

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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Previous funding received from The Gordon Hartman Family Foundation

Year	Funding \$
2019	\$15,000
Total	\$15,000

Has the organization applied to the Gordon Hartman Family Foundation in the past and been declined?
No

Grant Amount Requested \$:	Total Project Budget \$:	Organization's Annual budget \$:
\$25,000	\$25,000	\$575,534

Mission Statement:
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.

PROJECT INFORMATION

Program / Project Title:
Program Services Coordinator

PROJECT TIMELINE

Start Date	End Date
01/01/2021	12/31/2021

Program / Project Description:
The Chromosome 18 Registry & Research Society was founded 30 years ago by Dr. Jannine Cody when her daughter, Elizabeth, was born with a rare genetic disorder. Since our founding, we have been helping families with chromosome abnormalities lead healthy and productive lives. We work towards this goal through 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.

Thanks to the generous grant from the Gordon-Hartman Foundation, Chromosome 18 recently employed a part-time Program Service Coordinator (PSC) for the first time. For the last year, our PSC has provided support by helping families connect with each other, support organizations, and medical professionals. This has allowed our two full-time staff members, our Director of Operations and our Executive Director, the time to focus on new fundraising, logistics, and outreach programs without sacrificing the attention our members deserve. With continued grant funding, our PSC will be able to reach more families, provide higher quality services to members, and leverage our network of resources and volunteers more efficiently.

For the health and safety of our members during the Covid-19 pandemic, Chromosome 18 has canceled our in-person events, specifically our annual conference held in San Antonio. In addition to being our main fundraising event of the year, this conference was a way for our members from around the world to connect with each other. The cancelation of this conference, and other events, during the pandemic has resulted in families with chromosome 18 abnormalities reporting feelings of increased isolation and helplessness.

To combat this, our PSC has spent the year reaching families upon initial sign-up as well as continuing to check on families that are already in our database. She does this by managing all 18 of Chromosome 18's Facebook groups - the most used platform for our families to connect by both region and syndrome. Through these sites our PSC also connects families with Syndrome & Regional Coordinators. Our volunteer Syndrome Coordinators lead groups of our members whom share specific chromosome abnormalities, and our volunteer Regional Coordinators connect families in the same geographic area. Parents can exchange messages to the group and are asked to respond to specific questions about how they have dealt with a particular 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. This helps new members know there are other families going through the same experiences they are. The PSC is in regular communication with all of our coordinators, regularly providing them the support and resources that they need to connect with our families in a meaningful way.

In addition to improving these existing programs, Our PSC has begun Zoom calls for families who desire a face-to-face connection. This is a pilot program consisting of individual Video calls to families as well as hosting quarterly group video calls with attendance ranging from 10-30 members each session. As of September, our PSC has hosted over 40 unique Zoom family, resource, and activity calls for families to connect with each other and has personally connected with over 146 new members to the Chromosome 18 family. One member shared, "Thank you from the bottom of my heart. [My son in law] and [daughter] said, "Mom, [PSC] is absolutely amazing, she is a blessing!" showing the direct impact our families receive from our PSC. These virtual member connection events held via Zoom have received overwhelmingly positive feedback from our members and are consistently well-attended from families around the world. These unique events allow parents, siblings, and individuals affected by chromosome 18 conditions to connect with each other during a time of isolation due to the Covid-19 pandemic. These events would be impossible to maintain without our PSC.

The information our PSC provides to families on initial introduction explains 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 receiving the diagnosis. This can be a frightening time, and increasing the support that we have for direct contact with new members has improved the quality of care that newly diagnosed affected individuals can 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 who are diagnosed still do not know about these guides. Our PSC has been key in introducing our members to these guides which allows families prepare most effectively for the limited time they get with their physicians. This information ensures that they are able to get the highest quality of care for their child. Even with all of our resources available on our website, a new diagnosis can be overwhelming. Our PSC is able to connect with each family and help them find the resources they need most.

This past year, our PSC has been better able to focus on the quality of relationships with our members, as well as grow our impact in the San Antonio community. 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:

Since the hiring of our Program Service Coordinator in January 2020:

- Membership has increased from 1-5 new families a month to 15-20 a month.
 - Member contact has been the most notable improvement since introduction of the Program Coordinator. Same day contact has gone from no contact to 100% of new members being personally contacted on initial joining. This means every family that becomes a member has received a phone/video call from our Program Service Coordinator.
 - Database management has been expanded. Program Coordinator's role in contacting members has not only improved member satisfaction, but also allowed Chromosome 18 to better manage the information given to us by these families. Information such as age, locations, syndrome types, and family history can now be efficiently organized. This information is then given to the CRC which helps further their research on chromosome 18.
 - o -Participants in the Chromosome 18 Clinical Research Center has improved drastically. While welcoming new families, the Program Service Coordinator explains the benefits of joining the research study and provides all essential information about participating.
- In the next year, we will evaluate the Program Service Coordinator on the following metrics:
- o Continue the programs and services put in place during 2020.
 - o Increase membership engagement through fundraising to fulfill 80% of the salary of the Program Service Coordinator position.
 - o Increase the number of community partners directly involved in Chromosome 18 events by 5% each quarter.
 - o Grow our membership by 5 additional families each month, bringing the average number of families joining monthly to 20.
 - o Host 4 virtual member connection events monthly.

Plans to sustain project beyond the term of this request:

Our Program Coordinator has ensured members are better engaged, receive higher quality services, and has help spread awareness of our program to donators in the San Antonio area. The focus our Program Coordinator has been able to dedicate to outreach has led to higher turnout at our virtual fundraising events which has helped fill the gap in funding left by the cancellation of our in-person events due to the pandemic. Instead of outright canceling all events due to Covid-19, our Program Coordinator has helped convert these in-person events, into virtual connection events. While we had initially hoped that the Program Service Coordinator would be able to fund the position through increased member engagement, fundraising and donations have been severely impacted by Covid-19. Without continued support for this role, Chromosome 18 will have to reduce our member services and connection substantially. To fund this position, Chromosome 18 is seeking grant and family support.

Line item Budget:

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

BOARD OF DIRECTORS

LIST OF BOARD DIRECTORS

Name & Office Held	Corporate Affiliation
Jannine Cody/Founder & President	UT Health San Antonio
Katie Bailey/Vice President for Member Relations	N/A
Liz Woodfield/Vice President for Development	EMD Soreno Inc.
John Drymala/Treasurer	Valero Energy Corp.
Dave Aldrup/Secretary	Network, Control-Americas at ABB Enterprise
Tom Kunkel/Director at Large	U.S. Air Force

Carol Cohen/Director at Large	Retired
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