



Canadian
Ectodermal Dysplasia Syndromes
Association

Castleford Fishing Derby Donation

More than 750 ice fishing enthusiasts took to the ice in Castleford, Ontario on February 16, 2013 for the 8th Annual Charity Ice Fishing Derby. Along with thousands of dollars in cash and prizes, the Derby also raises money for three selected charities in Renfrew County each year. For the second year in a row, CEDSA was one of the chosen associations to receive the very generous contribution, along with Horton Recreation Centre and Community Living.

On March 21, Don Storie of the Castleford Charity Committee presented executive director and president of CEDSA Meghan Howard, and her son Jacob, with a \$2,300 cheque.

These much needed funds will help the association finalize its important projects, like the medical directory, the School and Community Information Package, the Online Forum as well as



support the established Support Fund Program (for more information see below).

The generosity of the community, and the support from the people of Horton, Renfrew and the Ottawa Valley has been instrumental in helping CEDSA become established and assisting all Canadians impacted by ectodermal dysplasia syndromes.

Thank you very much to the Castleford Fishing Derby Charity Committee for once again helping our association!

Support Fund Program Launched!



CEDSA is very proud to announce the launch of the new Support Fund Program!

Outlined in a Guideline and Policy document, the Support Fund provides small grants for equipment, treatment or care needs for supporters affected

by any ectodermal dysplasia for:

- Dental treatments;
- Wigs/hair pieces;
- Cooling garments and products; and
- Any other appropriate support deemed applicable by CEDSA.

Application forms and a complete set of guidelines can be found on the website under the Supporter Only section of the site, by contacting Meghan, Michelle or Dayna at:

meghan@ectodermaldysplasia.ca,
mkrickard@sympatico.ca; or
blair1849@rogers.com.

We look forward to seeing your application!

Webinar on Dental Management Success

In December, CEDSA hosted an interactive teleconference with **Dr. Marshall M. Freilich, BSc, DDS, MSc, FRCDC** and **Dr. Robert Carmichael, BSc DMD MSc FRCDC**. Dr. Freilich is the coordinator of oral and maxillofacial surgery at Holland Bloorview Kids Rehabilitation Hospital and a staff oral and maxillofacial surgeon at Humber River Regional Hospital and SickKids.

Dr. Robert Carmichael is the chief of dentistry and director of the Ontario Cleft Lip and Palate Craniofacial and Dental Program, coordinator of the International Team for Implantology Scholarship Centre at Holland Bloorview Kids Rehabilitation Hospital and coordinator of prosthodontics at SickKids and he is an assistant professor in dentistry at the University of Toronto.

Eleven people from across Canada and around the world participated in the teleseminar and Dr. Carmichael and Dr. Freilich were able to answer all the questions with informative and insightful information.

Dr. Freilich opened the meeting with generalized overview of information, including the services offered to children and families around reconstruction at Holland Bloorview Hospital in Toronto, Ontario.

“We work in tandem here at the Holland Bloorview Hospital where we have a multidisciplinary team of dental specialists that consist of prosthodontists like Dr. Carmichael, oral and maxillofacial surgeons like myself, and orthodontists. In children with ectodermal dysplasia, those treatments often mandate involvement from all three of those specialities to be able to provide comprehensive dental care,” explained Dr. Freilich.

“So we’re very lucky to be able to work within a situation where we have all of the specialists under one roof. This can often be a very helpful thing when we meet families who require multiple consultations or for many of the families who travel long distances to our centre to come to see us from distant locations. We specialize in advance



reconstruction in children and adolescents with missing teeth. Some of those reconstructions can involve the use of dental implants and in other situations they still involve the use of conventional dental bridges and removable partial dentures.”

Dr. Freilich went on to say that one of the greatest challenges in treatment is the variations in funding and treatment programs across Canada. Ontario and Québec do provide funding for dental work in children with ectodermal dysplasia but not adults, while other provinces do not provide any funding.

In an effort to raise awareness of the expertise and programs available in Ontario, and specifically at Holland Bloorview and Sick Kids, Dr. Carmichael spoke about the need to educate impacted families about available services. Dr. Freilich and Dr. Carmichael treat both children and adults at Holland Bloorview even though it is a pediatric rehabilitation hospital.

“We’ve always relied on word of mouth and disseminating information about our program and where we’re located over the years,” he said. “The message that keeps coming back to us is that word doesn’t really tend to get out that way. So we’re actually in the middle of initiating some marketing and promotional programs to see if we can spread the word a bit.”

Along with general knowledge of available programs, another challenge facing Canadians



impacted by ectodermal dysplasia syndromes is the education and knowledge of medical professionals. As many families have experienced, only too often it is up to the parent or the individual to inform the doctors and dentists about the details of their condition when seeking treatment.

“This underscores a central problem that we have in treating children with ectodermal dysplasia and that access to care is limited by geography, and the care of patients with this condition is not something that is taught, or indeed could be taught, in undergraduate dental programs,” said Dr. Carmichael. “If you’re lucky, as a graduate student in oral and maxillofacial surgery or prosthodontics, or orthodontics, you might see one patient and you might get to take part in the treatment of that patient.”

“I went through my entire undergraduate dental training, an advanced dental residency in Vancouver, and a residency in maxillofacial surgery at Dalhousie University without ever encountering this [ectodermal dysplasia],” added Dr. Freilich.

“It was my good fortune to spend a year as a

fellow in pediatric reconstructive surgery and that was where I found this training. But I think that just really touches on the limited exposure that a lot of dental programs – both undergraduate and graduate levels – have in this condition.”

After further expansion on some of the treatment options and services available for Ontarians with ectodermal dysplasias and across Canada, Dr. Freilich and Dr. Carmichael then opened the call for questions.

Inquiries pertained to the best age for receiving implants, funding, ways to prevent tooth decay in existing teeth, challenges around salivary flow, life span of implants, use of baby teeth in bridging, and grafting, among others.

A full transcript of the teleseminar is available under the Supporter Only section of the website at www.ectodermaldysplasia.ca. Thank you Dr. Freilich and Dr. Carmichael for the generous donation of your time and expertise. Those interested in receiving a copy of the referral form for treatment at Holland Bloorview can contact meghan@ectodermaldysplasia.ca.

The generosity of the ED global community

While there may be more than 150 known forms of ectodermal dysplasia impacting individuals in a myriad of ways around the world, there is one consistency we have discovered. From Germany to Mexico, the U.K. to Australia, the people and families impacted by ectodermal dysplasia syndromes support each other.

“I have had the pleasure of working in association management for more than 10 years, from small non-profits to large organizations, and met some truly amazing people, but I have never experienced anything like the ectodermal dysplasia syndromes community,” says Meghan Howard, CEDSA president and executive director.

“From the first panicked phone call I made as a parent to Diana Perry in the U.K., to the information from NFED, each time I approached

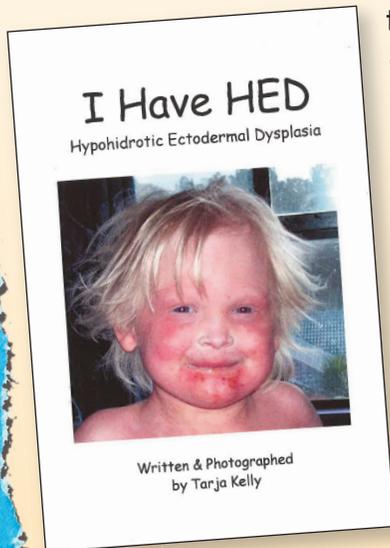
a person or organization involved with ectodermal dysplasia, the result has been overwhelmingly positive.”

This year has been no exception. Here are some of the highlights of the generous spirit of the ectodermal dysplasia community. We thank all of you for helping Canadians, our supporters and our association.

- Support from Faber Daeufer Itrato Cabot Law Group - U.S.
- Support from Edimer Pharmaceuticals – U.S.
- Support from Castleford Fishing Derby – Canada
- Teleseminar, Dr. Freilich and Dr. Carmichael – Canada
- Support from Straumann Canada – Canada and International
- Information and multiple resources - U.K., Austria/ Germany, Australia, Italy, Mexico, Poland, Spain, Norway, Denmark, France, The Netherlands, E.E.C. International, and Turkey, Sweden, Brazil and Singapore.

SPECIAL Recognition!

CRISTINA BOLZONELLA, PRESIDENT OF P63 EEC SYNDROME INTERNATIONAL When we asked about recommended skin creams and products on behalf of one of our supporters, Cristina sent us a big box of creams, shampoos, liquid soaps and more – it was amazing! We have been able to send some of the products out, depending on need and skin issues, for use. Thank you so much to Cristina, and to Mario Adamo for helping with the translations to make communication easier!



TARJA KELLY FROM AUSTRALIA Ms. Kelly is a truly exceptional mother and person. In 2007 she wrote and published a book called *I Have HED* in tribute to her beautiful three sons (and daughter) to help other children with hypohidrotic ectodermal dysplasia. When we

approached her about purchasing 20 books to include in our Parent and Community Education Packages, she said sure, but at no charge! She said she was lucky to have the support of her Lions Club (The Lions District 201-Q1 Northern NSW Community Trust) and wanted to support CEDSA in turn. She donated all 20 books to us.

"I wrote the book when my first born son was due to start school. It was a tool for him to explain what he had and how he wasn't any more different than any child was. It had to be 'easy' for a six-year-old to read and I wrote it as the voice of a child. I felt if there were questions directed back at the reader, discussion would happen and everyone would bond over their intricacies and special features. It worked really well," says Ms. Kelly.

"I too have found the international ED family to be wonderful. There's no 'mine's worse than yours' in the ED family, there is just a common goal to educate others; I love that about it. Thank

you so much for giving me such an amazing opportunity to help overseas!"

We are extremely grateful, and on behalf of all the families who will benefit from the books, thank you Tarja! You can find out more about her book, and her quest to raise awareness by joining her *I Have HED* page on Facebook.

THE INTERNATIONAL ECTODERMAL DYSPLASIA NETWORK The IEDN has been hard at work, under the guidance of Diana Perry in the U.K. and Ulrike Holzer in Vienna. They are updating the website, creating a new newsletter and creating an IEDN Directory.

In addition, they created a list of questions and issues that arose from the 5th International Conference on Ectodermal Dysplasias held in Erlangen, Germany. They have faithfully hounded the rest of us in the Network to answer the questionnaire for compilation. Thank you so much Ulrike and Diana, we appreciate being included in this dynamic group and look forward to the day we can attend an International Conference.



FOR SUPPORTERS ONLY!

Your \$20 a year is worth it. Not only are you contributing to helping build a strong association that will be here for you, and your family now and in the future, you are connecting with an international community, getting access to resources, product discounts, newsletters and funding support. Now you have your own section of the

website, with information and articles available only to supporters. User names and passwords can be obtained by contacting Meghan Howard at meghan@ectodermaldysplasia.ca. This information will be updated regularly to ensure the site stays secure. We will be launching a forum for supporters on that side of the site as well. Newsletters, transcripts of seminars, articles on ectodermal dysplasia syndromes, products and skin care information, and more can be found on this section of the site. It is our way of recognizing you for supporting us!

Research Findings:

Parental Support Needs and ED

As many of you may recall, in 2012, we disseminated a survey on behalf of Lemuel Pelentsov, a PhD candidate from Australia who was part of a research group looking at the psychological needs of parents caring for a child with ED.

Mr. Pelentsov sent us a summary of some of the findings, and is now focussing his PhD work on “delving deeper into some of the key findings discovered in the previous survey, including breastfeeding issues and the impact of ED on family relationships.”

He extends his heartfelt thanks to all the Canadians who replied to our call to answer his survey, and we hope you will be able to help Mr. Pelentsov with his research in the future, as it benefits us all to do so.

“We received response to our survey far exceeding our expectations, much to the credit of yourself and the other leaders of ED support groups. The findings from the survey have made a wonderful contribution to our understanding of the psychosocial needs of parents caring for a child with ED,” says Mr. Pelentsov.

To read the Abridged Summary; *Parental Support Needs and ED*, please sign in to the Supporter Only section of the website and look under Articles.

Having a Baby? Have the Conversation!

As ectodermal dysplasias are genetic, obviously for those at child-bearing age who have an ectodermal dysplasia, or are known carriers (or who partners with a carrier or someone with an ED syndrome), the decision to have a child can be a difficult one.

Likewise, how do you talk to your child about their future plans to have a family? Edimer Pharmaceuticals has a new resource to help, a website called *Have the Conversation*. You can find it at www.havetheconvo.com. In June 2012,

Edimer Pharmaceuticals received fast-track designation from the U.S. Food and Drug Administration (FDA) for EDI200, the company's novel and innovative treatment for XLHED.

EDI200 is the first of a new class of drugs designed to treat XLHED with a lifelong effect by correcting the genetic defect responsible for XLHED. If you are interested in learning more about Edimer's clinical trials, please visit www.clinicaltrials.gov.

With great research underway in the area of treatment for XLHED, if you are expecting a baby or are planning to add to your family in the future, let us know. CEDSA will be able to provide information and resources that may be of interest to you.

CHARITABLE STATUS UPDATE

We have filed our first set of required documents with Industry Canada! This is a very exciting time for us with more than two years of hard work having gone into establishing CEDSA to the point we could apply, and then meeting the requirements to file. Toronto lawyer Mark Blumberg, who specializes in charity law, has been a fantastic resource and we thank him for his work on our behalf. We expect a two to three month wait in reply to our file. If further details aren't requested, we will then file for incorporation. Our goal is to have our charitable status in place this year! Expect virtual champagne and toasts when we accomplish that goal!

BOARD MEETING NOTICE

The next CEDSA Board Meeting by teleconference is in late April. If there are any issues, as supporters, you would like to see raised or addressed, or programs you'd like to see implemented, please let us know!