## Foundation for Ichthyosis & Related Skin Types, Inc. Chief Financial Officer Report Fiscal Year End 09/30/18

Dear Fellow Members, Donors and Friends of FIRST,

I write this letter at the conclusion of my first full fiscal year as FIRST's CFO. The experience has provided me a better understanding for the financial health and wherewithal of our organization. While there are areas where we can improve, and much strategic and tactical efforts are working toward that, as of the end of fiscal year 2018, I am pleased to report that FIRST is in a position of financial stability.

This stability is the result of a willingness of our members, staff, Board and Emeriti to support and give back to the organization that serves and advocates for our ichthyosis family. The tremendous good that comes from our organization is made possible by of all of you.

While the full audited financials can be found in our Form 990,

I am excited to share some of the ways in which our pooled financial assets have been used to invest in and serve our community. The examples below include several highlights but certainly is not an exhaustive list of all the good work being done:

- In June 2018, FIRST had our largest ever National Conference, with 500+ attendees. More than 40% of attendees were there for the first time!
- We disbursed \$11,341 in UFIRST scholarship funding to college students.
- In partnership with Yale University, one of the leading institutions in ichthyosis research, we continue to co-sponsor the ichthyosis registry with a \$50,000 annual grant. This fantastic program offers our members free genetic testing, which provides a definitive diagnosis and allows for better, more targeted treatments and eventual cures (hopefully!). To date,1,429 total affected individuals are in the Registry. This is the largest pooled resource of genetic information for affected ichthyosis individuals in the world.

FIRST is able to offer many of the above initiatives because of the support we received from our members and community. In FY 2018, we received \$595,765 in grants and contributions. That includes a fantastic grassroots fundraising total of \$87,232, and \$74,000+ in grants.

Before we know it, it will be time for the next National Conference in Providence next summer and my family and I hope to see you there! I look forward to reporting on our progress and status for fiscal year 2019.

In deep gratitude for your support,

Sean McTernan CFO, FIRST