American Syringomyelia Alliance Project, Inc.


This report represents American Syringomyelia Alliance Project, Inc.'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.

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Mission:
ASAP's mission: "to improve the lives of persons affected by Syringomyelia, Chiari Malformation and related disorders while we find the cure."
The content of this Charting Impact Report is the sole product and responsibility of American Syringomyelia Alliance Project, Inc. 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)](http://www.guidestar.org/chartingimpact)
1. What are we aiming to accomplish?
increasing public awareness of the existence of the disorder and its devastating effects; financially supporting research efforts and raising funds to find all causes, to develop new treatments, and to improve existing treatments; coordinating the efforts of organizations working towards improving the lives of people with syringomyelia and/or Chiari.

2. What are our strategies for making this happen?
Funding new research grants; organizing a medical conference with specialist in the neurosurgery, pain management, neurological fields who treat the syringomyelia and Chiari population; creating a user friendly website with verified information.

3. What are our organization's capabilities for doing this?
A dedicated Board of Directors who volunteer their time and expertise to govern as well as provide hands-on guidance to volunteers. A dedicated staff who maintains programs, provides support and works together with the various Boards to further the organizations goals.

4. How will we know if we're making progress?
During this past year, we expanded our support programs, more than tripled our public awareness through national events, broadened our social media (Facebook, etc.), added more free webinars that were specifically requested and mailed thousands of information packets. Also, office staff and Board members personally answered hundreds of support calls. We also completed Investigation of the Disease Progression of Pediatric Patients with Incidental Chiari I Malformation (Children's National Medical Center, Washington, DC).

5. What have and haven't we accomplished so far?
The American Syringomyelia & Chiari Alliance Project, has provided support, funded research and distributed educational materials for over 25 years. We have grown from a grass-roots organization to one that is recognized as a leading authority in the field of Chiari and syringomyelia. Through our website and social media pages we reach hundreds of thousands looking for information and understanding.