This report represents Worldwide Syringomyelia & Chiari Task Force 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.

**Worldwide Syringomyelia & Chiari Task Force Inc.**
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**Mission:**
Our mission is to educate the world about Syringomyelia. We are a worldwide organization based in Georgia.
The content of this Charting Impact Report is the sole product and responsibility of Worldwide Syringomyelia & Chiari Task Force 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?
Worldwide Syringomyelia & Chiari Task Force Inc. is a 501c3 organization providing a voice for men, women, children, and canines who suffer in silence. We advocate for all who bravely battle Syringomyelia! Syringomyelia is a disease of the spinal cord. Our mission is to educate the world about Syringomyelia. Our organization is led by active nurses and physicians to bridge the gap in the medical profession by educating all specialties about this progressive disease in order to bring about positive changes that will ultimately improve the quality of life for all sufferers worldwide! The ultimate goal is to define specificity to this disease in order to improve care and outcomes resulting in decreased morbidity/mortality and improved quality of life!

2. What are our strategies for making this happen?
We strongly advocate for collaboration of all specialties to care for the individual with Syringomyelia. We do this by offering CME credits through nursing conferences and inservices to physicians and nurses followed by a multiple choice quiz to signify understanding of the disease Syringomyelia. We will issue a certificate of recognition for learning about this disease! We are working on the first medical treatment protocols for Syringomyelia to improve direct patient care! We are working on the first International HIPAA compliant Syringomyelia Registry for children and adults to collect updated data on this disease worldwide! We are also working on the Specifics of Syringomyelia project in order to further specify the disease to apply it in the practical setting. We want to research stem cells and their use for Syringomyelia and newer applications that hold promise for spinal cord injury! We utilize a patient-centered approach in all that we do!

3. What are our organization's capabilities for doing this?
We will broadcast live presentations and videos on demand by utilizing our own U-stream channel we have obtained to educate individuals all over the world!! Our physicians are actively working on presentations & models of care. We are going to present protocols to the medical community based on research and updated data in 2015. We also have exciting new educational tools to benefit everyone! We will provide direct resources to individuals who are battling Syringomyelia that qualify by providing assistance with durable medical equipment & prescription assistance as the organization grows. Each individual must present a letter of qualification and prescription from their treating physician that is reviewed by our Board for approval. We also broadcast stories of hope on our website from our members. We host live talk sessions on the first and third Saturday of each month moderated by administrators. We also offer live 24 hour support on Facebook!

4. How will we know if we're making progress?
Our organization has a new approach to Syringomyelia that is key to improving quality of care for individuals and canines worldwide! The need for change is crucial as evidenced by the lack of knowledge in the medical community that remains today although this disease was identified over 200 years ago. Awareness is vital but it is time for definitive action and our organization is proud to lead the way!

5. What have and haven't we accomplished so far?
Our organization has now passed proclamations in 25 of the 50 states recognizing Syringomyelia as a disease. It emphasizes the importance of having a universal medical treatment protocol for humans & canines. In addition the proclamations designate the month of May as Syringomyelia Disease Awareness Month. We submitted a video to the Neuro...
Film Festival this year to show the public our plight and introduced two educational power points to teach about Syringomyelia & Syringobulbia. In addition we have a growing medical advisory board full of physicians from all specialties who are advocates for positive changes to directly benefit the sufferer & back Syringomyelia as a disease evidenced by pathophysiology. We are going live with our channel in the coming months to broadcast worldwide! We are working toward offering continuous educational credits to all physicians and nurses. We have many more exciting announcements coming and we cannot wait to see the results! We also have a petition advocating for a medical treatment protocol with over 1,000 signatures in progress. We are actively collecting data to show the medical community the need for change! We are also listed on the Paralysis Resource Center for the Christopher Reeve Foundation to further public knowledge of Syringomyelia & Chiari! We are on Facebook, Twitter, PInterest, LinkedIn, and Google. Our website is http://www.wstfcure.org. We have a 24 hour online support group active with over 700 members. We have conducted multiple interviews with local and national media outlets. Our most recent interview was with Cosmopolitan in June 2015. We were most recently nominated by Global Genes for collaborations in advocacy award! We are national members of the National Organization for Rare Disorders. We are the first organization in the United States led by physicians and nurses to stand behind Syringomyelia as a disease! Beth Nguyen RN, CEO has been appointed the NORD Ambassador for Rare Diseases by NORD! We are now working on national recognition of Syringomyelia as a disease from now on in every state and country!