

# The EDucator

Newsletter of the National Foundation for Ectodermal Dysplasias

Winter 2010

## As I See It...

By Mary Kaye Richter

We've taken a bit of a departure from our usual practice with this issue of *The EDucator*. What you have received is our annual research report, *Connecting Lives*, with an abbreviated version of our typical newsletter included. This has been done to eliminate not only a mailing but some of the printing costs associated with producing materials like these. *The Educator* will provide information to which you should pay special attention like that related to the Education Scholarship Program or this summer's National Family Conference. There are deadlines associated with both which you cannot miss. You will enjoy both segments of the mailing. As I see it, this is a good way to moderate our costs while maximizing the amount of information being shared. As you see it, I hope you will tell your friends and family about the positive impact of NFED research efforts. Meanwhile, we give special thanks for the individuals who serve on our Scientific Advisory Council and all they do to make our research efforts meaningful.

By the time you receive this, the holidays will be behind us and we'll all be looking forward to the arrival of spring. One thing that I hope you do during this time is to give serious thought to joining us in Colorado Springs in July for the National Family Conference. On first blush, the costs may seem higher to you but keep in mind that we will be staying at a hotel for a price that includes not only your room but all of the conference costs and your meals. You'll also have access to some marvelous outdoor activities that children and those young at heart are really going to enjoy. Everyone we know who has stayed there has offered nothing but rave reviews. This will be an experience you should not miss!

## 2010 Topical Conference Call Line-up

All calls will take place on Tuesdays at 5 p.m. Pacific / 6 p.m. Mountain / 7 p.m. Central / 8 p.m. Eastern

*Recordings will be available for all calls.*

### January 5 – EDI200 (X-Linked HED Treatment) and NFED Patient Registry

*Presenters – Neil Kirby, Ph.D., CEO, Edimer Pharmaceuticals and Mary Fete, R.N., M.S.N., NFED Director of Research*

Edimer's vision is to improve the health and quality of life of future generations affected by X-linked Hypohidrotic Ectodermal Dysplasia (XLHED). Their goal is to make EDI200 (XLHED treatment) available to all families affected by XLHED.

The NFED is establishing an Ectodermal Dysplasias Patient Registry for all individuals affected by any ectodermal dysplasia. The goal of the Patient Registry is to facilitate communication between affected individuals, clinicians involved in their treatment and scientists who strive to advance

the research on ectodermal dysplasias.

To register, email Kelley at Kelley@nfed.org or on the NFED Web site.

### March 2 – Fundraising

*Presenters – Carol Agne, NFED Director of Development, and NFED Families*

Families share their experiences with fundraising. The NFED Director of Development will explain how the NFED helps lend support to the family hosting the event and answer questions.

### May 4 – Ear, Nose and Throat Concerns

### July 6 - School Accommodation Plans

### September 7 – The Big Three: Skin, Hair and Nails

### November 2 – Chat with Mary Kaye Richter

A full schedule of calls along with presenters and topic descriptions can be found at [www.nfed.org](http://www.nfed.org).



## College Scholarships Available

### Apply Now for a 2010-2011 Scholarship

The NFED believes in helping our members achieve their full potential. As a result, the Foundation will again offer education scholarships to individuals affected by ectodermal dysplasia through the L. Marie Heard Education Scholarship Program. Scholarships are awarded to students attending universities, colleges, junior colleges or trade school for the 2010-2011 academic year.

Applications were mailed in December to individuals living in the United States who are between the ages of 17 and 22. If you did not receive an application and want to apply, contact Kelley at Kelley@nfed.org or 618-566-2020. You can also download the application from our Web site ([www.NFED.org](http://www.NFED.org)).

If you live outside the United States and would like to submit an application, please contact Kelley Atchison at Kelley@nfed.org. **Applications must be postmarked no later than Friday, March 12.**

### Are you interested in speaking with someone in your area? Contact your liaison today.

Julie Claeys - Michigan, [jclaeys@charter.net](mailto:jclaeys@charter.net); DeAnn Huxman - Kansas, [deannnfedliaison@yahoo.com](mailto:deannnfedliaison@yahoo.com); Janet Johnson - Utah, [tayalnes@hotmail.com](mailto:tayalnes@hotmail.com); Jack Kriz - Oregon, [jacknfed@verizon.net](mailto:jacknfed@verizon.net); Dee Dee Olsen - New York, [dgoosw@verizon.net](mailto:dgoosw@verizon.net); Beth Pond - Massachusetts, [pondboys@charter.net](mailto:pondboys@charter.net); Jill Radley - Arizona, [JillNFEDLiaison@live.com](mailto:JillNFEDLiaison@live.com); Lauren Tomberlin - Florida, [laurenliaisonnfed@yahoo.com](mailto:laurenliaisonnfed@yahoo.com); Russ Wilson - Mississippi, [Wilson\\_russ@comcast.net](mailto:Wilson_russ@comcast.net).



National Foundation for  
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Dysplasias**

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The Educator  
Newsletter of the  
National Foundation for  
Ectodermal Dysplasias

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Founded in Mascoutah, Illinois, in 1981, the NFED is a tax-exempt, not-for-profit organization pursuant to Section 501(c)3 of the Internal Revenue Code.

## Ectodermal Dysplasias Awareness Month

One month out of the year, we ask our members to host awareness campaigns and fundraising events to raise money and educate the public about the ectodermal dysplasias. Ectodermal Dysplasias Awareness Month will be celebrated in February 2010. Bring awareness to your community by becoming the educating voice for you, your family and your loved ones.

### Here's How You Can Help

- Contact your local newspaper and tell them about Ectodermal Dysplasias Awareness Month. Share your personal story or let them know you will be hosting a fundraising event.
- The NFED has a brand new general brochure on the ectodermal dysplasias. Distribute to pediatricians, dermatologists and dentists in your area and educate them about ectodermal dysplasias.
- Purchase a copy of the children's storybook, Lionel Learns What Matters Most and donate it to your local school's library. Or, read it to your child's class.
- Sell or Hand Out Wristbands - The NFED has "Don't Sweat It" wristbands for sale. They sell for just \$2 and are a great way to raise awareness and funds for the NFED. Plan how you can sell the wristbands. They come in both adult and child sizes. We can provide you with a fact sheet on ectodermal dysplasias to distribute with them. Already having a fundraiser? You can sell the wristbands at your event. You could put them in a bowl and ask

## Let's Plan A Party Together!

Last year, Shana Frankel and Ruth Geismar hosted a Cinco de Mayo party as a fundraiser for the NFED, and raised more than \$5,000 with minimal planning! It was a simple happy hour affair with a few fundraising twists. We have been inspired by their success and want to ask you to help us "franchise" the concept. So, we issue this challenge to all families and friends of the NFED: Plan your local, personalized version of a "Cinco de Mayo" party—or any kind of party, as long as it is held during the week of May 5, 2010—and set a fundraising goal. Please sign up with the attached form and share your ideas about hosting a successful Cinco de Mayo Fundraiser. We would like to have fundraising parties all over the United States and all over the world – spreading awareness and raising money for the NFED during the same week! Return this form to Carol by March 31 to join the fun! Or call. Or email. She will give you ideas and tips on how to make it a success.

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ Email \_\_\_\_\_

Party Idea \_\_\_\_\_

Fundraising Goal \_\_\_\_\_

Comments:

friends and family to make a donation for them.

- Send an Email to all of your contacts explaining to them what ectodermal dysplasia is and how it affects your family. Ask them to go to the NFED Web site to make a donation in honor of you or your child for Ectodermal Dysplasias Awareness Month.

- Download a free, full color 8.5 x 11 Ectodermal Dysplasia Informational flyer. Post copies at your school, church, office, library, grocery store other public places.

If you have never done anything like this and are not sure where to start, please contact us at the NFED office. We have an easy to follow manual that we can send to you that is filled with great ideas and step by step instructions for planning a fundraiser or contacting the media. It's titled, You Can Do It, Too! A Guide to Raising Funds and Making Friends for the National Foundation for Ectodermal Dysplasias. Contact Jodi Edgar Reinhardt on the NFED staff at 618-566-2020 or [Jodi@nfed.org](mailto:Jodi@nfed.org) with your mailing address to receive a free copy. We are happy to help you with your plans and ideas.

Let the NFED know what you did to celebrate Awareness Month and we'll include your activities in the next issue of The Educator.

# Join Us In Beautiful Colorado Springs, Colorado For The 2010 National Family Conference! July 22-24, 2010

The NFED is headed to Colorado Springs, Colorado! Start saving your pennies and put July 22-24, 2010 on your calendar.

## If you attend this Family Conference, you will benefit from:

- Stimulating discussions, medical, dental and research updates.
- Sharing personal connections with other who understand.
- Meeting others to exchange ideas, support and advice.
- Gaining knowledge of helpful products and resources.
- Participating in research to advance our understanding of the ectodermal dysplasias.

## Kids' Camp

Special programs for the affected children and their siblings are an integral part of the conference. Each day, the children enjoy activities, entertainment, and refreshments.

## Conference Location

The conference will be held at the Cheyenne Mountain Resort ([www.cheyennemountain.com/](http://www.cheyennemountain.com/)). The Cheyenne Mountain Resort is only 15 minutes from the Colorado Springs Airport and 70 minutes from Denver. 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.

## Scholarships Available

The NFED is honored to offer scholarships to families to help them attend the conference. These scholarships include one sleeping room per family (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; breakfast and lunch on Saturday; all conference materials, clinical consults, workshops, general sessions and all Kids' Camp activities. Preference will be given to families who have not previously attended a National Family Conference, but all families in need are encouraged to apply. To be eligible, please fill out and return the application on the next page of *The EDucator* to the NFED office by March 12, 2010.

Our 2009 conference in Williamsburg, Virginia was the best attended in our 28-year history, with 400 people in attendance. We anticipate that next summer's conference will be even better. **We hope to see you there!**

## Join Us March 13th in Columbus, Ohio for a Regional Family Conference

The NFED is planning a Regional Family Conference on Saturday, March 13, in Columbus, Ohio. The event will be held at the Hyatt Regency Columbus and will take place from 10 a.m. – 4 p.m. Registration forms will be mailed to all families in Ohio and surrounding states and information will be posted on our Web site in January. Regional Family Conferences are a great way to meet other ectodermal dysplasia-affected families from your area, learn about the most up-to-date research and treatment on the ectodermal dysplasias and get your questions answered. Join us in Columbus and bring your children as they will have a blast in Kids' Camp.

## Conference Cost

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.

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

Room reservations for before or after July 22-23 are \$184 per night for single or double rooms.

## Make Your Own Luck by Making A Difference!

Even if you don't feel like this is your lucky day, you have an opportunity to make it one for the NFED and the more than 5,600 individuals affected by ectodermal dysplasias that we serve. Volunteer to sell raffle tickets for the annual Raffle in support of our families. If you are looking for an easy way to help support the NFED, this is it.

Funds raised from the Raffle support services such as education scholarships, Family Conference scholarships, Regional and National Family Conferences among so many others. The Raffle takes place during February as part of Ectodermal Dysplasias Awareness Month.

You can even be rewarded for your efforts. The family that sells the 1st place ticket will receive \$100. In addition, the family that sells the most tickets will receive a \$300 voucher to be used towards National Family Conference fees in 2010 or 2011.

Tickets sell for only \$1 each, and the drawing will be held on March 11th. Please join our families in selling tickets during Ectodermal Dysplasias Awareness Month in February - that way, we can all be winners. Plan now to participate and watch for the tickets to arrive in your mail in January.

Contact Jackie at 618-566-2020 or [jackie@nfed.org](mailto:jackie@nfed.org) to request additional tickets.

### 2010 Ticket Prizes

1st Place - \$1,000

2nd Place - \$300

3rd Place - \$200

# National Foundation for Ectodermal Dysplasias

## 2010 National Family Conference Scholarship Application

Scholarships will include one sleeping room per family (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; breakfast and lunch on Saturday; all conference materials, clinical consults, workshops, general sessions and all Kids' Camp activities.

Name \_\_\_\_\_  
 Address \_\_\_\_\_ City \_\_\_\_\_  
 State \_\_\_\_\_ Postal Code \_\_\_\_\_ Country \_\_\_\_\_  
 Phone \_\_\_\_\_ E-Mail \_\_\_\_\_

Names of Persons Applying	Adult	Child (Age 0-12)	Age of each child	Affected by ectodermal dysplasia
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>

Type of ectodermal dysplasia your family is affected by \_\_\_\_\_

(We must have a client survey on file at the NFED office for each affected family member applying for a scholarship.)

Have you attended a Family Conference before? \_\_\_\_\_ Yes \_\_\_\_\_ No

Annual Family Income

_____ Under \$20,000	_____ \$51,000-60,000
_____ \$21,000-30,000	_____ \$61,000-75,000
_____ \$31,000-40,000	_____ Over \$75,000
_____ \$41,000-50,000	

**Why do you want to attend a Family Conference? (Use additional paper if necessary.)**

\_\_\_\_\_

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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Please return this form to the NFED office no later than March 12, 2010.**  
 National Foundation for Ectodermal Dysplasias, P.O. Box 114, 410 E. Main Street  
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