

Biography – Gena Brumitt Gruschovnik

Gena Brumitt Gruschovnik is a 46-year-old American expatriate living in Ontario, Canada. Gena's mother, Lillian Ann "Pat" Barbrey (nee Brumitt), had RDEB Hallopeau-Siemens. She lived to the unheard-of age of 65, despite the horrific effects of severe EB. In the final five years of her life, Pat lost an arm and a leg to squamous cell carcinoma, which is prevalent in RDEB patients, and finally lost her battle to remain ambulatory. Pat's mother was just like so many EB parents – absolutely dedicated, attentive, concerned, wanting her child to live a reasonably "normal" life. She encouraged her child to look around her, because we all have challenges, and Pat prevailed by making it through the bandaging, infections, surgery after surgery, anemia, corneal problems, esophageal dilations, g-tube, and more – while she made a life and a home, married, worked, and gave birth to three EB-three children who gave her three EB-free grandchildren. Still, Henrietta lost her daughter too soon, and Gena lost her mother far too early. Pat is Gena's inspiration in all of her EB advocacy efforts.

Gena first learned there were others with EB in the mid-1980's, in the very early days of DebRA of America, when she attended sessions entreating the House of Representatives to fund EB research. This lobbying effort in the early infancy of the EB community, and the first national Patient Care Conference, made a profound impression.

Gena is Director of Awareness & Education for dEBra Canada (no typo, they do the "EB" differently north of the border). She asked for, and received, the unified support of DebRA and EBMRF for her press release efforts and volunteer-group energies toward passage of "National EB Awareness Week" legislation, in 2005 and 2006. She is a Coordinator for DebRA International, a role in which she assists EB families world-wide. She is also an enthusiastic supporter of EBMRF.

Gena again garnered the support of DebRA and EBMRF in unity to actively facilitate this inaugural national awareness campaign; while they have their own priorities, they are purposeful collaborators in this endeavor.

Gena is V.P. of Public Relations for London Western Toastmasters, and her background is in property and facility management and marketing. She also owns a writing/editing services business called "*ON the MARK*," and donated her journalistic talent to produce the booklet that will accompany "*The Boy Whose Skin Fell Off*," the documentary that has raised millions of dollars for EB research in the U.K. and won the 2004 International Emmy for Documentary award along with more than a dozen others. The DVD will be marketed by DebRA of America and dEBra Canada, who own the North American rights.

Gena has been writing a book about EB, a work of heart, since 2000, and this Relay-Rally will be its final chapter. The book's title is "*Good Things Come in Small Packages*," a slight modification to one of her 4'11-½"-tall mother's favorite axioms. Gena served as a consultant on the "*Seeds of Tolerance*" competition on Current TV, directed by Joseph Galata, his work about EB entitled "*Can You Make a Butterfly Cry?*"

She has developed a video podcast to introduce "Walk a Mile in My Shoes," which was produced by CIVA Communications for the EB Relay website and VEOH. An edited version is posted on YouTube and Google Videos.

Gena was asked to speak at the 2006 DebRA of America Patient Care Conference to persuade attendees to petition effectively for then-pending legislation, and was selected by dEBra Canada to attend the DebRA International Conference scheduled for November of this year. She has come to the aid of people with EB in some of our world's poorest nations, and she looks forward to spearheading other EB advocacy opportunities as needs arise.