

2016 Annual IMPACT Report



Thanks to You!

nfed
NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

A Year of **PROMISE.** Perseverance. **GROWTH.** *Creativity.* **Celebration.**

Dear friend,

I am very excited to share with you the 2016 Annual IMPACT Report for the National Foundation for Ectodermal Dysplasias (NFED). Preparation for our annual report allows us to reflect and evaluate the year's challenges and accomplishments so that we meet the needs for our ectodermal dysplasias community in the future.

This year, we asked ourselves, "In one word, how would we describe 2016 for the NFED?" Here is what our staff had to say: **PROMISING. PERSEVERANCE. GROWTH. CREATIVE. CELEBRATION.** This past year was one that began with challenges, yet ended with great accomplishment and promise for the future. We were faced with disappointment and sadness at the start of 2016. The Newborn XLHED Clinical Trial results were not what we had hoped. But, we remain optimistic that the long-term data analysis will be more **promising**.

With **perseverance** and tenacity, Dr. Holm Schneider continues the important x-linked hypohidrotic ectodermal dysplasia (XLHED) research that we began 30 years ago thanks to a \$25,000 seed grant from the NFED. In 2016, Dr. Schneider dosed male twins affected by XLHED in utero with EDI200. The early results show much **promise as you will read on page eight**. These preliminary findings provide incredible hope and only add to our fuel to find treatments and cures for all of the ectodermal dysplasias.

We experienced **growth** on numerous fronts in 2016. Our NFED community continued to **grow** in 2016 with more new families than anticipated joining us at the Family Conference and becoming engaged with us on social media. Our volunteer base **grew** and we **added** new Dental Treatment Centers in New Jersey and in New York to increase accessibility to care for our NFED families.

We successfully launched our new website in November which offers families **easier ways to connect** with both the NFED and other families. Funding for Send a Kid to Camp, the End-of-Year Campaign and Anniversary Celebration exceeded our goals. Thirteen families found **creative** ways to hold new fundraisers and raise awareness. We **celebrated** our 35th year of service to the ectodermal dysplasias community by hosting an Anniversary Celebration Dinner. We honored seven families and volunteers who have made significant contributions to our success throughout the years.

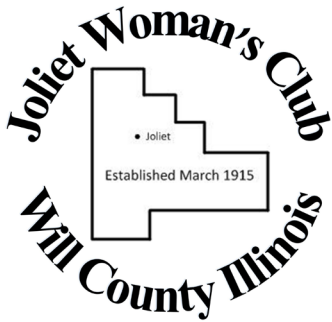
At the NFED, we want you to always feel supported and connected to what we do for you. We are launching several new initiatives in 2017 that will benefit the ectodermal dysplasias community. We look forward to sharing the results with you throughout the year. I hope you enjoy our Annual IMPACT Report. Our impact would not be possible with your dedication and love for the NFED.

Sincerely,



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

THANK YOU, SPONSORS!



LOUIS J. & JUNE E.
KAY FOUNDATION



CLAUDE & PAMELA COOKE CHARITABLE TRUST



THANK YOU, Joliet Woman's Club!

Mary Fete was honored to attend the last luncheon of the Joliet Woman's Club in April, 2016. The group disbanded and gifted the NFED with their remaining funds of **\$50,000!** We are humbled by these women and their dedication to our NFED family.

At 15 months, a dentist diagnosed our son with hypohidrotic ectodermal dysplasia.

We turned immediately to the NFED for information. They connected us with an NFED Family Liaison who provided thoughtful advice, and suggested questions to ask doctors as we went about confirming our son's diagnosis.

We quickly realized that the specialists were also turning to the NFED. As parents of a child with a rare syndrome, we needed to be educators and advocates for his care. The prospect of meeting other people with ectodermal dysplasias at the NFED's annual Family Conference gave us hope and proved invaluable.

At the 2016 Conference, we learned a great deal from members of NFED's Scientific Advisory Council. But most importantly, we met people at all stages of life living with ectodermal dysplasias. We connected with other families like ours and our son got to play with other kids who look like him.

The NFED has been a tremendous resource for our family and our son's doctors. We are already looking forward to this year's Family Conference.

- Christine





THANKS TO YOU...

343 family members and affected individuals contacted the NFED for the first time in 2016 to receive extensive information and compassionate care.

The NFED remains a vital resource to **8,100 families** in more than **85 countries**.

337 people attended the Family Conference in 2016 and 75 were first-time attendees.

2017 GOAL: In conjunction with the Advocacy Day on Capitol Hill, we are looking to have a banner number of people attend this year's Family Conference, July 20-22. The Conference continues to be the number one way for families to be educated, to find support and to connect with doctors and dentists who are experienced with ectodermal dysplasias.

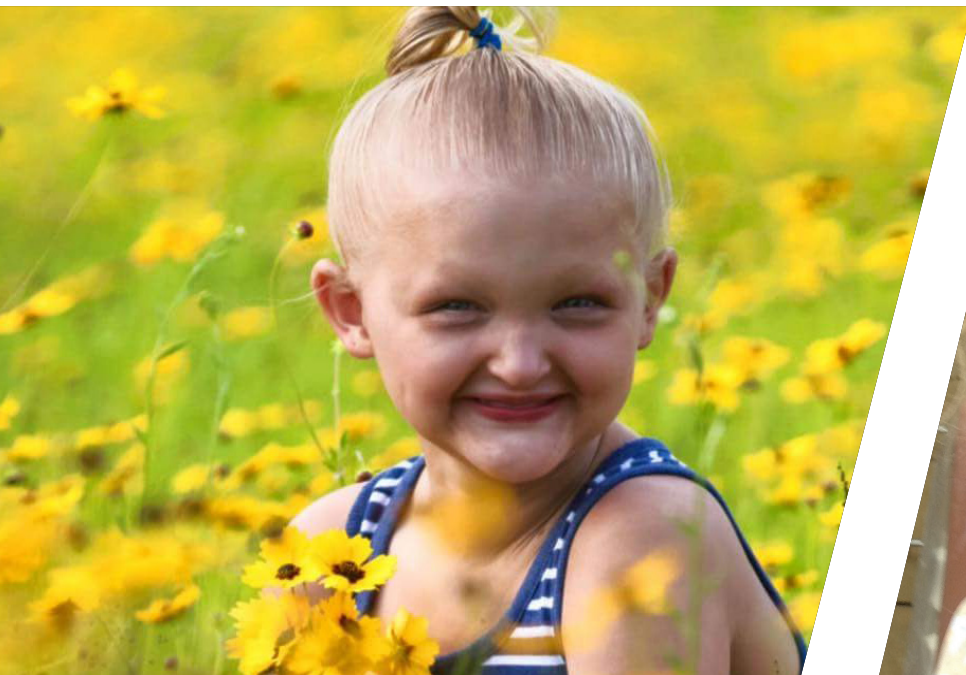
Your Impact:

Treatment

Vivacious, 10-year-old Brooklyn received the beautiful smile she's always dreamt of because of your contributions to the Treatment Assistance Program.

All her parents were hoping for was for Brooklyn to have the self-worth she deserves in life. Now, she has it. Thank you!

before



after

THANKS TO YOU...

Families received more than **\$13,000** in direct assistance or donated dental implants and services.

We mentored more than 100 families through the insurance process to get coverage for their dental care.

Straumann donated dental implants for four affected individuals. We are very grateful for Straumann's generosity and continue to alert families to the benefits of this great program.

"We have proudly supported the NFED for the last 12 years and hope to support them for many, many more." - Straumann

Over **60** people with ectodermal dysplasias were referred to one of our Dental Treatment Centers to receive care at a reduced cost.

For the past **35** years, the NFED has provided families and affected individuals with more than \$1.5 million in assistance for needed care.

2017 TREATMENT GOAL: We will work to change the legislation so that it mandates medical benefits for the dental care of ectodermal dysplasias. We must have the help of families throughout the United States in our battle for change. We will kick off this campaign on July 19, 2017 for our first Advocacy Day on Capitol Hill.



Lucy received donated implants from Straumann through a special program we have with the dental implant company.

In January, 2016, NFED announced that Edimer Pharmaceutical's Newborn XLHED Clinical Trial did not achieve the outcomes which we had hoped for.

In that trial, they dosed newborns who were affected by x-linked hypohidrotic ectodermal dysplasia (XLHED) with a protein called EDI200 shortly after birth.

There were some modest signs of improvement in the development and function of various body parts that XLHED affects. However, Edimer didn't see significant changes in sweat gland function, teeth and other early markers. All of us in the ectodermal dysplasias community were disappointed.

Despite this news, one of the initial primary investigators in the clinical trial, Professor Holm Schneider from Erlangen, Germany, continued research on EDI200. He, along with other researchers, believed that dosing after birth is too late to impact the development of sweat glands and other key markers. They hypothesized that injecting in utero will lead to better results.

Dr. Schneider has now treated three babies with EDI200 by injecting it into the mother's amniotic fluid, prior to birth. The early results are very encouraging.

Male twins were treated in utero at 26 weeks and again at 31 weeks. Dr. Schneider reports an impressive number of tooth buds were noted after treatment. It is too early to know how many teeth will develop. But, the number of tooth buds is encouraging.

The sweat glands have appeared to develop normally! Dr. Schneider noted that it was a very hot summer in Germany and the twins did fine regulating their temperature.

Another baby boy was treated in utero and born in Germany. He was dosed only once at 26 weeks. We anxiously await the data.





In 2016, Maranke I. Koster, Ph.D. and Peter J. Koch, Ph.D., at the University of Colorado School of Medicine continued to research the basis for skin and eye abnormalities that occur in patients affected by anykyloblepharon-ectodermal defects-clefting (AEC) syndrome and ectrodactyly-ectodermal dysplasia-clefting (EEC) syndrome through the mutations in the p63 gene.

They made an important discovery that Dr. Koster believes may explain the skin erosions that occur in AEC and EEC patients. The NFED also believe that these processes underlie corneal fragility in patients affected by AEC or EEC. In the worst case scenario, this corneal fragility sets off a cascade of events that leads to severe vision loss.



THANKS TO YOU...

Since 1987, we have funded more than **\$2.5 million** for ectodermal dysplasias research at over **40 centers** around the world. You have helped us sponsor numerous scientific conferences for specific syndromes and classification.

NFED-funded research projects have identified genes for numerous ectodermal dysplasias, established treatment protocols and characterized many of the syndromes.

2017 RESEARCH GOAL: We will continue to follow the babies in the initial Newborn XLHED Clinical Trial as well as those treated in utero to understand the long-term effects of this initial treatment.

We will continue the Natural History Study. This study enrolled boys and girls with XLHED during infancy. They will be followed until they are five years old. This important study will help us better understand the natural history of XLHED so we can improve care.

Families will have the opportunity to participate in a research project at the National Institute of Dental and Craniofacial Research while at the Family Conference. The study will look at the various oral manifestations and salivary function of ectodermal dysplasias.

We continue to create a new classification system for the ectodermal dysplasias to improve early diagnosis, help identify appropriate treatment and incite research.

- 1981 ● The NFED incorporates.
- 1982 ● 13 families attend first National Family Conference; Belleville Kiwanis gives NFED its first donation.
- 1983 ● Barry Manilow donates \$1,000 to start Treatment Fund; “We can’t smile without you” is the new NFED slogan.
- 1984 ● A Family Guide to the Ectodermal Dysplasias is published and distributed.
- 1985 ● Donated computers enable patient data, donations and finances to be tracked more efficiently. Staff writes to every NFED family a personal letter.
- 1986 ● The monthly newsletter is named “The EDucator” and is mailed to 340 homes in 43 states and eight countries.
- 1987 ● First patient receives assistance for dentures via Treatment Fund.
- 1988 ● Five Regional Centers established. Dr. Virginia Sybert’s article on peeling skin in neonates is published. Eight patients enroll in NIDR dental implant research project at the National Institute for Dental and Craniofacial Research (NIDCR).
- 1989 ● Dr. Jon Zonana granted first research award of \$10,000 to study XLHED gene identification. Mary Kaye Richter appointed to National Advisory Dental Research Council.
- 1990 ● Budget hits \$100,000.
- 1991 ● First Apple Classic Golf Tournament raises \$6,400. The 999 Club launches to raise research funds.
- 1992 ● Executive Director Mary K. Richter serves on the Oral Health 2000 steering committee and speaks at meetings of the NIDCR, Oral Health 2000, and the American Academy of Dental Schools and American Academy of Dental Research.
- 1993 ● Served families in 20 countries.
- 1994 ● 110 volunteers help NFED on a regular basis.
- 1995 ● L. Marie Heard Bequest launches Dental Implant Program and Education Scholarship Program.

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- 1996 ● Gene for XLHED identified. First web site goes live.
 - 1997 ● Dental survey of families conducted to quantify and qualify needed data related to timing of dental treatment, success of care, and third party payment.
 - 1998 ● Mary Kaye and Charley Richter given Patient Advocacy Award from Friends of the NIDCR.
 - 1999 ● First National Family Conference held outside the U.S. in the U.K.
 - 2001 ● First Halloween Bash raises \$300,000.
 - 2002 ● Participated in the European Conference on Ectodermal Dysplasia. NFED staff and volunteers made Congressional visits asking for increased research funding for both the skin and dental institutes at NIH.
 - 2003 ● Children's storybook, "Lionel Learns What Matters Most", published.
 - 2004 ● NFED convenes dental experts to identify obstacles to oral health care and solutions; First Ectodermal Dysplasias Awareness Month held in February.
 - 2005 ● Budget exceeds \$1 million.
 - 2006 ● AEC meeting expands understanding and research. Family Support Network launches.
 - 2007 ● \$95,000 awarded to three investigators for ectodermal dysplasias research projects. Findings from seven NFED-supported research projects were presented in peer journals or to peer audiences.
 - 2008 ● Largest gathering of families in history takes place at Virginia Family Conference.
 - 2009 ● Free topical conference calls educate families on medical and dental issues.
 - 2010 ● NFED Founder Mary K. Richter retires.
 - 2011 ● The NFED celebrates 30 years of servicing the ectodermal dysplasias community.
 - 2012 ● 20 Family Liaisons serve other families in eight regions of the United States.
 - 2013 ● First baby affected by XLHED dosed in Newborn XLHED Clinical Trial.
 - 2014 ● Largest gathering of ectodermal dysplasias community (449) in history at 2014 Family Conference.
 - 2015 ● Regional Family Conferences and Professional Symposia educate families and care providers in 4 regions of the U.S.
 - 2016 ● Twins with XLHED dosed in utero with EDI200. Early results show sweat glands appear to be working.

Your Impact:

Financial Support

Donor spotlight: **Karen**

“My daughter was diagnosed with an ectodermal dysplasia when she was young. If there had been a camp for kids back then, it is possible she would not have attempted to take her life. She would have had an opportunity to know others just like her and to know she was not alone. It was not until we found the NFED years later, that she had that opportunity and one that gave her wings to fly. Being a donor to the NFED not only gives me a chance to give back to the Foundation and members who gave so much to my daughter, it gives me the chance to let other children find their wings and see they are not alone; to see that they can be all that they dream as they become the person they want to be. What greater gift could one receive than knowing even the smallest donation can have such an impact in a child’s life?”



Donor spotlight: **Michelle and Matt**

“Contributing to the NFED helps to ensure the brightest possible future for our daughter and others who are affected by ectodermal dysplasias. Their focus and determination helps to guide research and promotes awareness for doctors and families.”



1,984 donors contributed 3,018 gifts totaling \$848,765.94 in 2016.

Guests at the 35th Anniversary Celebration Dinner that benefited the NFED



Your Impact:

Your Time

Volunteer spotlight: **Morgan Thom**

Morgan began interning for the NFED when she was 19 in 2014 and has volunteered every year during the summer since. Morgan found out about the NFED through her dad, Keith Thom, who served on our Board of Directors for 13 years in the past and is serving again in 2017. Morgan was thinking about becoming a pediatric dentist or a dental hygienist so she was passionate about learning more about the NFED and those affected by ectodermal dysplasias. Keith suggested she apply for a summer internship at the NFED. It was a perfect fit for a future career in dentistry.

The NFED has greatly benefitted from Morgan's volunteer and internship efforts. She attended the 2014 Family Conference in Ohio and the 2016 Family Conference in Missouri and made lots of family connections. She learned firsthand about the dental issues our families face every day. She had the opportunity to work closely with established dentists at the dental evaluation sessions at both conferences. It inspired her even more to make a difference for the ectodermal dysplasias community. She became involved in advocating for the NFED and ectodermal dysplasias. She helped put together First Connect packages and helped with developing and attending grass-root fundraising and awareness events.

Morgan has a great work ethic, positive attitude, wonderful leadership qualities and is well respected for getting things done in a timely matter. She was and will continue to be a great asset to our volunteer Helping Hands program. Morgan has been accepted into the Southern Illinois University School of Dental Medicine and can't wait to pay it forward to the NFED and those affected by ectodermal dysplasias when finished.



Morgan Thom, second to the right, with her family at our 35th Anniversary Celebration held in July.

THANKS TO YOU...

The NFED had **437** active volunteers who performed **4,900** volunteer hours

The NFED officially became a member of the United States' premier volunteer awards program. We will track our volunteer's hours and submit them for eligibility to receive a President's Volunteer Service Award. We share in the program's mission to inspire more people to answer the call to service. The awards program also helps us celebrate the impact NFED volunteers are making in the ectodermal dysplasias community, and ultimately the world.

For more information about this award, visit www.nfed.org/get-involved/volunteer/

Your Impact:

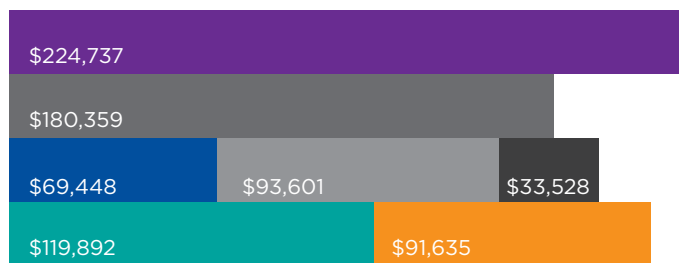
Financial Diversity

The NFED received financial support from a diverse group of resources in 2016.

- Individuals including the many family fundraiser participants, care providers, and friends of the NFED.
- Corporations including our 2016 sponsors, Straumann and Oracle and the many other community businesses who have sponsored family fundraisers.
- Immediate and extended families of affected individuals who know the benefit of NFED programming.
- Organizations such as Joliet Woman’s Club, Delta Theta Tau, Kiwanis Clubs and many other community groups who care about our mission.
- Foundations like the Hubbard Broadcasting Foundation who support 501c3 nonprofits which includes the NFED.

We thank all of you!

2016 total including contributions, stock investments and gifts in-kind per each segment: **\$813,358.94**

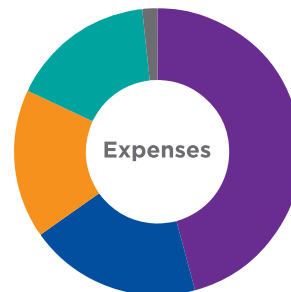
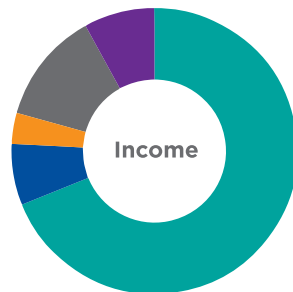


- Individuals - \$224,737
- Corporations - \$180,359
- Extended Families - \$69,448
- Organizations - \$93,601
- Affected Individuals - \$33,528
- Immediate Families - \$119,892
- Foundations - \$91,635

How We Spent Your Gifts

- Contributions - \$659,857
- Special Event Registrations - \$67,093
- Conference Registrations - \$38,358
- Investments - \$123,597
- Sales, In-Kind, Misc. - \$82,446

Total Income: \$971,352



- Support - \$374,348
- Research - \$159,498
- Treatment - \$138,195
- Fundraising - \$133,681
- Management/General - \$13,978

Total Expenses: \$816,527

**All figures that are listed are unaudited; estimated audit completion is 5/1/2017. Visit nfed.org in June to see our complete audit.*

STAFF

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

Executive Director

Kelley Atchison

Director, Family & Community Programs

Brittany Campbell, M.P.A., CFRE

Manager, Development

Jodi Edgar Reinhardt

Director, Marketing and Communications

Kayla Hollenkamp

Administrative Assistant

Lea Richardson

Manager, Community Engagement

BOARD OF DIRECTORS

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Ruth Geismar - Co-President

Jack Kriz - Secretary

Brian Randall - Treasurer

Rick Emery

Frank Farrington, D.D.S., M.S.

Karl Nelsen

Sarah Tevis Poteet, D.D.S., P.A.

Mary Kaye Richter - Honorary Member

Keith Throm

Marianne Vermeer

Anil Vora

J. Timothy Wright, D.D.S., M.S.

Thank you, **Anil Vora**, for six years as NFED Board President!

Anil joined the NFED family in 1987 after his son, Sean, was diagnosed with hypohidrotic ectodermal dysplasia. He, Sean and daughter, Aubrey, became regulars at the annual Family Conferences for the past 31 years. In the early years, you could find Anil playing soccer with the tweens at the Family Conference and helping to organize an NFED event in San Francisco near his home. In the 1990s, he often spoke on panels at Conference and shared his experiences in parenting an affected child. He was a generous supporter of NFED efforts and is always willing to help where needed.



In 2006, Anil joined the NFED Board of Directors. He lent his financial expertise to help streamline and establish best accounting practices. Anil became Board President in 2011 and ended his term in 2016. He has also served as Vice President and financial advisor and participated in the Budget and Finance Committee, the Development Committee, the Family Services Committee, the Human Resources Committee, the Investment Committee, the Strategic Planning Committee and the Website Committee. Anil is the Vice President of Oracle Financing at Oracle, Inc. When he's not helping the NFED, he enjoys playing soccer, traveling and painting. While Anil's service as the President has ended after many years, his dedicated service on the Board of Directors continues.

Anil has done a tremendous job as our Board President. We especially appreciate his efforts to organize our financials and implement a better budget process. He always leads with a focus on our mission. We thank him for his leadership!

nfed

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

Help us grow! Visit nfed.org to find out how you can support, get involved and spread the word today!

The mission of the NFED is to empower and connect people touched by ectodermal dysplasias through education, support and research.

