



Stay Informed. Stay Connected.  
The XLHED Network.

### XLHED Network: Visit us at the NFED Conference

Once again, we are pleased to be participating in the National Foundation for Ectodermal Dysplasias (NFED) annual family conference 21–23 July 2011 in O’Fallon, Illinois. We are looking forward to re–connecting with many members of the XLHED community. Our commitment to developing a potential treatment option remains strong, and we will be sharing an update on our research progress at the conference.

**[Kenneth Huttner, M.D., Ph.D., Senior Director of Clinical Research for Edimer](#)** will be presenting “Results from the Hypohidrotic Ectodermal Dysplasia (HED) Study at the **[NFED](#)** 2010 Family Conference: Answers, Questions and Next Steps Towards a Clinical Trial.”

Dr. Huttner’s presentation will be part of the HED breakout session on 21 July from 2 – 3:30 p.m. If you are attending the conference, please join Dr. Huttner as he discusses:

- Accomplishments from the past year, including findings from last year’s study at the NFED family conference.
- A preview of upcoming clinical research for 2011 and 2012.
- How you can become involved in advancing the understanding of XLHED and join the effort towards a treatment.

We hope you will stop by our table where **[Edimer](#)** representatives will be available to answer questions you may have about Edimer and our current research. We will also be happy to discuss how you can become involved in advancing a treatment for XLHED, and how to connect with us through **[Facebook](#)**<sup>®</sup>.

**[Our team members](#)** will also be on hand at the 30<sup>th</sup> Anniversary Gala and Tribute to Mary Kaye Richter, which will be held during the evening of 20 July in St. Louis, Missouri. Not only are we proud to be attending this celebration, but we are excited to have the opportunity to serve as an event sponsor.

## Voices From Our Community Members

Members of the XLHED Community play an important role in helping us to advance research. We welcome your thoughts and stories. Julie Claeys and Beth Pond share their families’ experience participating in a natural history study at the University of California, San Francisco this past May below.

### *“We Left our Sweat Glands in San Francisco”*

We were so thrilled when we found out that we both had been asked to participate in the HED Research Study in San Francisco. We have both been very active with the NFED since the boys were little, and now we were asked to get involved with Edimer and their research studies. We feel blessed to have had the opportunity to actually help the Edimer group to further their research to develop a treatment for future generations born with HED.

Carver, Nolan and Philip were just a few amongst many boys and young men who participated. The overall purpose of the study was to learn more about HED and to help identify treatment opportunities. The tests and procedures were quick, non–invasive and very interesting. The sweat gland count and sweat measurement tests were the most interesting to the boys and confirmed what we had always thought . . . no sweat glands! They also had a few other tests done including a hair count, 3D imaging of teeth and a dental exam. All and all it was quick and painless.

How exciting for our children to be part of what will be life changing for future generations. To meet new families and to see many old friends whom have been a part of the NFED and are living a life with the same struggles as our sons gave comfort and wisdom to us all as we confided in each other. It was wonderful to watch the guys hang–out and get to know each other with such ease and enjoyment. It was an experience we will never forget and I know it gave our sons more confidence about themselves and it taught them that they are active participants in aiding research to find a cure.

Thank you for your ongoing support and membership in the Network. We hope to see you at the conference.

Sincerely,  
Edimer Pharmaceuticals

P.S. Help advance XLHED research today by sharing the XLHED Network: [www.XLHEDnetwork.com](http://www.XLHEDnetwork.com).  
The more people get involved, the better equipped we are as a community to advance potential treatment options.

If you no longer wish to receive information about the XLHED Network, please click the following link: [xlhed@bbkworldwide.com](mailto:xlhed@bbkworldwide.com).

