



Request for Proposals CFC International 2023 Lillian's Legacy Grant

Amount: up to \$40,000

Deadline: July 31, 2023

Potential Focus Areas: Seizures, behaviors, sleep disturbances, longitudinal outcomes, adult-onset comorbidities, pain, and other topics welcome.

CFC International, with funding dedicated to Lillian's Legacy Research Fund, is accepting applications for a total of \$40,000 US for scientific and/or clinical research studies related to natural history, treatment and management of CFC syndrome. We welcome questions, comments, ideas, and appreciate your efforts in improving the quality of life for people living with CFC syndrome. Because the manifestations of the syndrome touch a wide range of specialty areas from neurology to cardiology to dermatology to behavior to endocrinology, this RFP is designed to cast a wide net. If you have an idea about how research can improve the lives of people with CFC syndrome, we want to hear it!

Research Objectives

The CFC International Lillian's Legacy Research Grant was established in 2018 to encourage meritorious scientific and clinical studies designed to improve the diagnosis, treatment, or management of individuals with CFC syndrome. Grants will be awarded to qualified researchers to initiate or continue small scientific research studies or clinical trials, the results of which could be used to obtain funding from the NIH, FDA, or other funding agencies, or to attract a corporate sponsor. Procedures or proposed therapeutic trials may be new, based on recent biochemical or pharmacological evidence, or in the preliminary stages of clinical investigation. Evaluation of proposals will include careful consideration of protocol design, objectiveness of parameters measured, and statistical evaluation proposed. Protocols that will focus on cause, natural history, early detection, diagnosis, or treatment (pharmacological, devices, surgery, or dietary) will be given priority. Priority will also be given, but not limited to, applicants with institutional IRB's.

Support

We aim to partner with you in research by providing access to the data in CFC International's patient registry, actively supporting recruitment through our connections to the international CFC syndrome community, and through access to CFC International staff, board, research committee, and Medical Advisory Board.

About CFC International

CFC International is the advocacy organization representing all patients and families affected by CFC syndrome throughout the world. We are dedicated to the advancement of treatment, research, and quality of life for individuals diagnosed with this very rare disorder. Currently, more than 794 individuals – mostly children – are affected by CFC syndrome globally, with many more presumed undiagnosed. An earlier study conducted in Japan indicated a prevalence of CFC syndrome in 1 in 810,000 individuals. CFC International began in 1999 as a small patient advocacy nonprofit, and has grown to provide clinical conferences, family support, and medical information to thousands of parents, caregivers, family members, and loved ones supporting someone with CFC syndrome. CFC International values strong leadership in its Board of Directors, Medical Advisory Board, and Staff to be able to lead and provide direction in research related to the disorder.

Application Procedure

All of the following application elements must be received. Incomplete applications may not be considered. CFC International may consider more than one application in a calendar year. For electronic submission (preferred), all application elements should be merged into a single PDF file and sent to research@cfcsyndrome.org with "Research Proposal" as the subject line. You may CC info@cfcsyndrome.org. Alternatively, applications can be mailed to the address below.

- Application summary
- Biographical sketch and bibliography for principal investigator (templates provided below)
- List of co-investigators, if applicable
- Reviewer information, optional
- Initial letter of intent
- Abstract of the proposal
- Brief budget outline (personnel, publication, travel, other items, total costs including indirects)
- Reasons why CFC International's funding is essential (explain applicant's particular interest in this grant). If applicable, explain how this funding ties in with prior funding from CFC International.

Awarding of Grant

- Award announcements will be made via email and posted on CFC International's website within 60 days of close of application period.
- Funding will begin after all necessary documents (e.g. IRB forms, patient consent forms, signed grant agreements) have been received by CFC International.

Further Information

- If the study involves human or animal subjects, copies of governance documents will be required from each site involved in the study before payment can be issued.
- Clinical drug trials must meet requirements established by the U.S. Food & Drug Administration (FDA).
- No more than 10% of funds directed by CFC International may be used for indirect costs.

Application

PRINCIPAL INVESTIGATOR INFORMATION	
Name	
Position/Title	
Email	
Mailing Address	
Telephone	
PROPOSAL INFORMATION	
Project Title	
Project Term	<input type="checkbox"/> 1 YEAR <input type="checkbox"/> 2 YEARS
Funding Amount Requested (\$ US) <i>not to exceed</i> \$40,000 US	
Institution(s) where research will be conducted	
City, State/Province, Country of Institution(s)	
Will research involve human subjects?	<input type="checkbox"/> YES <input type="checkbox"/> NO

Will research involve animals?	<input type="checkbox"/> YES <input type="checkbox"/> NO
How did you hear about this RFP?	<input type="checkbox"/> Medical Advisory Board <input type="checkbox"/> Website Posting <input type="checkbox"/> Email Subscription Service <input type="checkbox"/> Referral from Colleague <input type="checkbox"/> Medical/Research Publication <input type="checkbox"/> Other (please specify clearly below)
	Other:
Principal Investigator Signature:	
REQUIRED	

Biographical Sketch

Please provide a biographical sketch and bibliography for the principal investigator. Applicants may use this form, link to their ORCID, or attach the NIH Biosketch form. Please modify the form to include, when applicable, the following:

Name				
Position/Title				
Education/Training	Institution & Location	Degree	Year(s)	Field of Study
Begin with baccalaureate or other initial professional education and include postdoctoral training.				

<p>Research and Professional Experience</p> <p>Concluding with present position, list in chronological order previous employment, experience, and honors. Include present membership on any advisory committee.</p>	
<p>Honors and Awards</p>	
<p>Publications: List in chronological order the titles, all authors, and complete references of all publications in the last three years and representative earlier publications pertinent to this application. If the list of publications exceeds two pages, select the most pertinent publications.</p>	
<p>Please provide a brief summary of prior funding.</p>	
<p>Name of Co-Investigator 1 (Provide Biosketch for all Co-Investigators in attachments)</p>	
<p>Position/Title</p>	

Institution	
Email	
Name of Co-Investigator2	
Position/Title	
Institution	
Email	
Name of Co-Investigator3	
Position/Title	
Institution	
Email	

Reviewer Information (optional)

Please list up to five areas of scientific/medical expertise needed to review this application (optional). Do not list names of individuals.

1	
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Please list below any individuals on CFC International’s Medical Advisory Board or Board of Directors who should abstain from reviewing this application due to any conflicts of interest.

Name	Institution	Justification

Application Checklist

Deadline for Initial Applications: July 31, 2023

Application summary	
Biographical sketch and bibliography	
List of co-investigators, if applicable	
Reviewer information, optional	
Abstract of the proposal	
Brief budget outline. Funding can be used to cover expenses such as staff salary, technical assistance, supplies, and small equipment. Indirect cost requests cannot exceed 10%.	
Initial Letter of Intent, including cogent reasons why CFC International’s funding is essential	

Thank you so much for your contribution to the health of people living with CFC syndrome! We know that these applications take time, and we appreciate your effort. To receive notification of future funding opportunities through CFC International, send email to info@cfcsyndrome.org.