

Uniting Common Bonds



**National Foundation for
Ectodermal Dysplasias**

2003 Annual Report

Mission

Vision

The NFED seeks to enrich the lives of individuals affected by all forms of the ectodermal dysplasia (ED) syndromes.

Mission

The NFED will:

- Be the authoritative resource for information on the ED 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 ED syndromes.

Values

The NFED believes in:

- Public awareness to achieve worldwide recognition and understanding of the ED syndromes.
- Being responsive to the needs of its families through a variety of programs.
- Support for research into the causes and treatment of the ED syndromes by providing funding and access, when permission is granted, to members.
- Sponsoring events for affected individuals and their families to gather, learn and share experiences.
- Providing accurate information about the ED syndromes to professional groups who deal with individuals affected by the ED syndromes.
- Providing a compassionate experience for all who come into contact with the Foundation.
- Support for national advocacy efforts to ensure health care reform and to improve third party reimbursements for affected individuals.
- Facilitating partnerships with health professionals to provide quality care at reasonable fees for individuals affected by the ED syndromes and providing financial assistance for treatment when appropriate.
- Integrity in relationships with affected individuals and others.
- The value of volunteers to meet the Foundation's goals.
- The role of technology to enhance communication with families, practitioners, supporters, and the public.
- Assuring donors that their contributions make a difference.
- Enhancing the Foundation's visibility among philanthropic organizations to meet the Foundation's mission.

Dear Friends,

If one word was to be used to describe 2003 in National Foundation for Ectodermal Dysplasias annals, it would be *accomplishment*. The organization has enjoyed a long history of success but the year just ended was remarkable from beginning to end and *accomplishment* was the rule rather than the exception. Our philosophy is that non-profit organizations make their mark by what they accomplish. In our view, our mandate is to make formidable and substantive, positive change in the lives of individuals affected by an ectodermal dysplasia (ED) syndrome.

Within these pages you will learn about some of the remarkable accomplishments of the NFED during 2003. The year will always be remembered for an incredible skin erosion workshop that brought a totally new understanding and treatment approach to individuals affected by Hay-Well's syndrome. Two new publications, one for clinicians and the other for children, are marvelous additions to our arsenal of available information. Many of us eagerly watched "The View", a national television program, as one of our own was saluted as a Woman of Accomplishment. Lastly, the year was hallmarked by extraordinary research achievements as well as patient well being, as nearly \$150,000 was committed to each endeavor.

Remarkable *accomplishment* is only possible when many hands come together to lighten the load. Whether it is hands stuffing envelopes, hands working on fundraisers, hands directing programs, hands writing checks or hands clasped in joy or grief, we have been united in our cause and in our efforts.

We thank you for providing your helping hands as we all work to "Lift Hopes for the Future".

Sincerely,



Mary K. Richter
Executive Director



Keith Throm
President of the Board of Directors

Board of Directors

The Board of Directors approves and evaluates the National Foundation for Ectodermal Dysplasias' long-term goals, provides financial oversight, and works with the executive director and staff to fulfill the Foundation's mission.



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Detroit Receiving Hospital and
University Health Center

Family Services

National Family Conference

The NFED's 23rd annual patient education event, the **National Family Conference**, drew 246 people from five countries to Iselin, New Jersey. From July 16-19, families attended workshops, panel presentations, and support sessions to learn about the ED syndromes and treatment updates.

Kids' Camp

Seventy-six children attended the 2003 Kids' camp at the National Family Conference. The camp format offers an opportunity for the children to meet other young people who are similarly affected. Through games, activities, and presentations, campers address the fear of uncertainty and sense of isolation experienced by young people who live each day with physical and emotional challenges. Teens and young adults who are also affected by the ED syndromes supplement the camp staff to mentor younger children and offer encouragement. This year's campers enjoyed penny bingo, board game tournaments, a magician, and water color painting. Dr. Frank Farrington and dental hygienist Joan Pellegrini talked to the children about good dental health, which included watching a video, using materials for denture making to make an impression of their thumb, and receiving a toothbrush and toothpaste to take home.

The NFED's **Family Conference Scholarship Program** helped 27 families affected by ED attend the New Jersey event by offering \$22,783 in travel, hotel accommodations, and conference fees. For 21 of those families, it was their first time experiencing the Family Conference.

The 2003 National Family Conference was made possible by grants from the Dircks Foundation and the Hubbard Foundation.

Regional Family Conferences

In 2003, the NFED continued its commitment to provide one-day educational events in various regions of the country for ED-affected families.

The first Regional Family Conference of the year was held near Washington, D.C. in Silver Spring, Maryland with nearly 50 adults and children from three states participating in the event. Geneticist Sheri Bale, PhD, a former member of the Scientific Advisory Board, Jaime Brahim, DDS, an oral surgeon from the National Institute for Dental and Craniofacial Research, Dr. Preston Shelton, a pediatric dentist at the University of Maryland, and Dr. Roselyn Epps, a pediatric dermatologist at National Children's Hospital gave workshops at the conference.

The women of Nu Beta Chapter of Delta Theta Tau Sorority, Inc. volunteered their time and efforts to oversee the child care at the Silver Spring conference.

The second Regional Family Conference for the year was held in Dallas, Texas. Dr. Ronald J. Jorgenson, chairman of the NFED's Scientific Advisory Board, Dr. Robin Carder, a pediatric dermatologist, and dentists Dr. Eugene Dahl and Dr. Brody Hildebrand of Baylor College of Dentistry provided

"When we returned home and looked back over our weekend experience there was no way to hold back the **tears of happiness**. The fact that we look around every day and always feel like the outsider, to have the **chance to belong** and be able to **share common concerns** with each other is something that at one time seemed unreal. However, now we truly know that there are friends for us to talk with and for a short time **bond as if we are family.**" — K.B.



Dear ED Foundation,

Thank you for the **generous scholarship** once again. My family and I were truly surprised when we received the news. I will do my **best** to put it to good use throughout this year of college. I am looking forward to graduating in May with my degree in crop science. Your foundation has been a huge help in **achieving** this goal.

Sincerely,
J.W.



educational workshops. NFED family member, Karen Allen, and her family planned the activities for the children attending the conference. Volunteers from the local chapter of Delta Theta Tau Sorority, Inc. and Key Club assisted in childcare.

The Regional Conferences were underwritten by grants from the the American Dental Association Health Foundation, American Legion Child Welfare Foundation, William G. McGowan Charitable Fund, and the Maryland March of Dimes.

Seattle Picnic

A park in Seattle, Washington was the site of a gathering of families on June 1st with 70 individuals participating. Participants celebrated the 10th anniversary of the Regional Advisory Committee which has raised awareness and funds of the ED syndromes in the Pacific Northwest. Besides socializing, families had the opportunity to ask questions of health care professionals with experience in the ED syndromes.

The Seattle picnic was underwritten by a grant from Seattle King County Dental Foundation and the Washington Oral Health Foundation.

Louise Marie Heard Memorial College Scholarship Program

2003 was the eighth year in which the NFED presented college scholarships to individuals affected by ED syndromes for post-secondary education or training. It was also the year in which two accomplishments were noted: the largest number of awardees and the largest amount of funding in the history of the program. Awardees are studying every imaginable college major from mathematics to women's studies. Not only do the scholarships directly help the applicants who receive them, the program serves as ample evidence of the potential in our student population to parents of young children who may be affected by ED.

The NFED was proud to present the following individuals with scholarships:

\$3,250 Scholarships

David Jahn, Houston, TX
Jeremiah Weddle, Hagerstown, MD

\$2,250 Scholarships

Bethany Jones, Goreville, IL
Janet Neissner, Mundelein, IL
Jennifer Zwirn, New York, NY

\$1,750 Scholarships

Orion Bradshaw, Talent, OR
Amanda Griggs, Findlay, OH
Staphanie Sambor, Whitesboro, NY
Joseph Smith, DeSoto, IL
Amy Sporer, Chelsea, MI

\$1,250 Scholarships

Aaron Davis, Iowa City, IA
Heather Hooper, Shoreline, WA
Adam Rogers, Rudd, IA
Adam Viccaro, Mooresville, NC

\$1,000 Scholarships

James Erdman, Schaumburg, IL
Meghan Morris, Revloc, PA
Sean Vora, Fremont, CA

\$500 Scholarships

Joe Place, Oskaloosa, IA
Kyle Spilbeler, Bloomington, IN
Alan Tam, British Columbia, Canada

Education

Professional Symposium

The fear of the unknown is always an issue for those affected by a rare condition as well for the general public. Consequently, the education efforts of the NFED are key to replacing fear with hope for patients, enabling clinicians to provide early diagnosis and quality care and to minimizing misperceptions by the public. Hence, our education programs are of critical importance to all involved.

In conjunction with the National Family Conference, the NFED sponsored a professional symposium for area oral health professionals at the University of Medicine and Dentistry of New Jersey. Titled "Diagnosis and Treatment of the Ectodermal Dysplasias", the event specifically addressed the dental issues associated with ED syndromes. Dr. Milton Houpt, Chairman of the Department of Pediatric Dentistry, hosted the event.

The symposium was underwritten by a grant from the March of Dimes, New Jersey Chapter.

Parameters of Oral Health Care for Individuals Affected by Ectodermal Dysplasias

The NFED produced and distributed *Parameters of Oral Health Care for Individuals Affected by Ectodermal Dysplasias* to 3,000 care providers, families affected by ED syndromes and insurance providers. The document is an incredible resource for both families and clinicians in that it outlines age appropriate dental care for clients affected by ED. A panel of dental experts with experience in treating the dental complexities of ED wrote the guide.

The production and distribution of the *Parameters* was made possible by a grant from the Academy of General Dentistry Foundation.

Medical Guides

The Scientific Advisory Board reviewed and updated two of the Foundation's medical guides, *The Multi-Syndrome Guide to the Ectodermal Dysplasias* and *A Guide to the Eyes, Ears, Nose and Throat in the Ectodermal Dysplasias*. These two guides are a part of a series of six medical and dental publications that the NFED publishes for families and clinicians.

Website

Since 1996, the NFED's website, www.nfed.org, has been a critical awareness tool. In 2003, there were 25,272 hits on the site. Most of the new families who contact the NFED for services find the organization through the website.

The EDucator

Nearly 20,000 copies of *The EDucator* were published and distributed to patients, families, clinicians, researchers, and friends of the organizations throughout the year. The bi-monthly newsletter serves as an educational tool and lifeline for families. In the spring, the newsletter expanded from 12 pages to 16 pages to accommodate more articles and room for advertising which helps underwrite the cost of the publication.

"*The Parameters of Oral Health Care for Individuals Affected by Ectodermal Dysplasias Syndromes* is an **excellent informational** brochure for parents, patients, and general dentists as well as for prosthodontists who manage these patients, and for other specialist, both dental and medical who are involved in their care."

-C.H., DDS, MS, Indiana



This charmingly written and illustrated story conveys a powerful and important truth in a delightful and non-preachy manner. Lionel's realization that "It's what's on the inside that matters most of all" is a powerful one, and one that this picture book communicates to children very effectively.



James H. Borland
Chair, Department of
Curriculum and Teaching
Teachers College,
Columbia University



Billion Dollar Smile Program

The NFED launched its Billion Dollar Smile program in 2003 to educate children on the importance of good oral health. The program was an outgrowth of the 2002 National Family Conference at which a high rate of candidiasis was observed in children affected by ED. The program provided information on oral health care tips, good nutrition, and caring for dentures in targeted mailings, through *The EDucator* and in workshops at Kids' Camps.

Children's Storybook

The NFED published its first four-color children's storybook, *Lionel Learns What Matters Most*, about a lion that faces the same physical challenges typical of a child affected by ED - no hair, no nails, no sweat glands and no teeth - and emotional challenges. The story unfolds as Lionel learns that it is what is on the inside that matters most. Inspired by Alice Geismar, the goal of the book was to provide a vehicle for ED-affected children to better understand their skin disorder and the world around them. This book was made possible with support from the 2003 Halloween Bash, Alice Geismar, Ruth Geismar, Anthony Lewis, Julie Merberg, Virginia Shimchick, Elissa Stein, and Roundtable Press.

Advocacy

The NFED continues its commitment to keeping awareness of the ED syndromes in the minds of government officials, researchers, physicians, dentists, and legislators. Among the year's activities were participation in National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) Day and National Institute of Dental and Craniofacial Research (NIDCR) Day on Capitol Hill to raise awareness of the need for increased funding for skin disease and oral health research.

Executive Director Mary Kay Richter provided written and oral testimony for the U.S. House Committee on Health Appropriations for NIAMS and NIDCR and participated in a Illinois state meeting to discuss an oral health assessment tool for the Illinois Head Start Program.

NFED's Director of Education, Malinda Heuring, presented an educational workshop on ED and the importance of advocacy organizations at the Society of Investigative Dermatology Resident Retreat.

The NFED joined and participated in IFLOSS, an Illinois oral health advocacy organization.

NFED staff members represented the organization on the American Academy of Dermatology Patient Advocate Task Force, the Advocates Forum planning committee for the NIDCR, the steering committee for the National Oral Health Information Clearinghouse and provided leadership to the Coalition of Skin Diseases and the National Alliance for Oral Health.

The results of an insurance survey conducted with Texas families were presented at the National Oral Health Conference, which is sponsored by the American Association of Public Health Dentists.

Research

Creating an environment that stimulates a vibrant research program has taken time but the fruits of our efforts are being realized. Most importantly, new approaches to treatment and better understanding of specific ED syndromes have been realized and even the word “cure” has become a part of our vocabulary. There is much to celebrate and much more work to be done.

The NFED sponsored a landmark, scientific workshop on Skin Erosion and Wound Healing in Ankyloblepharon-Ectodermal Defect-Cleft Lip and/or Palate (AEC) on September 18-19, 2003 at the Saint Louis University School of Medicine Department of Dermatology. Nearly 100 dermatologists, researchers, and scientists from three countries examined eight children affected by AEC and skin erosion that varied from mild to life threatening. It was the largest gathering in history of individuals affected by this rare disorder. Seventeen scientists and clinicians presented research from their area of expertise in relation to skin erosion. The goals of the workshop were to better understand skin erosion as manifested in AEC; to document AEC clinical diagnostic features; to identify potential treatment methods; and to outline areas for further skin erosion research. These goals were met successfully and the participants plan to publish their findings in appropriate dermatology journals. Participants are confident that the knowledge gleaned from the workshop will also benefit patients with wound healing issues.

The Skin Erosion Workshop was made possible through financial support from the Geismar family, Saint Louis University (SLU), Dr. Scott Fosko and the Dermatology Department at SLU, SLUcare, Cardinal Glennon Children's Hospital, Molnlycke, Connecticut, Ferndale and Novartis.

The NFED awarded research grants to the following investigators for their work in the ED syndromes.

Clinical Research Projects Approved in 2003

A Cost Analysis of Dental Treatment for Ectodermal Dysplasias

Grant Award: \$15,000 and Patient Access
Investigator: Jessica Lee, DDS, MPH, PhD
University of North Carolina at Chapel Hill

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

Grant Award: \$2,329.50 and Patient Access
Investigator: Clark Stanford, DDS, PhD
The University of Iowa

Evaluation of Auditory System in Individuals with Ectodermal Dysplasia: A Prospective, Longitudinal Study

Grant Award: \$3,000 and Patient Access
Investigator: Christopher J. Hartnick MD
Massachusetts Eye and Ear Infirmary

“A one and a half day conference on AEC brought together families, basic scientists and clinicians in an **extraordinary time** of cross-fertilization and generation of ideas for management, investigation into basic biologic pathways, and molecular research. I am still **high** from the **level of excitement** that was generated by all these interested and bright people brainstorming.”

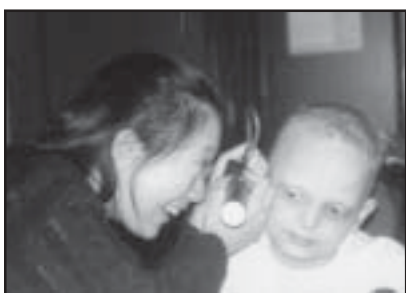
– Dr. Virginia Sybert.



"I've been meaning to write for along time since the Hay-Wells meeting to say **thank you**. Thank you for all your **hard work**, long hours and interest in making the conference happen . You are all such a **caring, welcoming** group of women. I was so **moved** by all the kids and parents, it was so **heartwarming** to see all the **amazing smiles** and meet the older boys who had such **confidence** and knowledge.

I **appreciate** all of you, for doing such an amazing job of **informing** all of us, **educating** my doctors and **advocating** for the families"

- M.S.



Growth and Nutritional Status of Children with Ectodermal Dysplasia Syndromes

Grant Award: \$3,000 and Patient Access

Investigators: Kathleen J. Motil, MD, PhD;
Timothy J. Fete, MD

Baylor College of Medicine, Saint Louis University

Oral Development

Grant Award: \$3,000 and Patient Access

Investigator: Frank H. Farrington, DDS, MS

Department of Pediatric Dentistry

Virginia Commonwealth University

School of Dentistry

Psycho-educational Characteristics in Children with Hypohidrotic Ectodermal Dysplasia

Grant Award: \$6,800 and Patient Access

Investigators: Rolanda Maxim, MD; Sam Zinner, MD;

Barry A. Tanner PhD; Timothy J. Fete, MD

Saint Louis University and Detroit Receiving Hospital

Basic Science Research Projects Approved in 2003

Gap Junction Defects Revealed as Cause of Keratitis-Ichthyosis-Deafness Syndrome

Grant Award: \$25,000

Investigator: Gabriele Richard, MD

Thomas Jefferson University

Incontinentia Pigmenti (IP; MIM#308310)

Grant Award: \$2,000

Investigator: Richard A. Lewis, MD, MS

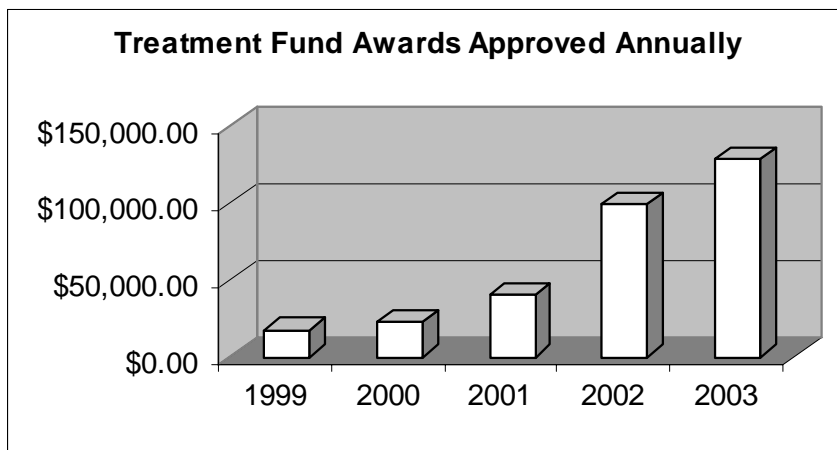
Baylor College of Medicine

Treatment

Treatment Fund

In 2003, the Treatment Fund Program helped more people and awarded more support than in any other year in our history. This program provides financial assistance for individuals affected by ED for medical and dental care necessitated by the condition. The NFED approved \$129,176.00 this year for treatment for 34 individuals affected by ED syndromes in Canada, Pakistan, and the United States.

Singer Barry Manilow gave a gift of \$1,000 to start the Treatment Fund in 1987. Since then, the NFED has expended \$239,716.08 to help families with various needs from air-conditioners to wigs and dentures to dental implants.



To each and everyone,

Your **gift** to Teejay so he could finally have his dentures was **over the moon**. He became a different person when he put those teeth in. Teejay is an **incredible little boy** and so many people have come forward to make our lives together easier but what you did was for him and his **self-esteem**. Thank you so much from Teejay's **heart** to you.

- J.Y, Canada



Every Gift Makes A Difference

The NFED is grateful to the clients, physicians, dentists, volunteers, and businesses that contribute to the Foundation's mission. The individuals and organizations listed here supported the NFED in 2003 by contributing to the Family Services, Treatment or Research Funds. We regret that space considerations keep us from listing the names of every person who supported us this past year. Every donation is important to us. You truly make a difference!

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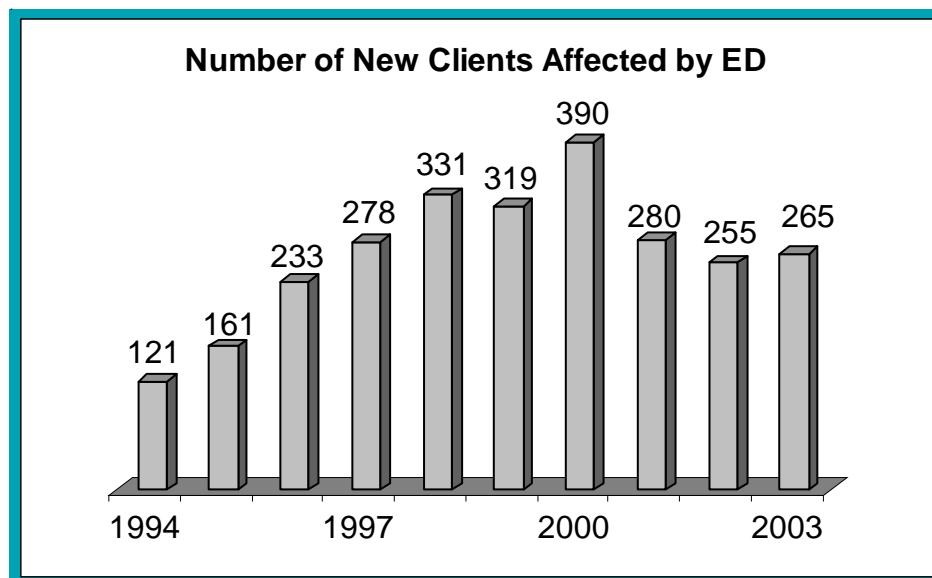
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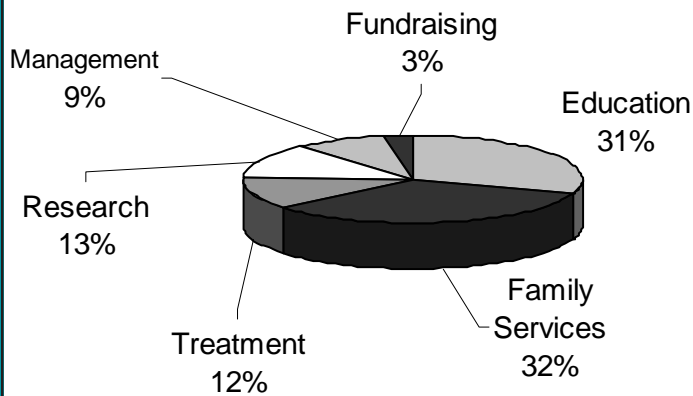
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Wendy Wonderley

Wood River Woman's Club
Collins Woodside
Maryellen and Edward Wrede
J. Tim Wright
Richard Yochem
Daniel Yoon
Cindee Zabler
Norman Zellers
Steven Zeschke
Stanley and Gloria Zwirn

Friends

\$25 - \$49
Sandy Abrahamian
Spilios Adamopoulos
Judith and Joseph Aguilera
Lawrence Alden
Arnold and Patricia Aloj
Filomena and Peter Aloj
Joseph Aloj
Josephine and Leonard Aloj
Robert J. Amen
Joellen Anderson
Connie Anderson Bielert
Vernon Andres
Ann Argetsinger
Bernadette Arocha
Laura Ash
Atonement Lutheran Church
and School
Bernadette Baldini
Evelyn Bare
Keith Bareman
Anna Barone
Anthony Barone
Joseph Barone
Barry Scher, Inc.
Juliann Barthelmess
Robert Bath
Jerry Bayer
Stephen Bearden
Eugene Beck
Eugene and Harriet Becker
Marilyn Bennett
Nat and Phyllis Berens
Greg Berlin
Rev. and Mrs. John Berstecher
Anne and John Beucler
Alexander and Sandra
Bienenstock
Richard Bills
Ron Biver
Matthew Blanks
Alan and Andrea Bloomfield
Tina Blythe
Barbara Bonner
Edward Boorstein
William Bosshard
Jeffrey Bowman
Robert Brandl
Kirk Brawner
Ambrose Bredbenner
Patricia Brennan
Robert Bromley
Gregory Broniak
Will Brown
Gene Browning
Beverly Budde
Mr. and Mrs. Donald Butzner,
Jr.
Rosalinda Calamusa
Don Caldwell
Joan Cantor
Mark Carlson
Ann Carlton

Tim Catherman
 Cayden Eagles
 CFA Flower Fund
 Susan Chestnut
 Lucy Chiantese
 Lisa Childers
 Christ Brothers Asphalt
 Florence Cinabro
 Civic League of Belleville
 Cheryl Claeys
 Douglas Clark
 Patrick Clark
 Craig Clough
 Robert Cohen
 Jennifer Cohen
 Roger Coiner
 Lisa and Ivan Cole
 Timothy Coleman
 Columbia Womans Club
 Mr. and Mrs. Gerald Cornell
 Richard and Donna Cory
 James Craig
 John Crewe
 Jackie Crigger
 Pamela Crimmins
 Denise Cunningham
 Curtis Dahlberg
 Mark and Kathy Dahler
 Joanna Daniel
 Joseph Daniel
 Fred Daniele
 Mike and Kathy Daniels
 Jason and Gina Defebaugh
 Francis Degnan
 Michael Deitz
 Nicholas deKrafft
 Jean Delsite
 Delta Theta Tau Sorority, Inc.,
 Eta Mu Chapter
 Delta Theta Tau Sorority, Inc.,
 Alpha Chapter
 Delta Theta Tau Sorority, Inc.,
 Alpha Omega Chapter
 Delta Theta Tau Sorority, Inc.,
 Theta Nu Chapter
 Delta Theta Tau Sorority, Inc.
 Iota Mu Chapter
 Delta Theta Tau Sorority, Inc.
 Theta Mu Chapter
 Mary DeSisto
 Ernest Deuchar
 Ralph Devaney
 Carol Dressel
 Norman Dressel
 Lorie Duke
 DuraKold
 Dyas Toyota
 East Alton Woman's Club
 Joan Ehas
 Thomas Ehrman
 Kenneth Eidman
 Richard and Nina Elder
 Jim Ennis
 Stephanie Evans
 Loraine Fahling
 Fairview Heights Women's Club
 Kevin Farrington
 Federated Women's Club of
 Greater Belleville
 Sidney Feldman
 Noreen and Christopher
 Feldmann
 Joan Fertig
 Lori Feyen
 Robert Feyen

Norman and Shelia Fishman
 Stanley Fleischman
 Tylor Flowers
 Flowers Balloons, Etc.
 Caryl Fox
 Michael Foy
 Sandra Franck
 John Frederick
 Freeburg Woman's Club
 Warren French
 Nathan Frickel
 Michael Fried
 Hiram Fry
 Mildred Funk
 Richard Galli
 John and Elizabeth Ganss
 Gregory Gay
 Arlene Geise
 David Geschke
 Randall Ginnan
 Edward and Barbara Goldstein
 Lyman Goodson
 Michael Gower
 Peter and Jennifer Gray
 Martin and Gail Greenspan
 Adam Gregorich
 Barbara Grill
 Robert Grodeon
 Harvey Groennert
 Timothy Groves
 GT Luscombe Co. Inc
 Kathleen Guttieri
 Laverne Hahn
 Ray Hampton
 Sarah Harley
 Andrew Harris
 Rev. Jerome Hartlein
 Russell Hartley
 Michele Heiman
 Deb Herchler
 Highland Civic Club
 Cary Horvath
 Jamie Howell
 Marcellus Huelsmann
 Rachel and Michael Hyman
 Klayre L. Ingerton
 Walter and Patricia Ingram
 James Jacob
 Michael Janniro
 Thomas Janus
 Andre and Lori Jaundoo
 Andrew Jayne
 James Jeans
 James Jensen
 Joseph and Lisa Jonak
 Kennie Jones
 Rebecca Jones
 Janiele Jordan
 David Jourdheuil
 Carol Joyce
 Sean and Diana Justice
 Rick Kaminer
 Charles Kamm
 Scott Kates
 Douglas Keller
 John King
 Robert Kishel
 Jack Klopmeier Construction
 Mark Klos
 Tommy Knopps
 Kevin Konkle
 Paul Krolikowski
 Leontine Kruse
 Ronald Kuehnau
 Jerry Kunzer

Patricia Landis
 Robert Landreth
 John Larocca
 Dorothy Larson
 Nancy Larson and Gary Harter
 Richard and Abbie Laskey
 Barbara LaValley
 Joseph Layden
 Mr. and Mrs. David Lembke
 Herman Leonard
 Leonard Drugs, Inc.
 Robert Leong
 Richard Letendre
 Victor Licause
 Arthur Liebschutz
 Dr. Preston Littleton
 Gail Loftsgard
 Dennis Lopata
 Lucille Antonello and Lucille
 Hussey
 Christopher Lugo
 George Luscombe
 M & M Bolt Co., LLC
 Sam Magliola
 Elizabeth Mair
 Richard and Ruth Manning
 Neil and Estelle Marcus
 Marissa Womans Club
 Pauline Maslak
 Martha Matthew
 Louise Basse May
 Peter Mayo
 Joseph McCAhill
 Norbert Meier
 William Mellin
 Nicholas Merola
 Natalie Merrill
 Cheryl Metheny
 Guiseppa Migliaccio
 Lucille Migliaccio
 James Miller
 Michael Mills
 Mauricio Molina
 Andrew Mueller
 Ardel Mueller
 Hugh Muldoon
 Diana Murray
 John Nazfizer
 Jeannie Nagel
 Lynn Nakashian
 Jimmy Nevitt
 Christine Newton
 Robert Nieman
 Phillip Nollar
 Duane Nyen
 O'Brien, O'Brien, O'Brien,
 DDS
 Jo O'Connell
 O'Fallon Rotary
 Colton Offley
 Pamela and Paul
 Olkowski
 Roger Olsen
 Cindy Olstrom
 Morris Oltmann
 Barbara Orenstein
 Bruce Owen
 Danielle Paletz
 Nancy Palushock
 Susan and George
 Papaioannou
 Michael Pastor
 Donald Pearson
 Tanya Peebles
 Alisha Perkins

Lisa Perossier
 Pfizer Foundation
 Matching Gifts
 Program
 Herb Pfremer
 Joseph Pimental
 Susan Pirie
 Linda Potash
 Patricia Price
 John Quiter
 Judy Radel
 Pamela and William Randall
 Rebecca Rask
 Freidoon Rasolkhani
 Thomas Redrow
 Allison Reese
 Fremont Reif
 George Renner
 Paul Renninger
 Dorothy Renth
 Randy Renth
 Mary Ellen Rhoades
 Michael and Jenna Riahi
 Laura Ricigliani
 Jim Riddle
 Frank Rios
 Leroy Ritter
 Gerald Roach
 Dennis Rock
 Russell Romjue
 Joseph Roskos
 James Rowe
 Gina Rubdie
 George and Tina Ruggiero
 Joseph Sansone
 Pasquale and Sandra
 Santaniello
 Anthony Santilli
 David and Jessica Saslow
 Edmond and Kathy Schlef
 Bridget and Gary
 Schlichtmann
 James Schnabel
 Reva Schneps
 Robert Schreppel
 Michael Schweitzer
 Daniel Scripsema
 Brett Sealove
 Ronald Segall
 Harold and Paula Shatz
 Dr. Michael Sheff
 Leroy Sheriff
 Mr. and Mrs. Joesph Sherrill,
 Jr.
 Michael Shields
 Lisa Silvestri
 Linda Simon
 William Simpson
 Robert Skwara
 Moshe Slavaticki
 Robert Smith

Scott Smith
 Michelle Smith
 Randy Spaniel
 Cyril Spaude
 Special T Unlimited
 David Sporer
 Bruce and Phyllis Staloff
 Julie Stanford
 Donald Starr
 Raymond Stephens
 Robert and Catherine Stevens
 Harriet Stewart
 Jerome Stewart
 Carolyn Stokes
 Kathi Stone
 Heidi Strader
 Ann Strehl
 Richard Sturtevant
 Donna Stutin
 Janis Sudal
 Terrence Sullivan
 Herbert Swanson
 Charles Taubman
 Barb Tchaou
 Cletus Tebbe
 Lois Tefft Van Deusen
 Larry Tieri
 James Tiffany
 Lionel Timmerman
 Richard Timmermann
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 Karen Towers
 Steven and Roberta Trachtman
 Thomas Vacca
 Robert Vander Pluym
 Rowena and Mel Villaruel
 Wayne Vonderharr
 Joseph Voss
 John Wacaser
 Marie Wagoner
 Richard Walker
 Lucile Walker
 Jake Walters
 Clyde Waters
 Dale Wehmeyer
 Glenn Wenger
 Dennis Wetzler
 Mary Jean Wheatley
 Sarah White
 Arthur Wilhelm
 Genevieve Willgnot-Sevens
 Bruce Williams
 Ms. Lisa Wilson and Stephen
 Kaminsky
 Eric and Rachel Wiseman
 Roxie Wittlich
 David Wolf
 Pat Wurster
 Caroleen Yaeger
 Loraine Yarber
 Pinelopi Ylisma





Independent Accountants' Report

Board of Directors
National Foundation for Ectodermal Dysplasias
d/b/a Skin and Dental Dysfunction Foundation
Mascoutah, Illinois

We have audited the accompanying statements of financial position of National Foundation for Ectodermal Dysplasias (d/b/a Skin and Dental Dysfunction Foundation) as of December 31, 2003 and 2002, and the related statements of activities, functional expenses and cash flows for the years then ended. These financial statements are the responsibility of the Foundation's management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audits provide a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of National Foundation for Ectodermal Dysplasias (d/b/a Skin and Dental Dysfunction Foundation) as of December 31, 2003 and 2002, and the changes in its net assets and its cash flows for the years then ended in conformity with accounting principles generally accepted in the United States of America.

BKD, LLP

January 22, 2004

Statements of Financial Position

National Foundation for Ectodermal Dysplasias d/b/a Skin and Dental Dysfunction Foundation

December 31, 2003 and 2002

| | 2003 | 2002 |
|-----------------------------------|------------------|------------------|
| ASSETS | | |
| Cash | \$29,714 | \$71,075 |
| Investments | | |
| General | 175,982 | 213,918 |
| Treatment | 394,806 | 348,262 |
| Research | 264,009 | 229,252 |
| Prepaid Expenses and other assets | 2,049 | 1,453 |
| Property and equipment, net | <u>14,171</u> | <u>8,432</u> |
| Total Assets | <u>\$880,731</u> | <u>872,392</u> |
| Liabilities and Net Assets | | |
| Liabilities | | |
| Accounts payable | \$17,464 | \$ 20,994 |
| Accrued expenses | 22,636 | 25,411 |
| Deferred revenue | <u>12,450</u> | <u>4,000</u> |
| Total Liabilities | <u>52,550</u> | <u>50,405</u> |
| Net Assets | | |
| Unrestricted | 147,099 | 244,473 |
| Temporarily restricted | <u>681,082</u> | <u>577,514</u> |
| Total net assets | <u>828,181</u> | <u>821,987</u> |
| Total liabilities and net assets | <u>\$880,731</u> | <u>\$872,392</u> |

NFED compiled the presented financial information from the Independent Audit conducted by BKD, LLP whose report is dated January 22, 2004.

Statements of Activities

National Foundation for Ectodermal Dysplasias d/b/a Skin and Dental Dysfunction Foundation

Years Ended December 31, 2003 and 2002

| | 2003 Temporarily Restricted | | | 2003 Total | 2002 Total |
|---|--------------------------------|-----------|-----------|---------------|---------------|
| | Unrestricted | Treatment | Research | | |
| Revenues, Gains and Other Support | | | | | |
| Contributions | \$175,525 | \$108,648 | \$106,766 | \$390,939 | \$315,831 |
| Grants | 49,860 | - | 4,600 | 54,460 | 9,400 |
| Fundraising events revenue | 307,131 | 673 | 348 | 308,152 | 402,513 |
| Less costs of direct benefits to donors | (65,671) | - | - | (65,671) | 70,772 |
| Net revenues from fundraising events | 241,460 | 673 | 348 | 242,481 | 331,741 |
| Interest and dividends | 2,797 | 3,304 | 2,291 | 8,392 | 10,193 |
| Net realized and unrealized gains (losses) on investments | 32,267 | 13,010 | 19,537 | 64,814 | (66,933) |
| Other | 22,450 | - | - | 22,450 | 13,530 |
| Net assets released from restrictions | 155,609 | (59,743) | (95,866) | - | - |
| Total revenue, gains and other support | 679,968 | 65,892 | 37,676 | 783,536 | 613,762 |
| Expenses | | | | | |
| Education program | 235,142 | - | - | 235,142 | 156,860 |
| Family services program | 254,100 | - | - | 254,100 | 214,524 |
| Treatment program | 91,979 | - | - | 91,979 | 65,195 |
| Research program | 97,241 | - | - | 97,241 | 118,067 |
| Total program services | 678,462 | - | - | 678,462 | 554,646 |
| Management and general | 67,008 | - | - | 67,008 | 53,752 |
| Fundraising | 31,872 | - | - | 31,872 | 32,754 |
| Total Expenses | 777,342 | - | - | 777,342 | 641,152 |
| Change in Net Assets | (97,394) | 65,892 | 37,676 | 6,194 | (27,390) |
| Net Assets, Beginning of Year | 244,493 | 348,262 | 229,252 | 821,987 | 849,377 |
| Net Assets, End of Year | \$147,099 | \$414,154 | \$266,928 | \$828,181 | \$821,987 |

NFED compiled the presented financial information from the Independent Audit conducted by BKD, LLP whose report is dated January 22, 2004.



**National Foundation for
Ectodermal Dysplasias**

410 E. Main St., P.O. Box 114

Mascoutah, IL 62258-0114

Phone - 618-566-2020

Fax - 618-566-4718

Website - www.nfed.org

E-mail - info@nfed.org

Dear Mary Kaye,

This is a significant day for the Smith family and especially, Joey, in that at 10 a.m. he has his last appointment at the SIU Implant Clinic. After some final adjustments, Joey's implant treatment is completed. We know he will continue to deal with his dental issues his entire life, but he has sure come a long way since that meeting we had with our dentist some 15 years ago when we were told Joey has some significant problems and they didn't have a clue as to why or really even what it was. Yet, it seems like only yesterday when a coworker handed me an article in a SIU journal about the NFED and the work you were doing with the SIUE implant clinic. After a memorable first conversation, you put me in contact with a couple of geneticists with Cardinal Glennon Children's Hospital and a name was finally associated with our son's host of unusual dental and medical problems. Through caring, encouragement, and education provided by the NFED and you in particular, Mary Kaye, we were finally beginning to understand what we could not change, and pursue what could be changed.

Di and I want to thank you for all that you have done for us and Joey – your encouragement during those early dark days; providing hope when everything looked hopeless; putting us in contact with treatment providers; and I cannot forget the financial blessing you have been. We will never be able to repay you for what you have provided us, or thank you enough for your support. But you will forever be mentioned in our family with the greatest respect and admiration for not only how you have helped us, but the hundreds or maybe thousands of other families as well. May God richly bless you, Mary Kaye and the NFED.

-D.S., Illinois

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS
PO BOX 114 410 E. MAIN ST
MASCOUTAH IL 62258-0114
UNITED STATES OF AMERICA

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