

I am

National Foundation for Ectodermal Dysplasias
2005 Annual Report



affected by

ectodermal dysplasia.

Executive Letter

Dear Friends of the National Foundation for Ectodermal Dysplasias,

Our Vision

The National Foundation for Ectodermal Dysplasias (NFED) seeks to enrich the lives of individuals affected by all forms of the ectodermal dysplasia syndromes.

Our Mission

The NFED will:

Be the authoritative resource for information on the ectodermal dysplasia syndromes.

Provide services that meet the physical, emotional, informational and social needs of affected individuals and their families, and that help them lead a more normal life.

Support research on the ectodermal dysplasia syndromes.

The NFED is the worldwide nonprofit organization that seeks to enrich the lives of individuals affected by all forms of the ectodermal dysplasia syndromes.

The NFED is a private, tax-exempt nonprofit organization pursuant to Section 501(c)(3) of the Internal Revenue Code, and all gifts and donations to the NFED are tax deductible. Tax ID number is 37-1112496.

Dear friends,

Other than a smile, I can think of nothing more endearing than the dreams of a child. On these pages, the dreams of one little girl will touch your heart. We all know that the fulfillment of dreams can be illusive but there are those golden moments when preparation and hard work pay off and dreams come true.

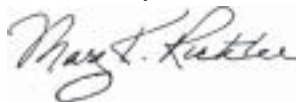


Mark Twain once said, "nothing happens unless first a dream." So it was in 1981 when the National Foundation for Ectodermal Dysplasias began to dream. We envisioned a future for all families affected by ectodermal dysplasia that included useful information, the opportunity to meet, financial assistance for care, and hope for the future.

This report is filled with information that serves as hard evidence of dreams coming true. Dreams of getting needed care. Dreams of academic success. Dreams of research. Dreams of a cure. In most cases, the dreams have been fulfilled. As research advances, even the dream of a cure is now within our grasp.

Just as our little dancer has big dreams...ours, too, continue. With your support, both moral and financial, we are confident that our dance will continue and cures will be found.

Most sincerely,



Mary K. Richter
Executive Director



Keith Thom
President

The photos on the front and back cover and page 22 are courtesy of Joy Vertz from Shot the Moon Photography, Mequon, WI.



The ectodermal dysplasia syndromes are a group of about 150 rare, heritable disorders in which two or more ectodermal structures (hair, teeth, nails & glands) develop and function abnormally. Missing teeth, the inability to sweat and sparse hair are typical symptoms of ectodermal dysplasia. However, a host of other challenges are possible, including skin erosion, cleft lip and palate, immunosuppression, recurring respiratory infections, and lack of breast development. Symptoms of ectodermal dysplasia range from mild to severe. Ectodermal dysplasia is not limited to any one culture or race. We are not sure how many people are affected by ectodermal dysplasias since there has never been a study. However, the *Birth Defects Encyclopedia* estimates that as few as one and as many as 7 out of 10,000 babies are born affected by ectodermal dysplasia.

I am



a friend.

The NFED began at the kitchen table of a farmwife who had a child affected by ectodermal dysplasia. Incorporated in 1981, the NFED is the only charity in the United States helping families affected by ectodermal dysplasia and is the leading clearinghouse of information on the conditions in the world. The NFED provides services to more than 4,200 clients and their families in 50 states and 64 countries.

Family Services

Helping Our Clients Help Themselves

We seek to provide services that meet the physical, emotional, informational and social needs of affected individuals and their families, and that help them lead a more normal life.

We believe in providing a compassionate experience for all who come into contact with the Foundation.

Can I pass ectodermal dysplasia on to my children? What is the best way to get a three-year-old to wear dentures? Do you know a dentist in my area who has experience in treating ectodermal dysplasia?

Every day, the staff fields and answers questions such as those above on the phone and via e-mail. They provide clear and well-researched answers and can mail families extensive information.

Every time a person calls or writes the Foundation, the most important thing they learn is that someone is there for them who understands what they are going through and is going to help.

- 274 new clients affected by ectodermal dysplasia contacted the Foundation for the first time in 2005. Some are seeking financial assistance for treatment, some

want the name of a care provider and all of them want any information they can have on the rare conditions. Each client receives the medical guide series, past issues of *The EDucator*, information on the numerous NFED services and the comfort in knowing they have a friend and resource in the NFED.

The NFED has 4,242 individuals on its database representing 40 types of ectodermal dysplasia.

I just wanted to say that I live in south Florida and I could not find anyone to help me with my 3-year-old son. He was missing all of his top teeth and most of his teeth on the bottom. I called you and got a list of doctors in Florida and found that two of the doctors on this list were willing to treat him. I did take the 4-hour drive to get to one of these dentists and I just wanted to thank you for his name. He was wonderful...We had to go back 4 weeks later and he now has a full set of top teeth and he loves them!

Thanks,
K.B.





- 65 families (211 individuals) from six countries participated in the 24th National Family Conference in Overland Park, Kansas. They came from Argentina, Botswana, Canada, Cuba, Mexico, and the United States for three days of networking and learning. 53 individuals attended with financial assistance from a Family Conference Scholarship. Newspaper and television coverage of the event raised awareness in the community and resulted in two new families being identified.

- The children who came to the National Family Conference with their parents engaged in special, age appropriate programming at Kids' Camp. The camp format offers a fun and active opportunity to meet other young people who are similarly affected. Through games, activities, and outings, they address the fear of uncertainty and the sense of isolation experienced by young people who live each day with physical and emotional challenges.



Louis University (SLU) staff, there is even more reason to celebrate the academic achievements of our students affected by ectodermal dysplasia. The work at SLU supported our perception that there is no reason to associate learning challenges with the presence of an ectodermal dysplasia syndrome. For the 11th year, the NFED awarded scholarships to help students pursue an education past high school. \$24,000 was awarded to 17 students studying subjects ranging from nursing and theater performance to law and elementary education.

Dear Mary Kaye and Staff,

I'm very glad all of us came to the Family Conference. I just wanted to include a note to say "thank you." It was an intensive, exhaustive three days, but it was worth every minute. We learned a lot, especially our son-in-laws. The kids had a great time with all the other kids, and enjoyed the activities provided. We appreciate so much all the hard work you put into this effort for all of us.

Thanks again,
N.S.

- A gift from an anonymous donor enabled us to mail a copy of our children's story book about a lion which is affected by ectodermal dysplasia, *Lionel Learns What Matters Most*, to affected children who are nine years old and younger in the United States.

- With the completion of the cognitive study relative to the ectodermal dysplasia syndromes done by Saint



Education

Sharing Knowledge. Promoting Understanding.

We believe in public awareness to achieve worldwide recognition and understanding of the ectodermal dysplasia syndromes.

Raising awareness of the ectodermal dysplasias is at the heart of every activity at the NFED. Educating our clients and building awareness in the medical and dental community is an ongoing pursuit and accomplished in several ways.

Eight families helped educate more than 50 professionals from the Kansas City community about the skin issues faced by

individuals affected by ectodermal

dysplasia by participating in a Professional Education Symposium in July. The format was a Grand Rounds at Children's Mercy Hospital Department of Dermatology and was held in conjunction with the 2005 National Family Conference in Overland Park, Kansas. This year's event specifically focused on the dermatological problems associated with the ectodermal dysplasia syndromes, the genetic impact of skin formation and wound healing and treatment options. Case discussions and professional presentations followed Grand Rounds.



The NFED sponsored a satellite seminar on Ankyloblepharon-ectodermal defect-clefting (AEC) in May at the Society for Investigative Dermatology Annual Meeting. Three experts on AEC shared information on the clinical and genetic picture of AEC, current and needed research and the research needed to understand the structure of the human skin and the mechanisms involved in skin healing to improve outcomes.

Thousands of publications about the ectodermal dysplasias were distributed at booths manned by NFED staff and volunteers at meetings of the American Academy

of Dermatology, American Academy of Pediatrics, American Association of Dental Research, American College of Medical Genetics, American Public Health Association, American Society for Human Genetics, Dermatology Nurses Association, National Association of School Nurses, National Society Genetic Counselors, National Coalition of Health Professional Education in Genetics, and the Society for Investigative Dermatology. Families also helped raise awareness by personally delivering ectodermal dysplasia brochures to dentists and dermatologists in their community. Mary K. Richter's guest editorial on oral health care for special care patient populations was published in the September/October issue of *Pediatric Dentistry*.

The Foundation's most successful awareness tool continues to be the web site, www.nfed.org. The site features extensive information on the ectodermal dysplasia syndromes as well as the latest research developments. The site had 39,156 hits for the year.

In addition to the web site, the NFED's most vital link to families, professionals, donors and volunteers is the quarterly newsletter, *The Educator*. It provides up-to-date treatment information, research developments and opportunities and testimonials from families. More than 23,000 copies were distributed in 2005.

NFED staff participated in the American Academy of Dermatology Solutions Summit and served on the same group's Patient Advocate Task Force. Awareness and advocacy efforts are further supported by Mary Kaye Richter's service on the Executive Committee of the Friends of the National Institute of Dental and Craniofacial Research (NIDCR), the Steering Committee for the National Oral Health Information Clearinghouse and the Monitoring Committee for the newly established Patient Based Research Network organized by the NIDCR.

The NFED plays a strong role in working with other agencies to reach common goals. The Foundation is associated with the following groups: Coalition of Skin Diseases, Friends of the NIDCR, National Health Council, National Organization for Rare Disorders, The Genetic Alliance, and Research!America.

The Foundation sponsored its third Ectodermal Dysplasia Awareness Month in February. Families participated in various ways from hosting fundraisers, writing letters and emails about ectodermal dysplasia to family and friends and participating in media stories. This grassroots movement continues to grow each year with more families participating.



Among its many volunteer duties, the Scientific Advisory Board oversees the NFED's research program, conducts workshops at Family Conferences and helps further our understanding of the ectodermal dysplasia syndromes.

Thank you for allowing me to learn more from a professional view. As a practicing dentist who will need to treat my son, this experience was invaluable!

Thank you,
Greg Keene, DMD



I am



a big
sister.

Our Circle of Friends

For 24 years, individual supporters have given the NFED its strength. With gratitude, we acknowledge all donors who have made a contribution during the past fiscal year (January 1, 2005 – December 31, 2005), regardless of the amount. Individuals who have made a donation of \$100 or more are listed below. We regret that space does not allow us to extend recognition to all of our contributors. We appreciate and depend on all gifts to help the more than 4,200 people diagnosed with ectodermal dysplasia.

Every effort has been made to ensure the accuracy of these listings. If you have given more than \$50 through a workplace giving program and your name is not included below, it is possible your name was not released to us. If there are any errors or omissions in this report, we sincerely apologize. Please contact the NFED at 618-566-2020 with questions or comments.



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I am honored to be named as a recipient of the L. Marie Heard Scholarship. This funding will be very helpful as I pursue my education at Richard Bland College of the College of William and Mary. The Foundation has had a strong impact on my life. My parents have received much support from NFED over the years, which in turn has helped me to grow into a self confident individual. In the future, I hope to be able to give back to the organization by helping younger children who have HED.

Sincerely,
A.C.

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Good morning, Mary Kaye,

Just a note of thanks for all the support and materials over the last few weeks. My husband, Rick, and I have been able to have a better understanding of Meagan's condition and in turn, been able to make informed decisions concerning Meagan's care.

C.J.

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The NFED acknowledges bequests from the following, generous individual who made provisions for the Foundation in her estate plans. We are deeply appreciative of the dedication of this donor in taking this step and we are honored to be a part of her legacy.

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**NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
d/b/a SKIN AND DENTAL DYSFUNCTION FOUNDATION
STATEMENT OF FINANCIAL POSITION
DECEMBER 31, 2005**

ASSETS

Current Assets:	
Cash and cash equivalents	\$ 762,616
Investments	412,703
Prepaid expenses	2,049
	<u>1,177,368</u>
Property and Equipment:	
Office equipment	33,182
Accumulated depreciation	(21,770)
	<u>11,412</u>
Other Assets:	
Investments	<u>4,063</u>
Total Assets	<u>\$ 1,192,843</u>

LIABILITIES AND NET ASSETS

Current Liabilities:	
Accounts payable	\$ 5,285
Payroll withholdings payable	2,205
Sales tax payable	76
Academic scholarship commitments	500
Treatment commitments	237,640
Accrued expenses	<u>27,148</u>
Total Liabilities	<u>272,854</u>
Net Assets:	
Unrestricted	
Undesignated	796,633
Designated	<u>123,356</u>
Total Net Assets	<u>919,989</u>
Total Liabilities and Net Assets	<u>\$ 1,192,843</u>

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS
d/b/a SKIN AND DENTAL DYSFUNCTION FOUNDATION
STATEMENT OF ACTIVITIES
YEAR ENDED DECEMBER 31, 2005

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
SUPPORT AND REVENUE:			
Contributions			
Donations	\$ 780,309	\$ 48,482	\$ 828,791
Grants		54,409	54,409
In-kind materials, facilities and services	605		605
Conference registration fees	13,750		13,750
Sales of publications / promotional items	5,650		5,650
Special event revenue	168,074		168,074
Less: costs of direct benefits to donors	(61,474)		(61,474)
Interest and dividend income	33,348		33,348
Net unrealized and realized gain (loss) on investments	10,824		10,824
Net assets released from restrictions	<u>102,891</u>	<u>(102,891)</u>	
 Total Support and Revenue	 <u>1,053,977</u>	 <u>-</u>	 <u>1,053,977</u>
 EXPENSES:			
Program Services:			
Education	138,600		138,600
Family services	149,716		149,716
Treatment	330,999		330,999
Research	222,860		222,860
Total Program Services	<u>842,175</u>	<u>-</u>	<u>842,175</u>
Supporting Services:			
Management and general	58,096		58,096
Fundraising	50,382		50,382
Total Supporting Services	<u>108,478</u>	<u>-</u>	<u>108,478</u>
 Total Expenses	 <u>950,653</u>	 <u>-</u>	 <u>950,653</u>
 Increase in net assets	 103,324	 -	 103,324
 Net assets beginning of year - restated	 <u>816,665</u>	 <u>-</u>	 <u>816,665</u>
 Net assets end of year	 <u>\$ 919,989</u>	 <u>\$ -</u>	 <u>\$ 919,989</u>

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Research

The NFED is playing an expanding role in ectodermal dysplasia research and directing further scientific discovery. Our efforts to encourage the scientific and medical community to study the rich complexities of the ectodermal dysplasia syndromes have been increasingly successful. We built on our history of providing seed grants to researchers by awarding a record number of dollars for ectodermal dysplasia research in 2005. The NFED supported seven research projects in 2005 with \$118,000 and access to clients affected by ectodermal dysplasia.

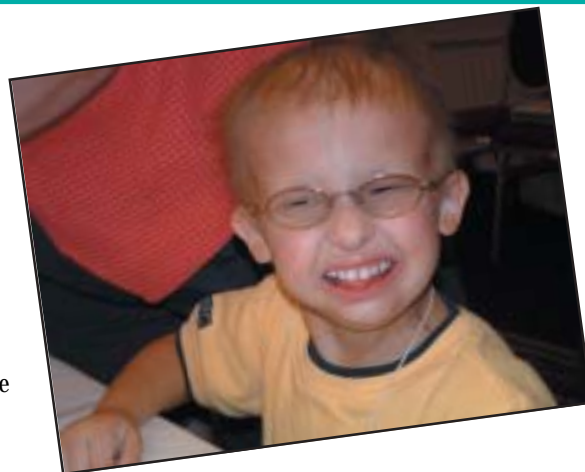
Our program encompasses genetics, clinical research, and quality of life.

TITLE	INVESTIGATOR / UNIVERSITY	AMOUNT
Characteristic of the p63 Target Gene Perp in the Development and Function of Ectoderm-Derived Tissues	Laura D. Attardi, PhD Stanford University	\$9,000
Do Children with Ectodermal Dysplasias Have Differences in Quality of Life: An Application of an Age Specific Child Oral Health Related QOL Assessment Instrument?	Clark M. Stanford, DDS, PhD University of Iowa	\$1,600
Generation of Knock-in Mouse Models Mimicking Hay-Wells Syndrome	Edward Ratovitski, PhD John Hopkins University	\$25,000
Generation of a Mouse Model for AEC Syndrome	Caterina Missero, PhD TIGEM-Telethon Institute of Genetics and Medicine, Italy	\$25,000
Msx1 Gene and Witkop Syndrome	Marianna Bei, DMD, DMSc Harvard University / Massachusetts General	\$25,000
Oral Development	Clark M. Stanford, DDS, PhD University of Iowa	\$1,600
Women's Health Survey	Jill Powell, MD Saint Louis University School of Medicine	\$12,000



Making Discoveries

Several articles resulting from past NFED funded research projects were published in professional journals in 2005. These articles helped bring attention to the conditions, patient needs, and the support for the research provided by the NFED. It was an extraordinary year in this regard with a record number of submissions accepted for publication. The published research established the first collection of auditory information on ectodermal dysplasia, that children affected by hypohidrotic ectodermal dysplasia have average to above average cognitive abilities and the first published growth patterns of HED.



Some of the most exciting research involves the success of treating canines affected by HED with a recombinant DNA to correct symptoms such as missing teeth, nonfunctioning sweat glands and sparse hair. The next step will be to see if the same treatment is successful in humans. The NFED will actively seek ways to support this research which could positively impact future generations of HED families by leading to a cure.

The data generated from these projects helps us provide

more extensive and accurate information on the disorders for our clients and medical and dental professionals.

A Cost Analysis of Dental Treatment for Ectodermal Dysplasia

Journal of the American Dental Association, September 2005
Jessica Y. Lee, DDS, MPH, PhD

Conference Report: Skin Erosion and Wound Healing in Ankyloblepharon-Ectodermal Defect-Cleft Lip and/or Palate (AEC)

Archives of Dermatology, December 2005
Elaine Siegfried, MD, Alana Bree, MD, Virginia Sybert, MD

Do Children with Ectodermal Dysplasias Have Differences in Quality of Life: An Application of an Age Specific Child Oral Health Related QOL Assessment Instrument?

Poster Presentation at the 2005 International Association for Dental Research in Washington, DC, March 10-12
Clark M. Stanford, DDS, PhD and Cindy Asmussen, RN

Growth and Nutritional Status of Children with Ectodermal Dysplasias

Pediatrics, August 2005
Kathleen Motil, MD, PhD

Immune Function in Canine Ectodermal Dysplasias

Veterinary Immunology and Immunopathology, August 2005
Margret L. Casal, VMD, PhD

Psychoeducational Characteristics of Children with Hypohidrotic Ectodermal Dysplasia

Poster Presentation at the 2005 Pediatric Academic Society's Meeting in Washington, DC, May 14-17.
Rolanda Maxim, MD



The Foundation participated in two Patient Advocacy Days in April in Washington D.C. We advocated for increased funding for the NIDCR and the NIAMS which would translate to increased research for conditions like ectodermal dysplasia.

These are the many ways in which the Foundation is taking an active role in advancing research on these rare disorders to find better treatments and hopefully, a cure.

Treatment

Dear NFED,

We would like to thank you for your dental assistance program. Our son, Ryan, has ED. We couldn't afford to have the needed dental work which he required. I am so grateful to learn about the Foundation and all of the various programs it has to offer. Through the dental program, Ryan now has his lower teeth which greatly improved his confidence, appearance and speech. In school, Ryan's speech therapy slowed because he was not capable of making the necessary sounds to enunciate properly. Now, Ryan can continue to advance with his lessons. We are so happy to see our son so thrilled with his new teeth. He proudly smiles to show them off. Thank you again for all that you do.

Sincerely,
The Martin Family

The ectodermal dysplasia syndromes can have significant dental manifestations ranging from multiple missing and misshapen teeth to defective enamel. At the National Family Conference and one-on-one, the NFED encourages and educates families to seek treatment as early as a child's 3rd birthday. We have evidence that children can wear dentures successfully at this age, leading to improved speech, nutrition, facial appearance and emotional well being.

Families affected by ectodermal dysplasia know first hand that achieving a normal appearing smile can come at a hefty price..often more than \$50,000. While the NFED has always had anecdotal evidence of this reality, an NFED funded research project by Dr. Jessica Lee at the University of North Carolina at Chapel

Hill helped establish them as facts. Her data

showed that dental treatment for ectodermal dysplasia had a marked financial impact on families and varied depending on type and duration of treatment.

Given the importance of early and ongoing treatment, the NFED provides financial assistance to families for the care they need. Treatment may include dentures, orthodontics, dental implants or medical care.



In 2005, the NFED helped a record number of clients through the Treatment Fund. We awarded more than \$247,000 to 38 individuals for care.

In addition to cost, travel distances to see a provider and a lack of qualified providers were identified as obstacles at a 2004 Access to Oral Health Care Meeting of dental professionals which the NFED sponsored. The NFED revamped and expanded its Dental Implant Program in 2005 to address those obstacles. We recognized that collaborating





with the oral health community and dental supply companies was going to be key in making the program successful.

We have partnered with seven universities throughout the United States who have agreed to treat ectodermal dysplasia patients. This network of treatment sites will also work toward a shared system of data collection for research purposes. The program is still in the initial stages and the Foundation will further develop it in 2006.

In addition, we are working with the American College of Prosthodontists which has reached out to its membership for support in treating the complex dentitions of our clients.

Straumann, an international company which offers products and services for dental implants,

stepped forward with a \$25,000 gift to support our efforts to improve access to oral health care.

All of these efforts help us to accomplish our goal of making quality oral health care available and affordable to all families affected by ectodermal dysplasia syndromes.

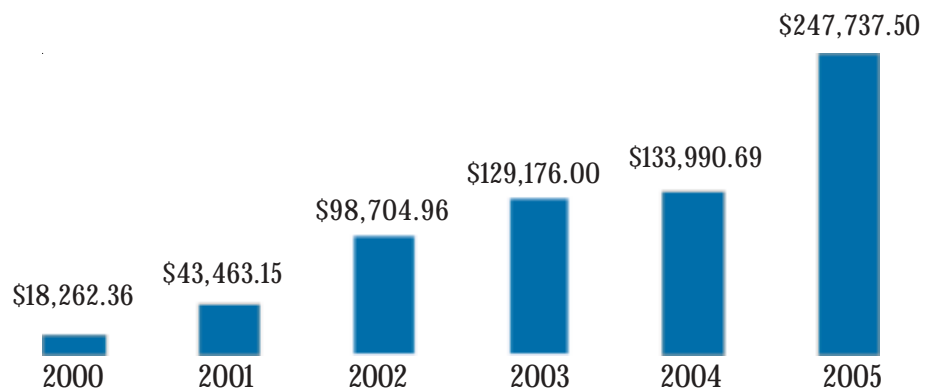


Dear NFED,

I want to thank the review committee from the NFED for giving me the opportunity to finish the rest of my needed procedures so I could finally smile after all these years with confidence...I don't have to worry about having any loose teeth that might fall out some day. As a young teen and now a young woman, this was a terrible thing to have to worry about all the time. The best part of this was all so simple, for the first time in my life, I was able to bite into an apple instead of using a knife!

Sincerely grateful,
H.J.

Helping Clients Through the Treatment Fund



I am



a Dancer

One Person Can Make a Difference

How You Can Help

When you support the National Foundation for Ectodermal Dysplasias, you become part of a network of people who are committed to helping individuals affected by ectodermal dysplasia live a normal life. You help us fund pioneering research that leads to lifesaving discoveries. You empower us to share knowledge and resources with people wherever they are in the world – including your community. You provide vital services that help families affected by ectodermal dysplasia in your town and around the world.

Thank you for supporting our efforts. We invite you to continue your generous support by giving in any way that is convenient for you.

Direct Donations

Make a donation by phone at 618-566-2020, online at www.nfed.org or by mail at P.O. Box 114, Mascoutah, IL 62258—0114. You can also make your gift in honor or in memory of someone special.

Planned Giving and Estate Planning

Become a partner in assuring the NFED's future by including the Foundation in your will and making a bequest. For more information, contact us at 618-566-2020.

Special Events

Support events like the Halloween Bash, golf tournaments, the raffle and other fundraisers. You'll have fun and your contributions go a long way in helping ectodermal dysplasia families. To support an event, call 618-566-2020 or visit www.nfed.org.

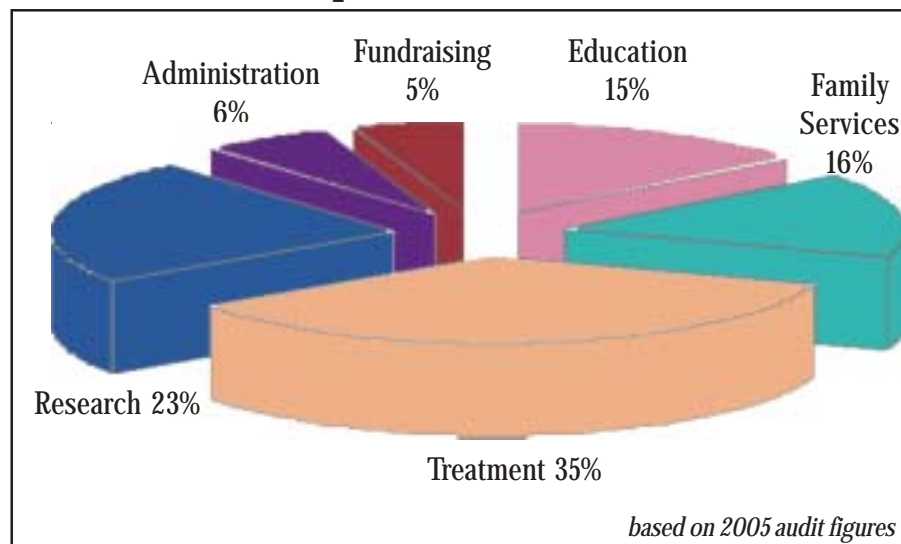


The NFED is the worldwide nonprofit organization that seeks to enrich the lives of individuals affected by all forms of the ectodermal dysplasia syndromes.

The NFED is a private, tax-exempt nonprofit organization pursuant to Section 501(c)(3) of the Internal Revenue Code, and all gifts and donations to the NFED are tax deductible. Tax ID number is 37-1112496.

To receive a copy of complete financial statements, contact the NFED at info@nfed.org or 410 E. Main St., P.O. Box 114, Mascoutah, IL 62258-0114.

How the NFED Spends Donations





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