

# A Message from the President and CEO Susan Peschin, MHS



In October 2014, the renown surgeon and writer Atul Gawande released Being Mortal: Medicine and What Matters in the End, which tackles end of life issues and challenges many traditionally held notions about the role of medicine. One of my favorite quotes from his book reads, "Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But

whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it the good we do can be breathtaking."

The Alliance has spent the last year focusing our health education and policy efforts to "serve the larger aims of a person's life." We push institutions, researchers, health care providers, and decision-makers to put themselves in the shoes of senior patients and their family caregivers. We do this in order to bridge the gap between what healthcare providers say and what patients actually hear; to improve development of, and access to, much-needed treatments for age-related diseases; and to remind those in power that there is nothing more consequential they can do than to support the health and well-being of those they serve.

I hope that you enjoy our 2015 impact report. We always remember that the work we get to do each day would not happen without your generous support. Thank you for traveling with us on our mission to advance science and enhance lives.

May the good we continue to do together in 2016 be breathtaking.

Best,

Susan Peschi



# Alliance for Aging Research

30 Years of Advancing Science and Enhancing Lives

## Valued Advocate & Influential Voice

The Alliance for Aging Research is the leading nonprofit organization dedicated to accelerating the pace of scientific discoveries and their application to vastly improve the universal human experience of aging and health. We are the respected source to get the facts right, understand the issues, and take action for healthier aging. The Alliance was founded in 1986 in Washington, D.C., and has since become a valued advocacy organization and a respected influential voice with policymakers.





## Advancing Science & Enhancing Lives

The Alliance believes that advances in research help people live longer, happier, more productive lives and help reduce health care costs over the long term, and that access to the latest scientific information empowers people to take control of their health. The Alliance strives to advance science and enhance lives through a variety of activities and initiatives—from policy issues to provider and consumer health programs—that generate knowledge and action on age-related issues.

# Our Impact

The Alliance has made aging research a fast growing priority for medical research today. Since 1986, federal support for aging research has more than tripled, private research and development in aging-related health has reached an all-time high, and new discoveries are making a lasting difference to the lives of millions of Americans.





#### Our Vision

America's science, innovation, and public spirit have the potential to avert the social and fiscal chaos that might otherwise accompany a "silver tsunami" of age-related diseases and lost productivity. The Alliance for Aging Research seeks to realize this potential and establish "healthy aging research" as a priority for our country as a whole. The advances we seek will make 85 years for most people look and feel like 65 today.

#### Health Education

The Alliance develops and disseminates educational materials on a variety of health topics that disproportionately impact older adults. From patient videos to health care professional toolkits, the Alliance aims to educate older adults and those they interact with at points of care to ensure the unique needs of older patients are taken into account when making medical decisions.

In addition to producing several new resources for patients, caregivers, and health care professionals, the Alliance also launched a new health information landing page, making it even easier to find resources by therapeutic area and audience. Check it out at www.agingresearch.org/health-information.



AGING RESEARCH



CAREGIVING HEALTH



DISEASES & CONDITIONS



DRUG SAFETY



HEALTH CARE PROFESSIONAL RESOURCES



HEALTHY AGING

### Grandparents' Safe Storage Tip Sheet

www.agingresearch.org/upandaway

Objective: To educate grandparents about safe drug storage and reduce the risk of unintended ingestion of household medications by children.

• Released in November 2014, campaign resources include an updated Up and Away "Tips for Grandparents on Safe Medicine Storage" tip sheet, a collaborative promotional letter from both the Alliance and CHPA, and a webcast for key leaders at organizations, interested press, and related experts to learn more about the initiative.



301 news outlets with an audience of 23 million displayed the press release



47,506 reached



8 million views of system wide ads placed on the D.C. Metro system



#### Silver Book®: Cancer

www.silverbook.org/condition/cancer

Objective: To raise awareness about the growing burden of cancer and the power of innovation (with special emphasis on personalized medicine and immuno-oncology) to reduce this burden—saving money and lives.

A release event for the Silver Book®: Cancer volume and factsheet was held on Capitol Hill on May 21, 2015. Speakers at
the event included Daryl Pritchard of PMC, Harvey Jay Cohen, MD of Duke University and AACR, and Beverlye Hyman-Fead,
our patient voice. The release event and resources were produced in partnership with the Personalized Medicine Coalition
and the American Association for Cancer Research.







3,400 volumes distributed to Congress, MED-PAC members, cancer groups, and more



37,857 reached on social media



# 21 organizations

represented at a standing room only briefing on Capitol Hill

#### Living with Atrial Fibrillation

## www.agingresearch.org/atrialfibrillation

OBJECTIVE: To increase awareness about atrial fibrillation (AFib) and the importance of preventing stroke in AFib patients.

Living with AFib resources, which include a brochure and two videos, were released in February 2015. Both videos are now featured in CardioVisual, an app designed for cardiologists to use as an educational tool for their patients.



24,000 resources distributed to health care professionals



60,057 reached on social media



130,852 views



### Living with Venous Thromboembolism

www.agingresearch.org/vte

OBJECTIVE: To increase awareness of what venous thromboembolism (VTE) is, how to detect it, and the importance of early detection and treatment.

Released in February 2015, the campaign features a Living with VTE video and brochure.





24,000 resources distributed to health care professionals



43,407 reached on social media



75, 143 views of the Living with VTE video

## Living with Valve Disease

www.livingwithvalvedisease.com

Objective: To provide resources for patients with valve disease and their caregivers.

Launched in June 2015, LivingwithValveDisease.com offers a one-stop online resource for valve disease patients and caregivers, with original and aggregated content from a host of reliable sources. The content includes articles, podcasts, videos, and the stories of valve disease patients.



32,351 reached on social media



65,688 views of the video series



26,657 views of the Living with Valve Disease webpage



#### Heart Valve Disease in Women: Workshop Kit & Video

www.agingresearch.org/valve\_disease

OBJECTIVE: To help women identify signs and symptoms of valve disease and seek treatment if necessary.

Released in September 2014, resources include a Leader's Guide, pocket film, participant quizzes, slide presentation, promotional poster, sign-in sheets, and evaluation forms.





40,000 resources

libraries, senior centers, etc.



312 news outlets distributed to health educators, with an audience of 22 million displayed the press release



33,542 views of the video

## **Public Policy**

One of the Alliance's most important missions is to advocate for aging research by working with legislators, health experts, and other like-minded organizations.



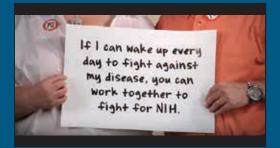
# Video Advocacy Spotlight

#### The Healthspan Imperative

The Alliance's Healthspan Imperative video continues to serve as an important tool advocating for more federal investment in geroscience. The video, narrated by Emmy Award-winning television show host Martha Stewart, features exclusive interviews about how insights from basic biology can help prevent multiple chronic diseases of aging.

- Since its release in July 2014, the Healthspan Imperative has been viewed more than 38,000 times on YouTube.
- A special screening at the E Street Theater in Washington, D.C., drew more than 100 thought leaders and experts in health research and aging.





#### Rally for Medical Research

The Alliance participates annually in the Rally for Medical Research Capitol Hill Day, organized by the American Association for Cancer Research. In 2015, the Alliance released a video at the Rally on the vital impact the NIH has on research

The video was debuted at the Rally for Medical Research before more than 300 organizations.



#### Adult Immunizations

Objective: To explore the drivers and obstacles of adult vaccine use.

Working with Bates White Economic Consulting LLC, the Alliance released "Our Best Shot: Expanding Prevention Through Vaccination in Older Adults" to form policy recommendations that might lead to increased immunization amongst older adults.

- The paper was presented during a poster session at the HHS Healthy Aging Summit in July of 2015 to an audience of 500 clinicians, public health officials, educators, researchers, students, and other participants.
- The Alliance hosted a standing room only Capitol Hill briefing that featured a pre-release of the HHS Adult Immunization Plan.
- The Alliance submitted recommendations from the white paper as proposals for inclusion in the Senate Finance Committee's initiative on multiple chronic conditions.
- Plans are under way to launch a major education initiative in 2016 to help seniors better understand the vaccine schedule and how the shots are covered under Medicare plans.

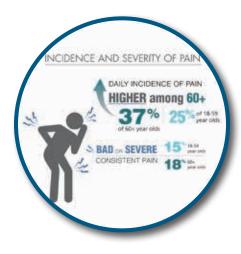
## Bioactives and Aging

OBJECTIVE: To examine the critical factors that contribute to healthy aging.

The Alliance was a major sponsor of the July 2015 Healthy Aging Summit that was attended by more than 600 public health professionals from around the country.

- The Alliance hosted a plenary session on the latest research in geroscience—an interdisciplinary field that aims to understand the relationship between aging and age-related disease featuring leaders from the NIA, the Buck Institute for Research on Aging, and the Mayo
- The Alliance also led a widely attended summit panel discussion titled, "Impacting the Health of Aging Populations: The Role of Bioactive Research, Innovation and Policy," in partnership with the Mars Center for Cocoa Health Science. The panel featured speakers from the USDA and the Human Research Nutrition Center on Aging at Tufts.





### Over-the-Counter Pain Management Survey

OBJECTIVE: To better understand patient attitudes about pain management in response to the FDA's reconsideration of dose-limiting extra-strength acetaminophen.

The Alliance conducted a survey to compare the views of the older population and the general public, particularly those suffering from multiple chronic conditions, and gauge the impact that restricted access to extra-strength acetaminophen might have on demographic subgroups.

- The Alliance worked with the Clarus Research Group to survey 1,600 Americans aged 18+ (800 respondents aged 18-59; 800 respondents aged 60+).
- Survey results were presented at the National Council on Patient Information and Education's Stakeholder Forum titled "Seeking Solutions: Advancing our Understanding of the Safe Use of Acetaminophen" in March of 2015.
- In response to the 77 percent of survey participants who prefer education about safe OTC pain med use to FDA restriction, the Alliance developed a series of pocket films on safe pain med use that were released in February 2016.

#### Healthcare-Associated Infections Roundtable

OBJECTIVE: To elevate the issue of antibiotic stewardship and the rise of HAIs, and make recommendations for feasible policy changes to improve outcomes.

- The Alliance convened a meeting of leaders from the fields of aging, infectious disease, health care, and government to discuss how to address the disproportionate impact of HAIs on older adults.
- The meeting featured presentations by the CDC, the White House Office of Science and Technology Policy, and the Peggy Lillis Memorial Foundation.
- Recommendations from the roundtable were submitted by the Alliance as proposals for possible inclusion in the Senate Finance Committee's initiative on multiple chronic conditions.





## Alliance on the Issues

#### **ADAPT Act & PATH Act**

The Alliance supported both the Antibiotic Development to Advance Patient Treatment (ADAPT) Act and Promise for Antibiotics and Therapeutics for Health (PATH) Act. The ADAPT Act would create additional incentives for the development of new antibiotics, antifungals, and for resistant HAIs. The PATH Act would streamline the regulatory pathway for anti-infective treatments intended for patients with unmet medical needs.

#### Medical Device Tax

The Alliance advocated in support of legislation to repeal the medical device tax by:

- Conducting a series of Capitol Hill visits to discuss the measurable impact this tax has had on innovation and the anticipated negative effect it would have on future research and development; and
- Submitting statements to the House and Senate committees of jurisdiction when they held hearings on the issue of repeal in the spring of 2015.



#### 21st Century Cures and Innovation Act

The Alliance worked with the U.S. House of Representatives' Energy and Commerce Committee to shape provisions in H.R. 6, the 21<sup>st</sup> Century Cures Act, including:

- Establishing an Innovation Fund;
- Providing additional incentives for young investigators to enter research;
- Expanding opportunities for patient and caregiver input in the drug development process;
- Revamping hiring procedures at the FDA;
- Strengthening endpoint review and clinical trial design; and
- Creating a pilot for real world data generation in the post-market setting.

H.R. 6 was overwhelmingly passed by the U.S. House of Representatives one year later. The Alliance continues to work on the U.S. Senate's Health, Education, Labor and Pensions Committee companion "Biomedical Innovation Agenda" effort.





Accelerate Cure/Treatments for Alzheimer's Disease (ACT-AD) Coalition (www.act-ad.org) is a coalition of committed national organizations seeking to accelerate the development of potential cures and treatments to slow, halt, or reverse the progression of Alzheimer's disease (AD) through research. ACT-AD continues its reputation as the preeminent multi-stakeholder partnership on regulatory issues in the AD space.

- ACT-AD convened its 7<sup>th</sup> FDA/AD Allies Meeting to discuss how to improve therapeutic development for early and mild stage AD. The meeting explored current strategies for demonstrating clinical meaningfulness in ongoing trials in early AD patients and how they might inform approaches for future trials.
- In the spring of 2015, ACT-AD launched a webinar series on scientific and policy topics relevant to drug development in AD. The first webinar covered the need for novel AD drug targets, provided an overview of the science behind the pursuit of novel targets, and highlighted current partnerships between the public and private sector to accelerate the identification and validation of these targets.



The Alliance's **AFib Optimal Treatment Task Force** has acted as an umbrella group for efforts to advocate for, and educate on the importance of, properly balancing stroke and bleeding risk in the treatment of older AFib patients.

- During its third year, the Task Force convened a symposium to further identify areas of policy and health that should be improved to address the problem of under-anticoagulation of older patients with AFib. This symposium included presentations by representatives from the FDA, NHLBI, NINDS, NIA, AHRQ, the CDC, and the VA.
- The Task Force continued advocacy efforts based on the symposium recommendations and secured report language in the FY2016 Labor HHS Appropriations bills that would further collaboration at NIH and increase activity at the CDC on risk reduction in AFib treatment.



**Aging in Motion (AIM)** (www.aginginmotion.org) is a coalition of organizations, led by the Alliance for Aging Research, working to advance research and treatment of sarcopenia and age-related functional decline.

- AIM developed and submitted a proposal to the CDC to add an ICD-10 code for the diagnosis of sarcopenia. Once accepted, the code will be available for use by health care providers as early as 2017, which opens up the potential for management of sarcopenia using physical therapy, nutritional interventions, and future pharmacologic treatments.
- AIM also continued to pursue recognition of sarcopenia by the FDA and their qualification of a functional measure for use in treatment trials for sarcopenia.



The Alliance returned as chair of **Friends of the National Institute on Aging (FoNIA)** (www.friendsofnia.org).

- FoNIA hosted "Turning Discovery Into Health," a successful Capitol Hill briefing, featuring presentations on the importance of NIA-funded research to stem the tide of chronic diseases of aging.
- FoNIA's advocacy activities on Capitol Hill and with the Obama Administration resulted in increases to the NIH and NIA budgets. The House and Senate FY2016 Appropriations bills included increases of \$300 million and \$350 million for aging and Alzheimer's research.

# 2015 Roundtable Discussion: "Aligning Regulatory Processes for an Aging Population"

The 2015 Roundtable Discussion, "Aligning Regulatory Processes for an Aging Population," brought together the perspectives of both U.S. and European officials to highlight strategies both have to align regulatory activities for medical products targeted at the aging population. The discussion focused on the appropriate inclusion of older adults in clinical trials, how best to employ scientific and data-driven initiatives to enable more rapid access to new medical products, and engagement in public-private partnerships to accelerate innovation.

For information about the September 20, 2016, Roundtable, visit: www.agingresearch.org/2016Roundtable.



**Dr. Roslyn Schneider**Pfizer | Moderator



**Dr. Jeff Shuren** FDA | PANELIST



**Dr. Janet Woodcock**FDA | PANELIST



**Dr. Francesca Cerreta**EMA | PANELIST

## 2015 Annual Bipartisan Congressional Awards Dinner

The Alliance for Aging Research held its 22<sup>nd</sup> Annual Bipartisan Congressional Awards Dinner on Tuesday, September 29, 2015, at the Willard InterContinental Hotel in Washington, D.C. The Alliance was proud to honor the following individuals for their contributions to advance the science of human aging:



Claude Pepper Award for Advancing Healthy Aging

The Honorable
Diana DeGette (D-CO-1)
U.S. House of
Representatives



Distinguished Public Service Award

The Honorable Kelly Ayotte (R-NH) U.S. Senate



Silver Innovator Award

Rudolph E. Tanzi, PhD Harvard University

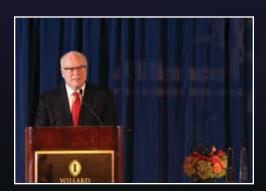


Indispensable Person of the Year Award

**Scott Simon**National Public Radio



Dr. Rudolph Tanzi accepts the Silver Innovator Award at the 22nd Annual Bipartisan Congressional Awards Dinner



The Alliance was honored to welcome back Kevin Rigby as the 2015 Master of Ceremonies



Representative Diana DeGette (center) receives the Claude Pepper Award with Susan Peschin (left) and Tom Spulak, Claude Pepper Foundation, Inc. (right)



The Alliance for Aging Research staff celebrate a successful Annual Dinner





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If you prefer to donate by check, make your check payable to "Alliance for Aging Research" and mail your check to: Alliance for Aging Research, 1700 K Street NW, Suite 740, Washington, DC 20006.



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