

## BECAUSE



## THE COST



## OF DOING NOTHING



## IS TOO GREAT.

## THE TIME TO ACT IS NOW

- ✿ **EB affects 1 in 30,000 – 50,000 births.** It occurs in every racial/ethnic group and affects both genders equally.
- ✿ There are estimated **1,000 – 2,000 cases of EB in Canada.**
- ✿ **There is no treatment or cure.** Daily wound care, pain management and protective bandaging are the only options available.
- ✿ **Pain is constant** in the lives of patients with EB.
- ✿ Severe cases have increased medical needs including: **Frequent visits and admissions** to the hospital.
- ✿ **Frequent surgeries:** to dilate their **feeding tube** (esophagus), to correct **hand deformity** and to remove **skin cancers.**
- ✿ Parents spend an **average of 2 hours a day** changing dressings
- ✿ Doctors have described it as **the most painful disease** you've never heard of...

*Help us build EB Awareness – send 10 friends to our Facebook and Twitter pages.*

 [facebook.com/debracanada](https://www.facebook.com/debracanada)

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### debra Canada

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



Imagine Your Child Living With...  
**“The Worst Disease You’ve Never Heard Of”™**

EPIDERMOLYSIS BULLOSA

[debracanada.org](https://debracanada.org)

## WHAT IS EPIDERMOLYSIS BULLOSA (EB)?

### The Worst Disease You've Never Heard Of



Epidermolysis Bullosa (commonly referred to as EB), is an umbrella term that covers several rare genetic conditions manifesting in skin and mucosal fragility in response to minor trauma or friction. The end result is frequent blistering of the skin and mucosal surfaces. Blisters are often described by doctors as being similar to 2<sup>nd</sup> or 3<sup>rd</sup> degree

burns – and depending on the EB type, sometimes recurring daily. Severe cases have an increased risk of complications as EB can affect many internal organs and result in skin cancer, disability, disfigurement and early death (in some cases) within the first few months of life.

Simple movements like crawling, walking, sitting, rolling over in bed, or the chafing of seams or tags can cause excruciating pain. Bathing and bandaging are so agonizing that strong pain medication is often required.

**There is no treatment or cure.** Daily wound care, pain management and protective bandaging are the only options available. EB affects every ethnic group and affects both genders. It is not contagious (it is genetic) and does not affect intelligence.

EB affects 1 out of every 30,000-50,000 births. Those born with EB are often called **Butterfly Children** because as the analogy goes, **their skin is as fragile as a butterfly's wing.** To learn more, visit [debracanada.org](http://debracanada.org).

## WHAT DOES DEBRA CANADA DO?

DEBRA Canada is a voluntary, registered, non-profit organization dedicated to providing support for families affected by Epidermolysis Bullosa (EB) and to increasing Canadians' awareness of this challenging disease. DEBRA is the only organizational body in Canada exclusively committed to the care and support of families and to improving their quality of life.

## DEBRA CANADA PROGRAMS AND SERVICES

### EB Fellowship Program - EB Advice

An initiative of DEBRA Canada and the Dermatology Department of The Hospital for Sick Children (SickKids) to help support patients and families affected by EB throughout Canada. This program helps bridge the gap in knowledge and patient care and assists in bringing together medical doctors across Ontario and the rest of Canada, with the goal of increasing best practices and a higher quality of care for our EB patients. The program aims to provide a source of comfort and re-assurance to our Canadian EB community, and alleviate some of the daily challenges our EB patient community face from living a life with a rare genetic condition. Visit our website for more information.

### Medical/Financial Assistance Program

DEBRA provides financial assistance to families for expenses related to the care and treatment of someone with EB. The request must serve a medical and/or quality of life purpose. This program is only for people with EB, who are members of DEBRA Canada.

### Infant Care/Patient Care Kits

Our EB Patient Care Kit provides a comforting support package for newborns and their families as they begin to care for a child with EB. Families receive practical, hands-on information on wound care, medical supplies, and information related to the care of an infant with EB. The EB Patient Care Kit may be provided to others, not only infants.

### Support for 3 Canadian EB Clinics

DEBRA provides support and funding to three EB clinics across Canada. These EB clinics are located at: The Hospital for Sick Children in Toronto, ON, CHU Saint-Justine Hospital in Montreal, QC and the BC Children's Hospital in Vancouver, BC. for regular updates on our programs and services.

### Conference Funding for Patients & Medical Community

DEBRA provides funding to EB patients, health and medical professionals to attend national and international conferences in order to further increase their knowledge toward best practices and EB patient care in Canada.

### Ambassador Program

Our Ambassadors are DEBRA Canada members who inform and educate the public about EB, create awareness about EB year round.



Visit [debracanada.org](http://debracanada.org)


## HOW YOU CAN HELP





In memory of Zainab Ahmad 2008 - 2011


 Donations can be made online at:  
<http://www.debracanada.org/products/donations>.


All donations are fully tax-deductible to the extent allowed by law.

 Subscribe to our monthly giving option:  
Visit our donations page,  
(<http://www.debracanada.org/products/donations>)  
click on the "Monthly Donation" option.

 Support DEBRA Canada:  
Attend or support one of DEBRA's events. Visit our "Events" section of our website.

 Organize your own local fundraiser

 Volunteer – Call or email us to learn about the many ways you can help.

 Register on our website to receive the DEBRA Canada newsletter.

**Please mail donations to:**  
(cheques payable to DEBRA Canada)

DEBRA Canada  
1500 Upper Middle Road, Unit #3  
PO Box 76035, Oakville, ON L6M 3H5

**Phone:** 1-800-313-3012  
**Email:** [debra@debracanada.org](mailto:debra@debracanada.org)

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