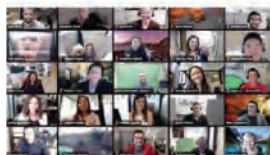
Christopher Boynton
Chief Executive Officer



Physician Referral—
Made **280** referrals to physicians who understand Ichthyosis



Financial Support—
provided grants for skin-care or scholarships to **37** members



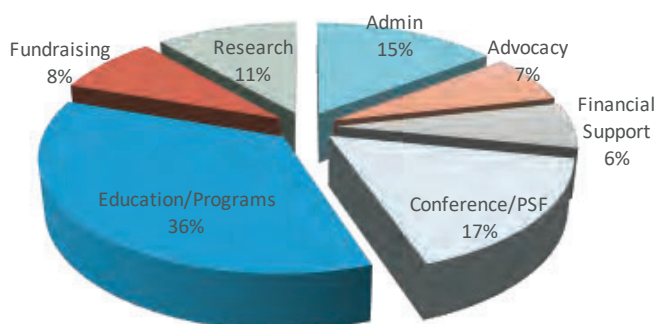
Virtual Programs—
FIRST hosted **15** virtual programs and workshops



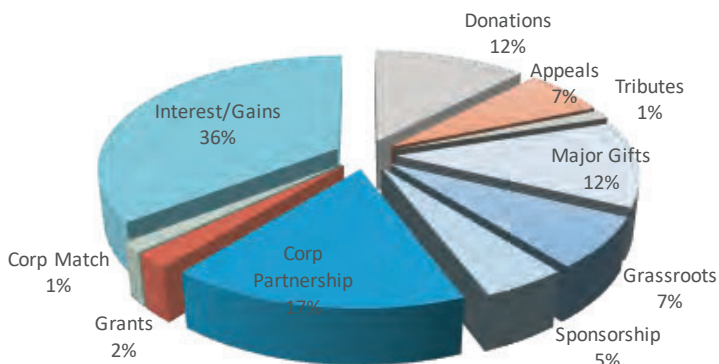
Patient Support Forum—hosted **22** members at a forum in Rehoboth Beach, Delaware

Financial Highlights September 30, 2021

Fiscal Year 2021 Expenses - \$603,844



Fiscal Year 2021 Income - \$933,641



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