



debra

because the cost of doing nothing is too great

Annual Report 2014

The Worst Disease You've Never Heard Of

Epidermolysis Bullosa (EB) is a rare, genetic connective tissue disorder with many genetic and symptomatic variations. All forms of EB share the common symptom of extremely fragile skin that blisters and tears from friction or trauma. Those that have the more severe forms of EB have many secondary complications and illnesses that require seeing a range of medical specialists. Every internal organ and all bodily systems can be harmed by this disease.

EB attacks the individual with EB and their family on every level – physically, emotionally, and financially. Chances are, those with the most severe forms of EB won't see their 30th birthday.



EB affects **1** out
of every **20,000**
live births in the
United States



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Letter from the Executive Director

Dear Friends,

This past year we saw commitment, determination, and hard work pay dividends for the EB Community. We helped more families living with EB through our free Programs and Services than ever before. debra of America hosted the single largest gathering ever, and that's globally, of those with EB at our 2014 Patient Care Conference. I spoke with a greater number of commercial entities that are interested in developing treatments than ever before. We realized real progress in the science for a cure and have witnessed more clinical trials being launched. To say it is an exciting time would be an understatement.

Strategically, debra of America continues to find new ways to raise awareness and the necessary monies to help the EB Community. Our efforts have not been in vain. We spent more than \$1,000,000 on our free Programs and Services in 2014, which have continued to be more successful year over year. They are being more widely utilized and are therefore making a greater impact. We see more families requesting services through our Wound Care Distribution Program, contacting our EB Nurse Educator

Program, and registering with our New Family Advocate Program – to name just a few examples. While it's obvious that the need is greater, it is also obvious that debra of America has been able to fulfill the increased need and expand our Program offerings. I think one of the best examples of our success is the decrease in time in which people first access our Programs after diagnosis.

The 2014 Patient Care Conference in Nashville, Tennessee, was an unmitigated success. We saw a 100% gain in attendance. 600 people came to learn from clinicians and researchers about EB and where research is headed. While parents participated in



Brett Kopelan introducing Dr. Jakub Tolar, who spoke about his bone marrow transplant trial and gene therapy research, at the 2014 Patient Care Conference in Nashville, TN.



lectures by esteemed EB speakers, their children were being entertained during specialized organized events. It was heartwarming to see EB families spend time together – a rarity in everyday life, where one EB patient may never meet another.

I want to thank our corporate sponsors for their generous support. I also greatly appreciate the hard work and dedication from all of the people who have thrown Local Events for our cause and of course my sincere gratitude to all of the individuals who have donated money or volunteered their time this year.

Without all of you, debra of America would not be able to make an impact in the lives of thousands. After all, and I think it is important to remember, you are a benefactor of hope to our EB Community. And I thank you for that.

2014 was a good year. 2015, our 35th year, is going to be even better.

Sincerely,

Brett Kopelan
Executive Director
debra of America

Our Programs & Services

Our mission is to support the EB Community by funding research for a cure or treatment and by providing free Programs and Services to those with the disease. In 2014, we spent **\$1,159,760.00** on our free Programs and Services.



86.4 cents of every dollar is dedicated towards research for a cure and our free Programs & Services

Wound Care Distribution Program

Through our Wound Care Distribution Program, we provide wound care supplies such as bandages, needles, and ointments to those with EB who may not be able to afford them. These specialized products can cost in excess of \$10,000 per month and in many cases are not covered fully or at all by private insurance, Medicaid, or Medicare. This Program aims to bridge these gaps in coverage. Last year, with the help of your donations, we sent more than \$400,000 of supplies to families in need across the United States.

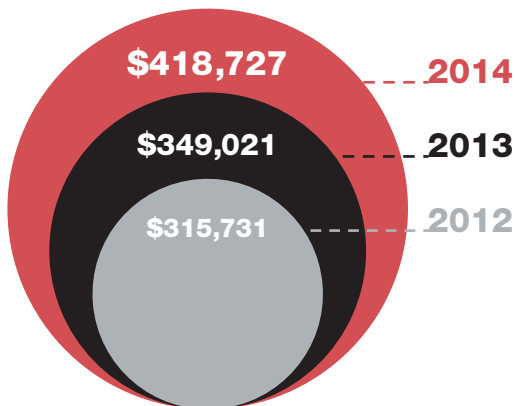
MAKE AN IN-KIND DONATION:

Interested in giving to the Wound Care Distribution Program? You can donate supplies, and we will cover the shipping! Just email woundcare@debra.org, and we will create shipping labels for you.

Here are a few easy, over the counter items that people with EB are always in need of:

- Aquaphor
- Rubber Gloves
- Gauze Rolls
- Polysporin

INCREASE IN TOTAL VALUE OF WOUND CARE SENT



Over the last 3 years, there has been a steady increase in the total value of supplies provided through our Wound Care Distribution Program.

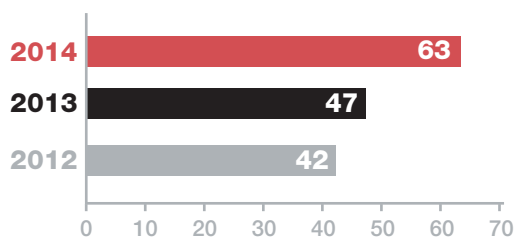


New Family Advocate Program

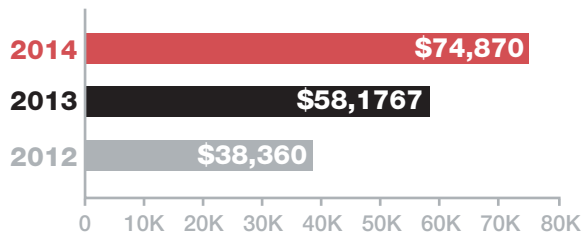
When debra of America learns of a newborn with EB, we send a care package with the needed products for the care of the child. Families also receive practical, hands-on information regarding wound care, medical supplies, medical insurance, and additional issues related to the care of infants with EB. Over the past three years, there has been a significant decrease in the time between an EB patient's diagnosis and the assistance they receive from debra of America. Through early support and outreach to new families with EB, it is our goal to help families provide their children with the best care at the earliest point possible.



NUMBER OF NEW FAMILY BOXES SENT



TOTAL VALUE OF NEW FAMILY BOXES SENT



We have seen a steady climb in the number and value of New Family Advocate packages sent over the last three years.



EB Nurse Educator Program

Geri Kelly RN, our EB Nurse Educator, serves as a point of contact to assist all of those with EB, their parents, and caregivers. She also provides healthcare professionals with helpful and necessary information to assist them in managing the care of EB patients. Individuals contact the EB Nurse Educator Program to learn about wound care, products, services, and the state of current research – or to just get a little emotional support. This Program also provides referrals to medical professionals who specialize in the various areas of EB care.

"I can't imagine living with EB these past 7 years without Geri. She has been so helpful when I have a question about wound care or the best ways to guard against infection. Being able to call someone who knows so much about EB has really made living with this disease just a little easier. I can't count the number of times she has helped over the years, and I am grateful that debra of America has this Program."

– Allen, Father of a 7-year-old girl with RDEB

For more information about debra of America's Programs and Services, visit debra.org/Programs or email woundcare@debra.org.

Letter from Gabrielle debra of America's Program Manager

Hi all!

For those of you whom I have yet to meet – my name is Gabrielle, and I am debra of America's Program Manager. I'm the voice on the other end of the line when you need to order wound care supplies, apply for the Smile Fund, request a New Family Advocate Program box, or just chat about EB!

My 23 years of living with EB Simplex has been largely trial and error – cutting clothes to make them more comfortable or coming home from a run only to tend to widespread blisters. Before I worked at debra of America, I did not know that there were bandages that I could wear other than Telfa and Spandage. At the 2014 Patient Care Conference, I put the first adhesive on my skin that did not cause any blistering – that feeling was indescribable! I think that everyone with EB deserves to feel like that. It may be hard to imagine, but when you have EB, an event as small as putting on a Band-Aid is something that you have been left out on, something that you may not even know you've longed for. It is empowering to have the tools and the knowledge to take care of yourself and your loved ones with EB. This is why I value our Programs and Services so greatly. Helping to improve the daily lives of people with EB through our Programs and Services is the most rewarding experience that I have had thus far in my life.

It is my goal to ensure that no person with EB will ever go without the supplies or services that they need to properly care for themselves. We can always do more and it's my goal to make our Programs and Services meet all of the needs of people with EB and have the greatest impact possible. It is because of your donations that debra of America is able to offer Programs and Services such as the Wound Care Distribution Program and New Family Advocate Program, both of which distribute wound care supplies free of charge to our families around the United States. Every single piece of wound care in our Distribution Center comes from supporters like you. Through your product donations, we have been able to keep the Center stocked with supplies that are desperately needed by families across the United States every single day. Your donations touch the lives of those with EB, and the impact that they have on families is truly immeasurable.

Thank you for your past, present, and future support.

For more information about our free Programs and Services, and how to get involved, contact gabrielle@debra.org.



Casey Fitzpatrick, Director of Events and Communications, and Gabrielle Sedor, Program Manager, at debra of America's 2014 Patient Care Conference.

debra Events

Thank you to our generous event sponsors, attendees, committee members, volunteers, and donors for continuing to help debra of America fund research and provide free, supportive Programs and Services for those with Epidermolysis Bullosa. To learn more about these events, please visit: debra.org/HostedEvents.

debra of America Annual Benefit

On October 22, 2014, over 400 guests attended the 16th Annual debra of America Benefit presented by Mölnlycke Health Care at B.B. King Blues Club in New York City. It was a memorable night! Co-Chairs Faith Daniels (debra of America Board Member) and Alan Kalter (voice of Late Show with David Letterman) honored the retirement of James Wetrich from Mölnlycke Health Care, and presented Robbie Twible with The Spirit Award and the Friedel Family with The EB Awareness Award. Dr. Richard Azizkahn and Dr. Anne Lucky, co-directors of the EB Center, accepted the Partners in Progress Award on behalf of Cincinnati Children's Hospital Medical Center. The night featured casino games, a silent and live auction, and a musical performance by Jeffrey Gaines. We'd like to thank everyone who made our Annual Benefit a successful celebration!



Robbie Twible (2014 Spirit Award Winner) and Thomas Misisco (debra of America Board Member) enjoying the 2014 debra of America Benefit at B.B. King Blues Club in NYC.



NYC Full & Half Marathons

Every year, debra of America is proud to be a Charity Level Partner in the TCS New York City Marathon and United Airlines NYC Half Marathon. Each race team consists of 10 dedicated runners who train and fundraise to support EB. Since 2012, our TEAM DEBRA runners have raised over \$100,000 for our free Programs and Services and for research to find a cure.

"I was very honored to run the 2014 NYC Half Marathon on behalf of #TEAMDEBRA. Racing through the streets of New York City is an exhilarating feeling and knowing that I was raising awareness and money for EB research made it even more special!"

– Natalie Busby



Over 600 people attended debra of America's 2014 Patient Care Conference in Nashville, Tennessee. It was the largest gathering of people with EB in history.

debra of America Patient Care Conference (PCC)

Every two years, debra of America invites those with EB, as well as their families, advocates, and care providers to our Patient Care Conference (PCC). Attendees listen to and meet with medical professionals who have developed expertise in particular areas of EB care, with academic researchers, and with organizations conducting research into treatments and a cure. Bandage manufacturers and wound care distributors attend as exhibitors to demonstrate their products and services to the community. Most importantly, the conference allows those with EB to meet new families and reconnect with others from around the country that share similar circumstances. The 2014 debra of America Patient Care Conference (PCC) was held from July 30 to August 2 in Nashville, Tennessee and was the highest attended conference to date with over 600 guests, making it the largest gathering of people with EB in history.

Annual Mats Wilander Foundation Tennis Pro-Am

On August 27, 2014, guests filled the grass courts of the legendary 100-year-old West Side Tennis Club in Forest Hills, NYC for the 2nd Annual Mats Wilander Foundation & debra of America Tennis Pro-Am. The event, held during the US Open, is a full-day of clinics, drills, and matches against former world-ranked pros including former world #1 champion, Mats Wilander. The charitable arm of Wilander on Wheels is dedicated to raising funds for EB research because of Mats' 18-year-old son, Erik, who has EB Simplex. This event is open to tennis fans of all ages and experience levels.



Mats Wilander (Former World #1 Champion) and Cameron Lickle (Wilander on Wheels) with former pro players at the 2014 Mats Wilander Foundation Tennis Pro-Am.

Local Events

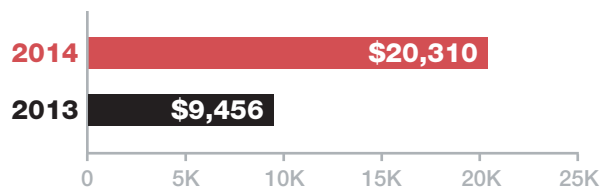
We would like to thank all of our national volunteers for their dedication to the cause and the hard work and commitment it takes to throw Local Events. More than 40 take place every year and it's these type of events that allow us to come one step closer to achieving our mission.

Jogging for Jonah

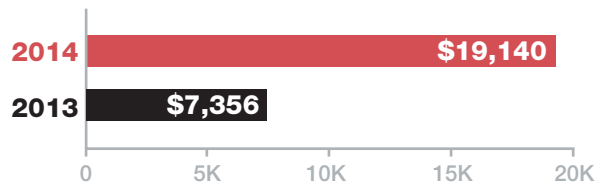
The 2014 Jogging for Jonah was a huge success! Jogging for Jonah is a successful community event that brings supporters back year after year in support of a little boy, Jonah, who lives with EB. Over the past 4 years, Jogging for Jonah supporters have raised over \$50,000 to help debra of America serve the EB Community. Jogging for Jonah was one of the first events to make use of our new Personal Fundraising platform, and the difference showed. They doubled the amount of money raised and added participants thanks to this new fundraising tool! In 2014, this event raised over \$20,000 (compared to just under \$10,000 in 2013) and saw a 15% increase in participation, growing from 230 to 270 runners.



TOTAL RAISED

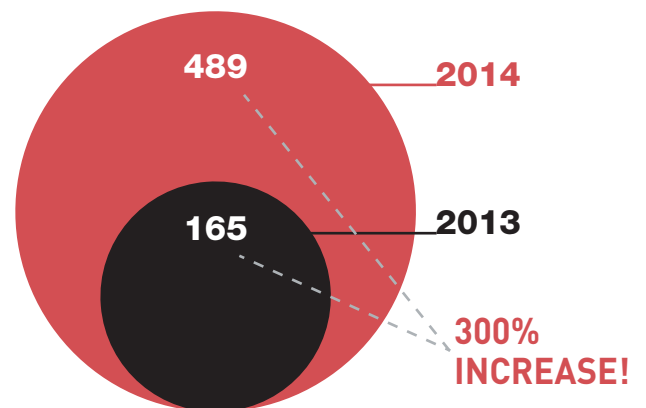


TOTAL DONATED VIA CREDIT CARD



The use of the new Personal Fundraising platform led to a 100% increase in revenue, and the amount of credit card gifts more than doubled.

JOGGING FOR JONAH DONORS



The use of the new Personal Fundraising platform increased the number of Jogging for Jonah donors by over 300%!



Butterfly 5K

The First Annual Butterfly 5k took place this past September at Salt Fork State Park in Cadiz, Ohio and raised over \$7,000 in honor of Hannah Blake, who lives with EB. They didn't just work hard in September though! This event team held events throughout the year in support of their 5k and debra of America, including a Celebrity Server Night where local celebrities donated their time as waiters to fundraise for EB. Good job team!

CovyCon

The 1st Annual CovyCon is proof that an event doesn't have to be a 5k to be successful. The friends and family of Michael "Covy" Covert came together to throw a tournament of his favorite game, Magic: The Gathering, in his memory. Their event raised over \$1,000 for EB research and also served as a loving reminder of an extraordinary person.



Thank you to all of our Local Event Organizers, who worked so hard this year to raise awareness and over \$350,000 for EB. We couldn't continue to fight EB without you!

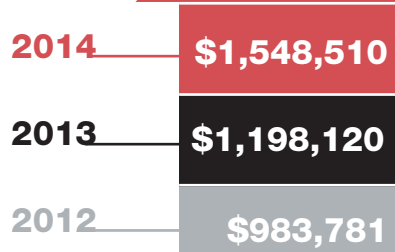
INTERESTED IN HOSTING A LOCAL EVENT OF YOUR OWN?

We're happy to help! Check out debra.org/PlanLocalEvent for ideas, or contact us at events@debra.org or **212-868-1573**.

Financial Analysis

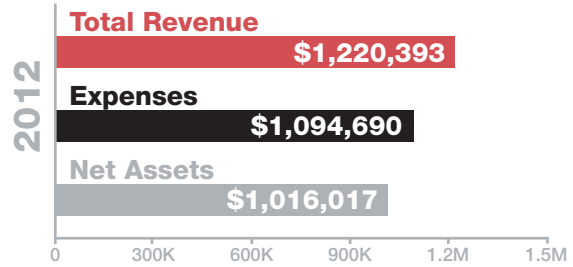
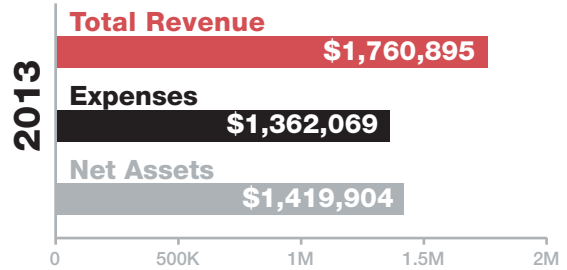
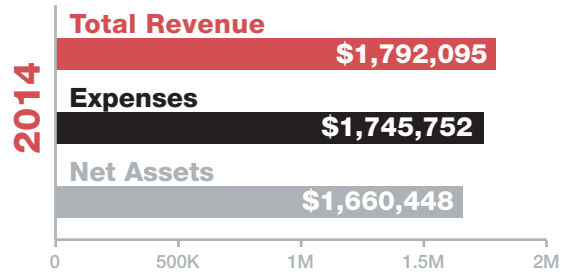
REVENUE	2012		2013		2014	
Special Events	119,737.00		622,050.00		486,111.00	
Contributions & Grants	948,110.00		716,217.00		819,178.00	
In-Kind Contributions	32,943.00		370,269.00		437,302.00	
Investment Income	2,892.00		3,917.00		-2,683.00	
Other	n/a		11,886.00		13,488.00	
Net Assets Released	116,711.00		36,556.00		38,699.00	
TOTAL REVENUE	1,220,393.00		1,760,895.00		1,792,095.00	
	2012		2013		2014	
TOTAL ASSETS	1,187,157.00		1,547,797.00		1,722,111.00	
Total Liabilities	171,140.00		127,893.00		61,663.00	
Unrestricted Net Assets	911,964.00		919,775.00		966,124.00	
Temporarily Restricted Net Assets	104,053.00		500,129.00		694,324.00	
Total Net Assets	1,016,017.00		1,419,904.00		1,660,448.00	
TOTAL LIABILITIES AND NET ASSETS	1,187,157.00		1,547,797.00		1,722,111.00	
EXPENSES	2012		2013		2014	
Education	147,880.00	12%	167,613.00	10%	235,606.00	13%
Patient & Family Services	500,010.00	41%	908,129.00	52%	1,159,760.00	65%
Advocacy	22,182.00	2%	25,142.00	1%	35,341.00	2%
Research	313,709.00	26%	97,236.00	6%	117,803.00	7%
TOTAL PROGRAMS EXPENSES	983,781.00	81%	1,198,120.00	68%	1,548,510.00	86%
	2012		2013		2014	
Management	36,970.00	3%	41,905.00	2%	77,096.00	4%
Fundraising	73,939.00	6%	122,044.00	7%	120,140.00	7%
TOTAL EXPENSES	1,094,690.00	90%	1,362,069.00	77%	1,745,752.00	97%

INCREASE IN PROGRAM SPENDING



Spending on Programs and Services has risen every year.

THREE-YEAR FINANCIAL ANALYSIS



How You Can Help



VOLUNTEER

Get Engaged. Get Involved. Raise EB Awareness!

- **Local Events:**
Help raise EB Awareness by hosting, attending, or volunteering at a Local Event.
- **NYC Benefits:**
Attend or volunteer at one of debra of America's NYC events, including our Tennis Pro-Am and Annual Benefit.

JOIN A COMMITTEE

- **Young Leadership Committee (YLC):**
The YLC is comprised of young professionals who host and participate in debra of America events across the country and whose mission is to fundraise and make an impact on behalf of those with EB.
- **EB Impact Committee:**
EB Impact Committee members advocate for the EB Community. They are members of EB families and can truly speak to the daily struggles of having EB.

For more information about volunteering or joining a committee, please email events@debra.org.



MAKE A GIFT

A gift from you directly impacts EB families. Here are a few ways that you can help...



-
- \$2,500** Sponsor an activity at the 2016 debra Care Conference in Dallas, Texas.

 - \$1,200** Provide a New Family Advocate box, which contains helpful EB information, products, and guidelines on wound care to a new EB family.

 - \$500** Help find a cure by supporting research.

 - \$250** Make a gift to the Smile Fund and help grant a wish for a child with EB.

 - \$173** Help 1 EB family beat a denial of insurance coverage with our Legal Aid Program.

 - \$100** Send free wound care supplies to 4 EB families.

 - \$35** Send 1 specialized, microsuede diaper to 5 babies with EB.

To make a gift, go to debra.org/Give.

For more information about supporting debra of America, please email donations@debra.org.



Our Supporters

\$50,000 +

Mr. John Lee

McKesson Patient Care Solutions Inc.

Mölnlycke Health Care

Scioderm

\$25,000 - \$49,999

Mr. J. Alec and Mrs. Cindi Alexander

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DONOR SPOTLIGHT

"My sister was born in 1938 with a severe form of EB and died of melanoma in 1978. I had been looking for an organization that supports EB research and, as a tennis fan, had read of Mats Wilander's involvement with debra of America. Mats connected me with Brett Kopelan, debra of America's Executive Director, and I became a donor several years ago. I watched what Brett was doing for debra of America, was happy with the organization's progress, and as a result I gradually increased my financial support. Last year, Brett asked me to join the Board of Directors. It's been a pleasure to be a part of an organization that does so much for the EB Community. I hope that someday we will find a cure." – John Lee



**\$1,000 -
\$4,999**

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\$999.99**

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Aristotle
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Services, Inc.
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Auslander-Stevens
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Deb Bailey Family
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DONOR SPOTLIGHT

“debra of America came into our lives like an angel from heaven! After my daughter Cattaleya (“Catt”) was born, doctors at RUMC NICU connected us with Columbia Presbyterian Dermatology who then contacted Geri Kelly, debra of America’s EB Nurse Educator. Geri and debra of America educated us on EB, provided us with tips on how to take care of Catt, and most importantly answered our millions of questions.



What does debra of America mean to me? Wow. This might turn into a romance novel. Most importantly, debra of America means hope. Hope that through their efforts of raising awareness and raising funds for research, we can obtain the goal of finding a cure for EB.

debra of America has become very dear to me. As all new EB parents know, not being able to obtain the necessary supplies to take care of our babies is the last thing we need to go through when facing this horrible disease.

Often, my insurance company declares that Catt’s wound care supplies are ‘over the counter’ and are therefore not covered. Hmm. Over the counter? I can just imagine walking into CVS and asking for Mepilex Transfer, MediHoney, and Tubifast – to name a few.

Well, this is where debra of America stepped in. One day, in the midst of my insanity over fighting with my insurance company and researching the prices of such ‘over the counter’ supplies, I called the debra of America office. Casey answered the phone. I was crying and asked him if there was a way for me to buy the supplies from debra of America at a more reasonable price. He paused, then said, ‘You have nothing to worry about. I’m going to email you a form. Fill it out and email it back to me. I will check what we have in stock and will send you a box.’

I couldn’t believe what I had heard! Prior to my call, I had made a list of all non-essential ‘luxuries’ our family needed to get rid of in order to afford Catt’s necessary wound care. I didn’t care. I could do without cable.

I had no idea debra of America could send supplies. And BOOM! The next day there was a box on my porch. I wept. It gave me a few more weeks to battle the insurance company. It gave me confidence and hope. Needless to say, debra of America, to me, means love.

I just want to say that even though this has been the longest 7 months of my life, I have been blessed with the strongest little girl ever. Cattaleya is such a happy baby. Even when her skin is raw and she is in pain, you can blow her a kiss and she will smile. She has shown us so much strength and courage. It’s very admirable. I am truly honored that God thought I was strong enough to be her mom, and I will not let him down.

We will find a cure!” – Linda Velazquez

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DONOR SPOTLIGHT

“I have Dominant Dystrophic Epidermolysis Bullosa and when I was born, not much was known about the condition. My parents were first-time parents and knew little about parenting, let alone EB. They were referred to a doctor who had previously seen only one case of Epidermolysis Bullosa (EB). My Mom asked the doctor, ‘How is that child doing?’ and the doctor, who obviously needed better bedside manner, replied, ‘Oh it died.’ So, of course my Mom was devastated and expected the same outcome for me.



It was kind of difficult growing up, but my parents were troopers. They let me be a child knowing that I could get hurt – they wanted me to know that I could do and be anything. They didn’t want me to feel sorry for myself. And here I am, fifty-something years later.

My Mom and I heard about debra of America thirty years ago and we decided to support the organization with the hope that someday a cure for EB would be found. We were so excited that debra of America was really doing something about this condition that no one knew about!

While I haven’t used debra of America’s Programs and Services myself, I greatly respect their EB Nurse Educator Program. Having someone you can call that will answer your EB questions – when so many doctors and nurses know little about this condition – is empowering, provides hope, and makes families feel less alone.

When I was born, there were no support services! Parents of EB children and EB patients were on their own, and you didn’t have anyone to discuss issues with or ask questions to. So having support out there like debra of America’s EB Nurse Educator Program – it’s the best thing in the world!

In October 2014, during EB Awareness Week, I hosted a wine tasting to help raise awareness. It turned out better than I had expected. So many people attended to support the cause and to support me because they know what I’ve been going through all these years. I always tell people, ‘There are children with EB that are so much worse. There are children whose fingers are webbed together, and they can’t walk. There are some that don’t live past their teenage years. I’m lucky!’ When you’re compassionate about EB, it makes people want to listen and get to know how they can get involved.

Yes, sometimes people stare, but I’d rather people ask about my EB. I want to tell them about it! I want to explain that now there’s research being done, there are organizations like debra of America and one day there will be a cure!” – Laurie Mucherino

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