“Have a Heart for EB” was held over Valentine’s Day weekend in Orlando, Florida and was a great experience for everyone who attended. Through a generous grant from National Rehab, each “Have a Heart for EB” family received three free “2-day” passes to Disney World. This year, DebRA of America agreed to help organize the event, making it as fun and worry-free as possible.

DebRA worked with its friends in the EB community to make the weekend memorable for all the participants. Volunteers decorated the gathering room with DebRA teddy bears and balloons. Hollister Wound Care hosted an ice cream social and Board Member Leslie Rader, a new member of the Hollister team, was in attendance. Madeline Weiner, RN, was also able to join us as a representative of RegeneRX, the sponsor of a pizza party. Additionally, National Rehab distributed goodie bags and “Have a Heart for EB” t-shirts. Continued on page 3
Restore Contact Layer Dressing
with TRIACT Technology

- Combines effective antimicrobial activity with virtually pain-free dressing removal
  Proven to be effective against bacteria most frequently associated with wound infections including MRSA.
  Sustained antibacterial activity for up to 7 days. ¹

- The one dressing choice for most wounds.
  Can be used on dry or exuding wounds simply by adjusting secondary dressing choice

- Enhances outcomes
  Non-adherent TRIACT Technology minimizes trauma to wound bed at dressing changes.
  Reduces pain for the patient.

Also available:
Restore Foam Dressing with Silver—combining our wound contact layer with an absorbent foam

¹ In vitro studies, data on file.
Hollister logo and wave logos are trademarks of Hollister Incorporated. Restore, TRIACT and graphic are trademarks of Hollister Wound Care LLC. Covered under one or more U.S. Patent No. 6,270,792 and 6,746,555, ©2008 Hollister Wound Care LLC, 2008
Our Door is Always Open

Now that the DebRA of America team has settled into its new offices* we’ve welcomed all of our friends and supporters to stop in for a visit. Just last December we had a visit from a stranger whom we now call our friend. After a surprising knock at the door, we opened it to find a smartly dressed, kind-faced man who had an air of sadness about him. He had found the DebRA website and arrived at our offices looking for help, support and hope.

We shook hands and he introduced himself as Mohammed from Jordan. He immediately told us that he had two grandchildren who both have EB, 3-year-old, Razan and 2-year-old, Rawan. The children live with their parents in Ramtha, Jordan. Mohammed shared that he had searched all over Jordan for anyone who could treat EB, and he hadn’t found a single doctor or dermatologist who had heard of EB. Then he found the DebRA website and he came to us for help.

As a supervisor for the Royal Jordanian Airlines, he traveled to New York City often and he felt that his visit to DebRA was crucial to the health of his grandchildren. As Mohammed sat in our offices, his grandchildren waited at home in Jordan, both in dire need of medical supplies and their parents desperate for information about EB and how to care for their EB children.

As they waited in Jordan, feeling hopeless and uncertain, Mohammed asked Mary, DebRA of America Executive Director, if she would write a letter of sponsorship to his ambassador so that he would be allowed to bring his grandchildren to the United States for treatment. Mary wrote the letter and Mohammed promised to return the next day.

When he returned, the DebRA team had found a doctor in Israel who runs a very busy EB clinic in Tel Aviv. We emailed the Israeli doctor and he agreed to treat Mohammed’s grandchildren. Along with the doctor referral Mohammed left with a large box of donated bandages.

Mohammed was overwhelmed with gratitude that DebRA would help a stranger. Until there is a cure, there is DebRA.

*DebRA is now located at 16 East 41st Street, 3rd Floor, NY, NY 10017

Have a Heart for EB

Many of the children had not seen each other since last June’s Patient Care Conference in Denver, Colorado. They quickly reconnected, playing and having a great time. Little girls dressed in Disney gowns, tiaras and fairy veils pranced amongst the guests while boys with swords and light sabers battled it out. They also had the opportunity to decorate cupcakes, made by Sara Denslaw. Slathered with icing and loaded with sprinkles, every cupcake was a work of edible art!

“Have a Heart for EB” created special memories for all in attendance. For the EB families, the trip allowed for family reunions, seeing far away friends, and even an adoption. Bruce Head and Cindy McCurdy used their trip to finalize the adoption of their son Armando. Cindy met Armando while working at Camp Discovery and quickly realized she wanted to have him become a part of her family. “Have a Heart for EB” was a tremendous success and loads of fun because so many big-hearted people in the EB community worked together. DebRA thanks everyone who pitched in and made this event a great success.
A symposium was held at Columbia University entitled “Genetics, Stem Cell Biology and Stem Cell Transplantation in Epidermolysis Bullosa.” The purpose of the meeting was to bring together experts from around the world to discuss the clinical challenges of EB, and to present their latest work on therapies for EB, in particular, protein and cell-based therapies using fibroblast and bone marrow derived cells.

The symposium opened with introductory remarks from Dr. Angela Christiano, Columbia University. Dr. Christiano was very pleased to announce her collaboration with Dr. Mitchell Cairo of Columbia University and their intent to begin using Reduced Intensity Conditioning (RIC) for Umbilical Cord Blood Transplant in RDEB at Columbia. IRB Approval was received in March 2009, and the first patients are expected to enroll by summer 2009.

Dr. Mitchell Cairo then gave an introductory lecture and overview of Reduced Intensity Conditioning and Umbilical Cord Blood Transplant for non-malignant diseases, such as sickle cell disease, for which he is running a clinical trial at Columbia. The risks and benefits of undertaking this therapy were discussed, as were the special considerations for performing transplantation in RDEB patients.

For more information and ideas to prevent the spread of MRSA please contact me at 866-332-7276, debranurse@yahoocom or visit www.debra.org for the full article.

1. Staph: Staphylococcus aureus
2. MRSA: Methicillin Resistant Staphylococcus aureus
3. ORSA: Oxacillin Resistant Staphylococcus aureus

Dear Worried Mom,

Staph\textsuperscript{1} is a common bacteria found on the skin.

MRSA\textsuperscript{2} is a Staph bacteria that has become resistant to treatment with Methicillin, (an antibiotic in the penicillin family) and other related drugs. Resistance means the drugs can’t fight the infection effectively and stronger drugs are needed. MRSA is also called ORSA\textsuperscript{3} in some laboratories. MRSA and ORSA are different names for the same bacteria.

It is important to note that if the MRSA is in the respiratory tract, it can be spread by droplets, otherwise MRSA is not airborne. Although sometimes MRSA can cause severe infections, usually it acts like other forms of Staph.

Many people carry MRSA on their skin or in their noses without being sick. They are considered colonized with the bacteria and can spread it to others. MRSA can be acquired in the hospital or in the community.

Geraldine Kelly-Mancuso, RN
DebRA EB Nurse Educator

Dear DebRA Nurse,

My child has EB and our pediatrician has told us he is colonized with MRSA. What is MRSA?

- Worried Mom

For what other professionals presented please visit www.debra.org.
This year eight campers enjoyed the 2nd Annual Winter Adventure Camp for children with Recessive Dystrophic Epidermolysis Bullosa (RDEB). Campers came from Texas, Tennessee and Colorado to enjoy a fun-filled week of winter activities. The Winter Adventure Camp promoted camaraderie, and independence in a supportive environment. The campers were most excited about their opportunity to ski. The eager campers picked up the skiing techniques quickly and by the second day they were able to race on the NASTAR course earning several medals.

The Winter Adventure Camp allowed those with EB to share in safe winter fun. All the campers were properly supervised with a staff-to-camper ratio of 1:1, by physicians, nurses, physical therapists and camp volunteers. In order to meet the varying needs of the campers, their meals were specially prepared. Most of the campers returned after having such a great experience last year and two were new to this experience.

The age of the campers ranged from 9 to 15 with one 29-year-old who acted as a counselor-in-training and participated in all the camper activities.

To keep the fun going, campers learned magic tricks and put on a show. The camp also included a dog sled ride and a snowmobile ride that allowed campers to take in the fabulous winter scenery before it was time to head back home and prepare for summer.

**Winter Adventure Camp 2010**
Sunday, Feb. 21 to Thursday, Feb. 25 | For more information email campspirit@comcast.net or call Kaycie Artus at 303-526-1018.
Paul Nunnari has joined the DebRA of America Board of Directors. Paul has a strong background in healthcare consumer products. He formerly served as the VP of Healthcare at ECRM—a consumer package goods trade association for Manufacturers and Retailers. Prior to this position, Paul was VP of Trade Development for the Johnson & Johnson Consumer Companies, where he spent over 29 years and held Management Board positions at 3 J&J companies. In addition, Paul has held Board positions at NACDS, GMDC, GMA and HDMA — trade associations in the consumer packaged goods industry.

Paul and his wife Teri Lynn live in the Philadelphia area with his 4 children and 2 stepchildren. After meeting Faith Daniels and becoming aware of EB, he was struck by the need to help the children suffering from EB and all of the great work that DebRA of America does. He will bring a great deal of passion and caring to the Board and help us continue to do what it takes to make life better for the children and their families.

New Board Member

Patients with Junctional or Dystrophic Epidermolysis Bullosa are being recruited for a wound healing study to test the safety and wound healing properties of Thymosin Beta 4 (Tß4) in EB wounds.

The study medication (Tß4 or placebo) will be applied once a day to a single lesion (a sore selected by the doctor for treatment). Study medication will be applied daily until the lesion heals or for up to 8 weeks, whichever comes first. Study participants will be seen every 2 weeks. The study is being done in 12 sites around the country. There is a travel expense reimbursement policy in place to ease patient participation. Tß4 is a naturally occurring substance present in all cells of our body except the red blood cell. Important to the wound healing process is Tß4’s ability to stimulate wound closure by re-epithelialization, organize the deposition of collagen and up-regulate the subepithelial adhesion protein, laminin-5, upon which the epithelium is anchored.

This is a thirty-six patient clinical trial. Twenty-three patients have been enrolled. Thirteen additional patients, meeting the study’s eligibility requirements, are needed. For more information about how to participate, you may contact Madeline Weiner, RN, consultant for RegeneRx Biopharmaceuticals Inc., at 919-929-1855.

Together We Can Help...

During these economic times EB families find themselves more vulnerable. This year DebRA has had 3 times as many requests for financial assistance as we did last year. The need for additional fundraising is more important than ever before. Thank you to all those who fundraise on behalf of DebRA and make a difference for our families in need.

DebRA Butterfly Pin

This beautiful, limited edition Butterfly Pin was specifically designed for DebRA by Liztech. Order at debra.org.

$75

EB Wound Healing Study

Third Annual Butterfly Wishes for Ellie

Dinner, Music and Auction
in Atlanta, Georgia, Organized by the Tavani Family. Raised over $35,000

Togetherness and Dinos

Wine Tasting and Auction
in Easton, Ohio, Organized by EB Mom and New Family Advocate Volunteer Lindsey Gregg. Raised over $1,200

Winos and Dinos
Dedicated to Serving the
EB Community & Proud
Sponsor of ebnurse.org

National Rehab is a Leading Provider of...
+ Quality Wound Care Products From All Major Manufacturers
+ Superior Customer Service
  — Assistance with Insurance Authorizations
  — Free Nationwide Shipping of Supplies
  — Caring and Knowledgeable Customer Service Ready
to Answer Your Product and Insurance Questions

To Order Products, Call: 1-800-451-6510
e-Orders: www.nationalrehab.com

Walk-a-Thon
Honoring Weston Zucha
Group Walk and Community Gathering
Organized by EB mom Dana Zucha, Crosby
Middle School Staff Nurse Susan Lee and Darlene
Vantine. Raised over $7,000

Butterfly Benefit
Fashion Show and Luncheon
in Louisville, Kentucky. Organized by
DebRA Board Member Leslie Rader.
Raised over $15,000

Fish Rodeo in
Memory of Grant Taylor
Fishing, Lunch and
Community Gathering
in Trion, Georgia, Organized by Vickie
Young and Waterville Baptist Church.
Raised over $4,000

DebRA Goes Green
In an effort to cut cost and save a few trees, DebRA will e-mail you our newsletter if you wish. Please
send your updated contact information and e-mail address to staff@debra.org to become a part of the
growing number of EB community members going green. If you would like to continue to have the
newsletter mailed to you there is no need to contact us, unless you would like to update your contact
information or share your email address.
Make a Difference
Order your new Amazon Kindle 2 and a portion of your purchase will go to DebRA. You must click through the DebRA website for DebRA to benefit from your order.

Go to www.debra.org

DebRA Wish List

Now is a perfect time to set goals and make a wish list for the needs of DebRA of America. Below is a list of in-kind items as well as crucially needed gifts that you may be able to sponsor. If you or someone you know can help with any of these items, please contact our offices. All donations to DebRA of America receive a personal thank you letter for your tax deductible purposes.

IN-KIND GIFTS
Printer Ink
Frequent Flyer Miles
Design Services
Paper
Printing

Special thanks to Cindy Laidlaw and the Laidlaw Group for their work on the DebRA newsletter and marketing materials. We appreciate your commitment to the EB community and to raising EB awareness.

Where Your Donations Went in 2008

Thanks to the generosity of countless donors DebRA of America was able to provide crucial programs and services to EB families across the country.

How DebRA Helps...

**Family Crisis Fund**
Approximately $30,000.00 was awarded to 21 families in need.

**Nurse Educator**
Our Nurse Educator worked with over 375 families in 2008 and made contact with over 2,500 individuals interested in more information about EB.

**New Family Advocate Program**
Nineteen EB families became a part of the DebRA family this year. Each new family received a basket full of the essentials for an EB newborn.

**Woundcare Clearing House**
Approximately $100,000.00 worth of products were sent directly to EB families from DebRA.