This report represents FAMILIAL DYSAUTONOMIA NOW FOUNDATION’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.

FAMILIAL DYSAUTONOMIA NOW FOUNDATION
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Mission:
The mission of FD NOW is to discover new treatments and cures for patients with FD.
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1. What are we aiming to accomplish?
FD NOW was created by parents and family members of individuals with familial dysautonomia (FD). The mission of FD NOW is to find safe, effective, meaningful treatments that optimize the health and quality of life of children and adults with familial dysautonomia (FD). FD is a life-threatening genetic illness that originated in the Eastern European Jewish population. Individuals born with FD have numerous health challenges, the most pervasive of which is being prone to autonomic crisis, characterized by debilitating periods of cyclical vomiting, dangerously high blood pressures and heart rates. While there is no cure for FD, innovative research has led to treatments that have stabilized the health of individuals with FD, moderated the triggers of autonomic crisis, and substantially improved the quality of life of individuals with FD.

2. What are our strategies for making this happen?
FD NOW deploys three primary strategies to achieve its mission: 1) Innovative Research-There are less than 400 known diagnosed cases of FD in the world. With a small population it is very difficult to get the attention of researchers and research institutions to conduct research, let alone translational research that bridges "lab to life" impacts. To achieve its mission FD NOW actively seeks out innovative, creative, "out of the box" thinkers to conduct research. Drs. Berish Rubin and Sylvia Anderson at Fordham University exemplify these attributes, stretching donated dollars to make large impacts in health. Research priorities currently include: 1) Identifying primary autonomic crisis triggers and developing treatments and approaches to prevent them or shorten their duration; 2) Preventing and reversing the advance of osteoporosis, common in individuals with FD. 2) Innovation in Fundraising-As a small community of 400 families, the majority of donations to FD NOW come from individuals with a tie to one or more families with a child or adult with FD. To raise the dollars sufficient to fund FD NOW's top research goals requires vigilance and creativity. Numerous fundraising events are held throughout the year to fund research. Over 90% of all dollars raised are directly allocated for research. 3) Timely and Credible Patient and Family Education- As new treatments or developments are discovered the FD NOW website serves as the most credible portal for informing families and providing key resources.

3. What are our organization's capabilities for doing this?
FD NOW is parent founded, parent managed, and parent led. Our love for our children provides our greatest capability and strength. The parents leading FD NOW are highly skilled professionals with over two decades of experience in healthcare and public service. The personal connections of our parents and family members drive our activity, and have led to the relationships we currently enjoy with researchers and the success of our fundraising efforts. FD NOW is working closely with a special group of researchers who are highly motivated to help this population.

4. How will we know if we're making progress?
FD NOW knows it is making progress when new safe and effective treatments for the triggers and symptoms of FD are introduced, and families report less challenges and higher quality of life. Since its inception, the research efforts funded by FD NOW have produced and published multiple effective treatments that address various underlying triggers of FD symptoms. FD NOW remains connected to the parent community and constantly queries about the health and wellness of individuals with FD, and how they are responding to various treatments.

5. What have and haven't we accomplished so far?
The accomplishments to date are impressive. Through the efforts of FD NOW and its research community, the gene for FD has been discovered, the mutation isolated and better understood, and safe, effective treatments developed to overcome the effects of the mutation. The lives of children and adults with FD have become much more stable and healthy as a result of these accomplishments. However, many challenges remain. There is no final cure for FD absent gene replacement therapy, which remains a distant vision. As children grow to adulthood numerous health challenges remain such as advancing osteoporosis, and degradation of an already compromised autonomic nervous system. Research efforts continue to focus on the origin of underlying triggers of autonomic crisis to prevent them and help minimize wear and tear on organ systems, and address the issues of adulthood such as osteoporosis.