

A man in a striped shirt is blowing bubbles in a park. A young girl in a yellow shirt is in the foreground, smiling and reaching out towards the bubbles. The background is a lush green park with trees and grass. The overall mood is joyful and nostalgic.

RESEARCH
AMERICA **30** YEARS

2019 ANNUAL REPORT

**THEN,
NOW,
IMAGINE:
30 YEARS OF IMPACT**

DEAR ADVOCATE,

2019 marked a milestone for Research!America: our 30th year working with you, our members and partners, at the intersection of research, innovation, and policy. This past year was a year of terrific accomplishment — highlighted below — as we made progress in making research and innovation for health a higher national priority.

We know there is much more to be done to assure research has the financial and human resources as well as the partnerships and policies to drive medical progress and to deliver better health, economic growth, prosperity, and national security. In the year ahead, we will be working to overcome a very tight budget scenario for federal science agencies as well as policy challenges around such complex issues as foreign government influence, fetal tissue research, and threats to research and innovation that could result in loss of U.S. global leadership. We will stand shoulder to shoulder with the broad science community in making common cause as we do this work.

We also will, as always in election years, be working with our partners to encourage candidates to speak out on the value of research and innovation. This year, based on successes we've seen with our social media initiatives, we will feature a social media push to Presidential and Congressional candidates across the political spectrum underscoring the high priority the public places on achieving medical and scientific progress.

ADVOCACY IN ACTION

Together with the collective voice of our members and others we changed the course of history for patients diagnosed with countless diseases. This happens one step at a time, meeting by meeting, letter by letter. Here is a snapshot of what we accomplished together in 2019.



RAISED THE BUDGET CAPS



PROTECTED FUNDING FOR AHRQ AND FOUGHT FOR REAUTHORIZATION OF PCORI



SECURED REPEAL OF THE MEDICAL DEVICE TAX



INCREASED FUNDING FOR NIH, CDC, FDA AND NSF

\$2.6 BILLION INCREASE FOR NIH IN FY20
\$636 MILLION INCREASE FOR CDC IN FY20
\$203 MILLION INCREASE FOR NSF IN FY20
\$91 MILLION INCREASE FOR FDA IN FY20



STRENGTHENED OUR PUBLIC HEALTH DISEASE TRACKING CAPABILITIES

We have long kept a finger on the pulse of public sentiment, and we will continue to provide that information to our members, public decision-makers, and the media on a timely and relevant basis.

The theme of this report, “Then, Now, Imagine,” is a message frame we have put to work for years. It is a clear and powerful way to capture progress made possible by our nation’s research ecosystem, and to align research and innovation with the aspirations we all have for a future we rightly imagine when scourges like cancer, Alzheimer’s, heart disease, mental illnesses, and more are consigned to the history books. We are relentless in our commitment to that imagined future, and we know you are as well. Let’s work together in this exciting new decade for research.

With thanks for your support and engagement and in anticipation of our continued partnership this year.



The Honorable
Michael N. Castle
Chair, Research!America

A handwritten signature in black ink that reads "Michael N. Castle".



Mary Woolley
*CEO and President,
Research!America*

A handwritten signature in black ink that reads "Mary Woolley".

In 2019 Research!America:



**ATTAINED 83 MILLION
MEDIA REACH**



**KEPT A FINGER ON THE
PULSE OF PUBLIC OPINION
WITH 4 NEW SURVEYS**



**RELEASED U.S. INVESTMENTS IN
MEDICAL & HEALTH R&D DETAILING
PUBLIC, PRIVATE, AND NONPROFIT
SECTOR FUNDING SOURCES**



**CONDUCTED TIMELY REAL-WORLD
EVIDENCE ROUNDTABLES IN SAN
FRANCISCO AND BOSTON**



**CONVENED FORUM ON THE
PIVOTAL ROLE THE LANDMARK
BAYH-DOLE ACT PLAYS IN THE
R&D ECOSYSTEM**



**LED MULTI-SECTOR EFFORT
AIMED AT INCREASING ACCESS
TO CLINICAL TRIALS**



Cystic Fibrosis

A REMARKABLE RESEARCH BREAKTHROUGH

THEN

In 1962, the median survival age for individuals diagnosed with cystic fibrosis (CF) was just ten years. In 1989, a team of pioneering scientists discovered the gene that causes CF, bringing hope to tens of thousands of patients and loved ones.

NOW

Research has led to the creation of 13 drugs for CF, including three that treat the underlying causes. Patient engagement supports development of better care. The life expectancy of people with CF who were born between 2014 and 2018 is predicted to be 44 years.

IMAGINE

Not just treatments for CF, but a cure that makes CF history.

ADVOCACY IN ACTION



Straight Talk: 2019 National Health Research Forum

A panel of women leaders in research kicked off the discussions at Research!America's annual National Health Research Forum. Forum panelists and speakers reflected on the challenges

and achievements of the past 30 years and highlighted hopes for the future to maximize the power of science and data to improve health. Special thanks to the [2019 Forum Sponsors](#) and [Lead Sponsor, Pfizer](#).



2019 Advocacy Awards

Leaders in medical, health, and public health research advocacy whose commitment to scientific progress transforms lives of individuals worldwide were honored at Research!America's Advocacy Awards Dinner. Nearly 500 distinguished leaders in government,

patient advocacy, scientific societies, independent research institutes, industry, and academia gathered to pay special tribute to the [honorees](#). Special thanks to the [2019 Advocacy Award Sponsors](#) and [Corporate Host, Johnson & Johnson](#).

HIV

CHANGING THE COURSE OF HISTORY

THEN

At the height of the HIV/AIDS epidemic in the U.S., an estimated 130,400 Americans acquired new HIV infections in 1985 alone. Most cases of HIV/AIDS were fatal.

NOW

Thanks to research discoveries about HIV transmission and treatment, public health efforts, and increased awareness, the number of new HIV diagnoses made in 2018 in the U.S. has decreased to 37,832. Through Active Retroviral Therapy (ART) and pre-exposure prophylaxis (PrEP) treatments, HIV has been transformed into a manageable chronic condition. And new advances have reduced treatments from dozens of pills to just one a day.

IMAGINE

A cure, a vaccine, and eradication of HIV/AIDS worldwide.

ADVOCACY IN ACTION

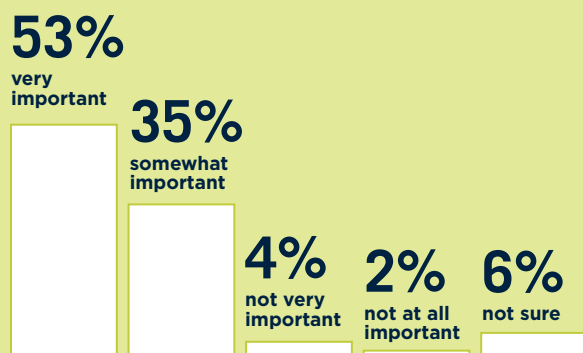
The Pulse of American Public Opinion

For over 28 years, Research!America has been commissioning surveys to keep a finger on the pulse of public opinion. Our surveys measure crucial topics such as public support for medical, health, and scientific research; Americans' priorities for political leaders; the importance of America's global leadership in health research; the visibility and invisibility of

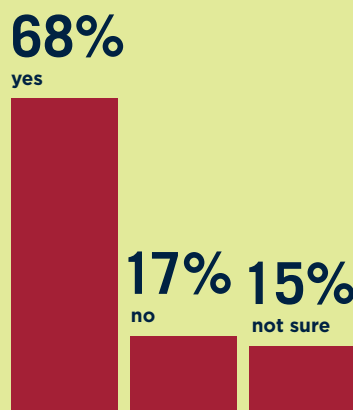
science; and related state-level issues. We also stay abreast of cutting-edge concerns such as vaccines, opioid and drug abuse, antimicrobial resistance, and climate change. This data is regularly used in research advocacy efforts with elected officials, press statements, social media, speeches and presentations, congressional testimony, and much more.



How important is it for the President and Congress to assign a high priority to ensuring faster medical progress?



Would you be willing to pay \$1 per week more in taxes if you were certain that all of the money would be spent on additional medical research?



SOURCE: A RESEARCH!AMERICA POLL OF U.S. ADULTS CONDUCTED IN PARTNERSHIP WITH ZOGBY ANALYTICS IN JANUARY 2020



Sickle Cell Disease

A PARADIGM SHIFT

THEN

Known as the “first molecular disease” sickle cell disease (SCD) was only curable with a bone marrow transplant—a treatment option not available for most patients. The average lifespan for an individual with SCD was 14 years.

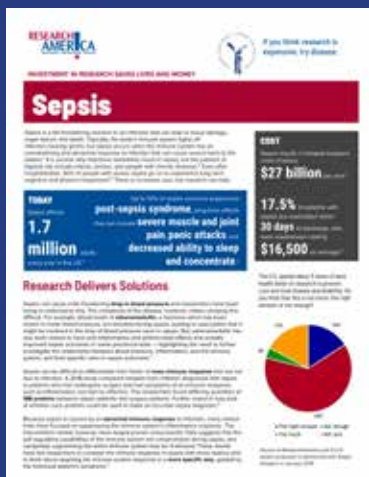
NOW

Thanks to advances in basic and translational research, gene therapies and gene editing tools, such as CRISPR/Cas9, are becoming possible treatment options for SCD. Individuals with SCD are living into their forties or fifties and beyond.

IMAGINE

A world in which SCD is cured with gene therapy.

ADVOCACY IN ACTION



Fact Sheets

Fact Sheets Available: 100+

In 2019 alone, Research!America released 30 new or updated fact sheets in partnership with the Lasker Foundation. The fact sheet library was visited 10,000 times over the course of the year, making it the 5th most-visited page on Research!America's site.

"Sepsis is a devastating condition that affects 1.7 million people in the U.S. every year, yet many people know little about what sepsis is. Research!America's fact sheet highlights the immense toll sepsis takes on our nation and the urgent need for increased national research funding and awareness."

THOMAS HEYMANN, EXECUTIVE DIRECTOR, SEPSIS ALLIANCE



Science Advocacy: Making Friends for Science

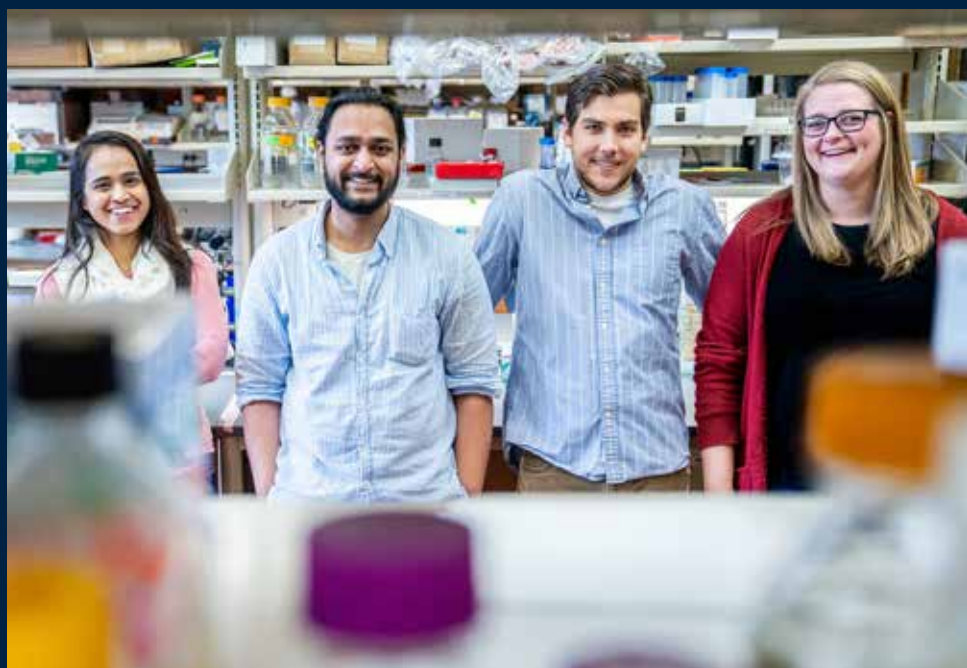
"I found [Mary Woolley's] talk very compelling. In fact, I already put into action the advice about finding common ground in skepticism. I have a friend who is skeptical of vaccines and using that technique made it much easier for me to calmly discuss the science behind vaccines."

KELLI F. MALOTT, PHD CANDIDATE, UNIVERSITY OF CALIFORNIA, IRVINE

Civic Engagement Microgrants

Empowered early-career scientists to be involved in local issues through competitive microgrants

The Research!America 2019-2020 Microgrant Initiative, with support in part by the Rita Allen Foundation, provides funding for graduate student groups' nonpartisan activities focusing on civic engagement, elevating the importance of scientific research, innovation and public health. These programs encourage dialogue between young scientists and local leaders about the roles science and research play in issues important to their communities.



The Virginia Tech Carilion Student Outreach Program has started a new science-focused podcast, "Big Lick of Science." The group plans to produce a bi-monthly podcast on communicating science to a wide audience.

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