

**WALK A MILE IN MY SHOES
RELAY - RALLY**



by Gena Gruschovnik, Director Awareness & Education

In 2005, legislation was sponsored in the U.S. for “National EB Awareness Week,” in Congress by Congressman Timothy Bishop (NY), and in the Senate by Senator Charles Schumer and Senator Hillary Clinton. The legislation was slow-moving after being referred to committees, Gena Gruschovnik asked DeBRA of America and EB Medical Research Foundation to allow her to draft unified press releases advocating the Bills. In 2006, Gruschovnik stepped up the lobbying activities, bringing together a group of volunteers who worked with her to write letters to every Member of Congress and every Senator. Letters were written by DeBRA of America and EBMRF representing the EB community, and these were hand-delivered by a Virginia volunteer to House of Representative Committee Members. In September 2006, National EB Awareness Week legislation was passed in the Senate. On the last day of Congress, the related Bill passed, thus formalizing this week in perpetuity, to take place the last week of October every year in the U.S.

In 2007, dEBra Canada participated as a sponsor of the American “Walk a Mile in My Shoes Relay-Rally.” This event was founded and organized by Gena Gruschovnik, an American living in Ontario who serves on the dEBra Canada Board of Directors. Gena’s mother, Lillian “Pat” Barbrey, had RDEB Hallopeau-Siemens. Walk a Mile in My Shoes was created to celebrate the lives of people with EB, including those whose lives were lost to it, as an advocacy and awareness tool so that society is better informed.

Walk a Mile in My Shoes had an early kick-off in Canada when the Tatum EB Hope Foundation, www.tatumbhope.org held a fundraiser in St. Thomas, Ontario. “Tatum” is 5-year-old Tatum Blackwell, who has Recessive Dystrophic EB. Her

mother, Natalie Blackwell, organized the fundraiser. Participants included West Jet, Adrian Peters from A&M Sounds, the St. Thomas Fire Department Association, the Masonic Foundation and Aylmer Shriners, St. Thomas Canvas and Awning, Yarmouth Mutual Fire Insurance, Herbal One. Donations were also received from Tim Horton’s, The Sparta Bakery, and the UPS Store, just to name a few! The Walk a Mile in My Shoes theme song by Natalie Merchant, “Wonder,” started off the walkathon, and musical groups “Famous for Nothing” and “Attison” played music after speeches and prize distribution. dEBra Canada made the news with this fundraiser, archived at <http://tinyurl.com/2wy4xo>. See www.ebrelay.org for information on the event’s outcomes, and to view plans after June 1 for the 2008 event.

Not to be outdone, Natalie Blackwell asked her Elgin-Middlesex-London Member of Parliament, Joe Preston, to sponsor a Bill on behalf of people with EB. On November 21, 2007, Preston made the motion in a Private Members’ Bill requesting this designated week in Canada, as M-408 (see <http://tinyurl.com/2Hszm>). As it stands at this writing, the motion is so far down on the order paper that it may not make First Reading before an election is called. That being said, Preston is trying to negotiate to get the motion moved up.

As the only charity in Canada representing people with EB, dEBra Canada will send letters on behalf of our constituency, asking that this legislation be created in perpetuity in Canada. Also, when the time is right, our Canadian EB community will be challenged to write to their own MP’s asking that they support this Bill, in order to see it passed. We can then ask Canadian legislators across the country to make proclamations of this official awareness week, thereby improving the public’s knowledge and understanding about EB. *More info to come...*



President's Message

I am the father of two Dystrophic EB children and have been active on the board of directors for **dEBra Canada** for 5 years. I became involved when my family was introduced to EB first hand. I will never forget the feeling that my wife and I had when we first found out that we were going to have an EB child. EB was very new to us. We had personally never been faced with this in the past. The medical staff were unfamiliar with EB and that made getting answers to our many questions difficult. The feeling of the unknown was an extremely uncomfortable one. Any parent or individual that has been touched by EB knows exactly what I am speaking about.

It was through pure coincidence that my mother found out about the charity, **dEBra Canada**, and put us in touch with Fran Molinaro, the president at that time.

My wife and I will never forget the feeling we had when Fran and her husband, Dave, met us at the hospital with our 2 week old son. They were living with EB. Their beautiful daughter, Deanna was diagnosed with Dystrophic EB. Having parents understand what you're coping with and more importantly providing you with their insight and coaching is a feeling that my wife and I will be forever grateful for...*thank you.*

It was soon after this experience that I knew that I had to help. That was 5 years ago and I continue to assist in any way I can.

dEBra Canada has achieved some fantastic successes. These successes have been made possible through passionate volunteers both on and off our board of directors.

I would like to personally thank each and every one of you who continue to support **dEBra Canada** and the entire EB community. I would like to extend a special thank you to our Past President Dave Gallant for the good work he did while leading **dEBra Canada**.

We have a board of directors that remain focused and passionate about continuing to create awareness, providing support and funding research where we can. Please feel free to contact any one of us to find out how you can help.

Thank you and I look forward to a very exciting future for **dEBra Canada**.

Jay Wilson, President

DebRA International

For many years, DebRA International was represented by a regional grouping of European DebRA chapters. Over the past few years, actions were taken to change this, toward the creation of a well-represented, international structure.

In 2007, **dEBra Canada** was asked for its input on the founding structure of the new international entity. That November, Jay Wilson and Gena Gruschovnik traveled to Avignon, France, for the 2007 DebRA International Congress. Several locations were considered for the registered office, and Vienna, Austria was chosen.

The DebRA International Association was founded to promote the well-being of people living with Epidermolysis Bullosa (EB) and to take any actions necessary in pursuance of this objective at the international level. One of the main functions of DI is to develop treatments for EB by coordinating the research programs of the member groups and by facilitating close collaboration with the principal EB research teams. The main focuses of current research are gene therapy, cancer in EB, wound healing and clinical research aimed at symptom relief.

The Founding Meeting took place by teleconference on March 4, 2008. The new DI Executive Committee members are Gena Gruschovnik (**dEBra Canada**), Dan Seigel (DebRA of America), Anna Kemble-

Welch (DebRA New Zealand) and Francis Palisson (DebRA Chile). These four join Guy Verdot (DebRA France), Heidi Silseth (DebRA Norway), Vlasta Zmazek (DebRA Croatia), Rainer Riedl (DebRA Austria), Margaret Webb (DebRA Ireland), Evanina Makow (DebRA Spain), Graham Marsden (DebRA UK) and John Dart (DebRA UK). *A new DI website will be launched soon and the DebRA promotion campaign is underway.*

The year has started out well with a donation to DI of £50,000 (about C\$100,000) from a UK businessman following a dinner at Lady Margaret Thatcher's home. Prospects for major donations are being cultivated around the world with the participation of DebRA chapters. If you would like to suggest contact names and details for potential major EB research donors, please contact Gena Gruschovnik at ggruschovnik@debracanada.org. A research grant round for the last part of 2008 has been advertised throughout the scientific community in anticipation of funding availability.

A research conference will be held in Vienna, Austria, in September 2009, and the 2008 DebRA International Congress will be held in October in Belgium. Further information will be available soon at www.debracanada.org. DebRA now has support groups in more than 30 countries around the world.

Medical Assistance Fund Continues to Help Canadian Families

In 2007, the Medical Assistance Fund received applications from two families – both families were granted financial assistance from the fund. In one instance a grant made it possible for a family to install a special bathtub to help make bandage changes easier. In the other, a grant helped with the purchase of special wheelchair seating to facilitate mobility.

If your family is struggling with exceptional costs for equipment related to EB (that is not covered by government or insurance programs), but would certainly make your life easier, don't forget about **dEBra Canada's Medical Assistance Fund**. Application details are provided on our website. For general enquires contact **Tim Christie: tchristie@debracanada.org**.

Gearing Up for Another Fantastic Annual Golf Classic Fundraiser!

The dEBra Charity Golf Classic for 2007 was held at Peninsula Lakes and raised \$20,278, bringing the nine-year total to just over \$123,000. Prizes to support this annual event have, for the most part, been supplied by The Golfer's Den and Larry's Sports along with major sponsors Queenston Chevrolet (Marty Muis), Bertram and Barry Insurance (Ron Barry), and Hank's Painting (Hank Spier, who also introduced us to Molson's) and the Molinaro's who brought in Labatt's.

"We're so excited about our 10th year in fundraising for dEBra," enthused Ida Powers from the Golfer's Den. "This really marks a milestone, not only for our involvement as organizers, but for all of the golfers and sponsors who have been so committed and eager to help, year after year."

As volunteers, we are honoured to continue to be involved and look forward with anticipation to the planning of this year's 10th Annual Golf Classic tournament. **Mark your calendar – the date is July 10th 2008, at Peninsula Lakes Golf Club, www.penlakes.com.** If you are interested in sponsoring the dEBra Charity Golf Classic please call 905-560-8640. Register today by emailing golfersden@on.aibn.com. See you all there!

Lee and Ida Power, Fred Cassidy



Scramble Format
Shotgun Start
1:00 p.m. sharp

\$225 registration fee
call: 905-560-8640
email: golfersden@on.aibn.com

The multi-award-winning documentary,

The Boy Whose Skin Fell Off,
will soon be available for
purchase in Canada at the
dEBra Canada website,
www.debracanada.org.

The film, which won an International Emmy award and was shown in the past on TLC/Discovery Channel, will be available in North America thanks to the efforts of **dEBra Canada** and **DeBRA of America**.



***It's an inspiring tale of
grace and courage.***

Thank you, Emily! On Saturday, September 15, 2007, Emily Boros-Rausch hosted her first art show to heighten awareness of EB and raise funds for **dEBra Canada**. Emily worked for months on her paintings and with help from her mother Linda, they were able to organize an event to display her bright and vibrant artwork at an art studio in Toronto. Emily's art teacher graciously offered her studio, ArteMbassy, for the show. They also offered refreshments (pink lemonade) and beautiful cupcakes – almost too good to eat!

The following week, Anthony (Emily's dad), arranged a similar but more private art show (a wine and cheese party) at his workplace, National Bank Financial. The bank hosts similar fundraising events each year for different charities and then bank employees donate funds. The National Bank Financial matches dollar for dollar what is raised at the events. Between both shows, Emily was able to raise over \$9,000! She requested that a portion of the funds be donated to the EB research department at The Toronto SickKids Hospital, and the balance be donated to **dEBra Canada**.

Many of Emily's family and friends (along with Linda Boros' and Anthony Rausch's colleagues) gathered to show their support for her. Mom and Dad are very proud of Emily and everything that she has accomplished in her short, albeit impressive 14 years of life. This was not Emily's first attempt at fundraising. In 2006, Emily held an event at a Chapter's book store in Toronto selling her handmade bookmarks to raise awareness of EB and **dEBra Canada**. At this previous event, Emily was able to raise over \$600! Furthermore, Emily wrote a speech about EB and how it has affected her life and presented it at her school; and subsequently sold **dEBra Canada** wristbands to raise funds. **dEBra Canada** has deemed Emily to be our "junior spokesperson." Knowing what Emily has been capable of doing, there should be no emphasis on the word "junior"!

Emily has made fundraising look easy and simple – and it truly is. Start with an idea, coupled with a little determination, and you will be amazed by what you can bring out of other people. Other EB supporters have produced and sold their own calendars, while other companies held bake sales at their workplaces to fundraise for **dEBra Canada**. Please contact **dEBra Canada** if you would like some information on how to get started on a fundraising event.

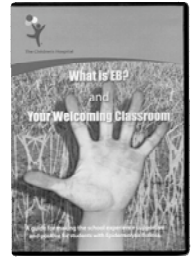
FREE School DVD!

A two-part DVD was developed by the multidisciplinary Epidermolysis Bullosa Team at The Children's Hospital of Colorado, and it is endorsed by **dEBra Canada**. This wonderful video is a guide that helps to make the school experience supportive and academically challenging for students with Epidermolysis Bullosa.

The first part of the DVD, *What is EB?*, is designed to familiarize students and teachers with some of the issues facing children with Dystrophic EB. This kid-friendly section is hosted by a child with EB. Other children with EB have roles, and their classmates and teachers share their perspectives about EB in the school environment. The objective of this section is to help students with EB feel less isolated and more accepted in the classroom environment.

The second part of the DVD, *Your Welcoming Classroom*, is designed to provide teachers, school nurses, aides and administrators with the information and tools to improve their understanding of EB.

This FREE DVD is available by contacting debra@debracanada.org to place an order.



The following is an overview of the content of **What is EB?** (5 min 49 sec)

- Genetic, not contagious
- Different types
- Integrating the student into the classroom
- Special needs
- Interview with parents
- Develop plan
- Classroom management
- Socialization
- Welcome EB students and involve them in activities
- Educate other students about EB
- Educate other students about abilities and limitations
- How can other students help?

Your Welcoming Classroom (17 min 33 sec)
Understanding the Issues of Importance for students with EB

- Swallowing
 - Esophageal blisters or scarring
 - Respect "no" if unable to eat
 - Have snacks available (i.e., puree foods, liquids)
- Bandages
 - Protect skin
 - Help heal skin
 - Overheating
- Odor
 - Help other students understand
 - Speak with nurse and/or parent
 - Be aware of infections
- Depression
 - Be aware of psychiatric symptoms
 - Talk with parents
 - May need psychiatric evaluation and support
- Bathroom
 - Set up bathroom time (i.e., 10 minutes)
 - Reward program or goal sheets
- Pain
 - Pain control and management
 - Rate pain, on scale of 0 - 10
 - Pain medications
- Parents
 - Communicate regularly
 - Written back and forth log
 - Common knowledge and goals
- Control
 - Need sense of control
 - Self-advocacy
 - Recognize talents and strengths
- Good Days and Bad Days
 - Status fluctuates
 - Pain
 - Schedule time to check in with the nurse
 - Allow breaks

EB Clinic Study at SickKids: Trimethoprim

For several years now, the Epidermolysis Bullosa (EB) Clinic at the Hospital for Sick Children has seen improvement in chronic wounds of patients treated with long courses of oral antibiotics. In addition to antibacterial effects, they have also been shown to have anti-inflammatory properties. The first report of these medications possibly playing a role in EB was published in the late 1990's. Two patients with EB Simplex, a father and a son, started on a course of Tetracycline due to acne. While they were taking this medication, they noticed decreased blistering and an overall improvement of their skin.

The EB Clinic at SickKids Hospital in Toronto designed a study to investigate the effects of one of the anti-inflammatory antimicrobials, Trimethoprim, in patients with severe forms of EB, to prove that the clinical improvements were due to a change in practice. The bigger goal was to ascertain if more

severely affected patients may benefit from this intervention. Patients alternatively took either Trimethoprim or a placebo. The goal of the study was to determine if patients treated with Trimethoprim had better wound healing and a reduced number of new blisters.

Ten patients were enrolled in the trial under principal investigator Dr. Elena Pope, but only seven completed both study arms (the study was limited to those aged 20 and under). The final data analysis is not yet available; however, preliminary data is favourable.

This study was made possible by grants from **dEBra Canada** and the Canadian Dermatology Foundation, and through a generous donation from Emily Boros-Rausch.

Conference Updates

Family Getaway / Halloween Party - October 27-28, 2007

Building on the success of the Family Conference Day in 2006; **dEBra Canada** hosted a very successful Family Weekend Getaway in Toronto on October 27-28th, 2007. The goal of the weekend was to facilitate ongoing relationships and networking between families living with EB.

The event combined the first annual Family Getaway Weekend with the Annual Halloween Party, (which is usually held in Stoney Creek, Ontario) in late October.

Seven families attended the Family Getaway Weekend at the Sheraton Parkway Hotel in Markham, Ontario. Everyone enjoyed the Halloween party, complete with a costume competition and an amazing performance from a magician on the Saturday evening. After the party, several families convened in the hotel lounge for more networking.

Sunday morning was designated for parent discussion groups, as well as a session for the older kids with EB social worker Nimrita Aujla. Nimrita (from the Sick Kids EB team), held a focus group for teenagers at last year's Family Conference Day.

dEBra Canada was pleased to cover the cost of the whole weekend for families attending - including meals and the hotel room. The Family Getaway is part of a continuing mandate to bring families together for the exchange of information and the development of friendships.

Plans for another family conference and a tentative date are still under discussion at this time. Please check our website for more details in the near future.



dEBra Canada Sends Delegates to the DebRA International Conference

by Jay Wilson, President

It was my absolute pleasure to represent **dEBra Canada** along with Board of Director Gena Gruschovnik, during the 2007 DebRA International Conference in Avignon, France.

The agenda for the three day conference was extremely comprehensive and provided a tremendous amount of information and networking with other DebRA chapters from around the world.

The annual international conference is very important to the continued growth of **dEBra Canada**. It provides an excellent forum for collaboration on fundraising activities, social marketing campaigns, EB research updates and networking with all of our DebRA partners world-wide.

EB research continues in North America, as well as in Europe. During the conference, we were provided with European updates on how this exciting research is helping to uncover and expose ways of treating various types of EB. Research teams from Italy, England and France provided a wealth of information on gene therapy, testing and ongoing clinical trials. Graphic evidence was provided to the group to help illustrate just how effective and exciting some of these treatment modalities are.

DebRA International held their Annual General Meeting with all representing chapters. A new board structure was proposed and agreed to. Formerly, the international body was represented, for the most part, by European delegates. This has been changed to allow for international delegates to be part of their board. With her great enthusiasm and passion, **dEBra Canada** elected to have Gena Gruschovnik represent us on the DebRA International board. This new structure will now make DebRA International, truly "international."

DebRA of America 2008 Patient Care Conference

Save the date for the FREE 2008 Patient Care Conference taking place in Denver, Colorado, this coming June 19-22. The conference will have meeting space and hotel rooms at the Renaissance Denver Hotel, 3801 Quebec Street.

Phone 888-236-2427 and ask for the Special Room Rate of \$99 (to get this rate, you must book by phone under "DebRA group." Book early for wheelchair-accessible rooms, roll-in showers, and any other special needs. When making a reservation, please indicate the number of beds needed in the room.)

While the Conference is free to attend, please note that a fee of \$100 will be charged for any room cancellations requested after May 19, 2008.

See www.debra.org for up-to-date information.

Preliminary Schedule

- **June 19:**
 - 5:00 p.m. - 8:30 p.m. Registration
 - 7:00 p.m. - 8:30 p.m. Welcome Reception
- **June 20:**
 - 8:30 a.m. - 9:00 a.m. Registration Continues
 - 9:00 a.m. - 5:00 p.m. Conference Programs
- **June 21:**
 - 9:00 a.m. - 5:00 p.m. Conference Programs
- **June 22:**
 - 9:00 a.m. - 11:30 a.m. Conference Programs

Maybe the Grass IS Greener!

It's that time of the year when thoughts turn to summer camp, and for children with EB, that can mean one of the specialized camps our community is so blessed to have.



Camp Wonder is a week-long camp launched by Francesca Tenconi, who also founded Children's Skin Disease Foundation. Camp Wonder is for children with serious and fatal skin disease aged 7-16 years old. Camp offers a wide variety of activities including swimming, boating, arts and crafts, games, archery, fishing, ropes course, nature walks, sports and recreation, silly olympics, theater and more. It's a great place to bond with other children of a similar age and have some wonderful experiences and fun! **There is no charge for children attending camp.** Because many families of children with severe skin disease are burdened with large medical expenses, children attend CSDF's camps without charge. To raise the funds for camp, CSDF depends on the generosity of supporters. Camp Wonder takes place in Livermore, CA on June 22-28/08. A second camp takes place in Randleman, NC, dates still TBD. You can learn more and apply at <http://csdf.org>.

The American Academy of Dermatology now runs four summer camps. Founded in 1993, Camp Discovery is for young people with serious skin conditions, and offers a summer camping experience unlike any they've ever had. Each year since 1993, the American Academy of Dermatology (Academy) sponsors a week of fishing, boating, swimming, water skiing, arts and crafts, and just plain fun. Under the expert care of volunteer dermatologists and nurses, Camp Discovery offers young people the opportunity to spend a week with other campers who have similar skin conditions. Many of the counselors have serious skin conditions as well, and can provide support and advice to campers.

There is no fee for camp. Full scholarships, including transportation, are provided by the Academy through generous donations from its members and other organizations. Dates are July 6-11 in Crosslake, MN for the Teen Camp (ages 15-16); July 12-18 in Crosslake, MN for the Junior Camp (ages 10-14); August 10-14 in Burton, TX for Camp Dermadillo (ages 9-16); and August 9-16 in Millville, PA for Camp Horizon (ages 8-13). See www.campdiscovery.org for further details and to apply for camp.



Accessibility for Ontarians with Disabilities Act

Ontario's first accessibility standard, the customer service standard, came into effect on January 1, 2008. The province's goal under the new Accessibility for Ontarians with Disabilities Act (AODA) is to achieve accessibility for Ontarians with disabilities by 2025. The "First Annual Disability Awareness Event" took place on January 26th at the Hamilton Convention Center.

Our dEBra Canada Director of Awareness & Education gave a presentation to the audience about EB and how the AODA has the potential to impact the disabled in our community. dEBra Canada was also represented by our Board President. Stakeholders including government representatives and other support groups were in attendance. Much was learned about the AODA and the advantages it will bring about, and potential advantages for our EB community are apparent. More information to assist the community in understanding the new legislation can be found here: <http://www.mcass.gov.on.ca/mcss/english/pillars/accessibilityOntario>

MEMBERSHIP APPLICATION

I would like to become a dEBra member. New members are always welcome, and there are no membership dues, although donations are welcome. Please complete the following form to initiate the membership process.

Name: _____

Address: _____

City: _____ Province: _____ Postal Code: _____

Phone # Day: _____ Evening: _____ Fax: _____

E-mail Address: _____

The person completing this form is: Patient Parent Relative Educator Health Care Provider

Mail to: dEBra Canada Postal Office Fruitland, Box No. 11111, Stoney Creek, Ontario L8E 5P9



**NEWSLETTERS ARE
AVAILABLE FOR
DOWNLOAD ONLINE**

Check us out at
www.debracanada.org

We welcome your
questions or comments.

BOARD OF DIRECTORS

A voluntary, non-profit organization
dedicated to those affected by EB.

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