

NEWSLETTER

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BC-YUKON MEETING NOTES

Tony Reynolds

The Canadian Fabry Association's Western Meeting was held in Vancouver BC on September 26, 2015, at the Holiday Inn Vancouver Centre, 711 West Broadway Avenue. It was attended by about seventy Fabry patients, family caregivers, medical professionals and pharmaceutical industry representatives, as well as most of the current board of the CFA.

Our theme for the conference was "Live Well with Fabry: Available Resources and the Route Forward". We chose this theme, as our aim both as an organization and as individuals is for the Fabry community members to live the best life possible.

Excellent and informative presentations were made by the following:

Dr. Seema Kanwal, ND - Seema is a naturopathic doctor at the Balance Medical Centre in Vancouver. Her presentation was entitled "Creating Balance Through Nutrition".

Frances Kirson - Frances is the Director of Education and Engagement at Pain BC as well as a faculty member at BCIT and consultant specializing in wellbeing and social sustainability. She spoke on the topic of pain management and resources that are available to the many Fabry patients that live with chronic pain.

Dr. Jeffrey Medin, PhD - Jeff is well known to most people in the Fabry community as he has presented at many of the Canadian Fabry Association's conferences over the past ten years. He is a professor at the University of Toronto and Senior Scientist at Princess Margaret Cancer Centre, Toronto Western Research Institute and Toronto General Research Institute. His research team has been working

for a number of years on the development and implementation of clinical gene therapy trials for the sustained systemic correction of Fabry disease. His presentation - "Update on the Status of the FACTs Gene Therapy Project" – an exciting report on what may well be a "cure" for Fabry disease.

Seia Roots - Seia is a Community Educator with the Vancouver-Fraser Branch of the Canadian Mental Health Association and an instructor with Mental Health First Aid Canada. She spoke on the topic of mental health and resources that are available to the many Fabry patients and family members that live with the mental health challenges that often accompany a chronic condition like Fabry.

Dr. Sandra Sirrs, MD – Sandra is the treating physician for most of the adult Fabry patients in BC and the Yukon so we all know her well. She received her medical degree from the University of British Columbia and is a clinical associate professor in the Division of Endocrinology at UBC. She is the medical director of the Adult Metabolic Diseases Clinic at Vancouver General Hospital, one of the largest free-standing clinics for adults with inborn errors of metabolism in the world. She is a principal investigator with Canadian Fabry Disease Initiative (CFDI). Her presentation was titled "Fabry VOUS – Variants of Unknown Significance". She provided an update on some interesting developments in the world of Fabry research.

As well as enjoying the rich input from the various speakers, the board of the CFA had a rare opportunity to meet face-to-face and strategize for the continuing role of the CFA and the route forward.

STEPPING DOWN

Darren Bidulka

Dear Members,

I have decided to resign from the board of directors. The time has come for me to move on to other pursuits.

It has been a pleasure working with all of you and we have accomplished a great deal together over the past ten years. Our collaboration has had a huge positive impact on the Canadian Fabry community. We have seen ERT funding stabilize, research advance in many exciting ways, and built important relationships in the rare disease community, medical profession and government bodies.

Perhaps, most important, we have shown the Fabry community that it is possible to "Live Well with Fabry". We have all seen the tremendous relief of a new patient when they meet others in the Fabry community and see that life can be very good despite the challenges. I think this is now our most important work.

Please feel free to contact me with any questions. I remain committed to the Fabry community.

I look forward to seeing you all again in Halifax in May 2016. Please do keep in touch.

SAVE THE DATE

May 6th – 8th, 2016

The Canadian Fabry Association is glad to announce our next National Patient Meeting at the Halifax Marriott Harbour Front Hotel.

Stay tuned to our website, email and social media for upcoming information.

Message from Dr. Medin

Jeffrey A. Medin, PhD

Dear Friends-

Some of you may have heard already that I will be moving my research group back to the States. This is true and will occur in/ around January 2016. I have been offered an Endowed Chair position at an up-and-coming Medical College in Milwaukee, Wisconsin. It is a chance for me to grow my program substantially and to develop more therapies to help more patients. There is an announcement to this effect on the MACC Fund website; they are the provider of the research monies for this new Chair position. Note that while that announcement of my joining the Medical College of Wisconsin focuses primarily on childhood cancers, I will also be continuing all my research on Fabry disease.

I would like to emphasize that last point even more. My laboratory in Toronto will remain open and fully functional. Some of my laboratory personnel will remain in Toronto; I will be coming back and forth often. We will be continuing our steps toward implementation of the first gene therapy protocol in the world for Fabry Disease in Canada. Nothing will change. Indeed I will remain appointed at the University Health Network in Toronto - though not paid by them - and will remain the head of the pan-Canadian FACTs TEAM that is putting this first trial together. On a very positive note, progress on actual implementation of that pilot clinical trial is really accelerating lately due in no small part to successful results involving important cells/tissues that were contributed by your fellow Fabry patients.

It is hard for me to think about saying goodbye to some very dear friends in the Fabry patient and research communities in Canada. You have always been there to walk the path with me concerning the development of novel therapies for this disorder. You have believed in us even when we/I have been very discouraged. It has been a true partnership. Yet my new position will offer resources that are well beyond what are available to me now. The goal is to build off the success we hope for in this first trial and then have the way paved already to expand the number of Fabry patients that can benefit from this approach. Or - as sometimes happens in research - we will need to go back and modify the approach itself. My new position will have resources to allow this too.

I wish you all the best. Thanks for your questions, comments, and support. We will stay in touch. Live Well with Fabry.

Sincerely

Jeffrey A. Medin, PhD
University Health Network, Toronto
Medical College of Wisconsin, Milwaukee

BECOME A MEMBER

Would you like to become a member of the Canadian Fabry Association? It will ensure you receive the most current information concerning your disease and its treatment. All information will remain completely confidential and will be shared with no other organization.

Date: _____ 20 _____

Name: _____

Address: _____

City: _____

Province: _____ Postal Code: _____

Home Phone: _____

Work Phone: _____

Email address: _____

Individual amount \$15.00
or Family membership (family living in the same home)
amount: \$25.00

Complete form and mail to:

Canadian Fabry Association
415 Crossing Bridge Place
Aurora ON
L4G 7N1
or register online by visiting our website:
www.fabrycanada.ca

MAKE A DONATION

Would you or a family member like to make a donation so that we can continue to educate and advocate for the best treatment as well as communicating with and for Fabry patients in Canada?

The Canadian Fabry Association (CFA) is a registered not-for-profit organization. Recently, through the generosity of one of our Board Members, the registered charity The Fabry's Charity Association has become available for the CFA's use. If you are interested in making a charitable donation and would like a tax receipt, please make your cheque payable to The Fabry's Charity Association.

100% of donations to the CFA are used to promote education, patient support and access to treatment for Canadian Fabry patients. You can make donation cheques payable to The Fabry's Charity Association and mail the cheque to us.

Send the cheque to:
The Fabry's Charity Association
415 Crossing Bridge Place
Aurora ON
L4G 7N1
or register online by visiting our website:
www.fabrycanada.ca

Thanks for your donation to the CFA! It goes to help Canada Fabry patients, their families and caregivers.

Live Well with Fabry

I have Fabry Disease ...

and it makes me stronger, more resistant, more patient, less judgemental, sympathetic to others, appreciative of simple things, grateful for good days, and thankful for life.

OUR FACEBOOK AND SOCIAL MEDIA PRESENCE

Julia Alton

The CFA now has more ways to stay connected. With our new and ongoing Social Media platforms we are able to reach out to our members and bring to them the latest updates.

Connect with us and join the platforms below!

Find us on:

Facebook: Canadian Fabry Association

Instagram: CanadianFabryAssociation

Twitter: Canadian Fabry Association

WEBSITE UNDER CONSTRUCTION

The CFA is committed to providing an up-to-date and interactive website. Our new website is under construction and expected to launch April 2016. Stay tuned!

THANKS TO SUPPORTERS

We would like to thank all of our supporters that helped make this newsletter possible.

We have received financial support from the three drug companies that are currently providing hope for Fabry patients through their research and the products they provide.



We would also like to thank all of the physicians, specialists and medical professionals that have helped in so many ways. From providing guidance on medical terms and details to caring for members of our community every day.

And of course we would like to thank all of the patients and family members that have volunteered their time and energy to assist in all the many ways that are necessary in the creation of such a large effort. It is through their efforts that we hope to inform and build a community of Fabry patients for the benefit of patients, their families and caregivers.