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Letter to Key Stakeholders and CFA Members

Darren Bidulka

Dear Canadian Fabry Community,

I am writing to share an exciting milestone as the Canadian Fabry Association (CFA) board of directors has elected its third executive committee. I have had the pleasure of being president for the last 4.5 years and was supported by executive committee members Rick Sgroi (VP), François Chabot (Treasurer), Graham Crouse (Secretary) and Brandy Jeary (Member at Large). The executive committee is a subset of our board of twelve volunteer members who all work towards our goals of supporting patients through access to treatment and fostering a community that is engaged and empowered to manage their health to the best of their ability. Our theme at every gathering is "Live Well with Fabry".

Renewal is critical to the long term success of any organization because with renewal comes new energy and new ideas. Our organization is very fortunate to have a depth of talent on the board. We started succession planning in late 2012 and it culminated in the election of a new executive on March 24th.

Before I introduce our new executive I want to thank Rick Sgroi and Graham Crouse our outgoing VP and secretary. Both Rick and Graham have been with the CFA since our first national meeting in 2006. In fact, Rick is a founding member of the CFA, served as our first Treasurer and then as VP. Both have given a tremendous amount of time to the Fabry community and we all owe them a debt of gratitude. Thank you for everything you have done and will do in your continuing roles as board members.

Now for our new executive committee. I am so very pleased to see the team that has been assembled and to see our younger board members becoming leaders in our community. Our new executive is:

- Gina Costantino as President. Gina was elected to the CFA Board in 2010. She is passionate about patient advocacy and awareness. She has attended many conferences and events as a representative of the CFA to learn the issues and challenges facing the rare disorder community. Gina lives in Hamilton, Ontario (email President@fabrycanada.com).

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A Message From Our New President

Gina Costantino

As the newly elected President of the Canadian Fabry Association (CFA) I would like to thank the outgoing Executive Committee members – Darren Bidulka (President), Rick Sgroi (VP), Francois Chabot (Treasurer), Graham Crouse (Secretary) and Brandy Jeary (Executive at Large) and all the Board of Directors. A special thank you goes to Darren who served as CFA President for the past 4 ½ years and gained the respect of so many in the rare disease community. It is my hope that we continue to nurture and strengthen the relationships with all patients, families, caregivers, medical professionals, provincial governments, pharmaceutical companies and other rare disease communities.

Our newly elected CFA Executive Committee members are: myself – Gina Costantino, President (president@fabrycanada.com) Julia Strauss, VP–Patient Support (vp-patientsupport@fabrycanada.com) Francois Chabot, VP–Operations (vp-operations@fabrycanada.com) Brandy Jeary, Treasurer (treasurer@fabrycanada.com) Ryan Deveau, Secretary (secretary@fabrycanada.com) Donna Strauss, Executive-at-Large (excutive-at-large@fabrycanada.com) and Darren Bidulka, Past-President (past-president@fabrycanada.com).

The CFA Board is a strong and collaborative one, made up of 12 volunteer members. Many of the current Board members have been advocating for Fabry awareness and treatments in their own provinces well before the formation of the CFA back in 2005. I thank you all for your continued commitment to supporting Fabry patients, families and caregivers.

Each member of the Board of Directors gives of their time voluntarily and works very hard for the betterment of the Canadian Fabry Community. We meet routinely via teleconference. We host Provincial Meetings where patients can gather, network and hear up-to-date information. We work collaboratively to host the CFA National Patient Meetings tri-annually to bring Canadians affected by Fabry from across the country together to share information and engage as a community. We have our own website that is currently being restructured, but we encourage you to visit at www.fabrycanada.com. Many Board Members

also give their time attending Conferences and Meetings such as those hosted by CORD, the Canadian Medical Association, other Rare Disease Community organizations, and the World Orphan Drug Congress and sit on various committees all with the aim of focusing on the health and well-being of Canadians living with Rare Disorders. This year, for the first time, I'm very pleased to announce the 1st National Fabulous Females of Fabry Retreat, being hosted in Nova Scotia in September 2014. Travel Scholarships are currently being accepted and spaces are filling up. Please go to our website for more information, or contact myself, Donna Strauss or Julia Strauss for more information.

It doesn't matter if you are newly diagnosed or you've been aware of your condition for some time – if you're searching for information or assistance or need to connect with someone who likely understands your situation – please do not hesitate to contact any one of us. We are here to help and support you in any way we can.

Wishing you the very best to
"Live Well With Fabry"
Gina Costantino

SAVE THE DATE

September 26-27-28, 2014

The Canadian Fabry Association is excited to announce a Women's Only Week-end Event!

**Location :Atlantica Hotel & Marina
Oak Island, Nova Scotia**

Keep informed by checking the
CFA Web Site & the Facebook Page

See last page for more info

Canadian Fabry Association Board of Directors

Gina Costantino
President
(Ontario)

Darren Bidulka
Past President
(British Columbia)

Julia Strauss
**Vice-President
Patient Support**
(Ontario)

François Chabot
**Vice-President
Operational Support**
(Quebec)

Ryan Deveau
Secretary
(Nova Scotia)

Brandy Jeary
Treasurer
(Alberta)

Donna Strauss
Executive-at-Large
(Ontario)

Graham Crouse
(Nova Scotia)

Christine Francey
(Manitoba)

Ross Perri
(Alberta)

Tony Reynolds
(British Columbia)

Rick Sgroi
(Ontario)

Heather Taylor
(Ontario)

Evelyn Williamson
(Nova Scotia)

Thank you Doctor Robin Casey for Making a Difference in Our Lives

Brandy Jeary

We were out celebrating my sister's birthday, but the mood was not celebratory, both our parents unusually somber. Something was up. Dad had been having worsening health problems over the past year. The thoughts circling around in my head was that the doctors had finally come to a diagnosis, and it must be serious. Leaving the restaurant, we pressed them. What is it? What's wrong? They would not give us an answer, saying that it could wait. But good luck getting my sister and I to wait for anything.

The explanation that came next was a bit of a shock. My father finally did have a diagnosis. However, along with that diagnosis came one for my sister and I as well. We tried to wrap our minds around what this meant, comprehension came slowly. Our minds jumping from question to question—What does this mean? Will I have problems even if I feel fine now? What does this mean for dad? When will he get access to treatment? And there were no easy answers to the questions that come up.

The first step on the journey for my sister and I was a visit to the Calgary Children's hospital. I remember sitting in a small room with my family, Doctor Robin Casey and Colleen McNeil. Dr. Casey began to explain the genetics behind why we (in all likelihood) would have Fabry and

that we would be tested. We had many questions that first day and he patiently took time to answer each one. We also had our first laugh together, when I questioned the need for testing since according to the diagram it was 100% certain my sister and would have Fabry. There was a silent pause before realization struck me--"oh...we need to make sure dad wasn't the mailman!"

Over the last ten years, Dr. Casey has been consistently supportive in navigating the sometimes turbulent waters of Fabry. He was always kind, compassionate and thoughtful. At times, it was apparent that he had his own health challenges yet he continued to tirelessly serve his patients. Many of us feel very grateful to have had Dr. Casey beside us when facing Fabry.

Dr. Casey was instrumental in diagnosing a number of metabolic disorders in patients across Alberta, Saskatchewan, and Manitoba. And, as one of the 5 doctors leading the CFI, he helped unionize access to ERT for Canadian's. As Dr. Casey embarks on his next journey into retirement, we would like to say thank you for everything he has done for the community and let him know that he will be missed.

Letter to Key Stakeholders and CFA Members

Darren Bidulka

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• Julia Strauss as VP Patient Support. Julia was elected to the CFA board at the first board meeting in 2006. Her passion is patient support and empowerment. She led the youth forum and community walk at the 2009 national patient conference. She lives in Thunder Bay, Ontario (email VP-patientsupport@fabrycanada.com).

• François Chabot as VP Operational Support. François was elected to the CFA board in 2008 and the executive committee in 2009 as Treasurer. He lives in Sherbrooke, Quebec (email VP-operations@fabrycanada.com).

• Ryan Deveau as Secretary. Ryan was elected to the CFA board in 2009. He lives in Halifax, Nova Scotia (email Secretary@fabrycanada.com).

• Brandy Jeary as Treasurer. Brandy was involved in advocating for access prior to the formation of the CFA. She was elected to the CFA board in 2009 and the executive committee thereafter. She lives in Calgary, Alberta (email Treasurer@fabrycanada.com).

• Finally, I will be staying on the executive as Past President and continuing as a board member (email past-president@fabrycanada.com).

I will take this opportunity to challenge the Fabry community on three fronts:

- First, do everything you can to "Live Well with Fabry".
- Second, we have three open board positions. Please consider volunteering your time as a board member. From a geographical standpoint we could use additional board members in each of BC, the Prairies and Quebec.
- Third, if a board position is too great a commitment we can always use assistance in organizing regional meetings and other initiatives.

Take care and "Live Well with Fabry".

Darren

Rare Disease Day in Montreal

François Chabot

Thanks to everyone who came to the walk on rare disease day (March 1st), in Montreal that was organized by the RQMO. We got some media exposure on that day and our visit at the IRCM after the walk proved that some scientists are interested in doing research on rare diseases. Thanks to Dr. Berthiaume and his colleagues, rare diseases are going to get much needed attention from clinical and fundamental researchers.

You are Invited to.....
The Fabulous Females of Fabry Retreat
 September 26-28th, 2014

Atlantia Hotel & Marina Oak Island
 36 Treasure Drive, Western Shore
 Nova Scotia, B0J 3M0

Join us for an opportunity of education and networking
 for Women Living with Fabry!

FEMALES living with Fabry
MOMS of children with Fabry
SISTERS or **CAREGIVERS** of a Fabry patient
This conference is for you!

Fabry in a Woman's Life - Retreat Topics

1. Fabry disease, our bodies, positive effects of treatments
2. Psychological effects of Fabry and Family/Patient Tools for Coping
3. CFDI Study - Then and Now
4. Dispelling the 'Carrier' myth, Family Planning, Pregnancy, Menopause...
5. The Fabry 'Team' - Patient Empowerment, Getting the Care You Deserve, Support Systems

Join us...

Friday Evening Sept 26th - Welcome Dinner and Gathering
 Saturday, Sept. 27th - Day of Learning
 Sunday, Sept 28th - Education and Retreat Day

Registration Opens: April 5, 2014

Registration Details:
 Travel Scholarships Available

Register online at www.innovative4you.com/fabfemales2014.htm

Contact Sherry Slim, Event Manager for more details at 1-866-855-8548
 or by email at sherry@innovative4you.com



THE CFA's website is shedding its skin!

Ryan Deveau

As you may or may not know, the CFA is re-designing its website. This will allow for easier updates and smoother navigation. The new website will work on mobile devices just as well as a standard laptop or desktop. It will allow you to download content from past annual general meetings and national patient meetings.

The website also has a forum for users to meet and pose questions and participate in discussions. This forum is available to all current members. We are all excited to see the launch of the new website and we hope you are too.

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.

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
 #314 - 1707 West 7th Ave.
 Vancouver, BC
 V6J 5E9

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 registered as a not for profit organization but it isn't a registered charity. To become a registered charity is quite expensive. Since the CFA is not a registered charity it can't issue tax deductible receipts.

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 Canadian Fabry Association and mail the cheque to us.

Send the check to:
 Canadian Fabry Association
 #314 - 1707 West 7th Ave.
 Vancouver, BC
 V6J 5E9

or visit our website: www.fabrycanada.ca

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

For better days.