

## Report from USA

### DebRA of America Mid-Year Report

New York, NY: Universally, DebRA of America is broadening its horizons. While we are still very much targeting research, we, at the same time, are exploring quality of life issues, including wound care insurance reimbursement. As the US struggles with health coverage for many of its citizens, those suffering from EB need help purchasing bandaging and antiseptics and fall through the cracks of health care insurance. Thanks to Executive Director Martin Hassner's connection to U.S. Senator Charles Schumer of NY, DebRA has, in fact, placed a wound care bill in the US Senate Health Committee. Realistically, with social security and medicare (senior citizen) coverage on the top of the priority list, it is unlikely our bill will be dealt with in the immediate future. In an effort to assist our membership in a more timely manner with coverage, we are in the process of gathering and communicating insurance information on a state-by-state basis and are receiving the cooperation of EB families.

We are preparing for our 5<sup>th</sup> Annual fundraising event -- the Mohegan Sun Mats Wilander Tennis & Golf Challenge to be held at the famed Westchester Country Club in Rye, New York. Hosted by Mats Wilander, whose five-year-old son has a mild form of Epidermolysis Bullosa, and his good friend John McEnroe, this is a great day for tennis players and golfers – and fundraising alike.

DebRA is planning a National Patient Care Conference to be held (we hope) in November, 2003 in Palo Alto, California, near Stanford Medical Center, noted for its outstanding EB care giving and research investigations.

We've spent the past year updating and adding to our Donor Perfect database for mailings, including appeals and our quarterly newsletter, Currents.

And, most recently there is our new web site. Still the same address, [www.debra.org](http://www.debra.org), but a whole new look and capabilities. We'd be interested in your feedback. We have hotlinked with many sites. If you would like to hotlink to our site, please contact [jwolf@debra.org](mailto:jwolf@debra.org).