RDDC™

RARE DISEASE DIVERSITY COALITION

Driving Inclusion, Advocacy, Policy, and Community Power in Rare Disease at the 2025 NMQF Leadership Summit

Tuesday, April 29, 2025
Conrad Hotel
Washington, DC

Driving Inclusion, Advocacy, Policy, and Community Power in Rare Disease at the 2025 NMQF Leadership Summit

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RARE DISEASE DIVERSITY COALITION

A heartfelt thank you to the **National Minority Quality Forum (NMQF)** for the opportunity to host a Rare Disease Track at your annual Leadership Summit on Health Disparities and Spring Health Braintrust.

Your visionary leadership and generosity remain a guiding light for diverse and historically underserved communities. The Rare Disease Track provided a vital platform to elevate the voices of those navigating the complexities of rare diseases within these communities. We are truly grateful for the opportunity to spotlight their needs, concerns, and lived experiences.

We are deeply grateful for your partnership and your unwavering commitment to health equity. Thank you for all that you do to lead, inspire, and elevate voices in this vital space.

— The Rare Disease Diversity Coalition (RDDC)

The **Rare Disease Diversity Coalition (RDDC)** is an initiative launched by the Black Women's Health Imperative (BWHI) to address the extraordinary challenges faced by historically underrepresented populations with rare disease. RDDC brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to reduce racial disparities in the rare disease community. You can find more information about RDDC at rarediseasediversity.org.

BWHI is a national non-profit organization dedicated to advancing health equity and social justice for Black women, across the lifespan, through policy, advocacy, education, research, and leadership development. The organization identifies the most pressing health issues that affect the nation's 22 million Black women and girls and invests in the best of the best strategies and organizations that accomplish its goals. You can find more information about BWHI at bwhi.org.

Driving Inclusion, Advocacy, Policy, and Community Power in Rare Disease at the 2025 NMQF Leadership Summit

Tuesday, April 29, 2025 | 9:45 AM - 3:00 PM
Conrad Hotel - Room: Conservatory B, Level 2

9:45 AM – 10:00 AM Welcome and Remarks

Gary A. Puckrein, PhD
President and CEO, National Minority Quality Forum

Jenifer Waldrop, MS
Executive Director, Rare Disease Diversity Coalition
Black Women's Health Imperative

10:00 AM – 11:00 AM Rare Disease Diversity in Clinical Trials

Anchored in RDDC's mission to eliminate health disparities across the rare disease continuum, this panel calls for bold, coordinated action to reshape the clinical research ecosystem to serve all communities. Panelists will share insights into how underrepresentation impacts trust and trial design, and they will spotlight strategies being advanced to close these gaps. In addition, the session aims to explore the current landscape of diversity in rare disease clinical trials—where we are, what's missing, and what's needed to drive more equitable participation.

Explore key topics such as:

- Recent advancements in rare disease research
- Clinical trials as a care option
- Increasing clinical trial participation among people with disabilities
- Collaborative efforts to address remaining inequities in rare disease research

MODERATOR:

Jenifer Waldrop, MS, Executive Director - RDDC at BWHI

PANELISTS:

LaVarne Burton, President & CEO - American Kidney Fund

Jamie Freedman, MD, PhD, Chief Medical Officer - Sobi

Dr. Harsha Rajasimha, Founder & CEO - Jeeva Clinical Trials, Inc.

Dr. Marshall Summar, CEO - Uncommon Cures

11:00 AM – 12:00 PM **Advancing Health Equity: Rare Disease Patient Advocacy Groups Charting the Course**

Rare disease advocacy groups are at the forefront of driving diversity, equity, and inclusion (DEI) within healthcare. This panel will feature representatives from leading advocacy groups who will share the initiatives they have undertaken to address health disparities, promote equity, and foster DEI within the rare disease space. Attendees will learn about successful models for improving patient outcomes and strategies for embedding DEI principles into the work of rare disease organizations.

Explore key topics such as:

- Community-driven initiatives addressing health disparities, promoting equity, and fostering DEI within the rare disease space
- Models for improving patient outcomes and strategies for integrating DEI principles into the work of rare disease organizations
- Current and future challenges in building more inclusive rare disease communities

MODERATOR:

Pam Rattananont, MPH, Senior Patient Advocacy Consultant - Links2Equity

PANELISTS:

Paula Eichenbrenner, Executive Director - The Myositis Association

Mary McGowan, CEO - Foundation for Sarcoidosis Research

Deborah Requesens, Co-Founder & President - Hispanic Society for Rare Diseases

Nicole Rochester, MD, Health Equity Medical Advisor - Immune Deficiency Foundation (IDF)

Dionne Stalling, Founder & Executive Director - Rare and Black

12:00 PM – 1:00 PM **Congressional Awards Luncheon**

1:00 PM – 2:00 PM	**Shaping Policy for Accessibility: Healthcare Policies Impacting Rare Disease Communities**

Legislative and policy initiatives are critical to addressing health disparities in rare diseases, particularly for historically marginalized populations. This panel will bring together policymakers, advocates, and experts to discuss current and emerging rare disease and healthcare policy initiatives that impact diverse communities. Panelists will examine how policies can advance health equity and what steps are needed to ensure that diverse populations have equitable access to diagnosis, care, and treatment for rare diseases.

Explore key topics such as:

- Current policy landscape for access to care, screening, and diagnosis, including Medicaid reconciliation
- Policy priorities for the rare disease community
- Call to action: 2025 and beyond

MODERATOR:

Dr. Larry Bucshon, Senior Policy Advisor - Holland & Knight

PANELISTS:

Sky Collins, Co-Founder - Oklahoma Rare

Victoria Gemme, Director, Policy & Regulatory Affairs - NORD

Dr. Maggie Kang, Life and Healthcare Coach

Annie Kennedy, Chief of Policy, Advocacy & Patient Engagement - EveryLife Foundation for Rare Diseases

Chris Porter, Vice President of Government Affairs & Policy - Travere Therapeutics

2:00 PM – 3:00 PM	**The Power of Community: Engaging Gatekeepers for Rare Disease Advocacy**

This panel will explore the vital role that community gatekeepers and leaders play in connecting rare disease advocacy efforts to local populations. Panelists will discuss strategies for building relationships with trusted figures in diverse communities and how rare disease organizations can better engage at the grassroots level to increase awareness, education, and access. Attendees will gain insights into mobilizing support for rare disease patients through meaningful community-centered partnerships.

Explore key topics such as:

- The vital role that community gatekeepers and leaders play in connecting rare disease advocacy efforts to local populations
- Strategies for building relationships with trusted figures in diverse communities and how rare disease organizations can better engage at the grassroots level to increase awareness, education, and access
- Mobilizing support for rare disease patients through meaningful, community-centered partnerships

MODERATOR:

Deanna Darlington, President - Links2Equity

PANELISTS:

Oya Gilbert, Founder & CEO - Health, Hope & Hip-Hop Foundation

George Kerr III, Elder - Westminster Presbyterian Church DC

Rob Long, Executive Director - Uplifting Athletes

Tiffany Scott, Co-Founder & President - Maryland Community Health Workers Association

Stephen Thomas, Professor of Health Policy & Management, Director of Maryland Center for Health Equity - University of Maryland

3:00 PM	**Closing Remarks – Jenifer Waldrop, MS**

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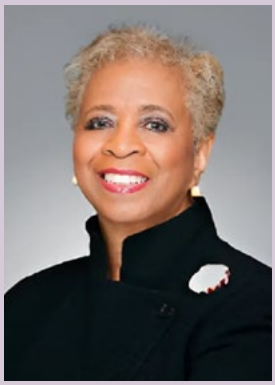
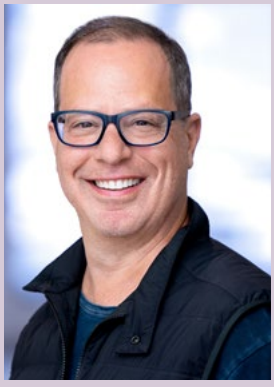
RDDC Rare Disease Panels at the 2025 NMQF Leadership Summit

RARE DISEASE DIVERSITY IN CLINICAL TRIALS

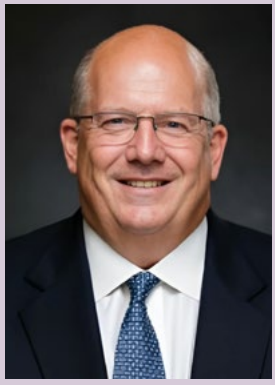


LaVarne Burton
American Kidney Fund



Jamie Freedman MD, PhD
Sobi

Dr. Harsha Rajasimha
Jeeva Clinical Trials, Inc



Dr. Marshall Summar
Uncommon Cures

Moderated By
Jenifer Waldrop, MS
Executive Director
RDDC

APRIL 29, 2025
10:00AM-11:00AM

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WASHINGTON, DC

MODERATOR

Jenifer Waldrop, MS
Executive Director
Rare Disease Diversity Coalition (RDDC)

Jenifer Ngo Waldrop, the Executive Director of the Rare Disease Diversity Coalition (RDDC), joined the coalition in October 2022. Before leading RDDC, she developed models and programs for diversity, equity, and inclusion initiatives to support multiple business units with Fortune 500 companies and organizations in Asia, Canada, and the US.

Jenifer has led initiatives at non-profit organizations where she recruited local community members to participate in numerous health-related fundraising events and developed programs to target disparities and underrepresented groups. In addition to facilitating development and fundraising, Jenifer developed a reputation for successful coalition building.

Jenifer received her undergraduate degree from Colby College and her Master of Human Resources Development from Villanova University. As the Professional Development Director of the National Association of Asian-American Professionals (NAAAP) of Colorado, Jenifer continues her outreach in society. Through this organization, she mentors formally and informally.

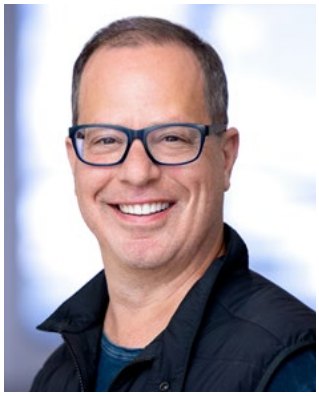
LaVarne Addison Burton
President and Chief Executive Officer
American Kidney Fund (AKF)

LaVarne Addison Burton is President and Chief Executive Officer of the American Kidney Fund (AKF), a national nonprofit organization whose mission is to fight kidney disease and help people live healthier lives. Led by Ms. Burton since 2005, AKF works on behalf of the 1 in 7 Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease, the fastest growing non-contagious disease in the country. With programs that address early detection, disease management, financial assistance, clinical research, innovation, and advocacy, no kidney organization directly impacts more lives than AKF.

Before joining AKF, Ms. Burton was a senior partner at Martin & Associates, a consulting firm for the healthcare industry, and to major health information management and technology companies. Previously, she served as President of the Pharmaceutical Care Management Association (PCMA), the national trade association representing pharmacy benefit managers. During her tenure, Ms. Burton collaborated with congressional committees to develop Medicare Part D, the prescription drug benefit modeled after the pharmacy benefit management (PBM) pioneered by PCMA member companies.

Ms. Burton served as Executive Secretary to the US Department of Health and Human Services, where she managed policy development and regulations and was advisor to the Secretary. She has served twice as Chair of the National Health Council Board of Directors. She is Chair-Elect of Kidney Care Partners, the nation's leading kidney care multi-stakeholder coalition representing patient advocates, physician organizations, health professional groups, dialysis providers, researchers, and manufacturers.

Ms. Burton was born in Augusta, GA and attended public schools there. She received her Bachelor of Arts degree from Howard University and Master of Arts from George Washington University, both in Washington, D.C.



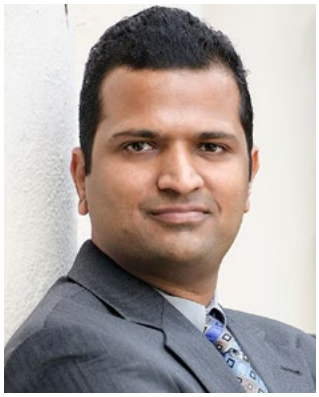
Jamie Freedman, MD, PhD
Chief Medical Officer
Sobi North America

Dr. Jamie Freedman is the North America Chief Medical Officer for Sobi. He provides strategic and operational leadership across key functions, including medical affairs, medical communications, and pharmacovigilance.

Prior to joining Sobi, Dr. Freedman worked at Genentech as Head of US Medical Affairs. Earlier, he had a distinguished career at AstraZeneca, where he held multiple leadership roles in Research & Development, Commercial, and Medical Affairs, including as President of AstraZeneca Canada, Executive Vice President of Oncology, and Head of Clinical Development at MedImmune. He also held senior leadership positions in Oncology R&D at GlaxoSmithKline and Merck, served as CEO and CMO at Locus Pharmaceuticals, and was head of R&D at OPKO Health.

Dr. Freedman is board certified in Internal Medicine, Hematology, and Medical Oncology. He has authored over 20 peer-reviewed papers and holds three patents. He is a co-founder of BAMCO Africa, providing reimbursable drug access in Sub-Saharan Africa, and holds an adjunct faculty position at the University of California San Francisco (UCSF), where he treats patients with hematological malignancies and solid tumors.

Dr. Freedman earned his Bachelor of Science in Biochemistry from McGill University and both his MD and PhD from Tufts University. He completed his residency in Internal Medicine at UCSF and subspecialty fellowship training in both Hematology and Oncology at Harvard.

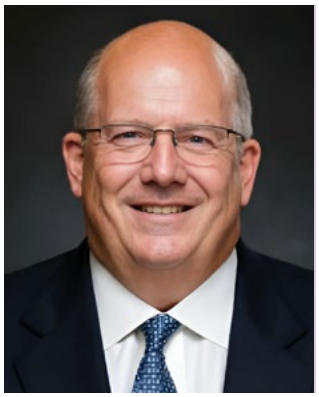


Dr. Harsha Rajasimhja
Founder and CEO
Jeeva Clinical Trials, Inc.

As the co-founding former board co-chair of the national umbrella organization for rare diseases in India, Dr. Harsha Rajasimha led the advocacy efforts resulting in the adoption of the National Policy for Rare Diseases (NPRD) in India in 2017 and later in 2021. The policy for the first time ever set aside a budget and established 11 centers of excellence for rare diseases across India for diagnosing, treating, and providing financial support for patients affected by officially recognized rare diseases.

Indian diaspora accounts for 15% of the world's population, yet only 1.2% of all clinical trials have included Indian participants to date. To address this massive inequity, Dr. Rajasimha founded the Indo-US Organization for Rare Diseases (IndoUSrare) in 2019 by bringing fierce advocates together. In 2024, the organization's advocacy with the Indian embassy in Washington, DC and to the ministry of health and family welfare in India, and to the US Congress and Senate, resulted in the drug controller general of India and CDSCO issuing a circular that US FDA-approved orphan drugs may apply for a waiver of additional clinical trials in India for marketing approvals.

IndoUSrare brings together policymakers, orphan drug developers, diagnostics companies, patient advocates, and clinical researchers at the annual Indo US Bridging RARE Summit. It also instituted and awarded Abbey Meyers Kushi Bridging RARE Awards to individuals who contributed toward bringing US and India closer together with collaborations for rare disease research, cross-border clinical trials, and data sharing. These awards and honorees continue to inspire the next generation of patient advocates and leaders.



Dr. Marshall Summar
Chief Executive Officer
Uncommon Cures, LLC

Dr. Marshall Summar is well known for his pioneering work in caring for children diagnosed with rare diseases. He is now the Chief Executive Officer of Uncommon Cures, LLC, a rare disease clinical trials company focused on physically consolidating trials and using innovative technology to reduce time and cost. From 2010 to 2022 at Children's National, he led the Division of Genetics and Metabolism and founded the Rare Disease Institute, the first dedicated home for the clinical care of patients with genetic rare diseases, and The National Organization for Rare Disorders, the first designated Rare Disease Clinical Center of Excellence. After 12 years at the helm, he stepped down in 2022 to run Uncommon Cures and work to improve the development of new therapies in the rare disease field.

Dr. Summar served as Chair of the Board of Directors of the National Organization for Rare Disorders and is the past president of the Society for Inherited Metabolic Disorders.

At the National Organization for Rare Disorders (NORD), he was part of the effort that created digital registries for families and the NORD Clinical Centers of Excellence program. In 2022, Dr. Summar was awarded NORD's Lifetime Achievement Award.

Dr. Summar's research work involved basic discovery and development of devices, diagnostics, and treatments for patients with genetic rare conditions and adapting knowledge from rare diseases to mainstream medicine. This work has led to over 170 peer-reviewed publications. His work has resulted in new drugs in FDA clinical trials for patients with sickle cell anemia, congenital heart disease, and premature birth. He has over 120 international patents. His laboratory is best known for its work in the rare diseases affecting nitrogen, ammonia, and amino acid metabolism centering on the urea cycle. Dr. Summar has also organized and led a number of international work groups to develop and publish standards of care and treatment for rare diseases. With Dr. Debra Regier and Dr. Paul Harris, he is currently leading a funded project to develop a new software platform for developing and housing practical clinical protocols for rare diseases called RareCap. He has built remote/telemedicine programs to reach patients currently without genetic care access.

Dr. Summar is board certified in Pediatrics, Clinical Genetics, and Biochemical Genetics.

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ADVANCING HEALTH EQUITY:

RARE DISEASE PATIENT ADVOCACY GROUPS CHARTING THE COURSE

Paula Eichenbrenner
The Myositis Association

Mary McGowan
Foundation for Sarcoidosis Research

Debbie Requesens
Hispanic Society for Rare Diseases

Nicole Rochester, MD
Immune Deficiency Foundation

Dionne Stalling
Rare and Black

Moderated By
Pam Rattananont, MPH
Senior Patient Advocacy Consultant
Links2Equity

APRIL 29, 2025
11:00AM - 12:00PM

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WASHINGTON, DC

MODERATOR

Pam Rattananont, MPH
Senior Patient Advocacy
Consultant
Links2Equity

Pam Rattananont is a lifelong patient advocate dedicated to breaking down barriers to care and improving care coordination. With a strong focus on mental and emotional well-being, she champions support services and education for both patients and healthcare professionals.

Ms. Rattananont collaborates closely with industry leaders, patient advocates, clinicians, policymakers, and researchers to shorten the diagnostic odyssey, accelerate clinical research, and enhance healthcare accessibility. Her expertise spans executive leadership roles in rare disease advocacy at Global Genes and healthcare communications organizations, as well as key positions in biotech and pharmaceutical companies across medical affairs, marketing, and patient advocacy. She also serves on the Boards of Directors for several patient advocacy organizations, including the Patient Empowerment Network, Uplifting Athletes, and Raregivers.

Ms. Rattananont holds a Bachelor's degree in Neuroscience from Colgate University and a Master of Public Health from Columbia University.

Paula Eichenbrenner
Executive Director
The Myositis Association (TMA)

Paula Eichenbrenner became Executive Director of TMA Precision Health in December 2023. Her prior leadership roles include Executive Director of the Academy of Managed Care Pharmacy Foundation and the American Society for Nutrition Foundation (ASNF) . Ms. Eichenbrenner is a Certified Association Executive (CAE) with fundraising and public affairs experience in diverse non-profit settings. She is also the Immediate Past President of the Association Foundation Group (AFG).

Ms. Eichenbrenner's passion for patient advocacy was developed through her role as care partner for her brother, who has a complex mental and behavioral health diagnosis. She volunteers for community organizations focused on veterans, behavioral health, and housing-first interventions to address homelessness. She is an avid reader and can often be found walking with her fiancé Lain and rescue poodle Leo.

Mary McGowan
Chief Executive Officer
Foundation for Sarcoidosis Research (FSR)

Mary McGowan joined the Foundation for Sarcoidosis Research (FSR) as the organization's first-ever Chief Executive Officer in 2020. As CEO, Ms. McGowan serves as the primary representative and spokesperson for FSR and leads the organization's strategic vision with patient engagement, strategic partnerships, fundraising, advocacy efforts, program direction, and an aggressive communications and research agenda.

Ms. McGowan brings 35 years of nonprofit leadership and management experience to the role of CEO. Prior to joining FSR, she served as Executive Director at The Myositis Association (TMA). There, she was featured and highlighted as a preeminent rare disease leader by numerous entities – including American Autoimmune Related Diseases Association, Global Genes, and the National Organization for Rare Diseases (NORD) – for her innovative national campaigns including Women of Color and Myositis, and for her leading of telemedicine initiatives for autoimmune patients during the COVID-19 pandemic.

Prior to her time at TMA, Ms. McGowan served as CEO of WomenHeart: The National Coalition for Women with Heart Disease. During her eight years in that role, she ensured the organization's long-term growth and sustainability as the leading voice for the 48 million American women living with or at risk of heart disease. Ms. McGowan also served as Executive Director of the Allergy & Asthma Network, the leading nonprofit organization dedicated to eliminating suffering and death due to asthma, allergies, and related conditions. Earlier, she held various positions with the American Academy of Pediatrics during her service of 18 years.

Ms. McGowan earned a Master's Degree in Human Resources Development from The George Washington University and a BA from Trinity University.

Deborah Requesens, PhD
Co-Founder
Hispanic Society for Rare Diseases

Deborah Requesens, PhD is the Director of the Orphan Disease Center's JumpStart Program. This program serves to establish and progress research agendas in emerging and neglected diseases. Dr. Requesens partners with patient groups and scientists to encourage scientific collaboration and drive therapeutic development for rare diseases.

Dr. Requesens also is the Co-Founder and President of SHER (Hispanic Society for Rare Diseases), an organization that promotes awareness about rare diseases in the Hispanic population and aims to increase the participation of this community in rare disease research and advocacy.

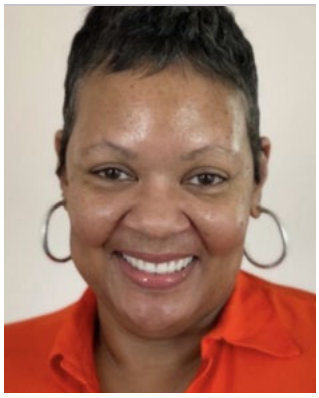
Nicole T. Rochester, MD
Health Equity Medical Advisor
Immune Deficiency Foundation (IDF)

Dr. Nicole T. Rochester is a pediatrician; a TEDx and keynote speaker; and the CEO of Your GPS Doc, LLC, an innovative healthcare advocacy and consulting company committed to eliminating health disparities and bridging the gap between healthcare providers, patients, and family caregivers. Dr. Rochester was inspired to start her company after caring for her late father and witnessing the complicated healthcare system from the other side of the stethoscope.

Dr. Rochester is a dynamic and engaging nationally recognized speaker and author who has been featured on television and radio, is a frequent podcast guest, has contributed to numerous digital publications, and has an active presence on social media. Her expertise in medical mistrust recently led to an article feature in *The Wall Street Journal*.

Dr. Rochester is the Medical Advisor for Health Equity for the Immune Deficiency Foundation and a Board Member of HealthAdvocateX. She serves on the Maryland Diabetes Action Committee; is an appointed Commissioner to the Maryland Commission on Public Health; and was the co-lead and subject matter expert for B.I.R.T.H. Equity Maryland, a statewide maternal health equity initiative.

A Maryland native, Dr. Rochester obtained her undergraduate degree from Johns Hopkins University and her medical degree from the University of Maryland School of Medicine. She is a Clinical Assistant Professor of Pediatrics at the George Washington University School of Medicine. Dr. Rochester is a member of the American Academy of Pediatrics; the National Medical Association; the Alliance of Professional Health Advocates; and Delta Sigma Theta Sorority, Inc. Most importantly, she is the proud mother of two young adult daughters.



Dionne L. Stalling
Founder & Executive Director
Rare and Black

Dionne L. Stalling is a beacon of empowerment and resilience in the realm of health advocacy. As the Founder and Executive Director of Rare and Black, her life's work is dedicated to amplifying the voices and experiences of Black individuals navigating the complex landscape of rare diseases. With over a decade of formal advocacy experience and a lifetime of lived experience, Dionne is a powerhouse advocate whose impact reverberates far and wide. She brings an unwavering commitment to inclusivity and justice and is a driving force behind initiatives that strive to ensure equitable healthcare access for all.

As a living testament to her mission, Ms. Stalling courageously battles not just one, but nine rare conditions with grace and determination. Her journey as a health advocate is deeply personal, stemming from her own experiences navigating a healthcare system often fraught with disparities and neglect.

Ms. Stalling's dedication to advancing health equity is further underscored by her prestigious training as a Washington University Community Research Fellow, through which she honed her skills and deepened her understanding of community-driven research methodologies. Beyond her role with Rare and Black, Ms. Stalling serves as a principal at Athari Strategies, a pioneering health equity consulting firm. In this role, she leverages her wealth of experience and expertise to drive meaningful change on a systemic level, working collaboratively with organizations to dismantle barriers and foster inclusive healthcare practices.

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SHAPING POLICY FOR ACCESSIBILITY:
HEALTHCARE POLICIES IMPACTING RARE DISEASE COMMUNITIES

Sky Collins
Oklahoma Rare

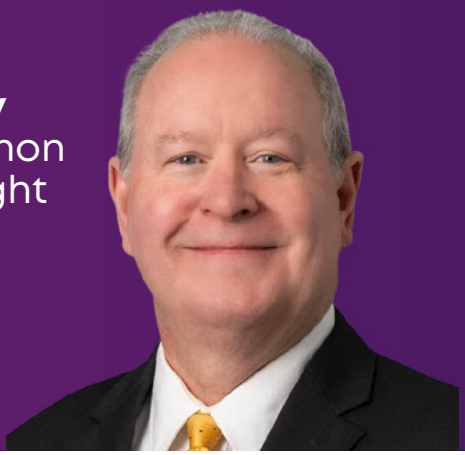
Victoria Gemme
NORD

Dr. Maggie Kang
Life and Healthcare Coach

Annie Kennedy
EveryLife Foundation for Rare Diseases

Chris Porter
Travere Therapeutics

Moderated By
Dr. Larry Bucshon
Holland & Knight



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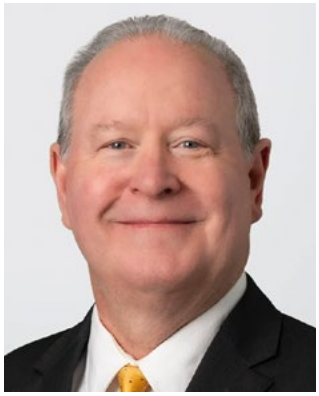


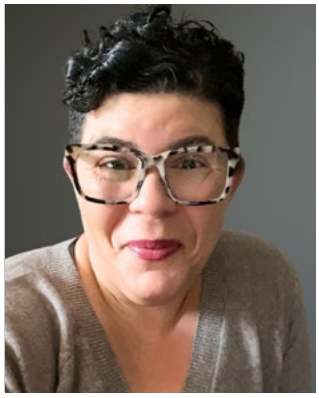
Larry Bucshon, MD
Policy Advisor and Lobbyist
Holland & Knight

Larry Bucshon, MD is a senior policy advisor and lobbyist in Holland & Knight's Washington, DC office and a member of the firm's Public Policy & Regulation Group. He focuses his practice on matters related to healthcare and energy.

As a Member of Congress from 2010 to 2025, Dr. Bucshon advocated for patient-centered healthcare reforms that support innovation and give patients access to high-quality, affordable, and timely care while also ensuring that patients and their doctors have the freedom to make their own healthcare decisions. He served as a senior member of the House Committee on Energy and Commerce and Vice Chair of the Subcommittee on Health, Vice Chair of the House GOP Doctors Caucus, and a Co-Chair of the Congressional Kidney Caucus. In the 117th Congress, Dr. Bucshon was selected to the Healthy Future Task Force and led the Subcommittee on Doctor/Patient Relationships.

Prior to his political experience, Dr. Bucshon was a practicing physician and surgeon specializing in cardiothoracic surgery. He also served as Chief of Cardiothoracic Surgery and Medical Director of the open heart recovery intensive care unit at St. Mary's (now St. Vincent) hospital in Evansville, IN.

During his surgical residency, Dr. Bucshon enlisted with the US Navy Reserve and served for almost a decade before being honorably discharged.

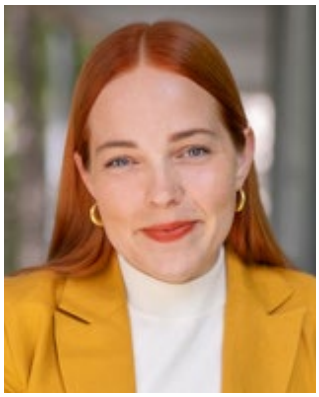


Sky Collins
Founder
Oklahoma Rare

Sky Collins is a dedicated rare disease advocate and community builder. Her experiences as a biracial woman navigating healthcare inequities have deepened her commitment to advocacy and systemic change. Ms. Collins is the founder of Oklahoma Rare, which works to connect, empower, and advocate for the rare disease community across the state. Her advocacy is deeply personal – her daughter, Presley, is diagnosed with Malan Syndrome, an ultra-rare genetic condition.

With experience at the local, state, and federal levels, Ms. Collins has helped drive policy change, served on multiple nonprofit boards, and co-led a PCORI-funded research initiative on rare diseases with connective tissue characteristics. She is a member of the Rare Disease Diversity Coalition, and she serves on the Malan Syndrome Foundation Parent Advisory Board and on the Oklahoma Supporting Minorities with Disabilities Coalition as a committee chair.

Ms. Collins is passionate about amplifying diverse rare voices, increasing access to resources, and shaping policies that improve the lives of individuals with disabilities and rare diseases.

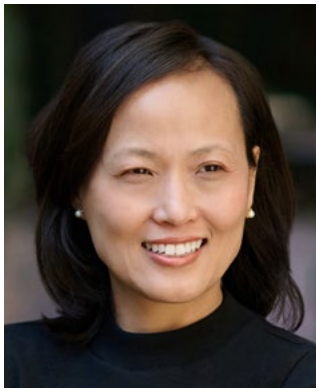


Victoria Gemme
Director of Policy & Regulatory Affairs
National Organization for Rare Disorders (NORD)

Victoria Gemme is the Director of Policy & Regulatory Affairs at the National Organization for Rare Disorders (NORD). In this role, she is responsible for crafting and implementing NORD's rare disease policy and advocacy engagement strategy with federal regulatory bodies – specifically the US Food and Drug Administration (FDA) and the National Institutes of Health (NIH) – as well as for leading NORD's legislative and regulatory policy development as it relates to medical research and development in an effort to promote access to safe, effective diagnostics and treatments for rare disease patients.

Ms. Gemme brings a decade of experience in healthcare and legislative and regulatory policy, including in the rare disease space. She most recently served as Assistant Research Director at Duke-Margolis Institute for Health Policy. Prior to her time at Duke-Margolis, Ms. Gemme worked for the Cystic Fibrosis Foundation, where she oversaw a policy portfolio covering basic science research and drug development, among other topics.

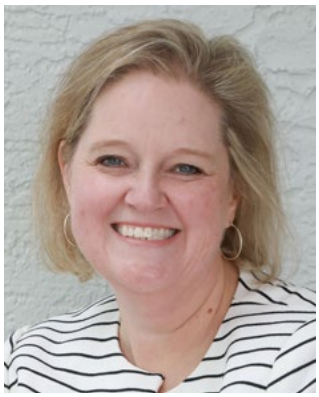
Ms. Gemme has a BA in Neuroscience from Vassar College, an MS in Ethics and Public Policy from Suffolk University, and an MBA from Quantic School of Business and Technology.



Dr. Maggie Kang
Certified Life and Healthcare Coach | Speaker
Rare Disease Advocate

Dr. Maggie Kang is a Yale-trained physician and certified life and healthcare coach who empowers parents to transform the journey of their child's diagnosis into opportunities for growth and resilience. After navigating her own daughter's rare disease, Dr. Kang uses her expertise to guide parents through the healthcare system, helping them turn health challenges into purpose, connection, and leadership.

A passionate advocate and TEDx speaker with nearly 200,000 views, Dr. Kang has reached national audiences through her inspiring talks at the UCLA Luskin Center and the National Organization for Rare Disorders (NORD), and her daughter's journey has been featured on CBS Evening News. She is also a contributing writer to *Psychology Today*.

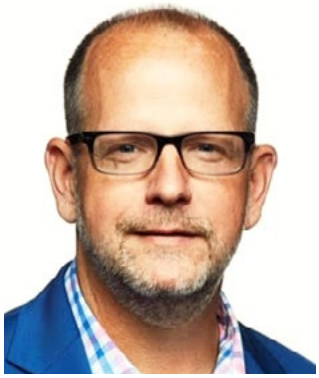


Annie Kennedy
Chief of Policy, Advocacy & Patient Engagement
EveryLife Foundation for Rare Diseases

A veteran leader in the patient-focused drug development movement, Annie Kennedy joined the EveryLife Foundation in 2018, where she's led numerous community-driven evidence development efforts including the *National Economic Burden of Rare Disease Study, the Guide to Patient Involvement in Rare Disease Therapy Development*, and *The Cost of Delayed Diagnosis in Rare Disease: A Health Economic Study*. Her advocacy efforts and community activation contributed to new federal infrastructure for rare disease, including the Muscular Dystrophy Coordinating Committee (MDCC) and the Rare Disease Innovation Hub at the US Food and Drug Administration (FDA).

Ms. Kennedy previously held leadership roles at Parent Project Muscular Dystrophy (PPMD) and the Muscular Dystrophy Association (MDA), where she led landmark legislative, regulatory, newborn screening, transitions, and access policy efforts; these included the MD CARE Act as well as the Patient Focused Impact Assessment Act (PFIA), which became the Patient Experience Data provision of the 21st Century Cures Act.

Ms. Kennedy's community roles have included service on the Board of Directors of Cure SMA, the National Duchenne Newborn Screening Steering Committee, and the NIH Strategic Planning Working Group on Engaging the Public as Partners in Clinical Research (NexTRAC), and as a member of the National Institutes of Health (NIH) NCATS Advisory Council.



Christopher Porter
Vice President of Government Affairs and Policy
Travere Therapeutics

Christopher Porter has over 20 years of government and public affairs experience, with deep healthcare policy know-how and advocacy successes spanning Congress, the Executive Branch, state governments, and the globe. He is a legislative policy and political behavior expert with extensive bipartisan relationships. Currently, Mr. Porter serves as Vice President of Government Affairs and Policy for Travere Therapeutics, a biopharmaceutical company focused on rare diseases whose mission is to deliver life-changing therapies to people with few, if any, treatment options. As an outspoken advocate for the Orphan Drug Act, innovation, and families living with rare disease, Mr. Porter has been the architect of Travere's national and state legislative and policy strategies since 2016.

Prior to his position at Travere Therapeutics, Mr. Porter spent 10 years at Novo Nordisk, helping build and ultimately lead the US government affairs and global public affairs teams in Washington and Copenhagen. In those roles, he drove a new comprehensive global public affairs strategy; built government relations, grassroots, and political infrastructure while executing high-profile events in the U.S., Europe, and China; and ultimately secured numerous commercial and patient legislative victories.

Mr. Porter served in Congress for 10 years in senior health policy roles including as Co-Staff Director of the Congressional Diabetes Caucus, Chief of Staff, and Legislative Director.

Mr. Porter serves on the Board of Directors for the Dance Institute of Washington, the Public Affairs Council, and the Corporate Advisory Board of Children's National Medical Center. He is the author of *How to Get a Job in Congress (Without Winning an Election)* and has been published in *The Washington Post*, *Washington Times*, and other newspapers.

RDDC
RARE DISEASE DIVERSITY COALITION

RDDC Rare Disease Panels at the 2025 NMQF Leadership Summit

THE POWER OF COMMUNITY PANEL

ENGAGING GATEKEEPERS FOR RARE DISEASE ADVOCACY

Oya Gilbert
Health, Hope & Hip-Hop Foundation

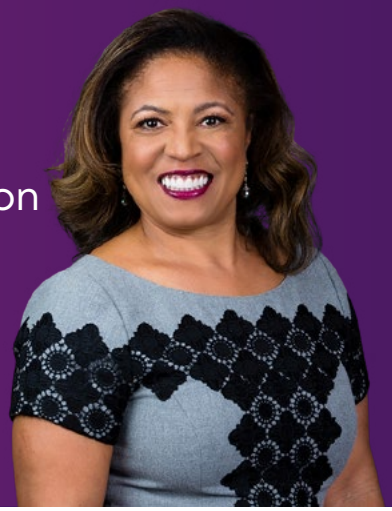
George Kerr III
Westminster Presbyterian Church DC

Rob Long
Uplifting Athletes

Tiffany Scott
Maryland CHW Association

Stephen Thomas
Center for Health Equity University of Maryland

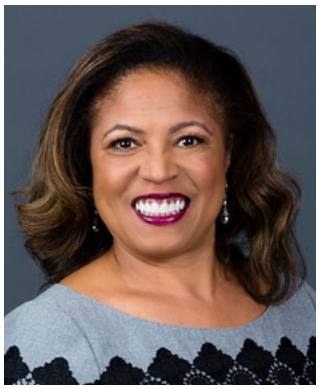
Moderated By
Deanna Darlington
Links2Equity



APRIL 29, 2025
2:00PM - 3:00PM

CONRAD HOTEL
WASHINGTON, DC

MODERATOR



Deanna Darlington
Founder
Links2Equity

Deanna Darlington is an advocacy relations professional with more than 25 years of experience in government and external affairs, patient advocacy, policy, reimbursement consulting, and related fields. She specializes in engaging patient advocacy organizations on access and policy issues, which includes a focus on health disparities for vulnerable patient populations. Ms. Darlington works closely with advocates on key policy issues that support dialogue and engagement to patient access to quality care and value. For 13 years at Amgen Inc., she held various roles that included policy and patient advocacy/alliance development. She also served as Director of Reimbursement and Policy at a number of other pharma companies.

Before joining the biotech and biopharmaceutical industry, Ms. Darlington served as the first Reimbursement Specialist for the American Society of Clinical Oncology, where she staffed the Clinical Practice Committee and developed the State Affiliate Program under the Association's public policy arm. She founded Links2Equity in 2021 after retiring from Amgen Inc., with the goal of serving patients and other healthcare stakeholders in all disease states and underrepresented communities such as Black, LatinX, Asian Pacific Islander, Aging, Rural, LBGTQ, and others.

Oya Gilbert
Founder & CEO
Health, Hope & Hip-Hop Foundation

Oya Gilbert, also known as "Grand G," is a father of three, a podcaster, and a prominent figure in Delaware's hip-hop scene. He began his journey by performing rhymes on the streets of Wilmington, which eventually led to a record deal and numerous song releases.

In December 2017, after two years of misdiagnoses by primary care physicians and specialists, Mr. Gilbert was diagnosed with multiple myeloma, an incurable blood cancer that affects the Black community at twice the rate of other ethnicities. Determined to raise awareness, he underwent a stem cell transplant in 2018 and continues to manage his condition with daily chemotherapy.

Mr. Gilbert is the creator and host of the "Hip, Hope, Hooray! Black Men Talking Health" podcast, available on all major platforms. This innovative podcast addresses the disproportionate cancer burden and health disparities faced by Black Americans. Through conversations with guests ranging from doctors to community members, the podcast offers practical tips, resources, and encouragement to assist Black men on their journey to better health. It serves as a health literacy movement, empowering and educating the Black community for a healthier future.

With invaluable support from organizations like the International Myeloma Foundation, various pharmaceutical companies, and The Leukemia & Lymphoma Society, Mr. Gilbert aligns diversity, equity, and inclusion with patient advocacy. He encourages and empowers people of color to take a proactive role in their healthcare plans.

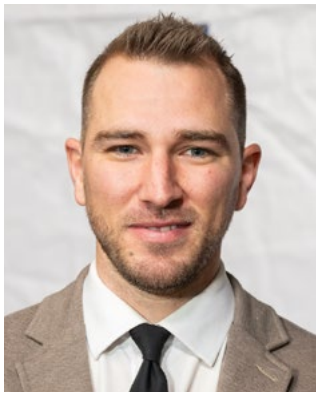
In 2024, Mr. Gilbert's passions led him to establish the Health, Hope & Hip-Hop Foundation, a non-profit organization dedicated to teaching health literacy and addressing Black health disparities at the grassroots level. The foundation utilizes the cultural influence of hip-hop as a catalyst for change.

George Kerr III
Elder
Westminster Presbyterian Church DC

George Kerr is committed to educating, training, advocating, and collaborating for social justice through his faith and harm reduction. He has a long and determined history of effectively working with some of the District of Columbia's most prominent health service providers. Mr. Kerr has motivated hundreds of individuals to advocate for those whom the stigma of HIV and substance use disorder has silenced. He believes that TOGETHER we can build a healthier community.

Current Community and Professional Engagement:
- Chair – Community Partner Council (CPC), DC CFAR
- Co-Community Lead – Harm Reduction Working Group, Long Live DC
- Co-Community Lead – Drug User Health (SIG), DC CFAR
- Elder – Westminster Presbyterian Church DC
- Member – Presbyterian HIV Network, PHEWA, Presbyterian Church (USA)

Research Projects:
- Community Engagement – Ending the HIV Epidemic Campaign to help improve the quality of PLWH your access to brain health care
- Community Engagement – Black Women and Faith in ART inherent



Rob Long
Executive Director
Uplifting Athletes

Rob Long was an All-American punter at Syracuse University. In 2010, during his senior season, he was diagnosed with a rare form of brain cancer. His treatment lasted 16 months and ended his NFL aspirations.

A Syracuse graduate, Mr. Long earned a BS from the Whitman School of Management and a Master's in New Media Management from the Newhouse School. He became the Executive Director of Uplifting Athletes in 2018 after joining the organization two years earlier Uplifting Athletes has now funded more than $1.2 million in research grants to the next generation of researchers and has provided unique Uplifting Experiences to more than 2,000 individuals impacted by rare diseases.

Tiffany Scott, CCHW, CHWI
Co-Founder & President
Maryland Community Health Workers Association

Tiffany Scott is an innovative and mission-driven leader with extensive expertise in Community Health Work (CHW), training, and program development. As the first certified CHW in Maryland, she has dedicated her career to advancing the profession, fostering inclusive healthcare solutions, and advocating for sustainable CHW infrastructure.

Since 2018, Ms. Scott has served as Vice-Chair of the Maryland CHW Advisory Committee, shaping statewide policies and initiatives. As the Co-Founder and President of the Maryland CHW Association, she has been instrumental in advocating for CHW workforce development and professional advancement. Additionally, she serves as the Chief Membership and Engagement Officer for Project CHAMPP, where she advocates for policies and practices that positively influence the CHW workforce and improve the health and well-being of the communities CHWs serve.

Ms. Scott's consultancy work and leadership extend across local and national platforms. As CEO of Scott Consulting Firm, she specializes in CHW training, curriculum development, reimbursement strategies, and workforce sustainability. With a strong background in strategic planning, virtual learning management, and stakeholder engagement, she has designed and led CHW training programs, supervised teams, and implemented data-driven strategies to enhance healthcare outcomes.

Committed to amplifying CHW voices and advancing policies that support health equity, Ms. Scott was an active participant in the ALEC Study (Amplifying the Lived Experiences of CHWs). She has shared her expertise as a panelist and presenter at national conferences, including the NYU Langone Health Community Health Worker Innovations Summit, the National Association of Community Health Workers, Pediatric Academic Societies Workshop, and the Academy Health Annual Research Meeting.

Dr. Stephen B. Thomas
Professor of Health Policy & Management, Director of Maryland Center for Health Equity - University of Maryland

One of the nation's leading scholars in the effort to eliminate racial and ethnic health disparities, Dr. Stephen B. Thomas has applied his expertise to address a variety of conditions from which minorities generally face far poorer outcomes, including cardiovascular disease, diabetes, obesity, and HIV/AIDS.

Dr. Thomas has received numerous awards for his professional accomplishments. His work has become recognized as one of the scholarly contributions leading to the 1997 Presidential Apology to Survivors of the Syphilis Study Done at Tuskegee. His current research focuses on the translation of evidence-based science on chronic disease into community-based interventions designed to eliminate racial and ethnic disparities in health and healthcare. Dr. Thomas is particularly interested in how the legacy of the Syphilis Study at Tuskegee (1932–72) has impacted trust and influenced the willingness of African Americans to participate in medical and public health research.

In 2012, Dr. Thomas was a member of the Maryland Health Quality and Cost Council's Health Disparity Work Group. The final report was translated into legislation and passed into law as the Maryland Health Improvement and Disparities Reduction Act of 2012. In 2014, Democratic Gov. O'Malley appointed Dr. Thomas to the Maryland Health Care Commission, an independent regulatory agency whose mission is to plan for health system needs, promote informed decision-making, increase accountability, and improve access to quality medical and dental care. In 2019, Republican Gov. Larry Hogan appointed him to a new full term on the Commission.

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RDDC™
RARE DISEASE DIVERSITY COALITION

On behalf of the Rare Disease Diversity Coalition, thank you for joining us at the National Minority Quality Forum Leadership Summit on Health Disparities, Rare Disease Track on Tuesday, April 29, 2025 in Washington, DC.

Your presence and engagement have made this important day of dialogue, learning, and collaboration incredibly meaningful. From thought-provoking discussions on clinical trial diversity and grassroots advocacy to actionable insights on healthcare policy and community engagement, we hope the summit has left you inspired and equipped to continue advancing equity in rare disease care.

To help us improve future programming and better serve the needs of our community, please take a few minutes to complete our post-event evaluation form:

Your feedback is invaluable and helps us shape future impactful events and initiatives.

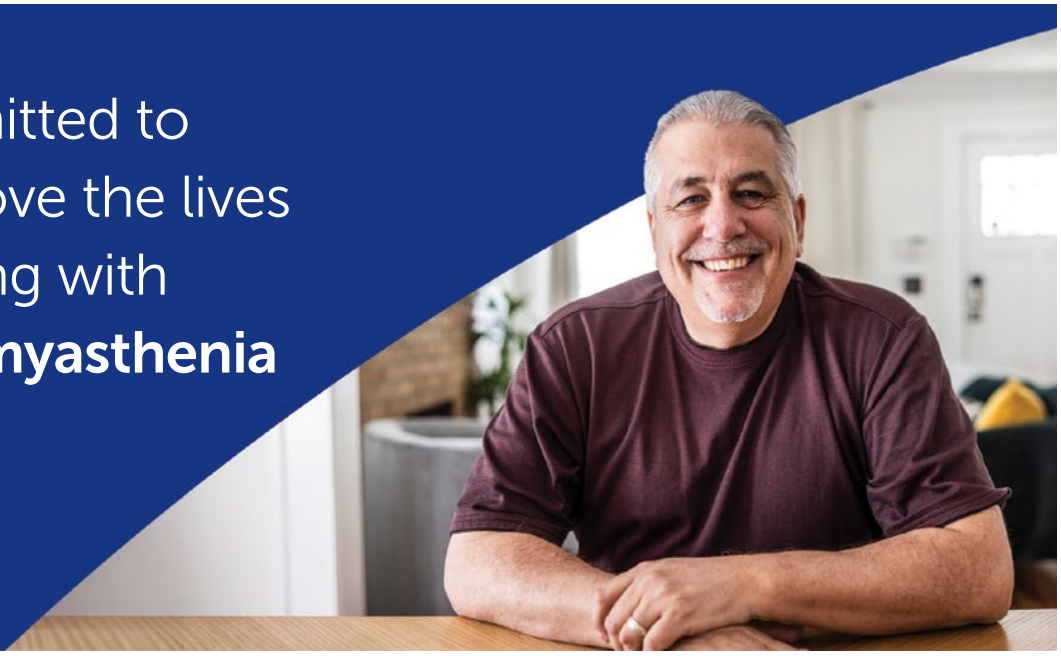
Thank you again for your participation and commitment to health equity in the rare disease space. We look forward to staying connected.

Warm regards,

Jenifer Waldrop
Executive Director, Rare Disease Diversity Coalition
Black Women's Health Imperative

NOVARTIS

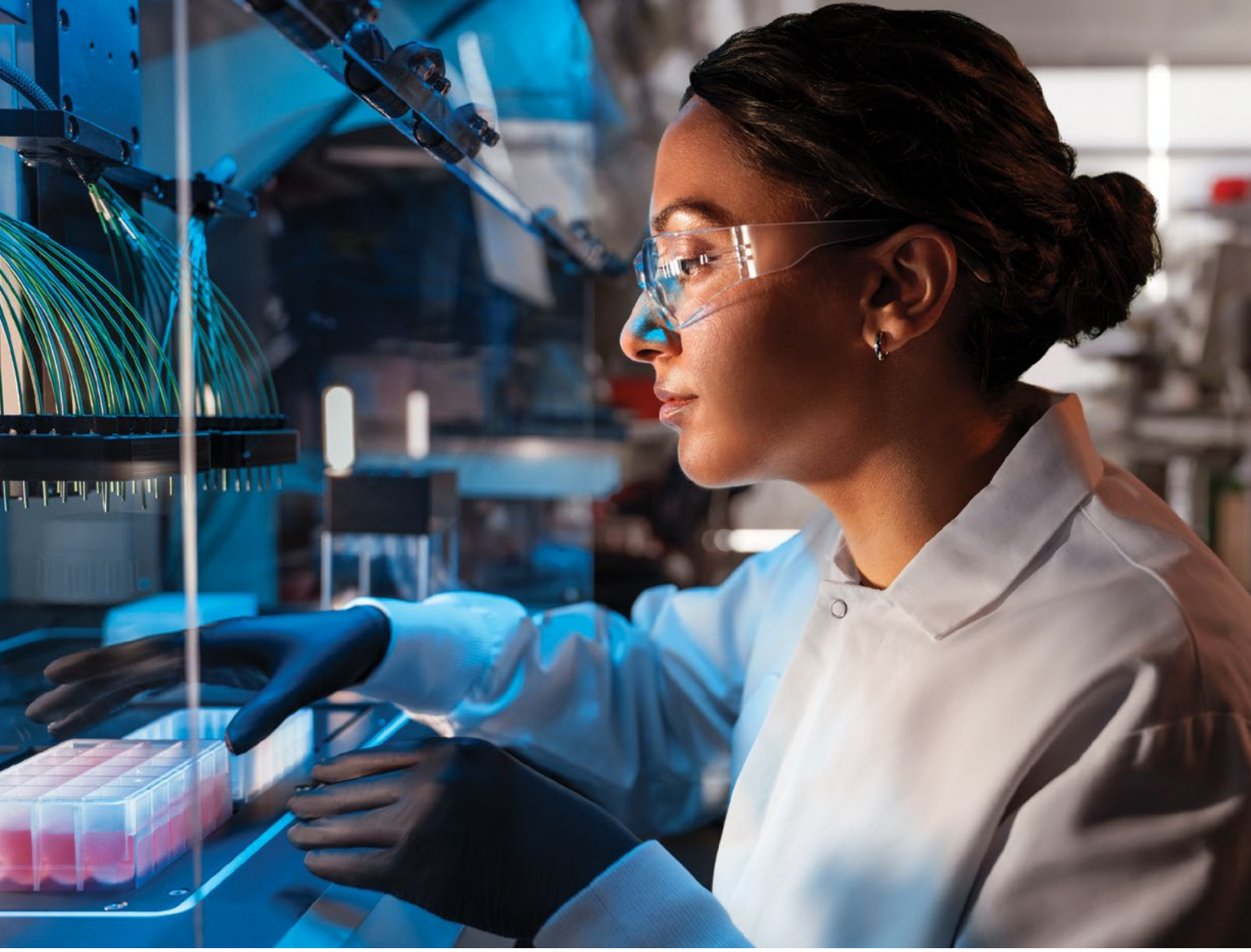
UCB is committed to helping improve the lives of people living with **generalized myasthenia gravis (gMG)**



No two individuals with gMG have the same needs. At UCB, we recognize that every individual has a different journey—**that's why we're proud to offer two treatment options for adults living with gMG.**

Explore our two targeted treatment options at UCBforGMG.com

Inspired by **patients.**
Driven by **science.**



We innovate with purpose

Patients will always inform and inspire our science-based innovations, which continue to change and save lives. Applying rigorous science with compassion, we will continue to confidently address the most complex healthcare challenges of our time and unlock the potential medicines and technologies of tomorrow.

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