

THE EIGHTH ANNUAL

RARE VOICE

Awards

A CELEBRATION TO HONOR ADVOCATES
WHO GIVE RARE DISEASE PATIENTS A VOICE
IN STATE AND FEDERAL POLICY

Wednesday, December 4, 2019

ARENA STAGE
WASHINGTON, DC



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EVENT PROGRAM

Master of Ceremonies

- Mike Porath
Founder, The Mighty

Awards Presenter

- Tilea West
2019 Cherry Blossom Queen

Congressional Leadership Award

- The Honorable Lucille Roybal-Allard (CA-40)
- The Honorable Roger Wicker (MS)

Announcement of the RareVoice Award Recipients

- Federal Advocacy – Congressional Staff
- Federal Advocacy – Patient Advocate
- State Advocacy
- Teen Advocacy

After Party Reception

- Please join us downstairs for dessert, refreshments and music to continue the celebration.

   @RareAdvocates
RAREADVOCATES.ORG

ABOUT THE ABBEY

The RareVoice “Abbey” Award was named after Abbey Meyers, the founder of the National Organization for Rare Disorders (NORD). Mrs. Meyers received the Lifetime Achievement Award at the inaugural RareVoice Awards in 2012 for her vital role in the passage of the Orphan Drug Act.

The statue was commissioned for the RareVoice Awards from the renowned sculptor Nobe, who specializes in bronze. The Abbey represents the “rare voice” speaking on behalf of patients, especially children, who might not otherwise be heard.



Abbey Meyers with EveryLife Founder, Dr. Emil Kakkis.



MASTER OF CEREMONIES

MIKE PORATH

Mike is the founder and CEO of The Mighty, the leading health community that reaches more than 20 million people a month. Mike’s entry into the rare disease community came through his daughter, who has Dup15q syndrome, a neurogenetic disease associated with autism spectrum disorder, intellectual disability, and epilepsy. Soon after her diagnosis, Mike joined the board of directors for Dup15q Alliance and now also serves as fundraising chair. The community he became a part of inspired him to create The Mighty to empower and connect people facing rare diseases and other health conditions. He also serves on the board of directors for the National Organization for Rare Disorders (NORD) and as a member of the Global Commission to End the Diagnostic Odyssey for Children With a Rare Disease. Mike spent most of his career as a journalist, where he won multiple awards and held a variety of reporting, editing, producing and executive roles at ABC News, NBC News, The New York Times and AOL. For his work building The Mighty, he was named as one of the top 50 philanthropists by Town & Country in 2017. He has become a leading voice for patient-centered healthcare and speaks at events around the world about leveraging people and technology to improve the lives of patients. Mike lives in the Los Angeles area with his wife Sarah and their four children.



AWARDS PRESENTER

TILEA WEST

Tilea is a 2018 graduate from the University of Georgia. She actively enjoys working in clinical trials research at Georgetown University Hospital and is currently in a post-baccalaureate pre-medicine program at Georgetown University. Tilea dreams of being a doctor one day, because of her own experience of living with a chronic rare disease. Tilea was diagnosed with hyper-immunoglobulin E syndrome (HIES), or Job syndrome, during her sophomore year of college. Tilea became the 2019 Cherry Blossom Queen due to the spin of a wheel, which she had a 1.9% chance of winning. Having grown accustomed to overcoming seemingly impossible odds by living with a rare disease, Tilea was not surprised. As Cherry Blossom Queen, Tilea's platform is to raise awareness for rare disease and her platform is "Think Zebra". She chose this platform, because in medical training, students are taught to assume the most common disease instead of something rare. Tilea chose to work with the EveryLife Foundation, because she admired that the organization provides a platform for patients to advocate on a personal, state and national level.



Photo credit: Carlos Alberto



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At Recordati, we focus on the few - those affected by rare diseases. They are our top priority and at the core of everything we do. Our mission is to reduce the impact of extremely rare and devastating diseases by providing urgently needed therapies. We work side-by-side with rare disease communities to increase awareness, improve diagnosis and expand availability of treatments for people with rare diseases.



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We are proud to support the 2019 RareVoice Awards

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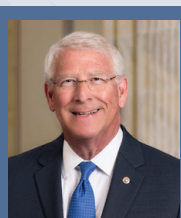
Thank you to our Rare Disease
Congressional Caucus Co-Chairs and Members



Representative
G.K. Butterfield (NC)



Representative
Gus Bilirakis (FL)

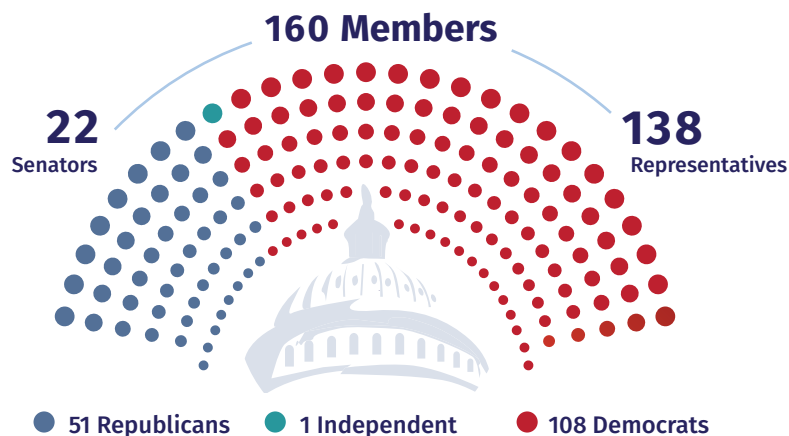


Senator
Roger Wicker (MS)



Senator
Amy Klobuchar (MN)

The Rare Disease Congressional Caucus is a bipartisan, bicameral caucus to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases.



Ask your Member to join today.

RARECAUCUS.ORG

CONGRESSIONAL LEADERSHIP AWARD

Representative Lucille Roybal-Allard (CA-40)

The Congresswoman is the first Mexican-American woman elected to Congress, the first Latina to serve as one of the 12 “cardinals,” or chairs, of a House Appropriations Subcommittee, as well as the first Latina to serve on the House Appropriations Committee. Roybal-Allard, along with Congressman Mike Simpson, introduced the original Newborn Screening Saves Lives Act which was passed and signed into law in 2008, and its reauthorizations in 2014 and 2019. The latest reauthorization of the Newborn Screening Saves Lives Act passed the House in July 2019. Congresswoman Lucille Roybal-Allard is the eldest daughter of the late Congressman Edward R. Roybal and Lucille Beserra Roybal. She is married to Edward T. Allard III. Together, she and her husband have four children and nine grandchildren. She received her bachelor’s degree from California State University, Los Angeles. She also holds an honorary doctor of humane letters degree from National Hispanic University.



Senator Roger Wicker (MS)

Senator Wicker is the chairman of the Senate Committee on Commerce, Science, and Transportation for the 116th Congress and co-chair of the Congressional Rare Disease Caucus. As Senator, Wicker co-sponsored the Patient Focused Impact Assessment Act (PFIA) which then became Sec 3001 of the 21st Century Cures Act, leading to the patient experience data section of the FDA review. During his time serving in the House of Representatives, Wicker introduced the MD-CARE Act which was signed into law in 2014. A native of Pontotoc, Mississippi, the Senator is the son of former Circuit Judge Fred Wicker and the late Mrs. Wordna Wicker. He was educated in the public schools of Pontotoc and received his B.A. and law degree from the University of Mississippi. Senator Wicker and his wife Gayle have three children and six grandchildren.



"I love you."

These are some of the
few words Sam says to her
younger brother Louis.

Sam was born with GAMT - a rare, inherited disorder that causes a creatine deficiency.

It took doctors five years to diagnose Sam. The treatment delay resulted in permanent brain damage, dangerous seizures and countless emergency room visits.

Because of Sam, doctors knew to test Louis for GAMT at birth. He was also positive. But with early treatment Louis has been able to develop like other kids his age.

Sam, now 16, has accomplished much, but she will never be able to live without support.

But thanks to Sam, Louis' life has the opportunity to follow a different path. Newborn screening changed the landscape for Louis.

Watch Sam's story at rarescreening.org

WALK TO FIND A CURE FOR
**Walk for
Strength**
2019
CREATING CREATIVE DEFICIENCY SYNDROMES

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**Walk for
Strength**
2019
CREATING CREATIVE DEFICIENCY SYNDROMES

NEWBORN SCREENING SAVES LIVES

- Newborn screening provides early diagnoses to begin life-altering treatment as soon as possible.
- Due to Congress's failure to act, this life-saving public health program is at risk.

SUPPORT NEWBORN SCREENING.

LIFE DEPENDS ON YOU. GO TO RARESCREENING.ORG



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2020 RareArtist Reception

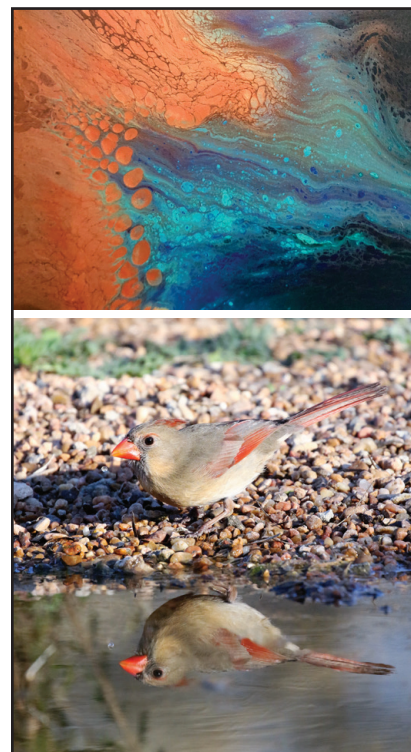
Thursday, February 27, 2020
5:00 p.m. – 7:00 p.m., Capitol Hill

Enjoy works of art by the
rare disease community.
Complimentary food and drink.
Free and open to the public.

RAREARTIST

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FEDERAL ADVOCACY: CONGRESSIONAL STAFF

Megan Axelrod, Senator Cory Gardner (CO)

Megan is a legislative assistant in the Office of Senator Cory Gardner (CO), where she predominantly focuses on health, education, and veterans affairs. She has been with the office since the beginning of 2017, and prior to that, was an associate with The Advisory Board Company, focusing on ambulatory network optimization. Megan holds a Bachelor of Arts in Economics and American Politics with Special Attainments in Commerce and a minor in Human Capability and Poverty Studies from Washington and Lee University.



Samantha Helton Elleson, Senator Roger Wicker (MS)

Samantha is the senior legislative assistant in the Office of Senator Roger Wicker (MS). In this capacity, she supports several of the Senator's legislative priorities, including telecommunications, environment, and economic policy. In May 2017, Samantha took over the domestic and global health care portfolio. She leads Senator Wicker's efforts as he serves as the Senate Rare Disease Caucus Co-Chair. Senator Wicker has been a champion for Duchenne muscular dystrophy and continues to support increased funding and coordination for biomedical research. A native of Jackson, Mississippi, Samantha earned a bachelor's degree in Public Policy from the University of Mississippi.



Nico Janssen, Senator Maria Cantwell (WA)

Nico serves as a legislative assistant to U.S. Senator Maria Cantwell (WA), focusing on health care policy. A native of Port Townsend, Washington, Nico holds a Master of Public Administration (MPA) in health policy from American University's School of Public Affairs.



Debbie "Deb" Jessup, Representative Lucille Roybal-Allard (CA-40)

Deb has over 40 years of experience in health care and policy. Her early professional experiences included positions as a genetics counselor, registered nurse, lamaze instructor and certified nurse midwife. Since 2005, Deb has been employed as health policy advisor with Congresswoman Lucille Roybal-Allard, where she has been actively engaged in both health appropriations work and helping the Congresswoman to promote her health legislative agenda. In this role Deb has helped form and staff the Congressional Caucus on Maternity Care and the Congressional Public Health Caucus. She has worked to develop and promote several pieces of health legislation, including the Newborn Screening Saves Lives Act (passed in 2007) and its 2 reauthorizations (passed in 2014 and passed by the House in 2019). Debbie is a Fellow of the American College of Nurse Midwives and completed a PhD in Nursing at George Mason University in 2012.



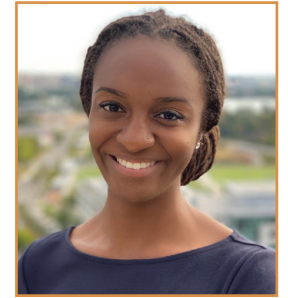
Brian Looser,
Representative John Shimkus (IL-15)

Brian was born and raised in Staunton, IL, graduating from Mt. Olive High School in 2001. He received his degree in Economics in 2005 from the University of Illinois, where he was also a member of Delta Tau Delta fraternity. Brian began working on Capitol Hill in 2006 as a staff assistant for Rep. Hastert (IL-14). The following year, Brian joined the office of Rep. Bachmann (MN-16), serving as health legislative assistant. In 2010, he joined Rep. Biggert's (IL-13) team, working on Education Committee issues. After three years as Vice President at McGuireWoods Consulting, representing clients in health care and higher education, Brian served as senior policy advisor for Sen. Kirk (IL). In 2017, Brian accepted his current role as legislative director for Rep. Shimkus (IL-15) with responsibility for Energy and Commerce Health Subcommittee matters. Brian is an active member of the University of Illinois Alumni Association, the Illinois State Society and the House Softball League.



Saundrea “Drea” Rupert-Shropshire,
Representative James P. McGovern (MA-2)

Drea is a senior legislative assistant in the office of Congressman James P. McGovern of Massachusetts's 2nd district. Drea assists the Congressman in his advocacy and leadership on two rare disease, bi-partisan caucuses—the Mitochondrial Disease Caucus, and the Cystic Fibrosis Caucus. She also facilitates the Congressman's notable work on hunger, nutrition, and food insecurity issues by coordinating with various stakeholders through the House Hunger Caucus. Drea's other legislative portfolio issue areas include education, judiciary, veterans, and campaign finance reform. From 2016 to mid-2018, Drea worked under then-Senator, Claire McCaskill of Missouri, where she focused on issues involving whistleblower disclosures and government oversight. Drea holds a bachelor's degree from Howard University and is a member of Phi Beta Kappa honors society. Drea is also an avid runner and rock climber.



Wendell Primus,
Representative Nancy Pelosi (CA-12)

Wendell is the senior policy advisor on budget and health issues to Speaker Nancy Pelosi (CA-12). In that capacity, he was the lead staffer in developing the Affordable Care Act. He also played a major role in the Sustainable Growth Rate legislation in 2015 and various budget agreements. Prior to this appointment in March of 2005, Wendell was the minority staff director at the Joint Economic Committee. He has also held positions at the Center on Budget and Policy Priorities, served in the Clinton Administration at the Department of Health and Human Services, and also served as chief economist for the House Ways and Means Committee and staff director for the Committee's Subcommittee on Human Resources. Wendell received his Ph.D. in economics from Iowa State University.



Shayne Woods,
Representative Gus H. Bilirakis (FL-12)

Shayne currently serves as a senior policy advisor for the Hon. Gus M. Bilirakis (FL-12). In this capacity, he plans and develops legislative initiatives while tracking legislation through the legislative process related to healthcare, taxes, agriculture, and energy. Additionally, Shayne prepares public statements, drafts correspondence, and meets with constituents and advocacy groups in regard to the aforementioned issues. Prior to Capitol Hill, Shayne was the founder and chief executive officer of FwdHealth [pronounced “forward health”] – a healthcare IT company that connected clients and their health apps to a network of nationally-certified fitness trainers through live, two-way video chat. In addition to FwdHealth, Shayne also founded and ran a healthcare consulting practice that advised key industry stakeholders on the Affordable Care Act while providing business development assistance. Shayne holds a B.A. from Washington University in St. Louis.





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FEDERAL ADVOCACY: PATIENT ADVOCATE AWARD

Isabel Bueso

Isabel, 24 years-old and a summa cum laude graduate of California State East Bay, was born with MPS VI. Isabel came to the United States to participate in a clinical trial. The trial resulted in FDA approval of Naglazyme, which has saved the lives of patients with MPS VI worldwide. For six years Isabel has advocated on rare disease issues, including newborn screening, NIH funding and orphan drug designation. She has organized numerous rare disease day awareness events and created a scholarship to support students with rare diseases. Most recently, Isabel was a leading voice in standing up for rare disease patients undergoing treatment through clinical trials who are facing deportation. Isabel's plight caught the attention of the national media, including People Magazine, The New York Times and ABC News. "The reason I advocate for patients with rare diseases is because everyone has a voice and, things will only change by speaking up. I'll use my own experiences to advocate, encourage change and expose the realities of living with a rare disease to the public."



Elisa Seeger

After losing her son, Aidan, to adrenoleukodystrophy (ALD) in April 2012, Elisa started a foundation in his honor, focusing primarily on newborn screening. Armed with the knowledge that newborn screening could have saved her son's life, Elisa has made it her mission to give other families grappling with ALD better outcomes. Thanks to Elisa's efforts, her home state of New York was the first to implement newborn screening for ALD in 2013. In the years following, Elisa traveled the country advocating in support of newborn screening. Her work was instrumental in ALD's addition to the recommended uniform screening panel (RUSP). ALD is now screened in 14 states. Elisa worked with her Congressional representatives to introduce federal legislation that would require states to screen for all diseases on the RUSP and to dramatically shorten the implementation period for newly added diseases.



Madison Shaw

Madison (Maddie) Shaw of Southbury, CT, is a junior at Emerson College and the founder of Maddie's Herd – a grassroots patient advocacy organization. Maddie established the 'herd' while in 8th grade after navigating her own diagnostic odyssey with primary immunodeficiency (PI). As a volunteer advocate leader for the Immune Deficiency Foundation, Maddie played an important advocacy role in passage of the extension of the Medicare IVIG Access Act of 2012, which established a three-year demonstration project providing coverage for home infusions of intravenous Immunoglobulin (IVIG). Maddie's effective leadership caught the attention of several Members of Congress, including Congresswoman Rosa DeLauro, for whom she served as an intern. Maddie has raised more than \$66,000 in support of research and patient resources, has served as a spokesperson for Make-a-Wish Connecticut and is currently a political communications major with double minors in environmental studies and post-colonialism. Maddie encourages other young adults with chronic illness by telling them, "These years are just your prologue."



Sarah Tompkins

Being an Ehlers-Danlos Syndrome hypermobility type, Sarah knows the challenge of searching years for a correct diagnosis, the frustration of doctors and people close to her not believing her, and the reality of being given a diagnosis for a disease that has no proven treatments or a cure. After losing her best friend, Kellie, to their shared disease (EDS), Sarah dedicated herself to advocating for rare diseases, especially EDS, dysautonomia (POTS), and gastroparesis. To do this, Sarah received multiple stabilizations, surgeries, and procedures to make mobility and traveling possible. Since 2015, Sarah has shared her story in support of rare disease legislation such as 21st Century Cures, OPEN ACT, RARE Act, and Newborn Screening Saves Lives Reauthorization Act. In her home state of Washington, Sarah served as an In-District Lobby Days (now Rare Across America) Leader and helped to establish a Rare Disease Day. Sarah serves as an administrator of her EDS Support Group, consisting of hundreds of EDS patients, and is working on launching a patient organization called EDS Northwest. Sarah lives in Bellevue, Washington with her husband, Troy, and their Jack Russell Terrier, Wilson.



Ashley Valentine

Ashley is Co-Founder and President of Sick Cells, a nonprofit organization. Her older brother and Co-Founder of Sick Cells, Marqus, has sickle cell anemia, Hgb ss. Ashley completed her Master's in Research Methods from the University of Aberdeen, Scotland. She focused on disparities in healthcare for people with SCD in London. After graduate school, she worked with University of Illinois in Chicago's sickle cell program and later transitioned into policy work in Washington, DC. While working as a policy researcher, Ashley successfully wrote sickle cell disease into part of an \$8 million Centers for Medicaid and Medicare Services funding opportunity to address disparities for adults in the emergency department. Ashley's work with Sick Cells has activated the SCD community to pass federal legislation in 2018 and become stakeholders in the rare disease space. In 2019, Ashley and her brother, Marqus, were named the Chicago Red Cross Heroes and inducted into the Fresenius Kabi Blood Donation Hall of Fame for their work in federal legislation and bringing awareness to sickle cell disease and the needs of the community.



Brian Wallach

Brian is an attorney and ALS patient. In the aftermath of his diagnosis in November 2017, he and his wife founded I AM ALS, a patient-led, patient-centric movement to lead the fight for a cure to the disease. Wallach is also an associate at the law firm Skadden, Arps, Slate, Meagher & Flom LLP. From 2014 to 2018, he served as an assistant United States attorney in the Northern District of Illinois. From 2011 to 2013, he was senior vetting counsel in the Obama White House, responsible for overseeing the vetting process for nearly all Senate-confirmed executive branch appointees and all presidential appointments as well as working on congressional oversight investigations. Brian's leadership has helped increase the ALS DOD funding from 10 million to 20 million dollars (pending Senate approval), form an ALS Caucus in the House of Representatives, and secure the release of the FDA's guidance for ALS therapy development.





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STATE ADVOCACY AWARD

Erica Barnes

Erica is a rare disease advocate whose passion flows out of her experience both as a mother who lost a child to a rare disease and as a speech-language pathologist who has provided services to rare patients. When her second child Chloe was diagnosed with a rare disease, Erica experienced the unique barriers to care that the community faces: Delayed diagnosis, lack of medical professionals familiar with her daughter's condition, and the absence of an effective treatment. Following the death of Chloe, Erica began interacting with families from other rare communities at Rare Disease Day events. She heard the same barriers repeated by these families regardless of the specific diagnosis and decided that the Minnesota rare disease community should take a collective approach. In 2019, after two years of advocating, the Chloe Barnes Rare Disease Advisory Council was passed. Erica now works as Council Administrator at the University of Minnesota.



Frances Broussard Denenburg

Frances "Frani" Broussard Denenburg is the founder and president of Arrivederci ALD, a charitable organization dedicated to raising awareness and funds for research to find more treatments and a cure for adrenoleukodystrophy and adrenomyeloneuropathy. The organization was founded after Frani, her mother, her two adult brothers, her young daughter, and toddler son were diagnosed with ALD in 2018. Frani started advocating within months of the diagnosis. She testified before the Texas House of Representatives Committee on Appropriations in support of newborn screening for ALD. Texas passed and funded the legislation, and Frani worked closely with staff at the Texas Department of State Health Services in advance of implementation. Frani is also dedicated to bringing awareness to the unique medical and personal challenges that women with X-linked disorders face through her work with Remember the Girls. Frani is an education lawyer and has represented public and private school districts for over 12 years.



Georgene “Gina” Glass

Georgene is mother of a 4-year old daughter with sickle cell disease (SCD). After relocating from California to Nevada (NV), Georgene discovered the lack of awareness and resources for children and families affected by SCD in the state. She went on to found Dreamsickle Kids Foundation, the first SCD organization in NV. The mission of Dreamsickle Kids is to #MakeSickleCellPopular and to celebrate, educate and support families impacted by sickle cell disease, while educating medical providers and the community on the impact of this debilitating disease. In just a year, NV passed their first SCD bill with Georgene testifying and rallying other parents, advocates, and medical professionals to do the same. Dreamsickle Kids has been recognized locally and nationally for their advocacy efforts that have changed the way NV supports SCD in a short time. Gina is proud that her daughter, also known as ‘Warrior Princess Gia,’ was the motivation behind Dreamsickle Kids and that now the organization is impacting the lives of children and families with SCD throughout Nevada.



Barby Ingle

Barby is a bestselling author, reality personality, and lives with multiple rare disorders, including reflex sympathetic dystrophy (RSD), migralepsy, PALB2-Var, endometriosis and other pain disorders. Barby is a chronic pain educator, patient advocate, and president of the International Pain Foundation. She is also a motivational speaker and best-selling author. Her blog, books, presentations, and media appearances are used as a platform to help her become a patient advocate, and she now travels the country attending healthcare conferences, speaking publicly, sharing her story and educating others. Barby shares her healthcare story because what happened to her should not happen to others. It took three years, 43 providers, and being over/under/mis-treated before receiving a proper diagnosis. It was another four years before she had a successful treatment option for her conditions. She wants other rare patients to have an easier time with diagnosis, treatments, and long-term outcomes. Barby advocated in support of the successful passage of the Arizona Copay Accumulator Bill - HB 2166 passed for better access to care for rare patients. She now serves on the Arizona Health Department’s Injury Prevention Advisory Council.



Kristen Vanags

After her son was born with Phenylketonuria (PKU), Kristen co-founded Georgia PKU Connect and became a leading advocate for medical foods coverage. She is a trusted expert on medical nutrition legislation and has lead advocacy initiatives at the state and federal level for more than 10 years. Kristen also serves on the Georgia Newborn Screening Advisory Committee and National PKU Alliance Board of Directors. She previously served on the board of the Southeast Regional Genetics Group and was the chair of the Southeast Newborn Screening & Genetics Collaborative Consumer Alliance. Kristen received the inaugural Applied Nutrition ROSE Award and coordinated the first National PKU Awareness Day with U.S. Senator Johnny Isakson (GA). Prior to her engagement in non-profit work, Kristen was a business process consultant with Accenture and later did freelance change management consulting. Kristen lives with her husband and two children in Atlanta, home of her alma mater, Georgia Tech.



Nikia Vaughan

A dedicated community leader in Baltimore, Maryland, Nikia has a passion for healthy living, community and ending stigmas in the African- American community. When her daughter Cimone was diagnosed with sickle cell disease SS in 2012, Nikia created a sickle cell awareness group, Cimone and Friends, to advocate on behalf of, and provide education for, families with children who suffer from sickle cell disease. In 2018, Nikia testified as a parent for SB 161, requiring the State Department of Education and the Maryland Department of Health to establish certain guidelines by December 1, 2018, for public schools regarding the administration of health care services to students with sickle cell disease and requiring the State Department of Education and the Maryland Department of Health by December 1, 2018, to provide technical assistance on implementation of the guidelines and to develop a process to monitor implementation of the guidelines. The bill was passed and signed into law by Governor Larry Hogan in May 2018. Nikia resides in Baltimore City with her husband Charmon and their two children, Langston (10) and Cimone (7).



Our passion for making a difference unites us.

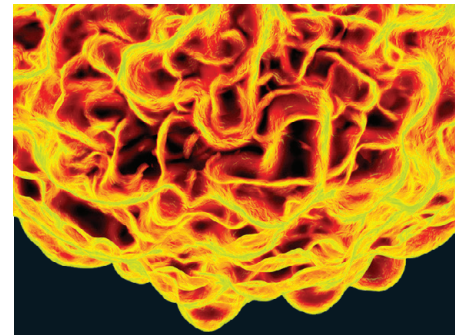
Amicus Therapeutics is a global, patient-dedicated biotech company focused on discovering, developing, and delivering high-quality medicines for people living with rare metabolic diseases.



Congratulations RareVoice Awardees!

Retrophin

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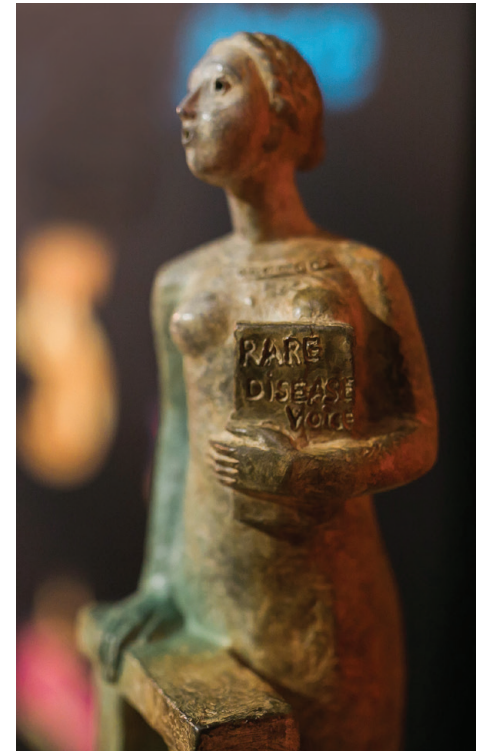


Congratulations to the recipients of
the 2019 RareVoice Awards!

As biopharmaceutical researchers
keep searching for breakthrough cures
they don't have to look far for inspiration.



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GREENWICH Biosciences is proud to support the RareVoice
Awards in honoring advocates giving a voice to rare disease patients.

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TEEN ADVOCACY AWARD

Aidan Abbott

Aidan is a 14-year-old rare disease advocate from Slinger, Wisconsin. Aidan enjoys playing basketball and is an avid Milwaukee Bucks fan. He was born with a rare disease, ectodermal dysplasias (XLHED), which affects his hair, skin, sweat glands and he is missing many of his teeth. Aidan became an advocate after struggling to receive health insurance coverage for the complex treatment of his missing teeth, a congenital anomaly. After fighting insurance for many years, Aidan shared his story with Senator Tammy Baldwin (D-WI) and inspired her to write the Ensuring Lasting Smiles Act (ELSA), which Aidan had the privilege of naming. This federal legislation would ensure that medical insurance pay for the medically necessary repair of congenital anomalies, including dental/oral treatments. Aidan has made it his mission to work with legislators on both sides of the aisle to move ELSA forward and get ELSA passed into law.



Emma Detlefsen

Emma is 11 years old and was born with primary lymphedema (LE) in her legs and feet. She was properly diagnosed when she was 18 months old. Emma's parents were shocked to discover the extreme lack of knowledge, treatment options, funding, insurance coverage, and overall general understanding of lymphedema. Instead of letting LE get the best of her, she decided to do her part to make it better for the millions who suffer from the disease. In 2015, she became a youth ambassador of Lymphatic Education & Research Network (LE&RN) and attended her first lobby day in D.C. in support of The Lymphedema Treatment Act, after making it her New Year's Resolution to pass the bill. Since then, she has dedicated her life to trying to fix everything that's wrong with LE. She's attended over 40 congressional meetings to date in support of the LTA and the LE&RN. Emma has been told that she is 1 of 100,000 who suffer from primary lymphedema. She is determined to be the one to help make this lymphedema less of a struggle for all who suffer.



Britney Thomas

Britney was diagnosed with juvenile idiopathic arthritis when she was 12, three years after the onset of symptoms. It took four years for Britney to see a rheumatologist, due to the shortage of them in the state of Arkansas. Due to Britney's arthritis going untreated for this period of time, she developed uveitis, which left her blind for weeks. Now 18, she has also been diagnosed with lupus, chronic recurrent multifocal osteomyelitis, uveitis, hypermobility, Duane syndrome, and other diseases. Today, Britney makes it her passion to advocate for herself and others suffering from rare diseases.



Vienne Weinert Wood

Vienne is fourteen years old and at age two was diagnosed with Doose Syndrome, a rare epilepsy, with myoclonic-atonic seizures. Because the drug required to treat her, called Epidiolex, is only indicated for seizures associated with Dravet and Lennox-Gastaut Syndromes, she was refused access to the medicine due to state law. Vienne, along with her parents and support dog Magic, testified in support of a bill that would change that. Vienne's advocacy helped inspire others to stand in support of the bill, which was signed into law by Governor Hickenlooper on June 4, 2018. Vienne's advocacy also extended to her local school district, resulting in the development of a national model to ensure special education students receive adequate funding for their unique needs and ensuring rare disease patients have access to all available therapies.





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