

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
2020	\$25,000
Total	\$40,000

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 \$:
\$30,000	\$70,000	\$609,030

Mission Statement:

The Chromosome 18's Registry & Research Society mission is to help people with chromosome 18 abnormalities overcome the obstacles they face so they may lead healthy and productive lives.

PROJECT INFORMATION**Program / Project Title:**

PSC - Making a Difference to Our Families

PROJECT TIMELINE

Start Date	End Date
07/01/2022	12/31/2022

Program / Project Description:

Thanks to the generous grant from the Gordon-Hartman Foundation, Chromosome 18 was able to bring a part-time Program Service Coordinator (PSC) onboard our team. During the last year, our PSC provided support by helping families connect with one other, with support organizations, and with medical professionals. The addition of the PSC has allowed our two full-time staff members to focus on new fundraising, logistics, and outreach programs without sacrificing the time and attention our members deserve. With continued grant funding, our PSC will be able to renew into the next year. While our services are utilized both nationally and internationally, we spend most of our funds in Bexar County - over 75% of funds raised in the last campaign were used for direct services in the San Antonio area.

Upon first contact with new families, our PSC provides the initial introduction and gives them an overview of what to expect with their child's syndrome. For most families, this is the only information they will receive about their child's syndrome after diagnosis. Following a call with our PSC, one new member stated, "Thanks for the magnificent work that you make for children and parents. In coming days, I will turn to you for some advice about treatment of newborn with tetrasomy" (Michal in Poland, dad to baby David). By increasing the support that we have for direct contact with new members through the PSC, we have been able to improve the quality of care that newly diagnosed individuals and families receive.

Evaluation Plan:

Member participation in the Chromosome 18 Clinical Research Center has improved drastically over the past year with funding for the PSC role. Already, the PSC has brought a huge boost to the numbers of new families we are able to reach. Last year saw a total of 103 new member families by July, while this year we have 134 new members at the same marker. When welcoming new families, the PSC explains the benefits of joining the research study and provides all essential information about participating. Continued funding for the PSC will allow us to increase membership engagements through local, regional, and international fundraisers. With the continuation of the PSC role, our goal is to continue to grow membership by a minimum of 20 new families per month. Additionally, Chromosome 18 will also Increase the number of community partners directly involved in our events by 5% each quarter. The addition of a PSC has enabled us to host four virtual member events every month, and the continuation of these four monthly events will be another key marker of the success of the project. These PSC-led member events provide families with a virtual platform to connect when travel is not possible.

Plans to sustain project beyond the term of this request:

The focus that our Program Coordinator (PSC) has been able to dedicate to outreach has led to higher turnout at our virtual fundraising events. This higher turnout has helped fill some of the gaps in funding left by the cancellation of our in-person events due to the pandemic. For example, our PSC was integral to the planning and success of our 2021 Virtual Conference this month. The conference saw 129 families register from over 30 different countries, with all continents represented except Antarctica. The conference and our monthly PSC-led virtual events have created numerous opportunities for international families to participate in our Chromosome 18 community even while living across the world. Previously, we had hoped that the PSC would be able to fund the position through increased member engagement. However, our fundraising, donations, and in-person events have been severely impacted by Covid-19. Nevertheless, the pandemic has made the need to continue the PSC role that much more pressing, as more than ever our members need a staff member dedicated to virtual and in-person connection events. Without continued support for this role, Chromosome 18 will have to reduce our member services substantially.

Line item Budget:

Line Item Description	Total Project Funds Allocation	Gordon Hartman Funds Allocation
PSC - Making a Difference to Our Families	\$70,000	\$30,000
TOTAL:	\$70,000	\$30,000

BOARD OF DIRECTORS

LIST OF BOARD DIRECTORS

Name & Office Held	Corporate Affiliation
Jannine Cody	UT Health San Antonio
Liz Woodfield	ViiV Healthcare
Kathy Glascock	Family Service Association of San Antonio, Retired
John Drymala	Valero Energy Corporation
Dave Aldrup	Control-Americas at ABB Enterprise
Carol Cohen	Arent Fox, Retired Partner
Tom Kunkel	US Air Force
Meredith Moore	Hilton
Brad Sheppard	Zions Bank