2023 Annual Meeting of Members

April 20, 2023
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

Deborah Trautman, 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


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, PhD
Duke University Medical Center

Ayman El-Mohandes, MBBCh, MD, MPH
City University of New York

Arthur C. Evans Jr., PhD
American Psychological Association

Dario 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

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
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.
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
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

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


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?
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

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 Cohesive National Plan maximizing strategic and coordinated federal efforts
“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
Progress To Date

• 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
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
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

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

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
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
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

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

1. 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
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.

- **92%** Say “Strongly or somewhat agree”
- **78%** Say “Strongly or somewhat agree”
- **76%** Say “Strongly or somewhat agree”
- **41%** Say “Somewhat agree”
- **8%** Say “Somewhat disagree”
- **7%** Say “Strongly disagree”
- **4%** Say “Strongly or somewhat disagree”
- **2%** Say “Not sure”

Young people (aged 18-24) less likely (74%) to say “Strongly or somewhat agree”.

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!*
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
<table>
<thead>
<tr>
<th>Name</th>
<th>Title and Department</th>
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<tbody>
<tr>
<td>Mary Woolley</td>
<td>President and CEO</td>
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<tr>
<td>Ashley Arabasadi</td>
<td>Senior Director of Global Health R&amp;D Advocacy</td>
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<tr>
<td>Erin Brown</td>
<td>Manager of Communications and Marketing</td>
</tr>
<tr>
<td>Sara Chang</td>
<td>Senior Director of Policy and Advocacy Programs</td>
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<tr>
<td>Mike Coburn</td>
<td>Executive Vice President &amp; Chief Operating Officer</td>
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<tr>
<td>Ellie Dehoney</td>
<td>Senior Vice President of Policy and Advocacy</td>
</tr>
<tr>
<td>Jasmine George</td>
<td>Manager of Advocacy Programs &amp; Formerly Dr. Louis Sullivan Science Policy Fellow</td>
</tr>
<tr>
<td>Katie Goode</td>
<td>Senior Director of Development and Membership</td>
</tr>
<tr>
<td>Emma Gogol</td>
<td>Development and Membership Associate</td>
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<tr>
<td>Tim Haynes</td>
<td>Senior Director of Communications</td>
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<tr>
<td>Sophia Kaska, PhD</td>
<td>Manager of Science Initiatives and Outreach</td>
</tr>
<tr>
<td>Jacqueline Lagoy</td>
<td>Global Health R&amp;D Operations and Events Coordinator</td>
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<td>Aimée Lefever</td>
<td>Director of Operations</td>
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<td>Taylarr Lopez</td>
<td>Director of Communications</td>
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<tr>
<td>Jenny Luray</td>
<td>Senior Vice President of Strategy and Public Engagement</td>
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<tr>
<td>Anne Mandeville</td>
<td>Vice President of Development and Membership</td>
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<tr>
<td>Samantha Miller</td>
<td>Associate Director of Policy &amp; Advocacy</td>
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<tr>
<td>Lisa Montgomery</td>
<td>Executive Assistant</td>
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<tr>
<td>Sheila Murphy</td>
<td>Vice President of Advocacy Programs and Initiatives</td>
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<td>Joel Nepomuceno</td>
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<td>Melissa Patton</td>
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<td>Michelle Reddersen</td>
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<td>Savannah Sims</td>
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<td>Dr. Leroy Hood Science Policy Fellow</td>
<td>Francesca Manzella</td>
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<tr>
<td>Lasker/Research!America Fellow for Civic Science</td>
<td>Fanuel Muindi</td>
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<tr>
<td>Burroughs Wellcome Fund Interns</td>
<td>Trent Carlson, Caterina DiBiase, Kelsey Hopland, Rachel Hostetler, Sophie Johnson, Leanna Kalinowski, Sarah Pol, Laurie Zabala</td>
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<td>Emma McMullan</td>
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Thank You to Research!America Staff
Thank You for Your Membership and Engagement!