

A Year of Innovation, Made Possible By You



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ANNUAL
REPORT



Executive Letter

Dear friends,

This year's annual report is truly an Appreciation Report for you, our supporters! Your contributions and dedication to our mission are the foundation of our success. As good stewards of your gifts, we have been innovative in our strategies to best meet our families' growing needs. The unique challenges of the ectodermal dysplasias require unique solutions.

It was a joyous day in the fall of 2013 when we learned that the first baby boy affected by x-linked hypohidrotic ectodermal dysplasia (XLHED) had received a potential treatment as part of a clinical trial. This monumental step culminated from 30+ years of collaborative research that you supported. We are incredibly grateful to Cally (see story on page one) and the families of the past three decades who volunteered to advance this research. It is our hope to do for Goltz, AEC, EEC and other syndromes what we have been able to accomplish for XLHED: trail blaze a path that leads to better treatments and potential cures.

No matter where our families call home, they become a part of a growing and compassionate community when they contact us. Thanks to you, our annual Family Conference was life-changing for Sherri (see story on page two) and numerous others. To extend the experience beyond the Conference, families are connecting through social media in our Facebook groups and with our growing team of liaisons who personally contact families in their regions.

Dental care costs continue to soar and our families face extraordinary challenges to get their smile. Our solution has been to create a network of Dental Treatment Centers which provides care at more affordable rates. Your generous donation gave Jackson his new smile. With your donation, we can help a greater number of people like Jackson (see story on page three) bring their smile to life.

We also continue to look for innovative ways to fund our mission. A record number of in-kind services helped offset Family Conference expenses. The sluggish economy continues to present fundraising challenges. While the Foundation is fiscally stable, thanks to donors like you, we critically need the ongoing, generous support of our community to sustain and expand our efforts.

In 2013, we made a strategic approach to build a strong, engaged community to advance our mission. We are inviting and challenging the entire NFED family to take action, volunteer, and explore what we can do together to make life better for people affected by ectodermal dysplasias.

Thank you for your caring heart and unwavering support! We hope that you enjoy reading the stories about our *Year of Innovation, Made Possible by You*.

Sincerely,

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

Anil Vora
President, Board of Directors

Research

With Help From You, the First Potential Treatment for XLHED Was Tested

Timothy Toupin III (see cover photo and photo at right) is an adorable six-month-old baby boy who has x-linked hypohidrotic ectodermal dysplasia (XLHED). Shortly after he was born in 2013, he was admitted to the University of California at San Francisco Medical Center to become one of the first infants to take part in a clinical trial to test a possible treatment for XLHED.

The decision to enroll their newborn son in a clinical trial was not a terribly difficult one for Cally and Timothy Toupin, Timmy's parents. Cally and her mother are carriers and her younger brother and a cousin have XLHED. Cally saw how her brother struggled growing up, not only with heat-related issues but also with bullying.

A lot of her family's attention and energy went into making sure that her brother's needs were met, particularly

when it came to keeping him safe from overheating. Cally didn't want Timmy to suffer in the same way and felt that if there was a chance of preventing that she was willing to try.

Cally had read about Edimer's clinical trial on the NFED website. For Cally, the experience has been a good one. Her fears about possible complications, the unknown and Timmy being in pain were unfounded; the whole thing was much less scary than she thought it might be. Cally and Tim aren't really sure of what to expect going forward since this is uncharted territory. They wanted to offer Timmy the possibility of an easier path in life, and Edimer's clinical trial does just that. They hope the ground-breaking research is successful and that Timmy will eventually be able to sweat and develop teeth. But if he doesn't, that's fine, too. Cally and Tim love him just the way he is.



Thanks to you...

- Our 30+ years of dedication to XLHED research paved the way for the first potential treatment to be tested in a clinical trial being conducted by Edimer Pharmaceuticals. Two newborn boys were the first in the trial to be given a protein called EDI200. If the treatment is as successful in the baby as it has been in mice and dogs, they will not need to undergo a lifetime of extraordinary dental care, may have nearly normal amounts of hair and may be less troubled by inactive sweat glands.
- Goltz syndrome is one of the more rare ectodermal dysplasias and for which little is known. In July, the largest group of individuals ever gathered to participate in the first International Research Symposium on Goltz Syndrome. They changed the course of history by providing blood, hair and skin samples all to aid in the research and treatment of the condition. The 19 families from three countries formed strong emotional bonds and continue to network through a Goltz syndrome Facebook group and Shutterfly site.

Nikhita Steward-Trivedi participated in the Goltz Research Symposium



Support

A Growing and Compassionate Community, Made Possible by You

Because of your support in 2013, we have been able to hold hands, instill courage, allay fears and give hope to families around the world living with ectodermal dysplasias.

Sherri left the Family Conference appreciative and thankful that she got to be a part of something so amazing.

"I am grateful to the staff for giving my children and me a scholarship that allowed us to attend. I left there with questions answered and many assurances that my daughter, Mariska, will truly be OK. I was more than relieved and I felt so very blessed and almost content."

This single mom kept back the tears for the first two days of the Conference, but by Friday night's Talent Show, there was no holding them back. She could not put into words the courage, determination and love that was in that room. She said that if you were not there, she cannot make you understand. Sherri was grateful to be there and so thankful that her sweet Mariska Anne was healthy and going to be just fine.

Mariska was on cloud nine. She fell asleep smiling on the way home. She was so excited to be around kids with little hair like her and was proud that she has the hair that she does. She didn't feel different while at the conference and for her, that was something more than amazing! As positive and loving and caring that people are when we are home, it's different being around others who are just like you, Sherri said.

Sherri met people that will always have a piece of her heart. She was amazed at the kindness that she was shown.

"I saw so much courage and determination to help, to get things done, and to make a difference. To my new friends, I thank you. To the kindness of doctors, I am speechless. I am so happy, and content and overfull with all the things that were shared and given to my family. From my overflowing happy heart, I heart your heart and am glad you are a part of my journey."



Vincent, Sherri, and Mariska Callahan's lives changed at the Family Conference.



Thanks to you...

- 258 families who contacted the NFED for the first time received extensive information and compassionate care.
- A growing team of 20 liaisons and staff provided outreach and resources to 6,900 families in 85 countries.
- We held the largest gathering in the world of families affected by ectodermal dysplasias in Houston, Texas. 253 people left the 2013 Family Conference educated on the syndromes, armed with treatment options and filled with gratitude for their new network of friends.
- More than 4,000 people connected on our Facebook page and private groups to share experiences and offer support to each other.

Treatment

You Help Bring Smiles to Life

Because of your help in 2013, we were able to expand our network of treatment centers to enable more families to receive dental care.

Jackson is a bright and beautiful five-year-old boy who is full of energy. But he very much wanted his teeth to look like everyone else's. His mom, Deborah, said she noticed when he was four years old that he stopped smiling with his "natural" teeth, which consisted of two baby teeth and four adult teeth, all conical shaped. It became increasingly apparent to Deborah and husband, Jon, that it was time for the next step: dentures.

They chose to get Jackson's care at the San Diego Ectodermal Dysplasias Dental Treatment Center, which is in the NFED's network. They made several visits with Dr. Peter Johnson and Jillian Grinfeld, the executive director. Their staff was incredible. The emotional day came when the parents got to see Jackson with a full set of teeth - in wax - in his mouth for the first time. Their eyes completely welled up.

They said to see Jackson's face when he had them in his mouth was worth anything they had to give to make this happen for him. When Deborah put him to

bed that evening, Jackson looked at me and said, "Mommy, I always wanted top and bottom teeth," and smiled. It doesn't get better than that.

On the day for delivery of Jack's actual teeth, the staff put together an exciting party for Jack to commemorate his new teeth. Dr. Johnson first allowed Jack to look at his teeth before putting them in. He examined them with a smile. With help from Dr. Johnson, he put in the uppers and lowers. Jackson was so excited that when he went to chomp his teeth together, Dr. Johnson's finger received Jackson's first full bite!

He looked into the mirror for the first time. A huge smile crept across his face. He now had a full set of his own teeth. Jillian, Jon and Deborah all cried. There was no stopping the happy tears!

As the days progressed, Jackson's adapted to his new teeth. He loved his teeth. He spoke extremely well and ate without any urging. He asked his parents to tell strangers about them. Deborah says Jackson's smile was already as beautiful as it could be. But, now, he will be able to have what he always wanted because of so many people: the NFED, Dr. Johnson, Jillian and people like you.



Thanks to you...

- 56 individuals received care in 2013 at one of the 21 NFED Dental Treatment Centers providing care to ectodermal dysplasias families at reduced costs.
- Thanks to you, families received \$35,000 in direct assistance and donated dental implants and services.
- The NFED team mentored 45 families through the insurance process to get coverage for their dental care.



The Power of Your Support

\$623,162 in Charitable Giving was Raised for Support, Research, Treatment and Operations

Thank you for partnering with us to empower and connect people touched by ectodermal dysplasias.

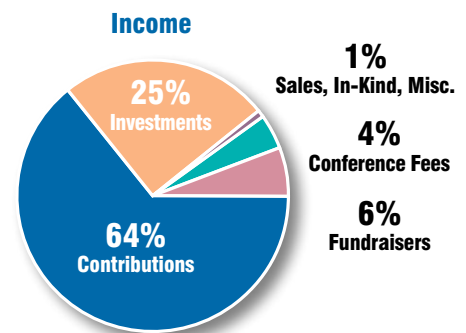
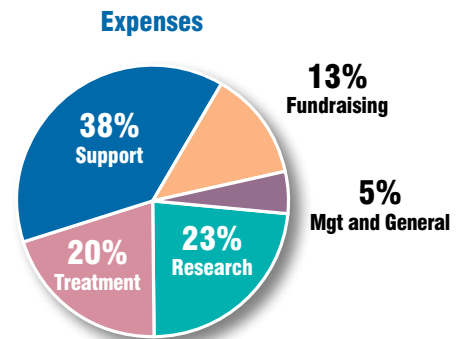
In 2013, 1,514 individuals, corporations, businesses and organizations supported us through financial contributions. Countless others lent their support through volunteering and sharing their story. For a complete list of donors and full financial report for 2013, please visit us online at NFED.org.

Income Total: \$849,225

Expenses Total: \$763,699

Ending Net Assets: \$1,374,958

Kelley Coffey and her son, Matthew, reconnected with old friends and met new ones at the Family Conference.



Volunteer

"I accepted the role of Family Liaison because I wanted to support the NFED and be a positive example of an adult living with ectodermal dysplasia. Being a liaison is great because it gives me opportunities to meet people from different walks of life and be a part of a community. I love putting people in touch with others who are facing (or have faced) similar challenges with ectodermal dysplasias and watching them connect over shared experiences."

— Heather McKelvie
Family Liaison

Thanks to you...

We have a growing team of volunteers who are giving their time to change someone's life. We launched our Helping Hands program as a way to expand our reach and to propel our mission in new and innovative ways. Together, we are stronger!



With Gratitude

Thank you for supporting our NFED family with your gifts!

The Danz Society

The F.G. Danz Society formally recognizes individuals who invest in our mission with gifts of \$1,000 or more within the fiscal year. This major donor society is named for a German, F.G. Danz, who wrote in 1729 a treatise titled Concerning Men Without Teeth. "In our neighborhood lives a Jewish family of which two adult sons, neither have, or ever have had, hair or teeth." This is the first instance of the ectodermal dysplasias being described in literature.

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Our Mission

To empower and connect people touched by ectodermal dysplasias through education, support, and research.

Ectodermal Dysplasias

The 180+ ectodermal dysplasias are rare genetic conditions that affect the development of hair, teeth, skin, glands and nails in men, women and children of all races and ethnic groups. Other body parts may be affected such as the skin, eye, parts of the ear, and limbs. Symptoms among syndromes and even within families can range from mild to severe. Only in rare cases do ectodermal dysplasias affect lifespan and very few types involve learning difficulties. As few as one or as many as 7 in 10,000 babies are born affected by ectodermal dysplasias.

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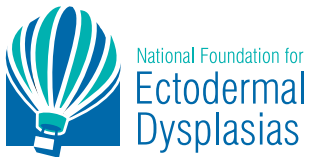
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Contact us at NFED.org, info@nfed.org or 618-566-2020