

FUNDING APPLICATION

GENERAL INFORMATION

Organization Information

Legal Name: Cystic Fibrosis Foundation		Federal Tax ID#: 13-1930701		501(c)(3) Public Charity 509 (a)(1)	
Address: 506 E. Ramsey Road Suite 3		City: San Antonio		State: Texas	
				Zip Code: 78216	
Website: www.cff.org		Fax: (210) 829-7267		United Way Funded: No	

Fiscal Year:

January 01 to December 31

Head Of Organization

Name: Terri Mauldin		Title: Executive Director	
E-Mail Address: tmauldin@cff.org		Phone: (210) 829-7267	

Application Contact

Name: Terri Mauldin	Title: Executive Director, South Texas Chapter	E-Mail Address: ahuzar@cff.org	Phone: (301) 215-7490
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Previous Najim Funding

Year	Funding \$
2020	\$10,000
Total	\$10,000

Has the organization applied to the Najim Charitable Foundation in the past and been declined?

No

Grant Amount Requested \$:	Total Project Budget \$:	Organization's Annual budget \$:
\$20,000	\$244,170	\$513,215

Mission Statement:

The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality, specialized care.

PROJECT INFORMATION

Program / Project Title:

To support Specialized Cystic Fibrosis Care at three Care Centers in San Antonio to include Children's Hospital of San Antonio, UT Health SA, & Tri-Services Military Cystic Fibrosis Center.

PROJECT TIMELINE

Start Date	End Date
09/01/2021	08/31/2021

Harvey E. Najim Charitable Foundation Priorities:

Medical Needs

Program / Project Description:

CF is a genetic disease affecting more than 31,000 people in the United States, of whom more than 2,000 live in Texas. In people with CF, a defective gene causes the body to produce thick, sticky mucus that builds up in the lungs and digestive system. Resulting lung infections progressively limit the ability to breathe and impeded pancreatic function leads to malabsorption of vital nutrients. These conditions combine to tragically shorten lives.

When the CF Foundation was established in 1955, children born with CF were not expected to live long enough to attend elementary school. Through the CF Foundation's efforts, the life expectancy of a child with CF has more than doubled in the last 30 years. Today, due to advancements in therapeutics development as well as improved quality of care, people with CF are living into their 30s, 40s, and beyond - and more than 50% of CF patients are 18 years of age or older. The CF Foundation is driven by a dream that one day every person with cystic fibrosis will have the chance to live a long, healthy life.

The CF Foundation pioneered multi-disciplinary, specialized care centers at hospitals in 1961. Since that time, the nationwide CF care network has grown to more than 130 pediatric and adult care centers, including the CF care centers at Children's Hospital of San Antonio, University of Texas Health Sciences Center - San Antonio and Tri-Services Military Cystic Fibrosis Center. Together, these centers treat approximately 144 children and 127 adults with CF annually. The CF Foundation's approach has led to dramatic improvements in life expectancy for people with CF and has been cited by the National Institutes of Health as a model of effective and efficient health care delivery for a chronic disease.

Each CF care center is staffed with a multidisciplinary care team. These teams have the knowledge and resources to keep people with CF in the best possible health, with a core focus on individualized treatment and specialized care. The CF Foundation requires multidisciplinary care teams include a pulmonologist, nurse, dietician, social worker, and respiratory therapist. In addition, the CF Foundation recommends adding a physical therapist, psychologist, research coordinator, and pharmacist on each center's care team. CF clinicians apply evidence and expertise to deliver coordinated care that is centered on each patient's individual needs.

At quarterly care center visits, the care team monitors the patient's health and collaborates with the patient and family to develop and revise the individualized treatment plan. The array of inpatient and outpatient services includes laboratory tests, lung function measurement, airway clearance technique instruction, nutritional assessment, therapies to fight lung infections and more. Care centers offer additional services to patients and their families, such as family counseling referrals and assistance with insurance reimbursement and coverage issues, which address other aspects of living with CF or caring for a person throughout all stages of the disease.

The COVID-19 pandemic is particularly concerning to CF patients, as respiratory infections put CF patients at much greater risk for in-patient hospitalizations, worsening lung disease, and death. Risk of exposure to COVID-19 required CF care centers to quickly pivot towards telehealth to deliver care. The CF Foundation provided leadership, training and resources to support this pivot, including procuring and distributing spirometers, a tool to measure lung function at home, to patients. As one respiratory therapist stated, "I feel I am flying blind without spirometry data." The ability of a CF patient to provide this data from the safety of his or her home is critical to the success of care via telehealth. Telehealth will continue to be a part of the health care delivery model as care centers return to in-person visits.

The goal of this program is to improve the quality and longevity of life for individuals living with CF in San Antonio. A traditional hospital environment does not provide the requisite level of care that this disease demands. Improving quality of care at the San Antonio care centers is a major focus in improving quality of life for all people with CF. In the past year, the UT Health Sciences Center's adult CF care center has increased its staffing and now has a complete care team dedicated 100% to adult CF patients. The CF care centers in San Antonio are involved in Quality Improvement projects to continually improve care delivery and outcomes for patients. In partnership with the care center network, the CF Foundation will support the CF care model to meet the future needs of people with CF across their lifespan and ensure clinicians and researchers are equipped to meet the changing needs of people with CF.

The CF Foundation is the world's leader in the fight against CF. Over the next few years, we anticipate the development of new therapies to address the wide range of symptoms associated with CF, including infections, inflammation, and nutritional needs. The development of these therapies will provide care teams with new treatment options, further improving quality of care for people with CF in and beyond San Antonio.

Evaluation Plan:

The CF Foundation evaluates care center success based on results for the following four key measurements of patient care:

- o Lung function (measured by FEV1 percent predicted)
- o Nutritional status (measured by body mass index or BMI)
- o Percent of patients screened for CF-related diabetes (CFRD)
- o Percent of patients who completed the recommended four clinical visits, one sputum or throat culture, and two lung function tests per year

Prior to receiving accreditation, CF care centers undergo an assessment by a peer committee to ensure that each center meets the requirements for providing the best possible care. CF care centers are re-evaluated annually so people with CF benefit from effective and consistent levels of care. These centers also collect data which is published annually in the CF patient registry and helps guide research and care efforts.

Plans to sustain project beyond the term of this request:

The funding for this project will be sustained through event revenue and donations from individuals, foundations, and corporations. The Cystic Fibrosis Foundation, a 501(c)(3) nonprofit organization, has unrestricted financial reserves of about 12 times its budgeted 2021 expenses. These reserves are a result of the Foundation's successful venture philanthropy model, through which we have raised and invested hundreds of millions of dollars to help discover and develop breakthrough CF therapies. With this model, we have received and may receive milestone-based payments, equity interests, royalties on the net sales of therapies, and/or other forms of consideration. These funds and any future revenue from our model are reinvested into the CF Foundation's mission to cure cystic fibrosis and to provide all people with CF the opportunity to lead long, fulfilling lives. To obtain a copy of our latest Annual Report, visit <https://www.cff.org/About-Us/Reports-and-Financials/>, email info@cff.org or call 1-800-FIGHT-CF.

Children Impacted:

How many unduplicated children will the TOTAL PROJECT INITIATIVE impact?	How many unduplicated children will NCF REQUESTED FUNDS impact?
144	144

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)	33%	African American	4%
Children (6-13)	34%	Asian American	0%

Young Adults (14-18)	33%	Caucasian	48%
TOTAL:	100%	Hispanic/Latino	46%
		Native American	0%
		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

Line item Budget:

Line Item Description	Total Project Funds Allocation	Najim Funds Allocation
Children's Hospital of San Antonio CF Care Center	\$96,830	\$6,666
University of Texas Health Sciences Center - San Antonio	\$99,840	\$6,668
Tri-Services Military Cystic Fibrosis Center	\$47,500	\$6,666
TOTAL:	\$244,170	\$20,000

OTHER FUNDING RESOURCES

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

PROJECT - PENDING

Funder Name	Amount Requested
Brown Foundation	\$200,000
Valero Energy Foundation	\$25,000
Gordon Hartman Foundation	\$15,000
TOTAL:	\$240,000

PROJECT - COMMITTED

Funder Name	Amount Requested
The Gordon Hartman Foundation	\$15,000
TOTAL:	\$15,000

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

ALL OTHER ORGANIZATION REQUESTS - PENDING

Funder Name	Amount Requested
Valero Services, Inc.	\$10,000
TOTAL:	\$10,000

ALL OTHER ORGANIZATION REQUESTS - COMMITTED

Funder Name	Amount Requested
University Health Systems	\$15,000
TOTAL:	\$15,000

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?

CF Foundation Board members are expected to demonstrate commitment to the values and mission of the CF Foundation; serve as a CF Foundation ambassador and help raise awareness and support; recruit, engage and steward volunteers and donors; contribute financially; support events and programs; and perform leadership functions such as providing strategic advice. Board members also help lead and support local programs and fundraising events, such as the CF Foundation Cares program to support caregivers and the Great Strides fundraising walks.

LIST OF BOARD DIRECTORS

Name & Office Held	Corporate Affiliation
Bobby Sims Jr.	HEB
Dr. Donna Beth Willey-Courand	UT Health San Antonio
Kevin Kirk	The San Antonio Orthopaedic Group
Mary Kirk	UT Health San Antonio
Bobbie Lacombe, Chair	Valero Services
Susan Osborne	CAMP CAMP
Suzy Fitzgerald	Retired/Community Volunteer
Colette Riddle	USAA Insurance
Claudia Dequin	Education
Dr. Holly Keyt	UT Health San Antonio
Susie Dorsett	University Health Systems
Robert Lopez	Capitol Chevrolet
Ginger Lopez	Chuck Nash Automotive Group
Tiffany Martindale	Citibank
Kay Keller	Keller-Williams City View
Ashley Thompson	US Navy
Eric Burnside	Leon Valley Fire Dept.
Halla Nickel	Community Volunteer
Dr. Holly Keyt	UT Health San Antonio

Signature

Terri Mauldin