

The EDucator

Newsletter of the National Foundation for Ectodermal Dysplasias

Summer 2008





National Foundation for
Ectodermal
Dysplasias

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As I See It...

By Mary Kaye Richter

Perhaps the questions and comments most likely to be heard by our staff are those related to dental treatment. At this time of year, cooling is often an issue but year in and year out dental questions are heard most. Over the years the concerns haven't changed much: finding a competent dentist, cost of care and age appropriate care.

Families living in sparsely populated areas will likely have more difficulty finding a dentist to provide care than families living in large metropolitan areas. In addition, the more complicated care becomes the more difficult it can be to find a dentist to provide it. Cost of care and insurance reimbursement are something we deal with here on a daily basis as we work with families applying to the Treatment Assistance Program. This is a huge problem, and one we continue to work on.

However, perhaps my greatest frustration involves families having difficulty finding a dentist to provide dentures for a young child. After all of these years, the issue should be gone, but yet we continue to find dentists using old excuses like "the child won't cooperate" or "the child won't wear the dentures" as reasons not to begin treatment. How do you know a child won't cooperate or wear the dentures unless it is tried? I look at the dentist who won't try to provide dentures for a young child as guilty of malpractice as the doctor who fails to write a needed prescription for a patient. It's an issue that makes my hair stand on end. It's a good thing my hair is short!

Some folks may believe that I am much too strident on this issue, but, perhaps if they had been here listening to families for 25+ years they would better understand why I feel so strongly. Are there children who go without dentures who grow up to be fine, successful citizens? Of course. However, I would say that it is much like a game of Russian roulette--- while sometimes it works out fine, that is not always the case. I do not know of a single case where having the dentures exacerbated emotional issues for a growing child, but I am aware that not having dentures certainly has. Is that a

risk you are ready to accept without trying? If a dentist is unwilling to provide care a parent's response is easy----find a different dentist.

Similarly, the growing child and teen need to have age appropriate restorations. If you have questions about what those may be, contact our office for a copy of our *Parameters of Oral Health Care for Individuals Affected by Ectodermal Dysplasia Syndromes*. This publication will apprise you of an experienced, expert panel's recommendations for care. While it is impossible to suggest a "one size fits all" approach, rarely is it impossible to do some sort of restoration at reasonable prices. We continue to be puzzled by dentists who, rather than provide interim care, want to wait until they can plop in a bunch of implants and collect the fees associated with them. Interestingly, as consumers, we are accepting treatment plans with all sorts of facets, i.e. sinus lifts, ridge augmentations, with little or no research to support them. We even saw a recent plan including botox. Consumer beware!

Recently, I heard from a family who was quite surprised to see a remarkable difference in their child after some teeth had been bonded. All would agree that the child was doing quite well even before the care was provided but clearly the care had positive effects on self-confidence and speaking. It was much like we saw when our 2 ½-year-old received his teeth. Our competent dentist had done an outstanding job of creating dentures where a minimal amount of ridge was present, we provided lots of encouragement and support and with our son's determination, the treatment was a complete success. We, too, saw an immediate and positive enhancement to his self-esteem and confidence.

As I See It, how could I not want that for all children? It was that success that prompted the formation of the NFED and my continual advocacy for early dental care. It is as important today as it was 30 years ago.





Rachael Morrissey, Troy Bielert, David La Valley, and Debbie La Valley join together at the Cold Sweat Concert in Massachusetts.

Raising Funds and Awareness

From east to west, families are raising funds and awareness for the NFED.

In California, the Paisley family continues to solicit donations through letters to family and friends, contacting local businesses, and giving presentations at schools. James Paisley's "Swim 4 Sweat" campaign culminates in the Maui Channel Swim later this summer on August 30. If Hawaii is not in your travel plans, be sure to cheer on his efforts from wherever you are.

In Massachusetts, David La Valley decided to use his musical talents and contacts to put together a blues concert called "Cold Sweat" to benefit the NFED. The concert was held on May 30 and was a huge success. The crowd of music lovers took time to participate in the many raffles in addition to just enjoying a great show. Carol Agne from the office staff shared information about the ED syndromes with the attendees.

The very next day, a little further to the east in Massachusetts, NFED Board Member Beth Pond hosted a Walk/Run to raise funds for the Foundation. Beth organized an event that allowed people

to sponsor the walkers/runners, and had a very successful day. She plans to make this an annual event, so watch later issues of *The EDucator* to take part next year if you are nearby.

On June 15, Troy Bielert ran in the Lake Placid, New York Half Marathon. He dubbed his efforts the "No Sweat Campaign," and he mailed letters to his family and friends asking for their sponsorship through donations made to the NFED.

All of these events, along with a few that were completed this past winter and spring, have raised a cumulative total of more than \$50,000 so far this year. Everyone at the NFED sends a huge thank you to all families and friends who have participated in any way with a fundraiser this year. We know that there are more events to come this year (see the calendar of events in this issue), so make every effort to attend and support them if you can.

If you would like to organize a fundraiser in your area, please contact the NFED office for an information packet. We look forward to hearing from you!

2008 Apple Classic Golf Tournament Weathers the Storm

Amid thunderstorm and tornado warnings, the 18th Annual Apple Classic Golf Tournament literally went off with a bang. Although storms threatened early, golfers were able to start play on time at the noon shotgun start. Alas, as has been typical in the Midwest this year, the rains came our way by mid-afternoon. As more serious weather moved into the area, we were forced to call golfers back to the clubhouse to wait out the storm.

While we had everyone's attention, we decided to move forward with the program and the live auction. Guy Phillips, a local radio personality, was our auctioneer for the 8th year. The NFED raised \$8,455 between our live and silent auctions. Another \$2,700 came to us through the raffle.

When all was said and done, the weather won the battle and the tournament was canceled after about eight holes of play. Everyone involved remained in good spirits, and genuinely had a great time raising money for a cause they believe in. Without all income and expenses booked at press time, we estimate that the tournament's net income will exceed \$28,000.

Thank you to all the NFED families who attended (see their photo on the cover) and the golfers who stuck it out through less than ideal circumstances. Thank you to the many volunteers from that day as well as the volunteer committee, who has been planning for the event since last July. Thank you to the BKD Foundation for sponsoring the event.

We made it through a challenging day, and are ready to begin plans for the 19th Annual tournament to be held in June of 2009!

Workplace Fundraising Campaigns Make Giving to the NFED Easy

This fall, there are several opportunities for you to help the NFED at your workplace if you live in the U.S.

USA - Federal Employees

#10604

If you are a federal employee, please consider supporting the NFED during this fall's Combined Federal Campaign (CFC). The CFC, which runs September 1st through December 15th, promotes and supports philanthropy through a program that is employee-focused, cost-efficient, and effective in providing all federal employees the opportunity to help the NFED. The NFED's (D/B/A Skin and Dental Dysfunction Foundation) designated number is #10604 on your donor form for 2008.



USA - State Employees

If you are a state government employee, please select the NFED in your state's employee giving program that allows donations through payroll deductions or as one-time gifts. Contributions received will assist the NFED in continuing our mission where we strive to enrich the lives of individuals affected by ED syndromes. Each state has its own eligibility requirements and the NFED currently qualifies and participates in the following state campaigns:

Arizona	Michigan	Rhode Island
Connecticut	New Jersey	Texas
Florida	New York	Utah
Illinois	Ohio	Washington
Maryland	Pennsylvania	Wisconsin
Massachusetts		

United Way

If your workplace participates in the United Way campaign, simply write in "The National Foundation for Ectodermal Dysplasias" on your donor designation form. Then, let Jackie Schmitz (Jackie@nfed.org) at the NFED know you have selected us, and she'll track the dollars to make sure the Foundation receives them from the United Way. Sending us a copy of the designation form is the most effective way for Jackie to track this.



Please forward this information to friends and family working for the federal and state government.

Please join Ruth & Keith Geismar for our 8th Annual Halloween Bash

An Evening to Benefit The National Foundation for Ectodermal Dysplasias

Wednesday, October 29, 2008

6 p.m.

Broad Street Ballroom

41 Broad Street

New York, New York 10004

Tickets \$150 in advance and \$200 at the door. Check, Cash or Credit Card accepted. All tickets sold in advance will be held at the door.

Event Hosts: Ruth and Keith Geismar.

Event Chairs: Alice and Bruce Geismar.

If you would like to support the Halloween Bash, go to the NFED Web site (www.nfed.org) where you can...

- Purchase tickets
- Make a cash donation
- Place an ad in the journal
- Volunteer at the event
- Donate an item (vacation packages, sports memorabilia, new jewelry, etc.)

Your Gifts...

The NFED's lifeline

Among my tasks each morning, is the opening of the mail. I have always enjoyed opening mail whether at my home or in my office. One never knows what may be delivered each day. Of course, there are some pieces that find their way to the wastebasket with hardly a second glance. There are bills that must be paid and occasional notes from friends and families. Here at the NFED the notes from our families are greatly appreciated and enjoyed. It's especially nice when they come with photographs. But it is the special envelopes with gifts for the organization that keep us percolating.

There are big gifts and small gifts but each and every one is important. There are folks who send a single gift and others whose monthly gifts arrive like clockwork. Names from the latter group are particularly easy to recall. I'm at the point, where I begin looking for a specific envelope because I know it's about time for the next gift to arrive. Some of these folks may not send a single large gift but by giving a little each month they provide an important and stabilizing impact on the Foundation. Over time, such gifts accumulate and become sizable. Today's \$10 gift multiplies quickly when repeated or matched by others.

In these challenging economic times, it would be easy to dismiss appeals like ours. However, your gifts, big or small, are the reason that NFED accomplishments continue. As we look to the future of ED research, escalating need for treatment assistance and increasing requests for services, it is your gift that keeps the NFED moving forward.

Start Spreading the Word

NFED Awareness Items To Give and Get Through The Year!

Set of 12 Full Color NFED Note cards \$12 (with 12 envelopes)
Handprints are those of children affected by ED.

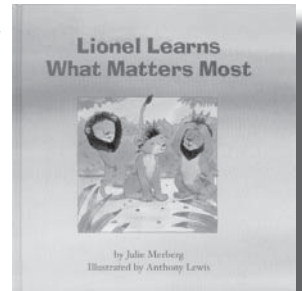


\$2



Child and Adult Sizes Available

Lionel Learns What Matters Most \$15
Silicone Awareness Wristbands

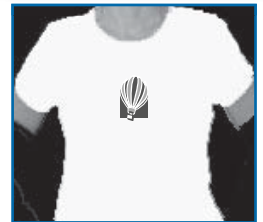


Men's T-Shirts \$15

Travel Mug \$7



Women's Fitted T-Shirts \$20



Can Huggie \$3



Men's Polo Style Shirts \$26

Scoop and V-neck Available



Mouse Pads \$5

Order Form

Please send ___ sets of NFED Note cards (12 cards) @ \$12 per set

Please send ___ Mouse Pads @ \$5 each

Please send ___ Can Huggies @ \$3 each

Please send ___ Travel Mugs @ \$7 each

Please send ___ Lionel Learns What Matters Most @ \$15 each

Please send ___ Silicone Awareness Wristbands @ \$2 each ___ Child Size ___ Adult Size

Please send ___ Women's Fitted T-Shirts @ \$20 each ___ Scoop neck ___ V-neck

___ Small ___ Medium ___ Large ___ X- Large ___ 2X- Large

Please send ___ Men's T-Shirts @ \$15 each ___ Small ___ Medium ___ Large ___ X- Large ___ 2X- Large

Please send ___ Men's Polo Style Shirts @ \$26 each ___ Small ___ Medium ___ Large ___ X- Large ___ 2X- Large ___ 3X- Large

___ Please send me the free brochure - You Can Do It, Too -- A Guide to Finding Friends and Funds for ED, for helpful tips on planning ectodermal dysplasias awareness and fundraising activities in my community.

Tax, shipping, and handling charges are included in the price of the item.

Please add \$5 for any order outside the United States.

Total Amount Enclosed _____

___ Enclosed is a check or money order ___ Please charge to my credit card ___ MasterCard ___ Visa ___ Discover

Card Number _____ Expiration date _____

Name on Card _____

Signature _____

Mail to: _____

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

You can order items on-line though the NFED marketplace at http://nfed.org/marketplace_publication.asp.

Remember to Remember

When you make a gift to **honor** someone and support the NFED, besides honoring them, you become part of a network of people who are committed to helping individuals affected by ED live a normal life. When you make a gift in honor of someone, the NFED sends a card to that person indicating that you have made a donation in his or her name. The amount of the gift is not disclosed.

Your **memorial** gift to remember someone helps us fund multiple programs and services such as 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 ED. What better way to remember a loved one that was an important part of our ED family? When you make a gift in memory of a loved one or friend, the NFED sends a card to the family of the person being remembered. You simply must provide their name and address information.

The following honoraria and memorial gifts were made to the NFED in the spring of 2008.

Honoraria

Max Anderson Harvey Gold Jewish Federation of Silicon Valley	Jeanne Edgar's volunteering Beverly and Dave Meier	Allyson Kelso Mark Kelso Terri Matus
Angelina Vince Maestranzi	Hunter B. Evans David Evans	Jack Kriz Tom Stern
Ariel Babak Dardashti, DDS	Zachary Franck Rosemary Franck	Mason Langefeld Claire Dase
The Birth of Eden Linda Marcus	Lucy Gable Pamela Crimmins	Mary Jane Litz, National President Mu Kappa Chapter, Delta Theta Tau Sorority, Inc.
Susan Bennett A Massage Inc. Dolores Bennett William Bennett Curt Brandt Marc Couvillion William Ford, III Joseph Hutchison Clarence Mamaril David Pederson Karl Smith Zubin and Navaz Taraporevala	Keifer Garrett Bryan Beaty Richard Garrett	The Lord Steven Bain
Susan Bennett's Birthday Jeffrey Bennett John Boehm Amy Deitemeyer Chris Ford William Ford, Jr. Carolyn Steen-Smith Fred Tenbrink Simon Turner	Keegan Gamble Raymond Meisels	Mary's great work Catherine Wittlich
Troy Bielert Everett Baroni Connie Anderson Bielert Ashleigh Jacobs David Jones Derrek Krasnicki James Morrissey Debra Morrissey Erinn Sosa Joseph Winski Callie Booth Joy Booth	The Gay family Joseph Nash, DDS	Mary Kaye and Charley Thurman Carver
Carver Claeys Julie & Craig Claeys	Ryan Geismar Florence Scheinman Mark & Deborah Russo	Terri Matus Alfred Paradise, Jr.
Daniel and Benjamin Cerny Sidney Feldman	Dr. Jack Gilster K. Moore, DDS	Michele Merideth Stephen Bearden
Zachary Comway Tanya Peebles	Brooks and Ryan Ginnan Dee Van Riper	Shayla Merrifield Aaron Merrifield
Diane Barbara DeRosa-Reynolds	Grandma Gloria's Birthday Robert Zwirn	Kevin Mulryan Patricia Manetti
Olivia Daniels and her programs Robert Toby Paltzer	Ryan Gruber Susan Gruber	Alex and Justin Murshak Mikhail Murshak
	Kayla Haflinger Martin Haflinger William Largent C. John Mostofi	Jacob Moss Arthur Winter
	Joshua Hill Jason Hill	The NFED Staff Joe and Lynn Van Cavage
	Madison Hoffman Danielle Fish Molly Maid of Cherokee County Linda Zenkovich	Alex Novak Leo Amend, Jr.
	Mary Jackson Doris Wikstrom	Michael O'Neal, Jr. Sharon O'Neal
	Caleb Jones Deborah Weiner	Olivia Sandra Abrahamian
	Alex Johnson Gretchen Johnson BP Foundation, Inc.	Olivia and her new smile Mike Daniels
	Aiden Kaufman Lee Anne Butler	Tyler Paisley C. Edwin Alter Consepcion Amescua Andrei Olenicoff Memorial Foundation Scott Anderson Richard Bachrach John Baggs, III Grant Berentsen Dick Bitterolf James Brandes Ronald Brockman Carol Caldwell

Kathleen Callahan Barbara Cargill Wayne Christoffersen Robert Colvett CS Financial, Inc. Charles Culp The Dapper Frog, LLC A. Michael Deichmann Mary Dolley William Dunn Ewan Elliot Richard Foullon MD Firstlink Freight Isidro Garcia Philip Godfrey Colette Goldstein David Goodman Terry Hambrecht Robert Hannon R. Todd Harbert Michael Hartel Charles Haupt Roland Hinz Kenneth Holt William Ivey Allen Johnson Scott Keihle Samuel Keller Toshio Komoda Larry Lewis Lila's Interiors Richard Martin Pat McKiernan David Minton Travis Moats Janice Myers Ernest Nardoni Steven Ness William Noonan Tom O'Neill Ermanno Pace Charles Paisley MD Jerold Perlstein Brian Porter Doris Quinn Merlin Robertson Bradley Roe Brad Ross Bonnie Russell Jane Ryan George Saunter Lawrence Seeger Steve Shedden Diane Shenk Joseph Skelly Cora Ann Smith Bill and Ellen Smith Robert Sneddon Jeff Sofro Roger Stebbins Gene Tambascio William Terrio N. Maryann Varciag Chuck Varga David West Bret Zinn	Caleb Peterson Cathy Ketchum	Memorial
	Philip and Nolan Pond Lillian Brown	Louie Cefalu Sal and Harriet Cefalu
	The Pond Family Nona King	Lucy Chiantese Lucille Migliaccio
	Rebecca Ponzio James Ponzio	Patricia De Leon Lea Ann Wallace
	Tyler Raisbeck Ann Gurtner	John F. DuBeck John Dubeck
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	Jaimie Wyckoff James Wyckoff	Everett Rustad Sandy Lind
	Loh Yih Hang	Frank Scilio Lucille Migliaccio
		John Sciancalepore Melody Reese
		Jenica Shirley Roger Shirley
		David Tinklepaugh Sandra Franck
		Oralia Zuniga Lucille Migliaccio
		Tian How Loh
		Your Grandson Robert Meader
	Kevin & Toni Paur Heather Meier	

NFED Continues to Fund Innovative Research

The NFED recently awarded five new grants totaling \$100,000 for research to help us better understand the ED syndromes and bring us closer to a cure. Some of these grants are funding ongoing research in key fields like genetics, and some grants are funding promising new projects. We will publish more detailed information about their projects later this year in our research newsletter, Connecting Lives. The NFED has now funded more than \$835,000 in research grants.



Margret L. Casal, Dr med vet, PhD

University of Pennsylvania

Novel Approaches to the Treatment of X-Linked Hypohidrotic Ectodermal Dysplasia

\$25,000



Sylvia A. Frazier-Bowers, DDS, PhD and J. Timothy Wright, DDS, MS

University of North Carolina

Genetic Determinants of the Phenotypic Variance in Ectodermal Dysplasias and Non-Syndromic Tooth Agenesis

\$24,000



Clark Stanford, DDS, PhD

University of Iowa

Oral Health Related Quality of Life in Children with Ectodermal Dysplasias

\$16,000



Dr. Abigail S. Tucker, Dr. Denis Headon, and Professor Paul Sharpe

King's College

Rescue of the Salivary Gland Defect in a Murine Model of Hypohidrotic Ectodermal Dysplasia

\$10,000



Ignatia B. Van den Veyver, MD

Baylor College of Medicine

Pathogenesis of Focal Dermal Hypoplasia (FDH) or Goltz syndrome and Related Disorders

\$25,000

Dental Treatment Center Program

In this issue, Michele Small writes about the quality oral health care she found for her twins affected by ED when she took them to the University of Alabama at Birmingham (UAB). UAB's dental school is just one of six universities across the country which participates in the NFED's Dental Treatment Center Program. If you are searching for a dentist, consider one of the following dental schools:

- Saint Louis University Center for Advanced Dental Education
- Southern Illinois University School of Dental Medicine
- University of Alabama at Birmingham
- University of Iowa
- University of Missouri Kansas City
- University of Pennsylvania

It is the patient's responsibility to make an informed decision as to the appropriateness of care and to make suitable arrangements for payment of associated fees. Fees vary according to the location. All travel, lodging and meal expenses associated with treatment are the patient's responsibility.

Individuals who want to participate in the Dental Treatment Center Program must complete an application. You can download the application from our Web site, www.nfed.org, email us at info@nfed.org, or call us at 618-566-2020.

The NFED contacts all applicants upon receipt and review of their application. Approved applicants will be referred to a contact person at the appropriate university. Applicants will be responsible for contacting the university to arrange an appointment for an intra-oral evaluation. The NFED will share the name of the approved applicants with the university staff.

An NFED Salute

Congratulations to Jill Radley from Arizona. She successfully got her medical insurance to cover dental implants for her son, Caleb.

Congratulations to Peter and Jennifer (Geismar) Hyman from New York on the birth of their son Nathaniel Everett Hyman.

Impressive Group of Students Wins Scholarships

The NFED recently awarded \$24,900 to 30 individuals affected by ED who applied to the L. Marie Heard Education Scholarship Program. Each scholar was judged on their academic ability, a written essay, financial need, extracurricular activities, community involvement, recommendation letters and employment. This year's class of winners had impressive credentials and achievements. They are pursuing majors such as architecture, criminal justice, education, engineering and industrial science.

Begun in 1995, the L. Marie Heard Education Scholarship Program has awarded more than \$238,150 to 230 students affected by ED syndromes for post-secondary education.

In addition to monetary awards, three scholarships have been created in honor of individual(s) who have made a financial commitment to the continuation of this program for their love of education and of the NFED. They are the Ethelyn Draser Boyd Scholarship, Louis J. and June E. Kay Scholarships, and the Clarence and Marion Bayles Scholarship.

Following are excerpts from "What Personal Success Means to Me" essays written by two of our scholarship winners.

Amanda Eckert
Elementary Education Major
Buffalo State College

Personal success is putting forth effort, thought and time into a goal that was designed to fulfill a dream ... Each step that I take along my educational journey takes me closer and closer to my dream. I will some day have my own classroom that will bring fun and learning to the children.



Douglas E. Coiner
Business Information Systems
Messiah College

...my pinnacle achievement has been the ongoing life challenges of my own disabilities.

Learning to eat orally at the age of seven, after being tube-fed since birth, was an accomplishment that enabled me to function a little more like my peers.

With contractures of my hands, I have learned to type on a laptop. Unable to move my eyes in their sockets, I have learned to adapt by turning my head as I read or drive a car. Fifteen surgeries, including two brain tumors and a neck fusion (which inhibits my ability to even turn my head easily), have helped me appreciate who I am and the strength that has been provided internally when my body is weakened externally. I have gone through times of home schooling and have been able to return to school still excelling in my classes, ranking in the top 10 percent of my class. Now that I have finished my first semester in college (and almost my second!), I have learned how to incorporate texts on CDs, peer note taking and double exam time to benefit my unusual struggles with learning.

I explain to you some of my life challenges, not to feel compassion for me, but to paint a picture of the self-motivation my parents, teachers, church and community have helped to instill in me. Throughout my life, everyone that I talk to say I am an inspiration to them because I am usually able to see the bright side of things. Even though most simple tasks can become complex, the quality of adaptability and perseverance has become my lifelong challenge, yet my most proud achievement.

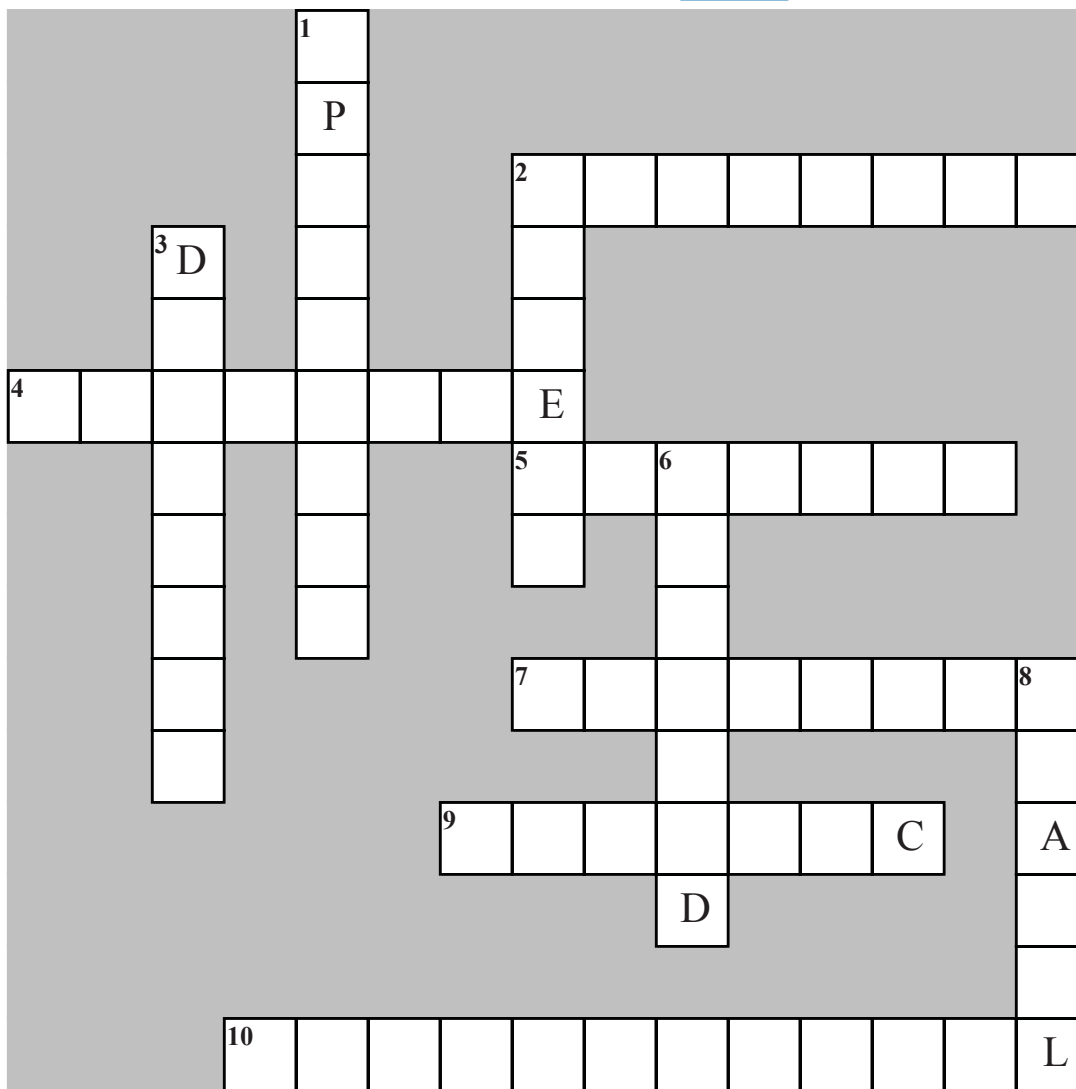
The struggles that I have tolerated have provoked me to be successful in my life thus far. I have learned that by continuously looking behind your shoulder at the past, one will never succeed and I am no exception. I am determined to reach for some significant pinnacles in life so I can serve others.



The NFED recognizes the following individuals as outstanding scholars and awards a named scholarship based on their exceptional applications. Following their name, the university they will attend in the fall is listed when known.

- Mohammed Abdel-Rahman Ali**, The American University in Cairo
- David Baer**, *Clarence and Marion Bayles Scholar*
- Levi Banker**, Southern Illinois University at Edwardsville
- Chris Barbey**, The University of Vermont
- Tiffany Berger**, Lindsay Wilson College
- Quinn Byslma**, Northern Michigan University
- Douglas Coiner**, *2008 Louis J. and June E. Kay Scholar*, Messiah College
- Joni Cucchia**
- Rachel Dahler**, The Ohio University
- Diane DeRosa-Reynolds**, Western Kentucky University
- Lauren Durante**, Rhode Island College
- Amanda Eckert**, Buffalo State College
- Jason Golebieski**, Pennsylvania State University-Erie
- Andrew Hebert**, University of Massachusetts
- Andrew James**, Bowling Green State University
- Allen Kuceba**, *2008 Louis J. and June E. Kay Scholar*, Bellevue Community College
- Brittany Martin**, Darton College
- Catherine McNelis**, RIT
- Jeremy Miller**, Berklee College of Music
- Kyle Offley**
- Jonathon Olney**, ETI Technical College
- David Partlow**
- Caitlin Proctor**
- Michael Putney**
- Aurelia Rohrbacker**
- David Sadowski**, Towson University
- Caitlin Sarubbi**, *2008 Ethelyn Draser Boyd Scholar*, Harvard University
- Timothy Smith**
- Bryant Sparks**
- Ryan Sylveira**

Kids Corner



Across

- 2 the outermost covering of the embryo
- 4 the repetitive co-existence of two or more abnormalities
- 5 the upper jaw
- 7 the lower jaw
- 9 pertaining to inheritance
- 10 referring to the head and face

Down

- 1 the outermost layer of skin
- 2 a superficial inflammation of the skin
- 3 artificial replacements for teeth
- 6 pertaining to genes on the X chromosome

- 8 the white, hard substance that covers the surface of the crown of a tooth

All of the answers can be found in the NFED series of medical guides.

WANTED Used Cooling Vests

If you have a used cooling vest in good condition that is no longer needed or is too small, please mail it to the NFED. We will make sure that another family will benefit from it.

Support Network is Connecting Families in Their Own Communities

Liaisons in the Family Support Network want to connect with you to talk and share experiences about ED. All of the liaisons are either adults affected by ED or the parent of a child affected by ED. They are also familiar with NFED services and resources and can share that information.

The network is working as a number of families have reached out to liaisons for various reasons. If you do not have a specific need to contact a liaison, then contact them just to say hello and meet someone else affected by ED in your area.

The Tyler family, a new family in Michigan accessed the Family Support Network and found a friend in liaison and mom, Julie Claeys. Read Tara Tyler's first thoughts of the new Family Support Network and her contact with Julie.

Dear NFED,
I wanted to write this letter and personally thank you and your staff for the support and guidance regarding our ten-month-old son, Audric.
Right away you sent us some very helpful information and gave me the name of the Michigan liaison in my community. I contacted her (Julie Claeys) and we have since become friends. Julie recommended us to a local dermatologist, he pointed out other characteristics that were different in Audric but common in the ectodermal dysplasias.
The Tyler Family



Update from Tara Tyler...

A few months back we had dinner with Julie and her children, Carver and Maria. We had a wonderful time together! It's truly a great comfort to Treaver and I to have Julie so close by. Through her own experiences with ED, Julie understands our concerns and is always willing to answer our abundance of questions whenever she is called upon. With the weather finally breaking, we are looking forward to another family get together and catching up where we left off.

Contact the Liaison in Your Community

Julie Claeys - Michigan
jclaeys@charter.net

Jack Kriz - Oregon
jack@mdgpc.com

Russ Wilson - Mississippi
Wilson_russ@comcast.net

DeAnn Huxman - Kansas
cdrthux@mtelco.net

Dee Olsen - New York
dgocsw@verizon.net

Janet Johnson - Utah
tayalnes@hotmail.com

Beth Pond - Massachusetts
pondboys@charter.net

Are you interested in hosting a picnic or other type of gathering for NFED families in your area? Contact **Kelley Atchison** at the Foundation, (618-566-2020, Kelley@nfed.org) for more information.

We Welcome the Following New Families to the NFED Family

The Allen Family from Texas
The Brooks Family from Missouri
The Brown Family from Ontario, Canada
The Buerman Family from Minnesota
The Burgett Family from Indiana
The Cooper Family from California
The Cox Family from Indiana
The Davis Family from Missouri
The DeLeon Family from California
The DiBernardino Family from Florida
The Dickey Family from Florida
The Espino Family from California
The Frea Family from Illinois
The Helmer Family from Wyoming
The Herbst Family from Wisconsin
The Hightower Family from Illinois
The Houston Family from Tennessee
The Hovancik Family from Pennsylvania
The Jalfron Family from Texas
The Jones Family from Kansas
The Khalil Family from New South Wales, Australia
The Kirby Family from Texas
The Krachman Family from Georgia
The Kump Family from Ohio
The Latimer Family from Puerto Rico
The LeFrancois Family from Massachusetts
The Lefrancois Family from Massachusetts
The Lippa Family from Missouri
The McDaniel Family from Texas
The McNeely Family from Pennsylvania
The Mefford Family from West Virginia
The Meyer Family from Texas
The Olson Family from Wisconsin
The Pechtel Family from New York
The Perry Family from Hawaii
The Pruitt Family from North Carolina
The Ramos Family from Texas
The Register Family from Massachusetts
The Remines Family from Maryland
The Roach Family from Missouri
The Saylor Family from Kentucky
The Sotello Family from Texas
The Taylor Family from Oklahoma
The Thurman Family from Virginia
The Walker Family from Ontario, Canada
The Wallace Family from QLD, Australia
The Woodburn Family from Teesside, England
The Woods Family from Hampshire, United Kingdom
The Zuluaga Family from Antioquia, Colombia

Volunteer Spotlight

Volunteers play an important and valued role in the National Foundation for Ectodermal Dysplasias. Whether it's stuffing an envelope or speaking at a Family Conference, NFED volunteers make a difference. As our volunteer program grows, we honor individuals who give so generously of their time. The volunteer spotlight recognizes people who share their time, energy and talents with us.

Carlos F. Salinas, DMD

Dr. Carlos Salinas is a dental professional who has been interested in the ED syndromes for more than three decades.

This past March, he co-chaired the International Conference on Ectodermal Dysplasias Classification sponsored by the NFED and the Medical University of South Carolina, where he is a Professor and Director in the Division of Craniofacial Genetics. Under his leadership, the conference, which took more than a year of planning, was a major success with scientists and clinicians from 23 countries attending. The conference was the first major step in working toward a classification system of the ED syndromes. Dr. Salinas will lead the committee charged at the conference with seeing the plan to fruition.

Mary K. Richter first wrote to Dr. Salinas in May of 1982 shortly after the NFED had formed. She was writing to all dental schools in the U.S. to inform them of NFED's existence and to ask if they had ever treated individuals affected by ED. He immediately responded that he indeed had seen such patients and that he was also interested in the NFED's goals.

Since then, Dr. Salinas has participated in many different levels in the ED community. He has diagnosed patients in the genetics clinic, provided care and dentures for affected individuals, and counseled patients as to treatment options and reimbursement for care.

In 1988, Dr. Salinas, along with John M. Opitz, MD and Natalie W. Paul, edited a book titled, "Recent Advances in Ectodermal Dysplasias." The book published the proceedings of a meeting chaired by Dr. Salinas that was held in Calloway Gardens, Georgia in July of 1985, called the "International Symposium on Interdisciplinary Approach to Ectodermal Dysplasias." It highlighted the advances at the time in elucidating the EDs and the importance of a multidisciplinary approach to the diagnosis and management of affected patients.

The NFED tips its hat to Dr. Carlos Salinas for his continued support of individuals affected by ED and of efforts to better understand these rare conditions. Thank you, Dr. Salinas!



Eye Concerns in the Ectodermal Dysplasias

Richard Alan Lewis, MD, MS

Departments of Ophthalmology, Medicine, Pediatrics, and Molecular and Human Genetics
Baylor College of Medicine



The ectoderm (or outer layer) of the embryo develops into many parts in and near the eye: eyebrows, skin of the eyelids, eyelashes, tear glands, conjunctiva, cornea, and lens, as well as most structures of the face. All these structures may be normal in individuals with ED, or one or more tissues may develop or function abnormally. Scanty, short, or fragile eyebrows and eyelashes may present a cosmetic concern but may also cause irritating debris in the tear film. In some forms of ED, because the skin may be unusually thin and because the skin of the eyelids is already among the thinnest skin of the body, a darkness caused by the blood vessel patterns (usually veins) in the deep tissues may cause some people to use cosmetics.

In some EDs, the lid margin may be loose, while in other forms, lids may be tight and scarred. If the lids are tight either because of excessive retention of the outer layers of the skin's surface as seen in some forms of ichthyosis, or if there is scarring and vertical shortening of the lid skin, the lids do not close on casual reflex blinking or when the eyes are at rest (while asleep, for example). Careful attention must be directed to lubricate the cornea and the

conjunctiva. Exposure caused by failure of the lids to close quickly permits drying of the outer surface of these tissues and encourages infection or scarring. Lubricating sterile ointments (e.g., Lacrilube® or Duratears®) or artificial tear supplements may be necessary as much as several times an hour to protect the ocular surfaces and at bedtime. Rarely, if the lids are lax or floppy, or if the lower lid curls outward away from the surface of the eye, then a surgical procedure ("tarsorrhaphy") may be done to support the lid and close the lid.

Sometimes eyelashes become misdirected and curl inward and scratch against the conjunctiva and cornea. These aberrant lashes can be removed, but relief is usually temporary. As soon as the lashes regrow, they may almost always be misdirected again. Misdirection of the lashes of this type can be repaired permanently by freezing the abnormal lashes, by burns with a laser, or by electrolysis.

Dry Eye Syndrome (caused either by insufficient tear volume or by inadequate tear components, such as underproduction of oil or mucus in the tear film) leaves the surface of the eye

irregular and irritated. The frequent use of artificial tears (these may be purchased without prescription) or holding a warm compress to the closed eyelids often will provide comfort. Sometimes, obliteration of the puncta, the "drains" near the inside corner of the eyelids that conduct tears into the nose, must be closed. The simplest way to do this semipermanently is with silicone plugs; alternatives include cautery or laser to scar the puncta closed. Whenever possible, use the plugs, as they can always be removed if circumstances change.

If a thick, purulent discharge or crusting of the eyelashes occurs, then this should be treated with an appropriate antibiotic. The occurrence of corneal opacities sufficient to affect vision is uncommon, but if it should develop, then visual improvement would be expected following corneal transplant. However, if the scarring has resulted from corneal drying or from exposure and poor blinking, the success of corneal transplant surgery is very limited. If a cataract develops prematurely, then cataract surgery may return vision to precataract levels. However, restorative procedures including artificial lens implants are substantially different and more complex in children and adolescents than in older adults; therefore, anyone contemplating cataract surgery should discuss carefully and in great detail the risks and complications of the specific procedure(s) proposed with the surgeon well in advance of any decision to undergo the surgery.

Many of the eye findings seen in young individuals affected by ED occur frequently in non-ED individuals as they get older. Dry eyes, thin eyelid skin, misdirected eyelashes, diminished tears, and cataracts are common events in an older adult population. These same treatment options are used by many people after age 50-60 years.

Arriving at a Diagnosis

One of the most frustrating experiences for parents of a child with ED can be the search for a diagnosis.

The first level of frustration is encountered in the delay of recognition that a child has ED at all. Often times the diagnosis, if any ED, is delayed because it is not realized that an ED is the cause for the child's fever or poor hair growth or failure to thrive is rather something else more common such as an immune problem or an infection.

For most parents, the diagnosis of an ED is usually a diagnosis of hypohidrotic ectodermal dysplasia (HED); it is the most common form of x-linked ED, the one most readily recognized, and it is the one for which we have the most information. It is, however, not the only form of ED and there are close to 100 other syndromes or conditions that have been categorized under the heading of ED. For parents whose search does not end with the diagnosis of Christ-Siemens-Touraine (HED) syndrome it is often confusing and distressing.

In trying to arrive at the correct answer for parents or individuals, a clinician familiar with ED will approach each patient trying to sort out which of the ectodermal structures are involved (for example is this a person who has abnormalities in the hair and the nails, but normal teeth or does this person have involvement of the teeth and the nail, but has normal hair?). The clinician will look for alterations in other organs that are not part of the ectodermal derivatives (does this patient have ectrodactyly or malformations of the hand; does this person have mental retardation). By sifting through all of the clinical features in a given individual, it is sometimes possible to arrive at a specific and correct diagnosis. The clinician will obtain a family history. Sometimes we distinguish among similar appearing forms of ED on

Virginia P. Sybert, MD
University of Washington,
Group Health Permanente

the basis of mode of inheritance. Some conditions are inherited parent-to-child, while others occur only among siblings or only affect males. The way that the condition is inherited is often an important factor for correct diagnosis.

Why do we care about correct diagnosis? It is relatively straightforward to manage the medical problems of a person with ED without a diagnosis. If one has problems with sweating, one avoids overheating, whether the diagnosis is Christ-Siemens-Touraine syndrome or Rapp-Hodgkin syndrome. If one is missing teeth, then orthodontia is required whether the diagnosis is dermo-donto-dysplasia syndrome or the AEC syndrome. A correct diagnosis is necessary for prognosis. In order to be able to predict what kinds of problems a person with ED may have and/or to predict what problems they won't have, one must know the natural history of the specific condition.

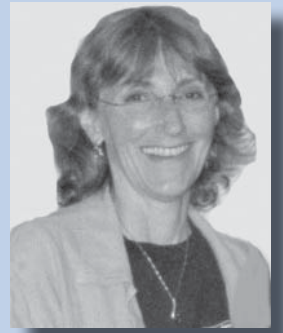
The second important issue that requires a correct diagnosis is recurrence risk. How is this particular form of ED inherited? Are the parents at increased risk to have a similarly affected child in subsequent pregnancies? Is an individual with ED at risk to pass the condition on to his or her children? These questions cannot be answered accurately without a correct diagnosis.

The majority of individuals with ED will ultimately be diagnosed or categorized correctly. There are always, however, those persons who don't fit neatly into one or another recognized category. There will

always be individuals with the label "ectodermal dysplasia-type unknown."

This situation is often extremely frustrating for families. It is important to recognize that some genetic conditions are unique. They result from a mutation or change in a gene that has occurred only in the one individual, and there is no precedent for the condition. Sometimes, one can fail to recognize a known ED because the affected individual has an unusual finding—a problem that is not generally considered part of the disorder. It is sometimes not possible to realize that the congenital heart disease in a child with Christ-Siemens-Touraine syndrome has nothing to do with his disorder but is simply the result of an unrelated occurrence. With less well defined syndromes, it might not be possible to ignore the presence of congenital heart disease and that feature might or might not be an important diagnostic point.

It is important to recognize that even within a specific diagnosis, not all affected individuals will have exactly the same problems to the same degree. None of us without ED is exactly alike; having ED doesn't protect us from differences either! The true nature of a specific condition is often difficult to know. The medical literature is always biased to more severely affected individuals and to those with unique or unusual findings. Every person with ED will need to seek his or her own level of comfort with a diagnosis or with the lack of a specific diagnosis.



Tooth Party Packets

Is your child getting a new set of dentures? Throw them a "Tooth Party"!

You can order everything you need to plan your own tooth party from the NFED. This packet includes games, activities, coloring sheets, and all the excitement you need to get your child excited about their new dentures. To order a Tooth Party Packet, send \$3 to NFED, P.O. Box 114, 410 E. Main, Mascoutah, IL 62258-0114 or call 618-566-2020.

From The Mailbox

NFED,

Hello, my name is Michele Small and I am from Selma, Alabama. My 10-year-old twins finally got their new teeth on April 14th.

They were born on December 29, 1998 on time. I did not realize that there was a problem until their teeth started to come in. I knew they looked different; they had two front teeth that were peg shaped and no bottom teeth. I also started to notice they could not tolerate the heat. They would start screaming when it got hot. Their aunt called me one day and told me she thinks they may have ED, because she knew a girl that had this condition.

I took them to see a craniofacial dentist in Birmingham, Alabama at the Children's Hospital. They were seen by a group of dentists and they told me that they had ED. I was relieved to finally find out that is what it was. My mom had tried to tell me for two years that they looked different, but I was not listening, because I just thought maybe they would get their teeth later.

I finally took them to a genetic clinic, and a group of genetic doctors looked at them and determined they had hypohidrotic ectodermal dysplasia. We started looking for a dentist, which took a while to find someone who would work on their mouth. I took them to the School Of Dentistry, in Birmingham, Alabama. They got braces first for their front teeth, and then when they got them off, they got dentures made by Dr. Wendy Auclair. They are so proud, and I am so proud. They look so pretty.

Sincerely,

Michele Small, Alabama

Dear Mary Kaye and Charley Richter,

Thank You. These two words on this plaque mean nothing if the person saying it isn't saying it with feeling and sincerity. These two words come from the bottom of my heart and with a tear of joy to my eye. Thank you, your foundation, and your entire staff and all the many others for all that they have done.

Until this year (that's when I learned about your foundation) I never knew much about my HED. My parents were giving the wrong information about what caused my birth defects. Only because little was known about Ectodermal Dysplasia back in the 1950s. and now thanks to Charley for being born we've all come this far.

Thank you Charley, Thank you Mary Kaye, Thank you Everyone,

Roy Pechtel "08", New York

Hi,

I am just writing to inform you of my good news. I read the article "Finding Money to Help Pay Your Conference Expenses" by Beth Pond, and checked into the Developmental Disabilities in Utah, where we live. It is good for others to know about the resource that is out there. When they called me, at the hospital (Bryce just had emergency appendectomy), last Friday to let me know of my award they were almost as excited as me! I was hoping to get \$500, but was very shocked that they granted me the entire request (\$1,200). They are interested in learning more about the disease. I plan to do a newsletter sort of thing with pictures of Bryce at the conference and what we did, etc.

Thank you for all that you do.

Penny, Utah

Can't You See, I Have ED

Don't worry about me when it's hot

Worry about me when it's not.

Don't worry about me being out in the rain

On a hot summer day it eases my pain.

Can I whistle?

You bet I can.

What can I eat?

Everything that's neat apples, candy, and yes even meat.

Can I play outside?

Sure, I can swim, swing, and even slide.

Can I play baseball?

If you got a bat, I got a ball.

Why does my hair look like cotton candy?

Because my family thinks I'm just dandy.

Can I work?

What do you need done?

How many other people are there like me?

Not very many and that suits me to a "T"

Don't look for all the things wrong with me,

Look at what I can really be.

I don't really know the tooth fairy

But I do know 2 angels named Mary Kaye

and Charley Richter.

Is it tough having Ectodermal Dysplasia?

NO SWEAT!! We like to take a BIG BITE out of LIFE.

Roy Pechtel '08'

Mary Kaye Richter Speaks at Launch of Mexican Association of Ectodermal Dysplasias



NFED's executive director, Mary K. Richter, spoke at the launch of the Mexican Association of Ectodermal Dysplasias "Mariana" (Asociacion Mexicana de Displasia Ectodermica) on April 30th in Toluca, Mexico. She wished the organization well and gave some advice to Karla Carmona Prantl who founded the organization. She and her husband, Alejandro, have a daughter, Mariana, who is affected by hypohidrotic ectodermal dysplasia and a son, Alejandro.

Mary Kaye said, "On behalf of more than 5,000 families in 70 countries, I want to congratulate Karla on this extraordinary day celebrating the creation of a support organization for families affected by ectodermal dysplasia syndromes throughout Mexico....the Asociacion Mexicana de Displasia Ectodermica...My wish for Karla is the courage to struggle on when times are difficult, the wisdom to know what to do and when, the patience and understanding to know that this is not a daylong journey but one of years and the support, assistance and love from her family, friends and anyone who can help her in any way possible. With all of that, success will be yours ...but more importantly individuals in Mexico affected by ectodermal dyplasia will live fuller, happier, healthier and more successful lives."

Check out the *new and improved* www.nfed.org

The NFED has completed a total redesign of our Web site, www.nfed.org. The look is brighter and the overall design makes it easy to navigate. We can still take secure donations through the website. Check out the marketplace to order all your NFED merchandise. All NFED families can visit the "member only" section to download publications and medical articles about ED that have appeared in previous editions of The EDucator. **Simply type in the username nfed and the password smile to access this page.**

If you are an AOL subscriber, please include your phone number in any e-mails that you send to the NFED office. Because of spam issues, AOL will not allow the NFED server to e-mail AOL addresses.

Calendar of Events

July 18

Board of Directors Meeting

July 23

Family Support Network Liaison Training
Coralville, Iowa

July 24-26

National Family Conference
Coralville, Iowa

July 24

Professional Symposium
University of Iowa College of Dentistry

July 24

Grand Rounds
University of Iowa Department of Dermatology

July 24

Scientific Advisory Board Meeting

August 9

Fourth Annual Rally for Ally
Hosted by the Kelso Family
Vienna, VA

August 30

Swim 4 Sweat by James Paisley
Fundraiser to Benefit the NFED
Hawaii

September 6

14th Annual Bruno's Golf Outing for NFED
Hosted by the Swierczewski Family
Blue Island, Illinois

October 29

8th Annual Halloween Bash
New York City, NY

November 7-8

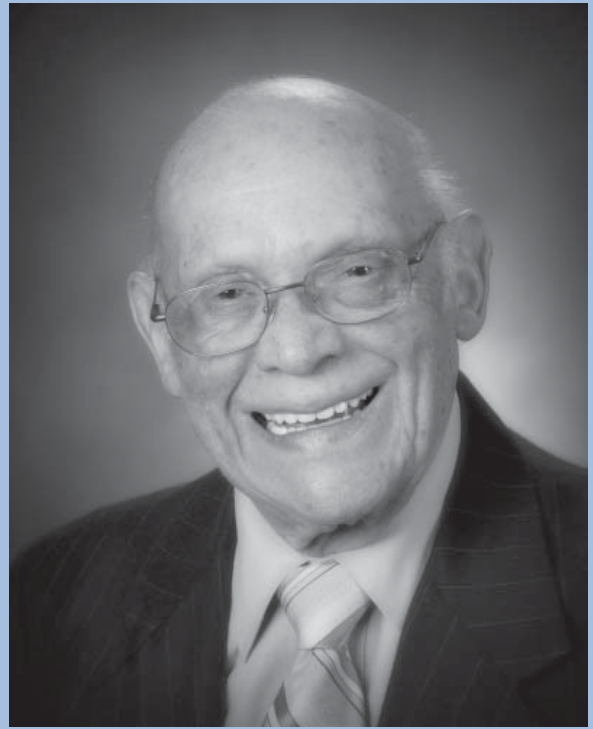
Board of Directors Retreat and Meeting

November 15

Regional Family Conference
Seattle, Washington area
More information coming soon.

We Salute Joe Barone of Pennsylvania and his Billion Dollar Smile.

The Billion Dollar Smile celebrates individuals affected by an ED syndrome who have recently completed dental work, received dentures or who are finding success with their dentures. If you would like to show off a Billion Dollar Smile, send a photograph to the NFED office and share your story.



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