The ninth annual

RARE VOICE Awards

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

DECEMBER **10** 7:00 P.M. E.T

presented by

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RDLA Rare Disease Legislative Advocates

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RAREVOICE Awards

EVENT PROGRAM

Masters of Ceremonies

- Elissa Taylor, EveryLife Foundation for Rare Diseases
- Ryan Colburn, 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
- Teen Advocacy
- Artist-to-Advocate

Congressional Leadership Award

- The Honorable Jaime Herrera Beutler
- The Honorable Tammy Baldwin

@RareAdvocates

#RAREVOICEAWARDS2020

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.

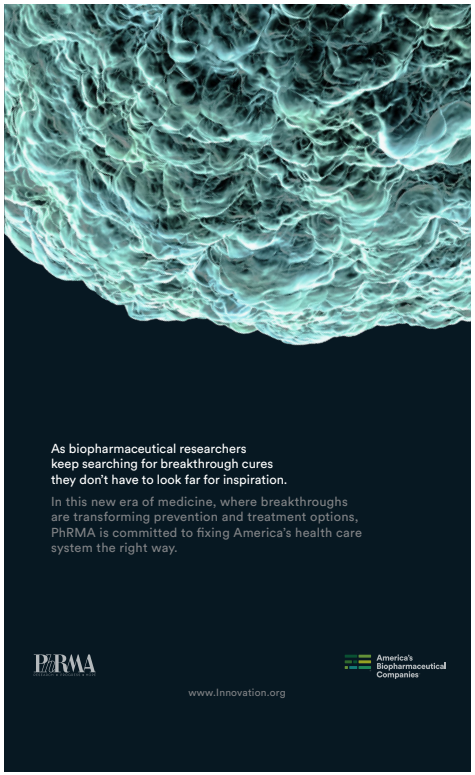
MASTERS OF CEREMONIES

ELISSA TAYLOR

Diagnosed with juvenile diabetes at 10-months-old, Elissa's parents were told that due to the delay in diagnosis, she would either pass away or live a life with severe brain damage. This wouldn't be the last time Elissa would beat the odds. Now 31, she is a two-time cancer survivor and mother to her three-year-old son Brycen and three rescue dogs. Her family endured another health challenge when her father was diagnosed with pulmonary arterial hypertension (PAH), following a seven year diagnostic odyssey. A rare, progressive disorder characterized by high blood pressure in the arteries of the lungs, PAH weakened his heart and required him to undergo a heart transplant. Her father continues to be Elissa's "Superman" role model and is one of the reasons why she is committed to uplifting the voices of people battling invisible and misunderstood illnesses. She has done this recently through her platform as Ms. Cosmos International and in her capacity as the EveryLife Foundation's Associate Director of Alliance Development.

RYAN COLBURN

Ryan Colburn is a rare disease patient advocate with a professional background in engineering and operations management. He has spent his career designing and manufacturing race cars, airplanes, rockets, and satellites. Although he experienced symptoms since early childhood, Ryan was just diagnosed five years ago at the age of 31 with Pompe disease. Since that time, he has dedicated his efforts to learning about patient empowerment and engagement and actively developing relationships with other patients, advocacy groups, researchers, and pharmaceutical companies. He is driven to improve the health of the rare disease ecosystem by shifting the view from patients as "subjects" to one of participants, collaborators and partners who help find the most effective ways to break down barriers to accelerating progress. Ryan has spoken at conferences and public meetings around the country about the importance of empowering patients in driving innovation and research.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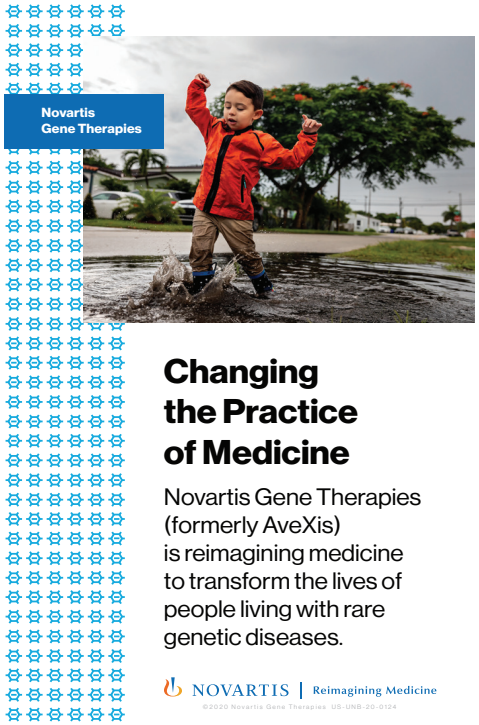
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The EveryLife Foundation for Rare Diseases is a
nonprofit, nonpartisan organization dedicated to
empowering the rare disease patient community to
advocate for impactful, science-driven legislation and
policy that advances the equitable development of and
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FEDERAL ADVOCACY: CONGRESSIONAL STAFF

Adeola Adesina, Congressman Eric Swalwell (CA-15)

Adeola is the Health Policy Advisor for Congressman Eric Swalwell (CA-15). In addition to health policy, she handles energy and environment, social security, banking, and trade for the congressman. During her time in this role, she authored language for children under Medicaid to have access to genetic testing and successfully launched the Personalized Medicine Caucus on Capitol Hill. She serves on the Congressional Black Associates' professional development com-mittee as the health care policy liaison. Before serving for Rep. Swalwell, she was a Legislative Correspondent for Democratic Leader Charles E. Schumer working on health and agriculture policy. She is originally from Arlington, Texas, earning her BS in communications and journalism from Texas A&M University and is currently pursuing a master's degree at Georgetown University in public relations and corporate com-munications. Her goal is to pivot into crisis communications in the health care sector.

Crozer Connor, Congressman Mike Thompson (D-CA)

Crozer is the senior Legislative Assistant for Congressman Mike Thompson (D-CA), handling tax, economic and health care policy. In that capacity, Crozer has overseen the process of crafting the CONNECT Act 2.0 and additional telehealth legislation for the 116th Congress. He has worked to advance substantial green energy and disaster related tax legislation and collaborated with constituents to advance funding for medical research, including neurofibromatosis. Crozer has worked for Representative Thompson since graduating from Colgate University in 2015.

James "J.P." Paluskiewicz, House Energy and Commerce Committee

James serves as Republican Chief Counsel for the House Committee on Energy and Commerce's Subcommittee on Health. In that role, he oversees all policy under the Subcommittee's jurisdiction, helps coordinate Committee activity, and leads bipartisan, bicameral negotiations. A regular on political, advocacy, and health policy panels, J.P. also frequently guest lectures on health policy and health advocacy at Washington, D.C.'s top universities and is an adjunct professor of graduate courses at George Washington University. J.P. has developed numerous policies through the legislative process, including the permanent repeal and replace of both Medicare's Sustainable Growth Rate formula and its outpatient therapy caps. He also worked extensively on the 21st Century Cures initiative. J.P. attended American University where he graduated with a double major in Political Science and Law and Society in 2001. In 2005, he earned his Master's in Legislative Affairs from George Washington University.

Stuart Portman, Senate Committee on Finance

Stuart Portman serves as Health Policy Advisor for the majority staff of the U.S. Senate Committee on Finance for Senator Chuck Grassley. In this capacity, he handles all policies related to Medicaid and CHIP, as well as issues related to the ACA Exchanges, health taxes, and health information technology. Previously, he served as the Senior Healthcare Legislative Assistant and Legislative Correspondent for Senator Orrin G. Hatch, where he focused on Medicaid, FDA-related issues, and issues affecting individuals with disabilities. Stuart received his Master of Public Health degree specializing in health policy from the Milken Institute School of Public Health at The George Washington University and his Bachelor's in Biology and Political Science from the University of Denver.

Caitlin Van Sant, Congressman G. K. Butterfield (D-NC-01)

Caitlin is a Senior Policy Advisor for Congressman G. K. Butterfield (D-NC-01). In this role, Caitlin advances the Congressman's health care, education, and labor priorities, with a focus on childhood cancer and rare diseases. Prior to joining the office of Congressman Butterfield in June 2019, Caitlin was a manager of federal affairs at the Children's Hospital Association, where she advocated on behalf of 220 children's hospitals across the country on Medicaid and CHIP policy. Caitlin also worked for the American Academy of Pediatrics as a federal lobbyist and the Biotechnology Innovation Organization, working on state policy. Caitlin graduated cum laude from George Mason University School of Law and was a notes editor for the George Mason Law Review. She holds a B.A. in International Affairs and a B.B.A. in International Business from James Madison University. Caitlin is licensed to practice law in the Commonwealth of Virginia.

FEDERAL ADVOCACY: PATIENT ADVOCATE/ORGANIZATION

Kevin Koser

Kevin Koser is one of two Co-Chairs of the National Foundation for Ectodermal Dysplasias (NFED) Family-Driven Advocacy Committee and serves as the Virginia State Lead for Advocacy. In these volunteer positions, Kevin is responsible for building grassroots, organizational, state, and federal support for solutions to issues that families face when trying to get health claims approved by insurance for medically necessary treatments of ectodermal dysplasia and other congenital anomalies. Kevin lives in Crozet, Virginia—a growing community west of Charlottesville in the foothills of the Blue Ridge Mountains—with his wife of seven-years, Rachel, and their two sons, Kannon (5-yrs) and Kage (1-yr). Kevin is an avid fan of his alma mater, the University of Virginia, especially its basketball, lacrosse, and football programs. He enjoys running, supporting the many local breweries, vineyards, and distilleries, and spending time with his family.

Lymphedema Advocacy Group

The Lymphedema Advocacy Group is an all-volunteer organization working to improve insurance coverage for the medical compression supplies that are the cornerstone of treatment for this chronic disease. Group members have succeeded in passing private insurance mandates in several states, but their primary goal is passage of the federal Lymphedema Treatment Act (H.R.1948/S.518). In addition to their general membership, the Lymphedema Advocacy Group has advocacy teams in all 50 states, whose members work closely with their Advocacy Training Committee. Empowering grassroots advocates by teaching patients how to find and use their voice and hone their message is at the core of the group's mission. When the fledgling Lymphedema Advocacy Group made their first trip to Capitol Hill in 2010 hardly any staff member had heard of lymphedema. Today, every health staffer knows what lymphedema is and the Lymphedema Treatment Act is the most supported healthcare bill in Congress.

#rarevoiceawards2020

Lymphatic Education and Research Network

LE&RN was founded in 1998 as the Lymphatic Research Foundation (LRF) when Founder Wendy Chaite's daughter, Melanie Rose Chaite, was born with a rare lymphatic disease and lymphedema. In 2002, LRF secured Congressional and NIH support for lymphatic research. In 2013, LRF became LE&RN with an expanded mission. In 2014, Academy Award-winning actress Kathy Bates, who lives with lymphedema, became LE&RN's spokesperson. In 2016, through LE&RN's advocacy, the US Senate and the NY State legislature recognized March 6 as World Lymphedema Day. In 2020, LE&RN accomplished a long-sought goal of establishing worldwide Centers of Excellence in the Diagnosis and Treatment of Lymphatic Diseases, and pursued an ambitious legislative agenda that included seeking the establishment of a National Lymphatic Commission at the NIH and attempting to secure lymphatic disease research funding through the DoD. Melanie Rose Chaite, who had been the inspiration for LE&RN, died at the age of 26 on February 12, 2020.

Amy Oliver

Amy J. Oliver, J.D. is the President and Founder of the Intermountain PKU and Allied Disorders Association, a non-profit patient organization based in Salt Lake City, Utah, and is the current President of the National PKU Alliance (NPKUA). Amy has been involved with the NPKUA since its founding, serving on the Board of Directors and as chair of the NPKUA Advocacy Committee. In 2018, she became one of the founding Charity Trustees for the Global Association for PKU, the first international PKU patient organization. Amy serves as a member of the Utah Newborn Screening Advisory Committeeand the Utah Newborn Screening Research Review Panel. She is also a member of the Association of Public Health Laboratories Newborn Screening Parent Consortium. Amy is a practicing attorney and the mother of three children, two of whom have PKU.

Sheryl Grossman

Sheryl has spent the last 24 years working to improve the quality of life for people with disabilities with a focusing over the last decade on multiple minority group issues and the unique needs of those with rare and pre-existing conditions. In addition to her paid work, Sheryl also founded an international support group for people with Bloom Syndrome, Bloom's Connect, in 1996 and continues to facilitate the group today. In her spare time, Sheryl has served as the Board Chair for Yad HaChazakah, the Jewish Disability Empowerment Center, for the last 2 years.

2019 RareVoice Award Recipients

Representative Sharon Cooper

Born in Houston, Texas, Sharon is proud to have called Georgia home for over 39 years and was married to the late Dr. Tom Cooper for more than 33 years. She was first elected in 1996 as a State Representative. In 2002, she was elected Caucus Chairman by her Republican colleagues — making her the highest ranking woman in the House at that time. Currently, Rep. Cooper chairs the Health and Human Services committee, one of the busiest committees in the House. She is also a member of the Rules, Judiciary Non-Civil and Regulated Industries committees. Rep. Cooper holds several degrees, including a B.S. in Child Development, a M.A. in Education and MSN in Nursing. Sharon 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.

Representative Jon Echols

Jon Echols is a fourth generation Oklahoman who's spent his whole life in Oklahoma City, where he is married to his childhood sweetheart, and now they are raising their three children. Jon is a local small business owner. His companies focus on healthcare. Jon understands what it takes to run a business and create jobs in our economy. Jon serves on the Board of Directors for the City Rescue Mission. He's proud of their work and the help they give to people in our community who need it the most. He's also the Co-Founder of Shelter Oklahoma Schools, a charity that has raised over $2.5 million to build storm shelters. Jon's peers quickly recognized his heart for service and strong legislative abilities. After just four years in office, Jon was named Majority Floor leader. He directs the flow of legislation, from committee assignments to bill presentations on the floor.

Delegate Kathleen Murphy

Virginia State Delegate Kathleen Murphy represents the Commonwealth's 34th District, located in Fairfax and Loudoun Counties. She is a member of the following House committees: General Laws, Finance, Transportation (Vice Chair), and Counties, Cities and Towns. Delegate Murphy is especially proud to have founded the Rare Disease Caucus in the Virginia General Assembly and, after several years of work, to have passed House Bill 840, which ensures that life-saving formulas and enteral nutrition products are covered by health insurance. She became a champion of this issue after learning that PKU affects the granddaughter of her close friend and because one of her own children has struggled with Cystic Fibrosis. Delegate Murphy is also a member of the General Assembly's Women's Health Care Caucus and serves on the fundraising board for the Cystic Fibrosis Foundation. She has four children and lives with her husband in McLean, Virginia.

Representative Wayne Sasser

Wayne Sasser graduated from Pharmacy School at UNC Chapel Hill in 1973 and has been a pharmacist for 45 years, owning independent pharmacies for the last 35 years. Five years ago, he started working with various organizations fighting the opioid crisis. His work with Senator Tom McInnis led to the passage of the "Stop Act," which reduces the number of opioid prescriptions that are written by prescribers. Three years ago, he sold his drug stores and is now a member of the North Carolina House of Representatives. He is a member of the Health Committee, as the only pharmacist in the 180-member legislature. He has worked to get Step Therapy and the Pharmacy Benefit Management bills passed. Presently, he is working to pass Prior Authorization and Pharmacist Collaborative Practice bills.

STATE ADVOCACY: PATIENT ADVOCATE

Denis Borel

Dennis is frequently called on for research, policy analysis and recommendations to the Texas Legislature and serves on multiple advisory groups to state health and human services agencies. He has successfully advocated for positive change in employment, transportation, housing, health care and architectural barriers to promote the full inclusion of people with disabilities in community life. He was Project Director for CTD's history-making Team Everest expedition, an internationally-recognized expedition by a team of people with diverse disabilities to the world's tallest mountain.In 2006, the University of Michigan honored Dennis with the national James Neubacher Award for creating opportunities for people with disabilities. In 2009, he received the National Advocacy Award from the National Council on Independent Living and in 2019, he was accorded the national Health Equity Award from DentaQuest. He is a former high school teacher and served as a Peace Corps volunteer in Morocco.

Tara Britt

Tara is the President and Founder of Rare Disease Innovations Institute (RDII). RDII is a global non-profit focused on educating, engaging and equipping the rare disease community to achieve a higher quality of life, accelerating diagnosis and enabling access and treatment. Through this non-profit and her rare disease network, RDII has developed exclusive toolkits for other states to build upon the learning and success of North Carolina enabling creation of successful councils and unique rare disease networks. RDII also partners with rare disease advocacy groups, state and federal government, industry and more to build disease specific models to support targeted disease populations. Tara also currently serves as Associate Chair of the North Carolina Rare Disease Advisory Council and Network. The council was created as a result of co-authoring legislation with a North Carolina patient advocate to create a Rare Disease Advisory Council signed into law, August 2015.

Jana Monaco

Two of Jana's four children have a rare inborn error of metabolism called Isovaleric Acidemia. Stephen, now 22, suffered severe brain damage at age 3 ½ due to lack of comprehensive newborn screening at birth. Caroline, now 18, was screened early sparing her of Stephen's fate. Jana has helped to expand newborn screening in all 50 states as a former member of the Secretary's Advisory Committee for Heritable Disorders in Newborns and Children. She serves on the Virginia Genetics-Advisory Council, as the Rare Action Network State Ambassador for NORD and the Advocacy Liaison for the Organic Acidemia Association. She is a member of the Patient/Family Advisory Council, and the External Advisory Committee of the Clinical and Translational Science Institute at Children's National. Jana has presented on newborn screening and rare diseases and included in the media and publications.

Tonya Prince

Tonya Prince is a strong leader in the Sickle Cell disease community, advocating for those affected, including her daughter. Tonya's advocacy in the state of Texas has resulted in the establishment of a task force for Sickle Cell diseases, which she still serves on, as well as many other bills that raise awareness and money for organizations that provide services to the Sickle Cell community. Aside from her advocacy work in Texas, Tonya serves on the Rare Disease Legislative Advocates Advisory Committee and the National Small Business Leadership Council. She credits her involvement in the Sickle Cell community to her daughter, because she wanted her family to work toward change for the Sickle Cell disease for their city of Houston after her diagnosis.

Caroline Arnette

Caroline is a rare disease advocate who has Narcolepsy with Cataplexy, a neurological sleep disorder. Her brain doesn't properly regulate the sleep-wake cycle, leading to chronic sleep deprivation, depression, terrible nightmares, and temporary paralysis from strong emotions. With treatment, she's thriving. She is dedicated to raising awareness about symptoms to help others get diagnosed. Caroline is the Lead Youth Ambassador at Narcolepsy Network and speaks at conferences, and to doctors, teachers, and legislators about Narcolepsy and rare diseases. Attending Rare Disease Week changed her life. She joined YARR and became passionate about advocating for other rare diseases. She is grateful to the advocates who made the Orphan Drug Act of 1983 and wants to continue their fight. She is a freshman in American University's Honors Program, where she majors in public health/biology. She plans to dedicate the rest of her life to research and advocacy in the rare disease community.

Zachary Berger

Zachary Berger is 16 years old from Conroe, Texas. He is a junior at The Woodlands College Park High School. He serves on the Community Service Committee of Student Council and does statistics for varsity baseball. Zachary suffers from lymphatic malformation, a rare disease consisting of non-malignant masses of fluid-filled channels or spaces thought to be caused by the abnormal development of the lymphatic system. At the age of 11, Zachary became the Texas Youth Ambassador for the Lymphatic Education & Research Network (LE&RN) and has raised thousands of dollars for the organization and spent hundreds of hours advocating for awareness of lymphatic malformation. Zachary loves math and baseball and hopes to study sports management, journalism and statistics in college to pursue a job in Major League Baseball. Zachary's family includes 11-year-old sister, Sadie and mom and dad, Holly and Marc, and labradoodle Bailey.

Grant Bonebrake

At age 11, Grant was diagnosed with a rare, genetic kidney disease, Alport syndrome, which causes renal failure, hearing loss, and vision problems. As a patient advocate for both Alport Syndrome Foundation and the National Kidney Foundation, Grant has annually advocated on Capitol Hill for legislation to support kidney disease patients for the past five years. He has also served as a featured speaker for an NKF dinner for patient advocates and participated in a Patient Focused Drug Development Meeting with the FDA. He has spoken to pediatric nephrologists and medical students at Cleveland Clinic to share insights as a young adult living with chronic kidney disease and attended Rare Disease Week 2020 as a patient advocate. Grant, now age 18, is a member of EveryLife Foundation's Young Adult Representatives of RDLA. He is hoping to pursue a degree in political science, with an emphasis on public health.

Esha and Arya Cyril

Esha and Arya are high shcool juniors and passionate rare disease youth advocates from Pleasanton, CA. The twins play racquetball for Team USA. A few years ago, they started volunteering at a free health advisory clinic at a local community center for patients with no health insurance. Since then, they have been extremely passionate about health policy. Motivated by family experiences with liver-related diseases both the sisters advocate for JoinJade based at the Asian Liver Center at Stanford University for hepatitis and liver related diseases. Esha is currently doing research on using AI to facilitate Alzheimer's Disease diagnosis where she hopes to help both the research and AD community. Arya is currently doing research on Autoimmune disease and involved in developing a low cost diagnostic kit for Lupus. Both the girls continue to find ways to support the rare disease community in any way they can and use their voice to make change. The twins feel that supporting the rare disease community and hearing their powerful narratives is a step forward.

TEEN ADVOCACY

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, hyper mobility, Duane syndrome, and other diseases. Today, Britney makes it her passion to advocate for herself and others suffering from rare diseases.

ARTIST-TO-ADVOCATE

Dona Krystosek

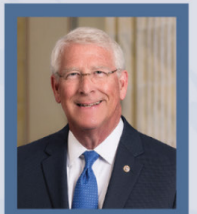
Dona lives her life embracing two guiding principles: Helping is Healing and GO Live Life! A resident of Ocean Springs, Mississippi, Dona served active duty in the US Air Force for six years. Later, she worked as a registered nurse for nearly ten years. In 2006, Dona's son Levi was born with an ultra-rare form of degenerative dwarfism called Jansen's Metaphyseal Chondrodysplasia. At that time, Levi was one of only 17 known cases in the world. Dona made the decision to stay at home and care for him. Over the last 14 years, she has become widely known as a passionate advocate for her son and others in the rare disease community. Dona was an awardee in the 2019 Rare Artist Contest. Her winning submission "Rare Reflection," prominently features Levi. Dona enjoys photography, vlogging with her son on his Facebook page, @littleLevi, and spending time helping others.

RARE DISEASE CONGRESSIONAL CAUCUS

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

Representative
G.K. Butterfield (NC)

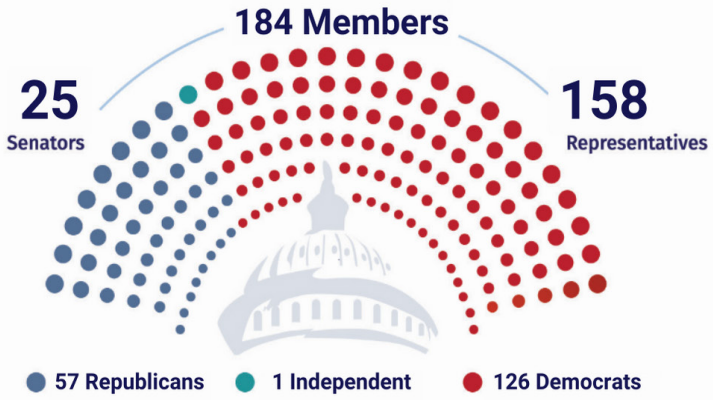
Representative
Gus Bilirakis (FL)



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.

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CONGRESSIONAL LEADERSHIP

The Honorable Jaime Herrera Beutler (WA)

Representative Beutler grew up in Southwest Washington and brings an independent voice and a desire to serve her home community to Washington, D.C. She has represented Washington's 3rd District in Congress since 2010. Ms. Herrera Beutler co-founded the bipartisan Maternity Care Caucus, the first of its kind in Congress, and has been a champion for maternal and child health. Most notably, Representative Beutler successfully spearheaded legislation that was signed into law to address maternal mortality, the largest step Congress has taken to prevent moms from dying during pregnancy, childbirth and postpartum. When her bipartisan ACE Kids Act became law, it allowed more than 300,000 children with complex medical conditions to access life-saving treatment – regardless of their family's income or their zip codes. And thanks to her leadership and advocacy through the caucus, the Food and Drug Administration made a critical change to help prevent fatal birth defects in Hispanic communities. Jaime, her husband Daniel Beutler, and their children Abigail, Ethan and Isana, reside in Battle Ground, WA.

The Honorable Tammy Baldwin (WI)

Senator Baldwin was born in Madison, Wisconsin and raised by her grandparents in the Badger State. In 1998, Wisconsin's 2nd Congressional District elected Baldwin as the state's first female member of Congress, and the nation's first openly lesbian challenger sent to Congress. After serving 14 years in the House of Representatives, Senator Baldwin was elected to the Senate in 2012, shattering the state's glass ceiling again as Wisconsin's first woman to serve in the Senate, and the first openly gay member elected. In 2018, Baldwin was reelected to the Senate with an 11-point victory. She serves on the Senate Appropriations Committee, the Senate Committee on Health, Education, Labor and Pensions, and the Senate Committee on Commerce, Science, and Transportation. In the Senate, Baldwin worked to ensure health insurance coverage for needed treatment and procedures for individuals born with congenital anomalies or birth defects. She introduced the Ensuring Lasting Smiles Act to close a coverage gap and ensure that health plans cover medically necessary services related to a patient's anomaly or birth defect, including any serious dental and oral-related procedures that are necessary to maintaining health and overall function.

CONGRATULATIONS TO ALL RARE DISEASE PATIENT ADVOCATES NOMINATED THIS YEAR

- Katie Campbell
- Marie Dagenais-Lewis
- Winslow Dixon
- Lauren Foster
- Julie Gortze
- Larry Gossard
- Keisha Greaves
- Jasmine Hightower
- Cami Lepire
- Alexia Mays
- Mary Nadon Scott
- Tara Notrica
- Corey Polen
- Dana Richter
- Kendall Strong
- Katie Wallace
- Katie Wright

THANK YOU TO THE RAREVOICE NOMINATIONS COMMITTEE

Jennifer Bernstein, Horizon Government Affairs

David Eckstein, Office of Clinical Research, NIH

Sarah-Lloyd Stevenson, Faegre Drinker

Lisa Schill, RASopathies Network

Kathleen Tighe, Sanofi Genzyme

Shayne Woods, Office of Rep. Bilirakis

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Emma and Signe, Fabry disease, Denmark

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

Sanofi Genzyme is grateful to advocates who give rare disease patients a voice. Congratulations, EveryLife Foundation for Rare Diseases, on the 9th Annual RareVoice Awards!

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