



## Understanding the Impact of the Ice Bucket Challenge on The ALS Association's Finances

The ALS Association has always been committed to transparency, including providing complete and accurate financial information on our [website](#). We continue to receive the highest ratings from charity watchdog groups tasked with reviewing our spending, fundraising, and management.

The Ice Bucket Challenge generated \$115 million for the national office of The ALS Association in 2014. Since that time, the Association has devoted a page on our website to provide a list of how those funds are being spent. You can always find that information by clicking on the "Ice Bucket Challenge Progress" button on our homepage, or you can view those investments [here](#).

After the Ice Bucket Challenge in 2014, The ALS Association's Board of Trustees determined that the best use of these proceeds was to immediately put them to work by increasing funding in our core mission areas. As a result, we doubled our operating budget, with most of the increase allocated to research and care service initiatives.

### **The Ice Bucket Challenge helped us expand our scope**

Since the Ice Bucket Challenge, the national office of the Association has spent more than \$131 million toward our mission (research, care services, and advocacy). The Association has almost tripled research spending and directed over \$89 million toward research. (The Association has an additional \$16.6 million in future research commitments.) Our support of treatment centers and other care initiatives has increased more than 600% on an annual basis when compared to spending levels prior to the Ice Bucket Challenge, helping make high quality ALS care more accessible to everyone.

### **Growing revenue while spending in a deficit**

The Ice Bucket Challenge was transformative for The ALS Association. It helped us grow and helped us envision new ways to accelerate our research program, serve more people with ALS, and increase our revenue to help sustain this higher level of operation for the next several years.

However, the Association is spending far more money than it is generating, even as revenues have grown. Overall, since the Ice Bucket Challenge, the national office of The ALS Association has spent nearly \$160 million. Since February 1, 2015, after the Ice Bucket Challenge ended, the national office of The ALS Association has generated nearly \$114 million in revenue. We are running a deficit of several million each year, even as we have taken on multi-year commitments to clinics and research studies. We need cash reserves to ensure we can meet our commitments to the ALS community.

In the four years prior to Ice Bucket Challenge, the national office of the Association raised an average of \$20.2 million per year in revenue while spending \$17.5 million per year, including \$12.3 million in program expenses. By contrast, in the four years since the Ice Bucket Challenge (not including the actual year of the Challenge) the national office has averaged \$28.4 million in revenue while spending an average of \$35.7 million, including nearly \$29 million on program expenses. This means the national office is spending almost 2.5 times what we previously spent per year on our mission.

There have been questions raised on social media about our 2017 990 tax form and the approximate \$96 million that is listed in our net assets line (22), along with erroneous claims that \$96 million is what is remaining of the Ice Bucket Challenge donations. In fact, as previously mentioned, the Association has spent or committed more money than we received since the Ice Bucket Challenge.

Because the Association has been a good steward of its resources, as a result of prudent investing, revenue growth and strong expense management, the Association remains financially healthy. We continue to make significant strides in the battle against ALS, and we have much more to do. The Association will not fall back to expenditure levels prior to the Ice Bucket Challenge. Until we reach a sustainable level of funding, we will continue to rely on deficit spending. We can't stop supporting the new clinics we helped open, or do anything to slow the pace of scientific discovery, until we have a world without ALS.

### **Expanding our research program**

We are working urgently to find a cure for ALS, and the \$115 million raised from the Ice Bucket Challenge has been a catalyst for research advancement. But it is not enough by itself to discover a cure.

It takes, on average, over \$2 billion to bring a single new drug to market, 17 times more than what was raised in the Ice Bucket Challenge. Even with the funding we have, the final stage of clinical trials, Phase III trials, often costs tens of millions, or even hundreds of millions of dollars. Once a trial reaches phase 3, it is traditionally funded by companies with greater resources. This is why virtually no patient advocacy organizations fund phase 3 trials. If The ALS Association was to spend a large portion of its assets on a phase 3 trial, and that trial fails (as is often the case), it would be detrimental to the entire ALS research pipeline.

Instead, like any wise investor, we diversified our research investment across hundreds of projects and investigators across the globe. We made the world our lab.

Further, even though the Ice Bucket Challenge helped us become the world's largest philanthropic funder for ALS research, the government and private sector spend much more. We use Association funds to complement and leverage these other research funders, and advance federal research spending through our advocacy program as well.

For example, since the Ice Bucket Challenge, we have invested \$40 million in completed research projects that directly generated over \$120 million in follow-on research grants from other funders. We have also

been investing in infrastructure, like programs to share scientific data and clinical samples, that have helped ALS investigators work together.

This leverage shows on a macro level as well. The National Institutes of Health spends five times more than we do on ALS, and their spending on ALS has grown 83% since the Ice Bucket Challenge. We work with Congress, the Centers for Disease Control and Prevention, and the Department of Defense to dedicate additional research dollars to ALS and have been successful in helping to grow these funding sources by over 30% compared to pre-Ice Bucket Challenge levels. And, as in all disease spaces, we rely on pharmaceutical companies to fund the final expensive trials needed to bring drugs to market.

### **Caring for more people with ALS**

Since the Ice Bucket Challenge, we are now helping assist more people with ALS. The number of people with ALS served by our chapters has increased 28% from 15,731 in fiscal year 2015 to 20,101 people served in fiscal year 2018. In addition, The ALS Association has established more Certified Centers of Excellence, growing from 33 funded Certified Centers of Excellence in 2013 to having 69 funded Certified Centers of Excellence and 21 funded Recognized Treatment Centers today. This is a 96% increase in access to multidisciplinary care teams.

### **Advancing our mission**

In short, the Ice Bucket Challenge has helped The ALS Association meet the needs of the ALS community at an unprecedented scale. We have spent more than we received from the Ice Bucket Challenge, and continue to spend more than we take in. The ALS Association endeavors to maintain or grow this level of funding into the future, until we reach our ultimate goal of a world without ALS.