

August 30, 2011

Dear DEBRA chapters and associated organizations –
THIS IS AN IMPORTANT ANNOUNCEMENT

DEBRA International is pleased to broadcast its endorsement of, and encouragement for “**International Epidermolysis Bullosa Awareness Week**” (IEBAW), which was founded by DEBRA International executive committee member, Gena Brumitt.

IEBAW takes place October 25-31 each year. Its genesis comes from “National Epidermolysis Bullosa Awareness Week” (NEBAW), legislated in 2006 by the U.S. Congress to take place the same week. Gena, an American who was much involved in the passage of NEBAW legislation, has lived in Canada for 20 years. (Here is an example of media promotion by one sponsor from 2007, when NEBAW began in the U.S.: www.regenerx.com/wt/page/pr_1196811331. YOUR sponsors can also do this and direct people to your website).

Gena’s involvement with EB is familial in nature, if a bit unusual – her late mother had RDEB Hallopeau-Siemens. Current President of DEBRA Canada and its Director of Awareness & Education, Gena’s history with DEBRA harkens back to 1984 when she attended the First National EB Conference in the U.S. with her mother and DEBRA of America founder, Arlene Pessar (a National EB Awareness Week was proclaimed solely for that year by then-President Ronald Reagan). Gena pursued NEBAW and founded IEBAW as a tribute to her late mother, and in honor of *all people with EB everywhere: past, present and future.*

DEBRA International is asking all of our national chapter members and all associated organizations to participate in this year’s awareness week, and in future years. Please, do what you can. **This is a potentially important time for you – you can use IEBAW to promote your DEBRA chapter throughout the region you represent!**

Press releases will be provided in the coming weeks that you can share with the media in your countries. Sample proclamations are available that you can share with your government leaders, to ask them to **declare their support for IEBAW.** Through this effort, your DEBRA chapter will receive greater recognition.

Some of you have participated in IEBAW since its origin in 2009 (and some tagged onto NEBAW in 2007 and thereafter). **We ask ALL of the DEBRA organizations and associated groups to USE October 25-31 to your advantage – use this week to promote awareness and fundraising goals, and to raise funds for EB research. We all work very hard on our NATIONAL endeavors. Here is an opportunity for us to work in harmony on a GLOBAL scale. When it comes to publicity, we are stronger in numbers.** Some helpful points follow...

- The www.mywalkamile.wildapricot.org website is moving to www.eb-awareness.org. **Harvest these websites for information and resources.** Feel free to search the internet for other ways that you can find to promote awareness during this week. *Please share your successes with us after October 31st!* Your stories will encourage others to participate in 2012. There are MANY ways that you can promote “our week” this year – walkathon’s, motorcycle rides for charity, a wear-jeans-for-charity day at the office – essentially **whatever kind of event you can dream up** for the IEBAW campaign.

- By mid-September, we'll share a **DEBRA International press release** that you can distribute. We recommend that you share it with the media – radio, newspaper, television, blogs, etc. - wherever you are by October 1st to achieve the utmost value from your campaign effort.
- A full-color **IEBAW global poster** will be available by then (thanks to Rocky Tesa of DEBRA Canada!). You can use the poster for your events or whatever helps YOUR group. The poster features DEBRA-approved photographs of people with EB from 25 countries, and this can be a key component of your group's media package this coming year. (You can still see last year's posters at www.walkamile.wildapricot.org to get an idea of what 2011's posters will look like.)
- If you are on **Facebook**, please join the active Facebook group **“2011 International Epidermolysis Bullosa Awareness Week,”** which presently has over 1,000 members. Add your own contacts to the group, too! This is a GREAT place to share and obtain additional information and resources about IEBAW from around the world. (Now would also be an excellent time to become a “fan” of the DEBRA International page!)
- Gena has secured **audio-video footage of actress Courteney Cox, promoting EB awareness for IEBAW**, through her longstanding collegial relationship with EB Medical Research Foundation, a fellow EB charity. **This footage will be used to create a 30-second public service announcement that YOU can use** on television stations (many of them will air PSA's from nonprofit organizations at no charge), post electronic bulletin boards in major cities, place on your websites, send to your past donors, and more. **All of our DEBRA national chapters and associated organizations should be able to use the PSA's for the purpose of promoting EB awareness and raising funds for EB research during the month of October for IEBAW.**

Please contact Gena at gena@debracanada.org if you have not done so, to request your copy of the resulting PSA's. The 30-second version is expected in 1-2 weeks; a longer version with additional educational information is expected in 2-3 weeks. Both will have a final page promoting www.eb-awareness.org and www.debra-international.org. The videographers are working on production now – once EBMRF and Ms. Cox have given their final approval, **we can all do OUR PART in maximizing EB awareness across the globe. So – with PSA's, global posters, proclamations, press releases, campaign resources, and your own chapter's ingenuity, we hope that your DEBRA group or associated organization will participate in IEBAW this year, and every year going forward.**

To ensure that people in your country find YOUR organization when they see press releases, etc., please **check the “clickable map”** at www.mywalkamile.wildapricot.org – click on “Countries,” hover over your country on the map (created thanks to Andres at DEBRA Argentina!), and ensure that contact information is correct, so the public can find you. Email Gena at gena@debracanada.org if you want to change the information – **but be sure to put IEBAW in the subject line of your email!**

Similarly, **check the drop-down menu** at www.debra-international.org to ensure that YOUR country's contact information is current and correct – provide as much information as possible, including website, contact person, and a primary email address. Your update information should be provided to John Dart at john.dart@debra.org.uk ASAP so that the DEBRA International website is updated. **Both above-mentioned updates should be made by September 15th at the latest.**

**Best wishes for your organization during IEBAW 2011!
Your 2010-2011 DEBRA International Executive Committee**