





With gratitude to our strong Epidermolysis Bullosa (EB) Community of patients, caregivers, researchers, and supporters. Thank you.



Because the cost of doing nothing is too great is an axiom that directs all we do to fulfill our mission. debra of America is dedicated to improving the quality of life for those living with EB. To achieve our mission, we do two things in parallel: we provide free programs and services to the EB Community in the U.S. and fund the most innovative research directed at symptom relief and a systemic cure.



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LETTER FROM BRETT KOPELAN

DEBRA OF AMERICA'S EXECUTIVE DIRECTOR

Dear Friends,

2019 proved to be quite a year. Our hope for an effective treatment for EB has turned into an expectation of multiple available treatments. We've gone from a hopeful time in academic research, to meaningful engagement in the drug development and regulatory process. With the help of our industry partners, we have therapies in all stages of drug development. We could see a real sea change in terms of available treatments in two years' time. We've made a difference, a big difference, and we have you, our supporters, to thank.



Brett Kopelan with Spirit Award Honoree, Eli Meyer, at the 21st Annual Benefit in New York City

Because of our advocacy, we are once again on the list of eligible diseases to receive funding through the Congressionally Directed Medical Research Program's Peer-Reviewed Medical Research Program. Through this Department of Defense Program, more than \$14 million has been awarded to academic researchers and biotechnology firms advancing therapies for EB.

Programmatically, 2019 was a busy year. The number of new families, the number of repeated engagements in a single program, as well as the number of programs accessed by each family have all increased. It's easy to see that the need for help has again risen and I am proud to say that the team at debra of America has risen to the challenge. We wouldn't be able to provide this kind of impact without your generosity.

By all accounts, 2019 was a successful year. We honored three more biotechnology companies for beginning to develop treatments for EB. We deepened our relationships with our other industry partners and with other advocacy groups. Your support has allowed us to effectively help the EB Community, increase institutional and public knowledge, and expand our scope. Thank you for your support.

I see your support as an investment in our organization. I believe it is important for us to deliver a return on that investment. I think we have. I know we have. We've built a foundation that attacks the issues of EB on many fronts. Thank you for your trust and confidence in our ability to provide that return on your investment. I promise that next year will be even better.

Many thanks,

Brett Kopelan

Executive Director, debra of America

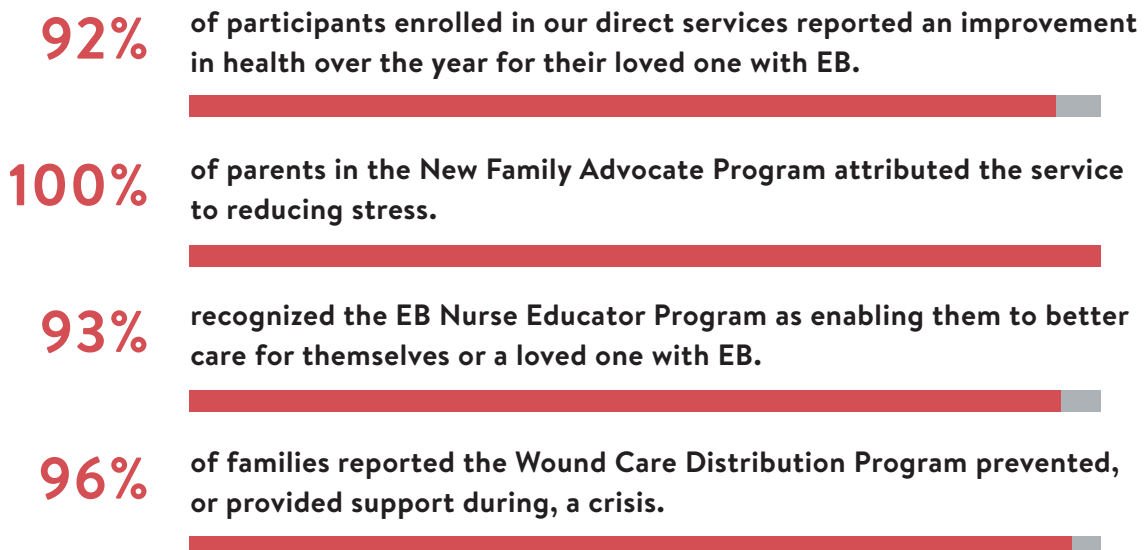
OUR REACH

In 2019, both our new and our committed donors made it possible for those impacted by Epidermolysis Bullosa to access debra of America's free direct-to-patient programs. These vital services provide immediate relief and improve the quality of life for hundreds of families across the United States.

In 2019, our program participants accessed:



Our Impact on the EB Community:



2019 AT A GLANCE

Elijah's Journey

“Elijah was born March 23, 2019 at 8:57am. He was born healthy and showed no signs of Epidermolysis Bullosa at first. That night, I noticed a small blister on his bottom, but the NICU doctor said it was just a water blister. The next day, I went to change his diaper and his entire bottom was filled with blisters everywhere. None of the nurses or doctors knew what it was. He spent 12 days in the NICU and we were told it could be an infection or EB, which I had never heard of before. Six weeks later, the genetic work came back positive for EB Simplex.

Life as I know it changed. I was so lost and terrified. Luckily, Elijah's dermatologist told me about debra of America. I got set up with a free care package, received resources and help. They even paired me with another EB family in my area. The care package was very helpful and made me feel a lot more prepared. I would still be lost if it wasn't for debra of America. When I have any questions, I know the team at debra will help.”

— Angel, Elijah's mom



Elijah H., living with Epidermolysis Bullosa Simplex



Elijah H. during NICU stay, March 2019. Like many, Elijah's family was unable to get answers from doctors or nurses, due to the gap in knowledge about Epidermolysis Bullosa.

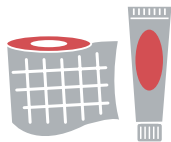
New Family Advocate Program

debra of America estimates that 200 babies are born with one form of EB every year in the United States. The New Family Advocate Program aims to provide a full support system to the parents and caregivers of each one of these children.

New families get a package of wound care supplies, instructions on how to use them, information about wound care distributors and insurance needs as well as how-to's on wound care, bathing, and prevention of blisters. Additionally, through this program, we encourage continued contact between us and the family to provide them with support through our other programs and services.

64%

of EB Families' medical insurance denies them coverage of necessary wound care supplies.¹
So, we send free bandages...



110,753

Bandages
and Medical
Supplies Sent



578

Care Packages
Delivered Across
the Country



\$1,040,492

Value of Wound Care
Supplies Provided to
Children and Adults with EB

Wound Care Distribution Program

Specialized bandages and other wound care supplies can have a price tag of **\$84,000 a month** for those with EB. Our Wound Care Distribution Program provides these supplies for free to adults and children, like brothers **Eli and Kade** (right), who both have Junctional Epidermolysis Bullosa.



“You guys [debra] are life savers and an answered prayer. We have tried again and again to appeal to our insurance with the help of our boys’ pediatrician and dermatologist, but keep getting denied.”

¹The challenges of living with and managing epidermolysis bullosa: insights from patients and caregivers. Bruckner et al. Orphanet Journal of Rare Diseases (2020)

GOVERNMENT & LEGAL AFFAIRS

In its fourth year of existence, our Government Affairs & Legal Aid Programs continue to expand and reap rewards from our efforts. Our Legal Aid Program helps more people with denials of service from insurance companies and school boards' refusal to enact clauses in Individualized Education Program or 504 plans, among other issues. Our work on Capitol Hill continues to pay off with stronger relationships with federal government officials and relevant agencies in addition to having more involvement with and leadership roles within other advocacy groups.

Federal Funding of EB Research

Due to our efforts advocating for federal research dollars to be allocated to EB initiatives, we are again on the list of diseases eligible to apply for funding through the Congressionally Directed Medical Research Program's Peer-Reviewed Medical Research Program. Through this Department of Defense Program, more than \$14 million has been awarded to academic researchers and biotechnology firms advancing therapies for EB. Our continued engagement with members of Congress and the Senate has provided this funding opportunity for individuals and companies alike.

Maintaining a Capitol Hill Presence

Our bi-partisan engagement on Capitol Hill has ensured what is called "report language" be included in Appropriations Bills for Fiscal years 2018–2020 from the congressional Department of Labor, Health and Human Services, Education and Related Agencies. This committee controls the budget for agencies like the FDA and NIH. (check that with Joe). Furthermore, our work with NIAMS, or the National Institute for Arthritis, Musculoskeletal, and Skin Diseases, a division within the NIH has led to the continued highlighting of EB.

Supporting the Needs of the EB Community

The number of engagements with people from the EB Community continues to increase within our Legal Aid Program. Unfortunately, some members of the EB Community face uncertainty when it comes to accessing or maintaining essential medical treatments, employment opportunities, educational support, as well as general ADA issues. Specifically, we have assisted families with: denials of service from their health insurance providers, Social Security Disability Insurance (SSDI) applications and denials, employment-related letter of support, wound care supplier issues with Doctor's offices and insurances, and general questions about navigating the hurdles life presents when you have a disability. We have increased our trusted network of professionals in the fields of disability law and advocacy to increase our assets because of the specialized needs of the EB Community.

"debra's Nurse Educator and Legal Affairs Director supported us in Clara's case with our local school board. We won our appeal for a request for approval of necessary services for Clara's educational needs. They were part of our team of encouragers who helped equip our ask to give Clara the services she deserves to thrive at school and beyond."

– Becky and Francisco Bodan on behalf of their EB Simplex daughter Clara

Selected Highlights of Partnership Activities :

- Submitted written public testimony to the House of Representatives Committee on Appropriations, Subcommittee of Labor, Health and Human Services, Education, and Related Agencies regarding the importance and critical need for federal investments promoting EB research.
- Invited to serve as a Co-Chair of the Everylife Foundation for Rare Diseases Community Congress Public Policy Working Group, an influential, Washington, DC grassroots group of rare disease advocates.
- Accepted invitations to speak and participate at key rare disease forums including the Coalition for Clinical Trial's Awareness, the Rare Disease Congressional Caucus, the National Center for Advancing Translational Science, Global Genes, and the Defense Health Research Consortium.

SUPPORTER LED EVENTS



dash4debra

The 5th Annual dash4debra hosted by Megan Gosselin in Lake Forest, IL was held in memory of a brave young man, Achyuth, who was born with EB and passed away in 2018. More than 100 day-of runners plus virtual runners from all 50 states and five countries, participated. In 5 years, dash4debra has raised over \$100,000 for debra of America.



San Antonio Butterfly 5K

The inaugural San Antonio Butterfly 5K was hosted by Whitney Ramsey and Angie Songster in Bulverde, Texas. There was so much enthusiasm for this family-fun event, which included medals, t-shirts for all participants and children-centric games. It was a tremendous success with more than 150 people attending. EB families, friends and runners were able to raise more than \$6,000.



Derrick Harding's Online Fundraising Page

Derrick Harding's online fundraiser for debra of America was in honor of his partner Nick, who has EB. Derrick's page raised much-needed funds and helped to raise awareness. His message of love and strength to people and families affected by EB is an inspiration.



Butterfly Wishes for Ellie

The Tavani family hosted the 13th Annual Butterfly Wishes for Ellie in Atlanta, GA in honor of their daughter, Ellie, who has EB. The event raised over \$50,000 and brought over 180 guests together to celebrate Ellie and all who struggle with EB. Guests danced to a coveted local rock band, bid on exciting silent auction items, and enjoyed a night under the stars.



In memory of Malia Bunion

The Bunion Family lost their precious EB Angel Malia after only 6 months. Because of their gratitude to debra of America for the support provided throughout Malia's six-month journey, they asked their family members and friends to donate to their personal fundraising page in Malia's honor. The response was overwhelming with 157 donations raising \$11,000 to benefit debra of America.



Painting with a Purpose

Cristina Spennato hosted Painting with a Purpose in Glen Mills, PA, which included a painting class, wine, an open buffet, and a raffle. The event raised awareness of the difficulties of living with EB and provided funding for debra of America Programs, in memory of Cristina's son, Josiah Robinson. Josiah was a sweet, loving boy who, despite his pain and suffering from living with EB, managed to be such an inspiration to so many. His strength and dignity made him a true EB warrior.

Interested in hosting an event of your own? We're happy to help! Visit debra.org/PlanEvent for ideas, or contact us at events@debra.org.

DEBRA HOSTED EVENTS



The 21st Annual debra of America Benefit

Over 350 guests joined us at the 21st Annual debra of America Benefit at Tribeca 360° in NYC. The event was filled with many highlights, and we were honored to recognize our evening’s award recipients: Al Lane, M.D. (Lifetime Achievement Award), Jeffrey S. Aronin (Corporate Hero Award), and our three Partners in Progress Award honorees, Aegle Therapeutics, Amryt Pharma, and Lenus Therapeutics. The evening was especially memorable as we heard very moving and poignant words from our two Spirit Award honorees, Hodges R. Caldwell, Jr. and 7-year-old Eli Meyer.

A huge thank you to our sponsors, supporters, volunteers, and guests for making the 21st Annual debra of America Benefit such a wonderful evening!



“I was deeply grateful to be selected for the Lifetime Achievement Award. Going to New York City to receive the award reminded me of Dr. D. Martin Carter who was a Professor at Rockefeller University. Dr. Carter was from one of the early leaders in EB care and debra. Dr. Carter died at the young age of 56. During his lifetime he taught many of us how to treat patients with kindness and compassion. The honor of receiving your Lifetime Achievement Award created in me a sense that we have truly followed in Dr. Carter’s path and the path of the early debra leaders. Today, more than ever, we are able to improve the lives of patients with EB with not only kindness and compassion but also we are advancing science to offer better therapies and exciting roads to a cure.”

— Al Lane, MD, Recipient of the 2019 Lifetime Achievement Award

“I attended the annual gala for the first time in 2018, accompanying a family friend who was receiving an award. I walked into Guastavino’s, where the event was held that year, knowing little to nothing about debra or EB. It was only a matter of minutes before I found myself in tears, so unbelievably moved from observing the children. That evening truly changed my outlook on life, and I knew I wanted to get involved with this amazing organization.”

— Mackenzie Alderman, 21st Annual debra of America Benefit Committee Member



3rd Annual EB at TPC

Thanks to our guests, committee members, celebrity participants, volunteers, and generous sponsors, Debra of America's EB@TPC Celebrity Golf Classic was a success. Players enjoyed the newly redone 18 holes at award-winning course, TPC Sugarloaf, in Duluth, GA for a great day of golf and prizes. We were thrilled to have PGA Tour Champion Stewart Cink join us as one of more than 30 celebrity guests. A very special thank you to our event co-chairs, NFL legends Kevin Butler and Brian Finneran as well as former NFL stars Drew Butler, Peerless Price, Dunta Robinson, former MLB pitcher Kris Medlen, and former NBA All-Star Dale Ellis. We would also like to thank Debra of America board members J. Alexander and Rob Rayl for aiding in the success of this wonderful day.



“My wife Erin and I have been involved in several charitable organizations over the last 2 decades and we will continue to help where we can. When I learned about Debra and the fight against EB I wanted to help in any way I could. The more I learned about EB the more I wanted to help, working with Brett and his staff has been great and we will continue to raise awareness and work towards a cure!”

— Brian Finneran, Former NFL Star (Atlanta Falcons)



2nd Annual Debra of America Benefit Concert

Grammy Award-winning guitarist Warren Haynes, keyboardist John Medeski, bassist George Porter, Jr., drummer Joe Russo, and saxophonist Karl Denson came together on Saturday, October 19th for an exciting night of music and fun at The Capitol Theatre in Port Chester, NY! Proceeds from the “One Night Only...Again” concert benefited Debra of America. Thank you to everyone who came out in support of the EB Community!

“As a parent, I couldn't help but be moved by the stories I heard from those directly affected by EB. When asked by the fine folks at Debra to assist in the mission to both raise awareness about EB and continue to fund research for a cure, I said yes without hesitation. I quickly realized I was not only presented with a great opportunity to help a great cause, but also, if everything lined up, to put together an amazing band for a one-time show.”

— Warren Haynes, Grammy-Award Winning Guitarist

Poker to Cure Tournament

In March, Mansfield Cares, Inc. and Debra of America hosted the Poker to Cure Tournament, one of several regional Texas Hold'em play-ins across the country, at the Playwright Irish Pub in New York City. The first-place winner won an all-expense paid trip to play at the finals table of the regional play-ins at Reynolds Lake Oconee with accommodations at the on-site Ritz-Carlton Hotel. Proceeds from the night benefited Debra of America and the Muscular Dystrophy Association.

TEAM DEBRA

TEAM DEBRA had 43 participants run, cycle, and walk in these events and more around the country to raise over \$90,000 for EB!



**Rock 'n' Roll
Washington DC
MARCH 9**

"I run for TEAM DEBRA in honor of my wife's family. Localized epidermolysis bullosa simplex is hereditary on my wife's mother's side of the family. You would never know this about my mother-in-law or her family because they never complain. I run for them."

- Joshua, EB Spouse



**New York City
Half Marathon
MARCH 17**

"I ran for TEAM DEBRA because EB has directly touched my life. My best friend's son has EB and I have seen the impact it has had on his family and their lives. However, his attitude is that his son is just another kid!"

- Heather, EB Advocate



**Cincinnati Flying
Pig Marathon
MAY 4-5**

"Running for TEAM DEBRA meant so much to me and for my son with RDEB. I enjoy running and the Flying Pig race is unique and quite large, so it was a great way to help raise awareness for EB."

- AJ, EB Dad





**TD Five Boro
Bike Tour**
MAY 5

“The mission of debra resonates deeply with me. I cannot imagine the privilege of physical activity and being part of the great outdoors being taken away from any child. To help alleviate the suffering of kids who are shortchanged on that experience in any way possible was what drove me to ride and raise funds for debra.”

– **Raj**, EB Advocate



**Chicago
Marathon**
OCTOBER 13

“I ran for TEAM DEBRA because I have family and friends who work intimately with trying to find a cure for EB. By running with TEAM DEBRA, I wanted to show my support for everyone involved with the EB Community.”

– **Cole**, EB Advocate



**NYC
Marathon**
NOVEMBER 3

“My husband has EB - he’s been able to do everything he’s wanted to do in life - including running marathons himself. I ran for debra to help the next generation of EB warriors.”

– **Jane**, EB Spouse

Want to Join TEAM DEBRA?

TEAM DEBRA is a group of individuals, friends, family members, and colleagues who are committed to training for EB. TEAM DEBRA runs, walks, cycles, trains, and moves to help find a treatment and cure for EB. Email teamdebra@debra.org or call **212-868-1573 ex 109** to learn more!

FINANCES

REVENUE	2017		2018		2019	
Special Events	\$ 705,275		\$ 1,213,898		\$ 850,383	
Contributions & Grants	656,801		595,150		698,656	
In-Kind Contributions	1,015,581		931,177		1,080,786	
Investment Income	106,135		(71,923)		(4,584)	
Other	1,700		6,126		3,347	
Net Assets Released	78,727		44,315		9,694	
TOTAL REVENUE	\$ 2,564,219		\$ 2,718,743		\$ 2,638,282	
	2017		2018		2019	
TOTAL ASSETS	\$ 2,874,508		\$ 2,398,499		\$ 2,874,508	
Total Liabilities	165,523		279,616		311,682	
Unrestricted Net Assets	\$ 1,857,982		\$ 1,304,758		\$ 1,283,751	
Temporarily Restricted Net Assets	851,003		814,125		811,647	
Total Net Assets	2,708,985		2,118,883		2,095,398	
TOTAL LIABILITIES AND NET ASSETS	\$ 2,874,508		\$ 2,398,499		\$ 2,407,080	
EXPENSES	2017		2018		2019	
Education	\$ 264,502	10.5%	\$ 389,769	18.1%	\$ 282,044	19.2%
Patient & Family Services	1,880,300	74.8%	1,218,364	56.6%	788,790	53.8%
Advocacy	39,674	1.6%	58,465	2.7%	42,306	2.9%
Research	132,250	5.3%	194,884	9.0%	141,022	9.6%
TOTAL PROGRAMS EXPENSES	\$ 2,316,726	92.1%	\$ 1,861,482	86.4%	\$ 1,254,162	85.6%
Management	\$ 66,126	2.6%	\$ 97,442	4.5%	\$ 70,511	4.8%
Fundraising	132,249	5.3%	194,884	9.0%	141,022	9.6%
TOTAL EXPENSES	\$ 2,515,101	100%	\$ 2,153,808	100%	\$ 1,465,695	100%

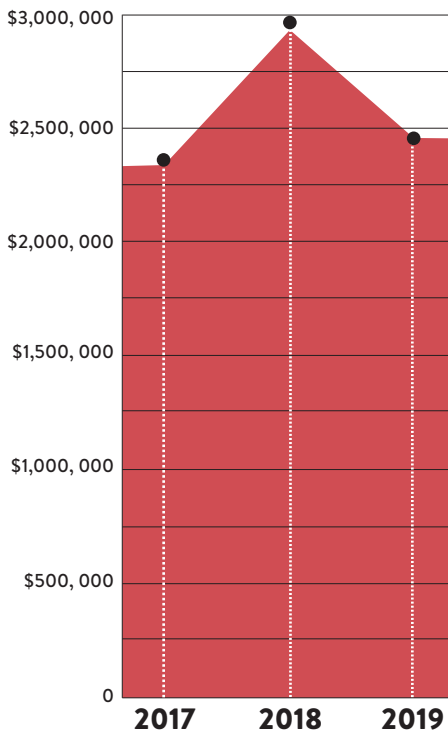


**2019 BREAK DOWN
OF PROGRAM EXPENSES**

- 80.5%** Patient & Family Services
- 11.7%** Education
- 5.8%** Research
- 1.7%** Advocacy



PROGRAM SPENDING



OUR SUPPORTERS

Thank you to our donors and sponsors for your invaluable support!

\$50,000 +

Mr. J. and Mrs. Cindi Alexander
Mr. John Lee
Mölnlycke Health Care

\$25,000–\$49,999

BERG
Castle Creek Pharmaceuticals
Fibrocell Science Inc.
Mr. Rick and
Mrs. Deborah Gallagher
Mansfield Oil
Mr. Johnny McCranie and
Ms. Nancy Sanderson
Paragon Biosciences

\$15,000–\$24,999

Amicus Therapeutics
EB Hope Foundation
Ms. Kathleen Marquardt
Mr. Eric and Mrs. Sarah Schmidt
Mr. Wonsuk Yang

\$10,000–\$14,999

Abeona Therapeutics, Inc.
Mr. Jeff Aronin
Mr. Robert Coull and
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ConvaTec
Kohl's National Giving Program
Ms. Cheryl Manor
McKesson Patient Care
Solutions Inc.
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Mr. Rick Rondinelli

\$5,000–\$9,999

Mr. Deepak and Mrs. Mansi Arora
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“My desire to support families with EB has been the main motivating factor in my decision both to attend medical school and to become a part of debra of America. My sister Rebecca passed away from Junctional EB (JEB), so I understand how devastating this disease can be and the important role that debra serves. I have enjoyed the opportunity to become as involved with debra as possible, from fundraising and volunteering as part of the Benefit Committee to conducting research in Dr. Jouni Uitto’s DEBRA Molecular Diagnostics Laboratory. Becoming a part of debra has been extremely rewarding, and I look forward to staying involved with the community throughout my career and beyond.”

— Hannah Number, 21st Annual debra of America
Benefit Committee Member



Top Junior Golfer, Luke Sample raised an incredible \$1,100 for the EB Community through the American Junior Golf Association Leadership Links program!

Luke shares, “debra of America represents one tiny way in which, through the game I love, I can help kids whose struggles are far tougher than bad rounds.”

A special thank you to our Hero Circle members and EB Champions! Their gifts allow us to invest in the long-term support of the EB Community.

HERO CIRCLE

Mr. Deepak and Mrs. Mansi Arora
 Mr. Nikolaus Csakany
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 Mr. Ryan Sykes
 Ms. Kathleen Tomsic
 Ms. Debra W Vernick
 Ms. Kathleen Winter
 Mr. Qasim Zubair



“I became a supporter of debra of America after I met Carson and Colby, who both live with EB. Once I met Carson, Colby and the Kissell family, I knew I had to do something to help find a cure for EB.”

— Cole & Christine McCollum, Milton, FL

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Timothy Wright, D.D.S., University of North Carolina at Chapel Hill



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visit: debra.org/get-help

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“I was compelled to get involved with debra of America from the moment I learned of the organization. The mission to support those with Epidermolysis Bullosa (EB) and their families from an emotional, social, economic and research perspective is unparalleled to any other organization. The compassion and warmth you encounter from everyone involved in debra is heartwarming. When I was asked to serve on the Benefit Committee, I was honored and overjoyed to get involved. In doing so, I was able to educate so many of my friends, family, and colleagues on what it means to have EB. Every year I look forward to the Benefit event knowing that I will see familiar faces, meet new and inspiring people and support such a worthwhile cause.”

— Susan Maksomski, 21st Annual debra of America Benefit Committee Member



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