

Who or What is DEBRA?

The first DEBRA chapter was founded in the UK by a group of parents whose children were affected by Epidermolysis Bullosa (EB). The original aims of the charity were to stimulate knowledge of, and interest in, EB for the benefit of those with the genetic disorder and their families, and to fund medical research. From these humble origins, DEBRA has grown significantly with DEBRA groups now established under the umbrella of DEBRA International in over 40 countries around the world.

About DEBRA Canada

DEBRA Canada was formed in 1998 by Ontario resident Fran Molinaro (Founder), who decided to form a Canadian DEBRA chapter after the birth of daughter, Deanna. Today, the organization has evolved into a volunteer Board of Directors consisting of 11 people who meet monthly to fulfill their objectives which include: patient programs, education, and the creation of awareness about this rare disorder. DEBRA Canada is a national chapter under the umbrella of DEBRA International.

DEBRA Canada is a registered charity (Reg. #868336751RR0001), the only organizational body in Canada exclusively committed to the care and support of people affected by EB, and to improving their quality of life.

Mission Statement

DEBRA Canada is a voluntary, non-profit charity dedicated to providing support for people affected by EB and their immediate families, and to increasing Canadians' awareness of this challenging disease.

Purpose/Objectives

- Provide a focal point to enable and empower individuals affected by EB and their families, to support one another by sharing their personal experiences and knowledge.
- Increase awareness and knowledge of EB and DEBRA Canada throughout the country, particularly at the government level and within the health and medical community.
- Act as an advocate for improvements in health, medical, educational, social, economic and government policies and services in both public and private policies and institutions on behalf of all people with EB and their families.
- Organize meetings, roundtables and conferences for all people with EB, their families, caregivers, health and medical practitioners and government officials.
- Produce and publish bilingual educational information/materials for health and medical professions and the general public.
- Provide support to patients through DEBRA Canada's Medical Assistance Fund, the DEBRA Canada EB Nurse Educator Program, the DEBRA Canada Patient Care Kit and the DEBRA Canada Ambassador Program. Details of these programs are outlined below.

DEBRA Canada Programs & Services

1. DEBRA CANADA'S MEDICAL ASSISTANCE FUND

The costs associated with Epidermolysis Bullosa can be challenging at times, and the health insurance in our provinces and territories does not necessarily cover all of these expenses. One of the ways that DEBRA Canada supports Canadian families living with EB is through our Medical Assistance Fund.

The Fund is available to assist with medical and related expenses that are not covered by other health assistance plans at any level of government. The Medical Assistance Fund Committee considers each request on an individual, case-by-case basis. Since the Fund's inception in 2003, many families have been helped. It includes help with a co-pay or deductible, to purchase medical supplies or comfort aids, or allow for increased independence. The request must serve a beneficial medical purpose for the recipient and/or improve the quality of life. In almost all cases, the recipient would be the vendor or supplier; in special cases, DEBRA Canada may agree to reimburse an expense, as long as the receipt is provided – but it is always best to make application as early as possible. This program is **ONLY** for persons with EB, who are members of DEBRA Canada. There is an annual maximum amount for each EB family.

2. DEBRA CANADA'S INFANT/EB PATIENT CARE KIT

DEBRA Canada's 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, provincial healthcare service options, and information related to the care of infants with EB. This program also provides the family with specially-made clothing and basic medical products. The EB Patient Care Kit may be provided to others, not only infants.

3. DEBRA CANADA AMBASSADOR / YOUNG AMBASSADOR PROGRAM

Our Ambassadors are DEBRA Canada members who inform and educate the public about EB, create awareness about EB year 'round, and advocate for as well as network with EB patients on non-medical issues.

4. The EB MAKE A WISH PROGRAM

The EB Make a Wish Program involves the granting of a wish to an EB patient to further the quality of life and inspire others to pursue their dreams/goals in the face of adversity. All EB patients are required to submit an application detailing how a potential granting of a wish would make a difference in their lives and inspire others in the EB community to reach/achieve their goals.

Recent Accomplishments – DEBRA International Congress 2012

DEBRA Canada, with The Hospital for Sick Children (Toronto, Dermatology Section) hosted the annual DEBRA International Congress on September 13-16, 2012, at the Fairmont Royal York Hotel. The event was a tremendous success with representatives from 25 countries around the globe including DEBRA delegates, pediatricians, dermatologists, researchers/scientists, and other health care professionals with EB expertise. The Congress successfully achieved its goal to increase participants' awareness and understanding of Epidermolysis Bullosa, and educate participants on international advances in treatment and diagnoses.

The Global Leader for International EB Awareness Week

The last week of October (October 25-31) is designated as International Epidermolysis Bullosa Awareness Week, and October 25th is recognized as EB Day! DEBRA Canada leads the global EB Awareness campaign effort to help spread the word about EB through government proclamation outreach, press release distribution, circulation of an International EB Awareness Week global poster (which has been translated into many languages), PSA's, local events and more!. DEBRA Canada also recognizes Rare Disease Day annually, the last day of February.

DEBRA Canada is Actively Involved in National Health Care Improvements Affecting its Members

DEBRA Canada is a member of the Canadian Organization for Rare Disorders (CORD). CORD is Canada's national network for organizations representing all those with rare disorders. One in 12 Canadians has a rare disorder. CORD rare disorder groups have one thing in common: their patients and families suffer from diseases that most people have never heard of, most doctors have never seen, and most drugs don't treat. These groups have lots of issues in common, and there is strength in numbers. CORD provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders, and they work with governments, researchers, clinicians and industry to promote research, diagnosis, treatment and services. CORD represents the orphan disorders community in the development of Canadian Orphan Drug Policy, including the proposed Expensive Drugs for Rare Disorders program within the National Pharmaceutical Strategy. They are working to promote state-of-the-art Newborn Screening in all provinces and territories, and also working to ensure Canada's Clinical Trials Registry works effectively for those with rare disorders. As well, CORD is committed to increasing access to genetic screening and genetic counseling for all rare disorders. For those reasons, an alliance between DEBRA Canada and CORD is important.

Publications/Website

DEBRA Canada produces newsletters and e-blasts and distributes them to 2500+ registered supporters. Copies of archived newsletters are available for download on the DEBRA Canada website, www.debracanada.org. Visit our website for information/resources on EB.

For More Information, Contact:

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