

The 29th Annual National Foundation for Ectodermal Dysplasias National Family Conference



July 22-24, 2010 Cheyenne Mountain Resort Colorado Springs, Colorado

Change Your Life at the 29th Annual National Foundation for Ectodermal Dysplasias National Family Conference, which will take place Thursday, July 22, through Saturday, July 24, in beautiful Colorado Springs, Colorado.

The Conference is for people of all ages who are affected by ectodermal dysplasias or care about someone who is affected by ectodermal dysplasia. It will provide you with the information you need—the latest medical and research updates—to better understand ectodermal dysplasias. You and your family will benefit in many ways:

- Learn you are not alone.
- Learn from stimulating discussions, medical, dental and research updates.
- Share personal connections with others who understand.
- Meet others to exchange ideas, support and advice.
- Gain knowledge of helpful products and resources.
- Participate in research to advance our understanding of the ectodermal dysplasias.

How to Register

Read the registration instructions carefully. Return your completed registration form and payment to the NFED by June 15, 2010.

NFED
P.O. Box 114, 410 East Main St.
Mascoutah, IL 62258-0114 USA

Upon receipt of your completed registration, the NFED will send you a confirmation packet verifying your registration.

Registration Fees

The Registration fee includes your sleeping accommodations (and all taxes, services charges and the facility fee) for Thursday, July 22nd and Friday, July 23rd; dinner on Thursday evening; breakfast, lunch and dinner on Friday; and breakfast and lunch on Saturday; all conference materials; clinical consults; workshops; general sessions and all Kids' Camp activities. All family members staying at the Cheyenne Mountain Resort and participating in conference activities must register for the conference.

Single Occupancy Adult - \$550

Double Occupancy Adult
(includes 2 adults) - \$760

Additional Child (age 4 and under) - FREE

Additional Child (age 5-12) - \$70

Additional Adult (age 13 and up) - \$150

When the NFED receives your registration, we will make your reservations for your sleeping accommodations (based on your registration) for the nights of Thursday, July 22 and Friday, July 23. If you wish to arrive early or stay additional nights you will need to book them by calling the Cheyenne Mountain Resort directly at 800-428-8886. Please tell them that you have already registered for the NFED conference through the NFED. Room reservations before or after July 22-23 are \$184 per night for single or double rooms.

If you would like to attend the conference but will not be staying at the Cheyenne Mountain Resort, the cost is \$175 for adults (age 13 and up), \$100 for children (birth to age 12).

Cancellations

Cancellations and refund requests must be made to the NFED by June 15, 2010. No refunds will be issued after June 15, 2010.

Resort Details

Cheyenne Mountain Resort
3225 Broadmoor Valley Road
Colorado Springs, CO 80906
Phone - 800-428-8886

The conference will be held at the Cheyenne Mountain Resort (www.cheyennemountain.com/). The Resort's on-site recreational

facilities include an 18-hole Pete Dye championship golf course, 18 tennis courts (six indoor), three heated swimming pools (one indoor), two Jacuzzis, squash and racquetball courts, and a fully-equipped fitness center, massage and spa facilities, and mountain bike rentals. Water sports on the 35-acre recreational lake include sailing, paddleboats and fishing.

Directions

The Cheyenne Mountain Resort is only 15 minutes from the Colorado Springs Airport and 70 minutes from Denver. Please visit http://www.cheyennemountain.com/about_us/our_location.asp to download directions to the Cheyenne Mountain Resort.

Ground Transportation

Transportation (provided by the resort) from Colorado Springs Airport:

- Round Trip Shuttle Service: Approximately \$30 roundtrip per person
- One Way Shuttle Service: Approximately \$18 per person one way

Children 12 and under are FREE .

Please schedule your shuttle arrivals by calling (in advance) the Cheyenne Mountain Resort at 800-428-8886. Departures are scheduled on the hour, every hour starting at 5 a.m.

Taxi Service: Approximately \$25 one way

Attire

Casual attire is appropriate for the entire conference. Please dress your children for play. Conference rooms tend to be chilly. Please plan accordingly.

Kids' Camp

Thursday, July 22 10:30 a.m. - 12 p.m.
12:30 - 5:30 p.m.
Friday, July 23 12:30 - 5:30 p.m.
Saturday, July 24 8:30 - 11:30 a.m.
12:30 - 3:30 p.m.

To support children affected by ectodermal dysplasias and offer programs that nurture their self-esteem, Kids' Camp and the teen program will be held at the hotel while parents attend sessions. Educational and social programs for the affected children and their siblings are an integral part of the conference. Each day, the children enjoy activities, entertainment, educational programs, and refreshments. Garen and Susan Gouveia, the owners of Corporate Kids Events (CKE), are carefully planning camp activities for ages birth-18. Support arises spontaneously as the children

interact with others who are affected by ectodermal dysplasias, as well as their siblings. Arts and activities are interspersed throughout the weekend as part of this support program.

To ensure their safety, children who participate in Kids' Camp will be photographed initially with their parent or guardian. Only those adults who appear in the photo with the child will be able to sign-out the child from camp. CKE has organized and managed camps for children of all ages for more than 21 years. All CKE counselors are certified in CPR and first aid and take part in an extensive training program. They are fingerprinted and background checked. Parents will be required to complete and return permission and emergency consent forms for each child who participates. Upon receipt of your completed registration, the NFED will send a conference confirmation packet. Kids' Camp and teen program is available at no additional cost for children who are 18 years of age and younger.

Kids' Camp T-shirts

Pre-order souvenir T-shirts for your children are available. The T-shirts will be California blue and will feature the NFED Kids' Camp logo. They cost \$8 each.

Talent Show

Bring your guitar, tell your best joke, or sing your favorite song. We'd love to showcase your talent in our 9th Annual Talent Show. The Show will be on Friday night and is open to all ages. All acts must be limited to three minutes. In order to give everyone the chance to perform, we will only allow one act per person or group. We will have a keyboard and CD player. Plan to bring any other props, costumes or instruments you need for your performance. If you have questions, contact Jodi at the NFED office.

Chance Auction

You can participate in our 7th Annual Chance Auction on Friday morning. Families reported having a great time at last year's auction, which raised more than \$4,000 for the NFED!

Here's how it works. A Chance Auction is a hybrid between a raffle and an auction. Families are asked to bring and donate one new item (or more!) for the auction. You might consider asking a business in your area to donate the item that you bring. Please know that bringing an item is NOT mandatory.

Items can be anything of any value from a Webkinz or squirt bottle for a child to a basket

of bath products for an adult. We have people of all ages attending. You may consider bringing an item that is indicative of your area, such as maple syrup from New England.

Attendees can purchase 2-part numbered tickets and "bid" on a specific item by dropping one part of their ticket in the container placed next to the item. At the end of the Talent Show that evening, a winning ticket will be drawn for each item. Tickets will sell two for \$1.

Plan now for what items you can donate! There will be a table at registration on Thursday of the conference where you can submit your donated item(s).

Workshops and General Sessions

Led by members of the Scientific Advisory Council who are experts in their field. Topics include: dental care and prevention, dental implants, development and behavior issues, ears, nose, and throat care, emotional well-being, eye care, genetic testing, skin, hair, and nail care, syndrome specific sessions, insurance issues, and pediatric concerns.

New for 2010

The NFED has added more support sessions to the program for the 2010 National Family Conference. These sessions include sessions just for moms, dads, affected women and affected men.

An afternoon of special sessions has been planned for all the grandparents in attendance.

Clinical Research

This is your chance to take advantage of services for you or your child while helping researchers find answers to ectodermal dysplasias questions.

The following projects will be offered to aid researchers and the NFED in their quest to better understand the ectodermal dysplasias. Advance sign-up is required.

Oral Development/Dental Consults

Dr. Clark M. Stanford

This project will collect data on the status of oral development and dental treatment on patients affected by ectodermal dysplasias. Dentists will conduct the examinations and there will be time during the conference for individual consultations from a variety of dental specialists.

In a research collaboration planned for the 2010 Family Conference, Edimer Pharmaceuticals, Inc. will be working with the NFED to standardize the use of non-invasive sweat gland testing in patients with hypohidrotic ectodermal dysplasia (HED). If selected to be part of the study, families with an HED-affected son will be considered for genetic testing done by a nationally-recognized testing laboratory. Through this study, Edimer is seeking to validate a rapid skin-assessment technology that could be applied to monitoring of sweat gland improvement in future clinical trials. Edimer Pharmaceuticals is a biotechnology company located in Cambridge, MA, that is dedicated to bringing into clinical trials a new treatment for XLHED. If you have questions, contact Mary Fete at the NFED, 618-566-2020.

Conference Sponsorships and Partnerships

A wide range of conference sponsorship opportunities is available to corporations, associations and individuals. Sponsorships ensure that NFED can continue the quality programs and events our conferees have come to expect and enjoy. Registration fees cover only a small portion of the cost of the conference. Contact Harry Ford at harry@nfed.org or call him at 618-566-2020 for more information on how you can help.

Thursday, July 22, 2010

Kids' Camp

10:30 a.m. – 1 p.m.

(for families attending the New Family Session or the HED Natural History Research Participants Meeting)
Lunch will NOT be served.

12:30 p.m. – 5:30 p.m. (for all families)

Registration

9 a.m. – 11 a.m.

All attendees must begin here to receive your detailed conference registration materials. Name tags are required to attend all sessions and meal functions.

New Family Session

11 a.m. – 12 p.m.

Session for families new to the NFED or families who have never attended a conference.

HED Natural History Research Participants Meeting
12 - 1 p.m.

Lunch on your own

11 a.m. - 12:45 p.m.

Program At-A-Glance

Thursday, July 22nd

9 – 11 a.m.

11 a.m. - 12 p.m.

12 - 1 p.m.

11 a.m. – 12:45 p.m.

1 - 1:30 p.m.

1:30 - 3 p.m.

3 - 3:15 p.m.

3:15 - 5:15 p.m.

5:45 p.m.

7 - 10 p.m.

Registration

Session for first-time conference attendees

Session for families participating in the HED Natural History Research

Lunch on your own

Welcome

Syndrome Specific Workshops

Break

General Session

Dinner

Family Social

Friday, July 23rd

7 – 9 a.m.

8 a.m. – 12 p.m.

11:30 a.m. - 12:45 p.m.

1 – 2:30 p.m.

2:30 – 3:45 p.m.

2:30 - 5:15 p.m.

3:45 - 4 p.m.

4 - 5:15 p.m.

5:30 - 6:45 p.m.

7 p.m.

Breakfast

Research/Chance Auction Bidding

Lunch

General Session

Workshops

Grandparents Session

Break

Support Sessions

Dinner

Talent Show/Chance Auction Winners Announced

Saturday, July 24th

7:30 – 9 a.m.

9 a.m. - 10:15 a.m.

10:15 - 10:30 a.m.

10:30 - 11:45 a.m.

12 - 1:15 p.m.

1:15 - 3:30 p.m.

Breakfast

Workshops

Break

Workshops

Lunch

General Session

Finale

Welcome

1-1:30 p.m.

Master of Ceremonies Mr. Jack Kriz, a long-time friend, volunteer and NFED Board Member will welcome everyone and give a brief overview of the events that will take place throughout the weekend.

Syndrome Specific Sessions

1:30 – 3 p.m.

Participants will be broken out into groups based on what syndrome affects their family.

- Hay Wells/Rapp Hodgkin/
Ectrodactyly-Ectodermal Dysplasia
With Clefting (EEC)
- Hypohidrotic Ectodermal Dysplasia
(HED)
- Other Syndromes
- Unknown/No Diagnosis

Break

3 – 3:15 p.m.

General Session

3:15 – 5:15 p.m.

“Meet the Huxman Family” - Chris and Family Liaison, DeAnn Huxman, will share stories from their journey on raising their four young boys. Two of these adorable boys happen to be affected by ectrodactyly-ectodermal dysplasia with clefting.

Update on EDI200 and the Ectodermal Dysplasias International Registry by Ken Huttner and Neil Kirby from Edimer Pharmaceuticals, Inc. and Mary Fete from the NFED.

Dinner

5:45 p.m.

Family Social

7 - 10 p.m.

Join your NFED family as we play volleyball, swim, climb on the playground equipment, splash around the splash pad, roast marshmallows at the bonfire and enjoy each other's company.

Friday, July 23, 2010

Kids' Camp
12:30 – 5:30 p.m.

Breakfast
7 - 9 a.m.

Oral Development Research
HED Natural History Research

8 a.m. - 12 p.m.
Please sign up in advance. Appointment times will be given to you in your conference registration packet.

Chance Auction Bidding

8 a.m. - 12 p.m.
Attendees can purchase 2-part numbered tickets and "bid" on a specific item by dropping one part of their ticket in the container placed next to the item. Winners will be announced at the Talent Show.

Dermatology Mini Sessions

8:30 – 9 a.m. Eczema
9 – 9:30 a.m. Hair
9:30 – 10 a.m. Nails
10 – 10:30 a.m. Sweat

Lunch
11:30 a.m. – 12:45 p.m.

General Session

1-2:30 p.m.
"Ask Chuck"--Chuck Richter, son of NFED Executive Director Mary Kay Richter, will give his insight on growing up affected by ectodermal dysplasia and with the NFED.

Genetics
Dr. Dorothy Grange

Workshops (choose 1)

2:30 – 3:45 p.m.
Dental Implants
Dr. Clark Stanford
This workshop includes an introduction to dental implants, a short history of dental implants, and a discussion of modern concepts of dental implant materials and designs. Questions concerning who should have dental implants, at what age should one consider having dental implants, and what are the risks and benefits of dental implants will be addressed.

Development and Behavior Issues
Dr. Timothy Fete and Dr. Margot Stein
Open forum to discuss concerns related to development and learning, school problems, and some behavior issues.

Skin, Hair, and Nail Care
Dr. Alanna Bree and Dr. Elaine Siegfried
Management techniques for eczema, rashes, dry skin and other hair and nail care issues associated with ectodermal dysplasias.

Grandparents Session

2:30 – 5:15 p.m.
Mary Kay Richter will moderate this session for grandparents or anyone who wants to learn more about the following topics:

- Dental Care—Dr. J. Timothy Wright
- Genetics—Dr. Kathy Grange
- NFED Services—Harry Ford
- Supporting your Family—Dr. Margot Stein

Break
3:45 - 4 p.m.

Support Sessions (choose 1)

4 – 5:15 p.m.
Peer-led support sessions just for affected women, affected men, moms, and dads

Dinner
5:30 - 6:45 p.m.

Talent Show / Chance Auction Winners
7 p.m.

Saturday, July 24, 2010

Kids' Camp
8:30 a.m. – 12 p.m.
12:45 – 3:30 p.m.

Breakfast
7:30 - 9 a.m.

Workshops (choose 1)

9-10:15 a.m.
Dental Care and Prevention
Dr. Timothy Wright
Oral health care issues excluding dental implants, i.e., first dentures, and restorations will be discussed.

Genetic Testing
Dr. Dorothy Grange
What genetic tests for the ectodermal dysplasias are available and how they are administered will be discussed.

Emotional Well Being
Dr. Margot Stein
This adult group will discuss issues raised by participants, with members sharing experiences and advice.

Pediatric Concerns
Dr. Timothy Fete

A parent-directed discussion of a range of general pediatric topics that may occur in ectodermal dysplasias affected children.

Break
10:15 - 10:30 a.m.

Workshops (choose 1)

10:30-11:45 a.m.
Ears, Nose, and Throat Care
Dr. Tim Fete
Nasal crusts, nose bleeds, sinus drainage, and remedies for moisturization of the nasal passages will be discussed.

Insurance Issues
Malinda Heuring
Discussion on getting medical insurance to cover dental aspects related to ectodermal dysplasias.

Eye Care
Dr. Richard Lewis
Lack of tears and vision complications related to ectodermal dysplasias will be discussed.

Effects of Ectodermal Dysplasias on the Entire Family Unit
Dr. Margot Stein
Children with chronic medical conditions are likely to have a significant effect on the entire family in terms of its individual members and as a unit. Unaffected children may sometimes feel neglected or less important than the affected sibling. Parents must balance a complex array of emotional, behavioral, and financial considerations not only for their children but for themselves as individuals and as a couple. This will be a discussion of the issues involved and strategies that others have found useful in managing such a complex situation successfully.

Lunch
12 - 1:15 p.m.

General Session

1:15 - 3:30 p.m.
NFED Research Update
Mary Fete, R.N., M.S.N. and Maranka Koster, Ph.D.

Raising Awareness and Funds for the NFED
Jodi Edgar Reinhardt, Carol Agne, Harry Ford

This interactive session will give you ideas on how you can make a difference on behalf of the ectodermal dysplasias community. Simple, practical and fun ways to raise awareness and funds in your own community will be discussed.

"FINALE"

Registration Form

NFED National Family Conference

July 22-24, 2010

Colorado Springs, Colorado

Family Name _____ Address _____
Please Type or Print

City _____ State _____ Postal Code _____

Country _____ Phone _____

E-Mail Address _____

I DO NOT give permission to the NFED to distribute my name and contact information to the other conference attendees.

Please indicate the type of ectodermal dysplasias that affects your family _____

Please list any special dietary restrictions _____
(We will do our best to accommodate these requests.)

	Names of Persons Attending	Age	Affected by ectodermal dysplasias		
<input type="checkbox"/> Single Occupancy Adult	_____	_____	<input type="checkbox"/>	@\$550	= _____
<input type="checkbox"/> Double Occupancy Adult	_____	_____	<input type="checkbox"/>	@\$760	= _____
<input type="checkbox"/> Additional Child (age 4 and under)	_____	_____	<input type="checkbox"/>	@FREE	
	_____	_____	<input type="checkbox"/>	@FREE	
	_____	_____	<input type="checkbox"/>	@FREE	
	_____	_____	<input type="checkbox"/>	@FREE	= _____
<input type="checkbox"/> Additional Child (age 5-12)	_____	_____	<input type="checkbox"/>	@\$70	
	_____	_____	<input type="checkbox"/>	@\$70	
	_____	_____	<input type="checkbox"/>	@\$70	= _____
<input type="checkbox"/> Additional Adult (age 13 and up)	_____	_____	<input type="checkbox"/>	@\$150	
	_____	_____	<input type="checkbox"/>	@\$150	
	_____	_____	<input type="checkbox"/>	@\$150	= _____
<input type="checkbox"/> Adult (not staying at the resort)	_____	_____	<input type="checkbox"/>	@\$175	
	_____	_____	<input type="checkbox"/>	@\$175	= _____
<input type="checkbox"/> Child (age 12 and under) (not staying at the resort)	_____	_____	<input type="checkbox"/>	@\$100	
	_____	_____	<input type="checkbox"/>	@\$100	
	_____	_____	<input type="checkbox"/>	@\$100	
	_____	_____	<input type="checkbox"/>	@\$100	= _____
<input type="checkbox"/> I would like to purchase _____ Kids' Camp T-shirts.				@\$8	= _____
_____ Youth X-Large (18-20) _____ Youth Large (14-16) _____ Youth Medium (10-12) _____ Youth Small (6-8) _____ Youth X-small (2-4)					

We cannot attend but would like to donate to help defray expenses for the conference. _____

TOTAL ENCLOSED _____

Method of Payment (check one) Bank Check Master Card Visa American Express Discover

Credit Card Number _____ Exp. Date _____

Print Cardholder's Name as on Credit Card _____

Signature _____

*(Please
complete
other
side.)*

I /We plan to perform in the Talent Show on Fri. evening. Name(s) _____
List Your Talent (play instrument/sing/read poem/skit/etc.) _____

Photo and Video Permission Release

I hereby give my permission to the NFED to use and distribute (including but not limited to use in newsletters, guides, appeals, Web site, and reports), at their discretion, any photographs or video tapes taken at the 2010 NFED National Family Conference in which I or members of my family may be a part.

Signature _____ Date _____

In consideration of the acceptance of this registration entry, I/we the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

Signature _____ Date _____

Clinical Research

This is your chance to take advantage of services for you or your child while helping researchers find answers to ectodermal dysplasias questions. We must schedule appointments for the clinical research projects and the consults. To do so, we must know if you plan to participate. If you have questions, contact Mary Fete at the NFED, 618-566-2020. The following projects will be offered to aid researchers and the NFED in their quest to better understand the ectodermal dysplasias. Sign-up is required.

Oral Development/Dental Consults

Yes , I will participate. Please sign me up for Oral Development.

Name _____

Name _____

Name _____

Name _____

Name _____

XLHED Natural History Research

Yes , I will participate. Please sign me up for the HED Natural History Research.

Name _____

Name _____

Name _____

Name _____

Name _____

Please return registration fees with your completed form to
NFED Family Conference
410 East Main St., P.O. Box 114
Mascoutah, IL 62258-0114

Registration Deadline

June 15, 2010

Questions? Call the NFED at 618-566-2020.