

## Fact Sheet

### Who is DEBRA?

The first DEBRA group 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 condition and their families and to fund medical research into EB. From these humble origins DEBRA has grown significantly with DEBRA groups now having been established in over 40 countries around the world.

### A Bit About DEBRA Canada

DEBRA Canada was formed in 1998 by Fran and Dave Molinaro (founders) of Stoney Creek, Ontario, who decided to form a Canadian chapter after the birth of their daughter, Deanna. Today, the organization has evolved into a volunteer Board of Directors consisting of 10 people who meet monthly to fulfill the association's goals.

### Mission Statement

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

### Purpose/Objectives

- Provide a focal point to enable and empower individuals and families affected by EB to help them and to support one another by sharing their personal experiences and knowledge.
- Increase awareness and knowledge of EB and DEBRA Canada throughout the country, but 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 institutions on behalf of all EB sufferers and their families.
- Organize meetings, roundtables and conferences for all EB sufferers, their families, caregivers, health and medical practitioners and government officials.
- Produce and publish information materials for the education, health and medical professions and the general public that will be available in both official languages.
- One of the ways that DEBRA Canada supports Canadian families living with EB is the MEDICAL ASSISTANCE FUND. The purpose of this FUND is to provide financial assistance to the victims of this crippling disease. The Medical Assistance Fund is available to assist with medical and related expenses that are currently not covered by any other health assistance plan from any level of government. The types of items that will be considered are varied and depend on the health plans of the respective provinces and territories.

### Publications/Website

DEBRA Canada produces a quarterly publication distributed to 500+ registered members. Copies are available for download on the DEBRA Canada website [www.debracanada.org](http://www.debracanada.org). Visit the link for detailed information/resources on EB.

### For more information, please contact:

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