



For application technical support, please contact nappleton@cff.org

Program Name: 2024 Success with Therapies Research Consortium (STRC) Award

Brief Program Overview/Description: The Cystic Fibrosis Foundation created the Success with Therapies Research Consortium (STRC) in 2015 for the purposes of identifying and studying interventions to enhance successful self-management and related health outcomes among individuals with CF. This consortium is part of the “Partnerships for Sustaining Daily Care” program which brings together key stakeholders in the CF community to better understand the lived experience, promote dialogue on the complexities of living with CF, and identify ways to support self-management and daily care. Accordingly, through this Request for Applications (RFA), CFF invites applications from interested faculty members in behavioral and psychosocial research.

Funding Amount: The maximum award amount is \$21,000 in direct costs plus twelve percent (12%) of indirect costs (\$23,520 total costs), per year for up to three (3) years.

Eligibility: U.S. based faculty members at CF Care Centers with expertise in the daily management of CF and/or behavioral or psychosocial research are welcome to apply to the STRC.

Key Dates:

	Spring 2023 Cycle
Published	December 7, 2023
Full Application Deadline	March 7, 2024*
Committee Review Date	May 8, 2024
Notification to Applicants	Early June 2024
Earliest Project Start Date	August 1, 2024

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*We strongly encourage all applicants pre-register their profile, institution, contacts, and Title of their application at least two weeks prior to the application deadline. This will help to ensure the CFF Grants & Contracts Management and Administration (GCMA) Office is able to assist all applicant with any potential system-related queries prior to the Application Deadline.

I. About the Cystic Fibrosis Foundation

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.

To achieve this mission, various types of grants and awards are offered to support meritorious research in CF.

II. Program and Award Overview

Despite the advances achieved in science and care in CF, managing CF in the context of daily life continues to be a significant challenge for many living with the disease. CFF recognizes that people living with CF, their families, CF care teams, and healthcare systems have varying barriers, resources, and motivation to successfully manage CF care in daily life. To this end, the CFF created the Success with Therapies Research Consortium (STRC) in 2015 for the purpose of identifying and studying interventions to enhance successful self-management and related health outcomes among individuals with CF. This consortium is part of the “Partnerships for Sustaining Daily Care” program which brings together key stakeholders in the CF community to better understand the lived experience, promote dialogue on the complexities of living with CF, and identify ways to support self-management and daily care (for more information refer to the information found on the CFF website at: <https://www.cff.org/Care/Partnerships-for-Sustaining-Daily-Care/>).

Accordingly, through this Request for Applications (RFA), CFF invites applications from interested faculty members with expertise in the daily management of CF and/or behavioral and psychosocial research.

Note: *A competitive renewal application will be required every three (3) years for members to continue in the consortium.*

Scope of Consortium:

The STRC is a hybrid research network/consortium conducting multi-center studies to support daily CF management. The consortium is comprised of physicians, behavioral researchers, psychologists, and pharmacists. Over the past seven years, our consortium has evolved in terms of studies and our mission statement. The mission of the STRC is the following:

To facilitate the clinical investigation of interventions that support Cystic Fibrosis (CF) self-management to optimize health outcomes and enhance quality of life.

All interventions are created, implemented, and distributed in collaboration with people with CF, their families, and care teams to:

- Be person-centered and empower people with CF.
- Consider people’s life experiences, backgrounds, and cultures.
- Be adapted to people’s specific strengths and needs.
- Be practicable, flexible, and feasible.
- Include validated measures of adherence and self-management in CF.

From its inception, the STRC has aimed to design studies with sustainability in mind to ensure an intervention can be integrated into clinical care and used in daily life. Therefore, some studies may involve interventions conducted in the clinical setting by clinical staff. Studies evaluating the reliability and validity of self-management measures are also conducted by the STRC. When there are complimentary projects, the consortium collaborates with other CFF committees/initiatives, including the CER/Registry Committee, the Clinical Research Committee, the Quality Improvement (QI) initiative and the Therapeutics Development Network Coordinating Center (TDN CC).

STRC studies originate in several ways including internal proposals initiated by STRC investigators or leadership, external collaborations, and feedback from the broader CF community.

Previous and current intervention studies conducted within the consortium include:

- Observational study on daily use of ETI and factors that affect ETI use.
- Validation and dissemination of the Daily Care Check-In.
- Video-based tele-coaching to support treatment adherence.
- Effectiveness of web-based mobile application to support treatment adherence.
- Feasibility, acceptability, and usability of new medication monitoring devices.
- Understanding the behavioral and psychosocial factors that support or hinder optimal nutrition.

Objectives of Consortium:

- A.** The goal of this call is to assemble a group of investigators and CF centers that represent diverse expertise and experiences to facilitate the conduct of rigorous research that supports people with CF in their self-management and daily care. The STRC intends to bring together a team of people with behavioral, psychosocial, and clinical research experience and/or lived experience expertise to support our efforts for people with CF and their families.
- B.** STRC investigators will work collaboratively with the Study Management, Data Management, and Operations Cores to identify, prioritize, develop, and test interventions relevant to the STRC mission, as well as to accelerate the process of disseminating, implementing, and sustaining them in the CF community.
- C.** During this award the STRC will initiate a new longitudinal data repository that will include the ongoing collection of data related to the STRC mission. All STRC sites are expected to participate in this initiative, for which a separate study award will be provided to fund study conduct.

Consortium Structure:

A. Leadership & Oversight

The consortium is led by two co-chairpersons who have been selected by CFF and work with and directly report to CFF's Senior Director of Partnerships for Sustaining Daily Care. Additional oversight and consultation are provided by the STRC Steering Committee.

Community and stakeholder input is highly valued and is sought as the STRC sets priorities and identifies and develops studies. These individuals are identified through current and former people with CF and family members who have served on the STRC Steering Committee, STRC sites, CFF's patient and family group, Community Voice, and CF Foundation leadership.

B. Core Centers

The consortium is supported by a team made up of three organizations:

- 1.** The Study Management Core (SMC), based at Boston Children's Hospital (BCH), is responsible for the administration and coordination of STRC research activities. The SMC at BCH also serves as the study sponsor for STRC studies.
- 2.** The Data Management Core (DMC) at Johns Hopkins University (JHU) is responsible for biostatistics and clinical data management for STRC studies.
- 3.** The Operations Core, based at the Cystic Fibrosis Foundation, is responsible for central operations and communications for the consortium.

C. Consortium Membership

Membership in the STRC is contingent on a site award. Investigators that join the STRC are expected to be reviewers on protocols, participate in research studies, help implement policies, and serve on working groups.

1. All consortium sites must designate one faculty member as lead Principal Investigator (PI) with administrative responsibilities that include the following:
 - Provide regular updates on study team changes, site capabilities, and study participation.
 - Be responsive to requests for information from the CFF or study cores.
 - Obtain institutional commitment to facilitate the contract and budget processes of the STRC.
 - Submit an annual progress report.
 - Oversee the conduct of research studies in the clinic setting including providing appropriate hiring and training of personnel, equipment, services, and access to patients necessary to complete studies following Good Clinical Practice.
 - More than one investigator may be included on the site award if their expertise is non-overlapping with other investigators on the award and relevant to the STRC. Please see page 8 for additional information on the budget.

2. All consortium investigators must agree to the following:
 - Actively collaborate to further the goal of the consortium, including the sharing of data, to comply with publication requirements.
 - Attend consortium meetings, calls, and training sessions.
 - Participate in working groups and the collaborative development of new reports or study protocols.
 - Consider taking on leadership roles such as serving on the Steering Committee.

III. Funding Amounts

The maximum award amount is \$21,000 in direct costs plus twelve percent (12%) indirect costs, per year for up to three (3) years. Allowable direct costs are the following:

- A minimum of two percent (2%) and no more than five percent (5%) salary support for the Principal Investigator (PI) and co-Investigator(s) to each fulfill the role described above and to:
 - Lead the STRC at their site (e.g., communication about STRC activities, coordination with other site activities).
 - Attend STRC meetings (3x/year; no more than 1 in-person meeting/year).
 - Serve on a protocol review.
 - Serve on a time-limited working group.
- Up to \$2,000 per person, per year, in travel-related costs for the investigator(s) to attend in-person STRC meetings in Bethesda, MD and/or NACFC, unless travel to NACFC is already covered by the site's center award.
- Up to \$2,000 per person, per year, in travel-related costs for one (1) Research Coordinator to attend in-person STRC meetings in Bethesda, MD.

All other costs are non-allowable without prior written approval from the CFF Grants and Contracts Office.

Funding for each research study is awarded separate from this site award and is dependent on the site being selected to participate. Selection is based on the study's eligibility criteria and the site's performance in prior studies.

For STRC leadership roles that require a higher degree of commitment and time than what is currently covered (e.g., the Steering Committee), additional funding will be awarded.

IV. Eligibility

U.S. based faculty members at CF Care Centers with expertise in the daily management of CF and/or behavioral or psychosocial research are welcome to apply to the STRC.

V. Mentorship Requirements

Not applicable to this RFA

VI. Goals of Research Currently of Interest to CFF/Priority Areas

The STRC defines self-management as the responsibilities an individual and their families undertake in managing their CF and overall health. This includes but is not limited to, performing medical therapies, maintaining mental/emotional health, monitoring and managing symptoms, managing nutritional health, exercising, communicating with the healthcare team, and balancing personal responsibilities, relationships, and life with health considerations or needs.

The following is a full list of self-management domains the STRC will consider for future studies.

- Manage mental/emotional health beliefs and cognitions
- Manage medical therapies
- Balance personal responsibilities and life with health needs or considerations
- Communicate with the Healthcare Team
- Monitor & Manage Symptoms
- Manage Co-Morbidities
- Manage Nutritional Health
- Access and Navigate the Healthcare system
- Navigate Transitions
- Engage in Physical Activity/ Exercise
- Communicate with Family, Friends, and Community
- Attend Medical Care Appointments
- Limit or Avoid Substance Use (drugs, alcohol, or tobacco)
- Manage Pain
- Manage Sexual and Reproductive Health
- Satisfy Basic Life Needs

VII. Review and Award

STRC sites will be selected through a peer-review process. Applications will be reviewed by the STRC Steering Committee and external reviewers. All awards are subject to observance of the applicable regulations and CFF policies.

The application review will focus on the experience of the investigators and research and clinical support staff, the site facilities, and access to CF patients. In addition, a demonstrated commitment to addressing CF self-management and research expertise in a relevant area will be considered as part of the funding decision.

VIII. Submission Information

Application deadline: Thursday, March 7, 2024, by 5:00 PM (Eastern)

Submit online through <http://awards.cff.org>

(Refer to Section X of these guidelines for specific submission instructions)

An application will be considered incomplete if it fails to comply with the instructions, or if the submitted material is insufficient to permit adequate review. CFF reviews applications electronically, and only documents submitted online at <http://awards.cff.org> will be reviewed.

General Timeline:

	2024 Cycle
Application Deadline	March 7, 2024*
Committee Review Date	May 8, 2024
Notification to Applicants	Early June 2024
Earliest Project Start Date	August 1, 2024

*We strongly encourage all applicants to pre-register their profile, institution, contacts, and title of their application at least two weeks prior to the application deadline. This will help to ensure the CFF Grants & Contracts Management and Administration (GCMA) Office is able to assist all applicants with any potential system-related queries prior to the Application Deadline.

IX. Letter of Intent Guidelines

Not applicable to this RFA

X. Full Application Guidelines

Applications must be submitted online at <https://awards.cff.org>

Documents should be typed using:

- Font: Times New Roman 12 or Arial 11
- Margins: No less than a half inch on each side

Note: *When all the documents have been uploaded to awards.cff.org, the system will compile them into a single PDF file. You may preview this file by selecting “Application Full Print”, as well as exporting the compiled PDF file.*

To login, please visit: <https://awards.cff.org>

For all first-time applicants in the new Grants Management System, we ask that you pre-register to create a username and password for “<http://awards.cff.org>” and complete a profile prior to submitting an application. **Please note:** Applicants should register their profile using the “Domestic Institution” or “International Institution” options to ensure that your profile aligns properly with the institution where the project will be conducted. We also request that as you begin your application, you enter the title of your project, if available. If you are registered and cannot remember your password, click on the “**Forgot Password?**” link below the “**Login**” fields.

Once logged in, the award opportunities, including this Request for Applications (RFA), will be listed in the **Funding Opportunities** tab on the opening screen.

Locate the listing for the “**2024 Success with Therapies Research Consortium (STRC) Award**” program. Click on the “Apply” button in the column on the far right to open the application form.

Applicants may stop at any point but must click the “**Save**” button at the bottom of each page *before exiting* in order to save their progress. When you wish to return to your draft application, please do not go through the “Funding Opportunities” tab. Instead, go to the “**My Applications**” tab in the right corner of the main page. When you are in the “**My Applications**” tab you will be able to find all your draft applications by clicking on the “Draft Applications” module.

The following sections are displayed as tabs across the application screen. Click on each section and follow the directions. Click “**Save**” as you complete each section.

GENERAL

Enter the title of your project, enter the project start and end dates, select the number of periods being requested, and complete any additional questions.

CONTACT PROFILE

If a profile was completed upon registration, the fields in this section will already be populated with the information entered in your Professional Profile. If you need to make any changes, you may update your profile in this section. Once updated you must **“Save and Validate”** prior to returning to continue your submission.

INSTITUTION

If a profile was completed upon registration, the applicant’s/principal investigator’s institution will be preloaded as the Lead Institution. Domestic applicants must verify their institution by entering the Employer Identification Number (EIN) or Tax Identification Number (TIN) to search the system for the correct institution. **Please be sure to use the dash formatting when entering your EIN/TIN (XX-XXXXXX).** If the EIN/TIN is not located, you may add the legal institution. Please also confirm if the project site is the same as the legal institution.

Verification of Applicant Institution’s Tax Status (upload as PDF documents):

The CFF GCMA Office must have a copy of the applicant institution’s current W-9 and 501(c)3 letter, or other documentation verifying its Federal tax status and will not issue Award Letters to Awardees if these documents are not received and on file.

- Applicants from for-profit organizations must submit a copy of the applicant institution’s W-9 and IRS documentation verifying the organization’s Federal tax status. Awards are not issued prior to having these documents on file with the CFF GCMA Office.

International Applicants:

Not applicable for this RFA

CONTACTS

Please note: The INSTITUTION tab must be completed prior to adding internal contacts to ensure that the contacts are properly associated with the applicant institution.

Complete the required contact fields by searching by name for existing contacts at your institution for each role. If the desired institutional contact is not available in the system, you may select **“Add Internal Contact”** to create a basic contact profile in order to add the individual to your application.

Additional contacts not associated with the applicant institution may also be added. These contacts are considered additional contributors involved in the proposed research plan. These may include consultants, collaborators, or subcontractors. In order to add contacts external to the applicant institution, please select the appropriate **“Add Subcontractors”** or **“Add Consultants/Collaborators”** button(s) and add the contacts in the table, then click **“Save”**.

REFERENCES (if applicable)

This section will appear if you have selected **“Yes”** for the question on the **GENERAL** tab **“Are you a junior investigator?”** However, please disregard this section as no Letters of Reference are required for this RFA.

CFF defines **“junior investigator”** as any individual who has not received a CFF/CFFT Research Grant or NIH equivalent (e.g. R01, R21, R23) as a Principal Investigator AND is within their first five years of their first academic appointment at the level of Assistant Professor or equivalent.

ABSTRACTS/RELEVANCE

In the space provided online for abstracts, provide a statement of no more than 2,000 characters (including spaces) explaining the subject of the research proposal and its relationship to CF. Two different abstracts are required, as follows:

- **Lay Abstract:** This statement will be used to inform the non-scientific departments of CFF and the general public of the nature of this work. Applicants should not include any confidential or proprietary information, including intellectual property, in the lay abstract.
- **Scientific Abstract:** This statement will be used to inform the scientific community.
- **Summary of Relevance to CFF mission:** All applications are reviewed and scored not only on scientific merit but also on relevance to CFF's mission:

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.

Provide a statement of no more than 3,000 characters (including spaces) summarizing the relevance of the proposed research to the health and well-being of CF patients, for a scientific audience who may or may not have a background in the subspecialty of the proposed research.

BUDGET

Select the **"Edit Budget"** button under Application Budget, to enter and begin completion of the application's budget detail for each year of funding being requested. The maximum award amount is \$21,000 in direct costs plus twelve percent (12%) of indirect costs (\$23,520 total costs), per year for up to three (3) years. There is a minimum of two percent (2%) and no more than five percent (5%) salary support for the Principal Investigator (PI) and co-Investigator(s).

Salaries & Benefits - List the names, positions, and percent effort of all professional and non-professional personnel involved in the project, **whether or not salaries are being requested**. For each individual, be sure to complete all fields on the Budget Detail in full on the template provided. In accordance with National Institutes of Health (NIH) policy, salary requests may not use an institutional base salary in excess of the current (FY2024) federal salary cap of **\$221,900**. Fringe benefits may be requested if they are treated consistently by the applicant institution as a direct cost to all funding agencies and foundations.

Travel - Travel-related costs to attend in-person STRC meetings in Bethesda, MD for the investigator(s) and one (1) Research Coordinator. No NACFC travel will be allowed under this RFA, unless travel to NACFC is not covered by the site's center award. Please note: expenses for travel outside the North American continent, including travel to Hawaii, Puerto Rico, and other U.S. territories are not allowable expenses without prior written approval from the CFF Grants and Contracts Office. Travel expenses may not exceed **\$2,000** per person, per year. Registration fees associated with conferences should be listed under "Other Expenses."

Budget Detail – Indirect Costs

Indirect costs of up to twelve percent (12%) may be requested from CFF. Indirect costs may be requested for all expenses except for the following:

- Major equipment (items over \$5,000 in value)
- Computer software
- Software licenses
- Tuition

FULL APPLICATION UPLOADS

Download the available templates applicable to the project, upload the completed templates to the corresponding attachment types within this section. Templates available for download include:

- Budget Justification
- Program Description and Organization Capacity
- Biographical Sketches for Key Personnel
- Other Support

BUDGET JUSTIFICATION

Describe costs listed in the Budget Detail. Use major categories, such as Salaries & Benefits, Consultant Costs, Major Equipment, etc. Justify in detail all items and make sure amounts and figures listed in the narrative are consistent with those listed in the Budget Detail. Note: travel expenses should detail how allotment will be spent (i.e. airfare, hotel, transportation, traveler name, etc). ****Budget Justification upload(s) should be provided individually for each year of funding support being requested. These can be uploaded as a single PDF or separate PDF uploads for each year. D***

PROGRAM DESCRIPTION – Program Description and Organization Capacity

Page limit: Six (6) single-sided pages, not including the Literature Cited. Applications exceeding this page limit will not be reviewed. Type the PI's name in the space available in the header of the document. The template available will track page numbers at the bottom.

1. Interest in Self-Management

Please describe why each investigator is interested in joining the STRC. What aspect(s) of self-management (as defined in section VI) would each investigator like to address?

***For existing and prior STRC members:** Why is each investigator interested in continuing with the STRC? In what opportunities does each investigator look forward to being involved?

2. Behavioral and Psychosocial Research Expertise Relevant to the STRC Mission

Describe each investigator's previous behavioral or psychosocial research experience with the STRC, in CF, or other chronic diseases:

- What was their specific role(s) on the project(s)?
- With what disciplines did they collaborate?
- Briefly describe the study(s)'s goals and results.
- If the results were disseminated, please provide citations.

3. Other Relevant Projects (e.g., Quality Improvement, Registry, Epidemiology, Health Services)

Please tell us about other projects relevant to the STRC mission that each investigator has done that would contribute to the STRC conducting rigorous research that can be implemented into clinical care:

- What was their specific role(s) and experience(s) on the project(s)?
- With what disciplines did they collaborate?
- Briefly describe the project(s)'s goals and results.
- If the results were disseminated, please provide citations.

4. Integration of Self-Management, Behavioral and Psychosocial Clinical Services

Please describe your center's clinical activities directed toward supporting daily care and improving self-management. Please address:

- What types of psychosocial and/or self-management screening does your center do?
- What types of psychosocial and/or self-management strategies and interventions does your center use?
- What skills and/or resources does your team have that demonstrate your ability to engage and lead psychosocial and/or self-management intervention studies at your center?

5. Community Engagement

Briefly describe each investigator’s experiences involving collaboration with community members (e.g., people with CF and families) in research, quality improvement, and/or clinical care.

6. Your Center’s Population

The STRC is committed to conducting studies that enroll a diverse and inclusive sample, including people who have historically been underrepresented in CF research.

- Provide how many people with CF are cared for at your center.
- Describe the demographic, CF, cultural, or other relevant characteristics of your center’s population, highlighting those that may be different from other CF centers. For example, consider the following:
 - i. Age
 - ii. Race/Ethnicity
 - iii. English as a second language or non-English speaking
 - iv. Socioeconomic status
 - v. Geographic representation
 - vi. Ineligibility for modulator therapy
 - vii. Advanced lung disease
 - viii. Transplant population
 - ix. Other cultural characteristics
- What strategies does your site use to recruit marginalized populations or those that historically have not been well-represented in CF clinical research?

NOTE: If you anticipate recruiting for STRC studies from both a pediatric and adult CF Center, to the extent possible answer the questions separately for each center.

BIOGRAPHICAL SKETCH(ES) OF KEY PERSONNEL

Complete and upload an NIH Biographical Sketch for all key project personnel, beginning with the Applicant/Principal Investigator. International applicants can upload a biosketch that is equivalent in content to the NIH template provided. (CFF defines “key personnel” as any individual with an advanced degree who will play an instrumental role in the accomplishment of the research project.) Do not exceed five (5) pages per person.

OTHER SUPPORT

Complete and upload the Other Support form for all key project personnel, beginning with the Applicant/Principal Investigator. There is no page limitation. Information on other support assists CFF in the identification and resolution of potential sources of overlap. Scientific and budgetary overlap should be minimized. Commitment of an individual’s effort greater than 100 percent, is not permitted.

LETTER(S) OF SUPPORT*

Letters of Support and Reference are weighed heavily in the review. All applicants are **required** to submit two (2) letters as outlined below:

- One (1) letter of support from the Center Director should be included with the application. The letter must indicate institutional support for the proposed and protection of the PI’s time to the project. This letter is mandatory. If both the pediatric and adults’ centers at the institution are participating, a letter is needed from the Pediatric Center Director and the Adult Center Director. If the Center Director is the applicant, a letter of support should be included from the Department Head or Division Chief. The letter should be no longer than (1) page.
- One (1) letter of support from an individual with CF or family member should be included with the application. The letter must indicate how the care team supports and values self-management, and their ability to partner with the community on this research. This letter is mandatory. If both the

pediatric and adults' centers at the institution are participating, a letter is needed from an individual with CF or family member at the Pediatric Center and the Adult Center.

****See the last page of this document for additional guidance on Letters of Support***

APPENDICES (OPTIONAL)

Appendices are restricted to the following two (2) categories:

- Up to three (3) reprints of the applicant's work relating to the mission of the STRC may be uploaded in PDF format.
- Signed Letters of Support and/or Collaboration: A Letter of Collaboration from Co-PIs, if any, should be uploaded and included in the application.

Validation and Submission

Prior to selecting "**Sign & Submit to AIO**", please complete a thorough review of the entire application. The "**Sign & Submit to AIO**" button will trigger validation on all required fields and identify any upload errors or incomplete fields. Upon selecting Sign & Submit to AIO, the ability to edit the application will be locked pending review and approval by your AIO.

After selecting "**Sign & Submit to AIO**", the applicant will receive an email asking them to sign the application FacePage electronically using Adobe Sign. Once signed by the PI, the FacePage will then be routed to the AIO contact that is listed on the application for review and signature.

To ensure the application is fully signed and submitted ahead of the Application Deadline for this program, please be sure to complete the application, and begin the Sign & Submit to AIO process in advance of the 5:00 PM EST deadline. The status of your application will display "Submitted" once fully signed, to indicate that your application has been received by CFF.

XI. Other Information

Not applicable to this RFA

XII. Contact Information

For technical support and program/content information:

Primary CFF GCMA Office contact Nicholas Appleton at nappleton@cff.org or 301-841-2614

Secondary CFF GCMA Office contact grants@cff.org or 301-841-2614

For scientific questions:

Cynthia George, MSN, FNP at cgeorge@cff.org

STRC Co-Chairs

Kristin Riekert, PhD at kriekert@jhmi.edu

Gregory Sawicki, MD, MPH at Gregory.Sawicki@childrens.harvard.edu

Your care team is applying to participate in the Cystic Fibrosis Foundation’s Success with Therapies Research Consortium (STRC). **As part of the application, each team is asked to submit a letter of reference from an individual with CF or family member at their center.**

The STRC is a hybrid research network/consortium conducting multi-center studies to support daily CF management. The consortium is comprised of physicians, behavioral researchers, psychologists, and pharmacists. Over the past seven years, our consortium has evolved in terms of studies and our mission statement. The mission of the STRC is the following:

To facilitate the clinical investigation of interventions that support Cystic Fibrosis (CF) self-management to optimize health outcomes and enhance quality of life.

All interventions are created, implemented, and distributed in collaboration with people with CF, their families, and care teams to:

- Be person-centered and empower people with CF.
- Consider people’s life experiences, backgrounds, and cultures.
- Be adapted to people’s specific strengths and needs.
- Be practicable, flexible, and feasible.
- Include validated measures of adherence and self-management in CF.

Self-management areas of study interest include:

Managing medical therapies

- Managing nutritional health
- Access and navigating the healthcare system
- Engaging in physical activity/ exercise
- Managing mental/emotional health beliefs and cognitions
- Managing sexual and reproductive health
- Attending medical care appointments

For the letter of support, we are asking for no more than 1-single sided page. Examples of topics and questions that you could comment on include the below. You do not need to address each item.

- How the care team supports and values self-management.
- How has the care team considered the lives, experiences, backgrounds, and cultures of people with CF in their research?
- How does care team partner with the community on research?
- How does the care team support and value self-management and the challenges patients and families face with daily therapies?
- How has the care team or investigator gone above and beyond the scope of care for patients in research?

How does the care team work to include the community in programs, studies, and decisions?