ANNUAL REPORT 2016

debra

because the cost of doing nothing is too great

"I had never heard of EB before I met [my wife] Andrea. I knew she had a skin disorder but got my first real EB education from a close family friend who donated to debra of America every year in Andrea's honor. By nature and profession, I'm curious, so I looked into the organization further and was amazed at the strides debra of America has been able to take to find a cure."

— **DAVID, YLC member & husband to Andrea, a 32-year-old with EB**

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PHOTO CREDIT: ARI ESPAY, 2016 (OPPOSITE & COVERS)

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

Dear Friends,

As we look forward to the promise of 2017, I want to say thank you for your continued dedication and commitment to debra of America. I previously wrote that 2015 was a year of firsts for our organization, and I am happy to report that with your support, we were able to capitalize on those firsts and built a foundation for continued success. Our foundational work this year will certainly engender future successes as we strive to make a systemic impact not only on the disease itself but also on the societal factors that impact the quality of life of those with Epidermolysis Bullosa (EB).

Brett Kopelan speaking at the 18th Annual debra of America Benefit in New York City

In our second year of the Government Affairs Program, we were successful in obtaining bipartisan support in both the Senate and House of Representatives for our legislative agenda. In fact, we had sponsors from both sides of the political aisle submit language into appropriations bills. That language highlighted the success of public/private partnerships we've formed and instructed federal agencies to prioritize EB in terms of policy development, scientific meetings, and government funding. To best capitalize on our early successes, we formed an Ad-Hoc Committee to our Board of Directors to help guide the development of our long-term strategy for our government affairs activities. This Committee is made up of members with a broad range of complimentary experience within industries relevant to government affairs.

In 2016, our #ItWontHurtToWatch advertising campaign appeared on television, in Times Square on a digital billboard, and in various online properties. Our targeted media buys allowed us to drill down on engagement rates and find an audience that supports our cause. We found that the average donation resulting from this campaign dwarfed typical nonprofit benchmarks by more than 400%. Furthermore, Havas Tonic was awarded six prestigious advertising awards from this campaign.

Programmatically, 2016 was a busy year. We saw utilization rates continue to climb substantially across all our programs and services. We surveyed participants and demonstrated that our work improved the quality of life for those who engaged with our staff. debra of America wouldn't be able to provide this kind of impact without your generosity.

When I became Executive Director in 2011, there were no pharmaceutical or biotechnology companies working hand-in-hand with us to develop therapies. By 2016, we partnered with eight industry sponsors to commercialize symptom relief and disease modifying remedies. debra of America works with our partners in protocol development and recruiting for actual ongoing trials. It is an exciting time in our disease space. We are so close to making a sea change for those living with EB. Just imagine what 2017 will bring.

Many thanks,

Brett Kopelan
Executive Director, debra of America

IMPACT

Our Integrated Services

In 2016, debra of America undertook a variety of activities that broadened our expertise in patient-focused support and strengthened our capacity to make a positive impact on the lives of those who live with Epidermolysis Bullosa (EB). Our integrated approach combined the pillars of Education, Support, Research, and Advocacy to help those with EB meet their everyday challenges.

In 2016 alone, nearly three-quarters of the families who utilized our services went on to benefit from at least two of our direct programs. From crisis prevention to connecting patients with clinical trials, debra of America's continued progress depends upon the generosity and dedication of our supporters and we are immensely grateful for all that you do to make our work possible.

100% of parents in the **New Family Advocate Program** attributed the service to reducing stress of EB infant care

95% of issues addressed through the **EB Nurse Educator Program** were solved 'very effectively'

79% of families enrolled in the **Wound Care Distribution Program** reported an improvement in health over the year

86% of combined program participants credited **debra of America services** with enabling them to better care for themselves and loved ones

2016 Program Evaluation Study reported outcomes.

> *"Navigating life with a misunderstood condition can be incredibly challenging, as many care providers don't listen to my questions and concerns. debra of America has given me a voice; promoting my self-efficacy and ability to plan and coordinate my care."*
>
> — **SARAH, University of Scranton, Class of '16**

2016 debra Care Conference

Families and patients from around the United States and abroad gathered this year in Dallas, TX for debra of America's biennial debra Care Conference (DCC). This extraordinary event brought those with EB together to meet, learn, share, and grow. With EB experts present, including physicians, nurses, and child pain psychologists, families received an opportunity to learn from and network with those on the cutting edge of research and treatment. Perhaps most importantly, bonds were created and lifelong friendships were forged among those who finally felt at home.

4 DAYS

548 ATTENDEES

152 CHILDREN

40 PRESENTERS & EXHIBITORS

8 LIVE BROADCASTS
FOR THOSE THAT COULD NOT ATTEND

> *"I was honored to be asked to be the keynote speaker at the 2016 debra Care Conference. I've been to many patient conferences for many diseases over the years but this one was really remarkable. These kids were beyond courageous and inspiring. Words can't describe their resilience and the strength and love of their families and caregivers. Hope we can make a difference for the more than 50,000 living with EB."*
>
> — **John F. Crowley, Chairman and CEO of Amicus Therapeutics, Inc.**

> *"I attended the entire conference, viewed all the sessions and enjoyed learning from each one. Being part of the conference was one of the most inspiring and worthwhile activities of my adult life."*
>
> — **SAMANTHA, DCC attendee**

Wound Care Distribution Program

Receiving the required amount of wound care supplies is critical for those living with EB. Sadly, many do not get an adequate supply. Many insurers, including public and private insurance plans, do not provide good coverage for these medical supplies, resulting in a huge unmet need. Thanks to our supporters, the Wound Care Distribution Program breaks existing barriers, providing free bandages and other wound care supplies to those in need, while educating patients and care providers around the country on proper wound care.

IN 2016...

DEBRA OF AMERICA SENT **475** SHIPMENTS OF WOUND CARE PACKAGES TO EB FAMILIES THROUGHOUT THE UNITED STATES

THAT'S **75,876** PIECES OF SPECIALIZED BANDAGES AND NON-ADHESIVE DRESSINGS, OINTMENTS, AND GAUZE

EQUALING **$700,901** WORTH OF SUPPLIES TO CHILDREN AND ADULTS WHO WEAR BANDAGES

ON UP TO **75%** OF THEIR BODIES **24** HOURS A DAY

OUR PROGRAM PARTICIPANTS:

52% FEMALE

48% MALE

AGE RANGE:

47%	0-10
18%	11-20
35%	21+

"I truly don't know how I would have gotten this far without debra. debra of America has helped me raise Patrick in every sense, from helping with medical supplies to teaching me how to help Patrick handle the physical and emotional stress of living with EB!"

— **AMBERLEA,**
Mom to Patrick,
a 7-year-old with EB

"The Wound Care Distribution Program really gives me peace of mind. I know that if my referral is late or Medicare doesn't send me enough of my wound care supplies, I can always call debra of America."

– **HODGES, a 37-year-old with EB**

"EB has affected my entire life, even my hobbies. Everyday tasks become hard to do and are painful...showering, walking, shopping — they all lead to chronic pain. I am most grateful for debra of America and all that the organization has provided me with. I rely on them for support with monthly care packages of bandages, and I'm not sure where I would be without their support."

— **DAWN, a 47-year-old woman with DDEB**

Government Affairs & Legal Aid Programs

In its first full year of advocacy efforts, debra of America's Government Affairs and Legal Aid Programs had some great successes and developed a long-term strategy to benefit the EB Community. We've secured bi-partisan support at the federal and state levels for the EB cause as well as developed key relationships with government agencies including the National Institutes of Health (NIH). We've further deepened our existing partnerships with other advocacy organizations, such as *Research!America*, *EveryLife Foundation for Rare Diseases*, and the *Rare Disease Legislative Advocates*.

We've become an effective voice for EB and other rare diseases among our elected leaders, government agencies, as well as private industry groups, who have called on us to speak at rare disease policy conferences, on Capitol Hill, and at State Capitols.

Our efforts centered around 3 key areas:

FEDERAL & STATE AGENCY OUTREACH & INITIATIVES

- For the 2017 fiscal year's Department of Labor, Health and Human Services, Education, and Related Agencies Appropriations Bills, we obtained bi-partisan support and secured language promoting EB research, inserted in both the U.S. House of Representatives' and U.S. Senate's Committee Bill Reports. This was significant; for it instructs the NIH to place more emphasis on EB-specific research initiatives and lays the groundwork for future EB government affairs projects and goals.

- Through our efforts, EB was highlighted in the July 14, 2016 edition of the *Congressional Record*, the official record of the proceedings and debates of the United States Congress.

- In 2016, we launched a strategic outreach initiative to open new federal EB research funding streams within the Department of Defense (DoD). EB previously received over $1 million in federal research funding through the DoD's Peer-Reviewed Medical Research Program. Our goal is to bring EB back onto the list of DoD's list of eligible diseases to apply for federal funding.

KEY PARTNERSHIPS

- debra of America participated in Rare Disease Week on Capitol Hill and met with senior health care representatives from the U.S. House of Representatives to discuss EB legislative priorities.

- The Rare Disease Legislative Advocates (RDLA) hosted Executive Director Brett Kopelan to speak on *“How to Work with Industry”* from a patient advocacy perspective during their Rare Disease Week conference, which was attended by over 300 national rare disease advocates. Joe Murray, debra’s Director of Government and Legal Affairs, was a featured speaker at rare disease policy forums at the Rare Disease Congressional Caucus, the National Center for Advancing Sciences at the NIH, and additional industry events.

- debra of America formed a new Government Affairs Ad-Hoc Committee to the Board of Directors that 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 will undoubtedly benefit the EB Community by providing strategic advice on developing a long-term proactive legislative and policy strategy for our organization.

- In 2016, we partnered with Biomarin in advocating for the successful reauthorization of the Pediatric Rare Disease Priority Review Voucher Program, a strong incentive to industry to develop therapies in the pediatric rare disease space. Brett Kopelan wrote a featured article in *Morning Consult* on this topic.

LEGAL AID ASSISTANCE

- In 2016, we expanded our legal aid efforts and assisted over 50 individuals and families by providing support surrounding insurance coverage, federal health and disability benefits, and other related concerns.

- debra of America published a memo describing information about current laws pertaining to commercial flight requirements, specifically those that allow for free air-travel baggage when transporting medical supplies.

More exciting initiatives have already been accomplished and are moving forward in 2017!

For more information about debra of America’s programs and services, visit debra.org/Programs or email programs@debra.org.

THOMAS JEFFERSON RESEARCH STUDY

This year we committed to funding a study at Thomas Jefferson University. This project focuses on the role of inflammation in wound healing and in the development and growth of squamous cell carcinoma, a form of skin cancer that is often deadly for those with EB.

Why study skin inflammation and wound healing?
Chronic wounds, or wounds that are not able to heal, are prone to developing squamous cell carcinoma and are therefore a serious concern in the EB population. While inflammation is a normal process in wound healing, the inflammatory phase never ceases in EB – thus preventing the wound healing process from progressing. This important study aims to investigate whether decreasing levels of inflammation will allow chronic wounds to heal more effectively. Furthermore, researchers are evaluating whether the decrease in the inflammatory response will influence tumor development and growth.

Why study squamous cell carcinoma?
An often curable type of cancer, squamous cell carcinoma is one of the leading causes of death among those with the more severe forms of EB. Approximately 90% of those diagnosed with this cancer die within five years of first presentation. We at debra of America recognize that squamous cell carcinoma is one of the most concerning complications of EB. Therefore, we are very supportive of Thomas Jefferson University in researching this type of cancer.

Thank you to all those who supported our mission in 2016 and allowed us to fund groundbreaking research. We're closer than ever before to the first FDA-approved treatment for EB and currently, several trials are being conducted to address critical EB concerns. We are excited to be a part of the EB research frontier.

Dr. Jouni Uitto accepting the Lifetime Achievement Award at the 18th Annual debra of America Benefit. Dr. Uitto has been Professor and Chair of the Department of Dermatology and Cutaneous Biology at the Sidney Kimmel Medical College, in Philadelphia, Pennsylvania, since 1986. He is also Director of the Jefferson Institute of Molecular Medicine at Thomas Jefferson University. Dr. Uitto and his team are responsible for finding the genetic basis of EB.

THE 18TH ANNUAL DEBRA OF AMERICA BENEFIT

On October 24, guests filled Gotham Hall's historic rotunda to celebrate the 18th Annual debra of America Benefit and to kick off National EB Awareness Week. The event was filled with hope for the EB Community, as we celebrated the strides that have been made in EB research and the progress that is to come. Award recipients included Partners in Progress Award Winner Abeona Therapeutics Inc., Lifetime Achievement Award Winner Dr. Jouni Uitto, Corporate Hero Award Winner Doug Davis, and Spirit Award Winner Harlee Bass. Our Master of Ceremonies, J.R. Martinez, led the evening's programming and his passion for the cause was truly infectious, as he encouraged guests to donate more than $100,000 during a single ask, which triggered a dollar for dollar match. **A special thank you to our many guests, sponsors, and volunteers for making the evening such an incredible success!**

NY YANKEES VS. BOSTON RED SOX

In July, over 50 guests traveled from across the tri-state area and joined debra of America in the Bronx to watch one of baseball's biggest rivalries: the NY Yankees vs. the Boston Red Sox. While the crowd was evenly split in terms of their allegiance, they were unanimously united in their goal to fight EB. **Thank you to the NY Yankees for their support and for featuring debra of America, as well as our guests, on their jumbo-tron!**

To learn more about upcoming debra of America events, please visit debra.org/HostedEvents.

"Our team was greatly honored to be presented with the 2016 Partners in Progress Award during debra's 18th Annual Benefit. The resources and support that debra provides to individuals and families impacted by EB are absolutely critical and irreplaceable. Brett and the team's legislative activism and collaborative interactions with researchers bring this community closer and closer to meaningful therapies. Abeona Therapeutics is committed to the EB community and advancing the potential RDEB gene therapy, EB-101, forward through clinical trial and beyond."

— **Timothy Miller, Ph.D.,**
President and CEO,
Abeona Therapeutics

"I was truly humbled amongst the bravery of the EB community, and the spirit of life that everyone embodies facing this challenge. Receiving the debra of America Corporate Hero award will stand as one of my life's proud moments, and I will always count myself a part of the EB community as it drives towards a cure for this horrible disease."

— **Doug Davis,**
Founder and Owner,
The Davis Firm

"My family has been utilizing debra of America since I was born as a resource and guide to all things EB. As a young adult, I have found debra's resources helpful in identifying care providers, answering questions, and staying current on all things EB. Before contacting debra, I was very discouraged that I would find someone I would feel comfortable with treating me, but thanks to debra, I have found a team of care providers I can trust."

– SARAH, a young woman with EB

TEAM DEBRA

TEAM DEBRA brings athletes from across the country together to raise awareness and funds for EB. Members of TEAM DEBRA channel their passion for endurance events into their passion for fighting EB.

TEAM DEBRA has participated in endurance events around the country, including:

- **Cincinnati Flying Pig Marathon**
- **Skechers Performance Los Angeles Marathon**
- **United Airlines NYC Half**
- **TCS New York City Marathon**

TEAM DEBRA....

Supports Our Mission

Fundraising dollars directly support debra of America, which provides free programs and services to the EB Community and funds EB research

Gets Fit For A Cause

From coast to coast, TEAM DEBRA members join fellow athletes in world-renowned athletic events across the United States

Fundraises for EB

Provides a fundraising web page for each TEAM DEBRA member, and staff are available to help set up, personalize, and promote each member's page

Raises EB Awareness

TEAM DEBRA members are provided with materials that help them educate their communities about EB

2016 UNITED AIRLINES NYC HALF MARATHON

TEAM DEBRA was proud to be a Charity Level Partner in the 2016 United Airlines NYC Half Marathon. Few events can shut down New York City's Times Square, but the 2016 United Airlines NYC Half did! Over 20,000 runners ran 13.1 miles from Times Square to Wall Street, including 5 runners for TEAM DEBRA. Thank you to all our TEAM DEBRA runners who participated in the 2016 United Airlines NYC Half and other 2016 endurance events!

To learn more about TEAM DEBRA or to join an upcoming endurance event, please email teamdebra@debra.org.

Hailing from Columbus, Ohio, Michelle and Patrick Brane ran for TEAM DEBRA in the 2016 United Airlines NYC Half in honor of their son Cameron who has EB.

> *"It provided us with a way to support debra of America while also educating others about EB and our son's condition through social media as well as teaching him more about his condition the older and more aware he becomes."*
>
> — **Patrick Brane**

SUPPORTER LED EVENTS

INAUGURAL PITTSBURGH DASH4DEBRA

The Inaugural Pittsburgh dash4debra 5K Run/Walk was held in October, a week before National Epidermolysis Bullosa Awareness Week. Event organizer Rachel Calhoun was inspired to pioneer the event after attending the debra Care Conference in Texas. She felt compelled to do more to help the EB Community.

Rachel shares: *"I really wanted to spread more EB Awareness in the local Pittsburgh area as well as at our local University. It was really nice to get people together for such a great and impactful cause."*

> *"My favorite part of the day was seeing everyone lined up at the starting line, with RMU's mascot leading the way. It was visible at that moment that everyone was in the race together, supporting the EB Community."*
> — **Rachel Calhoun, Pittsburgh dash4debra Coordinator and Marketing Specialist at McKesson Patient Care Solutions, Inc.**

Young runner Hanna Hupp won the title for first female finisher, and 4th overall! Hanna participated along with her team, "Hanna's Helpers," to spread awareness and raise funds for EB.

What started as a grassroots initiative with a philanthropic University campus, hand-made running bibs, and support from the local community and businesses, grew to become a large event with over 90 attendees – and even a few four-legged guests!

Together with debra of America, Rachel realized her dream of doing something larger for the EB Community.

Thank you, Rachel, the McKesson Patient Care Solutions Team, and Robert Morris University for supporting this incredible event. And thank you to all of those who participated and volunteered.

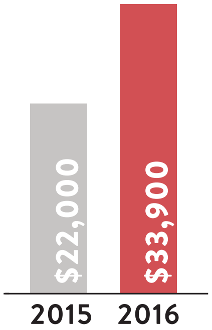
We can't wait for next year's 2017 Pittsburgh dash4debra!

THE 5TH ANNUAL JOGGING FOR JONAH

In 2016, we rang in the 5th Annual Jogging for Jonah, a 5K Run/Walk and Fun Run, in honor of 8-year-old Jonah Williams and all individuals affected by EB. Organized by the Williams family, along with the help of friends and community members, Jogging for Jonah is a family-friendly, fun-filled event that Winston-Salem, NC residents look forward to each year! Runners and attendees enjoyed a friendly, yet competitive, race as well as DJ entertainment, face painting, refreshments, and a large raffle with amazing prices.

In 2016, Jogging for Jonah was one of the first events to use debra of America's new fundraising platform, Team Raiser, to collect donations, solicit sponsorships, accept registrations, and sell t-shirts. With the help of Team Raiser, Jogging for Jonah planned their large-scale event, increased their participation, and hit their highest fundraising total to date!

Thank you to the Williams family and to all those who support Jogging for Jonah each and every year!



IN 2016, JOGGING FOR JONAH SAW A **54%** INCREASE IN THEIR FUNDRAISING COMPARED TO THEIR FIRST EVENT IN 2012! JOGGING FOR JONAH HAS RAISED OVER **$144,100** TO DATE FOR EB.

THE STRENGTH OF A PERSONAL CHALLENGE

2016 was filled with personal and competitive challenges! Daring and tenacious EB advocates stepped up to the plate and pushed themselves to their limits to raise money for EB.

Pursuit for Patterson

Inspired by her nephew Patterson, who was born in 2015 with Recessive Dystrophic EB, Kristy Deeds completed four trail races in four months, a total distance of over 70 miles. Kristy raised over $7,000 and exceeded her fundraising goal!

Rock 'n' Roll Raleigh

John Peluso ran his first-ever Half Marathon to honor the memory of his best friend, Michael, who lost his battle with EB in 2013. John shares, "Michael taught me to love this life as it is and to take each day as a new opportunity to do some good for mankind." John harnessed his best friend's strength and used it to push himself past the finish line. Friends and family sponsored each mile, bringing his fundraising total to over $550!

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.

CAMPAIGNS

"To those who have helped with the #600Strong4EB Campaign: thank you. To those who suffer from EB and supported the Campaign: the research you've helped make possible means a chance to hope, and a promise of relief. Time is the only factor left. Treatments, and hopefully a cure, cannot be far off. The support you've given brings us all closer. So once again, thank you for all that you've done, and all you'll continue to do. Thank you."

— **Cole Connelly**, **#600Strong4EB supporter**

#600STRONG4EB CAMPAIGN

In 2016, debra of America presented a challenge to our supporters. If we were able to encourage 600 people to donate to the #600Strong4EB Campaign between September 1 and December 31 a donor, who wished to remain anonymous, would contribute $100,000.

We were overwhelmed by the outpouring of support. More than 800 donors were inspired by the #600Strong4EB Campaign and over $200,000 was raised.

THANK YOU TO THOSE THAT SUPPORTED OUR MISSION AND WERE **1** OF THE **600** STRONG!

#WEFIGHTEB SELFIE CAMPAIGN

In honor of National EB Awareness Week (October 25-31), we launched the #WeFightEB Selfie Campaign. This social media campaign celebrated the power of "We" and showed the world that although we are rare, we are not alone.

EB Community members, donors, and supporters snapped a selfie with a debra of America #WeFightEB bracelet and shared their photo on their social media pages with the hashtags: #WeFightEB and #EBweek. With the help of a generous supporter who pledged to donate $10 towards EB research for every selfie taken, we raised nearly $3,000!

A big thank you to everyone who supported and participated in these Campaigns. Together, #WeFightEB!

YOUNG LEADERSHIP COMMITTEE (YLC)

The Young Leadership Committee (YLC) is comprised of students and young professionals who work to promote EB awareness through fundraising and 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 permits us to fund EB research.

In 2016, the YLC hosted several events to help spread EB awareness and raise funds. YLC members attended a YLC Hockey Night and watched the New York Islanders take on the New Jersey Devils at the Prudential Center. Several YLC members also attended the 18th Annual debra of America Benefit and assisted by serving on the Benefit's Young Leadership Benefit Committee.

EB IMPACT COMMITTEE (EIC)

debra of America's EB Impact Committee (EIC) is comprised of parents, grandparents, and EB advocates who are committed to supporting the EB Community. Many EIC members are directly affected by EB and are thereby an important bridge between debra of America and the EB Community. Each year, the EB Impact Committee votes on the Spirit Award winner, participates in various outreach efforts, and provides feedback on debra of America's free programs and services. In 2016, the EIC chose Harlee Bass as the recipient of the Spirit Award, and several members attended and volunteered at the 2016 debra Care Conference in Dallas, Texas.

2016 Spirit Award Winner Harlee Bass with Master of Ceremonies J.R. Martinez at the 18th Annual debra of America Benefit.

Interested in joining a Committee? Please email events@debra.org to learn more.

EIC MEMBER SPOTLIGHT: JENNIFER HARBUCK

"My name is Jennifer and I'm 43 with RDEB, Inversa. Growing up, I didn't have a lot of help, except for debra of America. I always wanted to help others with EB and being a part of the EB Impact Committee allows me to help make a difference in the lives of others with EB. [Being a member of the EB Impact Committee gives me the] chance to give hope and encourage others that with our strength, anything is possible!"

VOLUNTEERS

Volunteers at the 2016 DCC in Dallas helped children during the Canvas Painting Party, checked guests in at registration, assisted in the Kids' Room, and more!

In our New York City office and across the country, volunteers created EB Butterfly Cards that were distributed to hundreds of EB families and children for Valentine's Day.

DONATING THEIR TIME

Our committed group of volunteers are located around the country and have jumped in to assist us in a variety of ways: by helping send wound care supplies, working at our fundraising events, and educating their communities about EB. Here are a few ways that our volunteers partnered with us 2016:

- **Wound Care Supplies** – Volunteers helped debra of America staff manage the inventory of donated supplies and ship boxes to needing families.
- **EB Butterfly Valentines** – Across the country, students and employees created heartfelt Valentine's Day cards that were sent out to members of the EB Community.
- **debra of America Events** – We were assisted by several volunteers at the 2016 DCC in Texas and were grateful to have volunteers join us the 18th Annual debra of America Benefit in New York.
- **Raising Awareness** – Volunteers shared debra of America materials with physicians to help raise EB awareness and to educate professionals about this rare disease.

THE DEBRA OF AMERICA INTERNSHIP PROGRAM

debra of America's Internship Program is ideal for high school or college students interested in pursuing a career in the nonprofit sector, advocacy, development, and/or event coordination, while making a difference in the lives of people living with and affected by EB. Interns assist with a variety of tasks in our NYC office, including data collection, research, social media, and program management.

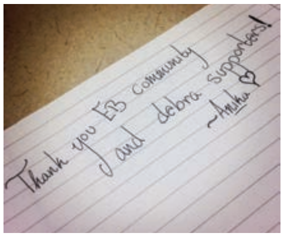
For more information about volunteering or interning for debra of America, please email staff@debra.org.

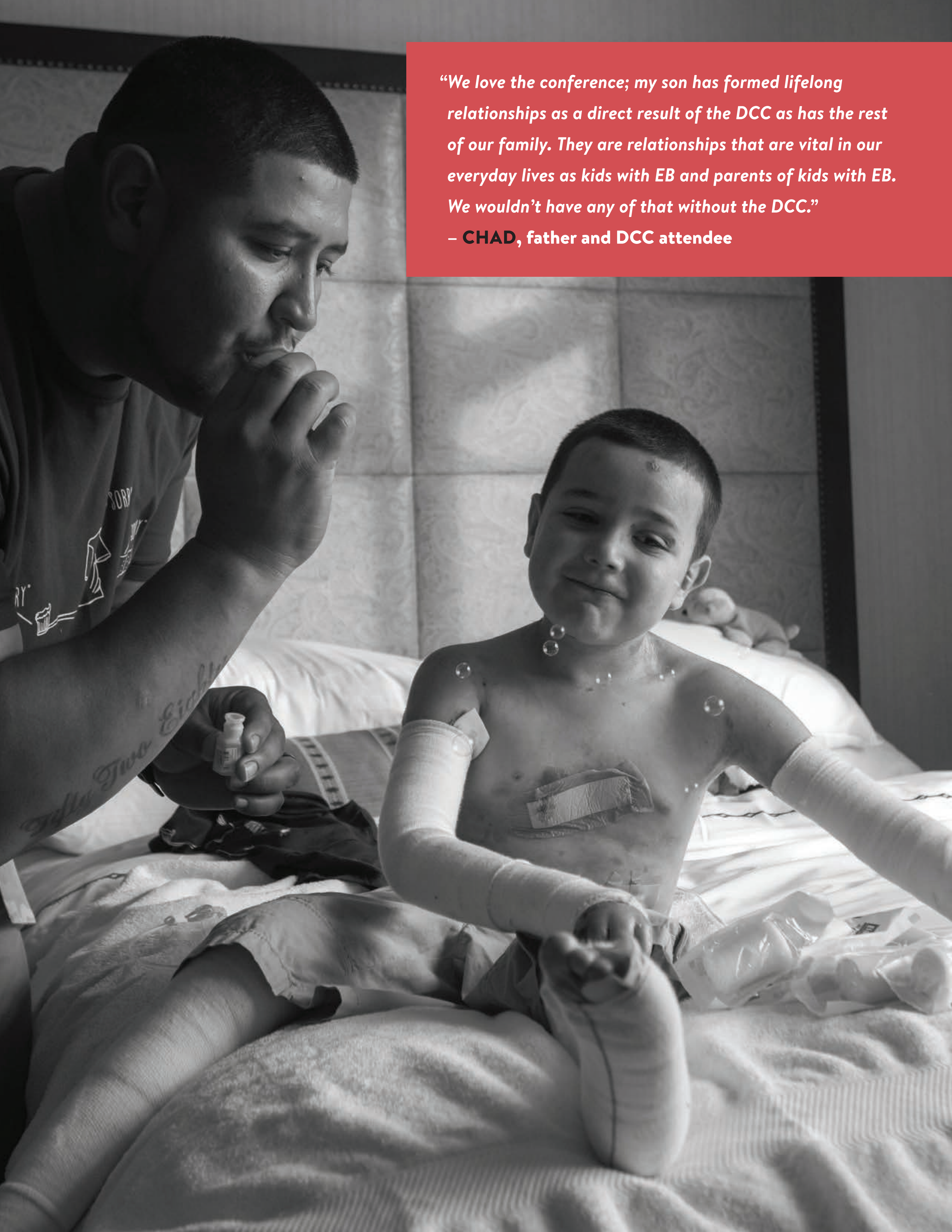
MEET DEBRA OF AMERICA SPRING 2016 INTERN ANIKA LANGBERG:

Anika was a Sophomore at New York City's School of the Future during the time she interned at the debra of America office. Her interest in aid and humanitarian work, and her curiosity of the inner workings of a nonprofit organization, attracted her to the opportunity.

INSTAGRAM TAKEOVER!

For one week, Anika took over the debra of America Instagram (@WeFightEB) to give our followers a sneak peek into the life of a debra of America intern:





"We love the conference; my son has formed lifelong relationships as a direct result of the DCC as has the rest of our family. They are relationships that are vital in our everyday lives as kids with EB and parents of kids with EB. We wouldn't have any of that without the DCC."

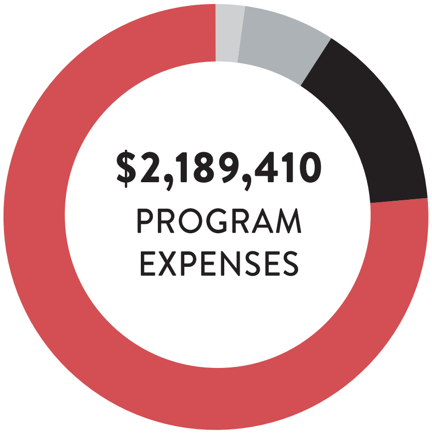
– **CHAD, father and DCC attendee**

FINANCES

REVENUE	2014	2015	2016
Special Events	$486,111	$921,598	$848,770
Contributions & Grants	819,178	356,209	606,178
In-Kind Contributions	437,302	1,374,112	967,437
Investment Income	-2,683	3,168	-41,876
Other	13,488	4,578	8,942
Net Assets Released	38,699	177,294	29,943
TOTAL REVENUE	**$1,792,095**	**$2,836,959**	**$2,419,394**

	2014	2015	2016
TOTAL ASSETS	**$1,722,111**	**$2,721,102**	**$2,835,239**
Total Liabilities	61,663	37,835	59,379
Unrestricted Net Assets	$966,124	$1,873,082	$ 1,851,852
Temporarily Restricted Net Assets	694,324	810,185	924,008
Total Net Assets	1,660,448	2,683,267	2,775,860
TOTAL LIABILITIES AND NET ASSETS	**$1,722,111**	**$2,721,102**	**$2,835,239**

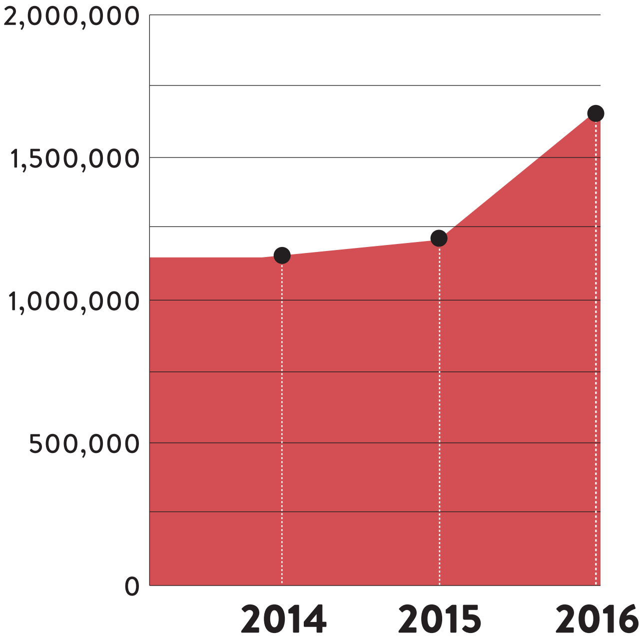
EXPENSES		2014		2015		2016
Education	$235,606	13.5%	$315,317	15.3%	315,704	12.9%
Patient & Family Services	1,159,760	66.4%	1,231,316	59.9%	1,668,498	68.4%
Advocacy	35,341	2.0%	47,298	2.3%	47,354	1.9%
Research	117,803	6.7%	157,659	7.7%	157,854	6.5%
TOTAL PROGRAMS EXPENSES	**$1,548,510**	**88.7%**	**$1,751,590**	**85.2%**	**$2,189,410**	**89.7%**
		2014		**2015**		**2016**
Management	$77,096	4.4%	$78,829	3.8%	78,925	3.2%
Fundraising	120,140	6.9%	224,659	10.9%	172,289	7.1%
TOTAL EXPENSES	**$1,745,746**	**100%**	**$2,055,078**	**100%**	**$2,440,624**	**100%**



2016 BREAKDOWN OF PROGRAM EXPENSES

- ● **12.9%** Education
- ● **68.4%** Patient & Family Services
- ● **1.9%** Advocacy
- ● **6.5%** Research

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



Spending on **patient and family services** has grown significantly over the last three years.

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

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"I was contacted by debra of America after Daxten was born. I was so comforted knowing there was some kind of support out there, especially when some of the doctors weren't sure what they were looking at. I just wasn't sure how I was going to do this and I was absolutely terrified. So thank you so much debra for this amazing organization. You have no idea how special it is."

— **JAMIE**, Mom to Daxten,
a newborn with EB

HOW YOU CAN HELP

JOIN A COMMITTEE

EB Impact Committee (EIC): The EIC consists of members and supporters of the EB Community who advocate for people with EB by participating in awareness activities, providing feedback on debra of America programs and services, and by voting for the Spirit Award winner each year.

Young Leadership Committee (YLC): The YLC is comprised of students and 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.

FUNDRAISE FOR EB

Do Something You Love *for a good cause*.
There are so many ways to turn a hobby or passion into something more. Every year, fund raisers across the country come up with fun and creative ways to raise money for EB. Do you love to paint? Sell your pieces of art and designate the proceeds to the area of your choice within debra of America. Are you an avid runner? Get a running group together and ask for donations per runs completed. The possibilities are endless! Reach out to debra of America with your fundraising idea, and we will assist you in bringing it to life!

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

GET INVOLVED ON SOCIAL MEDIA

debra of America is active on a number of platforms that allow us to spread awareness, share news and research updates, promote debra-hosted and supporter-led fundraisers, and engage with the EB Community. Supporters can follow, like, and share debra of America's content to help spread awareness about EB across the web. 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 spread the word and show your support for the EB Community.

Learn more at debra.org/socialmedia and find us on the following platforms:

Facebook: @DebraofAmerica
Twitter: @debraofAmerica
Instagram: @WeFightEB
LinkedIn: linkedin.com/company/debra-of-america
Tumblr: debra.org/blog
YouTube: youtube.com/user/DebraofUS

VOLUNTEER FOR A CAUSE

debra of America runs six direct service programs that benefit the EB Community, and you can become involved with each and every one! Whether it be helping to coordinate wound care supplies that are sent to EB families, contacting your local and state legislative leaders on behalf of EB advocacy efforts, or even working on translating EB care-related materials, come help make a difference in the lives of people living with and affected by Epidermolysis Bullosa.

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

DONATE TODAY AND SUPPORT OUR MISSION.
VISIT DEBRA.ORG/GIVE

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visit: debra.org/PlanEvent

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"I am amazed to see the new bandages and wound care that people with EB are wearing these days. That kind of protective wound care was never an option for me! And it's amazing to read about the new research that's being undertaken to find a cure. When I was young, doctors didn't know about EB so the treatment options were limited – or, well, bizarre! I'm so happy to see the progress that has been made in my lifetime.

I would like all the kids suffering with EB to know that there is hope. Don't let EB hold you back!"

— **FOREST, a 78-year-old man with EB Simplex**

debra

because the cost of doing nothing is too great

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75 Broad Street, Suite 300
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