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**A Quarterly Newsletter from Dystrophic Epidermolysis Bullosa Research Association of Canada**

## President's Message

Having been involved with **DEBRA Canada** for eight years now, I am truly energized by recent events and global research that continue to make strides toward effective EB treatments.

In our last issue, we asked for your assistance with lobbying local, provincial and federal governments in proclaiming International EB Awareness Week (the last week of October) across this great nation of ours. We were overwhelmed by the responses received back from this campaign. So many local and provincial governments stood with us in proclaiming International EB Awareness Week. For that, I would like to personally and sincerely thank all of you for your assistance.

**DEBRA Canada** also successfully participated in a *first ever International EB awareness/fundraising event...Tomorrow Think of Me*. Three metropolitan cities held EB awareness/fundraising events: Rome, New York City and Toronto.

We also have an EB celebrity in Liz Trinnear. You can read more about Liz and her winning the Much Music VJ2.0 competition. She is an inspiration to our entire EB community and posses a wonderful spirit.

Thank you for your continued commitment to **DEBRA Canada**.

*Jay Wilson, President*



Jay Wilson, President of DEBRA Canada with Suzie McNeil at Tomorrow Think Of Me 2009

## ICN Radio Interview

*By Jay Wilson, President*

On December 28th, 2009 I participated in a telephone interview with ICN Radio on the Ciao Tony Show. Tony Pasquale is the host of this Italian focused radio program. I had the opportunity of meeting Tony at the Tomorrow Think of Me (TTM) event held in Manhattan, New York City. Josephine Maietta of the Association of Italian American Educators (AIAE) who was co-hosting the event introduced me to Tony. As with most people who learn about EB, he wanted to do more and understand more. Tony suggested a live on-air interview to talk about EB, the TTM event and **DEBRA Canada** to help raise much-needed awareness. It was my pleasure to assist. The live interview was heard locally in New Jersey, and internationally over the internet.

I cannot thank Tony and Josephine enough for what they did for EB awareness and more importantly, what they will continue to do in the future.

Grazie!!

## LOOK FOR THIS STORY IN OUR NEXT DEBRA NEWSLETTER...

Our Director of Awareness & Education, Gena Brumitt Gruschovnik, will represent **DEBRA International** on March 13<sup>th</sup> at the 2nd United Arab Emirates Wound Care Conference. Five hundred attendees will attend this conference in Abu Dhabi, chaired by Dr. Gary Sibbald. Gena is currently **DEBRA International's** Vice-Treasurer and DI "EB Without Borders committee" ambassador for the Middle East and the Americas. She has been helping people with EB in these countries from afar for about five years.

Gena will give a 10-minute talk about EB and **DEBRA International's** mission and objectives, in the hope of sowing seeds for several new DEBRA groups in the Middle East. A **DEBRA International** booth will be provided for discussions during the breaks. Currently, people with EB in most Middle Eastern countries reach out to the world for help; new DEBRA groups and networked medical professionals in this region would be a huge boon for EB patients. **DEBRA International** plans to continue its effort to help where help is needed.

Spring 2010



*The first CHU Sainte-Justine's EB clinic team pictured above :*

*Dr. Catherine McCuaig, Dr Julie Powell, Dr. Danielle Marcoux, Dr. Afshin Hatami (dermatology), Isabelle Lavoie (dermatology nurse), Louise Forest-Lalande and Chantal Leduc (enterostomal therapy nurse), Dr. Mélanie Vincent (paediatrician), Dr. Emmanuelle Lemyre (genetics), Lise Primeau (nutritionist), Dr. Nago Humbert (palliative care), Dr. Nicole Falaha (ophthalmology), Dr. Margaret Haig (anesthesia), Dr. Christophe Faure (gastroenterology), Dr. Patricia Egerszegi (plastic surgery), Dr. Julie Dubé (psychiatry), Dr. Annie Lapointe (ENT), Dr. Lionel Cudzinowski (dental medicine) and Renée Hamilton (occupational therapy).*

### The First EB Clinic at CHU Sainte-Justine Hospital in Montreal October 22<sup>nd</sup>, 2009

*By Dr Catherine McCuaig, Paediatric dermatologist, CHU Ste-Justine*

The first EB clinic took place on the morning of October 22<sup>nd</sup>, at the dermatology clinic at CHU Sainte-Justine Hospital. This is the first French-speaking clinic in Canada, and the second after Toronto's Hospital for Sick Children. A second clinic at CHU Sainte-Justine will be held in June 2010. A multi-disciplinary team is very important because EB is a disease with many characteristics.

### Research Updates for the SickKids EB Clinic, Toronto

In the 1990's, improvement was noted in the rate of new blister formation in patients with EBS who were treated with long courses of oral antibiotics with anti-inflammatory properties such as tetracycline.

A recent study completed in patients with RDEB using Trimethoprim, another antibiotic that has additional anti-inflammatory properties, revealed a great improvement in the rate of wound healing.

We observed that while on Trimethoprim, 6/7 patients had more than 50% reduction of the affected blistered surface area compared to only 2/6 patients who received placebo (a sugar water solution with no active medication). Trimethoprim appeared to be well tolerated, and there was no evidence of the development of methicillin-resistant *Staphylococcus aureus* or an increase in the rates of infections.

While the study was small, with a limited number of patients, the trend toward a greater reduction in the total wound surface area following treatment with Trimethoprim suggests that this treatment holds promise for the future.

Further studies are needed with this medication as well as other oral antibiotics that have anti-inflammatory properties.

### Amniotic Membrane in Epidermolysis Bullosa Patients with Chronic Wounds

The amniotic membrane (AM), the outer layer of the human placenta, has many natural biological properties that prevent scarring, reduce inflammation, stop the formation of blood vessels, minimize infection, and promote wound healing.

There are several successful reports of AMs used in patients with extensive burns and venous ulcers where it was demonstrated to be safe, easy to use, and extremely beneficial in allowing fast healing of the skin.

A study performed at SickKids in patients with RDEB revealed at least a 50% reduction of the blistered area in 4 out of 8 applications of AMs. One blistered area completely healed after 1 application, 3 applications resulted in significant improvement, 2 in mild and 2 in minimal improvement. The average time period for a decrease in the affected area by 50% was 40 days. Considering that these wounds were present for years, this represented a significant improvement for these patients.

Our findings suggest that AMs are beneficial in terms of promoting wound healing in patients with chronic wounds. Further studies are needed in larger number of patients.

*Dr. Irene Lara-Corrales, Dermatology Fellow and Dr. Elena Pope, Head, Section of Dermatology, Medical Director, Epidermolysis Bullosa Clinic, The Hospital for Sick Children, Toronto.*

The Canadian Organization for Rare Disorders (CORD) recently invited me to represent **DEBRA Canada** in a teleconference call with other Canadian rare disease patient support groups, in consultation by the Canadian Agency for Drugs and Technology in Health (CADTH). The following is my report on the subject matter discussed in this teleconference.

CADTH is a national body providing federal, provincial and territorial health care decision makers with “credible, impartial advice and evidence-based information about the effectiveness and efficiency of drugs and other health technologies.”

This organization is working on an approach to incorporate patient input into the Common Drug Review (CDR) process and the deliberations of the Canadian Expert Drug Advisory Committee (CEDAC). CADTH, CDR-participating drug plans, and CEDAC members agree that the patients’ perspective in regard to living with an illness, and the impact of drug therapy on patients’ lives, are important considerations for CDR reviews and CEDAC recommendations.

A working group comprising CEDAC members, drug plan representatives, and CDR staff collaborated to propose an approach that includes input from **DEBRA Canada** and groups like it. They promised to provide us with a template with specific questions listed, to facilitate submissions from our members. In this way, they hope to bring patient input into the decision-making process.

It is extremely valuable for **DEBRA Canada** (and you!) to be included in this decision-making discussion, because we are confident that effective treatments for EB are in our near future. When I attended EB2009 last September in Vienna, Austria, several scientific researchers and EB doctors spoke frankly to me. They said that the *work we are doing* is extremely important - that impactful involvement of patient support groups will make a huge difference in whether EB treatments become available in specific countries. This is exactly the circumstance they spoke of: the need to become involved at the ground level and stay involved. In other words - this is a critical time for ALL of us to work together.

**DEBRA Canada** intends to work with our policy-makers and medical community to set wheels in motion that will allow access to effective treatments as they are developed. Researchers are working diligently on a variety of treatment options, and some of these methods look very promising.

If you wish to learn more about the CDR process, please see this link: [www.cadth.ca/index.php/en/cdr](http://www.cadth.ca/index.php/en/cdr). We’ll keep you informed as the government shares more about this process.

And, if you have ever thought about volunteering for **DEBRA Canada**, please email us at [debra@debracanada.org](mailto:debra@debracanada.org) and let us know. We operate almost entirely as volunteers. As our team is gearing up for several important projects this year, your help would be much appreciated!



## **ANNUAL GENERAL MEETING**

You are cordially invited to join us for  
**DEBRA Canada’s AGM.**  
**Sunday March 28, 2:00 pm.**

**The Beer Store Corporate Office,  
5900 Explorer Dr., Mississauga ON.**

### **The Agenda will include:**

- President’s report
- Summary of 2009 activities
- Treasurer’s report
- Medical Assistance Fund Report
- Report from **DEBRA Canada’s** delegate to the 2009 Debra International Conference
  - Open comments from the floor
  - Appointment of New Directors.
  - Initiatives for 2010

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 email [jwilson@debracanada.org](mailto:jwilson@debracanada.org)

# “Tomorrow Think Of Me 2009” Three Cosmopolitan Cities United for Simultaneous Event To Benefit Epidermolysis Bullosa Research

On Monday, December 14<sup>th</sup>, 2009, **DEBRA Canada** was pleased to take part in the first-ever international fundraising event for EB, “**Tomorrow Think of Me.**” The concept for Tomorrow Think of Me was developed by related charities, the **Dystrophic Epidermolysis Bullosa Research Associations (DEBRA) of Italy and Canada**, with the generous pro bono support of Laura Rossi International, an Italian PR agency dedicated to social justice.

In Rome, the event took place at the Temple of Hadrian; in New York City, at the prestigious Cipriani Wall Street; and here in Toronto, **Tomorrow Think of Me** took place at Canada’s most celebrated architectural triumph, Toronto’s CN Tower.

This unprecedented fundraising event served a dual purpose: to raise awareness for EB, and to generating donations for EB research. Money raised from all three events was designated for EB research. **DEBRA Canada** proceeds are slated to fund vital EB research and patient care through SickKids Foundation at Toronto’s Hospital for Sick Children. SickKids houses the most progressive EB clinic in Canada.

With just over 130 guests on hand, patrons enjoyed an incredible afternoon of award-winning cuisine, celebrity musical entertainment, and guest speakers from the EB community. Global TV’s weekend anchor and reporter Carolyn Mackenzie did a wonderful job as Chair of the event.

Singer/songwriter John Ellison performed his original “Some Kind of Wonderful” and other selections. (John was so touched by what he learned about EB that he enthusiastically offered to write a song for 2010 International EB Awareness Week - a remarkable offer from the man who wrote the 3<sup>rd</sup>-most-played song in the world!) Suzie McNeil performed her 2010 Olympic theme song, “Believe,” which brought tears to the eyes of most of the audience. In addition to the musical entertainment, paediatrics EB researcher Dr. Jakub Tolar (UMN), travelled from Minnesota to provide an informative talk on the status, and future, of EB research.

Patrons at the Toronto, Rome and New York City events enjoyed an exclusive art and jewellery auction arranged by LRI. Other impressive silent auction items were offered thanks to **DEBRA Canada’s** PR agency, Solutions With Impact.

“I am so very proud of **DEBRA Canada’s** participation in what has marked the first of many international fundraising events to come in the years ahead,” enthused Jay Wilson, President of **DEBRA Canada**. “Events like this allow us the opportunity to unite with other DEBRA affiliate groups in a common goal to raise vital funds for EB research, and it makes an impact at a time when scientific research is burgeoning worldwide... international participation in events such as this will truly boost EB awareness in Canada, and on a global scale.”

Visit [www.tomorrowthinkofme.org](http://www.tomorrowthinkofme.org) for information about future TTM events.

*“You could make a difference in the life of someone living with EB by helping us raise much-needed funds for research, so please join me in our fight to find a cure for EB.” -*

Courteney Cox (Actress/EB Advocate) invited others to attend the Toronto TTM Event in an exclusive Public Service Announcement which ran for four weeks on Global TV prior to the event. Our deepest thanks go to EBMRF and Courteney Cox for their help!



Gena Gruschovnik, Director of Education and Awareness, DEBRA Canada and Jay Wilson, President of DEBRA Canada spoke to a room full of supporters at the TTM 2009 Event.



Dr. Jakub Tolar (Paediatrics EB researcher, UMN) spoke on the future of EB research.



TOP: Singer/Songwriters John Ellison and Suzie McNeil gave memorable performances.

BOTTOM: Guest enjoyed award winning cuisine and entertainment at the CN Tower's Horizons restaurant.

## Cardinal Newman Catholic High School Raises \$2,320 for DEBRA Canada

Cardinal Newman Catholic High School in Stoney Creek had a special fundraiser in support of **DEBRA Canada**. Each student in the school was given the opportunity to donate \$2 (in turn receiving a **DEBRA Canada** bracelet), and were allowed to participate in a special out-of-uniform “Civi’s Day.”

Grade 12 student council member David Saric (a close friend of Deanna Molinaro, who is affected by EB) initiated the fundraiser. He was on hand at the December 14<sup>th</sup> Tomorrow Think of Me event to present **DEBRA Canada** President, Jay Wilson, with a cheque totaling \$2,320.

**DEBRA Canada** would like to thank the entire student body for this inspiring school fundraiser!!!



Jay Wilson President of DEBRA Canada accepts a cheque from David Saric, on behalf of the entire student body from Cardinal Newman High School in Stoney Creek.

## 2009 Halloween Party

**DEBRA Canada** was pleased once again to provide a Halloween Party at the Kiwanis Club in Stoney Creek last October. “The Halloween party is always a great event for our local members,” said Jay Wilson, President of **DEBRA Canada**. The kids spent most of the afternoon doing Halloween crafts and enjoying snacks, while the parents enjoy getting the chance to talk and mingle with other EB parents and seeing their kids enjoy a special Halloween event .



The children enjoyed an afternoon of games and crafts.

The afternoon was also extra special, as Liz Trinnear dropped in. Liz has EB Simplex. She has now become a local celebrity in her own right! At the time, Liz was competing to be the next Much Music VJ. As part of the competition, she had one week to raise funds for a charity of her choice. Liz of course chose **DEBRA Canada**, and dropped by with her video crew to interview Jay Wilson, President, and present **DEBRA Canada** with a cheque for \$4,500. We can’t thank you enough, Liz!



Liz Trinnear presents a cheque to DEBRA Canada for \$4,500.

## Upcoming Fundraising Events - Save the Date!

**Annual Charity Golf Classic** - On Thursday July 8<sup>th</sup>, 2010 The Golfers Den and Larry’s Sports will host the 12<sup>th</sup> Annual Charity Golf Classic in support of **DEBRA Canada** at Peninsula Lakes Golf Club. As per previous years, we are anticipating capacity golfers and are hoping our corporate partners will assist in making this another successful tournament. We welcome our returning golfers who have participated and contributed to the success of the DEBRA Charity Golf Classic year after year, and of course, welcome all new participants... see you there! For more information on this fantastic event, contact Ida Power, The Golfers Den at phone: 905-560-8640, or email: [golfersden@on.aibn.com](mailto:golfersden@on.aibn.com)

**DEBRA Halloween Party 2010** - This wonderful event specifically organized for our EB kids will take place on Sunday October 24<sup>th</sup>, 2010 at the Kiwanis Club of Stoney Creek. For more information, please contact Erin Hoyos at [ehoyos@debracanada.org](mailto:ehoyos@debracanada.org). This year’s party will be extra special, as we are planning to engage the children with hired entertainment... don’t miss it!!!

**6<sup>th</sup> Annual Dinner & Entertainment Fundraiser** - Get ready for a wonderful evening of fine dining and entertainment at Carmen’s Banquet and Convention Centre in Hamilton, Ontario. This fundraiser will take place on Friday September 24<sup>th</sup>. More information regarding the entertainment line-up will be posted on the **DEBRA Canada** website.



The main objectives of International EB Awareness Week, and the Walk a Mile in My Shoes campaign, are to boost awareness among policy-makers and society at large about EB and its intrinsic impact on the lives of patients and patient families. The week is October 25<sup>th</sup> – 31<sup>st</sup>, 2010.

Visit [www.mywalkamile.org](http://www.mywalkamile.org) for more details.

## Walk a Mile in My Shoes Campaign Raising Awareness and Reaching Policy Makers across the Globe!

The Walk a Mile in My Shoes campaign has grown significantly in scope from its initial 2007 “EB Relay.” That cross-country 3,500-mile journey has expanded in capacity to become an international awareness campaign with a multitude of related activities, beginning with walk-a-thons but certainly not ending there.

“When I think of how far we have progressed in such a short timeframe, I feel invigorated and encouraged. It began with a dream of a better future for people with EB – and I think it is best not to mess with a paradigm that works!” says Gena Brumitt Gruschovnik, Founder of the Walk a Mile in My Shoes campaign. “The goal is really about understanding... for the average person to appreciate what it’s like to walk in the shoes of someone who has this disorder.”

It all started out with the EB Relay, a week-long journey across the United States from New York City to Stanford, with rallies and awareness initiatives at every stop along the way. This was how Gruschovnik kicked off National EB Awareness Week, which was formally approved by the US Congress in late 2006. The EB Relay had the harmonious support of **DEBRA of America** and the **EB Medical Research Foundation**. The following year’s campaign in 2008 (minus a cross-country expedition) concentrated on local fundraising events, with the addition of **DEBRA Canada** and **DEBRA Mexico** as partners.

In 2009, the EB Awareness Week endeavour grew into a full-fledged international campaign under the wing of Gruschovnik and **DEBRA Canada**. It was further augmented by the endorsement and participation of **DEBRA Italy**, **DEBRA Argentina**, **DEBRA Belgium**, **DEBRA Australia**, **DEBRA New Zealand**, **DEBRA Turkey** and **DEBRA International**, and the support of EB families in Puerto Rico, Trinidad & Tobago, and Pakistan. **EURORDIS**, **CORD** and **NORD** (rare disease alliances) gave their sanction, too. The DEBRA affiliates worked extremely hard to contact policy-makers in their respective countries, with the goal of obtaining proclamations from policy-makers endorsing International EB Awareness Week.

**DEBRA Canada** was extremely successful in 2009, obtaining 20 proclamations from Mayors and Provincial Health Ministers across the country. Our goal for 2010 is to

double, if not triple our success, with EB proclamations from policy-makers from every province and territory in Canada. **DEBRA Canada** also continues in its effort to formalize a National EB Awareness Week through the efforts of MP Joe Preston of Elgin-Middlesex-London.

“Researchers, doctors, specialists and nurses at international DEBRA conferences are excited about the outreach work we’re doing to raise EB awareness,” states Gruschovnik. “They believe in what we are doing, and it’s essentially a partnership. When effective treatments are found - or better yet, a cure - we will be in a more favorable position to lobby policy-makers for sponsorship and funding, because they will have heard of EB. Our job is to introduce them to this disease now, so the efforts of researchers are rewarded. More than anything, they want people with EB to benefit from their labours.”

### How You Can Help - Volunteers Needed For This Important Outreach Initiative!

If you want to help with this international EB awareness effort (even one hour a week will help!), please contact Gena Brumitt Gruschovnik (**DEBRA Canada’s** Director of Awareness & Education) by email: [ggruschovnik@debracanada.org](mailto:ggruschovnik@debracanada.org) or [gena@mywalkamile.org](mailto:gena@mywalkamile.org). The work is social outreach - emails, the use of social media, and letter-writing. It would be helpful to have at least one volunteer from every province and territory.

It is very easy to request a proclamation from your local and regional policy-makers, and EB Awareness Week is a great time to educate society about EB by talking with the media. Resources are posted for your use on the [www.mywalkamile.org](http://www.mywalkamile.org) website. As proclamations are issued around the world in 2010, they will be posted on the website.

Last but not least, you may also want to consider hosting a 2010 International EB Awareness Week fundraising event to **support EB research and patient support programs**. Valuable resources are listed at [www.mywalkamile.org](http://www.mywalkamile.org) to help you host an event of your own. Remember – it’s the last week of October every year.

Here’s to a successful 2010 campaign and increased EB awareness!!!

## A "HAPPILY EVER AFTER" BEGINS WITH A BRIGHT FUTURE AHEAD! - By Maureen and Mark Trinnear

Our daughter's story is not quite finished; in fact, Liz's story/adventure is truly just beginning. However, if we were pressed to write a beginning to the new life that she has embarked upon, we just might start it with "and she lived happily ever after."

You see, a lifelong dream was met when our daughter Liz recently won the Much Music 2.0 VJ search this past December 2009. Ever since Liz was in grade three, and watched George Stroumboulopoulos interview Gwen Stefani of No Doubt, she knew what she wanted to do when she grew up. Years later, being a Much Music VJ was written in her high school yearbook. A few years ago, speaking at a fundraiser for DEBRA in Hamilton, Liz told the 400 plus people in attendance, that maybe she would be the first Much Music VJ with EB.

**A Life with EB...** Liz was seven days old when the first blister appeared on her toe. When she was 18 months old (after many doctor visits and biopsies), we were informed that she had Epidermolysis Bullosa or EB. Every night was the same - bath and blister care. When she went to school we told the teachers about this little-known condition, and told them that we did not know her limitations, but asked that they let her do whatever she can. With the encouragement of our doctors, we decided that we did not want Liz to "live in a bubble," but rather, we wanted her to live as normal a life as possible. So, as Liz grew up, she wanted to play t-ball, so a friend ran for her. Later, she wanted to play basketball - watching her run was like watching someone run on broken glass. In high school, she sometimes needed a scribe to help her write notes and tests.

In grade 4 Liz's entire school went out for a cross-country run. She had a lot of blisters on her feet, and at that point, told the cross country coach that she could run no further. The coach did not believe her, and forced her to run. That night, skin care turned into hours and hours of work. Soon after, all the teachers in the school were notified by the Principal of her condition. It was from this incident, that we realized the importance of EB awareness in the community.

Years of people asking and making reference to the sores on Liz's hands and face came to an end when Liz entered her teen years. At this stage in her life, the blisters were most prevalent on her feet and hands. She blossomed into a beautiful teenager, and her desire to be a VJ continued. EB may have given her some limitations with her hands and feet, but not her voice or intellect.

Liz enrolled in a course at The University of Western Ontario called "Media, Information and Techno-culture." Liz studied the media industry, and in first year university she had her own radio show on campus. Then, there was a summer job with a local radio station as a cruiser girl. This was followed by a summer internship in Toronto with a company that put music to commercials, movies and TV shows. All the while, Liz worked on promoting local bands and expanding her knowledge base in music.

In September of this year, Liz announced that she had sent in an audition tape to a Much Music contest to be the next new VJ. We were not surprised, as she once again proved her determination to chase her dreams. Eliminations occurred over the following months, and those that survived were given various tasks. One task was to raise money for a charity. Not a second thought was given, it would be **DEBRA Canada**. With the help of DEBRA, it proved to be a successful venture. The week she was given to raise money also happened to coincide with EB awareness week - it was meant to be!

Four thousand people sent in applications to become the next Much Music VJ. There were cuts down to 16, eight then four contestants. Liz remained in the quest. The last week she was interviewed by the judges, and was asked if EB would affect her ability to do the job. It was at this point in time, that Liz told her EB story. How she always wanted the job, and how we (her parents) did not put her in a bubble but rather, encourage her to do anything she wanted and to follow her dreams. She explained how meeting others with EB gave her strength, and about how losing a friend to this devastating disease made her even more determined to live the life she always wanted. She spoke of why EB children are called "butterfly children." She proudly said that she was honoured to be a role model for those with physical limitations, and that she wanted to show other people with limitations that their dreams could also come true!

When they announced her as the winner she stated she had her dream job, and that she will actually get paid for doing it!

It was humbling for us as parents to accept congratulations from those who know Liz. It was touching to hear stories from our adult friends describing their feeling when she won. A tear of joy was a common theme.

On January 4, 2010, Lizzy did her first live Much Music VJ show solo. Her dream has indeed come true. In February, Liz went to the Olympics with Much Music to do live shows on location.

This Spring Liz will walk across the stage at Alumni Hall on the UWO campus and accept her BA degree. We are quite sure a thank you will be said to all the people who helped her and supported her over the years. If you asked her now, she would say she is living a dream and living happily ever after!



From Left to Right: Maureen, Liz and Mark Trinnear.

# IN TRIBUTE TO PAOLA ZOTTI... WITH A NOD TO RARE DISEASE DAY 2010

By Gena Brumitt Gruschovnik, Director of Awareness & Education

[The following is reprinted from the EURORDIS (Rare Diseases Europe) February 2010 newsletter, an editorial by Yann Le Cam, Chief Executive Officer]



Dear Readers,

Every year, the rare disease community suffers unspeakable loss. Every day in the EU, at least 1,000 patients die of rare diseases. Their lifetime has been much shorter than that of the average person and their quality of life has been considerably worse. Let's put faces to these lives.

Paola Zotti, representative of the Italian Alliance for Rare Diseases (UNIAMO) passed away in December 2009. Exhausted, her health had been declining for some time and she finally suffered a stroke that took her life. She leaves behind her daughter Beatrix, 19 years old, affected by a severe form of Epidermolysis Bullosa. When elected to EURORDIS' Board, Paola declared, "I thoroughly believe that research is ultimately the way forward to therapy and that patient organisations have a strategic role to play in this respect."

Marianna Lambrou, representative of the Greek Alliance for Rare Diseases (PESPA), which she founded a few years ago, lost Katerina, her beloved daughter affected by Tuberous Sclerosis, in July 2009. For 30 years, Marianna travelled to the best expert centres in Europe to have her daughter diagnosed and to attempt to provide her with the best possible care, surgery and medicines. Marianna knows what patient mobility means in real life; she also knows what hope in research for a cure meant for her daughter. We were all used to seeing Katerina, as a young adult, accompanying her mother to Board meetings and conferences all over Europe. We all knew nobody could look after her in Athens with as much care as her mother. The impact of rare diseases is double: the lives of patients are taken; the lives of caring parents or relatives are often shortened.

Only last year, the EURORDIS' Board of Directors experienced these two dramas. During the same period, at least 360,000 similar dramas affected families across Europe. We don't want these lives, dramas, suffering and deaths to be lost for no reason.

Research is a Number 1 priority in EURORDIS' Strategy 2010-2015. We will focus on Research Policy. We need to provide policy makers with clear answers to these three questions: Why have a research policy on rare diseases? Why increase budgets for rare disease research? What is the research agenda that can specifically increase scientific knowledge and medical advances for rare disease patients? We need to come up with integrated, comprehensive, sustainable policies and a set of actions at national, European and international levels.

Rare disease patient organizations can be valuable partners for progress in research. Patients often act as catalysts for increased collaboration amongst researchers, clinicians, industry and patients. It makes sense!

Patients need research... research needs patients... research needs policy and money

This International Rare Disease Day 2010 is a major endeavour to raise awareness of these life-saving challenges, and of the importance for patients and researchers to work closer together, as Partners for Progress & Partners for Life. Join us!

## AN ADDITIONAL NOTE FROM GENA:

This reprint speaks of European statistics, European loss; here in Canada, we are impacted similarly. There must be patient support, and there must be research. People affected by EB must participate in the research in order to make progress. With such a small patient cohort, this is the ONLY way to make scientific advances. We have the scientific talent, the funds and the interest here (see [http://www.cirm.ca.gov/PressRelease\\_102809](http://www.cirm.ca.gov/PressRelease_102809)). **DEBRA Canada** is working with EURORDIS and its partners, the Canadian Organization for Rare Disorders (CORD) and the National Organization for Rare Disorders in the U.S. (NORD), to promote Rare Disease Day 2010 on February 28<sup>th</sup>.

**Paola Zotti** was the President of **DEBRA Italy**, and a beloved personal friend of mine. Her focus was on EB, and her heart was filled with love for her daughter, who has a severe form of the condition. In Paola, one could sense a very strong energy - an aura that fairly vibrated in its intensity. She had such amazing drive! I think this is why we got along so well from the very moment we met.

Paola demanded to know everything about my mother - how it was that she gave birth to three children while living with RDEB Hallopeau-Siemens, and how she lived to 65 years of age. I wish I could have given her something more tangible than my opinion. But, Paola and I sat and talked for hours, well into the middle of the night; we cried buckets of tears, and laughed some, too. We found that we shared a bottomless dedication to social action and social justice. Thus, it was not difficult for **DEBRA Canada** to take action in concurrence with Paola's vision when she invited us to co-host the first-ever international EB awareness event and fundraiser, "Tomorrow Think of Me" in December 2009.

Dear Paola, your passion was a great inspiration for me and for many others - and will continue to be! It will take many people at **DEBRA Italy** to do the work you did, as one. You are sorely missed by many because you loved so well, and you will live on forever in our memories!

  
Working for a life free of pain.  
Pour une vie sans douleur.

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

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