19TH ANNUAL BENEFIT

OCTOBER 26, 2017
GUASTAVINO’S
NYC

because the cost of doing nothing is too great
The 19th Annual debra of America Benefit

Our compassion for patients drives our passion for science.

COCKTAILS & SILENT AUCTION

DINNER SERVICE

WELCOME REMARKS

PARTNERS IN PROGRESS AWARDS
AMICUS THERAPEUTICS, INC.
BERG HEALTH

CORPORATE HERO AWARD
MICHAEL DELVACCHIO, 3M MEDICAL

PARTNERS IN PROGRESS AWARD
CASTLE CREEK PHARMACEUTICALS

LIFETIME ACHIEVEMENT AWARD
FRANK J. SASINOWSKI, HYMAN, PHELPS & MCNAMARA, P.C.

SPIRIT AWARD
ZACK TROOP

DESSERT

REMARKS
BRETT KOPELAN, EXECUTIVE DIRECTOR, DEBRA OF AMERICA

CLOSING REMARKS & GOOD EVENING
While this night is one of joyous celebration, I ask you to take one minute to recognize those that have lost their struggle with EB this year. It was a difficult year in that regard. Yet, every year with every new Partner in Progress, we come one step closer to beating this devastating disease. We come one step closer to ensuring we don’t need to take a minute to recognize tragedy this disease inflicts. One step closer to fulfilling our mission. Thank you for your continued support. Thank you for understanding the axiom, “because the cost of doing nothing is too great.”

Sincerely,

Brett Kopelan
Executive Director and father to Rafi, a 10-year-old with recessive dystrophic EB

DEAR FRIENDS,

We are honored that you are here to celebrate the evening with us. On behalf of the Board of Directors and staff, welcome to the 19th Annual debrA of America Benefit. 2017 has given us a lot to celebrate and provided reason for excitement for the coming year. With the help of you, our sponsors, donors and volunteers, we are able to service the EB Community in a myriad of ways. Your continued support furthers our mission and provides an immediate impact to the lives of thousands. Thank you from all of us in the debrA of America family.

Tonight, we welcome in National Epidermolysis Bullosa Awareness Week with an incredible array of award recipients and with the launch of a special tribute campaign for Ella Murray. Ella was highlighted in a Washington Post article and video. Close to 1 million people viewed her story and in it, she expressed a wish to play tag, just like her friends do on the playground. Ella has recessive dystrophic eb, so running around is difficult at best. We would like to give her the gift of a virtual game of tag. Please ask us about the #TagWithElla social media campaign and please participate. Let’s make Ella smile and enjoy a fun pastime.

Our award recipients this evening are just incredible. Zack Troop, our Spirit Award winner, lives by his motto “be an example, not an exception” and for that alone, he is deserving of our appreciation. I don’t think there is someone more deserving of a Lifetime Achievement Award than Frank Sasinowski. His advocacy and work in the rare disease space is legendary. Michael DelVacchio, our Corporate Hero Award recipient, is bringing the full weight of 3M Healthcare into the skin care arena. And, of course, we are incredibly thankful for our Partners in Progress Award recipients: Amicus Therapeutics, Berg Health and Castle Creek Pharmaceuticals.

SEATED DINNER MENU

FIRST COURSE
TUSCAN KALE AND BRUSSEL SPROUTS
Toasted Walnuts
Lemon and Mustard Vinaigrette

MAIN COURSE
ROASTED HALIBUT
Sweet Corn Puree
Wilted Pea Tendril
Chive Vinaigrette
Silent Vegetarian Option Available

DESSERT
MOLTEN CHOCOLATE CAKE
White Peach Ice Cream, Raspberry Coulis

COFFEE AND TEA SERVICE
THANK YOU FOR YOUR GENEROSITY AND SUPPORT!

IN MEMORY
OF THOSE WHO LOST THEIR BATTLE WITH EPIDERMOLYSIS BULLOSA
FROM NOVEMBER 2016 – OCTOBER 2017

ADDYSON  GABRIEL  OLIVIA
ALI  HARLEY  RYLAN
BRIANNA  HARRISON  TAYLOR B.
CODY  KAHLEEL  TAYLOR K.
ERIN  KAIKEN  ZACHARY
MARLO

Those who passed away and their families will not be forgotten as debra of America continues to search for a cure.
AMICUS THERAPEUTICS

Amicus Therapeutics is a global biotechnology company at the forefront of advanced therapies to treat a range of devastating rare and orphan diseases. The company has a robust development pipeline of novel, first-in-class treatments for a broad range of human genetic diseases.

BERG HEALTH

Berg is a Boston-based biopharma company focused on taking a bold “back to biology” approach to therapeutic discovery using its unique AI-based Interrogative Biology® platform. This platform combines patient biology and artificial intelligence-based analytics to engage the differences between healthy and disease environments. The patient’s own biology drives the platform’s results and guides us in the discovery and development of drugs, diagnostics and healthcare applications. Our platform utilizes patient population health data to bring actionable Patient Intelligence™ to precision medicine applications. This means faster discovery and development of treatments, more effective precision treatments for individuals as well as a reduction in costs to our healthcare systems.
Michael J. DelVacchio is a healthcare veteran with 25+ years in the healthcare industry. He is currently the Vice President of the Medical Markets Center, within the 3M Health Care Business Group. Prior to joining 3M, Michael has held positions of increasing responsibility at Boston Scientific, Johnson & Johnson and Acelity. Michael was most recently Sr. Vice President of Sales & Marketing for Xenex Corp where he is still an advisory Board Member.

Michael holds a BS in Business Administration and an MBA in Marketing from Villanova University.

Castle Creek Pharmaceuticals is a privately held biopharmaceutical company dedicated to the development of advanced therapies that have the potential to treat debilitating dermatologic and head and neck conditions with high unmet medical needs. Our lead development product is diacerein 1% ointment (CCP-020) for treatment of epidermolysis bullosa simplex (EBS).
LIFETIME ACHIEVEMENT AWARD

FRANK J. SASINOWSKI, M.S., M.P.H., J.D.

Frank J. Sasinowski, M.S., M.P.H., J.D., assists sponsors and patient organizations in developing new medicines and has helped secure FDA approval for hundreds of new drugs, including more than 45 new molecular entities, often for serious and/or rare diseases. Mr. Sasinowski joined the FDA in 1983 as regulatory counsel in the Center for Drugs and Biologics, where he was key to implementing both the 1983 Orphan Drug Act into law and the 1984 Hatch-Waxman law. In 1987, he left the FDA as Deputy Director of the health policy staff in the Commissioner’s office and joined Hyman, Phelps, & McNamara PC.

In its March 2012 issue, the Drug Information Journal published Mr. Sasinowski’s seminal analysis on therapies for rare disorders: “Quantum of Effectiveness Evidence in FDA’s Approval of Orphan Drugs: Cataloguing FDA’s Flexibility in Regulating Therapies for Persons with Rare Disorders.” Other papers on Accelerated Approval and Orphan Drugs are cited by FDA officials as well.

In December 2014, Frank was appointed an Adjunct Professor of Neurology at the University of Rochester Medical Center.

Mr. Sasinowski’s work has been widely recognized by industry and political leaders, as well as notable organizations. For example, Mr. Sasinowski was asked by both political parties to testify at the May 2014 inaugural hearing of Congress’ 21st Century Cures Initiative. In May 2013, the National Organization for Rare Disorders (NORD), which represents the 30 million Americans with rare diseases, awarded Mr. Sasinowski its first ever NORD Lifetime Achievement Award. In 2000, Mr. Sasinowski was elected to NORD’s Board of Directors, where he has served as Chair and as Vice Chair, and where he remained on the Board until 2016. In October 2012, President Obama recognized Mr. Sasinowski’s contributions to the President’s Council of Advisors on Science and Technology (PCAST) report, “Propelling Innovation in Drug Discovery, Development and Evaluation.”

Based on his extensive experience with the FDA, from both the agency and client side, Mr. Sasinowski possesses a detailed understanding of the regulatory process. He regularly shares his insight on drug development issues with physicians, scientists, and regulators, and has served on the boards of several biotechnology companies. Mr. Sasinowski has been Chair of the Food and Nutrition Section of the American Public Health Association (APHA) and has taught health law at American University. Mr. Sasinowski has also served on the Board of Directors of the United States Pharmacopeia (USP).
Zack Troop is a 15-year-old teen from Bountiful, Utah who lives with Recessive Dystrophic Epidermolysis Bullosa (RDEB). He is a freshman at Bountiful Junior High where he is an honor student and serves as a Student Body Officer. Zack has undergone almost 30 surgeries in his young lifetime, but he does not let EB hold him back. He is big brother and role model to 6 younger siblings and lives by the motto, “be an example, not an exception.”

Zack’s ambition has led him to do anything he sets his mind to, which includes being an active participant at Camp Spirit, completing the Courage Classic bike tour, and fundraising for The Children’s Hospital of Colorado. His nominator’s share that “Zack faces his struggles quietly and gracefully, and he is a leader in every sense of the word.”

The debra of America Spirit Award Winner is a person with EB in the United States who possesses great courage and strength in the face of EB. Recipients rise above the daily struggle of living with this rare disease to serve as an example to others in their community and the world at large in understanding EB. The Winner is chosen from a group of finalists by debra of America’s EB Impact Committee.
WHAT IS DEBRA OF AMERICA & EPIDERMOLYSIS BULLOSA?

Because the cost of doing nothing is too great. This axiom defines debra of America’s mission and directs all that we do. debra of America is dedicated to improving the quality of life for those living with Epidermolysis Bullosa (EB). To achieve our mission, we do two things in parallel: we provide free services and programs to the EB Community in the United States and fund the most innovative research directed at symptom relief and a systemic cure. Our funding identified the genetic basis of EB and supports the science, which is at the forefront of gene and stem cell therapy, RNA repair, protein replacement and inhibition of squamous cell carcinoma. Until there is a cure, debra of America will continue fighting the “worst disease you’ve never heard of.”

Epidermolysis Bullosa (EB) is a rare connective tissue disorder with many genetic and symptomatic variations. All forms of EB share the most prominent symptom of extremely fragile skin that blisters and tears from the slightest friction or trauma. It’s often referred to as a skin disease — but that is reductive. The more severe forms have a long list of complications and secondary illnesses that require multiple interventions from a range of medical specialists. Internal organs and bodily systems are often severely affected. EB is always painful and often times debilitating. In the more severe forms, it is fatal within the first few months of life.

CORE AREAS OF SUPPORT

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

Because the cost of doing nothing is too great. This axiom defines debra of America’s mission and directs all that we do. debra of America is dedicated to improving the quality of life for those living with Epidermolysis Bullosa (EB). To achieve our mission, we do two things in parallel: we provide free services and programs to the EB Community in the United States and fund the most innovative research directed at symptom relief and a systemic cure. Our funding identified the genetic basis of EB and supports the science, which is at the forefront of gene and stem cell therapy, RNA repair, protein replacement and inhibition of squamous cell carcinoma. Until there is a cure, debra of America will continue fighting the “worst disease you’ve never heard of.”

Epidermolysis Bullosa (EB) is a rare connective tissue disorder with many genetic and symptomatic variations. All forms of EB share the most prominent symptom of extremely fragile skin that blisters and tears from the slightest friction or trauma. It’s often referred to as a skin disease — but that is reductive. The more severe forms have a long list of complications and secondary illnesses that require multiple interventions from a range of medical specialists. Internal organs and bodily systems are often severely affected. EB is always painful and often times debilitating. In the more severe forms, it is fatal within the first few months of life.

DEBRA OF AMERICA’S FREE PROGRAMS & SERVICES

EB NURSE EDUCATOR PROGRAM
Our nurse is available by phone or email for EB families, the public, and the professional community to answer questions, refer doctors, and provide guidance.

GOVERNMENT AFFAIRS & LEGAL AID PROGRAM
debra of America works at all levels of government to educate legislators about important laws, regulations, and policies that will benefit those with EB. Legal Aid is designed to help people with EB, and their families, advocate for themselves when issues arise.

NEW FAMILY ADVOCATE PROGRAM
Wound care products and informational materials are sent to all new EB families. Each package is valued at $1,200. An experienced caregiver is also available upon request for hands-on training on how to care for someone with EB.

SMILE FUND
In partnership with Grace Peshkur’s family and friends, debra of America grants mini-wishes for people with EB. These smiles not only benefit the Butterfly Child or Adult, but they also create priceless memories.

DEBRA CARE CONFERENCE (DCC)
A biennial conference where EB families come together to share their experiences and learn from clinicians and researchers who specialize in EB. Most importantly, the DCC allows those with EB to meet new families and reconnect with others from around the country that share similar circumstances. Nearly 600 people attended debra of America’s 2016 DCC in Texas, and our 2018 DCC will be held in Arizona.

WOUND CARE DISTRIBUTION PROGRAM
Supplies are distributed to those who cannot afford them. These specialized bandages can cost in excess of $10,000 per month.

For more information on debra of America Programs & Services, visit: debra.org/programs.
CELEBRATE NATIONAL EB AWARENESS WEEK

National Epidermolysis Bullosa Awareness Week (Annually, October 25-31) is a time to raise much-needed awareness of EB, to promote the need for a cure, and to spur advocacy on behalf of families suffering with the emotional, financial, and physical burdens of the disease. First legislated by Ronald Reagan and the United States Congress in 1984, #EBweek is now recognized as October 25-31.

TAG WITH ELLA

Visit tagwithella.com to see who’s playing tag!

This National EB Awareness Week, we are inspired by Ella Murray, a 10-year-old little girl living with Recessive Dystrophic Epidermolysis Bullosa (RDEB).

In May 2017, the Washington Post featured Ella in an article that chronicled some of the challenges of living with EB. In the article, it’s said that, due to her EB, she’ll never play tag on the playground. Here at debra of America, we believe that where there’s a will, there’s a way.

Harnessing that philosophy, we’re on a mission to give her the gift of a game of tag, just in time for the holidays - and we want you to join us!

The #TagWithElla campaign, which will run from October 25-December 25, 2017, takes tag off the playground and brings it online - creating an unforgettable game of tag that Ella can take part in, with the hope of spreading awareness of the challenges that are present for those living with EB. We ask you to help us bring Ella’s wish to life by taking a moment to record a short video of yourself saying, “Tag, Ella! You’re it!” or taking a selfie with a #TagWithElla sign and posting it on your Twitter, Instagram, or Facebook accounts as a public post with the hashtag #TagWithElla in your caption.

Let’s give Ella a holiday gift that she is truly deserving of!
THE PAST AND THE PRESENT

In 2017, we’ve taken the time to reflect on pivotal moments for both debra of America and Epidermolysis Bullosa. As we continue to strengthen our efficiency in supporting the EB population, bridging the gap between their needs and what is currently available through our healthcare and government systems, we feel that it is an important time for self-reflection. At each table tonight, you will find an important snippet from a chapter in EB history. Share with us in remembering the past, and looking forward to what can and will be accomplished in the future.

1970 Eric Lopez, son of Arlene Pescar, is born with RDEB. Arlene will become the founder of debra of America

1983 debra is one of the key agencies involved in the passage of the Orphan Drug Act

1991 Researchers on the debra of America Medical Scientific Advisory Board identify genes responsible for the two major forms of EB, with funding from debra

1993 Successful prenatal testing of EB of junctional EB is performed

1986 A record amount of funding of $1 million is awarded to EB research

1997 EB Research Lab is established at Jefferson Medical College, which now serves as the debra of America EB Clinic as of Fall 2017

2000 debra funds Thomas Jefferson University Study, which produced the first mouse model with RDEB for research

2004 New Family Advocate Program is launched by Laurie Risher. This program provides a care package to new families who have just received a diagnosis of EB

2007 The first child to receive a BMAT to treat EB takes place at University of Minnesota Masonic Children’s Hospitals. Since 2007, approximately 5 patients per year have undergone this experimental treatment.

2012 debra hosts the 1st Annual Ride with the Keppler Family. To date, Rides for Research has raised more than $1 million for research

2015 Abarelix Therapeutics, Inc. acquires Sobi, Inc., marking the beginning of their involvement in EB Research

2017 University of Southern California begins their clinical trials for RDEB.

2017 Castle Creek Pharma announces first patient enrolled in CCRH70 trials for EB simplex (EBs)

2016 debra changes the name of the Patient Care Conference to the debra of America Conference, recognizing our community members as people, not patients.

2016 debra holds International Research Symposium, bringing together over 103 leading EB researchers and government officials to assist families and advocate for rights at the government level.

2015 debra hosts debra of America International Research Symposium, bringing together over 103 leading EB researchers and government officials to assist families and advocate for rights at the government level.

2015 debra of America is incorporated as a national nonprofit organization

2017 debra of America is recognized with the EB Awareness Award by the US Congress

2017 ProQR is developing herbal medicines to treat and cure B Bullous Skin Conditions

2017 debra of America and EB research.

2017 because the cure for EB is not yet found

ProQR is developing herbal medicines to treat and cure Bullous Skin Conditions

2017 debra of America is recognized with the EB Awareness Award by the US Congress

2017 because the cure for EB is not yet found
THANK YOU TO OUR COMMITTEE MEMBERS AND VOLUNTEERS FOR THEIR INVALUABLE SUPPORT AND EFFORTS!

BENEFIT COMMITTEE CO-CHAIRS
- Gabriel Cavazos
- Anya Cole
- Robert Coull
- Pamela Mayer
- Andrew Tucker
- Kim Tucker

BENEFIT COMMITTEE
- Carolyn Buntic
- Frank Cardullo
- Jill Cardullo
- Julie Conroy
- Peter Corbin
- Wendy Corbin
- Georgia Alexandra Davis
- Ashley Garrett
- Jennifer Rajan
- Kerry Rea
- Gary Thomas

YOUNG LEADERSHIP BENEFIT COMMITTEE
- Jason Barron
- Samantha Blanchetti
- Braden Candela
- Peter Clarke
- Jonathan Kaufman
- Megan McKeever
- Anjali Rajan
- Emily Rea
- Geri Kelly
- Hana Khalil
- Emily King
- Adrienne & Peter Provost
- Whitney Solomon
- Shawn & Andrew Tavani
- Linda Velazquez

VOLUNTEERS
- Braden Candela
- Morgan Chittum
- Alex Corbin
- Max Corbin
- Francesca Guerrera
- Linda O’Neill
- Anjali Rajan
- Haley Slosberg
- Rory Smith
- Lambert Tamin
- Karuna Vikram

STAFF
- Brett Kopelan, Executive Director
- Jeanette Gissen, Director, Programs
- Meghan Jay, Director, Development
- Jason Kelly, Manager, Database
- Joseph R. Murray, Esq., Director, Government & Legal Affairs
- Mike Powers, Director, Finance
- Neila Sanon, Associate, Special Events & Development
- Aggerim Saparova, Manager, Social Media & Development
- Gabrielle Sedor, Manager, Marketing & Supporter Led Events
- Shawn Tavani, R.N., Acting Nurse Educator
- Bethany Tillema, Associate, Programs & Development

BOARD OF DIRECTORS
- Richard Gallagher, Chair
- Andrew Tavani, Vice Chair
- J. Alec Alexander, Treasurer
- Daniel Siegel, M.D., Secretary
- Leslie Rader, Chair Emeritus
- Angela Christiano, Ph.D.
- William Cornman
- Faith Daniels
- Tom Gillespie
- Frank Kacmarsky
- John Lee
- Robert Meirowitz, M.D.
- Robert Rayl
- Jeanne Rohm
- Robert Ryan, Ph.D.
- Jouni Uitto, M.D., Ph.D.
- James Wetrich
MAKE AN IMPACT NOW
A GIFT FROM YOU DIRECTLY IMPACTS EB FAMILIES

$5 Enables our EB Nurse Educator to answer an EB family’s questions about wound care, treatment options, & much more

$10 Can provide a newborn with an EB-friendly soft cloth diaper

$25 Can gift a baby a Haberman bottle. The bottle’s specialized nipple decreases sucking, which prevents friction + painful mouth sores and ensures EB babies get the nutrition they need

$25 Sends two EB families a New Family Advocate Box. These boxes provide new families with wound care supplies and critical information about EB and how to take care of their newborns

$50 Enables four EB patients to receive supplies through the Wound Care Distribution Program. Each box of supplies is valued at approx. $1,500

$100 Helps grant a wish for a child with EB through our Smile Fund

$250 Supports innovative research for treatments and a cure

$500 Helps improve EB awareness by funding a digital + social media campaign

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 services and programs, 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, fundraisers 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.

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. All proceeds from the 19th Annual debra of America Benefit support our mission to find a cure for Epidermolysis Bullosa (EB) - The Worst Disease You’ve Never Heard Of. Visit debra.org/give
A SPECIAL THANK YOU TO OUR EB FAMILY SPONSORS AND SILENT AUCTION DONORS! AS OF 10/13/17

EB FAMILY SPONSORS
Berg Health
Jamie Calandrucio
Robert Coull and Pamela Mayer
Richard and Debbie Gallagher
Horizon Government Affairs
Rik and Amy Kopelan

SILENT AUCTION DONORS
((305)) Fitness
Gale & Ron Alexander
Alliance Dermatology
Book of the Month
Broadstone Bar & Kitchen
Brooklyn Botanic Garden
Brooklyn Brinery
Brooklyn Brewery
Brooklyn Nets
Buffalo Bills
Lucy Bugea & Victor Wrotnschuk
Butter & Scotch
 selecting
bird
Bitter & Esters
Blue Apron
Bonobo Winery
Book of the Month
Broadstone Bar & Kitchen
Brooklyn Botanic Garden
Brooklyn Brinery
Brooklyn Brewery
Brooklyn Nets
Buffalo Bills
Lucy Bugea & Victor Wrotnschuk
Butter & Scotch
Carlos Falchi
Carnegie Hall
CBS Television Distribution
Chateau Chantal
Chateau Grand Traverse
Chicago Bears
Chicago Pizza Tours
City Bike
City Winery
Jennifer & Douglas Clarke
Conrad New York
Cohen’s Fashion Optical
Wendy & Peter Corbin
Corridor-Dan Snyder
Crosby Street Hotel
CVC Fitness
Dennis Basso
Denver Broncos
Destination Kohler
dōTERRA
Edible Arrangements
Eileen R. Corbin
Interior Design
Ellen Weldon Design, LLC
Epicurean
Equinox
Ari Espay
EVF CrossFit
Columbus Circle
Fjällräven
Felice Ristorante
Flushing Room
Fine & Raw Chocolate
Flash Lab Laser Suite
Fletcher & Company
Literary Agency
Flywheel Sports
Francesca’s Restaurant
Freshmade NYC
Gianna’s
Charlotte Gould
Gumuchian
HANIA by Anya Cole
Lagunitas Brewing Co.
Landmark Theatres
Lauren Galippo & CBS News
L’escalade Restaurant
Li-Lac Chocolates
Loews Royal Pacific Resort
Macinaw Brewing Company
Masana NYC
Pamela Mayer & Robert Coull
McKittrick Hotel
Metropolitan Opera
Mini Melanie
Miracle Springs
Resort & Spa
Monsieur Touton Selection
New York City Ballet
New York Jets
New York Mets
Nubian Skin
Obey Giant Art
Odette New York
Oxford Street
The Rock Club
Trevor Noah
The Flattoon
The Rock Club
Terminology Biological Reserve
Thirty-One
The Subterranean Theory
Thunder Ridge
Tone House
Trout On Inn
Trunk Club
Umbra
Unum
Uplift Studios
UV Skinz
Vu Hair New York
Warren Tricomi Salon
Work Train Fight
Y7 Studio
YogaSpark Tribeca
Zulu Nyala

Hotel Bougainvillea
Insomnia Cookies
Intercontinental Hotel
INSCAPE
Intermix
Dr. Bernard Jay
J.R. Marti
Rob Jennings
Julie Kent & Washington Ballet
Kimpton Palomar Hotel
Kings County Distillery
Kurt Busch Inc.
Jess LaGreca
Lagunitas Brewing Co.
Landmark Theatres
Lauren Galippo & CBS News
L’escalade Restaurant
Li-Lac Chocolates
Loews Royal Pacific Resort
Macinaw Brewing Company
Masana NYC
Pamela Mayer & Robert Coull
McKittrick Hotel
Metropolitan Opera
Mini Melanie
Miracle Springs
Resort & Spa
Monsieur Touton Selection
Janet Murray & Frederick Yorker
Muse Paintbar
New Jersey Devils
New Orleans Steamboat Company
New York Boat Show
New York City Ballet
New York Jets
New York Mets
Nubian Skin
Obey Giant Art
Odette New York
Oxford Street
The Rock Club
Trevor Noah
The Flattoon
The Rock Club
Terminology Biological Reserve
Thirty-One
The Subterranean Theory
Thunder Ridge
Tone House
Trout On Inn
Trunk Club
Umbra
Unum
Uplift Studios
UV Skinz
Vu Hair New York
Warren Tricomi Salon
Work Train Fight
Y7 Studio
YogaSpark Tribeca
Zulu Nyala

Hotel Bougainvillea
Insomnia Cookies
Intercontinental Hotel
INSCAPE
Intermix
Dr. Bernard Jay
J.R. Marti
Rob Jennings
Julie Kent & Washington Ballet
Kimpton Palomar Hotel
Kings County Distillery
Kurt Busch Inc.
Jess LaGreca
Lagunitas Brewing Co.
Landmark Theatres
Lauren Galippo & CBS News
L’escalade Restaurant
Li-Lac Chocolates
Loews Royal Pacific Resort
Macinaw Brewing Company
Masana NYC
Pamela Mayer & Robert Coull
McKittrick Hotel
Metropolitan Opera
Mini Melanie
Miracle Springs
Resort & Spa
Monsieur Touton Selection
Janet Murray & Frederick Yorker
Muse Paintbar
New Jersey Devils
New Orleans Steamboat Company
New York Boat Show
New York City Ballet
New York Jets
New York Mets
Nubian Skin
Obey Giant Art
Odette New York
Oxford Street
The Rock Club
Trevor Noah
The Flattoon
The Rock Club
Terminology Biological Reserve
Thirty-One
The Subterranean Theory
Thunder Ridge
Tone House
Trout On Inn
Trunk Club
Umbra
Unum
Uplift Studios
UV Skinz
Vu Hair New York
Warren Tricomi Salon
Work Train Fight
Y7 Studio
YogaSpark Tribeca
Zulu Nyala

Hotel Bougainvillea
Insomnia Cookies
Intercontinental Hotel
INSCAPE
Intermix
Dr. Bernard Jay
J.R. Marti
Rob Jennings
Julie Kent & Washington Ballet
Kimpton Palomar Hotel
Kings County Distillery
Kurt Busch Inc.
Jess LaGreca
Lagunitas Brewing Co.
Landmark Theatres
Lauren Galippo & CBS News
L’escalade Restaurant
Li-Lac Chocolates
Loews Royal Pacific Resort
Macinaw Brewing Company
Masana NYC
Pamela Mayer & Robert Coull
McKittrick Hotel
Metropolitan Opera
Mini Melanie
Miracle Springs
Resort & Spa
Monsieur Touton Selection
Janet Murray & Frederick Yorker
Muse Paintbar
New Jersey Devils
New Orleans Steamboat Company
New York Boat Show
New York City Ballet
New York Jets
New York Mets
Nubian Skin
Obey Giant Art
Odette New York
Oxford Street
The Rock Club
Trevor Noah
The Flattoon
The Rock Club
Terminology Biological Reserve
Thirty-One
The Subterranean Theory
Thunder Ridge
Tone House
Trout On Inn
Trunk Club
Umbra
Unum
Uplift Studios
UV Skinz
Vu Hair New York
Warren Tricomi Salon
Work Train Fight
Y7 Studio
YogaSpark Tribeca
Zulu Nyala
Congratulations to
ZACK TROOP,
Winner of the
2017 Spirit Award!

MICHAEL & KELLY REEDER
RICHARD SWARN

We are honored to receive the
2017 debra of America
Partners in Progress Award.

At the Forefront of Therapies
for Rare and Orphan Diseases®
We are honored to receive the Partners in Progress Award and are proud to support debra of America.

Congratulations to this evening’s honorees & Michael DelVacchio on receiving the Corporate Hero Award!
Abeona Therapeutics is honored to join in the support and care for the Epidermolysis Bullosa community and to sponsor debra of America’s 19th Annual Benefit.

Abeona Therapeutics, a clinical stage company, was created with the goal of transforming scientific discoveries into breakthrough therapies for people living with rare and life-threatening diseases.

At Amryt Pharma, we strive every day to deliver transformative medicines to people affected by rare, debilitating conditions, providing hope for those with the greatest need.

We firmly believe in the importance of working closely with organizations such as debra of America in an ethical and responsible way, breaking new ground and facing up to challenges that help change lives across the world.

To learn more about us and what we do, visit www.amrytpharma.com

Protect your site, protect your skin.

No Adhesive Injuries
Kills 99.99% of Microorganisms
Full Site Visibility

Request an evaluation sample*

Protect your site, protect your skin.

*Some conditions apply. IV Clear is a trademark of Covalon Technologies Ltd. © 2017 Covalon Technologies Ltd.

1660 Tech Avenue Unit 5 Mississauga, ON, Canada L4W 5S7.
1-877-711-6055 | ivclear@covalon.com
MCKESSON

Exceptional Service
- Dedicated EB Advocate Team
- Trained representatives and insurance specialists
- Ships supplies to individuals and bills their insurance

More Quality Wound Care Products
- Wound care products from a range of manufacturers
- Support continuity of care

More Resources for the EB Community
- Informative EB Nurse website
- "The EB Advocate" on social media and e-newsletter

For more information, please contact:
855.5EB.line
(855.532.5463)

Congratulations to Amicus Therapeutics on a well deserved recognition

W2O is proud to support Amicus Therapeutics in its mission to remain at the forefront of therapies for rare and orphan diseases.
Zack,
Thank you for being you – a kind, smart, handsome young man who isn’t defined by EB. You and your family are an inspiration.
Congratulations on this well-deserved honor!
From, the entire EB team at Children’s Hospital Colorado

Dermpath Diagnostics is a proud sponsor of the 19th annual debra of America Benefit

Cannabinoid pharmaceuticals for difficult-to-treat diseases.
www.inmedpharma.com

Compassionate & Comprehensive Dermatology

Jennifer Rajan, MD
Lusia Yi, DO
Leah Kincaid, MD
Lawrenceville, NJ
609-799-1600

Water Island Capital
WWW.WATERISLANDCAPITAL.COM

LEERINK
THE HEALTHCARE INVESTMENT BANK
Our clients are developing and commercializing the innovative products and services that are defining the future of healthcare. LEERINK provides the capital markets expertise to finance this innovation and the strategic advice to identify and effect transactions.
LEERINK Partners is proud to support debra of America and their mission to improve quality of life for people with EB while working towards a cure.

Cannabinoid pharmaceuticals for difficult-to-treat diseases.
www.inmedpharma.com

Water Island Capital
WWW.WATERISLANDCAPITAL.COM

Quest Diagnostics
WWW.QUESTDIAGNOSTICS.COM

WWW.ARTISANALIMPORTS.COM
Every morning as the sun rises, Unitex is behind the scenes cleaning, preparing, and delivering the linen that helps healthcare professionals provide the best care to their patients. We do it proudly because we know our customers are a vital resource to the community. Unitex—We Care about You and Your Patients.

CASTLE CREEK PHARMACEUTICALS IS PROUD TO SUPPORT DEBRA OF AMERICA

CONGRATULATIONS TO THE EVENING’S AWARD RECIPIENTS!
Do Not Disturb.

Mölnlycke Health Care offers a range of products ideal for the treatment of Epidermolysis Bullosa (EB). These dressings feature Safetac® technology which reduces pain and trauma for patients.

Mepitel®
- Wound contact layer (double sided)

Mepilex® Lite
- Absorbent thin foam dressing

Mepilex® Ag
- Absorbent antimicrobial foam dressing

Mepilex® Transfer
- Exudate transfer dressing

Tubifast® Garments
- Ready-to-wear for use in dressing retention and wet or dry wrapping

---

1. Davies, P., Rippon, M. Evidence review: the clinical benefits of Safetac® technology in wound care. Journal of Wound Care 2006; Supplement. 3-31

The Mölnlycke Health Care, Mepitel, Mepilex, Tubifast and Safetac trademarks, names and logo types are registered globally to one or more of the Mölnlycke Health Care Group of Companies. Distributed by Mölnlycke Health Care US, LLC, Norcross, Georgia 30092. © 2016 Mölnlycke Health Care AB. All rights reserved. 1-800-882-4532. MHC-2016-24913