


**Stay Informed. Stay Connected.**  
**The XLHED Network.**
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**Research Spotlight: Q&A with Neil Kirby, President and CEO, Edimer Pharmaceuticals**


At Edimer, we are proud to be led by a team of seasoned biotechnology industry veterans with experience in drug development, and complemented by a strong network of world-class clinical and scientific advisors. President and CEO Neil Kirby, Ph.D., recently discussed the team's current efforts and dedication to advancing a potential treatment option for XLHED. We are pleased to share a few highlights with our XLHED Network members.

**Can you discuss Edimer's commitment to developing a potential treatment for XLHED?**

We are trying to make a difference in the lives of patients with XLHED and their families, and we are dedicated to making this happen. We have a tremendous amount of focus and commitment to developing EDI200 as a potential treatment option for XLHED. This is what we are doing – this is our lives.

**Rare genetic diseases pose many research challenges. What is the biggest challenge you and your team face?**

The challenges that we face are nowhere close to the challenges that XLHED patients face in life. We just keep that in mind. We are trying to do something quite spectacular for these patients. They don't lead an easy life so it shouldn't be easy for us to develop this drug, and it won't be. The biggest hurdle will be identifying patients, because EDI200 will be administered early in life, and it's a rare genetic disorder. We want to make sure that when EDI200 is available for clinical trials, that we are able to inform patients about the opportunity. We will continue to rely upon the support of the XLHED community and patient associations around the world to help us in this effort.

**What is EDI200?**

EDI200 is the investigational therapeutic protein that we are developing as a potential treatment option for XLHED. It is a genetically engineered version of the protein that is missing in patients with XLHED. EDI200 is derived from animal cells, but the protein itself is synthetic in the fact that it is made in an animal cell and not a human cell – but it has the human sequence. It's what we would term "fully humanized." It will bind to a receptor in the same way as the naturally occurring protein would bind to a receptor.

### **Has EDI200 demonstrated effectiveness in preliminary research?**

Yes, it has. We have studied it in two animal models – a dog model and a mouse model. And in both of those species with the equivalent of XLHED, EDI200 has been shown to correct the developmental disorder that we would normally see in those animals. It's remarkable in that a relatively short course of therapy in the dog and the mouse models – a week or two weeks of therapy, administered during the development phase – actually corrects the disorder for the lifetime of the animal.

### **How important is the support of the XLHED community?**

I think that if the XLHED community is anything like the other disease communities I've worked in, they have a long-term vision of helping other people. Our relationship with patients and families will become more and more important as we get closer to clinical trials, and we will need them to become advocates for us. To support this effort, we have created the XLHED Network ([www.XLHEDNetwork.com](http://www.XLHEDNetwork.com)) as a tool for sharing information. The Network benefits the entire XLHED community as it improves our understanding of XLHED and provides us with an opportunity to keep members informed of our research efforts. We actively encourage members of the Network to share it with family members and the medical community as a way to contribute to the effort.

### **Will Edimer be participating in any upcoming conferences?**

We will be among the sponsors of the National Foundation for Ectodermal Dysplasias' annual meeting. We will be sharing updates on our research progress, and we will be inviting attendees to stop by our table where we will be conducting a data collection study to help advance our understanding of XLHED.

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**In addition to the XLHED Network,  
stay connected with Edimer through Facebook.**

**"Like" [Edimer Pharmaceuticals](#) to see photos from recent events, stay up-to-date with Edimer's most recent news and articles, and keep tabs on conferences where you can meet and speak with members of Edimer's team.**

Thank you for your ongoing support and membership in the XLHED Network. As we work towards a potential treatment option, we welcome the opportunity to speak with you about your experience with XLHED. Please contact Ramsey Johnson or Tessa Lorenze directly. If you would like to learn more about Edimer's research efforts, go to [www.edimerpharma.com/press](http://www.edimerpharma.com/press).

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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)