



**debra**

because the cost of doing nothing is too great

“It’s hard to write just one sentence since your organization has helped me even before the birth of my daughter Lindy. Since I myself suffer from EB, I reached out to debra of America before getting pregnant to learn what the odds were that my children would get EB too. Once I got pregnant, my doctors were unfamiliar with EB and I reached out to debra again for information to provide to them for the birth. The information was very helpful in the hospital so they knew how to handle my daughter.

After coming home, it has been so helpful to have debra as a resource for ideas on how to help her and for the box of medical supplies that you provided to us. I really rely on your organization for this knowledge since our Pediatrician is unfamiliar with EB.

—RICHELLE, EB MOM



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 services and programs to the EB Community in the US and fund the most innovative research directed at symptom relief and a systemic cure.

PHOTO CREDITS: ARI ESPAY 2016



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A Letter from Brett Kopelan, debra of America's Executive Director

Dear Friends,

2017 proved to be quite a year. Our hope for an effective treatment for EB has turned into an expectation of a better life. The utilization rates of our free programs and services increased exponentially year over year and our advocacy work in DC reached as high as the White House. We've made a difference, a big difference, and we have you, our supporters, to thank.

Because of our advocacy, the Department of Defense, through the Congressionally Directed Medical Research Program, awarded more than \$9 million to EB researchers in fiscal year 2017. What's even better is that EB is once again on the list of eligible diseases to receive funding through this program in fiscal year 2018. The relationships we've built on Capitol Hill have paid off. Looking at it in investment terms, we've realized a larger than 10,000% return on our investment into this initiative.

We've analyzed our direct to patient services and have demonstrated that they have proven to reduce stress, to increase efficacy of care, and to bring greater knowledge to those



**Brett Kopelan with
Mistress of Ceremonies,
Rebecca Jarvis, at the
19th Annual Benefit in
New York City**

who have utilized at least one of our programs. 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 provide an immediate impact and our success is all thanks to you, our dedicated supporters.

EB was also in the news more in 2017 than in the past. We worked with a writer from the *Washington Post* on an article and a video piece that was picked up by many other outlets. They told us that a video piece is considered successful if it achieves 15,000 views. The story of Ella was viewed more than 1 million times. In response to that story, we developed a social media campaign called Tag with Ella. Ella said in the article that if she didn't have EB, she would want to play a game of tag with her friends. So, our goal was to give Ella a gift of a virtual game of tag. We asked people to use the hashtag #TagWithElla in a social media post. We then aggregated the posts that contained the hashtag on an off-brand website. It was very successful. Congressmen, Senators, the general public, and celebrities like Josh Groban and Gal Gadot all participated.

By all accounts, 2017 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. We were asked to be featured speakers at conferences covering topics like market access, pricing, and using real world data versus placebo controlled trials. 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.

In fact, 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 2018 will be even better.

Many thanks,

A handwritten signature in black ink that reads 'Brett'.

Brett Kopelan

Executive Director, debra of America

Whether it was our Wound Care Distribution Program, EB Nurse Educator, or Legal Aid Program, more people than ever before utilized our free programs and services in 2017. We equipped each community member with the right resources at the right times. This had the effective result of lessening the painful burdens that come with this serious and complex disease. While we have seen a year over year increase for the need of our services, 2017 proved to be a year in which the need increased at an unprecedented level. Your support enabled us to answer the call. **Thank you for being part of the debra of America family.**

MORE PEOPLE ARE USING DEBRA'S SERVICES THAN EVER BEFORE

Total Value of Wound Care Supplies Shipped:

\$1.09 MILLION

39%↑
FROM FY16

Services in Action:

NURSE HELPLINE

780 HOURS SPENT EDUCATING FAMILIES AND CLINICIANS

EMERGENCY KITS

300 EB EMERGENCY KITS DISTRIBUTED IN OVER 30 STATES

LEGAL AID

37 FAMILIES ASSISTED WITH OBTAINING DESERVED INSURANCE COVERAGE

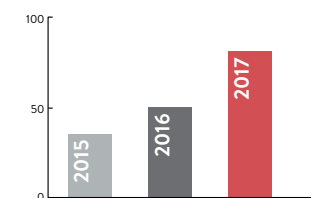
SMILE FUND

12 SMILES CREATED IN 2017 BECAUSE OF MINI-WISHES SENT EVERY MONTH

NEW FAMILY CARE PACKAGES

81 REPORTED NEWBORNS WITH EB RECEIVED NEW FAMILY CARE PACKAGES IN 2017

DISTRIBUTION OF NEW FAMILY CARE PACKAGES



65%↑
FROM FY16

Most Common Areas We Addressed:



WOUND CARE



INSURANCE ISSUES



MEDICAL REFERRALS

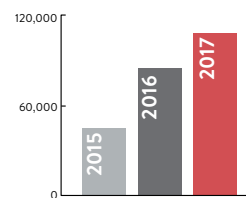


EMOTIONAL SUPPORT

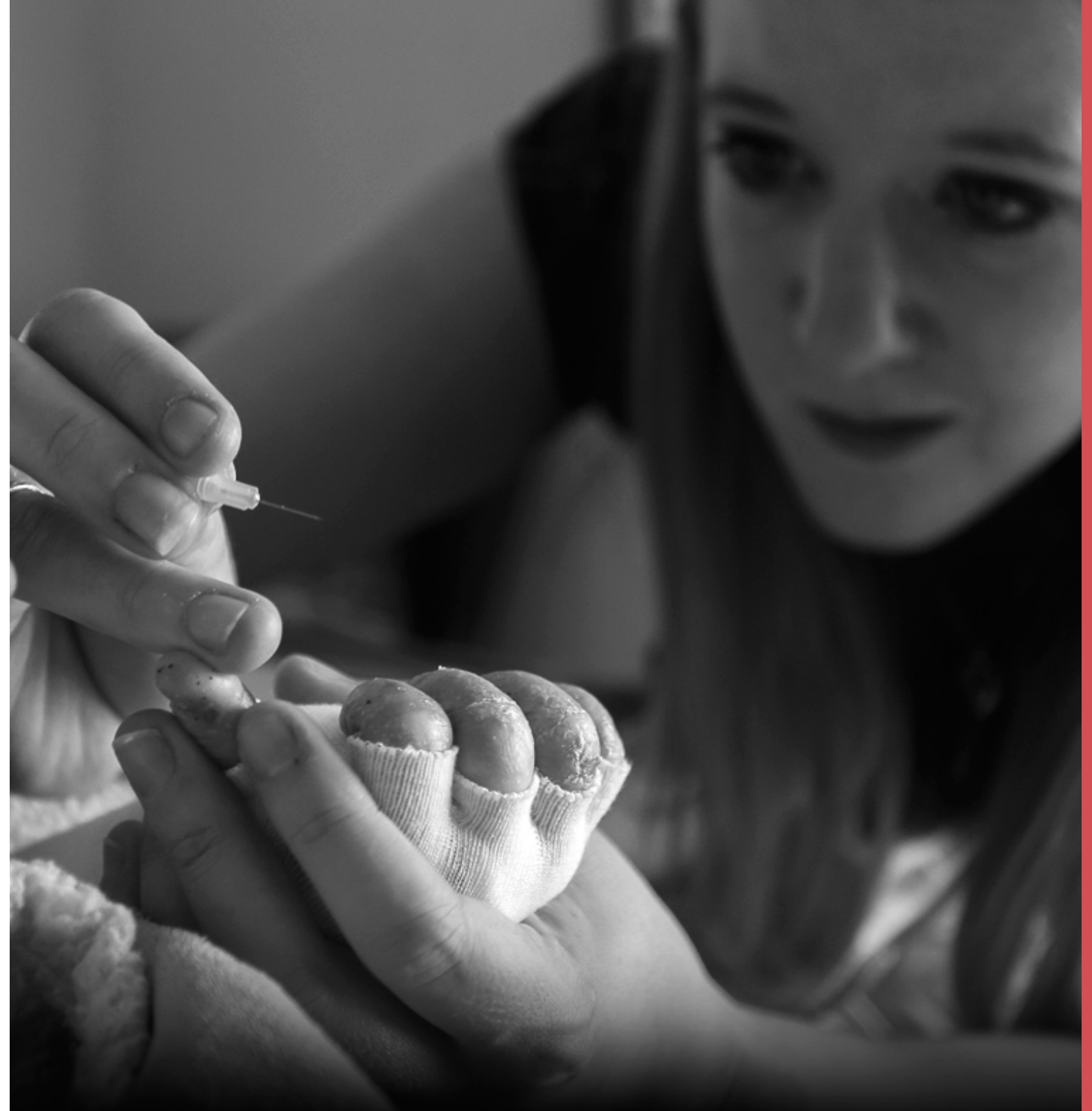
WOUND CARE
108,336

PIECES OF WOUND CARE SENT TO FAMILIES ACROSS THE US

DISTRIBUTION OF WOUND CARE PIECES



27%↑
FROM FY16



“For years, we have been grateful to debra of America for the supplies and peace of mind they have provided me and my family. The additional help of debra’s Legal Aid Program, in walking me through some trouble I had resolving, has become the hallmark of their organization.”

— ROBIN KAUFMAN, EB SIMPLEX

365 days at debra of America

Simply put, **EB is all-consuming**. For families dealing with this disease, every hour or day may come with a different set of issues to overcome or manage. Often, several of our services work in unison to meet and address the needs of one family during one contact. This multiple modality approach to service offerings allow us to meet the changing or increased need so many families face on a daily basis. Below, we take a look at how we address these needs and feature some of the families we've helped along the way.

SUPPORT AND OUTREACH



Our EB Nurse Educator is often a family's first point of contact at debra of America. She or a NICU medical professional will refer a new EB family to our New Family Advocate Program. Through the Program, we foster continued contact with the family and provide them with much-needed support and assistance while they learn to care for their infant. Healthcare professionals throughout the US also utilize this Program to assist them in managing the care of their new EB patients.



LINDY, 7 MONTHS

"debra of America has been an invaluable resource for my family and for the providers and staff involved with my daughter's care. We got better care at the hospital because of the knowledge and information debra gave to the providers and staff regarding how to handle EB." – RICHELLE, LINDY'S MOM

EDUCATING PATIENTS AND PRACTITIONERS

Daily living with EB can bring on a lot of unknowns. Through the EB Nurse Educator Program, we answer questions that are wide-ranging: from concerned parents whose toddler is becoming more active and injured, to older adults who are experiencing new symptoms as they age. Clinicians also rely on this Program to connect them to the most up-to-date guidelines and practices in their field.



RAYAH, 4 YEARS OLD

"We had no idea what EB was when our daughter was diagnosed. Thanks to debra, we receive the right information and different supplies to try, and we are forever grateful for the services they provide."

–FALLON, RAYAH'S MOM

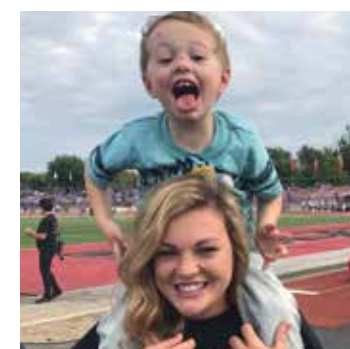


NAVIGATING CHALLENGING ISSUES

Barriers to proper health care coverage and issues with educational rights are just two of the challenges that can come up at unexpected times. Our Legal Aid Program helps families better advocate for themselves by helping them gain access to, or appeal for, their deserved benefits.

PROVIDING MEDICAL SUPPLIES

Specialized bandages and other wound care supplies can have a price tag of \$10,000 a month for many people with EB. Our Wound Care Distribution Program delivers free supplies to families located throughout the US during times of need.



HUNTER, 17 YEARS OLD
CRUZ, 3 YEARS OLD

"Without debra of America, I don't know what I would do! Having to live on one paycheck so I can stay home to take care of my EB babies, there is no way we could afford all the bandages and other items to keep my kids healthy and infection free!"

– NATALIE, HUNTER AND CRUZ'S MOM



REGIONAL EB MEETINGS

Our Regional EB Meetings enabled families to connect with each other, learn from EB experts, and have some fun! In 2017, Regional Meetings were held in New York City, Denver, Chicago, and Phoenix.



At the New York City Regional Meeting, guests attended a MLB game (Washington Nationals vs. NY Mets), Executive Brett Kopelan threw out the first pitch, and debra was a recipient of the Mets' Spirit Award.

"Once in a lifetime experience to be able to sit in a box and watch a professional game. Great to hear about the strides in the research being done. Nice to see there is hope."

– JULIE H., ATTENDEE OF THE NY REGIONAL MEETING

FOR MORE INFORMATION ABOUT DEBRA OF AMERICA'S PROGRAMS AND SERVICES, VISIT DEBRA.ORG/PROGRAMS OR EMAIL PROGRAMS@DEBRA.ORG.

Government Affairs & Legal Aid Programs

Our Government Affairs and Legal Aid Programs experienced a banner year by advancing initiatives to benefit the EB Community. The Programs' areas of focus included: EB engagement, awareness, strategic partnerships, and promoting advocacy among our federal government officials on Capitol Hill and relevant agencies.



“Joe Murray and his team from debra went right to work and helped me navigate through different challenges in health care coverage, operations, and logistics to help me in my EB time of need.”

– **NANCIE FORREST-DEFREITAS**

EB RESEARCH OPPORTUNITIES CAPITALIZED

Thanks to the advocacy work and execution of our Government Affairs strategic plan, the Department of Defense (DoD) awarded over \$9.2 million to EB researchers through the DoD's Congressionally Directed Medical Research Program's Peer-Reviewed Medical Research Program (PRMRP). To date, this is the largest tranche of EB research federal government funding awarded and represents a significant step forward in establishing EB as an important focus area through the DoD's PRMRP. EB first received approximately \$1M in DoD funding in FY2010; however, EB later fell off the DoD's approved topic area list. Our efforts to bring it back and obtain funding brings excitement and hope for a potential cure or therapy.

ADDITIONAL LEGISLATIVE ACCOMPLISHMENTS

During 2017, we advocated for EB to be included within the FY2018 Department of Labor, Health and Human Services, Education, and Related Agencies Appropriations Bill. That effort yielded EB's inclusion within the accompanying Committee Report as a disease that the National Institutes of Health's (NIH) National Institute for Arthritis, Musculoskeletal, and Skin Diseases should continue to emphasize with intensification and attention. This is the second year bi-partisan leaders within Congress have urged the NIH that EB should be a research focus area.

ASSISTING MEMBERS OF OUR EB COMMUNITY

In 2017, dozens sought out our Legal Aid Program and asked for assistance with health insurance needs, public health programs such as Medicaid and Social Security Disability Insurance (SSDI), and general questions regarding navigating through important areas of care. The Program has networked with other professionals in the fields of disability law and disability advocacy to strengthen our knowledge base and better serve the needs of the EB Community. We strive to address the needs of our Community by matching them with the correct professionals or resources.

STRATEGIC RELATIONSHIPS STRENGTHENED

Building off last year's foundation, the Government Affairs Program amplified its activities in 2017.

- Participated in Rare Disease Week on Capitol Hill. During which, the NIH featured EB on its website and promoted Rare Disease Week. And PhRMA, which represents the country's leading biopharmaceutical research companies, published a blogpost article by debra's Executive Director, Brett Kopelan.
- Led a Patient Advocacy Group coordinated letter, which was signed by 18 additional organizations and addressed to Capitol Hill leaders. The letter highlighted Off-Label reforms in connection with the Prescription Drug User Fee Act (PDUFA) legislative reauthorization.
- Partnered with the Defense Health Research Consortium on defense health care related issues.
- Assisted an EB family's attendance and participation at two healthcare related discussions sponsored by the White House in Washington, DC in the Spring and Summer.
- Worked with the Government Affairs Ad-Hoc Committee, a group of individuals with wide-ranging political, patient advocacy, and biotechnology experience, to develop long-term proactive legislative and policy strategy for our organization.

LOOKING AHEAD

In the coming year, we will continue to ramp up our efforts and will work to ensure that both EB research funding through the DoD and NIH continue. And through official testimony and relationship development with key staffers and elected officials, we will advocate to have our voice heard within the Halls of Congress and State Capitols so we can better address the needs of our EB Community.

“This recently launched Ad-Hoc Committee has already gained traction to support those afflicted with Epidermolysis Bullosa; coming alongside the leaders of debra to develop impactful policy proposals for our elected officials.”

– **MARK OLMSTEAD**
Founding debra Ad-Hoc Government Affairs Committee Member, and Vice President of Government Affairs, Reimbursement & Health Economics for Mölnlycke Health Care





The 19th Annual debra of America Benefit

In October, guests joined us at Guastavino’s in NYC to kick off National EB Awareness Week. The event was filled with many highlights, and we were honored to recognize our evening’s award recipients: 3M (Corporate Hero Award), Frank Sasinowski (Lifetime Achievement Award), and Amicus Therapeutics Inc., Berg Health, and Castle Creek Pharmaceuticals (Partners in Progress Award). Zack Troop, our 2017 Spirit Award winner, inspired guests by sharing his positive take on EB; the fact that it’s given him a new family, how he’s learned from having EB, and that he doesn’t let it stand in the way of his goals.

Thank you to our sponsors, supporters, and guests for making our 19th Annual Benefit such a wonderful evening! And a very special thank you to our Mistress of Ceremonies, Rebecca Jarvis, Chief Business, Technology, and Economics Correspondent at ABC News.

“I was honored to be a part of debra’s 19th Annual Benefit. Prior to the event, I admit I’d never heard of EB. But meeting those who struggle with the disease and hearing their stories has forever changed me. I’m so thankful to have been a part of such an incredible event and to support debra, an organization that is working to change the lives of all affected by EB.”

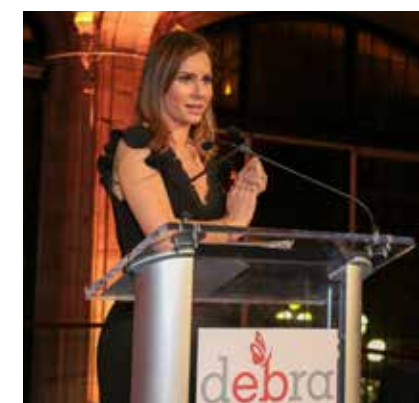


— **REBECCA JARVIS**, Chief Business, Technology, and Economics Correspondent at ABC News & The 19th Annual debra of America Benefit Mistress of Ceremonies



“I was touched deeply by being honored with debra’s 2017 Lifetime Achievement Award. The evening’s highlight for me was sharing a dinner table with Rafi, Ella, Ellie, & Zack - whose daily suffering had no apparent impact on the kindness and cheer they showered on me. This encounter moved me to speak both of the Love I felt that night, as well as the need to reach out to the FDA on behalf of all EB patients and families. It is no exaggeration to say that our evening together resulted in a truly extraordinary meeting of debra and EB advocates with the FDA in April, 2018. Onward together in Love!”

— **FRANK SASINOWSKI**, Director at Hyman, Phelps & McNamara PC & recipient of the 2017 Lifetime Achievement Award





“debra of America is a lifesaver... only parents that have children with EB can truly appreciate them! And hey.. I have 2! Thank you, debra.”

— NATALIE HOUCK, EB MOM



Inaugural EB at TPC

Thanks to our sponsors, guests, committee members, and volunteers, debra of America’s Inaugural EB at TPC golf outing was a success! Golfers joined us at award-winning course, TPC Sugarloaf, in Duluth, Georgia, for a fun-filled day of golf and socializing. Players participated in several hole contests, including a chance to win a Ford F-150 truck. And four lucky raffle winners played to win \$1 Million.

A very special thank you to event Co-Chairs, NFL legends Kevin Butler and Morten Andersen, as well as former NFL stars Brian Finneran and Drew Butler, former MLB pitcher Kris Benson, former MLB and NFL star Brian Jordan, and former NBA All-Star Dale Ellis. We would also like to thank debra of America board members J Alexander, Andrew Tavani, Rob Rayl, and Bill Cornman for aiding in the success of this wonderful day.

TO LEARN MORE ABOUT UPCOMING DEBRA OF AMERICA EVENTS, PLEASE VISIT DEBRA.ORG/HOSTEDEVENTS.

“The Inaugural EB at TPC was a huge success, and we want to send a special thanks to Kevin Butler and Morten Anderson for hosting our outing. Our sponsors, local celebrities, golfers, and EB families were incredibly generous with their time and support. Everyone involved agreed that ‘the cost of doing nothing is too great,’ and we’re looking forward to our next outing in 2018!”

— **ROBERT RAYL**
EB at TPC Co-Chair & Member of debra of America Board of Directors



Spreading awareness and raising money for EB across the US!

TEAM DEBRA raised over \$70,000 for EB in 2017! Our team members included EB advocates, biotech company employees, and many who are personally affected by EB. TEAM DEBRA participated in running events, bike tours, and everything in-between.



Cincinnati

“Training is always very time consuming, but I know how important these runs are. When I’m close to wanting to stop, I think of Maxx and all the children and adults who have to live with this disease. It pushes me to keep going.”

— LINDSEY GREGG, *EB Mom*



St. Louis

“Our butterflies ran for my beautiful granddaughter Rowan and debra of America, to help raise awareness for the worse disease you’ve never heard of. We need a cure, and we can’t find a cure without spreading our wings.”

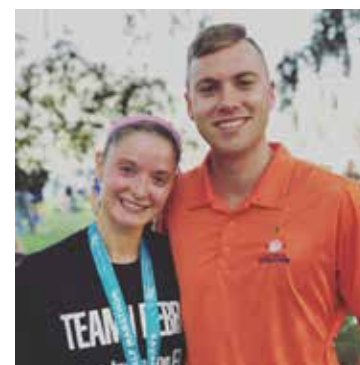
— LORI SPILKER, *EB Grandma*



New York City

“It was so amazing to have the opportunity to fundraise and ride for TEAM DEBRA in the TD Five Boro Bike Tour! As someone who has EB Simplex, I feel honored to represent individuals living with EB and am hopeful that with all our efforts we will find a cure!”

— KIMBERLY KNAPP, *EB Simplex*



Savannah

“I’ve been running marathons and half-marathons for 6 years, but running the 2017 Rock n’ Roll Half Marathon in Savannah was special to me because I was running with a purpose. In 2017 I had the opportunity to meet Ellie, an 11-year-old girl with EB. After hearing more of her story and learning about life with EB, it was an honor to run for TEAM DEBRA and represent Ellie and others like her.”

— TAMMY BLUNT, *EB Advocate*

TO LEARN MORE ABOUT TEAM DEBRA OR TO JOIN AN UPCOMING ENDURANCE EVENT, PLEASE EMAIL TEAMDEBRA@DEBRA.ORG.

Thank you to those that supported our cause by organizing events in 2017!



Jack in the Box Preschools Trike-a-Thon

JACK IN THE BOX PRESCHOOLS HOSTED ITS ANNUAL "CHILDREN HELPING CHILDREN" TRIKE-A-THON AND DONATED THEIR PROCEEDS TO DEBRA OF AMERICA. **\$3,000** WAS RAISED!



3rd Annual Dig Up a Cure for EB

VOLLEYBALL FANS GATHERED FOR A FAMILY-FRIENDLY TOURNAMENT TO BENEFIT AND BRING JOY, CHEER, AND RESPITE TO CHILDREN WITH EB. OVER **\$500** WAS RAISED.

3rd Annual Butterfly Breakfast

EB ADVOCATE KELLY MCCAULEY INVITED HER FRIENDS AND FAMILY TO ATTEND A BUTTERFLY BREAKFAST FLAPJACK FUNDRAISER AT APPLEBEES IN MILLER PLACE, NY. SUPPORTERS RAISED NEARLY **\$700**.



3rd Annual dash4debra

RUNNERS CAME OUT FOR THE 3RD ANNUAL DASH4DEBRA IN LAKE FOREST, ILLINOIS IN MAY 2017. OVER 100 GUESTS ATTENDED THE 5K RUN/WALK AND DONATED OVER **\$21,000**.



11th Annual Butterfly Wishes for Ellie

THE TAVANI FAMILY HOSTED THE 11TH ANNUAL BUTTERFLY WISHES FOR ELLIE IN HONOR OF THEIR DAUGHTER, ELLIE, WHO HAS EB. THE EVENT RAISED OVER **\$57,000** AND BROUGHT OVER 150 GUESTS TOGETHER TO CELEBRATE ELLIE AND ALL WHO STRUGGLE WITH EB.



Raise for Rafi

STUDENTS AT DISCOVER CAMP CAME TOGETHER TO SUPPORT RAFI KOPELAN AND DEBRA OF AMERICA BY DONATING THEIR SPARE CHANGE. NEARLY **\$2,000** WAS RAISED DURING THE 3-DAY FUNDRAISER.



Team Butterfly Jerusalem Marathon

IN MARCH 2017, TEAM BUTTERFLY GATHERED 70 RUNNERS TOGETHER TO PARTICIPATE IN FULL AND HALF MARATHONS, AS WELL AS A 10K. TEAM MEMBERS RAN WITH A PURPOSE THROUGH THE BEAUTIFUL STREETS OF JERUSALEM AND RAISED OVER **\$63,000**.



6th Annual Jogging for Jonah

JOGGING FOR JONAH BRINGS ATTENDEES BACK YEAR AFTER YEAR TO SUPPORT A LITTLE BOY, JONAH, WHO LIVES WITH EB. IN 2017, JOGGING FOR JONAH RAISED NEARLY **\$24,000** TO HELP DEBRA OF AMERICA SERVE THE EB COMMUNITY.

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.

EB Impact Committee (EBIC)

The EBIC serves as an important link between debra of America and the EB Community. Members include EB parents and grandparents, advocates, and those personally affected by EB. Each year, the EBIC participates in various outreach efforts and provides feedback on debra of America's free programs and services. In 2017, the EBIC selected Zack Troop to receive the Spirit Award at debra of America's 19th Annual Benefit.



The Provost Family paused for a picture while hosting their 2017 Midwest EB Picnic in partnership with debra of America

"We were introduced to debra when our youngest child, Caroline, was born with Junctional non-Herlitz EB in 2005. Our goal every day is to empower Caroline (and our family) to rise above the daily challenges of living with EB to be the best we can be. We believe in debra's mission to support the EB Community - to raise awareness, advocate, and share information and moral support. We are honored to serve on the EB Impact Committee in the hopes that we may help everyone living with EB to make the most of their lives - and until there is a cure, to live with hope."

— **ADRIENNE & PETER**, *EB Parents*

Young Leadership Committee (YLC)

The YLC is comprised of young professionals who work to promote EB awareness by participating in debra of America events across the country. Their work and support help us to provide thousands of families with our free programs and services and fund groundbreaking EB research. In 2017, YLC members hosted the Inaugural debra of America Oscar Viewing Party at sideBAR in NYC. Several YLC members also assisted in Benefit fundraising efforts by serving on the Young Leadership Benefit Committee.



YLC Members, Michelle and Patrick Brane, with their family

"We noticed our son's first blister when he was 6 weeks old, which was closely followed by another blister. After many pricks and biopsies, our infant son was diagnosed with Epidermolysis Bullosa Simplex, a condition we had never heard of... ever. We came to rely on debra for information and support. We are honored to be active with debra's Young Leadership Committee to help raise awareness for EB." — **MICHELLE & PATRICK**, *EB Parents*



INTERESTED IN JOINING A COMMITTEE? PLEASE EMAIL STAFF@DEBRA.ORG TO LEARN MORE.



Our Volunteers

debra of America volunteers are located across the country; each volunteer assists us in their own unique way. In 2017, our volunteers counted donated wound care supplies and crafted butterfly Valentine's Day cards to send to members of the EB Community. Others shared educational materials with their local communities and assisted us with event fundraising efforts.



“Because EB consists of a variety of different but similar diseases, it has been helpful for me to work with individuals with a lifelong chronic disease like mine. I have contributed by helping set up fundraisers to raise money for debra of America. Also, I helped organize last year's Oscar Party and volunteered at the Annual Benefit. Meeting so many others with EB at that event was amazing

for me. But perhaps the most invaluable thing that the YLC has given me is community. I hope to continue my commitment to this organization in the future.” — **ANJALI RAJAN**, Volunteer and YLC Member with EB Simplex

The debra of America Internship Program

debra of America's Internship Program is ideal for college students interested in pursuing a career in the nonprofit sector, advocacy, development, and/or event coordination. Our interns make a difference in the lives of people living with and affected by EB by assisting with a variety of tasks at our Manhattan office, including counting and coordinating inventory for our Wound Care Distribution Program, assisting with event preparation, and updating and editing content for debra.org and social media.

MEET OUR 2017 SPRING INTERN, DARCY

Darcy Montana was a Junior at Midwood High School in Brooklyn, NY when she interned at our Manhattan office. She learned about debra of America through our partnership with HANIA by Anya Cole, where she models in her free time. The brand's efforts in raising funds for the EB Community inspired her to dedicate her own time to the cause!



INSTAGRAM TAKEOVER!

For one week, Darcy took over our Instagram account (**@wefighteb**) to give our followers a sneak peek into the life of a debra of America intern.

Check out a few of her snapshots:



#TagWithElla

In May 2017, the *Washington Post* featured 10-year-old Ella Murray in an article and video that chronicled some of her challenges of living with EB. In the article, it's said that due to her EB, Ella can't play tag. Inspired by Ella, we took tag off the playground and brought it online – creating an unforgettable game of tag that she *could* take part in.

To participate in the campaign, supporters were asked to record a short video of themselves saying, "Tag, Ella! You're It!" or to take a selfie with a #TagWithElla sign and post it on their social media accounts. Over the course of 3 months, hundreds of individuals joined in on the game, including actor Gal Gadot, journalist Rebecca Jarvis, and singer/songwriter Josh Groban!



Thank you to all who made Ella's wish come to life, and in turn, spread awareness across the web!

Facebook Fundraisers

In 2017, Facebook rolled out a personal fundraising feature that allows users to raise money for any of the 1.5 million nonprofits on the platform. With nearly \$11,000 raised from these fundraisers, our supporters were quick to take advantage of this new tool in support of those with EB!

If you would like to fundraise on Facebook, getting started is easy!

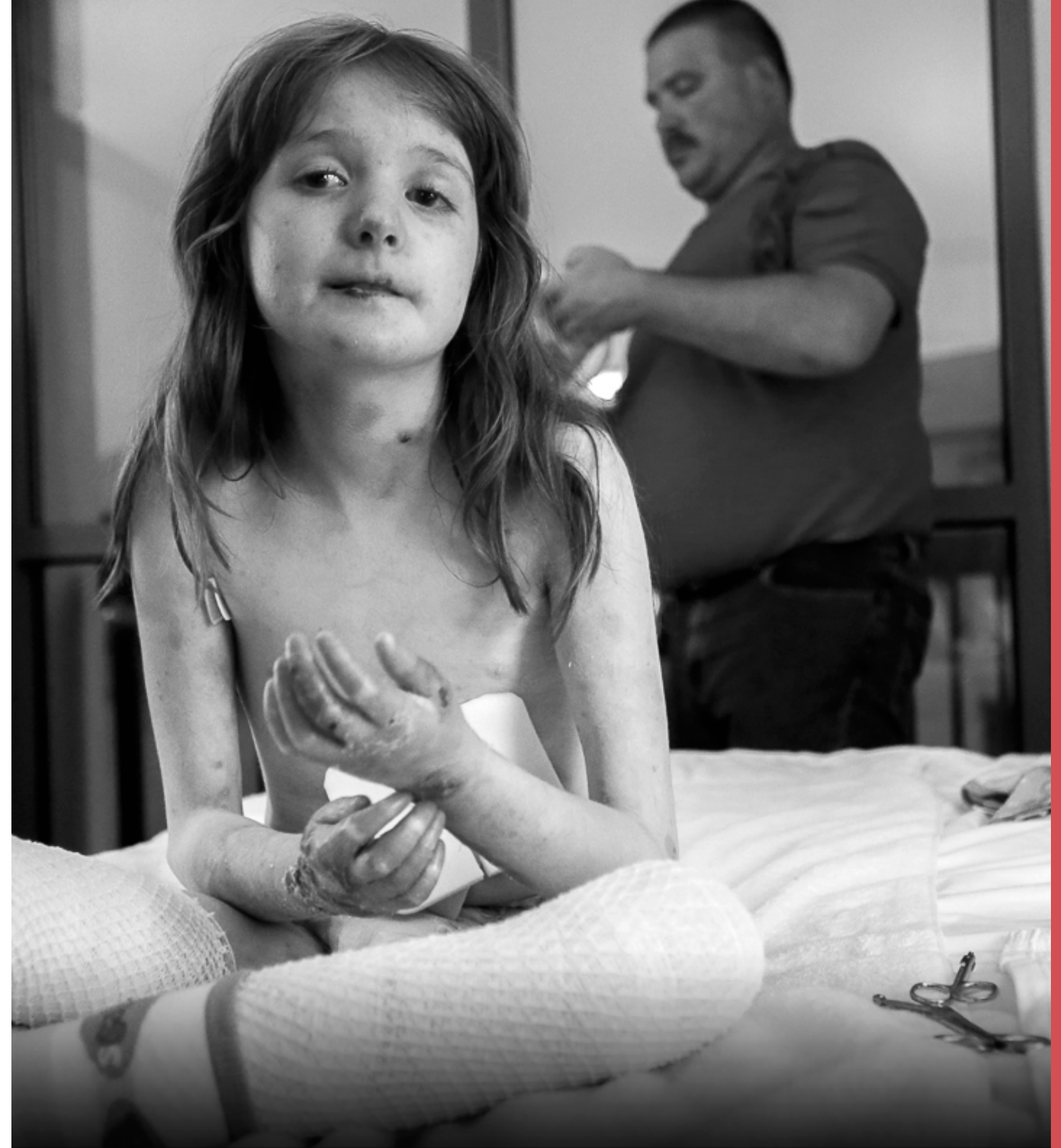
Please visit www.facebook.com/debraOfAmerica/fundraisers for more information.



Fundraiser Spotlight!

R. Thor Williams, a Substance Abuse Case Manager and City Councilmember from Bethel, Alaska, started his Facebook fundraiser in April 2017 in memory of his late granddaughter, Mia Stanley, who was born with EB. He surpassed his \$500 goal and raised a total of \$685!

"The Facebook fundraiser experience has given me the ability to reach out to a lot of friends from around the world to help educate them on EB and give them a chance to give money to a cause that helps EB children...One person can reach out and connect to hundreds of their friends in the Facebook world, reaching more people than in my rural community in Alaska."

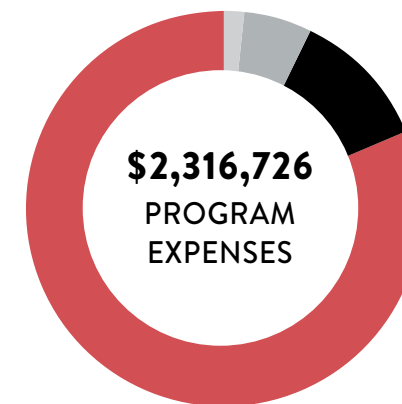


"Easy access, quick response, and timely deliveries of medical supplies give us peace of mind in difficult times... this noble work should continue."

—HIRRA, EB MOM

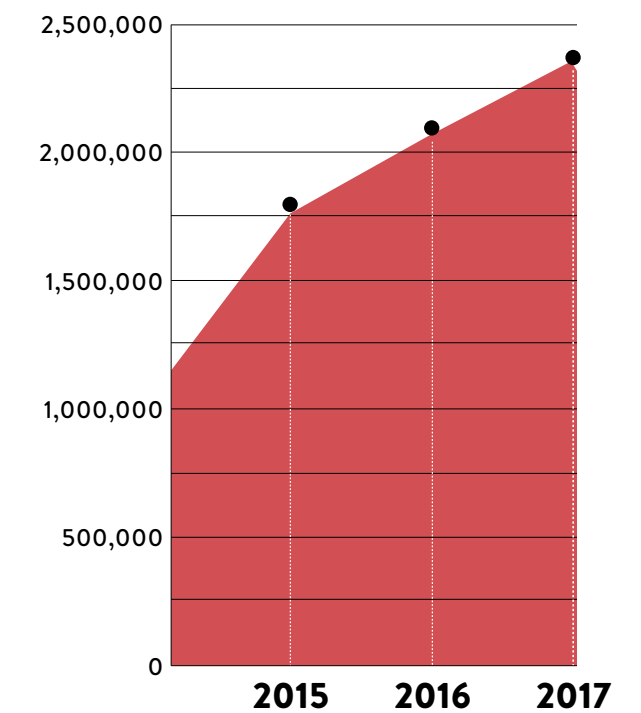
Financial Analysis

REVENUE	2015		2016		2017	
Special Events		\$921,598		\$848,770		\$705,275
Contributions & Grants		356,209		606,178		656,801
In-Kind Contributions		1,374,112		967,437		101,5581
Investment Income		3,168		-41,876		106,135
Other		4,578		8,942		1,700
Net Assets Released		177,294		29,943		78,727
TOTAL REVENUE		\$2,836,959		\$2,419,394		\$2,564, 219
		2015		2016		2017
TOTAL ASSETS		\$2,721,102		\$2,835,239		\$ 2,874,508
Total Liabilities		37,835		59,379		165,523
Unrestricted Net Assets		\$1,873,082		\$ 1,851,852		\$ 1,857,982
Temporarily Restricted Net Assets		810,185		924,008		851,003
Total Net Assets		2,683,267		2,775,860		2,708,985
TOTAL LIABILITIES AND NET ASSETS		\$2,721,102		\$2,835,239		\$2,874,508
		2015		2016		2017
EXPENSES						
Education	\$315,317	15.3%	315,704	12.9%	264,502	10.5%
Patient & Family Services	1,231,316	59.9%	1,668,498	68.4%	1,880,300	74.8%
Advocacy	47,298	2.3%	47,354	1.9%	39,674	1.6%
Research	157,659	7.7%	157,854	6.5%	132,250	5.3%
TOTAL PROGRAMS EXPENSES	\$1,751,590	85.2%	\$2,189,410	89.7%	\$2,316,726	92.1%
		2015		2016		2017
Management	\$78,829	3.8%	78,925	3.2%	66,126	2.6%
Fundraising	224,659	10.9%	172,289	7.1%	132,249	5.3%
TOTAL EXPENSES	\$2,055,078	100%	\$2,440,624	100%	\$2,515,101	100%



2017 BREAKDOWN OF PROGRAM EXPENSES

- 74.8% Patient & Family Services
- 10.5% Education
- 5.3% Research
- 1.6% Advocacy



Spending on our mission has grown significantly over the last three years

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

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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.

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“I first became aware of EB and debra of America through my good friend and HANIA Brand Ambassador, Julie Kent. I gradually became involved with debra and the more I got to know about just how horrible EB is, and after meeting Rafi who is such a strong and amazing person and getting to know her family, I just wanted to help however I could and raise awareness. I’m honored to be a part of the debra of America family as they work towards finding a cure for EB.”

— ANYA COLE, *Benefit Committee Co-Chair*

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“When our nephew Jonah was born, we saw firsthand what a lifeline debra is for families. We want to support the work that debra does to help families, provide a community, and research for a cure.”

— KIM AND ANDREW TUCKER, *Benefit Committee Co-Chairs*

Join a Committee

EB IMPACT COMMITTEE (EBIC): The EBIC consists of members of the EB Community, including parents or caregivers, advocates, and those personally affected by EB. Committee members provide feedback on our programs and services, which allows us to better serve the EB Community.

YOUNG LEADERSHIP COMMITTEE (YLC): The YLC provides young professionals with an opportunity to leverage their professional networks to promote debra's mission and events. The Committee also participates in networking opportunities with known industry leaders from various fields and gains invaluable nonprofit board and leadership experience.



"I love being a part of the YLC. I also interned for debra of America my freshman year of college. It was an honor to be able to fundraise and help plan an Oscar party for the organization."
 — **MORGAN CHITTUM**, YLC Member

GOVERNMENT AFFAIRS AD-HOC COMMITTEE: The Ad-Hoc Committee provides strategic counsel in terms of government affairs. This Committee brings together individuals with wide ranging areas of expertise from the political, patient advocacy, pharmaceutical, political, and biotechnology arenas. Members' experience in public policy and advocacy benefit the EB Community by providing strategic advice on developing a long-term proactive legislative and policy strategy for debra.

For more information about joining a committee or planning an event, please contact events@debra.org.

Help Further the Mission!

Taking an active role to support the debra mission can be fun and rewarding. Whether you want to organize an informal dinner or a large 5K run, we are here to support you. We provide you with the software platform that allows you to easily build an event site where you can sell tickets or recruit others to organize teams. We are here to help you at every step of the way. We have infographics, informational materials, and of course letters of support for local vendors.

You can choose to support one or all of our programs that provide an immediate impact to the EB Community, or you can allocate all of the proceeds to research that will ultimately find an effective treatment and a cure. The choice is yours. Reach out to us and let's talk about your ideas to make an impact.



Jack Shute, Director of Sales for Sagamore Spirit Distillery out of Baltimore, Maryland, lives with EB Simplex and has been involved with debra of America since 2006.

"We live in a digital age, and social media has proven over and over to be a way to communicate ways to support the cause, as well as educate those who might not know EB even exists... For my recent 36th birthday in February, I decided to try out Facebook's new fundraiser campaign application. I did not have high expectations, so I set a goal of raising \$500. By the time the campaign ended, I was able to donate nearly \$2,000 to debra!"

Give Your Time & Talent

You can help further our mission and make a direct impact on the lives of children and adults living with EB by lending your time to our EB advocacy, awareness, and educational efforts. debra relies on volunteers for a host of activities and always welcome more support. Whatever your talents or interests, we have a place for you!

To learn more about our in-person and virtual volunteer opportunities, email: programs@debra.org.

Get Involved on Social Media

Social media makes it easy for us to stay in touch with the EB Community and our supporters. You can find debra of America on a number of platforms, which we use to spread awareness, announce news and research updates, promote debra-hosted and supporter-led events, and share the personal stories of the individuals who inspire us to do what we do every day. EB advocates and supporters can help push our mission forward by following our accounts and liking and sharing our content!

We also provide free and easy-to-use social media "shareables," pre-made profile pictures, banners, and photos that can be uploaded onto your personal accounts to help spread awareness and show your solidarity with the community. Together, **#WeFightEB**.

You can find us on the following platforms:

Facebook: [@DebraofAmerica](https://www.facebook.com/DebraofAmerica)

Twitter: [@debraofAmerica](https://twitter.com/debraofAmerica)

Instagram: [@WeFightEB](https://www.instagram.com/WeFightEB)

LinkedIn: [linkedin.com/company/debra-of-america](https://www.linkedin.com/company/debra-of-america)

Tumblr: debra.org/blog

YouTube: [youtube.com/user/DebraofUS](https://www.youtube.com/user/DebraofUS)

BLOG Spotlight!

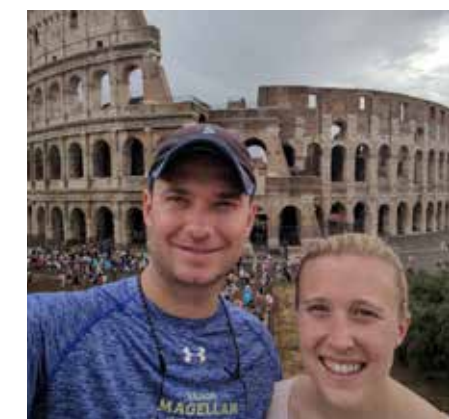
debra of America's blog, EB, etc., is a source dedicated to sharing personal stories and helpful advice with our community.

Andrew Conrad, who lives with Recessive Dystrophic EB, is a regular contributor to our blog. He works as a professional real estate investor in Chicago, IL. Throughout 2014, he contributed monthly posts to our Family Stories series on debra.org, where he wrote about his childhood, college life, and the challenges he had overcome as a young man with EB.

Three years later, in 2017, he launched a monthly blog series, Andrew's EB Story, that you can find on EB, etc., where he continues to share his personal story and connect with readers impacted by EB.

"debra of America has always been a part of my family's life growing up...My hope is that, through my blog posts, I can spread awareness and open a discussion on the disease. I hope that they find some tips in the way I do certain things that can make their life easier."

To read his **Andrew's EB Story** blog series, please visit: debra.org/blog



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92 cents of every dollar was dedicated towards research for a cure and our free programs & services.



DONATE TODAY AND INVEST IN OUR MISSION.
VISIT DEBRA.ORG/GIVE



“We received debra’s care package and we are overwhelmed with how much you all provided for Kingsley. We cannot thank you enough for all the support debra provides. Thank you so much! This helps us in so many ways.”

—ALISSA, MOM TO KINGSLEY



debra of America
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(855) CURE-4-EB

