ANNUAL REPORT 2015

debra

because the cost of doing nothing is too great

"I was born with RDEB. All I can say is that it has definitely not been easy. It's not something that I'd wish upon anybody, but despite all of the struggles that EB brings and will continue to bring into my life, I can assure you that I'll continue to strive for my goals and for the things that I'm passionate about.

I also always remember to not let EB get the best of me because although I was born with EB, it doesn't mean that my life has to be any different from another person's life. Even with EB, I still go out with friends, go to concerts, and I still plan to go to prom. EB is something that will accompany me, but it will never define me."

— **ARIANA**, a 16-year-old girl with RDEB

"My parents sent me to many dermatologists when I was a child, but I wasn't diagnosed with EB until I was in my late 20's. None of the doctors knew what I had. I was given all kinds of silly treatments. When penicillin was a miracle drug, I had shots of penicillin every day for 21 days. Doctors also placed me on a carrot juice diet. No treatment ever helped, but I never let EB stop me. I've been married and have children. And I grew up riding horses and used to breed race horses. I would like all of the kids suffering with EB to know that there is hope. And don't let EB hold you back!"

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

PHOTO CREDIT: ARI ESPAY, 2015 (OPPOSITE & COVERS)

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A LETTER FROM BRETT KOPELAN, DEBRA OF AMERICA'S EXECUTIVE DIRECTOR

Dear Friends,

On behalf of the debra of America staff and the Board of Directors, I would like to say thank you. Because of your continued support, this past year we were able to continue providing the essential programs and services for the EB Community and expand in some meaningful ways. 2015 was a year of firsts for the organization. We launched our first advertising campaign, our Government Affairs efforts, and our Legal Aid Program. These new initiatives are a huge step forward in executing our mission and making an impact for our Community.

JOHN REA AND PHIL SILVESTRI FROM HAVAS WORLDWIDE TONIC WITH EXECUTIVE DIRECTOR BRETT KOPELAN AT THE 17TH ANNUAL DEBRA OF AMERICA BENEFIT

Year over year we see an increase in the need, the asks, and the utilization of our services from the EB Community. Given that trend, we decided to expand upon our current slate of programs to systemically address the societal issues that impact our Community. Our Legal Aid Program was launched in 2015 to educate the Community so that they could better advocate for themselves. For instance, denials of service from insurance companies is unfortunately the norm for many EB patients and families. We therefore emulate tried and true appeals to help people obtain the required services from private insurance carriers by educating them to develop an effective strategy of data collection and by providing boilerplate letters that imitate prior successes. We also refer people to other resources and pro bono law firms, should the need arise.

We also needed to develop a means by which to educate federal, state, and local elected officials on types of legislation that would benefit not only our Community but those within the general rare disease community. Our Government Affairs Program was designed to educate those that could introduce legislation or waiver programs that would be impactful to our Community. In 2015, we were able to have language submitted for two different bills on Capitol Hill that would bring EB into the spotlight at the federal level. We were able to engender support from both Congressmen and Senators in this regard. Furthermore, we will continue our efforts to advocate for EB to once again be allocated federal research dollars. Four years ago, more than $1 million dollars of federal monies were granted to EB researchers; our goal is to have more money allocated and available every year for those searching for a treatment or cure.

Most importantly, in 2015, with the help of Havas Worldwide Tonic, we developed television commercials intended to attract new donors to our cause. Havas's generosity resulted in the development of two commercials that we will use online, on television, and on digital billboards. We started testing the commercials' effectiveness in 2015 on television and online, and we're planning a full national rollout in 2016. You can follow our efforts at #ItWontHurtToWatch.

2015 was also a year in which research initiatives took a giant leap forward. EB is on the forefront of personalized or "precision" medicine. With gene therapy, gene editing, RNA repair, and other autologous initiatives moving forward, we are proud to support the current and future initiatives. In fact, we hosted the DEBRA International Research Symposium where we brought more than 100 researchers together to discuss the basic science, the translational science, and the commercialization progress and initiatives. This conference, supported by the NIH, provided an environment for researchers to plan collaborative initiatives, allowing for data sharing that will "push the needle forward" faster.

By all accounts, 2015 was a successful year. A year of giant strides organizationally as well as incremental steps forward towards a treatment and a cure. I often said in 2015, "This is the first time I can see the light at the end of the tunnel and know it's not the oncoming train." That's a huge step forward, and I look forward to making even larger strides in 2016.

Many thanks,

Brett Kopelan
Executive Director
debra of America

OUR MISSION

To improve the quality of life for all people living in the United States with Epidermolysis Bullosa (EB), their families, and caregivers by funding research to find a cure and treatments for EB, while providing free programs and services.

CORE AREAS OF SUPPORT

- ☑ NURSE EDUCATION
- ☑ LEGAL AID
- ☑ GOVERNMENT ADVOCACY
- ☑ MINI WISH GRANTING
- ☑ WOUND CARE SUPPLIES

OUR IMPACT

In 2015, expanding our reach was at the center of all that we achieved, and our six direct service programs only grew stronger. We regularly helped parents cope with an EB diagnosis of their newborns. We helped **FAMILIES** make ends meet by providing specialized wound care at no cost. We strengthened the **COMMUNITY** by connecting families, and we eased their stress by helping them face important medical decisions, evaluating different approaches to care, and answering their questions. Our services also guided **LOCAL INSTITUTIONS** such as schools, hospitals, and other social service agencies – enabling them to care for EB patients, just as we would.

Our Government Affairs and Legal Aid division was unveiled in the summer of 2015, and we laid the important groundwork to overcome long-term barriers and advance **NATIONAL POLICIES** to make systems work better for the often isolated EB population. We also started providing legal aid to address the wide-ranging issues families so often come up against. And on an individual basis, we taught families how to advocate for themselves in order to gain stability and better meet their essential needs.

We are sincerely grateful to continue to provide these services towards hope and healing for the many mothers, fathers, sisters, brothers, friends, children, and other loved ones who have found in us a safe place and **SUPPORT SYSTEM**. **We are committed to seeing families thrive - not just survive - and together, with your help, we will continue to improve the quality of life and long-term prospects for those with EB.**

OUR PROGRAMS & SERVICES

WOUND CARE DISTRIBUTION PROGRAM

FILLING THE GAP.

Too many families living with EB have the odds stacked against them. With increasingly limited health care, more families are finding themselves unable to afford the specialized bandages that can cost upwards of $10,000 a month. Our **Wound Care Distribution Program** provides these vital supplies at no cost to those in need, ensuring that all those suffering with EB have the best possible chance of treating themselves with proper wound care. In 2015 alone, 262 supply shipments with a total value of $307,442 were provided to the EB Community, and families in every region of the country were served.

TYPES OF WOUND CARE SUPPLIES DISTRIBUTED

18%
OINTMENTS & TOPICALS

42%
SPECIALIZED BANDAGES

29%
ROLLED GAUZE & NETTING

11%
MISCELLANEOUS

34,211
TOTAL
PIECES OF WOUND CARE DISTRIBUTED

> *"I am so incredibly thankful to debra of America for this amazing blessing of the Wound Care Distribution Program...without you all and this Program, Gunner's life would be on the line because of infection."*
>
> — **EMILY, Gunner's mom**

> *"We have received the debra package for Vu today and are forever grateful for debra's support to EB children. This gives me a lot more motivation to help my brother and EB patients and find a cure for EB one day. Thank you very much."*
>
> – **HUYGEN, Vu's sister**

SNAPSHOT INTO THE PROGRAM AND ITS PARTICIPANTS

DECEMBER

MOST POPULAR MONTH FOR WOUND CARE REQUESTS

1 MONTH– 68 YEARS

SPAN OF EB PATIENTS' AGES PARTICIPATING IN OUR PROGRAM

17 YEARS OLD

AVERAGE AGE OF A WOUND CARE RECIPIENT

$920,649

TOTAL DOLLAR VALUE OF WOUND CARE SUPPLIES DONATED TO THE PROGRAM IN 2015

PHOTO CREDIT: ARI ESPAY, 2015

> *"When we got Julianne a year ago from China, it was obvious she had not been being bandaged at all…our insurance in the U.S. doesn't cover ANY of our supplies…with the daily bandage changes, supply costs just skyrocketed. We are SO thankful for the wound care from debra to help get us through."* – **WHITNEY, Julianne's mom**

NEW PROGRAM SPOTLIGHT

GOVERNMENT AFFAIRS & LEGAL AID

CHANGING THE GAME.

For thirty-five years, debra of America has been the leading EB patient advocacy organization in the United States by funding research for an EB cure while also providing services to help provide answers, support, and assistance to the EB Community.

PHOTO CREDIT: ARI ESPAY, 2015

While excitement has grown over the last few years due to more clinical trials being registered and undertaken and there is a higher probability of a treatment or product coming to market, there are nonetheless ongoing, glaring issues we need to address. For instance, there are many practical daily needs that the EB Community still strive to fulfill, such as private and governmental insurance coverage of necessary bandages, additional funding resources for expert EB researchers, and overall EB awareness by our nation's leaders.

debra of America's leadership team has always recognized these needs. And in 2015, we decided to address them head-on by launching the **Government Affairs and Legal Aid Programs**.

These two programs are led by Joe Murray, an EB dad with seven years' experience working in federal health care policy in the U.S. Senate and House of Representatives, and were created to promote the rights of individuals and families impacted by EB. Through advocacy efforts surrounding a broad range of issues that include legislative advocacy on Capitol Hill and State Capitols, executive and regulatory agencies, and legal advocacy through partnerships with attorneys from disability law organizations, these programs seek to advance systemic positive change through EB advocacy efforts at the local, state, and federal government levels.

2015 was an instrumental year in laying the foundation necessary for these two new programs and advancing EB policy goals on Capitol Hill and beyond. The programs' efforts focused on fostering relationships and promoting EB awareness with members of Congress and their staffs, electedstate leaders in Virginia, and with relevant federal agencies that authorize disease research funding and reviews.

debra of America's focus in these two areas is already showing results early on in 2016. Stay tuned as we report new initiatives coming out of the Government Affairs and Legal Aid programs!

JOE MURRAY, DEBRA OF AMERICA'S DIRECTOR OF GOVERNMENT AFFAIRS & LEGAL AID, WITH HIS FAMILY

Dear debra of America supporters
and members of the EB Community,

I am honored to be a part of the debra of America family by serving as the Director of Government Affairs & Legal Aid. Since joining the debra staff in 2015, we have experienced positive advancements and increased EB awareness with elected leaders in the U.S. Congress and in State Capitols. As a dad to a beautiful RDEB nine-year-old daughter named Ella, my heart is always joined with the EB Community to promote research for an EB cure and treatment while supporting our families with the services and programs they need and deserve. Thank you for your commitment to debra of America. We will not rest until EB is conquered.

Sincerely,
JOE MURRAY
Director of Government Affairs & Legal Aid

SMILE FUND

ENRICHING LIVES.

Daily activities such as bathing, sleeping, and eating can feel like insurmountable chores for people with EB. On a monthly basis, our Smile Fund grants one mini-wish of choice to an individual who endures these constant hardships. Through this Program, we make families feel better emotionally by bringing a little normalcy (and fun!) into their lives.

CHARLOTTE'S SMILE

Smiles are for kids like Charlotte, a 10-year-old girl who loves My Little Pony and McDonald's. She has Recessive Dystrophic EB (RDEB) and met her best friend, Bee, at a skin disease camp 3 years ago. Living in Alabama, and far away from Bee, Charlotte longed for a way to see her friend all of the time.

By receiving an iPad through the Smile Fund, Charlotte is now able to see and speak with her best friend whenever she wants. "Bee also has RDEB, and we help each other through the rough days and laugh with the good days. Even though she lives in Miami when we FaceTime it feels like she is in Alabama with me."

> *"Charlotte is so excited to have won!!! She gave an ear-piercing squeal of joy when I told her."* —**DEBBIE, Charlotte's mom**

PAUL'S SMILE

Paul's smile was created with video games. Paul is a young adult who has Recessive Dystrophic EB (RDEB) and is a champion for the EB Community. "Even though in the real world I'm considered a young man, by EB standards I'm considered an old man. I deal with esophagus issues, getting throat dilations, hair loss, and getting skin cancer biopsy checks every 6 months." Video games help Paul take his mind off the pain of living with RDEB and are a good stress reliever for him. "Even with both of my hands fully webbed, I'm still able to play video games in my own unique way and have become pretty good at it, which makes me happy."

ESTREYA'S SMILE

Meet Estreya, a 16-year-old high school student living with Recessive Dystrophic EB (RDEB), from Colorado. Estreya's mom nominated her to receive a shopping spree through the Smile Fund, and the teen was speechless when she found out her mini-wish of shopping for books and clothes had been granted. Estreya is a typical teenage girl who, despite coping with the persistent pain of living with EB, lives by the phrase, "Laughter is the best medicine." We are happy to have made Estreya smile!

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

DEBRA OF AMERICA EVENTS

THE 17TH ANNUAL DEBRA OF AMERICA BENEFIT

On November 16, at the world renowned Solomon R. Guggenheim Museum in New York City, over 400 supporters attended the 17th Annual debra of America Benefit, presented by Mölnlycke Health Care. The evening celebrated our 35th anniversary and was a record-breaking success. Nearly $800,000 was raised to fund EB research and provide services for the EB Community.

Guests were treated to the premiere of three emotional television commercials developed by 2015 Partners in Progress Award Recipient Phil Silvestri and his team at Havas Worldwide Tonic, one of the largest advertising companies in the world. When Havas learned of EB, it affected them to such a degree that they donated their services and created commercials that depict the struggles of living with EB and the hope for finding a cure.

The evening also included a once-in-a-lifetime performance led by legendary, former American Ballet Theatre Principal Dancer Julie Kent, and a live DJ set by platinum-selling artist Kate Nash. It was truly an unforgettable night!

We want to extend a very special thank you to our honorees, including John F. Crowley, Phil Silvestri, Julie Kent, William Barbee, Ariana Covarrubias, and Arlene Pessar, as well as Emcee Michelle Miller, DJ Kate Nash, and the American Ballet Theatre dancers who performed. And to our sponsors, guests, volunteers, and fellow EB advocates: thank you for your support and dedication.

> *"The 17th Annual debra of America Benefit was such a spectacular evening. I always get emotional seeing how this organization can impact peoples' lives. The generosity of the family and friends of those with EB is such an exciting thing, because I know it is creating a positive impact on the lives of those living with this disorder."*
> — **ANDREA FRANTZ-IVERSEN, Young Leadership Committee Member**

1. ATTENDEES ENJOY A COCKTAIL RECEPTION AT THE SOLOMON R. GUGGENHEIM MUSEUM 2. SPIRIT AWARD WINNER ARIANA COVARRUBIAS & EMCEE MICHELLE MILLER 3. CORPORATE HERO AWARD WINNER JOHN F. CROWLEY WITH WIFE AILEEN CROWLEY & RAFI KOPELAN 4. GUESTS OF MÖLNLYCKE HEALTH CARE

THE 3RD ANNUAL MATS WILANDER FOUNDATION & DEBRA OF AMERICA TENNIS PRO-AM

MATS WILANDER, JOHAN KRIEK, CAMERON LICKLE, AND OTHER SPECIAL GUESTS AT THE 2015 TENNIS PRO-AM

On September 2, guests joined Former World #1 Champion and International Tennis Hall of Fame Member Mats Wilander for a fun day of tennis at the historic West Side Tennis Club in Forest Hills, New York. The event included an exhibition match viewing and a full day of clinics, drills, and matches against former world-ranked pros including Mats Wilander, Johan Kriek (two-time Australian Open Champion), and Cameron Lickle (Wilander on Wheels).

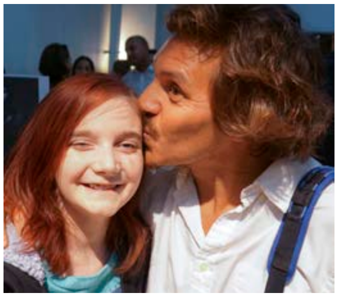
Thank you to the MW foundation, Wilander on Wheels, and our guests and attendees for helping us raise much-needed funds and awareness for EB.

FACES OF EB

On October 27, guests filled Punto Space, an event performance venue in New York City, for an exclusive photography exhibition by award-winning photographer Ari Espay.

Prior to the Faces of EB exhibition, Ari invited individuals with EB and their families to participate in a photo shoot. The exhibition was the product of that shoot, and the images on display illustrated the beauty, resilience, and strength of Ari's subjects.

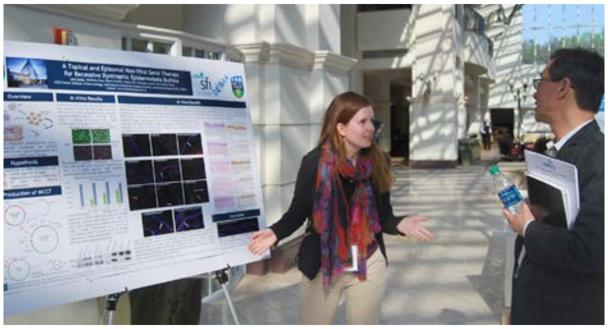
Thank you to Ari Espay and Liza Politi for spearheading the photo shoot and the Faces of EB exhibition. Their work not only showcased the many faces of EB, but they also raised much-needed awareness. Thank you also to Punto Space, Duggal, and Fancy Girl Street Boy Productions for assisting in the evening's success.

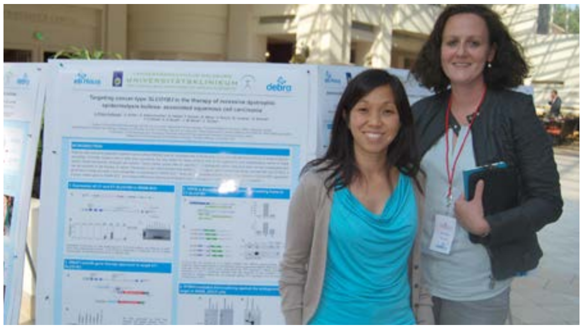


> *"I want these photographs to capture these extraordinary kids and the challenges they face in their daily lives. I hope these photographs inspire people to get involved with debra of America."* — **ARI**

Many of the photos featured in the 2015 Annual Report are a result of Ari's photo shoot and were featured at the Faces of EB exhibition.

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





THE 2015 DEBRA INTERNATIONAL RESEARCH SYMPOSIUM

In 2015, debra of America was the proud host of the triennial DEBRA International Research Symposium, a conference that invites EB researchers from around the globe to present their work, initiatives, and questions. It was exciting to see all of the devoted researchers and physicians under one roof, dedicated to working towards one common goal: a cure for EB.

Speakers covered many interesting topics including patient perspectives, quality of life issues, gene editing, protein replacement strategies, as well as updates on EB clinical trials and developing therapies. Most importantly, the Symposium provided an environment that allowed researchers to plan for current and future collaborative projects.

Rainer Riedl, President of DEBRA International, CEO of DEBRA Austria, and most importantly a father to a young woman who has RDEB, shared "Even though we didn't hear of any major breakthrough, we all share the impression that EB research is speeding up dramatically and that we can expect a striking number of new clinical trials and some new medical products in the very near future."

Thank you to the National Institutes of Health (NIH) for providing financial support of the Symposium so that collaborative opportunities in the search for a cure can be expanded upon. We are filled with hope for the future, and we are excited to follow these research initiatives as they advance through the process to becoming potential viable treatments for EB.

THE SYMPOSIUM BROUGHT TOGETHER OVER 100 ATTENDEES TO COLLABORATE, DISCUSS, AND FURTHER EXPLORE CURRENT EB RESEARCH AND TREATMENTS. OVER 10 COUNTRIES WERE REPRESENTED, INCLUDING THE UK, JAPAN, AUSTRIA, GERMANY, SPAIN, AUSTRALIA, AND IRELAND.

SUPPORTER LED EVENTS

BUTTERFLY WISHES FOR ELLIE

In 2015, the Tavani family hosted the 9th Annual Butterfly Wishes for Ellie in honor of their 9-year-old daughter, Ellie, who has EB. Guests danced to a coveted local rock band, bid on exciting silent auction items, and enjoyed a night under the stars in Atlanta, Georgia. Thanks to a loyal and supportive community, Butterfly Wishes for Ellie has raised over $250,000 since its inception! This event brings families from far and wide to celebrate Ellie and to honor all individuals and families who struggle with EB every single day.

200 ATTENDEES ________ **2015**

145 ATTENDEES ________ **2014**

2015 SAW A
38% INCREASE
IN EVENT ATTENDEES!

Shawn Tavani (debra of America's acting EB Nurse Educator) and Andrew Tavani (member of debra of America's Board of Directors) share why the success of this event is so important to their family and others affected by EB:

> *"No child should be denied their childhood and be forced to face such difficulty...to be so adult so early. For 9 years we have been waiting for a cure... if not a cure, at least a treatment...something, so that Ellie can be more normal... or at least slow this gradually debilitating disease that she has endured every day of her young life. And while we are closer than we were 9 years ago, there is still no cure or treatment available.* ***Ellie, and children like Ellie, need something to happen now!****"*

A huge thank you to the Tavani Family for their dedication to raising money and awareness for EB. We can't wait to celebrate the 10th anniversary of Butterfly Wishes for Ellie with you next year!

WHEELS HEALING WOUNDS CAR SHOW

The first-ever Wheels Healing Wounds Car Show was held in October 2015 in Lexington, North Carolina in honor of a young boy living with EB. The event began as a school project, spearheaded by a young student Robert Cline and his mother Dana, and grew to be a full-scale event featuring cars of all makes and models and drawing individuals from across the area to support EB. Spectators enjoyed a fun-filled day including a rare car show viewing, refreshments, music, a silent auction, and more! Admission to this event was free, and the hosts raised over $1,000! What a great display of true generosity and community support.

INAUGURAL BUTTERFLY BREAKFAST

The Inaugural Butterfly Breakfast took place in April 2015 in Miller Place, New York. Donna and Kelly McCauley, the dedicated event hosts, invited supporters to gather at the local Applebees for a delicious pancake breakfast for a great cause. Over $4,500 was raised. What an inventive way to raise money for EB! Donna and Kelly spent several months leading up to the event soliciting auction items including trips to vineyards, hotel stays, and dinner vouchers. The McCauleys were overwhelmed by the support that they saw from their community, and they are looking forward to the 2nd Annual Butterfly Breakfast!

Thank you to all of our Supporter Led Event Organizers who worked so hard this year to raise awareness and over $360,000 for EB.

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 or 212-868-1573.**

RAISING AWARENESS

#ITWONTHURTTOWATCH CAMPAIGN

In 2015, debra of America launched a series of TV and web commercials, which aired on the Discovery Channel, and advertised on a number of websites alongside a campaign entitled #ItWontHurtToWatch. These powerful commercials were generously produced by Havas Worldwide Tonic, an award-winning health & wellness advertising agency, and featured two young children who live with EB.

YOUNG LEADERSHIP COMMITTEE

The Young Leadership Committee (YLC) is comprised of young professionals in their 20's through 40's who work to promote EB awareness through fundraising, influencing programmatic changes, 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 fund groundbreaking EB research.

In 2015, the YLC hosted a number of events to help spread EB awareness and raise funds, which included a SoulCycle charity ride, a Charles Schwab networking event, and several happy hours.

VOLUNTEER SPOTLIGHT

"Let me begin by saying how very helpless I felt during the first 6 months of my granddaughter Ella's life. All I could do was pray, help my daughter in small ways, and learn as much as I could about EB. But the urge to do something more was always there, and as a retired teacher, I knew the one thing I could do was educate others about this rare disease. Awareness seeks education which prompts giving to fund research for a cure. As a speaker at various women' organizations, I always find a way to weave in Ella's story and educate about EB. People always have questions and are eager to know what they can do to help. Everywhere I go I seem to find a teachable moment."
— GALE ALEXANDER, EB Impact Committee Member

DEBRA OF AMERICA VOLUNTEERS

debra of America's Volunteer Program is an easy way for individuals to get involved in the fight against EB. Volunteers are crucial to the success of debra of America events, such as the Annual Benefit and Supporter Led events, which take place across the country.

VOLUNTEER SPOTLIGHT

"I'm very thankful to be a part of this great organization for EB support and awareness. I feel that we could be the primary people to change the moniker of 'the worst disease you've never heard of' to just 'the worst disease,' to finally, the 'cured disease.' Change first comes through awareness, and the YLC is the instrument of that change."
— LORI GUILBEAU, Young Leadership Committee Member

EB IMPACT COMMITTEE

debra of America's EB Impact Committee (EIC) are members of the EB Community who raise awareness, influence programmatic changes, and advocate on behalf of fellow EB patients and families. Every year, the EIC votes for the debra of America Spirit Award winner, a member of the EB Community who possesses great courage and strength in the face of EB. The Spirit Award winner is honored at debra of America's Annual Benefit.

In 2015, the EIC was essential in the launch of debra of America's #ItWontHurtToWatch commercials. They aided awareness efforts by sharing the commercials amongst their professional and personal circles via social media. Throughout the year, the EIC provided debra of America with input on our free programs & services. As many EIC members are directly or indirectly affected by EB, their input allows the organization to make the necessary changes in order to remain an important resource for the EB Community.

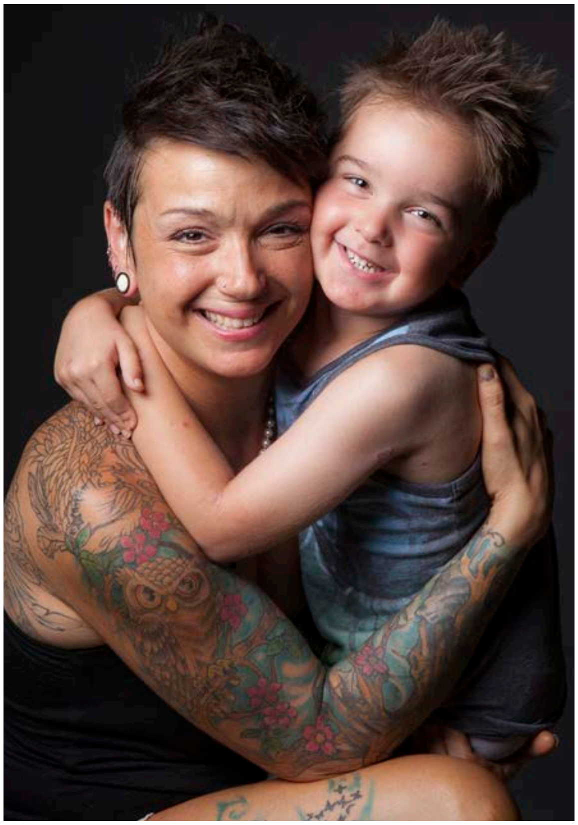


PHOTO CREDIT: ARI ESPAY, 2015

FINANCIAL ANALYSIS

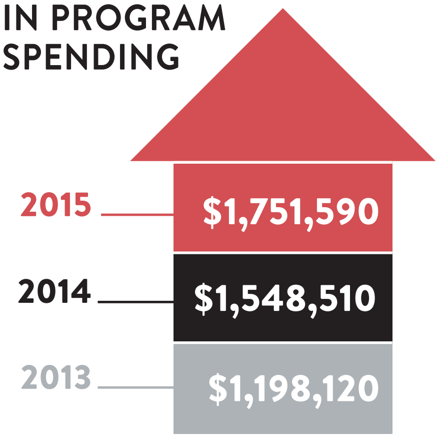
REVENUE	2013	2014	2015
Special Events	$622,050	$486,111	$921,598
Contributions & Grants	716,217	819,178	356,209
In-Kind Contributions	370,269	437,302	1,374,112
Investment Income	3,917	-2,683	3,168
Other	11,886	13,488	4,578
Net Assets Released	36,556	38,699	177,294
TOTAL REVENUE	**$1,760,895**	**$1,792,095**	**$2,836,959**

	2013	2014	2015
TOTAL ASSETS	**$1,547,797**	**$1,722,111**	**$2,721,102**
Total Liabilities	127,893	61,663	37,835
Unrestricted Net Assets	$919,775	$966,124	$1,873,082
Temporarily Restricted Net Assets	500,129	694,324	810,185
Total Net Assets	1,419,904	1,660,448	2,683,267
TOTAL LIABILITIES AND NET ASSETS	**$1,547,797**	**$1,722,111**	**$2,721,102**

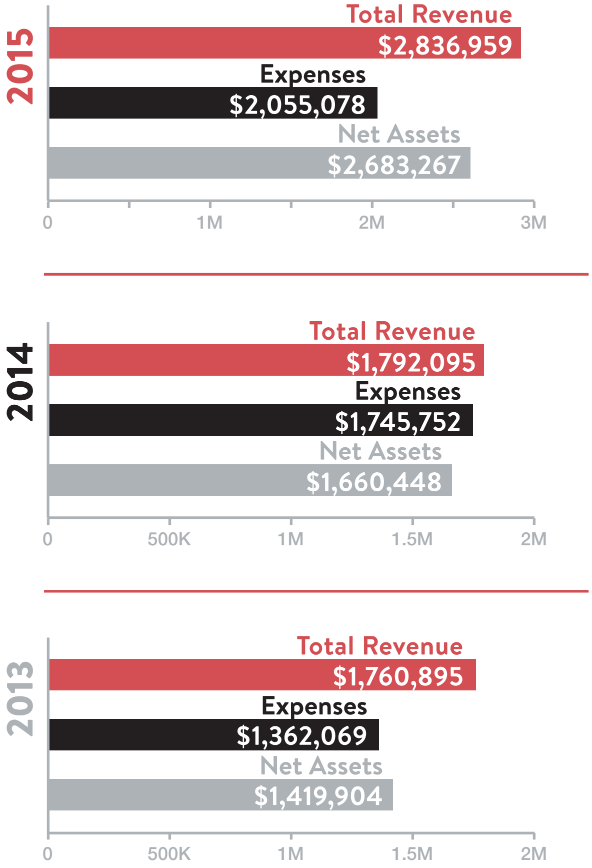
EXPENSES	2013		2014		2015	
Education	$167,613	10%	$235,606	13%	$315,317	15%
Patient & Family Services	908,129	52%	1,159,760	65%	1,231,316	60%
Advocacy	25,142	1%	35,341	2%	47,298	2%
Research	97,236	6%	117,803	7%	157,659	8%
TOTAL PROGRAMS EXPENSES	**$1,198,120**	**68%**	**$1,548,510**	**86%**	**$1,751,590**	**85%**
	2013		**2014**		**2015**	
Management	$41,905	2%	$77,096	4%	$78,829	4%
Fundraising	122,044	7%	120,140	7%	224,659	11%
TOTAL EXPENSES	**$1,362,069**		**$1,745,752**		**$2,055,078**	

PHOTO CREDIT: ARI ESPAY, 2015

INCREASE IN PROGRAM SPENDING



THREE-YEAR FINANCIAL ANALYSIS



OUR SUPPORTERS

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

$50,000 +

Mr. J. Alec and Mrs. Cynthia Alexander

Mr. John F. Crowley

Fisher Brothers Foundation

Mr. John Lee

Estate of Marjorie Lightfoot

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Mölnlycke Health Care

Ms. Leslie Ziff

$25,000-$49,999

Mr. Bill and Mrs. Carolyn Aliski

Mr. Johnny McCranie

Scioderm

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As a co-founder of Scioderm, Inc., a biopharmaceutical company developing a unique and proprietary topical treatment for all subtypes of EB (presently in phase 3 clinical trial with Amicus Therapeutics, which acquired Scioderm in 2015), I became aware of EB and debra of America in 2010, about 3 years prior to getting Scioderm financed in 2013. As Scioderm became fully operational in 2013, we developed a close relationship with debra of America to better understand the needs of people living with EB. Shortly thereafter, my wife Pamela became actively involved in debra through fundraising, and we are both committed to helping debra in any way we can.

From the time we first learned of EB, we saw the challenges and suffering this disease brings to EB patients and their families, so we wanted to support debra of America, which brings front line support to patients.

Pamela and I see debra of America as a very informal, collegial group that includes all EB Community members in its significance and promise, especially the EB patients and their families who really give it the spirit and soul it has today.

What does the EB Community mean to you?
Now, having developed personal relationships with families and people affected by EB, the EB Community holds a very special place in our hearts and minds. The EB Community is a strong network of families, health care providers, researchers, industry participants, and patient advocacy groups such as debra of America that provide support and promise to EB patients and their families.

Why is EB awareness important?
EB is among the many devastating orphan and other diseases that our world faces. It is important that all of the key participants in the EB Community, as well as those outside of the Community, be aware of the challenges of this disease and the realizations that come from commitment and focus on developing treatments. The more aware the specific EB and general communities are, the more support patients are provided (in the first instance), and the more investment and related research becomes targeted at finding treatments and eventually cures. This is the same for all diseases... each and every one of them needs champions.

A special or inspirational moment you've experienced while supporting debra of America.
While there are many special moments; among them, is speaking with patient families and debra of America organizers who have shared their experiences (many have EB children). One of the debra of America events that is always motivational is Rafi's Run. At Rafi's Run there is a complete feeling of community – patients, their families, friends, and friends of friends, all running together alongside each other exhibiting hope and inspiration for people and children with EB, all initially inspired by Rafi, a spirited and determined 8-year-old with EB who never gives up and never gives in. Last year was truly inspirational as we watched Rafi herself run, knowing how difficult this is for her, with everyone cheering her on shouting "go Rafi go, go Rafi go" over and over again.

— ROBERT & PAMELA COULL

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HOW YOU CAN HELP

JOIN A COMMITTEE

Young Leadership Committee (YLC)

The Young Leadership Committee (YLC) is comprised of young professionals who work to promote EB awareness through fundraising, influencing programmatic changes, and by participating in events across the country.

EB Impact Committee (EIC)

debra of America's EB Impact Committee (EIC) are members of the EB Community who raise awareness, influence programmatic changes, and advocate on behalf of fellow EB patients and families.

PLAN AN EVENT

There are so many ways to fundraise for EB – through events large and small, and even through fundraisers hosted solely online! You can organize a bake sale, raffle, pasta dinner, or an athletic event, just to name a few ideas.

We help develop a cobranded website that allows you to recruit other people to help you fundraise, enables you to collect donations and event registrations via credit card or check, and gives you simple access to reports that let you see how your event is doing. We will offer support every step of the way – by providing event materials, customizing your event site, and assisting with donations and registrations. We are committed to making your fundraiser fun, creative, and successful!

VOLUNTEER

Help raise EB awareness in your community by volunteering at a debra of America or Supporter Led event.

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

HOLD A WOUND CARE DRIVE

You can help meet the basic health care needs of children and adults with EB and directly improve their quality of life by organizing a wound care drive. Invite your family, friends, co-workers and community members to join in on collecting over-the-counter supplies. These easy to obtain items, such as gloves, wound cleansers, and paper tape, go a long way in preventing infection and staving off wound complications.

To request a Wound Care Drive Tool Kit, please email woundcare@debra.org.

BECOME A LEGISLATIVE ADVOCATE

Stay up-to-date on advocacy issues and have the opportunity to participate in grassroots advocacy activities, including partnering with local, state, and national leaders to help open doors through your outreach.

To receive alerts when debra of America needs you to contact your elected officials, or to get more involved in helping to change the laws and policies that affect those with EB, please email programs@debra.org.

PHOTO CREDIT: ARI ESPAY, 2015

GET INVOLVED ON SOCIAL MEDIA

debra of America is active on a number of social media platforms, which are used to raise awareness of EB and engage with the EB Community. EB advocates and supporters can follow, like, and share debra of America's content to help spread EB awareness across the web. You can find debra of America on the following platforms:

- **Facebook:** facebook.com/DebraofAmerica
- **Twitter:** @debraOfAmerica
- **Instagram:** @wefighteb
- **Tumblr:** debra.org/blog
- **LinkedIn:** linkedin.com/company/debra-of-america
- **YouTube:** youtube.com/user/DebraofUS

MAKE A GIFT

A gift from you allows us to send free wound care to members of the EB Community. It will also help us get one step closer to finding a cure...

ROAD TO A CURE

1 EB IS CAUSED BY AN ERROR IN THE DNA AND WE HAVE IDENTIFIED THE ERROR

2 WE FUNDED THE SCIENCE THAT CORRECTED THE ERROR, CURING EB IN THE LAB

3 **THE LAST STEP:**
TURNING THE LAB WORK INTO A MEDICINE THAT WILL HELP THE 25,000 EB PATIENTS SUFFERING WITH EB IN THE U.S.

THIS IS WHERE YOU COME IN!

A DONATION FROM YOU WILL ALLOW US TO TAKE THAT LAST STEP

To make a gift, go to debra.org/Give
For more information about supporting debra of America, please email donations@debra.org.

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“The best piece of advice I’ve received was in a book called Think and Grow Rich by Napoleon Hill. In it, there was a quote that hit me hard: ‘Don’t let your disability be a liability, instead use it as an asset of great value.’ I think no matter what our situations are in life, we can find the positives in anything.”

— **PAUL**, a 33-year-old man with RDEB

“EB is horrible, it hurts and it’s challenging at times but I won’t let it get me down. I’ll still do what I want (if my mom gives me permission). EB will never slow me down. Ever! One day there will be a cure. Until then, EB won’t win.”

— **CHARLOTTE**, a 10-year-old girl with RDEB

because the cost of doing nothing is too great

debra of America
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