Canadian
Ectodermal Dysplasia Syndromes
Association

Free fall dental management WEBINAR

Meet with **Dr. Marshall M. Freilich, BSc, DDS, MSc, FRCD(C)**, Coordinator of Oral and Maxillofacial Surgery, Holland Bloorview Kids Rehabilitation Hospital, Staff Oral and Maxillofacial Surgeon, Humber River Regional Hospital and The Hospital for Sick Children, and his colleague, **Dr. Robert Carmichael, BSc, DMD, MSc, FRCDC**, Certified Specialist in Prosthodontics.

This is an amazing opportunity for you to ask questions of the experts directly – but we need you to register with us for meeting arrangements. You can also send your questions or queries in advance and we will provide them to Dr. Freilich and Dr. Carmichael!

Attendees will be provided with a toll-free number and an access code. You will simply have to dial in, to connect to two renowned experts. Please contact Meghan Howard as soon as possible to register for this great event; at meghan @ectodermaldysplasia.ca.

Date and time TBA.

Medical expertise!

Do you have a family doctor, dentist, nutritionist, dermatologist, surgeon, allergist, geneticist or other medical expert who has been particularly helpful in treating ectodermal dysplasias?

We are building our directory and are looking for experts. CEDSA will approach them professionally to ask if they would be interested in participating. Send us your suggestions at meghan@ectodermaldysplasia.ca.

Straumann event SUCCESS!

Almost 200 dental implantologists and periodontal specialists gathered at Polsen Pier, Toronto on September 21 to support CEDSA as part of the ITI Congress.

Tickets were $50 per person, and funds were also raised through the Silent Auction which featured high-quality items like signed guitars and original musical score sheets

The food, entertainment and support were all fantastic. A special thanks to organizers Carolyn Cox, Kelly Binns and Straumann president Alain Laroche for inviting CEDSA to the event and for raising money to help Canadians and their families with ectodermal dyplasias.

A very special thank you to the many specialists who have generously offered their time, expertise and skills to help some of our members.

Total funds raised are still to come, but the opportunity and support of CEDSA was overwhelming. Thank you Straumann!

Caricature artists were a highlight of the evening – pictured here are executive director Meghan Howard, her husband Ian and board member Michelle Rickard.

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Research on the fast track!

Edimer Pharmaceuticals, a U.S. biotechnology company focused on developing an innovative therapy for the rare genetic disorder X-linked Hypohidrotic Ectodermal Dysplasia (XLHED), has recently announced it has received Fast Track designation from the U.S. Food and Drug Administration (FDA) for EDI200. EDI200 is the company's novel, proprietary, recombinant protein. As many of us know, XLHED is one of the many ectodermal dysplasia syndromes. XLHED has a range of symptoms including, lack of sweat glands, poor temperature control, respiratory problems, and hair and tooth malformations.

Edimer is a supporter of the Canadian Ectodermal Dysplasia Syndromes Association, and its work is one of the most exciting for those of us waiting for a medical breakthrough in the treatment of ectodermal dysplasias.

The Fast Track program of the FDA is a process designed to facilitate the development and expedite the review of new drugs that are intended to treat serious or life-threatening conditions and that demonstrate the potential to address unmet medical needs. A drug that receives Fast Track designation is eligible for more frequent meetings with FDA to discuss the drug's development plan and ensure the collection of appropriate data needed to support drug approval. In addition, it offers more frequent written correspondence from FDA about such things as the design of the proposed clinical trials. Fast Track-designated drugs typically qualify for priority review, which can further expedite the FDA review process.

"We are diligently working to develop EDI200 as the first treatment for XLHED and are delighted that the FDA recognizes the potential for this novel therapy to treat this serious, potentially life-threatening disorder," said Neil Kirby, PhD, president and chief executive officer of Edimer. "Correction of developmental abnormalities early in the life of XLHED-affected patients may provide clinically significant, life-long health benefits. We will continue to work collaboratively with clinical investigators, health authorities and patient advocacy groups around the world to develop EDI200."

"We are thrilled about Edimer's work, and commitment to finding a treatment for XLHED; this latest progress is fantastic news for all of us, around the world – the future for those with an ectodermal dysplasia syndrome just got a little brighter," said Meghan Howard, CEDSA executive director. "We strongly encourage our members to join the XLHED Network set up by Edimer to receive important research progress news and announcements, at www.edimerpharma.com."

About EDI200

EDI200 is an ectodysplasin-A (EDA-A1) replacement protein, representing the first of a new class of molecules rationally designed to correct a specific developmental disorder. EDI200 has been shown to bind specifically to the EDA-A1 receptor, activating the signaling pathways that lead to normal development. EDI200 has demonstrated substantial and durable efficacy in mouse and dog models of XLHED with notable reduction in mortality and morbidity.

About XLHED

XLHED (also known as Christ-Siemens-Touraine Syndrome) is a rare disorder of development resulting from genetic mutations in the ectodysplasin gene (EDA). Patients affected by XLHED are at risk for life-threatening hyperthermia based on their inability to regulate body temperature, and for clinically-significant pneumonias resulting from their abnormality in respiratory secretions. Cardinal signs and symptoms in XLHED include diminished/absent sweat, reduced and abnormal airway secretions, few and often misshapen teeth, and absent or early hair loss from face and scalp.

XLHED patients surviving infancy are predisposed to atopy presenting with eczema and asthma, chronic sinusitis, recurrent nose bleeds and dry eye complications. Almost uniformly, they require dental interventions including early prostheses and later implants. Their susceptibility to hyperthermia, facial appearance, abnormal dentition and hair loss may affect their normal participation in outdoor activities, sports and school attendance. Both medical and self-esteem issues are life-long in this disorder. As is generally true with X-linked inheritance, males are fully affected while females are variably affected.

About Edimer Pharmaceuticals

Edimer is a privately held biotechnology company based in Cambridge, Massachusetts, and dedicated to delivering a significant and durable improvement in the health and quality of life for future generations affected by XLHED.

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What's New and What's Coming!

- CEDSA is developing a database for medical doctors, dentists and implantologists who are familiar with the treatment of ectodermal dyplasias in their various areas of expertise.This will enable us to provide contact information to our supporters.

- We are looking into partnering with an organization that raises funds for wigs! We will keep you posted on any developments in this area.

- Our first dental webinar is being planned. Thank you to Dr. Freilich and Dr. Carmichael for generously donating their time and expertise. Make sure you register early to ensure a place on the call. It is your opportunity to ask questions directly of these dental experts.

- Our charitable status is grinding along. Next step will be our bylaws and we will keep supporters posted as new developments occur.

- We continue to connect with other ED syndrome associations around the world and to post information about their events, along with their newsletters, on the website. If you are travelling, or just interested in what is happening in other countries, explore this area of our website.

- Fundraising efforts continue. With each dollar raised we are able to implement new programming and resources. While we do have some corporate support, it is the donations of individuals such as yourselves that we are rely on. Thank you for your continued support.

- Finally, we are building a Members Forum on our website. We will send supporters the login information so you will have an opportunity to meet and talk to other families and individuals. The forum will be monitored for content, and your privacy at all times will be protected and respected.

Enjoy the fall colours and the cool weather – this is the season for those with an ED syndrome – sunny, cool and a great chance to enjoy the outdoors without overheating!

Supporter dues

Thank you to all our supporters for your continued commitment to CEDSA. Your $20 a month enables CEDSA to grow and build its programs for you and Canadians with ectodermal dysplasia syndromes.

Unfortunately, some of you have let your support lapse, and we ask you kindly to renew – an email blast with a request for renewal of your commitment will be sent this month.

Family in France seeking insight

If you are a Francophone, or bilingual, and would be willing to connect with another family, we need you! We have been contacted by a mother France – her daughter has anhidrotic ectodermal dysplasia and she is looking to speak / email with other families for advice, support and information. If you are interested, please contact us.

Board Meeting Notice

The board will be meeting by teleconference in October. If there are any issues, as supporters, that you would like to raise or have addressed or any programs you would like to see implemented, please let us know!