2014 PATIENT CARE CONFERENCE
July 30 through August 2 in Nashville, Tennessee

Every other year, debra of America invites those with EB, as well as their families, advocates, and care providers to hear and meet with members of the medical profession who have developed expertise in particular areas of EB care. Academic researchers and organizations conducting research into treatments are also invited to speak to and meet with our invited guests. From July 30th to August 2nd, debra will host the 2014 Patient Care Conference (PCC) at the Gaylord Opryland Resort & Convention Center in Nashville, Tennessee. Guests will learn about a range of topics, including genetic counseling, clinical trials, wound care, and cardiac issues. The PCC features Kids Rooms for our younger attendees. Children play games, watch movies, create art, and enjoy visits from special guests while their parents attend talks. It’s an opportunity for them to meet and socialize with other kids who have EB. The conference also includes an offsite Family Field Trip. Bandage manufacturers and distributors are invited to demonstrate their products and services to the community. debra also welcomes EB advocates and medical professionals who would like to learn more about the disorder and meet families. To learn more, visit debra.org/pcc2014

“I see the PCC as a huge success for kids with EB, for EB research, and for harmonization of academia, industry, and debra. I am proud to be a part of the process.”
- Jakub Tolar, MD, PhD

TO DONATE visit, debra.thankyou4caring.org/2014news or call toll free, 855-CURE-4-EB (855-287-3432)

Support International Rare Disease Day
On February 28th

February 28, 2014 marks the 7th international Rare Disease Day coordinat-ed by EURORDIS and organized with rare disease national alliances in 24 countries. On this day, hundreds of patient organizations from more than 70 countries and regions worldwide are planning awareness-raising activities making it the largest day in history.

CONTEST: Become a star on our Facebook page! Take a photo of you with your family and friends raising your hands for EB awareness. Make sure to hold a sign with your city and state written in large letters. Email the photo to events@debra.org and it could be selected as our special Facebook cover photo during the week leading up to Rare Disease Day!

Learn more at debra.org/rarediseaseday

WHAT IS EB?

Epidermolysis Bullosa (EB) is a rare genetic connective tissue disorder. There are many genetic variations, but all share the prominent symptom of extremely fragile skin that blisters and tears from minor friction or trauma. Internal organs and bodily systems can also be seri-ously affected by the disease. EB is always painful, often pervasive and debilitating, and is in some cases lethal before the age of 30. EB affects 1 out of every 20,000 live births and those born with it are often called ‘Butterfly Children.’ There is no treatment or cure.

CONNECT WITH US!

Facebook.com/debraofamerica
Twitter.com/debraofamerica
Linkedin.com/debraofamerica

HOW TO ATTEND

debra is offering a special discounted rate for EB families attending the PCC. Financial aid available.
Visit: debra.org/pcc2014
Email: PCC@debra.org
Phone: 212-868-1573

BECOME A SPONSOR

Become an official sponsor of the 2014 PCC, including sponsoring an EB family to attend. Levels include Exhibit Space, Speaker Session, Program Advertisement, and more. Email PCC@debra.org for details.
MESSAGE FROM BRETT KOPELAN
EXECUTIVE DIRECTOR

Dear Friends,

I hope everyone is having a wonderful new year so far.

It’s amazing to think about all that has happened in our community since the last issue of Currents. Between the advances in research, the increase in the number of commercial entities interested in Epidermolysis Bullosa, the increase in the number of people that hold Local Events which drive awareness of EB, as well as the rise of social media and how it promotes awareness while providing avenues of support, the amount of change is almost mind boggling. What I can say, in a nutshell, is that it is all exciting.

That is not to say it’s all been rosy. We’ve lost far too many, and I know we have all experienced some tough roads and situations along the way. I can tell you that my family has. With that said, I look back, and I hope you do too, and smile at the overall progress, and at the things we’ve achieved, and hold in our heart of hearts that good things are about to happen.

Until these things happen, if you need help, reach out to us at debras of America. We are here to help. We want to help and we will.

Happy New Year,
Brett Kopelan
(father to Rafaella, a 6-year-old with Recessive Dystrophic Epidermolysis Bullosa)

MEET THE DEBRA STAFF

Karen Bjornst
Manager, Events

Geri Kelly, RN, BSN
EB Nurse Educator

Kelsey Dashidl
Manager, Programs & Services

Elizabeth Lecher
Manager, Database

Casey Fitzpatrick
Director, Communications & Events

Ella McGorry
Intern

Rita Garson
Director, Finance

Karen Wertheimer
Chief Development Officer

Contact us by email, staff@debra.org or by phone, 212-868-1573

ASK THE EB NURSE >> GERI KELLY

visit debra.org/asknurse for the complete answers and to read more questions.

Q: Which is better for an EB baby, cloth or disposable diapers?
A: Cloth and disposable diapers have both been used by parents with EB newborns. When using cloth diapers, however, you should consider investing in wicking diapers, as opposed to traditional cotton diapers that stay wet against the newborn’s skin. Some options include FuzziBunz, Happy Heiny’s, Lovely Pocket Diapers, Sugar Peas Diapers, Swaddlebees, and Thirsties Duo Wrap Snap.

Using disposables is sometimes possible, either on their own or inside a microfiber diaper cover if the diaper insert cannot absorb enough. Options include Huggies Supremes, Huggies Ultrafits, Pampers Swaddlers, and Walmart White Cloud.

Q: I’m an adult with EBS, and my feet are a big problem area. What can I try to reduce blistering?
A: There are a number of products that families have used to reduce the risk of blistering. Ask your medical provider about these options: Bodyglide, BlisterShield from ZToms, or Atrid XX Dry. When your feet have blisters and open areas, Domboro Soaks may be an option. Make sure to check with your medical provider before trying new products.

Q: My daughter has thickened nails with very jagged edges. Is there any good way to trim them?
A: You may need to start out with a podiatrist quality nail clipper to trim any excess length. If her nails are very thick, regular clippers may not be effective. After a bath, her nail edge can be gently filed, taking care not to injure the surrounding skin, till the edge is smooth. Afterwards, you can file across the face of the nail (where nail polish would be applied) in order to thin them. If you file a little after every bath, you should be able to maintain the results.

Q: When I was diagnosed as a child, I was told I have EBS, Weber Cockayne. I don’t see my type listed on your website. What happened?
A: I understand your confusion. The EB experts around the world got together and revised the language we use to identify EB to reflect what we have learned. They published a paper in 2008 regarding these changes. You can view the classification chart at debra.org/careproducts and request a new case every 3 months. This program is available to US residents. Customer Service: 800-227-4703.

Q: How do I find a new wound care supplier? And how can I get dressings if I run out before the new supplier is up and running?
A: You may wish to contact one of the EB experienced distributors listed online at debra.org/careproducts. No one company works with every insurer, but these companies understand the issues around EB. If you need supplies before you have a new supplier, please contact debra’s Wound Care Clearinghouse at woundcare@debra.org.

Did you know?
Beiersdorf, the maker of Aquaphor, has a program for high-use users. You can receive a case of 12 jars free of charge. A letter from your medical provider is required and should state that you/your child has Epidermolysis Bullosa and that Aquaphor is a medically necessary part of care. Fax the letter to 203-563-5940. Once you are on file, you can call and request a new case every 3 months.

Did you know?
The right socks can make all the difference. Wicking socks like Smart Wool running socks (smartwool.com) or Dri-Sox (dri-sox.com) can keep your feet dry and may reduce breakdown.
Helping EB Families in 2013

debra directly impacted the lives of over 600 people living with EB through our Programs and Services in 2013. If you need a hand this year, we’re here to help.

“I’m choosing between buying bandages or food.”

Whether your coverage changed, you don’t have insurance, or didn’t get your shipment in time, debra’s Family Crisis Fund provides grants to people with EB and their families to help everyone get the level of care they deserve. Last year, we contributed to everything from dental work to insurance copays to an electric wheelchair lift.

“The doctor said my baby has a skin disease, and I should call this number.”

Having a child with EB changes your life. debra’s New Family Advocate Program is here for parents as they start the journey. We ship care packages containing information, supplies, and gifts for the new baby.

To learn more, visit debra.org/programs

EB NEWS & 2013 HIGHLIGHTS

SCIODERM
January 6, 2014
Scioderm, Inc. announces the initiation of a Phase 2B study designed to evaluate the efficacy and safety of SD-101, a novel topical therapy, for the treatment of non-healing wounds in patients with Epidermolysis Bullosa. Read the press release at: debra.org/epidermolysisbullosanews

BOSTON MAGAZINE
September 2013
Feature story on Boston venture capital firm, Third Rock Ventures, funding promising pharmaceutical research towards finding a cure or treatment for Epidermolysis Bullosa. Read the article at: debra.org/epidermolysisbullosanews

GOOD MORNING AMERICA
February 22, 2013
Good Morning America produced a special online news piece highlighting several EB Ambassadors, including Megan Barron (pictured left). Barron graduated from Duke University last May, where she started its first ever student disability advocacy group, the Duda Disability Alliance. She currently works for the National Organization For Rare Disorders in Washington, D.C. and writes a blog about Epidermolysis Bullosa.

SHIRE
January 8, 2013
Shire Pharmaceuticals announces that it has signed an agreement to acquire Latea Tissue Repair, a biotechnology company developing the first and only protein replacement therapy being investigated for the treatment of Dystrophic EB. Read the press release at: debra.org/epidermolysisbullosanews

USA TODAY
February 18, 2013
USA Today visited Lizzy Hendrickson (pictured below), a 4-year-old girl in Phoenix, Arizona who loves the color pink, watches Nick Jr., and emulates her older sister. Lizzy was born with Epidermolysis Bullosa and her skin tears at the slightest touch. Lizzy and her family shared their experiences with the newspaper hoping to spread awareness of this painful disease.

CNN
February 23, 2013
CNN learned about Rafi Kopelan and decided her story had to be heard. Rafi is a typical 5-year-old. She’s mastered Candyland and learned to read. Given a choice, she’d spend hours on the playground swings. But unlike her classmates, Rafi’s body is covered in blisters from her scalp to her feet. Her corneas are scratched, her toes are fused together, and her esophagus is lined with so much scar tissue that she can barely swallow.

Did you know that you can create an online account with debra of America?

Never miss a single update! Go to debra.thankyou4caring.org/register to sign up today.

You can manage your personal information, update your communication preferences, and set up recurring donations in one convenient place.

Are you interested in volunteer opportunities?

Fill out our volunteer sign-up form at debra.thankyou4caring.org/volunteer. Once we have your information, we can contact you with relevant opportunities.

TO DONATE visit, debra.thankyou4caring.org/2014news or call toll free, 855-CURE-4-EB (855-287-3432)
The Brewster High School Girl’s Volleyball team holding an EB Awareness Fundraiser at one of their games.

Join our Local Event Supporters:

Thank you to all of our wonderful Local Events from 2013. Together, we raised over $400,000 for EB Research, our Programs and Services, and raised EB awareness in communities all across the United States. It’s thanks to all of you that debra is able to help the families and patients who suffer from EB.

The Brewster High School Girls’ Volleyball team holding an EB Awareness Fundraiser at one of their games.

Donate for the runners! Thedebra of America staff was on hand to answer questions and help out. Thanks to everyone’s hard work, Rafi’s Run raised over $175,000 for EB research!

Rafi’s Run was created because there is no cure or treatment for Rafi, a 6-year-old girl from New York City who lives in pain. Knowing this, a group of friends got together to make a difference. Rafi’s Run was started to raise money for the research to find a cure for all children who suffer from EB.

Breakfast of coffee and pastries was served for the runners.

To donate visit, debra.thankyou4caring.org/2014news or call toll free, 855-CURE-4-EB (855-287-3432)

Thank You!!!

The NRLCA Raised Over $80,000 For debra of America Last Year!

“Program of Love”

The National Rural Letter Carriers Association selected debra of America as their official non-profit for the 2012-2013 fundraising year. Program creator Kay Carter chose debra as their official charity, speaking about meeting Debbie, an EB child in her community, “I know from experience it can be a big ordeal. Seeing Debbie waving her little hand walking into church… I saw a lot of fathers and grandfathers with tears in their eyes.” Fundraisers, contests, and events were held by local chapters throughout the country.

EB patients, families, and friends spoke at a number of events, including debra EB Ambassador and Ms. Captivating USA, Lindsey Gregg, and debra Executive Director, Brett Kopelan.

The NRLCA serves as an example of how many smaller, grassroots events can come together to make a big difference. Truly inspiring!

Coming March 9th!

The 3rd Annual Rafi’s Run is now accepting registrations! This dedicated group is returning to Riverside Park in NYC on March 9th, 2014. If you would like to participate, or donate to support this annual event, you can check them out at rafisrun.com. Help make this year the biggest yet!

This year saw the East Coast debut of the original play, “What Were We Talking About?” by the four talented ladies who make up the Wyoming Magnolias. Linda Stoval, Gretchen Wheeler, Gale Alexander, and Vickie Cawbra met while performing in “Steel Magnolias” at Casper College in 1990 and have since adopted the name Wyoming Magnolias for their group. “We’ve always wanted to do another play together. The difficulty is that when you become a woman of a certain age, there aren’t a lot of scripts out there,” Vickie Cawbra said. Eventually they decided to write their own play.

Alexander’s granddaughter, Joella Gale Murray, was born with EB. This became a prompting moment for the Magnolias. The ladies began referring to her as their “Magnolia Bud.” They decided to produce the play as a fundraiser for debra. “The play isn’t about my granddaughter, it just so happens that the $10 you spend for a ticket will go to this organization,” Alexander said. Originally debuting in Casper, WY, the Magnolias performed this year in the beautiful Spring Lake Theatre, with help from Joella’s family, headed up by her other grandmother, Janet Murray. The Murrays have lived in the Spring Lake area for over a decade, and brought all of their efforts to bear on making this a success in their community. All of their hard work paid off, as they raised almost $50,000 for debra. The only question now is where will the Magnolias take their play next?

Butterfly Wishes For Ellie

Butterfly Wishes For Ellie is an annual event in honor of Ellie Tavros, a beautiful little girl who was born in April 2006 with EB. The 7th Annual Butterfly Wishes For Ellie Benefit and Silent Auction was held on Thursday, May 9, 2013 at The Park Tavern in Midtown Atlanta. With the help of over 100 supporters, they raised over $47,000. With their event in its 7th year, they asked us what helps them to hold a successful event each year. The answer? Relationships! Establishing relationships in the community with individuals, organizations, and businesses is a very important part of throwing an event. While not everyone is able to donate directly, they may be able to help in their own way, and you can see the proof with this event. Keep your eye out for information on the 8th Annual Butterfly Wishes For Ellie!

There are many types of events, big and small. Here are some ideas of easy-to-plan Local Events you can do in your area:

- Bake Sale
- Office Jeans Day
- Birthday Party
- Car Wash
- Game Night
- Selling EB Awareness Bracelets
- Lemonade Stand
- Personal Fundraising Page

- Never Hosted an Event?

Interested in holding your own Local Event, but not sure where to start? Let us help! The debra staff is here to assist you with planning, executing, and funding your Local Event - no matter where it is.

Contact us anytime at: 212-868-1573

Or email: events@debra.org

Visit: debra.org/events

EASY WAYS TO GET INVOLVED

Jogging For Jonah

On Saturday, May 4, 2013, the 2nd Annual Jogging For Jonah took place in Tanglewood Park in Clemmons, NC. Over 100 people showed up to run and fundraise for EB, raising almost $15,000. Interested in participating in the 3rd Annual Jogging For Jonah on May 10, 2014? Registration opens soon, so keep your eyes on debra’s Facebook page!

When was your Local Event? Let us know! Interested in holding your own Local Event, but not sure where to start? Let us help! The debra staff is here to assist you with planning, executing, and funding your Local Event - no matter where it is.

Thank you to all of our wonderful Local Events from 2013. Together, we raised over $400,000 for EB Research, our Programs and Services, and raised EB awareness in communities all across the United States. It’s thanks to all of you that debra is able to help the families and patients who need our support.

Join our Local Event Supporters: debra.org/events

Contact us anytime at: 212-868-1573
Or email: events@debra.org
Visit: debra.org/events
Hi Everyone,

I remember once at school when I was about 7, someone commenting on my scars. I was quietly walking to class, when someone stopped me. I was wearing a short sleeve shirt, and the pink scars on my elbows were visible. The person said, “GROSS,” and pointed to my scars. I quietly walked away hurt. It took me a few years to realize why this event happened. I realized the reason for this is because people are ignorant of Epidermolysis Bullosa. debrabrings people away from their ignorance.

I was born with Dominant Dystrophic EB. Growing up, my parents would turn to debrabrings for questions that they had. They made me feel like I was not alone. I realized that I was not the only one affected by EB.

Last summer, I became the debrabrings intern. My school requires student community service and I thought that it would be interesting to help with a cause that has affected me. Throughout my time working with debrabrings, I have learned more about the EB community and the many programs and services that they provide. This experience has enabled me to talk more openly about EB and teach others about the disorder.

Warmly,

Ella McGorry, the debrabrings Intern

MATS WILANDER TENNIS PRO-AM

Thank you to all our generous sponsors, attendees, donors and volunteers for participating in the successful launch of the Inaugural Mats Wilander Foundation Tennis Pro-Am presented by Mölnlycke Health Care on August 28, 2014.

The event raised more than $50,000 to support debrabrings’s mission. Over 70 guests joined us during the 2013 US Open week to take part in instructional clinics, pro challenges, and experience the sprawling grass courts at the 100-year-old West Side Tennis Club in Forest Hills, New York.

The event also marked the official launch of the MW Foundation, which is the new charitable division of Wilander on Wheels. Mats Wilander and Cameron Lickle will continue raising money and EB Awareness throughout the year as they travel around the country teaching tennis.

The Pro-Am was open to tennis fans of all ages and experience levels. You can view highlights of the event at debrabrings.org/tennisproam

For information on the 2nd Annual Mats Wilander Tennis Pro-Am, email events@debrabrings.org

FAMILY CORNER >> MEET OUR INTERN

See more photos from the benefit at debrabrings.org/benefits

15TH ANNUAL DEBRA OF AMERICA BENEFIT

This year’s 15th Annual debrabrings Benefit presented by Mölnlycke Health Care kicked off National Epidermolysis Bullosa Awareness Week on October 24, 2013 at The Museum of Modern Art in New York City.

Over 300 guests attended to support our mission and celebrate the achievements of our distinguished honorees, Mats and Sonya Wilander, for their 15-years of helping debrabrings raise money and spread awareness.

The benefit included passed hors d’oeuvres and specialty cocktails, private viewing of the galleries, a live DJ, and an exciting silent and live auction hosted by Alan Kalter of Late Show with David Letterman.

The evening concluded with a very special moment as debrabrings brought nine families on stage that have adopted EB children to recognize their inspiring strength and courage.

For information on the upcoming 16th Annual debrabrings Benefit email events@debrabrings.org

Sponsorship opportunities available.

TO DONATE visit debrabrings.thankyou4caring.org/2014news or call toll free, 855-CURE-4-EB (855-287-3432)
BE PART OF THE CURE WITH EVERY SWIPE!

debrapay Capital One Platinum Visa Credit Card

by using this card, our organization receives:

• $50 after your first purchase
• 2% donation on gas and groceries
• 1% donation on all other purchases
• Up to 10% donation at select merchants!

APPLY TODAY: debra.org/creditcard

<< SHOP AND DONATE

BY THE NUMBERS >>

431 is the number of “I-FIGHT” t-shirts being worn throughout the world.
Order yours at debra.org/shop

6 is the number of Patient Care Conferences held since 2002.
Learn about the upcoming PCC at debra.org/pcc2014

24 is the day EB Awareness Week begins every October. It runs until the 30th. Mark your calendar and learn more at debra.org/epidermolysisbullosaawarenessweek

7 is the number of Grand Slams won by our EB Ambassador, Mats Wilander. Play tennis with him at our annual Pro-Am. Learn more at debra.org/tennisproam

200 is the estimated number of children born every year with Epidermolysis Bullosa. Help us find a cure by donating at debra.thankyou4caring.org/2014news

TO DONATE visit, debra.thankyou4caring.org/2014news or call toll free, 855-CURE-4-EB (855-287-3432)

THANK YOU TO THE SPONSORS OF THE 15TH ANNUAL DEBRA OF AMERICA BENEFIT

TITLE SPONSOR

PLATINUM SPONSOR

SILVER SPONSORS

BRONZE SPONSORS

TRANSPORTATION SPONSOR

MEDIA SPONSOR

UNIVERSITY SUPPORTER

WISCU