

FUNDING APPLICATION

GENERAL INFORMATION

Organization Information

Legal Name: The Chromosome 18 Registry & Research Society		Federal Tax ID#: 74-2557551		Are you a 501(3)(c) charity? Yes	
Address: 7155 Oakridge	City: San Antonio	State: Tx		Zip Code: 78229	
Website: www.chromosome18.org		Fax: (210) 657-4968			

Head Of Organization

Name: Jannine Cody	Title: President & Founder
E-Mail Address: office@chromosome18.org	Phone: (210) 657-4968

Application Contact

Name: Neale Parker	Title: Executive Director	E-Mail Address: office@chromosome18.org	Phone: (210) 657-4968
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Has the organization applied to the Gordon Hartman Family Foundation in the past and been declined?

Yes

2014 - Funding for Database Software

Grant Amount Requested \$:	Total Project Budget \$:	Organization's Annual budget \$:
\$25,000	\$35,000	\$717,200

Mission Statement:

Chromosome 18's mission is to help individuals with chromosome 18 abnormalities overcome the obstacles they face, so they may lead healthy and productive lives.

PROJECT INFORMATION

Program / Project Title:

Program Services Coordinator

PROJECT TIMELINE

Start Date	End Date
01/01/2020	12/31/2020

Program / Project Description:

The Chromosome 18 Registry & Research Society's mission is to help individuals with chromosome 18 abnormalities overcome the obstacles they face, so they may lead healthy and productive lives. Our mission has three facets: building community, expanding education, and advancing research. Our shared vision is that one day, children with chromosome 18 abnormalities will have the same aspirations and achievements in life as their siblings.

For nearly 30 years, Chromosome 18 has connected families across the United States and around the world with social support, education resources, and treatment recommendations through the Chromosome 18 Clinical Research Center. Chromosome 18 provides support by helping parents make connections to other parents, support organizations, and medical professionals. We have two full-time staff members, our Director of Operations and Executive Director, whom each work approximately 45 hours per week. With this grant, we would like to add a Program Services Coordinator to reach even more families, provide higher quality services to members, and leverage our existing network of resources and volunteers more effectively.

Our website, www.chromosome18.org, has centralized information about chromosome 18 conditions in an easily accessible format. The site includes Chromosome 18's history, syndrome & treatment recommendations, member stories, fundraising & educational events, and resources for families. Visitors can also become members to stay connected to Chromosome 18. Through this membership, Chromosome 18 offers many social media options for our members and supporters including a multiple, closed & monitored Facebook groups, an Instagram, a LinkedIn site, and Twitter account. Through these sites, Chromosome 18 also connects families with Syndrome Coordinators of the most common syndrome groups. These volunteer coordinators moderate private groups for families affected by that particular syndrome. Parents can exchange messages to the group and are asked to respond to specific questions about how they have dealt with a specific question in a private, safe environment with others who have shared similar experiences. In addition to the aforementioned coordinators, we also have a volunteer Sibling, Bereavement, and Self-Advocate Coordinator. These coordinators provide additional support to families beyond information about syndrome specific questions. Chromosome 18 Volunteer Regional Coordinators cover 10 regions in the U.S. and 4 internationally. Regional Coordinators host support and education events for families and professionals yearly in their regions. The list of regions and their coordinators can be found on our website.

The Chromosome 18 Registry and Research Society holds an annual conference that is highly anticipated by many families of children with Chromosome 18 abnormalities. Families return for multiple years to have access to the latest findings and research on Chromosome 18 abnormalities. Our 2019 Annual Conference marked the 26th year that families joined us from all over the world. Over the course of three days, families can meet other families affected by chromosome disabilities and gain invaluable support, resources, and education from the world's leading researchers on Chromosome 18 disabilities. A Program Coordinator would be instrumental in increasing the number of families attending, improving their experiences, and expanding opportunities for families in attendance.

Syndrome descriptions are provided to families and are posted to our website. The information explains in lay language the syndrome their child has and what to expect. For most families, this is the only information they will receive about their child's syndrome after their initial diagnosis. This can be a frightening time and increasing the support that we have for direct contact with new members would improve the quality of care that newly diagnosed affected individuals would be able to receive. In addition to the syndrome descriptions developed by the Chromosome 18 Clinical Research Center (CRC) through Chromosome 18's funding, the CRC has also developed Physician's Management Guides. These Physician's Management Guides encapsulate over 27 years of research and act as road map to preventative care. With these guides, families can get the best quality of care even if their doctor is unfamiliar with chromosome 18 conditions. However, many families still do not know about these guides. The Program Coordinator would be able to help families prepare most effectively for the limited time they get with their physicians and ensure that they are able to get the highest quality of care for their child.

Currently, all of the above member impacts and services are being managed through our two full-time staff members, only one of whom is working out of the Bexar office. These two full-time staff members are also directly responsible for the member services of over 4,000 Chromosome 18 members around the world, meaning that their attention is often split between many projects at once. Chromosome 18 is incredibly proud of the member services we have cultivated over the past 28 years with the help of volunteers. However, we are aware that our limited resources have not allowed these resources to develop to their fullest potential. By utilizing a Program Services Coordinator, Chromosome 18 would be better able to focus on the quality of relationships with our members, as well as grow our membership as a whole. The Program Service Coordinator will be dedicated to reaching families upon initial sign-up as well as continuing to check on families that are already in our database. This, in turn, will allow current full-time employees to focus on event coordination and logistics without sacrificing the attention our members require.

While our services are utilized both nationally and internationally, we spend a majority of our funds in Bexar County. Well over 75% of the monies raised in the last campaign was used for direct services in the San Antonio area. We serve families in the following Texas counties: Henderson, Gregg, Guadalupe, Hamilton, Coryell, Bexar, Harris, El Paso, Burnet, Hildago, Liberty, Montgomery, Williamson, Bell, Smith, Lamar, Denton, Tarrant, Collin, Dallas, Orange, Brazoria, Hays, Travis, Brown, Potter, Nueces, Howard, Tom Green, Comal, Bastrop, Tyler, and Houston.

Evaluation Plan:

Need:

Full-time Program Coordinator to join staff to increase the sustainability of member services, grow existing programs, cultivate new members.

Desired Outcomes:

-Program Coordinator will increase member engagement, and thereby fundraising, to a level that creates a self-sustaining position over the next 3 years. In the intermediary time, the position will be funded by this grant and by Chromosome 18's financial reserves.

Evaluation Metrics:

-Increase membership engagement through fundraising to fulfill 80% of the Program Coordinator salary.

-Increase the number of community partners actively engaged by 5% each quarter.

-Grow our membership by 25 families each quarter to increase the number of children we serve.

-Increase the number of children participating in the CRC's research study by 4 each quarter

Plans to sustain project beyond the term of this request:

A Program Coordinator would ensure members are better engaged, receive higher quality services, and spread awareness of our program to donators in the San Antonio area. Both duties will lead to higher turnout at fundraising events which will in turn fund the Program Coordinator after initial funding.

Line item Budget:

Line Item Description	Total Project Funds Allocation	Gordon Hartman Funds Allocation
Project Coordinator	\$35,000	\$25,000
TOTAL:	\$35,000	\$25,000

BOARD OF DIRECTORS

LIST OF BOARD DIRECTORS

Name & Office Held	Corporate Affiliation
Jannine Cody, President	UT Health San Antonio
Liz Woodfield, Vice President for Public Relations	EMD Serono Inc
John Drymala, Treasurer	Valero Energy Corporation, Lead Transportation Analysis Specialist
Dave Aldrup, Secretary	Network, Control-Americas at ABB Enterprise, Senior Vice President
Katie Bailey, Vice President for Member Relations	N/A