This report represents Amyotrophic Lateral Sclerosis Association's responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.

Amyotrophic Lateral Sclerosis Association
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Mission:
Leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

The content of this Charting Impact Report is the sole product and responsibility of Amyotrophic Lateral Sclerosis Association. This report does not in any way represent an endorsement from Independent Sector, BBB Wise Giving Alliance, or GuideStar, nor does it represent fulfillment of the BBB Wise Giving Alliance's Standards for Charity Accountability. For more information on Charting Impact, visit www.guidestar.org/chartingimpact
1. What are we aiming to accomplish?

The ALS Association's ultimate goal is to find treatments and a cure for ALS while helping patients and their families manage the impact of the disease through various programs and services. Our mission priorities include raising public awareness about ALS; a global research program; providing people with ALS access to high-quality care and resources; and advocating for increased funding for ALS research and patient services.

2. What are our strategies for making this happen?

The ALS Association conducts public awareness campaigns to increase awareness and strives to be the go-to source for up-to-date information. Our research program TREAT ALS(TM), is presently funding and directing 98 global projects worth $18.1 million; this includes fellowship grants to young scientists just starting their careers in ALS. The Association works to provide patients with the highest possible quality of multi-disciplinary care through our Certified Center Program in order to prolong and improve the quality of life. Our nationwide network of 38 chapters offers programs, services, resources and education on the disease, life planning, strategies for medical and non-medical options and general support. Our annual National Advocacy Day and Public Policy Conference brings together patients, family members and concerned individuals from all over the United States to advocate for policies to help people with ALS. We work at the local, state and federal levels to foster government partnerships to increase services to people with the disease and to raise money for research.

3. What are our organization's capabilities for doing this?

The ALS Association commits over 70% of its annual budget to delivering program services, including research. We have a senior leadership team at the national office that includes individuals with expertise in chapter management, communications and marketing, care services, public policy and finance. Our Chief Scientist is internationally respected and leads The Association's global research program. Our nationwide network of 38 chapters provides a consistent organization presence in communities across the US. We work alongside many partners to improve the lives of patients living with the disease. These partners include MDA, ALS-TDI and Project ALS. We are actively involved in the National Health Council and foster partnerships with government agencies, including the U.S. Center for Disease Control, along with pharmaceutical companies, biotech companies and academic institutions.

4. How will we know if we're making progress?

Every fiscal year, The ALS Association establishes measurable objectives that support the strategic plan. The CEO reports on progress towards these objectives to the National Board of Trustees of The Association on a regular basis. In addition to completing key projects as an indicator of success towards intended impact, The Association also has metrics related to the following: donated media value, media placements; social media audiences; online engagement; research expenditures, workshops and strategic meetings; research webinars and news updates; certified centers; distribution of educational materials; partnerships and other collaborations; government funding for ALS-related projects, and more. The Association also has a strategic planning committee on its Board of Trustees, which reviews the organization's five-year strategic plan and develops a collaborative process to provide input on new plans.

5. What have and haven't we accomplished so far?

As of March 31, 2014 The ALS Association has approximately 98 research projects actively engaged in six areas of research...
committed to determining the causes of ALS disease. Projects that The Association funds are often published in major medical journals and these are available at www.alsa.org. The Association has 39 Certified Treatment Centers of Excellence (CTCE) and expects to have 47 CTCE's by the end of 2014. Core requirements of CTCE's include strong chapter relationships, a lead ALS neurologist, a multidisciplinary team and engagement in active research related to ALS. The Association partnered with U.S. Food and Drug Administration to convene the first ever ALS specific public hearing and worked with Congress to secure continued funding for the ALS Research Program at the Department of Defense ($7.5 million) and the National ALS Registry at the Centers for Disease Control and Prevention ($6 million). The Association earned $6 million in donated media and is working on a new campaign to raise awareness about the disease.