

VISION

CREATING A WORLD WITHOUT ALS



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Buckets of Ice Heat Up ALS Research

By Richard Robinson

Four major research initiatives made possible by Ice Bucket Challenge funding are poised to accelerate the search for the causes and treatments for ALS. “Advances in the research field have brought us to an exciting and very promising point in our quest to understand ALS,” said ALS Association Chief Scientist Lucie Bruijn, Ph.D., M.B.A. “The unprecedented new funding will now allow us to push forward to make the most of those advances.”

Each of the new initiatives is a collaborative effort among top ALS researchers, joining together to increase the depth and breadth of their research. Major research areas include developing a full understanding of the genes that contribute to ALS; using stem cells to model the disease; developing biomarkers for tracking disease progression and response to therapy; developing new treatments, including antisense therapy against the most common genetic forms of ALS; and strengthening the infrastructure for central data and biosample storage and dissemination.

Recently, scientists have begun to discover that genes account for a much larger fraction of ALS cases than previously suspected. This has given new urgency to the search for genes that cause the disease or influence age at onset or rate of progression. Two initiatives, led by the New York Genome Center (www.nygenome.org) and Project MinE (www.projectmine.com), will hasten the discovery of such genes through sequencing the genome, or the entire set of DNA, in thousands of individuals with ALS. Discovery of new genes that influence ALS risk and progression provides new targets for therapy development.

Therapy development is the focus of the Neurocollaborative. In partnership with Biogen and ISIS Pharmaceuticals, this initiative will pursue development of antisense therapy for the C9orf72 and SOD1 genes, the two most common genetic causes of ALS. Antisense has emerged as among the most promising ways to prevent disease-causing genes from being expressed; therefore, stopping the disease at its earliest cellular stages. Successful antisense

‘The unprecedented new funding will now allow us to push forward...’

—Lucie Bruijn, Ph.D., M.B.A., ALS Association Chief Scientist

therapy may also provide important clues to developing treatments for other forms of ALS. The Neurocollaborative will also be hosting a central facility for creation of clinical-grade induced pluripotent stem (iPS) cells, which will be openly shared with the ALS research community. (iPS cells are a key research tool and potential source of therapeutic cells in ALS. Derived from skin cells, they can be converted into unlimited numbers of neurons for study and engineered to carry protective factors as a possible treatment strategy.)

A key need for speeding ALS clinical trials is development of biomarkers that can track progression and response to treatment. Meeting that need is one goal of ALS Accelerated Therapeutics (ALS ACT), a novel academic-industry partnership that will develop neuroimaging tools for use in clinical trials and provide funding support for trials that incorporate biomarkers in the design of the trial. In addition, ALS ACT will strengthen ongoing collaborative efforts in support of clinical trials, including NeuroBANK, a central repository for clinical research data in ALS, and the NEALS (Northeast ALS Consortium) Biorepository.

“Each of these four new initiatives has the potential to make major strides in developing new treatments,” Dr. Bruijn said. “But just as importantly, the synergies we can expect to see among them—sharing data, rapidly converting new genetic discoveries to disease models with iPS cells and drawing on centralized databanks to better classify different types of ALS—will further accelerate research in each of these areas. We are deeply grateful for the new opportunities provided by the Ice Bucket Challenge, and fully expect that these new initiatives, along with critical ongoing studies elsewhere, will open new avenues for rapid therapy development.”

Challenge and Hope

Message from The ALS Association
President and CEO Barbara J. Newhouse

When I joined The ALS Association in June, the organization already had robust programs in research for treatments and a cure, care services for people and families living with ALS, and public policy. After only two months on the job, the Ice Bucket Challenge took the country by storm and changed the fight against ALS forever. By the end of the summer, The ALS Association and its chapters had raised more than \$115 million, thanks to the most successful disease awareness activity of all time.



President and CEO
Barbara J. Newhouse

Following the media frenzy, we quickly set about consulting with patient groups, chapters and our Board of Trustees to strategize on the most effective way to translate this success into supporting the mission of The Association. In October, we announced an investment of \$21.7 million toward several new projects in ALS research, care services and public policy to expedite the search for better treatments and a cure. We would not have been able to invest in these projects or sustain them in the future had it not been for the generous support of millions of Americans. The Ice Bucket Challenge has also enabled us to build closer alliances with other ALS organizations to collaborate in the search for ALS therapies. We were also helped by Major League Baseball's commitment to ALS research during the year that marked the 75th anniversary of Lou Gehrig's "Luckiest Man" speech.

For the second consecutive year, The ALS Association received the coveted "four-star" rating from Charity Navigator, one of the leading independent charity rating groups. In addition to the November activities surrounding National Family Caregivers Month and Veterans Day, we organized and held a Clinical Care Conference with nearly 400 participants from across the country. The Association also participated in the Society of Neuroscience international conference, followed in December by the International Symposium on ALS/MND.

The Ice Bucket Challenge and the subsequent activities initiated by The Association have significantly changed the landscape in the quest to create a world without ALS. Additional opportunities for partnerships and collaborations position our Association to lead the way into a new era of hope for truly effective treatments and ultimately a cure for ALS.

Building Government Support to Fight ALS

Thanks to the efforts of people with ALS and ALS advocates across the country, The ALS Association realized significant successes in Washington, D.C., in 2014. They included:

National ALS Registry: Congress provided \$8 million for the registry in 2015 (nearly a 30 percent increase) to fund: research projects designed to find causes of ALS; the potential addition of a biorepository; reports examining risk factors, ALS incidence, prevalence and demographic data; and efforts to increase clinical trials and speed enrollment by notifying eligible registry participants about trials.

ALS Research Program at the Department of Defense: Congress provided \$7.5 million for 2015, bringing total funding to nearly \$60 million for the program, which is specifically designed to find ALS treatments.

Speech generating devices (SGDs): In 2014, Medicare imposed new rules limiting coverage for SGDs. The Association secured the support of 200 Members of Congress who sent a joint letter opposing the changes. Medicare subsequently rescinded one of the rule changes. The Association helped lead a coalition of key

stakeholder organizations that joined together to fight the SGD coverage changes and recommend new SGD coverage policy.

Modernizing Our Drug and Diagnostics Evaluation and Regulatory Network (MODDERN) Cures Act: Congress enacted several provisions of the bill to speed patient access to new diagnostic tests. Significant Congressional support was generated for the remaining MODDERN provisions, which would provide new and increased opportunities to develop an ALS treatment. Nearly 100 Members of the House of Representatives now have cosponsored the legislation. Importantly, a companion bill was introduced in the Senate in December. The bicameral bipartisan support provides critical momentum as The Association works to enact the MODDERN Cures Act in 2015.

VA Housing Grants: The Veterans Administration implemented new regulations that automatically make veterans with ALS eligible for up to \$68,000 in grants to adapt their homes, speeding up the grant process by up to 12 months.

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GETTING CREATIVE

FOR A WORLD WITHOUT ALS

As the Ice Bucket Challenge came and went, an unprecedented number of local, regional and national corporations joined forces with The ALS Association. Some companies got involved on behalf of employee connections to ALS, while other were challenged by peers or other company representatives. These organizations used many fun and exciting approaches to get employees involved.

The store managers of Cumberland Farms, a premier convenience store and gasoline retailer with locations throughout the Northeast and Florida, were challenged by one of its national executives to step up to the plate and “do something big” with this—and did they ever. For several weeks during the summer, they donated to The ALS Association 20 cents for each bag of ice sold. The company raised \$46,000.

Amazon.com posted a “donate now” button for less than 48 hours, which resulted in donations of \$45,739 from thousands of people. Live Nation’s CEO, Michael Rapino, challenged his employees around the world to take the Ice Bucket Challenge, and Rapino pledged to

By Meghan Tallakson



donate \$100 for every video that was submitted. The Association received a check for \$146,000.

Vineyard and Vines, an American clothing and accessory retailer, hosted an ALS Day at its stores across the nation and helped raise \$16,000 in less than three hours. JPMorgan Chase matched employee donations, and the total company and employee donations reached \$176,884.

These stories are just a few highlights of the incredible outpouring of support received from corporations that have never before been engaged with The ALS Association’s mission. To all of you—THANK YOU!

In addition, ALS Association national partners Permobil, Quantum Rehab, Numotion, Phi Delta Theta and BAYADA, which have been with us over the last few years—THANK YOU—for engaging your employees in new ways around the Ice Bucket Challenge.

It’s been a wild and wet year for The Association and corporate America. The Association is grateful to everyone who has helped us move closer to creating a world without ALS.

Phi Delta Theta

By Andrew Christy

Phi Delta Theta, Lou Gehrig’s fraternity, has been a model philanthropic partner of The ALS Association for many years. In 2014, that partnership strengthened even further, as the Phi Delta Theta chapters demonstrated their support of The ALS Association by participating in the Ice Bucket Challenge.

Members of the fraternity brought the challenge to their campuses to rally their brothers and classmates to stand up in the fight against ALS. Phi Delta continued to demonstrate leadership in support of ALS Association chapter events across the country and helped to push the Walk to Defeat ALS® to new heights in many cities. The Association is thankful for the fraternity’s outstanding show of volunteerism, fundraising and public awareness.

The ALS Association is proud to have the Phi Delta Theta fraternity working at our side in the fight to put an end to Lou Gehrig’s Disease. We look forward to another successful year in 2015.



Hundreds of Phi Delts volunteered their time this year in order to help our events be as successful as ever.



Caregivers Need Care

By Amber Walters

Family caregivers are the lifeline to people living with ALS. On top of taking care of their loved one's personal needs, they assume the crucial but often undervalued role of maintaining the entire household and family structure. With quiet acceptance and determination, caregivers are responsible for such duties as financial management, arranging doctor appointments, housework, emotional support, transportation, childcare and much more. In addition, many caregivers work a full- or part-time job to help put food on the table and a roof over their family's head.

November is National Family Caregiver's Month (www.alsa.org/news/media/press-releases/caregivers-month-2014.html), a time taken each year to acknowledge and thank the individuals who bravely and selflessly take care of those who need it most. This year's theme was "Care Comes Home." For caregivers that need referrals for home healthcare or a respite program for some relief, The ALS Association's network of chapters is available to help and provide resources.

Caregivers can also receive assistance by organizing a Care Connection team, which can be accessed on The Association's website. Through this program, each family creates a list of potential team members and caregiving tasks that are specific to the needs of the person with ALS and the family. Getting help with everyday tasks, such as making a meal, running an errand or simply spending time with someone with ALS, provides welcome respite for the caregiver.

The ALS Association encourages everyone to remember how important it is to take care of the needs of caregivers, not just during November, but throughout the year. The caregivers' wellbeing ensures that those with ALS are cared for as well.

MAKING A BIG SPLASH

Ice Bucket Challenge Spurs ALS Awareness, Raises Funds and Media Presence for The ALS Association

By Stephanie Dufner

It was *the* viral event of summer 2014, involving notable entrepreneurs, celebrities and everyday people with buckets of water. It prompted a surge in ALS awareness globally. The ALS Ice Bucket Challenge allowed millions of people from around the world to become cognizant of ALS, and it raised more than \$115 million for The ALS Association. Additionally, it grew the organization's traditional and social media presence.

Last July, three men fighting ALS and their families made the challenge go viral. Pat Quinn, Pete Frates and Anthony Senerchia and their loved ones galvanized their social networks and inspired friends

and colleagues to take the challenge. The challenge involves pouring a bucket of ice water on one's head, nominating others to do the same on video, and then sharing that he or she is taking the challenge to spread ALS awareness. Those nominated had 24 hours to

complete the challenge and/or make a donation to the ALS charity of their choice. Nominated individuals continue this process and designate their family and friends to take the challenge. Prominent individuals who willingly drenched themselves include Microsoft co-founder and philanthropist Bill Gates (www.youtube.com/watch?v=XS6ysDFTbLU), "Tonight Show" host and comedian Jimmy Fallon (www.youtube.com/watch?v=b_kdke345NQ), and *Vogue* editor Anna Wintour (www.youtube.com/watch?v=E3ZRpzZ82yc).

During the challenge's zenith, The Association saw a cascade in donations. From late July to mid-September, the challenge yielded an astounding \$115+ million to the organization. More than two million new donors made contributions to The Association in the fight against ALS.

"These contributions will enable us to make strides toward achieving our mission," (www.alsa.org/about-us/mission.html) said Barbara Newhouse, The Association's President and CEO. "We can fund more research, care services programs and public policy endeavors that benefit people and their families living with ALS."

In early October, The Association announced an initial commitment

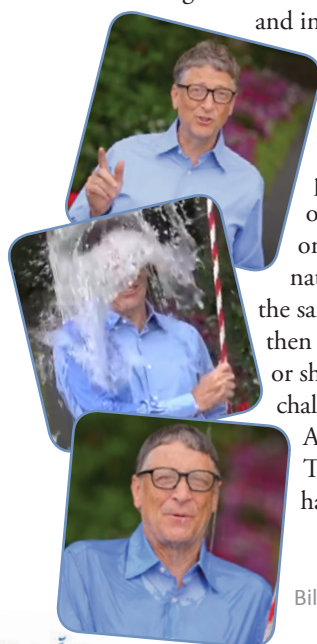
of more than \$21 million (www.alsa.org/news/media/press-releases/ibc-initial-commitment.html) toward treatments and a cure for ALS. The funding included investments in research with other ALS organizations: ALS ACT, the New York Genome Center, The Neuro-collaborative and Project MinE.

"Supporting these initiatives gives us more insight into this disease. That will bring us closer to finding treatments and ultimately a cure," Newhouse added. As part of a long-term strategy, The Association also agreed to triple its spending on ALS research.

Aside from the gush of donations to The Association, we saw a swell in social media followers. In early July, The Association's Facebook page had 35,300 page "Likes." Two months later, the page's "Likes" grew close to 333,000. Similarly, our Twitter feed listed nearly 9,000 followers at the start of the challenge; by September, we had 22,000 followers on this site.

Traditional media also increased outreach to The Association. Members of The Association's Board of Trustees and Executive Staff appeared on national cable news stations such as Fox Business Network, Bloomberg Television and CNBC. In addition, during the

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Bill Gates

SPLASH

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event's height, The Association received an average of 200 media contacts daily compared to approximately 10 per day prior to the challenge launch. Inquiries arrived from print and electronic news outlets based in the United States and throughout the world. An organization called GOOD Inc. created an animated video to show how the Ice Bucket Challenge spread around the globe, which can be viewed at:

www.youtube.com/watch?v=qTEchen97rQ



Jimmy Fallon

The ALS Association 2014 Clinical Conference



By Cynthia Knoche

During the first week in November, nearly 400 healthcare professionals gathered in Phoenix, Arizona, to learn about the latest technology and best practice care and support options for people living with ALS. The Association hosted the multi-day professional clinical conference attended by ALS Association Chapter Care Service staff, Certified Center clinical practitioners and licensed healthcare professionals from more than 42 states and Canada.

Conference attendees viewed leading-edge equipment and services available to those diagnosed with ALS. Whether maintaining quality of life through home care nursing services or accessing life-supporting ventilation equipment, attendees were able to discuss the features and benefits of a wide variety of equipment and services with representative clinical specialists during the conference's Exhibit Experience.

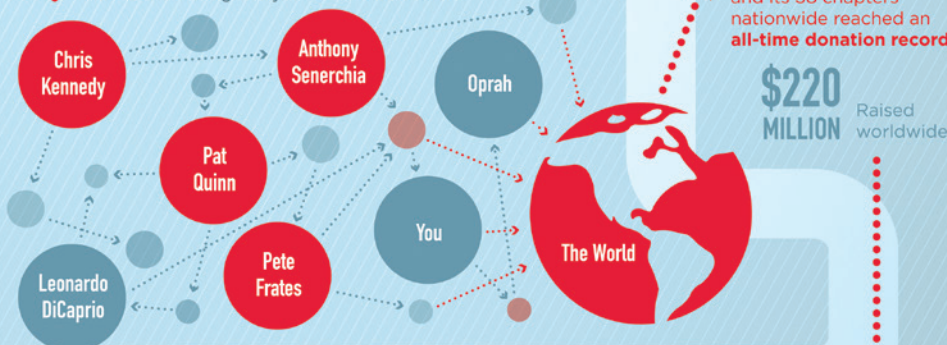
Concluding the conference, The ALS Association President and CEO Barbara Newhouse confirmed The Association will continue to support professional clinical education and announced that The Association is hosting the 2015 ALS/MND International Alliance Symposium next December in Orlando, Florida.

PROGRESS BY THE BUCKETFUL



FROM ONE TO MILLIONS

It all started on July 15, 2014, with golfer Chris Kennedy and quickly spread from his social network to others living with ALS. Within six weeks, more than 2.5 million people participated and/or donated including many celebrities worldwide.



MORE FUNDS = more progress where it matters most



RESEARCH

Tripling our annual research spending
Funding major new collaborative projects
Ensuring promising research remains funded



PUBLIC POLICY

Speeding up treatments to patients
Encouraging companies to invest in ALS research
Breaking down barriers for drug approval



CARE

Increasing grants to Certified Centers of Excellence
Expanding access via alternatives of care delivery
Broadening scope of programs and services

WHY IT MATTERS: the chilling facts about ALS

\$ 1 Billion+
cost of bringing one new drug to market

5000+
people are diagnosed each year

2-5 Years
average life expectancy

Why stop now? You have a shot at changing the world, in a way, and there's no reason to stop having fun... not only have fun, but you're creating awareness for a disease that has something special that's happening. God-willing, a cure could come."
—Pat Quinn

2x Military Veterans are twice as likely to get ALS

Touching the Future—



The Legacy Society recognizes those special individuals who have included The ALS Association in their long-term charitable plans. This includes gifts through a will or living trust; charitable gift annuity; or beneficiary designation in an IRA, 401K or other account. Gifts of any size are welcome, and you have the option of giving anonymously. You might consider honoring a friend or family member with a special legacy gift.

Among the most valued supporters of The ALS Association, members of The Legacy Society have determined that their legacy will be one of hope—hope that treatments and a cure for ALS will be found and that those living with ALS will be inspired to continue to fight this disease with awe-inspiring tenacity, courage and optimism.

If you would like to learn more about the many ways you can leave a legacy of hope, please contact:

David Moses, Director of Planned Giving at (888) 949-2577 x212, dmoses@alsa-national.org, or visit us at www.legacy.vg/alsa/giving.

We encourage you to let us know if you have included us in your will or financial plan as we would like to say “thank you” and welcome you into our family of Legacy Society members.

We extend a very special welcome to our newest members, listed here.

Anonymous (6)

Angelene Adler
in loving memory of Sue Harris

Diane Anderson

Rita E. Bagot

Martha Beachy

Beverly Beavers
*in loving memory of my husband,
James R. Beavers*

Britta Berge

Danny Beverage

Mary Blanton

Norman G. Block

Bernice Blohm

Belinda Boatwright

Mrs. David C. Bole
*in memory of my husband David,
and two of his Bole cousins, and one
nephew...all victims of ALS*

Elizabeth Bolton
in memory of Andy Bolton

Gay Brinkley Miriello

Ed Britt

Robert Brooks

Mady Brown

Mary Bucko

Jerry E. Byrd

Sandra Cantz

Philip and Janet Carlock

Lucille Caron

Laura D. Certano
*in memory of my husband,
James A. Certano*

Kathy Chrisman

Sue Lenke Clark

Rogene and Dr. Robert+ Conn

Kathleen Cooke

Harold Cosel

Bob and Sharon Danielson
*in loving memory of my dad,
Richard L. Gibson*

Joyce Davison

George De Coster

Pamela Deckard
*in loving memory of my husband,
David C. Hill*

Barbara C. Deeming

James B. Dietrich

Claire Drummond

James L. and Ann E. Dunn
in memory of our son, Jeffrey Lewis Dunn

Enid Dwyer

Barbara Emeigh

Kim Everhart

Mary Lou Fenn

Linda Fewell

Mary Ann Fiene

Margaret Fox-Warren

Donna Franklin

Pamela Friedman

Robbie Garritano

Nancy L. Golden, M.D.

Kimberly Goslin

Norman Green

Joseph P. Gross
*in loving memory of my mother,
Helen Gross*

Marjorie A. Gustin

Frances L. Hansen

Linda L. Hanson

Mr. and Mrs. David M. Heimos

Mary Hensley

Rebecca Huffer

G. Hungerford

Emilda Jaccard

Joseph Jance

Wanda Jennings

William Jurney

Karla M. Kraeszig
*in loving memory of my father,
Harry E. Kraeszig, gone but not forgotten*

Seymour Kraver

Raymond Krust

Charles Kusek

Randy+ and Debi Kyte

Bonnie Lajoie

Nelson E. LeBarron

Mervin LeBlanc

Richard and Nancy Ledford
in memory of Peggy Marie Rhyne Ledford

Al Lee and Alexis Halmy

Tina Ling

Richard Lissy

Patricia Mallon

Doug and Claudia McClure

Peter McKown
in memory of my father, John McKown

Carol Miller

Judith Jones Moore
*in loving memory of my mother,
Peggy Jones Bicket, who courageously
fought ALS*

John G. Morgan
*in loving memory of my mother,
Shirley Morgan*

William C. Morris

Rhoda J. Mull

Berjuhi Nazarian

Ralph and Susan Nicholson

Donald and Joyce Nielsen

Don and Rachel Novak

Joshua Nyman

Randy and Karen O'Hare
*in loving memory of our mothers,
Dee O'Hare and Diane Stone*

M. Eloise Olson

Thomas and Joan O'Reilly

Vaneda Orth

Bonnie and Stuart Pastman

Sue Payne

Shontea Price

Irene I. Reece
*in memory of my husband,
John C. (Bill) Reece*

Carol R. Resides

Kay Riper

Arnold Robbins

Patricia Rogers

Dawn Rossow

George and Judy Rowland

George M. Shafer

Jordan and Jen Sing
*in loving memory of my father,
Larry Sing*

Danielle Smith
*in loving memory of my mother,
Patricia Smith*

Warren and Dorothy Smyth

Laurie Speight+

Evelyn Spivack

Louis R. Stephon, Jr.

Brenda Struck

Harold Thompson

Martin Tivador

Tony Topp

Nancy Vaughn

Susan Waligora

Daniel Wardenburg

Virginia P. Wentreck

Duane Wing

Sylvia M. Wolff

John and Carolyn Wragge

William J. Zeigler

Alan Zimmerschied

*Every effort has been made to ensure the accuracy of this listing.
If your name has been inadvertently omitted or listed inaccurately,
please accept our apologies and contact our office at (888) 949-2577.*

+ Deceased



Make Your ALS Promise

By Maegan Bracken

Leave a lasting legacy in the fight against ALS. Establish your ALS Promise Fund to honor a loved one's battle against this dreadful disease, and create a virtual platform that commemorates your ALS journey.

After we receive your commitment,* we will work with you to build and customize your own tribute web page that can feature a story about your personal connection to the disease, photos of your loved one and family, spoken remembrances and a guestbook for visitors to leave their personal sentiments.

To learn more about the ALS Promise Fund, please visit www.alspromise.org or call Maegan Bracken at (202) 465-8807.

* Minimum commitment to establish your ALS Promise Fund is \$25,000 over five years.



Thousands of participants walked through red and white arches to begin the Walk to Defeat ALS® this year.

2014 Walk to Defeat ALS® Recap

By Andrew Christy

With the debut of the Ice Bucket Challenge this summer, the Walk to Defeat ALS had its most successful year yet. Whether reinvigorated by the Challenge or new and concerned about our cause, more than 150,000 ALS supporters nationwide participated in chapter Walks this year. It was incredible to feel your support, as Walks across the country broke fundraising and attendance records, and enthusiasm was off the charts. Celebrities and people near and far were not only accepting the Ice Bucket Challenge, but also coming out in droves to show their support, some even participating in multiple Walks.

The ALS Association's premier event is an opportunity for communities across the nation to demonstrate their concern for the urgent need to find the cure for ALS. What began 15 years ago as a grassroots effort to increase awareness has turned into a tremendous event to raise funds in support of The ALS Association's mission.

The ALS Association is thankful to everyone for helping to make the 2014 Walk season so successful. Every walker brings us one step closer to a cure.



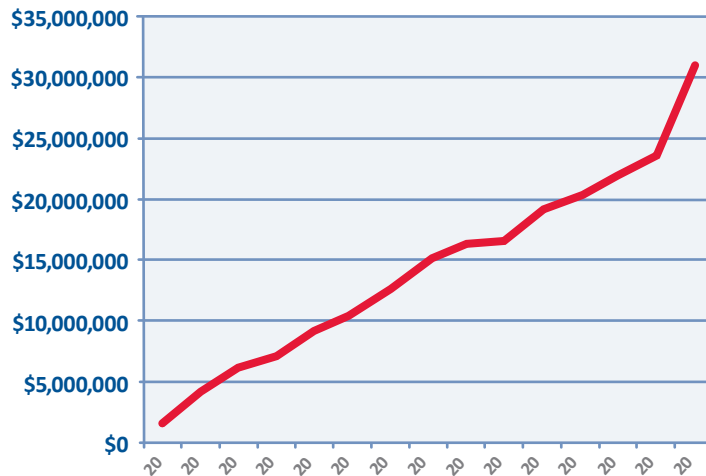
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2014 Walk Participants Raised More Than \$30M



Building Government Support

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Therapy Caps: Congress to extend the exceptions process that enables people with ALS to exceed imposed spending limits on occupational, physical and speech therapy services.

National Institutes of Health: Congress increased NIH funding by more than \$150 million and funding for the National Institute of Neurological Disorders and Stroke (NINDS) by more than \$17 million.

For more information and to get involved, please visit the Public Policy website at www.alsa.org/advocacy.