



MISSION PROGRESS

2023



ALS
ASSOCIATION

OUR MISSION
TO DISCOVER TREATMENTS AND A CURE
FOR ALS, AND TO SERVE, ADVOCATE FOR,
AND EMPOWER PEOPLE AFFECTED BY ALS
TO LIVE THEIR LIVES TO THE FULLEST.

WHAT IS ALS?

ALS, or amyotrophic lateral sclerosis, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Sometimes referred to as Lou Gehrig's Disease, ALS eventually leads to the death of nerve cells along with the loss of the ability to initiate and control muscle movement. As the disease progresses, people with ALS lose the ability to walk, talk, eat, and eventually breathe. It is always fatal, and there is no cure. People with ALS have an average life expectancy of two to five years after their diagnosis.

The ALS Association is the largest philanthropic funder of ALS research in the world. We fund global research collaborations, assist over 20,000 people with ALS and their families through our nationwide network of care and certified clinical care centers, and advocate for better public policies for people with ALS.

OUR GOAL IS TO MAKE ALS LIVABLE FOR EVERYONE, EVERYWHERE, UNTIL WE CAN CURE IT. THAT MEANS HELPING PEOPLE LIVE LONGER, HIGH-QUALITY LIVES AND PREVENTING OUR LOVED ONES FROM GETTING ALS.

WE DO THAT BY:



**FINDING NEW
TREATMENTS
AND CURES FOR
ALS**

**OPTIMIZING
CURRENT
TREATMENTS
AND CARE**

**PREVENTING OR
DELAYING HARMS
ASSOCIATED
WITH ALS**



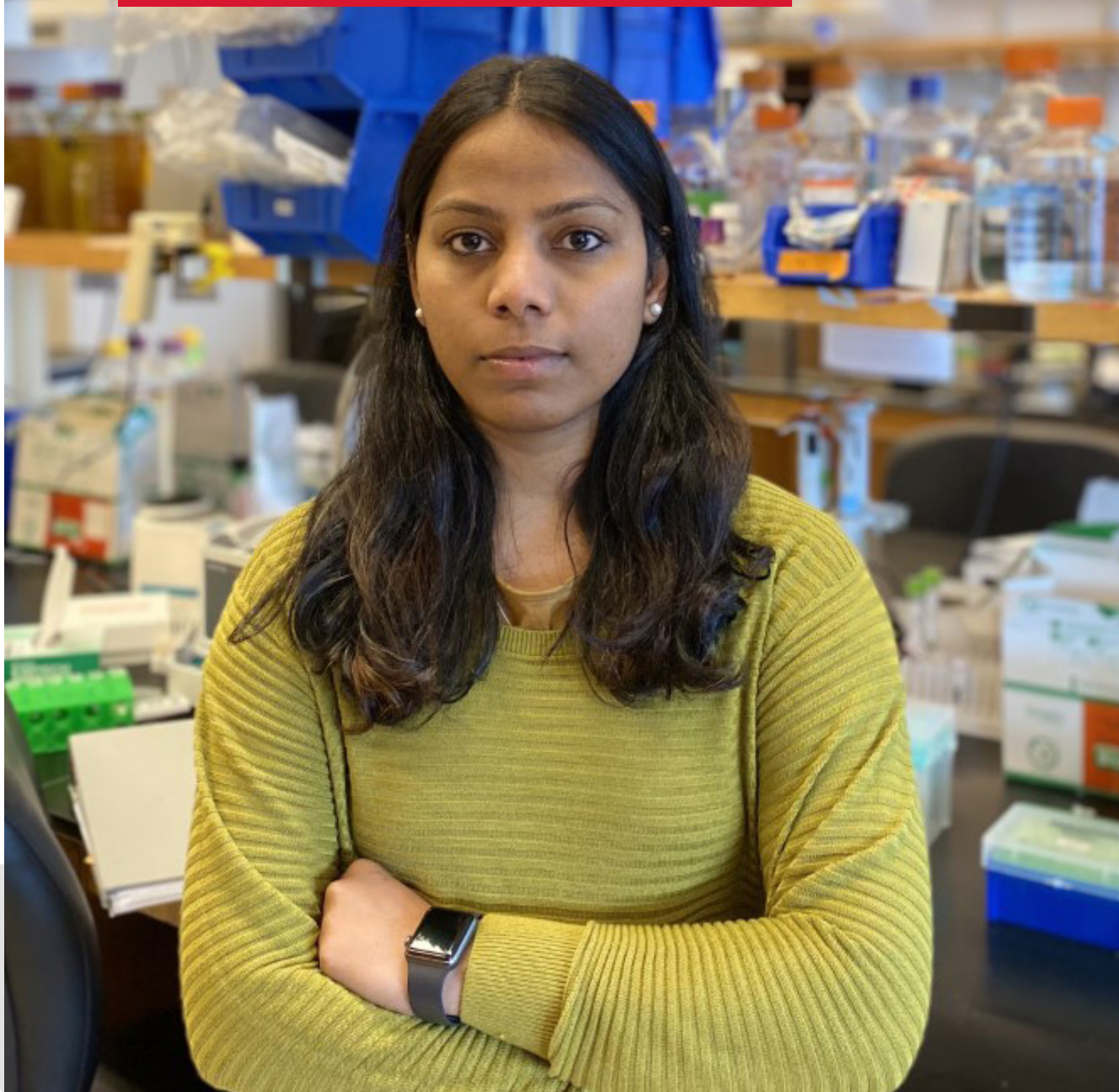
IN THE PAST YEAR WE HAVE SEEN INCREDIBLE PROGRESS IN OUR FIGHT TO CREATE **A WORLD WITHOUT ALS.**

In fact, we saw approval of the first drug developed with ALS Ice Bucket Challenge funding shown to slow down disease progression and extend life when the FDA approved Relyvrio for the treatment of ALS.

We work in communities across the country to make sure people with ALS have access to the best quality care and support available. Last year we served 21,654 people through our nationwide network of care. And we mobilized 40,000 advocates to fight for ALS in many ways, including increasing federal spending on ALS research and advocating for passage of a bill to speed the discovery of new treatments for people living with ALS through more clinical trials and expanded access to investigational drugs.

Our commitment is that every person living with ALS, regardless of where they live, should be able to access high-quality care and effective treatments. Together we are making progress toward building a world without ALS. Keep reading to learn more about the tremendous work being done throughout the Association.

FINDING NEW TREATMENTS AND A CURE





DRUG DEVELOPMENT RESEARCH

It can cost \$1-3 billion and take 10 – 15 years to develop a drug and get it approved by the FDA. Maintaining and growing the drug-development pipeline and accelerating the process is critical to realizing our vision of a world without ALS. Our global research program funds projects from the earliest phases of discovery into supporting clinical trials.



ADVOCACY FOR FEDERAL FUNDING

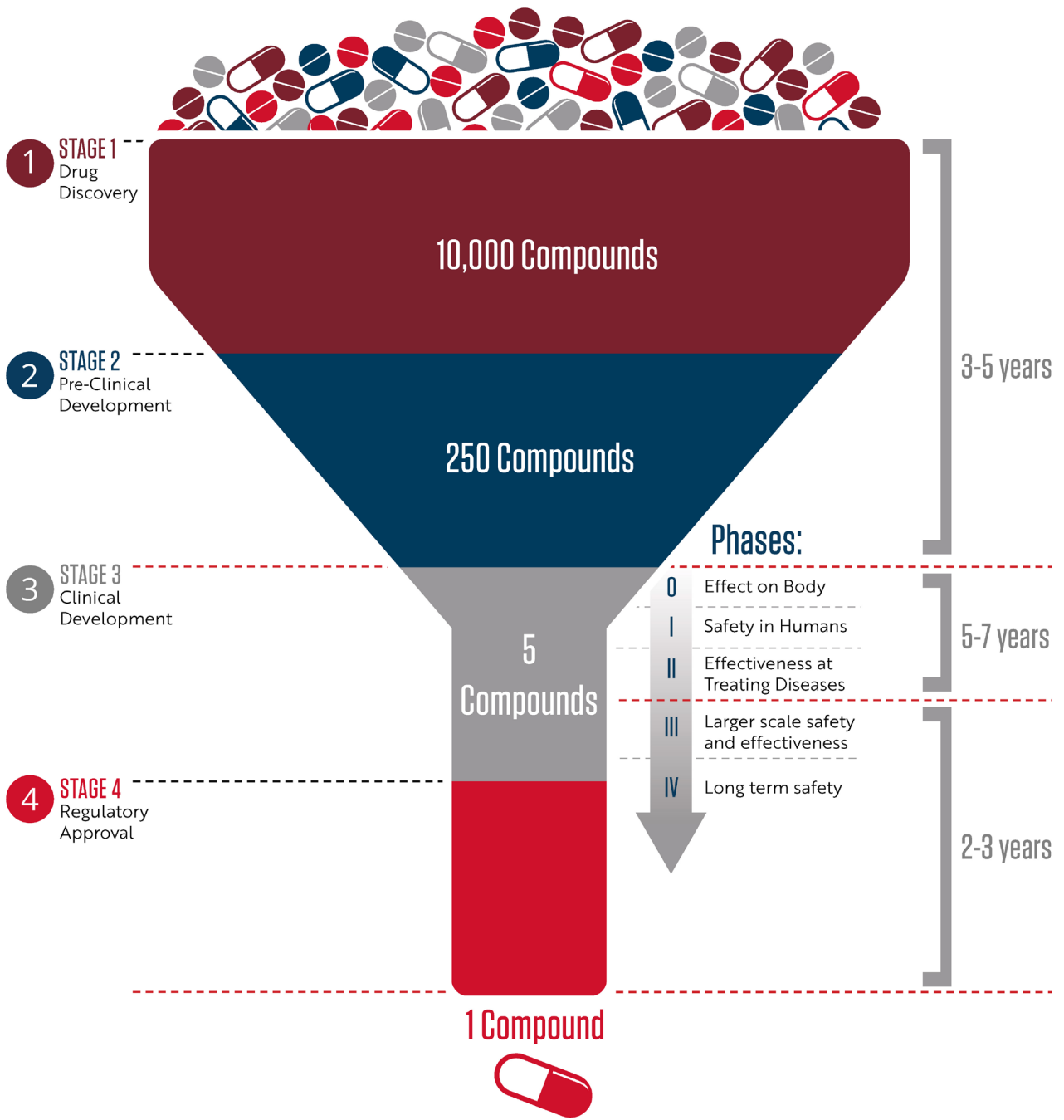
While The ALS Association is the largest philanthropic funder of ALS research in the world, we cannot create a world without ALS without robust spending from the federal government. We have mobilized more than 40,000 advocates in recent years to increase federal funding for ALS research. Funding has increased at the National Institutes of Health from \$48 million in 2014 to \$124 million in 2022 and at the Department of Defense from \$5 million in 2008 to \$40 million in 2022. Also \$5 million in NEW funding specifically for ALS research began at the FDA in 2022.



Once a drug is shown to be safe and effective, it is imperative that the FDA acts with urgency to make that drug available. When Amylyx Pharmaceuticals filed a new drug application with the FDA, we organized an online townhall pressing for quick approval, gathered 50,000 signatures on a petition calling for swift approval and presented testimony before the agency's advisory committee, which eventually voted to endorse approving the drug.



This year we launched a new grant program to fund research infrastructure into expanding clinical trial capacity to enable more people to participate in clinical trials. We also provided support that led to the development of a cutting-edge platform trial to speed up drug development by reducing the cost of research by 30% and decreasing the trial time by 50%.



DRUG DISCOVERY AND DEVELOPMENT TIMELINE



OPTIMIZING CURRENT TREATMENTS AND CARE



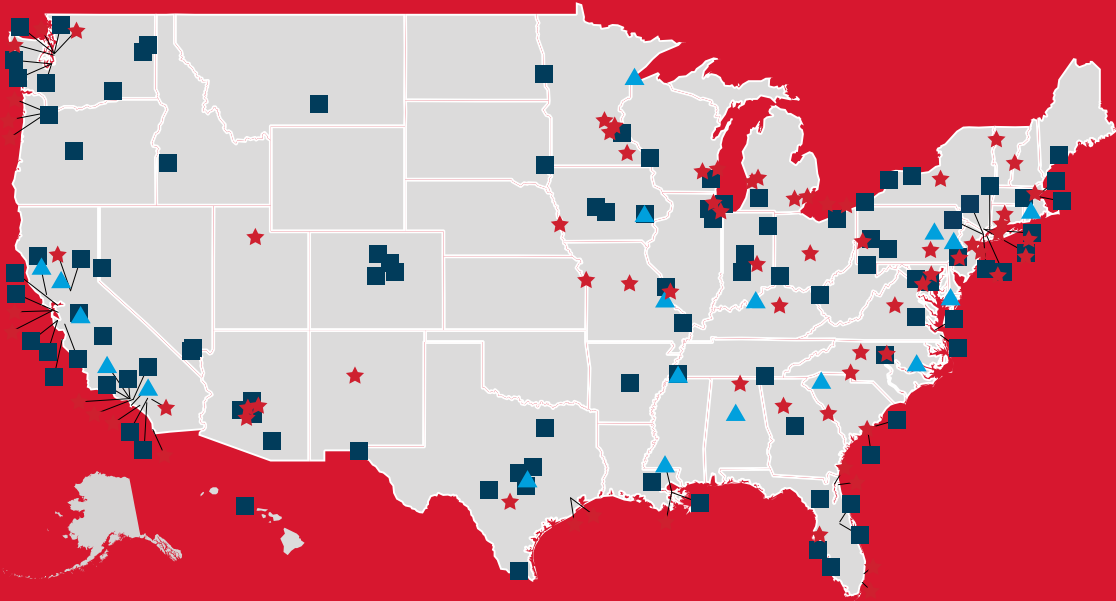
EXPANDING OUR CLINIC NETWORK

Multidisciplinary care has been shown to extend life and increase quality of life. That is why we are committed to expanding access to our nationwide network of multidisciplinary care centers, which also can function as clinical trial sites. Last year we provided \$4.8 million in grants to support our certified center program.



COORDINATING CARE AND SUPPORTING PEOPLE WITH ALS

An ALS diagnosis can be devastating. Our local care services teams are in the community helping people with ALS navigate the health care system and making sure they have the resources they need to live the highest quality of life possible. Last year, our team served 21,654 people with ALS, including 2,081 military veterans. We also coordinated support groups attended by 29,957 people.



CLINICAL PARTNER NETWORK



ADVOCACY FOR TELEHEALTH

As ALS progresses, it can be difficult for people living with the disease to get to a multidisciplinary clinic, especially if their clinic is far away. That is why we have led the fight to protect and expand access to telehealth services. We mobilized more than 5,000 advocates to send a message to Congress to support permanent access to telehealth.



RESEARCHING BETTER WAYS TO MANAGE ALS

Our research program funds investigations

into ways to help people manage living with ALS, including studies on psychological interventions that could reduce stress and improve quality of life, ways to enhance social connections for people who have lost the ability to speak, and empowering people with ALS to make informed decisions about the use of noninvasive ventilators to promote higher quality of life.



FOCUSING ON THE NEEDS OF THE ALS COMMUNITY

Through our ALS Focus survey platform, we

are going directly to people living with ALS and their caregivers to hear about their needs. This program collects data that can be used to inform research priorities, optimize access to and delivery of care services and uncover public policy needs. We have already heard from over 1,700 participants on challenges they face ranging from navigating insurance, meeting their mobility challenges and caregiver stress and burnout.

PREVENTING OR DELAYING HARMS ASSOCIATED WITH ALS

FINANCIAL BURDENS OF ALS

ALS caregivers provide essential care to people living with ALS. Most ALS caregivers work outside the home to provide health care coverage for the person with ALS as well as to cover the cost of housing, food and all necessities. We have worked with other patient advocacy organizations to develop a new national paid family leave program. If they choose to continue to work, they should have access to paid family medical leave to take care of their loved ones.

Many, but not all, people with ALS become eligible for Social Security Disability Insurance (SSDI) when they are forced to stop working as the disease progresses. In addition to providing a modest monthly check, SSDI beneficiaries are also eligible for Medicare which is critically important for a person with ALS who is under 65. Most people who apply for SSDI because of a disability are forced to wait two years and five months after they submit their paperwork to actually receive SSDI and Medicare. But the ALS Association convinced Congress to waive all waiting periods, so anyone with ALS who qualifies for SSDI does not need to wait to get their SSDI check and Medicare right away.

QUALITY OF LIFE GRANTS

For families living with ALS, the physical, emotional, and financial challenges can be overwhelming. As the disease progresses and the person with ALS loses more and more of their abilities and independence, family members often have the responsibility of their care and more. The annual cost associated with a person diagnosed with ALS can reach \$250,000. A financial grant to assist with day-to-day caregiving, home/yard/car maintenance, transportation, home accessibility, and communication needs helps to support and maintain quality of life for individuals, caregivers and families, who are living with ALS. Our Quality of Life Grant Program is designed to provide financial grants to help cover expenses associated with an ALS diagnosis, including respite and assistance for caregivers and families, durable medical equipment, communication devices, home modifications, travel to clinics/ doctor visits/medical care, and other needs.



LEADING THE WAY ON THE SCIENCE OF ALS PREVENTION

In order to truly make ALS a livable disease, it is critical that we advance the science of prevention. By deepening our understanding of the causes and risk factors of ALS, developing ways to predict when the disease will develop in a person with known risk factors, we will be able to develop ways to prevent ALS. We have led the way on prevention science, launching a prevention grants program that provided \$2.4 million to six promising prevention research projects in its first year and publishing a prevention roadmap. Our efforts have led to broader focus on prevention by the ALS community, including prevention science elements in the new NIH strategic plan.

REDUCING PNEUMONIAS AND OTHER BREATHING COMPLICATIONS

The ALS Association worked with respiratory physicians and therapists and others to protect access to respirators for people living with ALS. We were the patient voice on the Safeguarding Medicare Access to Respiratory Therapy Act of 2019 which sought to stop efforts by Medicare to drive down reimbursement for ventilators. If reimbursement was reduced too low, access to the respirators and respiratory therapists who support patients would be greatly reduced. We rallied support from Congress for the SMART bill which then pressured Medicare to back away from reducing access.

REDUCING TIME TO DIAGNOSIS

ALS is a difficult disease to diagnose. There is no one test or procedure to ultimately establish the diagnosis of ALS. To help doctors diagnose ALS faster and refer people to multidisciplinary care much sooner, we have created thinkALS, a diagnostic tool to help get people to ALS clinics sooner. More than 1,400 people have already accessed our thinkALS tool.



HOME MODIFICATION SUPPORT

Most homes are not accessible for people with disabilities. As ALS progresses there are ways to adapt the home environment to make it safe and livable – like installing ramps at the entrance to the home, widening doors to accommodate wheelchairs and installing grab bars and guardrails in the shower. We work with families to figure out what they can do to adapt their home environment and fight for public policies that make home modifications accessible and affordable.

CALMES SCHOLARSHIP

In addition to the physical and emotional tolls faced by people affected by ALS, the financial strain of the disease can devastate a family's ability to plan for future expenses. Families impacted by ALS often do not have the financial means to support the pursuit of college degrees or vocational certificates. This year, our Jane Calmes ALS Scholarship Fund awarded \$350,000 in scholarships to 70 students who have been impacted by ALS. To date, the fund has awarded over \$1.5 million and 309 scholarships.

PREPARING FOR FUTURE TREATMENTS WITH GENETIC COUNSELING AND TESTING

If people know their genetic status, it is easier for them to participate in clinical trials for new genetic therapies, and benefit from any new genetic treatments faster. Over 40 genes have been associated with ALS, many discovered with support from our research program, and 10 are currently under study for clinical treatment, some again with support from the Association. The Association helped fund counseling guidelines to help people understand the benefits and consequences of genetic testing, and continues to promote additional counseling and testing across the country. The Association is also leading the way to fight genetic discrimination, supporting anti-discrimination bills states across the country.



MISSION IN ACTION: RELYVRIO

IN SEPTEMBER 2022 THE FOOD AND DRUG ADMINISTRATION APPROVED RELYVRIO, THE FIRST DRUG TO TREAT ALS SUPPORTED WITH DONATIONS FROM THE MILLIONS OF PEOPLE AROUND THE WORLD WHO TOOK THE ALS ICE BUCKET CHALLENGE. THANKS TO THEM, THE ALS ASSOCIATION WAS ABLE TO SUPPORT THE RESEARCH THAT LED TO THE DEVELOPMENT OF RELYVRIO AND LEAD THE FIGHT FOR FDA APPROVAL.



RELYVRIO BY THE NUMBERS

THE ALS ASSOCIATION PROVIDED \$750,000 TO AMYLYX PHARMACEUTICALS FOR RESEARCH INTO THE THERAPY

THE ALS ASSOCIATION PROVIDED \$1.4 MILLION TO THE NEALS CLINICAL TRIAL CONSORTIUM TO SUPPORT THE PHASE 2 CLINICAL TRIAL

50,000 PEOPLE SIGNED A PETITION CALLING ON THE FDA TO APPROVE THE THERAPY FOR USE IN THE TREATMENT OF ALS

13,000 EMAILS WERE SENT TO THE FDA DURING ITS REGULATORY REVIEW CALLING FOR SWIFT APPROVAL

SINCE THE FDA APPROVED RELYVRIO, WE HAVE SENT LETTERS TO THE VA, MEDICARE AND 43 PRIVATE INSURERS URGING THEM TO MAKE THE DRUG AVAILABLE AND ACCESSIBLE TO PEOPLE LIVING WITH ALS.



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