

FUNDING APPLICATION

GENERAL INFORMATION

Organization Information

Legal Name: Chromosome 18 Registry and Research Society (The)		Federal Tax ID#: 74-2557551		501(c)(3) Public Charity 509 (a)(1)	
Address: 7155 Oakridge Dr		City: San Antonio		State: Texas	
				Zip Code: 78229	
Website: www.chromosome18.org		Fax: (210) 657-4968		United Way Funded: No	

Fiscal Year:
January 01 to December 31

Head Of Organization

Name: Neale Parker		Title: Executive Director	
E-Mail Address: office@chromosome18.org		Phone: (210) 657-4968	

Application Contact

Name: Neale		Title: Parker		E-Mail Address: office@chromosome18.org		Phone: (210) 657-4968	
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Has the organization applied to the Najim Charitable Foundation in the past and been declined?
Yes
2020, 2019, 2018, 2016, 2015

Grant Amount Requested \$: \$25,000	Total Project Budget \$: \$100,000	Organization's Annual budget \$: \$711,600
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Mission Statement:
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:
Reduced Mortality & Increased Life Expectancy for Trisomy 18 Infants: High Resolution Molecular Analysis

PROJECT TIMELINE

Start Date 06/01/2021	End Date 03/31/2022
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Harvey E. Najim Charitable Foundation Priorities:
Disabilities/Special Needs

Program / Project Description:

In 2018, there were roughly 3.79 million live births in the United States. Of these 3.79 million live births, 1,007 infants were born with Trisomy 18, meaning 101 infants in Texas and 20 infants in San Antonio were affected. Unfortunately, most infants with Trisomy 18 die within days or weeks of their birth. But Trisomy 18 is not destiny; it is a genetic condition that affects thousands of families around the world. Chromosome 18 Registry & Research Society (C18) wants to improve the quality of life and life expectancy for children affected by Trisomy 18.

The prevalence of full Trisomy 18 is 1 in 3,762 births. In order to begin to understand and correct major health problems caused by Trisomy 18, we need to determine which genes are the few on chromosome 18 responsible for the condition. One way to approach this is to identify people with small chromosome 18 duplications; partial Trisomy 18. Once we have identified individuals with partial Trisomy 18, we can define their exact chromosome 18 change and evaluate their medical issues. As we correlate specific issues with specific regions of chromosome duplication, we will hone in on the causative genes. We have done this with the deletion syndromes of chromosome 18 and are now turning to the duplication (trisomy) syndromes. To date, the Chromosome 18 Research Center has enrolled ten individuals with duplications of portions of chromosome 18 and have collected their medical records. We hope to enroll many more as well. However, in order to determine exactly which genes their chromosomes have duplicated and contribute to trisomy, we need to perform a high resolution analysis of their chromosomes. We need additional funding in order to perform this molecular analysis.

Chromosome 18 Registry & Research Society support the Chromosome 18 Clinical Research Center (CRC) based at UT Health - San Antonio which has been serving families for over 30 years and is the only research center in the world dedicated to chromosome 18 conditions. Raising \$25,000 would help allow us to complete 20 high resolution molecular analyses that would help bring us closer to the root of the problem. If we can learn which genes on chromosome 18 are lethal then we can begin to make progress toward treatment. In addition, this will provide enough data to also build out specific management guides for physicians and families to enable better treatment options for Trisomy 18 children. Once the Trisomy 18 Management Guide is developed, it will be shared directly with C18's members initially but quickly after, will be made widely to everybody which will directly impact the quality of life and life expectancy for individuals affected by Trisomy 18.

C18 and the CRC have helped individuals with chromosome 18 abnormalities by building a community of affected individuals, families, and friends; expanding education for both medical professionals and families; and advancing research that directly leads to treatment recommendations and improved quality of life for tens of thousands of chromosome 18 affected children in the US and around the world. 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. The CRC's mission is to provide individuals and families affected by chromosome 18 abnormalities with comprehensive medical and educational information with a focus on treatment options. With over 700 participants in this long-term study at the CRC, with the partnership of UT Health San Antonio, is instrumental in improving the lives of individuals affected by chromosome 18 conditions. Together, C18 and CRC work to ensure that families affected by chromosome 18 conditions receive access to all available resources and support so that they are able to connect with other families and receive critical medical treatment. To date, Trisomy 18 families have been underserved and underrepresented in research, due to the high mortality rate associated with Trisomy 18 conditions. This project will help ensure that 1000's of Trisomy 18 families have access to the research backed treatment recommendations that would result from the proposed high resolution analysis.

Individuals with Chromosome 18 (C18) conditions are often left feeling isolated due to a bleak diagnosis by doctors with no knowledge of C18 conditions; with the help of the CRC, families are receiving information vital to their children's health that they cannot receive anywhere else in the world. Because of the rare, complex nature of C18 conditions, many families find themselves with little to no information and support following diagnosis. The symptoms of C18 abnormalities vary greatly in severity between patients and include heart and organ defects, problems in physical development, and varying degrees of autism and issues with mental development. C18 has over 3,000 active members in the USA and an additional 2000 from around the World.

Evaluation Plan:

In order to evaluate the success of the project, once the children have been identified and their medical records have been obtained, then high resolution analysis of their chromosomes will be performed on each child. This information will be reviewed by CRC staff and results then extrapolated. Results will then be peer-reviewed and published in a medical journal. Additionally, the results used to compile a Trisomy 18 Clinical Management Guide. Upon completion and depending on the results, the next process would be to hone in on the causative genes.

Plans to sustain project beyond the term of this request:

This project is part of the 30 years of research, education, and publications that the CRC has contributed to the scientific and rare disease community. The project's progress will be reviewed on a bimonthly basis and funding from our families, community partners and foundation grants keep research projects, like the high resolution analysis for partial Trisomy 18, moving forward for the future. This information is made available at no charge to the global Chromosome 18 Community or anybody that requires these resources. This Clinical Management Guide will help 1000s of physicians across the country and around the globe to provide better healthcare for infants and children with Trisomy 18 conditions.

Children Impacted:

How many unduplicated children will the TOTAL PROJECT INITIATIVE impact?

10,000

How many unduplicated children will NCF REQUESTED FUNDS impact?

20

Please provide the percentage of each group below that will be served by the project in which funds are being requested. Do not leave any area blank. If that specific group will not be served, include zero. The percentage should total 100%.

A. Population Served Age		B. Population Served Ethnicity	
Infants (0-5)	100%	African American	7%
Children (6-13)	0%	Asian American	2%
Young Adults (14-18)	0%	Caucasian	58%
TOTAL:	100%	Hispanic/Latino	30%
		Native American	1%
		Other and Define	2%
		TOTAL:	100%

City Council District for Which Children are Being Served:

District1, District2, District3, District4, District5, District6, District7, District8, District9, District10, Outside San Antonio

Counties applicant is in:

Atascosa, Bandera, Bexar, Comal, Guadalupe, Kendall, Kerr, Medina, Wilson

Line item Budget:

Line Item Description	Total Project Funds Allocation	Najim Funds Allocation
High resolution molecular analysis	\$25,000	\$13,000
Enrollment criteria review	\$7,000	\$2,000
Coordination of samples collection	\$4,000	\$0
Data analysis	\$15,000	\$4,000

Data preparation for scientific publication	\$10,000	\$3,000
Physician Management Guide creation	\$22,000	\$3,000
Indirect costs (laboratory and office use)	\$11,000	\$0
Samples shipping and office supplies	\$6,000	\$0
TOTAL:	\$100,000	\$25,000

OTHER FUNDING RESOURCES

For Project being Requested: Funding sources and amounts, pending and committed.

PROJECT - PENDING

Funder Name	Amount Requested
St. Luke's Lutheran Health Ministries	\$10,000
Go Fund Me	\$15,000
Collins Foundation	\$11,000
Champions for Charity	\$10,000
GlaxoSmithKline	\$7,000
HRJ	\$25,000
Harvey Najim Family Foundation	\$25,000
Benefit for Children	\$20,000
TOTAL:	\$123,000

PROJECT - COMMITTED

Funder Name	Amount Requested
*None Provided	\$0.00
TOTAL:	\$0

Other funding sources and amounts, pending and committed not specific to this request.

ALL OTHER ORGANIZATION REQUESTS - PENDING

Funder Name	Amount Requested
Klesse Foundation	\$5,000
Lizanell & Colbert Coldwell Foundation Foundation	\$13,000
Valero Energy Foundation	\$25,000
St Susie's	\$5,000
Seemes Foundation	\$10,000
Musk Foundation	\$25,000
SWBC	\$10,000
Earl Sams Foundation	\$10,000
Impetus Foundation	\$12,000
HEB	\$10,000
HRJ	\$55,000

UT Health	\$25,000
Whitaker Foundation	\$12,000
St Lukes	\$9,450
TOTAL:	\$226,450

ALL OTHER ORGANIZATION REQUESTS - COMMITTED

Funder Name	Amount Requested
Baptist Healthcare Foundation	\$75,000
MZ Foundation	\$10,000
Gordon Hartman Foundation	\$10,000
Amazon Web Services	\$2,500
San Antonio Area Foundation	\$25,000
HEB	\$5,000
TOTAL:	\$127,500

BOARD OF DIRECTORS

What percentage of your board contributes financially to the organization?
100%

If Board giving is not at 100%, please explain why?
N/A

How are board members expected to participate in your organization?
Board members each have their own title and corresponding duty within the organization, including Treasurer, Secretary, Vice President for Development, Vice President for Member Relations and Director at Large positions. Board members are expected to attend monthly Board meetings where strategic direction for the organization is discussed and most serve on different Committees as well. We have a diverse Board with many specific talents such as medical, legal, financial, fundraising, etc. that represent a cross section of our members and have an intimate insight into how best to carry out our mission.

LIST OF BOARD DIRECTORS

Name & Office Held	Corporate Affiliation
Jannine D. Cody Ph.D - Founder & President	UT Health
Thomas Kunkel - Director at Large	US Air Force - The Joint Staff, J3
Liz Woodfield - Vice President for Member Relations	EMD Serono, Inc.
Dave Aldrup - Secretary	Hitachi ABB Power Grids
John Drymala - Treasurer	Valero Energy Corporation
Carol Cohen - Director at Large	Retired Partner, Arent Fox
Kathy Glascock - Vice President of Development	Retired, Family Services - San Antonio
Meredith Moore - Director at Large	Hilton Hotels
Brad Sheppard - Director at Large	Retired, Zion Bank

Signature
Neale Parker