



# Celebrating 40 Years





Dear NFED Family,

It is with great honor and excitement that I announce our 40th anniversary, and we have a lot to celebrate! We have grown and branched out considerably since the early 1980s, when little was known about these rare conditions.

At the time of our founding, the medical literature cited only a half dozen individuals affected by ectodermal dysplasias in the United States. Today, we know there are more than two million individuals worldwide who are living with an ectodermal dysplasia. **We currently serve over 9,200 affected individuals and families in 118 countries!**

To celebrate 40 years of supporting you and supporting each other, we are ramping up to make an even **bigger impact in 2022 and the years to come!**

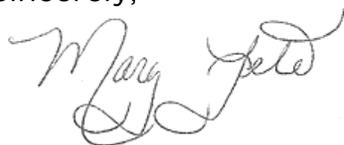
Our 2022 agenda is very full. As part of our celebrations we have a big plan. We will be increasing support services for our families, providing additional financial support for treatment, and spearheading and funding more research projects than ever before.

Additionally, we will once again meet with our NFED family, in person, at our 2022 Family Conference in St. Louis this July 14 - 16. We anticipate it will be our biggest conference ever, where we will be able to provide more support to our families and impact many lives in a positive way!

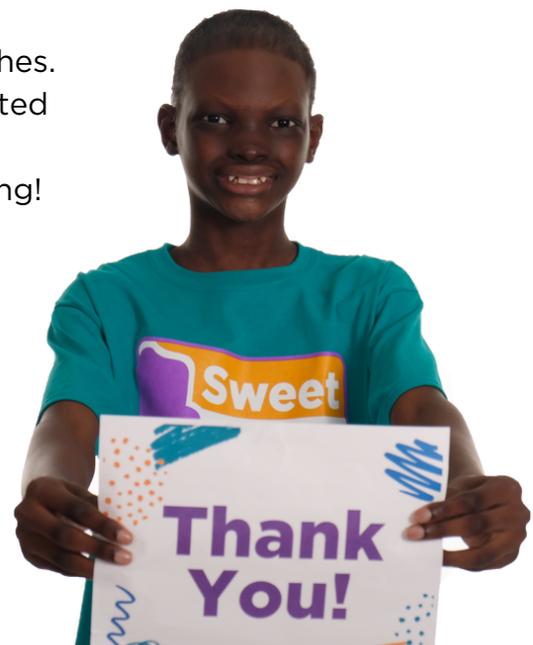
The theme for our 40th anniversary is Deep Roots, Strong Branches. Our journey has been long, required tireless dedication and resulted in continuous growth of our life-changing services. We couldn't do it without you. Thank you for making our first 40 years amazing!

**Please join as we highlight our history and accomplishments and build a plan for another strong 40+ years.**

Sincerely,



Mary Fete, M.S.N., R.N., C.C.M.  
Executive Director



**Deep Roots...**

# Make Strong Branches

At the NFED, we are celebrating 40 years of supporting families who don't know where else to turn, pushing forward research to develop treatments and cures, advocating at the Capitol for mandatory insurance coverage, and raising awareness around ectodermal dysplasias. **We have deep roots.**



After learning her toddler, Charley, had been diagnosed with hypohidrotic ectodermal dysplasia (HED) syndrome, Mary Kaye Richter was looking for answers on how to best care for her son. She soon realized there was little information available, and Mary Kaye, along with 12 other families affected by ectodermal dysplasias, organized and founded the NFED in Mascoutah, Illinois on December 24, 1981.

## **We have a lot to celebrate!**

Because ectodermal dysplasias are so rare, many individuals don't know where to turn to understand their syndrome. When families aren't sure what steps to take next, the NFED:

- Provides a range of up-to-date educational resources to meet their changing needs and understand treatment options.
- Works with families to find financial assistance and help secure insurance coverage for dental treatment related to their diagnosis.
- Partners with doctors and dentists to ensure effective treatment plans.
- Offers one-on-one support to families for a lifetime.

Most importantly, we walk with families wherever they are on their journey and connect them with other families who have gone or are going through similar things.

**We make sure families  
are not alone!**





“ I am extremely grateful to the NFED for being the family that they are and that they have been to our entire family... And that's why we say it's not just a foundation. It's a FAMILY!

- Virginia Higgins, NFED founding family member, volunteer and advocate

