



**Dystrophic
Epidermolysis
Bullosa
Research
Association of Canada**

Newsletter March 2011

DEBRA CANADA ANNUAL GENERAL MEETING INVITATION

You are cordially invited to join us at the **DEBRA Canada** AGM.

Sunday March 27, 2:00 PM

The Beer Store Corporate Office, main boardroom

5900 Explorer Dr. Mississauga, ON, L4W 5L2

THE AGENDA WILL INCLUDE:

- President's Report – Summary of 2010 Activities
- Treasurer's Report
- Medical Assistance Fund Report
- Open Comments from the Floor
- Report from **DEBRA Canada** delegates to the 2010 DEBRA International Conference
- Appointment of New Directors
- Initiatives for 2011/2012

You may also attend this meeting via conference call. Please contact Jay Wilson for details on how to phone in at **800-313-3012** or by e-mail at jwilson@debracanada.org

NOMINATION FORM – DEBRA CANADA BOARD OF DIRECTORS

I hereby nominate _____

To become a member of the board of directors for **DEBRA Canada**. The duration of the term to be 2 years.

Nominated by 1. _____

2. _____

Expectations for Members of the Board of Directors.

- Attendance at monthly conference calls (one Sunday of most months 9:00 PM EST)
- Participation in one or more committees (including fundraising, medical assistance fund, communications)
 - Attendance and participation at fundraising events throughout the year
- Interest in enhancing the effectiveness of **DEBRA Canada** to support EB families and raise awareness about EB across Canada

Please note: Much of the board of director's work is facilitated by the extensive use of e-mail, so computer and e-mail access are essential.

www.debracanada.org

Five Ways YOU

Can Make A Difference:

- 1 Make an online donation.**
debracanada.org
- 2 Register on our website to become a DEBRA Canada volunteer.**
- 3 Organize your own local fundraiser.**
- 4 Help us Build EB Awareness – send ten friends to our Facebook and Twitter pages.**
 facebook.com/debracanada
 twitter.com/debracanada

- 5 Purchase an original LeahChristina Design Butterfly Necklace**
20% of the proceeds from your purchase go toward programs supporting families affect by EB. Visit leahchristina.com



RARE DISEASE DAY – February 28th, 2011

On February 28th, 2011, Gena Brumitt (Director of Education and Awareness) will be representing **DEBRA Canada** in Ottawa at Rare Disease Day events presented by the Canadian Organization for Rare Disorders (CORD). Hundreds of patient organizations in more than 40 countries will be coming together to celebrate the advances in knowledge and treatment of rare diseases. CORD's reception will feature Honourary Chair Dr. Kirsty Duncan, MP, who has been influential in important rare disease legislation. CORD is Canada's national network for organizations representing all those with rare disorders. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada.

Upcoming Fundraising Events

SAVE THE DATE!

**13th Annual DEBRA Golf Charity Classic –
Thursday July 7th, 2011.**

On Thursday July 7th, 2011, the 13th Annual Charity Golf Classic in support of **DEBRA Canada** will take place at Peninsula Lakes Golf Club. As per previous years, we are anticipating capacity golfers and are hoping our corporate partners will assist in making the event a success. We welcome our returning golfers who have participated and contributed to the success of the DEBRA Charity Golf Classic. To register please contact Lee and Ida Power at **905-515-4653** or idapower@cogeco.ca

JUNE FUNDRAISER AT THE ROYAL ONTARIO MUSEUM

Please stay tuned to the **DEBRA Canada** website for details on an upcoming fundraiser benefitting EB families at the Royal Ontario Museum – ROM, in Toronto.