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 the disease Syringomyelia, Syringobulbia, Chiari Malformation, and the complications that can co-exist with them. Our focus is to provide updated education to all medical specialties about these diseases through online teaching videos, conference calls, and delivery of peer to peer inservices. We provide members, families, caregivers, medical professionals of all disciplines, and attorneys excellent resources to navigate Syringomyelia, Syringobulbia, and Chiari with emphasis on collaboration and continuity of care across all medical disciplines using patient-centered approaches that center on our mission of education. Overall, our desire is to increase understanding across all medical disciplines to improve direct patient care and save lives!
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 that can damage the spinal cord and the spinal nerves. Our mission is to educate the world about Syringomyelia, Syringobulbia, Chiari, and their complications. Our organization is led by active nurses and physicians to bridge the gap between current research and updated education to deliver updated education to the public and all medical disciplines beginning with primary care. We would like to improve direct medical care delivery through implementation of effective advocacy tools and peer to peer advocacy in medicine to improve the quality of life for men, women, and children worldwide! The ultimate goal is to define specificity to these disease processes in order to improve care and outcomes which will result 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 individuals with Syringomyelia, Syringobulbia, Chiari, and their complications. We do this through peer to peer medical professional inservices to physicians and nurses. We are spearheading work on the first medical treatment protocols for Syringomyelia and Chiari to improve direct patient care! We are working on the first International HIPAA compliant Syringomyelia and Chiari worldwide Registry for children and adults to collect updated data on these diseases worldwide to increase understanding of how they affect daily life! 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 are reviewing new minimally invasive approaches to therapy to reduce recovery times and improve patient outcomes in the direct care setting. We author medical publications monthly as well through our partner Rare Disease Report. We utlize patient-centered approaches in all that we do because we care about the well being of the men, women, and children who are affected.

3. What are our organization's capabilities for doing this?
We will broadcast live presentations and videos on demand on our website and You tube to help educate individuals all over the world!! We have partnerships with two media channels....one broadcasts to millions of medical professionals...another broadcasts to millions of patients. 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 2018. We also have exciting new educational tools to benefit everyone! We will provide direct resources to individuals who are battling Syringomyelia, Syringobulbia, Chiari, and their complications by offering to connect them with our partners for travel assistance, flight assistance, and encourage all qualified members to apply with our partners for a disability dog. As we continue to grow we aim to offer assistance with durable medical equipment and scholarships as well. Each individual must present a letter of qualification and prescription from their treating physician that is reviewed by our Board for approval when applying for services. We also broadcast stories of hope on our website from our members. We also offer live 24 hour support on Facebook in three closed groups moderated by registered nurses!

4. How will we know if we're making progress?
We will know about our progress measured by organization yearly growth, member sign ups and use of the patient registry, contacts for resources, downloads of the advocacy models of care, healthcare professionals attendance and participation at inservices, views of videos and scientific publications as well as shares on social media platforms.
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 listed on the NIH website! 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! Most recently we were awarded the first ever worldwide patient registry for Syringomyelia and Chiari by NORD. Our CEO received the 2017 NORD Rare Impact Award. We have authored numerous articles for medical professionals in collaboration with our Medical Advisory Board.