

2023 Annual Meeting of Members

Mary Woolley

President & CEO
Research!America



Sudip Parikh, PhD

Board Chair Research! America

CEO

American Association for the Advancement of Science (AAAS)

Executive Publisher
Science Family of Journals



Derek Rapp

Nominating Committee Member Research! America

Managing Director
RiverVest Venture Partners



New Board Members

New Board Members for election to a three-year term:



Deborah Deas, MD, MPH, Vice Chancellor for Health and Dean of the School of Medicine, University of California Riverside



Karen Knudsen, PhD, CEO, American Cancer Society



David Reese, MD, Executive Vice President, Research & Development, Amgen



Keith Yamamoto, PhD,
Professor Emeritus; Vice
Chancellor for Science Policy
and Strategy; Director, UCSF
Precision Medicine, University of
California, San Francisco

Re-election of Board Members

For re-election to the Board of Directors for an additional two-year term:



Georges Benjamin, MD, Executive Director, American Public Health Association



Mikael Dolsten, MD, PhD, Chief Scientific Officer and President of Worldwide Research, Development and Medical, Pfizer



Sudip Parikh, PhD, CEO, American Association for the Advancement of Science and Executive Publisher, Science Family of Journals



PhD, RN,
President and CEO,
American Association
of Colleges of Nursing



Roy Wilson, MD, President, Wayne State University



Re-election of Board Members

For re-election to the Board of Directors for an additional one-year term:



Nancy Brown, CEO, American Heart Association



Victor Dzau, MD, President, National Academy of Medicine



Hon. Bart Gordon, Partner, K&L Gates LLP; U.S Representative (1985 - 2011)



Mary Hendrix, PhD, President, Shepherd University



Mark McClellan, MD, PhD, MPA, Director, Robert J. Margolis Center for Health Policy, Duke University



E. Albert Reece, MD, PhD,
Dean Emeritus and Former University Executive
Vice President; Endowed Professor and Director,
Center for Advanced Research Training and
Innovation (CARTI); Co-Director, Center for Birth
Defects Research, University of Maryland School of
Medicine



Herbert Pardes, MD, Executive Vice Chairman, Board of Trustees, NewYork-Presbyterian Hospital



Amy Comstock Rick, JD, Principal, Leavitt Partners

Thank You to Our Continuing Board Members

Sudip S. Parikh, PhD, Chair American Association for the Advancement of Science

Georges C. Benjamin, MD, Vice Chair

American Public Health Association

Mary Woolley, President Research!America

E. Albert Reece, MD, PhD, MBA, Secretary University of Maryland School of

Medicine

Amy Comstock Rick, JD, Treasurer Leavitt Partners, LLC

Nancy Brown American Heart Association

Hon. Charlie Dent
The Aspen Institute
DLA Piper LLP
U.S. Representative (2005-2018)

Mikael Dolsten, MD, PhD Pfizer Inc

Victor J. Dzau, MD National Academy of Medicine

Kafui Dzirasa, MD, PhDDuke University Medical Center

Ayman El-Mohandes, MBBCh, MD, MPH

City University of New York

Arthur C. Evans Jr., PhD American Psychological Association

Darío Gil, PhD IBM

Hon. Bart Gordon K&L Gates LLP U.S. Representative (1985-2011)

Mary J.C. Hendrix, PhD Shepherd University Hon. Rush D. Holt, PhD U.S. Representative (1999-2015)

Mark McClellan, MD, PhD, MPA Duke University CMS (2004-2006) FDA (2002-2004)

Michelle McMurry-Heath, MD, PhD

Jessica L. Mega, MD, MPH

Herbert Pardes, MD NewYork-Presbyterian Hospital

Harold L. Paz, MD, MS Stony Brook University

Mary Pittman, DrPH Public Health Institute

Guillermo J. Prado, PhD University of Miami

Derek K. Rapp RiverVest Venture Partners Lewis G. Sandy, MD, FACP UnitedHealth Group

Hon. Donna Shalala, PhD U.S. Secretary of Health and Human Services (1993-2001) U.S. Representative (2019-2021)

Deborah Trautman, PhD, RN, FAAN

American Association of Colleges of Nursing

M. Roy Wilson, MD Wayne State University

Cynthia Zagieboylo National MS Society

Elias A. Zerhouni, MD NIH (2002-2008)



Thank You to Our Outgoing Board Members



Resolution of Thanks and Appreciation

As Adopted by Research!America's Membership

At the Annual Meeting of Members on April 20, 2023

Whereas, the following individuals will be ending their respective terms of service as Research! America Board Members today;

The Honorable Mike Castle

Susan Dentzer

Laing Rogers

Whereas, each is recognized for their unwavering advocacy for research and science to achieve better health for all:

Whereas, because of their leadership and service, Research! America is a stronger and more effective organization;

Therefore, on this 20th Day of April 2023, the members of Research! America thank each of these individuals for outstanding service to the organization and wish each of them the very best.

Sudip Parikh, PhD, Board Chair

Mary Woolley, President & CEO

Hon. Michael N. Castle

Research! America Chair Emeritus Governor of Delaware, 1985-1992 U.S. Representative, 1993-2011

Susan Dentzer

Research!America Chair Emerita President and CEO, America's Physician Groups

Laing Rogers

Community Leader



Georges Benjamin, MD

Vice Chair Research! America

Executive Director

American Public Health Association



Amendments to Research! America's Bylaws

A Governance Task Force of Research! America's Board of Directors reviewed the organization's governance practices ensuring that an optimal governance structure is in place to support the ongoing success of the organization.

Included in its review, the Task Force focused on the board's committee structure and recommended proposed amendments to the Bylaws that enhance the board's ability to meet fiduciary responsibilities.

At its meeting on March 15, 2023, Research! America's Board of Directors approved the proposed amendments to the bylaws and recommends approval by the membership.

A summary of the proposed amendments was sent to all members prior to this meeting and is linked in the chat box.

RESEA

Remarks

The Honorable Dawn O'Connell
Assistant Secretary for Preparedness
and Response, Health and Human Services



Gary L. Disbrow, PhD

Deputy Assistant Secretary; Director,
Biomedical Advanced Research and
Development Authority, Administration for
Strategic Preparedness and Response, HHS



Georges Benjamin, MD
Executive Director, American Public
Health Association





Fireside Chat

The Honorable Lauren Underwood U.S. Representative (D-IL-14)



Amy Comstock Rick, JD
Treasurer, Research! America
Principal, Leavitt Partners





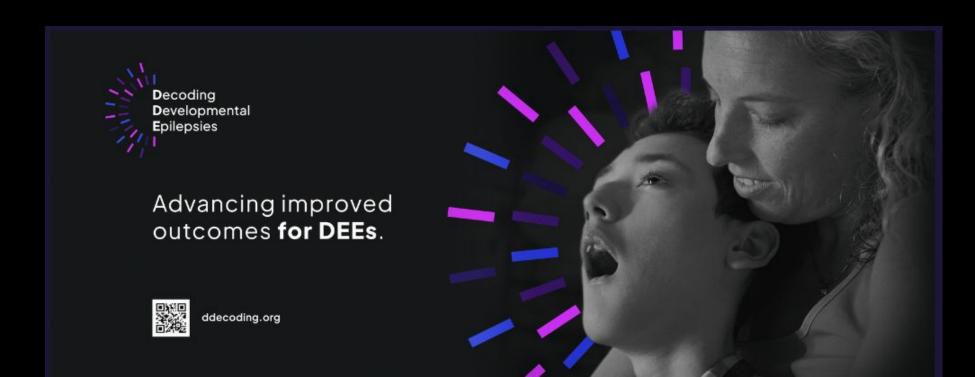
Advocacy in Action

Gabrielle Conecker, MPH Co-Founder and President, International SCN8A Alliance



A Caregiver Journey to Action

Gabrielle Conecker, MPH
Research!America Annual Meeting
April 20, 2023









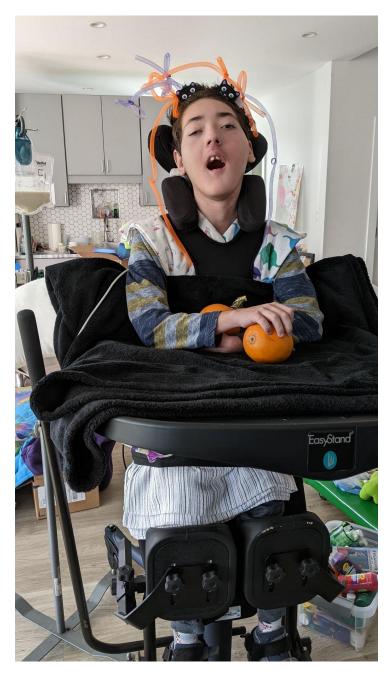




MEET ELLIOTT









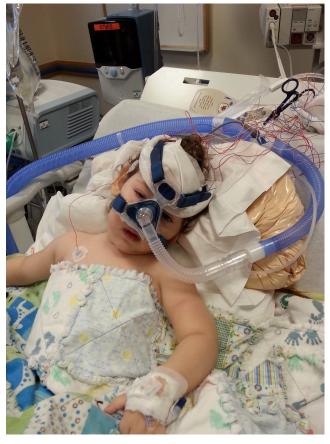


ELLIOTT'S EARLY YEARS









The Diagnosis

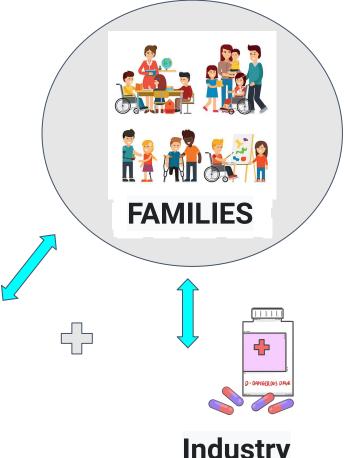
No clinical evidence
No treatments
No prognosis

The solution?





in partnership with **Global SCN8A Partner Organizations**











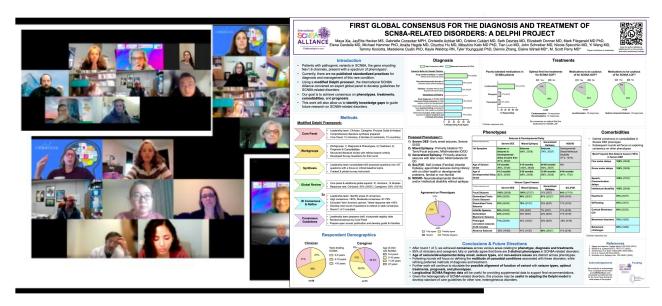
Scientific Meetings





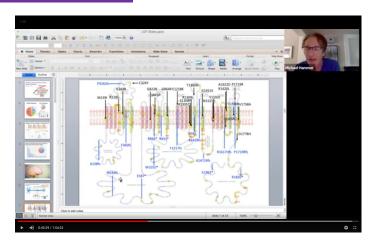


Clinicians Network



Family Networks





The Isolation and Uncertainty of Raising a Severely Impacted Child

No resources

No community despite much overlap

The solution?



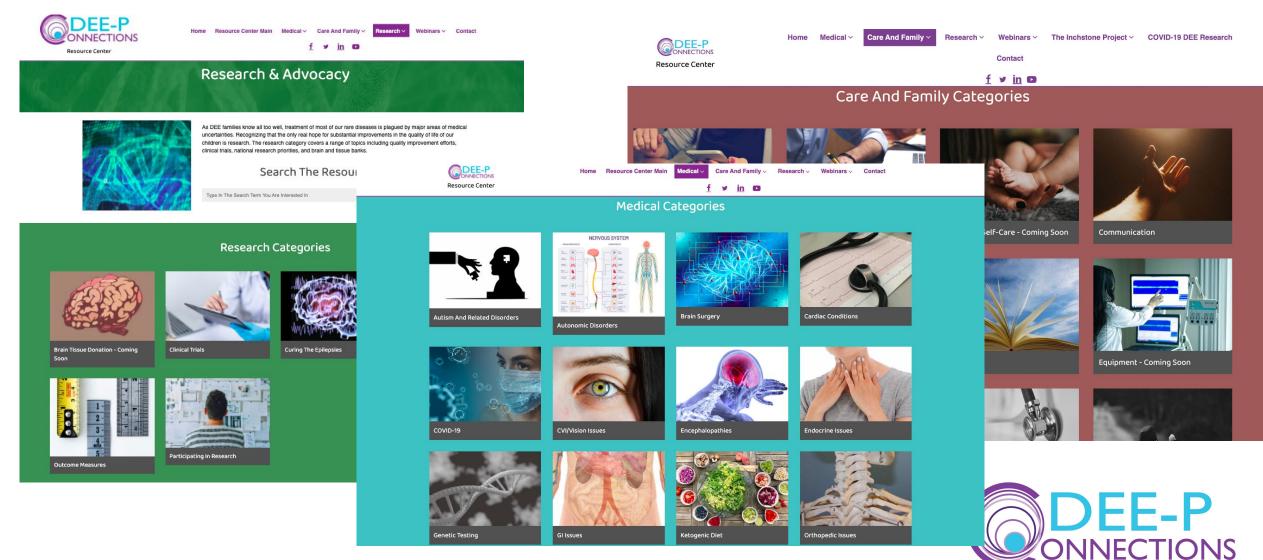


DEE-P works collaboratively to provide resources, information & support to improve the lives of families with children severely affected by DEEs and conduct targeted research across the DEEs.





The Resource Center provides a one-stop shop of curated resources for DEE families



Emerging Clinical Trials - Would they be able to measure change in Elliott?

A lack of cross DEE efforts to solve this problem Clinical Trials are inequitable

The solution?





The Problem





The Inchstone Project Mission

We aim to make clinical development more inclusive by developing a battery of FDA-approved Clinical Outcome Assessments -

So that every person, regardless of the severity of their disease, can have even their smallest achievements, or inchstones, counted.

Successes from Year 1

- 1. Recruited Research Team, Steering Committee of Experts and Industry Advisory Panel
- 2. Feedback on draft FDA guidance on COAs

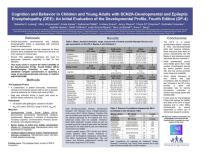
THE INCHSTONE PROJECT

PRECISION MEDICINE REQUIRES PRECISION MEASUREMENT



3. Workshop & 4 Posters on Non-Seizure Outcomes at Largest Global Epilepsy Meeting - American Epilspsy Society 2022











- 4. Symposium at Gatlinburg 2023.
- 5. Accepted for Child Neurology Society panel 2023.



Ensuring clinical outcome measures capture abilities and progress for people with severe neurodevelopmental impairments

Patient- and Family-Centered

Collaborations with parents, advocacy groups, multi-disciplinary team

Clinically Meaningful

Cognition, communication, motor function, quality of life

Evidence-Informed

Optimize psychometric properties, responsiveness, meaningful change

Fit for Purpose

Ready for real world use in clinical trials and for monitoring progress

Priority Activity Areas for 2023



Goal: Assess what non-seizure outcomes are most important for children and young people with DEEs and their families

International survey and focus groups, multiple DEEs

CONSULT Family Survey - What is important?

Goal: Adapt, refine, and expand 'Inchstone COAs' to be fit-for-purpose

Perform preliminary testing of psychometric properties

VALIDATE Instrument Adaptation

Goal: Assess the feasibility of *existing* 'Inchstone COAs' in the severe DEEs and generate data for instrument adaptation

Multicenter study with fifty families to test adapted outcomes

TEST Feasibility Study

Goal: Engage with a wide range of patient advocacy, pharma, regulator, and academic stakeholders to maximize impact

Connect for collaboration, dissemination, knowledge translation

DISSEMINATE
Stakeholder Engagement

No change in the outcomes for those living with epilepsy

Despite the emergence of the genetic revolution, increased diagnostic capabilities and improved research techniques –

It isn't translating to improved outcomes.



The solution?



Home Our Mission The Epilepsies Urgent Action Needed About Us Join News & Updates

Our Mission

Advancing strategic national policies, innovative research programs, and funding to improve the lives and outcomes of ALL those living and struggling with The Epilepsies.











The Challenge

- Cause unknown in 50% of cases
- Few biomarkers for epilepsy
- 30% refractory; higher for rare, genetic epilepsies
- No decrease in premature deaths, especially among children

NO improvements in incidence, seizure control, comorbid conditions, excess premature death

Our Solution

- Improved surveillance and understanding of incidence, burden, and deaths
- More integrated approach
- No more barriers delaying translation of research to improved treatments and outcomes
- Investment commensurate with incidence, personal cost, and economic burden

Work toward a <u>Cohesive National Plan</u> maximizing strategic and coordinated federal efforts

National Advisory Board



Christopher P. Austin, M.D.
CEO
Vesalius Therapeutics, Former founding
Director of the National Center for
Advancing Translational Sciences (NCATS)
at the National Institutes of Health (NIH)



Anne T. Berg, Ph.D.

Adjunct Professor of Neurology

Northwestern Feinberg School of Medicine



ABCN, FAES
Professor of Neurology and Pediatrics, Chief
of the Comprehensive Pediatric Epilepsy
Center
Dell Children's Hospital, Dell Medical

Dave Clarke, MBBS, ABPN,

School, University of Texas-Austin



Tony Coelho
PIPC Chairman; Former United States
Congressman from California, and Primary
Author and Sponsor of the Americans with
Disabilities Act



Greg Grunberg Actor, Co-Founder, Talk About It Company



Lori L. Isom, Ph.D.
Professor and Chair of Pharmacology,
Professor of Molecular and Integrative
Physiology, Professor of Neurology
The University of Michigan Medical School



Howard K. Koh, M.D., MPH
Harvey V. Fineberg Professor of the Practice
of Public Health Leadership
Harvard T.H. Chan School of Public Health |
Harvard Kennedy School, Former 14th
Assistant Secretary for Health for the U.S.
Department of Health and Human Services
(2009-2014)



Daniel Lowenstein, M.D.
Professor of Neurology
University of California, San Francisco



Rosalind Picard, Sc.D., FIEEE, FACM, FAAAC, FAPA Director of Affective Computing Research MIT



Charlene Son Rigby, MBA
CEO
Global Genes, and STXBP1 Foundation



Kari Luther Rosbeck
President and CEO
TSC Alliance

"[EAN] honestly feels potentially transformational in terms of finally getting us to a point where we can actually get the resources needed for the population that we serve."

Dan Lowenstein, Mar. '23







Building Coalition & Collaboration

- Community Conversations & Listening
- 225 stakeholders signed onto a letter to Biden to Increase Epilepsy Funding
- Launched National Advisory Board

Connecting with Federal Agencies

- White House Mtg
- ARPA-H advocacy
- Mtgs w/ NINDS, NCATS, CDC

Advocating for Appropriations

- Support for 1st Epilepsy Caucus launched by Epilepsy Foundation
- 100+ Requests & Mtgs with Congressional Staffers

Building a Better Tomorrow, Together











Rare Disease

Connecting and Collaborating: Lessons From a Decade of Caregiving and Activism





If you're like me, the holiday season is an emotional time. Last month marked the 10th Christmas, Chanukah and New Year we celebrated with Elliott, our son who is profoundly affected by SCN8A — one of the many rare developmental and

















Mary Woolley

President & CEO
Research!America



Securing a Science Strong Future



- Advocated for increased NIH, NSF, FDA, CDC, and AHRQ funding during appropriations process
- Informed conversations on key initiatives including PDUFA, ARPA-H, Pandemic Preparedness, and more
- Supported Science and Tech Action Committee to make the case for a far bolder approach to bolstering our nation's federal R&D investment
- Held 87 Congressional meetings; submitted Congressional testimony focused on NIH, CDC, NSF, FDA, and AHRQ; held 46 meetings with the Biden Administration and agency officials; led 42 alliance discussions

Civic Engagement Microgrant Program

Who: Early career STEM researchers

What: Civic science projects

Why: Create opportunities for community connection,

change, and professional development

How: Microgrants of \$1k-\$4k + training + mentoring

Where: 86 grants issued to groups in 28 states

Types of Projects Among Grantees	
Community Outreach	New Group
Competition	Podcast
Data Visualization	Policymaker Outreach and Education
Demonstration/Tour	Workshop
Public Forum	Bipartisan Candidate Forum (funded only in 2018-2019)



Politics Under the Microscope at The Tri-Institute (Tri-I) NYC



Oklahoma Policy Engagement Network at the Oklahoma Medial Research Foundation



Women's Association of Minority Scientists at the University of Texas Medical Branch



2018-2023 Civic Engagement Microgrant Program Supported by the Rita Allen Foundation



Exploring the Impact



In this report, we reflect on our Microgrant program, now in its 5th year, and early-career science civic engagement through competitive microgrants.

- Studied over 60 final reports and surveys
- Conducted In-depth interviews
- Contributed our own observations
- Support for paper from Rita Allen Foundation

Key Learnings

- New skills
- Community connections
- Understand intersection of science and policy
- Career Exploration

Recommendations

- Earlier training, increased mentoring
- Achieve university and faculty support
- Normalize civic science training

Early Career Summit



Our second annual Early Career Summit offered the super-star researchers of the future opportunities to learn and engage about improving communication skills, civic engagement and more.

Summit offered the following Workshops:

- Building a strong LinkedIn profile
- Effective science communication
- Fostering successful mentorship
- Becoming an effective science advocate
 - Scientists and startups





2022 NATIONAL HEALTH RESEARCH FOR RUM

STRAIGHT TALK: THEN, NOW, IMAGINE

1,100+ attendees
70 speakers
13 high-ranking government officials







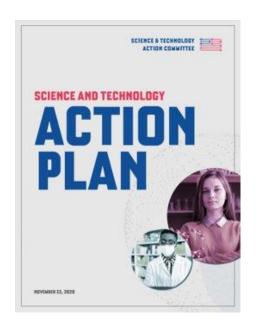




Discussion topics included:

Clinical Trial Diversity
Global Health
Patient Centered Research and Treatment
Health Services Research
Health Equity
Antimicrobial Resistance
Science Trust
Biomedical Workforce Diversity

Science and Technology Action Plan



23 non-profit, academic, foundation, and corporate leaders working to make the case for a bold approach to bolstering the nation's R&D capacity.

LEADERSHIP

Elevate the OSTP Director to a cabinet-level position endowing S&T with voice at the highest level of government.

COORDINATION

Incentivize greater cross-agency collaboration across federal departments/agencies conducting R&D to harness the full power of our public science and technology enterprise.

INVESTMENT

At least double federal expenditure for R&D and STEM education as a share of the U.S. economy over the next five years, from 0.7% to 1.4% of GDP.



Science and Technology Action Committee

STAC's 2023 Agenda

- Build on 2022 legislative successes, including passage of the CHIPS and Science Act, to secure additional federal R&D appropriations
- 2. Ensure US remains leader on global R&D by highlighting need for ongoing investments
- 3. Build support for science and tech investment by completing report on State of Science in America highlighting future priorities



Freshman Project: Cultivating New Champions



1)

Build stronger ties between new Members of Congress and the science community

2)

Create platform to hear from freshman Members and staff on role science and technology play in their districts

3)

Engage new Members of Congress through public and private science organizations, their wide network of members, and the constituent science community



Research! America In the News



Bloomberg Law













nature

San Francisco Chronicle









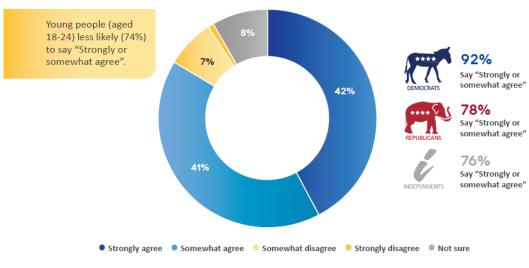
America Speaks! Poll Data Summary Vol. 23



Thanks to the American Medical Association for support of America Speaks! Poll Data Summary Volume 23.

HIGH BIPARTISAN SUPPORT FOR BASIC RESEARCH

Do you agree or disagree with the following statement? Even if it brings no immediate benefits, basic scientific research that advances the frontiers of knowledge is necessary and should be supported by the federal government.



Source: A Research! America survey of U.S. adults conducted in partnership with Zogby Analytics in January 2023.



































Coming Soon

- 2023 National Health Research Forum- Coming September 19 & 20!
- 2023 Early Career Summit Coming in June!
 - Session 1: Career Tour Session
 - Session 2: LinkedIn and Resume building
 - Session 3: Elevator Pitch
 - Session 4: Science Communication
 - Session 5: Science and Startups



2024 Advocacy Awards- Nominations Deadline is June 30!

Discovery | Innovation | Health Prize



Generously Supported by Pfizer

- A \$200,000 prize will recognize and provide support for a bold vision for progress against pandemic threats
- Applications will be open mid-May through mid-June
- A highly esteemed jury, led by Dr. Victor Dzau, will select the final awardee
- Prize awarded in September 2023 at our National Health Research Forum
- Coming Soon: More details on our web site; social media marketing; press release
- Contact: prize@researchamerica.org



Thank You to Research! America Staff

Mary Woolley

President and CEO

Ashley Arabasadi

Senior Director of Global Health R&D Advocacy

Erin Brown

Manager of Communications and Marketing

Sara Chang

Senior Director of Policy and Advocacy Programs

Mike Coburn

Executive Vice President & Chief Operating Officer

Ellie Dehoney

Senior Vice President of Policy and Advocacy

Jasmine George

Manager of Advocacy Programs & Formerly **Dr. Louis Sullivan Science Policy Fellow**

Katie Goode

Senior Director of Development and Membership

Emma Gogol

Development and Membership Associate

Tim Haynes

Senior Director of Communications

Sophia Kaska, PhD

Manager of Science Initiatives and Outreach

Jacqueline Lagoy

Global Health R&D Operations and Events Coordinator

Aimée Lefever

Director of Operations

Taylarr Lopez

Director of Communications

Jenny Luray

Senior Vice President of Strategy and Public Engagement

Anne Mandeville

Vice President of Development and Membership

Samantha Miller

Associate Director of Policy & Advocacy

Lisa Montgomery

Executive Assistant

Sheila Murphy

Vice President of Advocacy Programs and Initiatives

Joel Nepomuceno

Director of Membership

Melissa Patton

Operations and Database Coordinator

Michelle Reddersen

Controller

Victoria Schneider, PhD Global Health R&D Program Manager Savannah Sims

Senior Associate, Global Health R&D Advocacy

Dr. Leroy Hood Science Policy Fellow

Francesca Manzella

Lasker/Research!America Fellow for

Civic Science Fanuel Muindi

Burroughs Wellcome Fund Interns

Trent Carlson
Caterina DiBiase
Kelsey Hopland
Rachel Hostetler
Sophie Johnson
Leanna Kalinowski
Sarah Pol
Laurie Zabala

Civic Engagement and Science Initiatives Intern

Emma McMullan



Thank You for Your Membership and Engagement!