10th ANNIVERSARY

RARE VOICE Awards

A celebration to honor advocates
who give rare disease patients a voice
in state and federal policy

12.15.21

7:00 P.M. E.T.

presented by

SANOFI GENZYME

EVERYLIFE FOUNDATION FOR RARE DISEASES

RDLA
Rare Disease Legislative Advocates

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RAREVOICE Awards

EVENT PROGRAM

Masters of Ceremonies

- Abbey Hauser, Patient Advocate
- André Marcel Harris, Patient Advocate

Announcement of the RareVoice Award Recipients

- Federal Advocacy: Congressional Staff
- Federal Advocacy: Patient Advocate/Organization
- State Advocacy: State Legislator
- State Advocacy: Patient Advocate
- Federal or State Advocacy: Teen
- Diversity Empowerment: Patient Advocate/Organization
- Artist-to-Advocate
- Congressional Leadership
- Lifetime Achievement

@RareAdvocates

#RAREVOICE2021
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.

MASTERS OF CEREMONIES

ABBEY HAUSER

Abbey Hauser is a young adult rare disease advocate with Classical Ehlers-Danlos Syndrome. Abbey started advocating for rare disease, disability, and chronic illness after starting her blog, *Owning My Story*. Since then she has worked alongside a group of advocates to pass a Rare Disease Advisory Council Bill in Minnesota, graduated from the YARR Leadership Academy, met with law-makers during Rare Across America and Rare Disease Week on Capitol Hill, participated in many rare disease conferences and spoken at various events for rare disease and adaptive sports advocacy. Abbey is also a certified personal trainer, where she shares her passion for adaptive sports for people with rare diseases and connecting people with forms of activity that feel good for their bodies. In her down time, she is an avid reader, an outdoor enthusiast, a collector of quotes, and a lifelong learner.

ANDRÉ MARCEL HARRIS

André is currently pursuing a PhD in Social Work at the University of Houston's Graduate College of Social Work. Mr. Harris is serving in his second term on the Rare Disease Legislative Advocates Advisory Committee and as President of the National Association of Black Social Workers (NABSW) University of Houston chapter. André also serves on the Executive Board of the Sickle Cell Association of Houston and holds positions on several other advisory boards for sickle cell and rare disease stakeholders to include Forma Therapeutics, NHLBI, and HHS. He is a proud member of Phi Beta Sigma Fraternity, Inc. and was recently appointed as the National Sickle Cell Liaison Director, a position that allows him to strengthen the social action interests the fraternity has in supporting the sickle cell community.

CHANGING POLICY, SAVING LIVES

EVERYLIFE FOUNDATION FOR RARE DISEASES

The EveryLife Foundation for Rare Diseases is a nonprofit, nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures.

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RDLA
Rare Disease Legislative Advocates
POWERED BY THE EVERYLIFE FOUNDATION

Rare Disease Legislative Advocates (RDLA) is a program of the EveryLife Foundation for Rare Diseases designed to support the advocacy of all rare disease patients and organizations.

@RareAdvocates

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FEDERAL ADVOCACY: CONGRESSIONAL STAFF

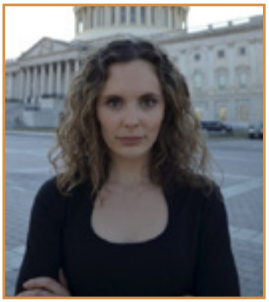
Christina McCauley, Representative Doris Matsui (CA-6)

Christina is the Legislative Director for Representative Doris Matsui (D-CA). She handles the Congresswoman's House Energy and Commerce healthcare portfolio as well as food and agriculture policy. Prior to joining the Congresswoman, Christina worked as a health policy and investment analyst in Washington, D.C. Christina has a master's degree in public health from the University of Texas Health Science Center and an undergraduate degree from Texas A&M University.

Kirby Miller, Senator Roger Wicker (MS)

Kirby Miller currently serves as legislative assistant for Senator Roger Wicker of Mississippi. In this role, she advises Senator Wicker on policy related to health care, as well as telecommunications. As legislative assistant, Kirby supports Senator Wicker's efforts as Co-Chair of the Rare Disease Caucus, among other legislative priorities. Prior to joining Senator Wicker's office, she worked in the House of Representatives. A native of Natchez, Mississippi, Kirby attended the University of Mississippi where she received a bachelors degree in dietetics and nutrition.

Erin Dugan,
Senator Tammy Baldwin (WI)



Erin Dugan is the Senior Health Policy Advisor for U.S. Senator Tammy Baldwin (D-WI), a member of the Senate Health, Education, Labor and Pensions (HELP) and Appropriations Committees. In her role, she advises Senator Baldwin on a number of health care priorities, including prescription drug pricing, implementation of the Affordable Care Act, and maternal and child health. Prior to coming to Senator Baldwin's office, Erin was a Truman-Albright Fellow in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) at the Department of Health and Human Services (HHS). She is a proud graduate of the University of Delaware.

Jay Eberle,
Senator John Barrasso (WY)

Jay Eberle currently serves as Senator Barrasso's health legislative assistant. Senator Barrasso is Chairman of the Senate Republican Conference and a member of the Senate Finance Committee. Jay joined Senator Barrasso's staff in 2011. He began his career on Capitol Hill working for Senator Jim Bunning (KY). After Senator Bunning's retirement, he worked for Representative Chip Cravaack (MN-8), handling the Congressman's work on the House Science, Space and Technology Committee. He holds an undergraduate degree in government from Centre College and a master's degree in legislative affairs from George Washington University. Jay is married to his wife Alison, a nurse practitioner at Johns Hopkins Hospital. They are the parents of three children.

FEDERAL ADVOCACY: PATIENT ADVOCATE/ORGANIZATION

Christine Brown

Christine Brown is the Executive Director of the National PKU Alliance. She has led the organization since 2009. Christine has more than 30 years of experience in building and leading non-profit organizations at the local, state, national and international level. Her background includes working in rare diseases, health care policy, rural economic development, domestic violence, and human rights. Christine received her BA in Global Peace and Justice Studies from St. Norbert College in DePere, WI and her Masters in Organizational Management and Leadership from Springfield College in Springfield, MA. Christine is a member of the Wisconsin Newborn Screening Committee, the FDA's Patient Engagement Collaborative, a mentor in the Chan Zuckerberg Rare as One Initiative, a founding trustee of the Global Association for PKU and has co-authored several articles on the patient voice in public advocacy and drug development. Christine lives in Eau Claire, WI with her husband, Kevin and sons Keagan, Connor (PKU) and Kellen (PKU).

VHL Alliance

The VHL Alliance (VHLA) is the preeminent resource and clearinghouse for those affected by von Hippel-Lindau disease, including patients, caregivers, researchers, and the medical community. VHLA is a 501(c)(3) non-profit organization founded in 1993 which is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL. VHLA is the leading funder of VHL research, funding over $2.6 million in grants to support studies designed to find a cure.

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Takeda

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We come together every day to help patients, families and caregivers of all backgrounds as they navigate life with a rare disease. On this path, we know the need for treatment options is urgent — that is why our global team works with the rare disease community to identify, develop and deliver life-changing therapies. In pursuit of this mission, we continuously seek to understand the diverse perspectives of rare patients and to courageously forge new paths to make a difference in their lives and provide hope — today and tomorrow.

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TRAVERE™ THERAPEUTICS

Marc Yale

Marc was diagnosed in 2007 with Pemphigoid, a rare autoimmune blistering skin disease. Like others with a rare disease, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. In 2008, he joined the International Pemphigus and Pemphigoid Foundation (IPPF) as a Peer Health Coach. In 2016, Marc became the Executive Director of the IPPF. He now serves as the Advocacy Research Coordinator of the IPPF focusing on research and advocacy for all of those affected by pemphigus and pemphigoid. He is a member of the American Academy of Dermatology Drug Transparency Task Force, sits on the Executive Board of Directors for The International Alliance for Dermatological Patient Organizations, serves on the RDLA Advisory Committee and is a Board Director for the Haystack Project.

Jenn McNary

Jenn is a trusted voice in the rare disease community as a mother, public speaker and fierce advocate. Formerly as the director of outreach and advocacy at a Massachusetts based non-profit foundation, she was responsible for the organization of the largest FDA advisory committee hearing in history, with over 1000 duchenne advocates, families, clinicians and researchers in attendance. Jenn has unique experience in the drug development field, as a parent of children enrolled in the clinical trials, an advocate engaging with the regulators and as a consultant helping to develop programing for patients. Currently, Jenn is consulting in the biotechnology space with an expertise in caregiver/patient engagement, including bringing the patient voice to drug development and solving barriers to access. Her other activities include serving as the Founder of One Rare, a non-profit formed to meet the needs of young adults with rare and chronic conditions and raising her four children in Massachusetts.

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VIRTUAL PHOTOBOOTH

Share your RareVoice Awards 2021 experience by taking a selfie in our Virtual Photobooth and posting it on social media with the hashtag #RareVoice2021

Thank you to our Virtual Photobooth Sponsor

SANOFI GENZYME

2020 RareVoice Awards Recipients

Representative Sharon Cooper (GA)

Born in Houston, Texas, Representative Cooper is proud to have called Georgia home for over 39 years. Married to the late Dr. Tom Cooper for more than 33 years she was first elected to the Georgia House in 1996. Representative Cooper is Caucus Chair Emeritus and chairs Health and Human Services, one of the Houses' busiest committees. She also serves on the Special Committee on Access to Quality Healthcare, Rules, Judiciary Non-Civil and Regulated Industries. Rep. Cooper holds several degrees, including a B.S. in Child Development, a masters in Education and an MSN in Nursing. She has written two textbooks on Psychiatric Nursing and a how-to book encouraging political participation. Recently, Rep. Cooper has focused on fighting the opioid crisis and being a champion for our most vulnerable citizens, both children and the aging.

Representative Jarvis Johnson (TX)

Jarvis Johnson has dedicated his life to making a difference in the lives of those around him. He is a native Houstonian and the father of two beautiful children. As a community organizer, entrepreneur, strategist, consultant, and developer he has worked for positive change that empowers the community and improves the lives of its citizens. For over thirty years, he has looked for opportunities to engage the community and local businesses to create a successful society that works for everyone. Since being elected to serve in May of 2016, Representative Jarvis Johnson has been busy creating opportunities for District 139 and all Texans. Representative Johnson's main legislative priorities are criminal justice and child welfare reforms, environmental protections, and access to care for individuals with Sickle Cell Disease.

Representative Hannah Kane (MA)

Hannah Kane serves as the State Representative for the Eleventh Worcester District, representing the towns of Shrewsbury and Westborough, and was sworn in to serve her fourth term in January of 2021. Hannah graduated from Boston University's School of Management in 1993 and has significant experience in both the public and private sectors. Hannah serves as the Ranking Minority Member for both the Joint Committee on Health Care Financing and the Joint Committee on Public Health. She is also a member of the Joint Committee on Mental Health, Substance Use, and Recovery and the new Joint Committee on Racial Equity, Civil Rights, and Inclusion. Hannah also currently serves as the Minority Leader's designee to the inaugural MA Rare Disease Advisory Council. Hannah and her husband Jim live in Shrewsbury, with two daughters in college, one of whom has two chronic diseases, and a son in high school.

Representative Allison Russo (OH)

State Representative Allison Russo is currently serving her second term in the 134th Ohio General Assembly representing House District 24. She serves as the Ranking Member on Health Committee in addition to serving as a member on the Joint Medicaid Oversight Committee, Finance Committee, Finance Health and Human Services Subcommittee, and Families, Aging and Human Services Committee. Rep. Russo is also the Co-Chair of the bipartisan Legislative Children's Caucus and Policy Chair of the Democratic Women's Caucus. Additionally, Rep. Russo was appointed as the Ranking Member of the Ohio Health Advisory Committee and serves on the Ohio Attorney General's Elder Abuse Commission, as well as the State Council on Educational Opportunity for Military Children. Rep. Russo brings a practical approach and evidence-based solutions to the critical issues facing Ohio, introducing several pieces of important legislation that address health care access, the protection of public health and safety, and the financial security of family caregivers and aging adults.

Lesa Brackbill

Lesa Brackbill is a wife, mother, and advocate living in Hershey, Pennsylvania. Lesa's daughter, Tori, had Krabbe Disease. During her short life, Tori inspired Lesa to use her political science degree (and lobbying experience) to impact babies born in Pennsylvania. The journey was long, but on November 25, 2020 that legislation was signed into law (Act 133 of 2020). As of May 2021, every baby born in Pennsylvania is now screened equally – and screened for Krabbe – and Pennsylvania is RUSP-compliant. Lesa helped form the Leukodystrophy Newborn Screening Action Network (LDNBS.org) and works to build coalitions of advocates across leukodystrophies. She is the author of *Even So, Joy: Our Journey Through Heartbreak, Hope, and Triumph.* She hopes to one day see a world where a child born with a leukodystrophy receives the best possible chance at life and will work to achieve that goal for as long as it takes.

Randi Clites

Randi became an advocate for affordable access to healthcare for medically fragile children when her son Colton was born in 2002 with hemophilia and also diagnosed with leukemia a short time later. She began her advocacy efforts chairing the parent advisory councils at both Akron Children's Hospital and Ohio's Title V Program – Children with Medical Handicaps. In 2012, she represented Ohio as a Family Scholar for the Association of Maternal and Child Health Program. She has been the advocacy coordinator for a coalition of providers, patients, and non-profits serving bleeding disorders patients for over 10 years. She joined the Little Hercules Foundation in 2021 as the Rare Disease Policy Director, after taking her passion of working on policy to public office, serving as State Representative for the 75th Ohio House District in 2019-2020. While serving she was able to pass legislation to establish a Rare Disease Advisory Council.

Bob Graham

Bob has hemophilia and been active in the bleeding disorders community since 1991. For more than 30 years Bob has volunteered as a counselor and director at bleeding disorder youth and family camps. Since 2008, Bob has volunteered as Public Policy Director of the New York State Bleeding Disorders Coalition (NYSBDC), working on legislative advocacy for people with bleeding disorders. NYSBDC has been active in passing laws on pharmacy access, step therapy, high-cost co-pays, non-medical switching, and the NYS Rare Disease Council to give all ptients access to quality, affordable care. Bob has spent years traveling to Albany to meet legislators, and during covid has helped lead virtual advocacy efforts to make sure patients are heard. Bob also serves on the Medicaid Matters NY Coalition Steering Committee. Bob lives in Varysburg, NY with his family and works at the NY School for the Blind in Batavia.

Jessica Keogh

Jessica Keogh, M. Ed resides in West Chester, Pennsylvania where she teaches students who have difficulty regulating their emotions. Being born with a yet to be diagnosed type of neuromuscular Dystrophy, Jessica has dedicated her life to educating, advocating, and empowering people with disabilities (and those without) so they can live their most empowered lives! Jessica has done this through the way she lives, teaches, and advocates for meaningful policy change for people with disabilities. She is currently pursuing her doctorate in educational policy, leadership, and administration, and once she earns her degree, she will write policies that help all children. Jessica is also the CEO and founder of Faith Above my Ability, a nonprofit organization geared towards empowering people of all abilities.

Richard Pezzillo

Richard Pezzillo is the Executive Director of the New England Hemophilia Association (NEHA). Prior to joining NEHA, Richard worked in Washington, DC as the press secretary for Senator Sheldon Whitehouse, and then as the Communications and Marketing Director for the Hemophilia Federation of America (HFA). Richard is the former co-chair of the National Hemophilia Foundation's (NHF) Youth Leadership Institute. He is the recipient of the Ryan White Meritorious Service Award, NHF Advocate of the Year Award, and a "40 under Forty" winner for the Association for Healthcare Philanthropy and Providence Business News. Richard graduated from Western Connecticut State University and currently resides in Providence, Rhode Island.

Yash Krishnan

Yash is a 13-year-old boy who lives in Cary, NC. He has an ultra-rare disease called Biallelic/Constitutional MisMatch Repair Deficiency (CMMRD/BMMRD). CMMRD is considered the most aggressive cancer predisposition syndrome associated with multi-organ cancers, often presenting in childhood. Yash's diagnostic odyssey started when he was 4 years old. At the age of 6 he received his first scope and his first surgery at the age of 8. Since then he has undergone multiple surgeries to remove cancerous lesions from his GI tract. Aggressive monitoring and surgery remain the current regimen of care. Yash believes in the power of advocacy and representation. Yash began his advocacy journey after his sister passed away. Growing up with a non-verbal sibling he felt even more motivated to share his own journey to fight for others who could not. He hopes that by sharing his story with various stakeholders will accelerate research, create standardized treatment plans and hopefully find a cure in his lifetime.

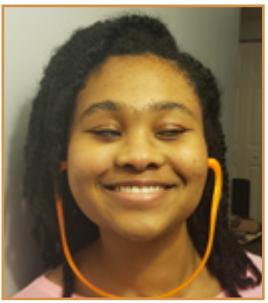
Krteyu Ramanathan

Krteyu moved to the USA from India in 2008. He has always worked to help causes. Starting in fifth grade, he got involved in the advocacy aspect of making change by advocating for immigration reform. This led to a passion for advocacy, and eventually led to his advocacy for the cause of Rare Diseases.

Avery Roberts

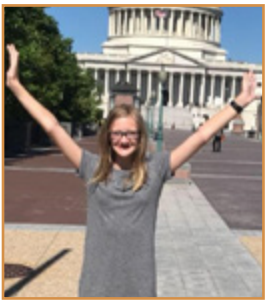
Avery Roberts is a 14-year-old rare disease advocate with Congenital Muscular Dystrophy (CMD). She has attended many conferences including Cure CMD Scientific & Family Conferences, since she was in elementary school and now works as a community outreach and engagement volunteer for the organization. She has established a Cure CMD Webinar Series, expanded their Young Adult Programming by creating a mentorship program & resource page, and brings the community together by hosting monthly game sessions via Zoom. She has been participating in Rare Disease Week since February 2020, but has been advocating her whole life. She is very passionate about giving back to the rare disease community, having raised over $4,000 as part of Living in the Light and Cure CMD's "I Stay Home For Rare" fundraising campaign. She believes social media is a powerful tool for the rare disease & disability communities and wants to encourage more young people to use their voices.

Jemma Rosewater



Jemma is a 17-year-old rare disease advocate whose goal is to help raise awareness about hyperacusis and other rare disorders/chronic pain conditions, put in place laws to accommodate those with hyperacusis, and push for more research to be done on hyperacusis. In addition to advocacy work, she also enjoys writing and plans to become a full-time writer/author.

Allison Steele



Alli Steele is a 15-year-old who lives in Waukee, Iowa. She was diagnosed with Hypohydrotic Ectodermal Dysplasia at age 6. Her hair, nails, skin, and teeth are affected. She is missing 18 of her permanent teeth, and treatment for her birth defect is not covered under medical insurance. Alli believes advocating on Capitol Hill is important so those with birth defects can have medical insurance coverage for their medically necessary treatments. The Ensuring Lasting Smiles Act is lead by Senator Joni Ernst, from Iowa. She shared her story with her, which inspired Senator Ernst to take action. A big part of her advocacy is focused on encouraging and teaching youth to share their stories with their legislators. She has witnessed children sharing their stories and immediately capturing the hearts of legislators resulting in them taking action to support the Ensuring Lasting Smiles Act.

Hannah Yale

Hannah Yale has been an advocate for the Everylife Foundation and the International Pemphigus and Pemphigoid Foundation since 2017. She has attended RDLA's Rare Disease Week on Capitol Hill annually since 2017, and she is also a member of the Young Adult Representatives of RDLA. In 2020, Hannah served on the Funding Committee for Living In The Light's "I Stay Home For Rare" Emergency COVID-19 Relief Fund. Hannah is living with Ehlers-Danlos Syndrome, although she began her rare disease advocacy to support her father (who has Mucous Membrane Pemphigoid) and her mother (who also has a rare disorder). Hannah is currently a student at St. Mary's College of Maryland, where she is majoring in public policy and minoring in english and philosophy.

#HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR #HearUsYARR

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DIVERSITY EMPOWERMENT: PATIENT/ORGANIZATION

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The Black Women's Health Imperative (BWHI)

The BWHI launched the Rare Disease Diversity Coalition (RDDC) in May 2020 to address the extraordinary challenges faced by rare disease patients of color. Born out of the collective commitment to be a catalyst for progress for people of color with rare disease, the Coalition empowers diverse voices in the rare disease community. The Coalition brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to alleviate the disproportionate burden of rare diseases on communities of color. Since its inception, the RDDC has empowered diverse voices in rare disease advocacy. Also, the RDDC continues to raise awareness and underscore the plight of the diverse rare disease community through patient stories, webinars, keynote speakers, and publications.

Eric Lipp

Eric founded Open Doors Organization (ODO) in 2000, after personally experiencing the restrictions that people with disabilities face in everyday life. At 30 years old, Eric was diagnosed with Von Hippel Lindau and as a result, experiences reduced mobility and a number of medical conditions. Under Eric's leadership, ODO has assisted countless companies in the travel industry to better serve the disability community, expanding its expertise and influence to cover every mode of transportation including air travel, cruise lines, motorcoach, rail, and accessible taxis and ridesharing services. Eric is a recognized expert in ADA and ACAA regulations and universal design. He speaks globally on access in travel and tourism and represents the disability community on numerous accessibility advisory boards including that of Alaska Airlines, the Port of Seattle, Pittsburgh Airport, Royal Caribbean Cruise Lines, United Airlines, and the Transportation Security Administration Aviation Security Advisory Council.

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Michele Wright

Tuskegee native and Arkansas resident Michele Wise Wright, Ph.D. is the Nations of Women (NOW) Change Makers 2021 Global Leadership Award Winner. She is the Co-Founder and Board Chair of the National Organization of African Americans with Cystic Fibrosis (NOAACF), a 501(c)(3) organization with a mission to engage, educate, and raise cystic fibrosis (CF) awareness in the African-American community to help bring valuable resources, knowledge, empowerment, and support to CF patients, families, healthcare professionals, and the community. Dr. Wright co-founded and co-chairs the annual Blacks, Indigenous, and Other Minority Ethnicities with Rare and Genetic Diseases (BIOMERGD) Conference; created and launched the Advocating for Health Equity and Addressing Disparities (AHEAD) Initiative; and led the development of The Wright Cystic Fibrosis Screening Tool© to help individuals self-identify symptoms that could be related to CF and doctors potentially identify individuals with CF, including individuals who are Black, Indigenous and People of Color (BIPOC).

Sick Cells

Sick Cells is a national sickle cell disease (SCD) advocacy nonprofit founded in 2017. Sick Cells' mission is to elevate the voices of the SCD community and their stories of resilience. In highlighting the grave disparities this community faces, they hope to influence decision makers and propel change. Through their Ambassador program and the Faces of SCD Storytelling program, Sick Cells hopes to influence decision makers and propel change by highlighting the grave disparities the community faces. Sick Cells envisions that their narrative work will achieve the following: ignite public interest in making sickle cell a public health concern, humanize SCD, which is a relatively invisible disease, inspire the general public to advocate for SCD, influence policy makers, educators, employers, healthcare providers to act to improve treatment and care for the SCD population, drive research and drug development to lead to better treatments, empower the community to share their stories and know that they are not alone.

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ARTIST-TO-ADVOCATE

Award exclusively sponsored by WCG Clinical

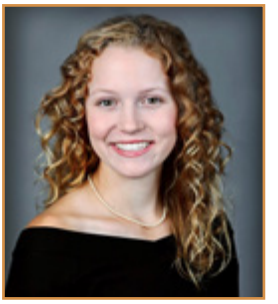
Alena Galan

Alena Galan living with a rare disease has beat all odds! She is a talented and accomplished singer and songwriter. Within the last five years, she has performed at Carnegie Hall, interned at CBS 2 News, starred on a TLC Reality show, modeled adaptive wear for Fashion Week for Runway of Dreams as well as completed her undergraduate degree in Marketing with Communications along with her MBA in an accelerated 3+1 program. She hopes to continue to make a difference in the lives of others by bridging the world of work with her passion and her desire to work in the television and entertainment industry. The camera continues to be her life and home. She continually demonstrates that anything is possible. Continuing to climb the ladder of hard work with perseverance, and being the possibilitarian that she is, standing tall at 4'3" proving that big things DO come in small packages.

Ella Balasa

Ella Balasa is a patient advocate, consultant, and a person living with cystic fibrosis. She was diagnosed at 18 months old and has experienced countless hospitalizations since being a child. She is an advocate for the development of novel therapies for the treatment of antibiotic-resistant infections and speaks publicly at conferences, meetings, and to companies about the value of patient voice in research. She also has a passion for writing; distilling clinical information for patient communities, and sharing about the hardships yet triumph that comes with living with a chronic illness. She has been published in journals, news sites, and blogs. Through opportunities working with healthcare organizations and sharing her journey through writing, public speaking, and art expression, she aims to affect the healthcare landscape by raising awareness of CF, promoting self-advocacy to patients, and valuable insights to organizations.

Olivia Ohmer



Olivia Ohmer is a 17-year-old from Michigan who lives with multiple autoimmune diseases, including Chronic Solar Urticaria, Hashimoto's Thyroid Disease and Type One Diabetes. She is an advocate for patient voice, the International Children's Advisory Network, The American Diabetes Association and the Rare Community. She has always been a creative person. When she was diagnosed with a rare disease known as Chronic Solar Urticaria (account for only 0.4% of all Urticarias), she knew that she was not alone, and there were other people who had a connection to rare disease. She painted everything she saw or wanted to see. From the most mountainous regions to the flat-most dirt terrain, she painted it. When she heard about the RareArtist competition, she knew immediately that this was something she could do. Going back to her favorite form of art, drawing, she developed an image to represent everyone. She wanted to highlight the beauties of society's people and everyone who make up it. She wanted to express the need of inclusivity, whether it be disease, height, eye color or ethnicity. She wanted to show that not all diseases are visible. She is a patient who lives with invisible diseases and this was very important to her.

RARE DISEASE CONGRESSIONAL CAUCUS

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

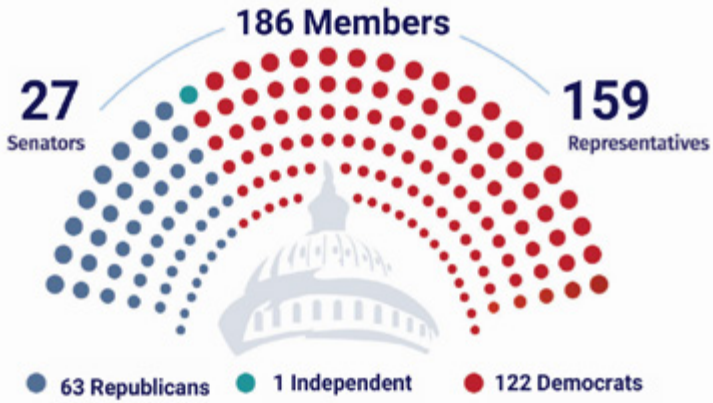
Representative
G.K. Butterfield (NC)

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

Representative Frank Pallone, Jr.

Frank Pallone, Jr. represents New Jersey's Sixth Congressional District. Throughout his career, Pallone has fought to make health care more affordable and accessible, protect and strengthen Medicare and Medicaid, and make the country's food system safer. During the 116th Congress, as the nation confronted the COVID-19 pandemic and the resulting economic crisis, Pallone played a pivotal role in ensuring Congress provided the tools and resources needed to bring an end to this terrible pandemic. He helped shepherd four bills through the House to combat the coronavirus that became law. Pallone led the bipartisan effort to end surprise medical bills by holding patients harmless when they receive a surprise bill from an out-of-network health care provider. As Chairman of the Health Subcommittee during the 111th Congress, Pallone played a key role in authoring and passing the ACA. The landmark law extends health care coverage to millions of Americans, while driving down health care costs, and reigning in abusive tactics used by insurance companies to deny medical treatment. Frank Pallone, Jr. was born in Long Branch, New Jersey where he grew up and still resides. Pallone began his political career in Long Branch. He was elected to the Long Branch City Council in 1982. In 1983, he was elected to the state Senate, representing the Monmouth County coastline. He was re-elected in 1987.

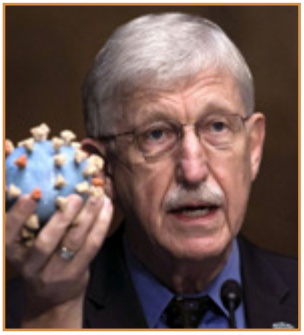
Senator Richard Burr

First elected to the U.S. House of Representatives in 1994, Richard served five terms in the House and is currently serving North Carolina in his third term in the U.S. Senate. During his time in the House, he led legislation modernizing the U.S. Food and Drug Administration (FDA), and began his work to improve our nation's biodefense and pandemic preparedness capabilities. In the Senate, Richard serves as Ranking Member of the Health, Education, Labor, and Pensions Committee. Promoting innovation in America's healthcare system has been a priority for him throughout his time in Congress. Richard has led on a number of significant legislative priorities, including the creation of today's pandemic response framework through the passage and reauthorization of the Pandemic and All-Hazards Preparedness Act (PAHPA), improving FDA's ability to regulate cutting-edge treatments for patients, and consistently championing funding for medical innovation and research. Richard spearheaded the passage of the Stephen Beck, Jr. Achieving a Better Life Experience (ABLE) Act. This legislation allowed for individuals with disabilities to save money in their own name without losing critical benefits, including health care. In 2014, the ABLE Act was signed into law. He also serves as a Board Member of Brenner Children's Hospital and on the West Point Board of Visitors.

LIFETIME ACHIEVEMENT AWARD

Dr. Francis S. Collins

Dr. Francis S. Collins, M.D., Ph.D. was appointed the 16th Director of the National Institutes of Health (NIH) by President Barack Obama and confirmed by the Senate. He was sworn in on August 17, 2009. In 2017, President Donald Trump asked Dr. Collins to continue to serve as the NIH Director. President Joe Biden did the same in 2021. Dr. Collins is the only Presidentially appointed NIH Director to serve more than one administration. In this role, Dr. Collins oversees the work of the largest supporter of biomedical research in the world, spanning the spectrum from basic to clinical research.



Dr. Collins is a physician-geneticist noted for his landmark discoveries of disease genes and his leadership of the international Human Genome Project, which culminated in April 2003 with the completion of a finished sequence of the human DNA instruction book. He served as director of the National Human Genome Research Institute at NIH from 1993-2008.

Dr. Collins is an elected member of both the National Academy of Medicine and the National Academy of Sciences, was awarded the Presidential Medal of Freedom in November 2007, and received the National Medal of Science in 2009. In 2020, he was elected as a Foreign Member of the Royal Society (UK) and was also named the 50th winner of the Templeton Prize, which celebrates scientific and spiritual curiosity.

WHAT'S YOUR STORY?

More than 30 million Americans are living with one or more rare diseases.

Each one of us has a story. We want to hear yours.

"I was diagnosed with Narcolepsy when I was sixteen years old and I fell asleep at the kitchen table. As a patient advocate, I am enthusiastic about making sure that the home health and telemedicine options that have been expanded due to the pandemic continue to remain in place."

– Nicole E., Texas

Submit your story by March 2nd, 2022 for a chance to win a $1,500 donation to the patient advocacy organization of your choice!

SCAN FOR MORE INFO

EVERYLIFE FOUNDATION FOR RARE DISEASES

CONGRATULATIONS TO ALL RARE DISEASE PATIENT ADVOCATES NOMINATED THIS YEAR

- Jonathan Alvarez
- Rose Adare
- Sarah Chamberlin
- Khrystal Davis
- Morgan DeBoth
- Winslow Dixon
- Donna Fogle
- Sheilah Gauch
- Andre Harris
- Intermountain PKU and Allied Disorders Association
- Sharon King
- Kathi Luis
- Alexia Mays
- J. Maurice McCants-Pearsall
- Tara Notrica
- Christina Pohlamn
- Alison St. Paul
- Mark Schleiss
- Dan Shockley
- Heather Shorten
- Jennifer Vitelli
- Christine Von Raesfeld
- Casey Witte

THANK YOU TO THE RAREVOICE NOMINATIONS COMMITTEE

David Eckstein, Office of Clinical Research, NIH

Stephen Groft, EveryLife Foundation Board Member

Sarah-Lloyd Stevenson, Faegre Drinker

Lisa Schill, Patient Advocacy and Engagement Consultant

Kathleen Tighe, Sanofi Genzyme

Shayne Woods, Office of Senator Tim Scott

RARE DISEASE WEEK ON CAPITOL HILL

VIRTUAL
FEB 22- MAR 2
2022

REGISTRATION OPEN

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RDLA
Rare Disease Legislative Advocates
POWERED BY THE EVERYLIFE FOUNDATION

#RAREDC2022

@RareAdvocates

Emma and Signe, Fabry disease, Denmark

FOCUSED ON DEVELOPING SPECIALTY TREATMENTS

for debilitating diseases that are often difficult to diagnose and treat, providing hope to patients and their families.

We're proud to support EveryLife Foundation as they celebrate 10 years of RareVoice awards to recognize the efforts of advocates who give rare disease patients a voice on Capitol Hill and in state government.

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