



## REQUEST FOR PROPOSALS

**Cardio-Facio-Cutaneous International (CFC International) with funds designated to Lillian's Legacy**

*Announces Research Grant Money  
up to \$30,000 US for*

# **Neurological and Seizure Research: Studies, Outcomes, Treatment**

**DEADLINE FOR INITIAL APPLICATIONS: July 31, 2020**

CFC International, with funding dedicated to Lillian's Legacy Seizure Research, is accepting applications for a total of \$30,000 US for scientific and/or clinical research studies related to seizure natural history, treatment and research. Seizures in individuals with CFC Syndrome have long been a complication that has been difficult to control and, in some cases, can lead to death. Seizures often present at variable times during diagnoses individuals' lives and can be difficult to detect at the onset. Often caregivers are given sequences of treatment options to control seizure activity anecdotally indicating that it is a "trial and error" method of finding something that works. There has been little evidence to this point of being able to effectively abate seizure activity in an individual with CFC Syndrome once they've had their first seizure. We eventually seek effective protocols and AEDs. Frequency varies among child, and may even vary among the genetic variations (BRAF, KRAS, MEK1, MEK2, YWHAZ) of CFC Syndrome.

### **Research Objectives**

The CFC International Lillian's Legacy Seizure Research Grant was established in 2018 to encourage meritorious scientific and clinical studies designed to improve the diagnosis or therapy of individuals experiencing seizures with CFC Syndrome. Grants will be awarded to qualified researchers to initiate 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 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 that have institutional IRB's.

---

CFC International  
8720 W Bent Tree Drive  
Peoria, AZ 85383  
(623) 248-7992 | [info@cfcysyndrome.org](mailto:info@cfcysyndrome.org)

## 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 [tdyer@cfcysyndrome.org](mailto:tdyer@cfcysyndrome.org) with “Seizure Research Proposal” as the subject line. Alternatively, applications can be mailed to:

CFC International  
8720 W Bent Tree Drive  
Peoria, AZ 85383

- Application summary (page 3)
- Biographical sketch and bibliography for principal investigator (templates provided on pages 4-5)
- List of co-investigators, if applicable (page 6)
- Reviewer information, optional (page 7)
- Initial letter of intent (maximum one page)
- Abstract of the proposal (maximum one page)
- Brief budget outline
- Cogent 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. To account for length, recipients of prior funding may choose to submit a 3-4 page proposal en lieu of the letter of intent and abstract.

### **INCOMPLETE APPLICATIONS MAY NOT BE CONSIDERED.**

### **AWARDING OF GRANT**

- Award announcements will be made via email and posted on CFC International’s website within 30 days of receipt of complete application.
- 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).
- Overlapping funds from any other private or public source are not to be used.
- No more than 10% of funds directed by CFC International may be used for indirect costs.

### **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 500 individuals – mostly children – are affected by CFC Syndrome globally, with many more presumed undiagnosed. An earlier study conducted in Japan indicated a prevalence

CFC International  
8720 W Bent Tree Drive  
Peoria, AZ 85383  
(623) 248-7992 | [info@cfcysyndrome.org](mailto:info@cfcysyndrome.org)



of 1 in 810,000 individuals have CFC Syndrome. CFC International began in 1999 as 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 SUMMARY

### Deadline for Initial Applications: Rolling

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 \$30,000 US</i>	
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 below)
Please be as specific as possible:	

CFC International  
 8720 W Bent Tree Drive  
 Peoria, AZ 85383  
 (623) 248-7992 | [info@cfc syndrome.org](mailto:info@cfc syndrome.org)

Principal Investigator Signature

**REQUIRED**

## BIOGRAPHICAL SKETCH

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

<b>Name</b> Position/Title				
<b>Education/Training</b> Begin with baccalaureate or other initial professional education and include postdoctoral training.	Institution and Location	Degree	Year(s)	Field of Study
<b>Research and Professional Experience</b> Concluding with present position, list in chronological order previous employment, experience, and honors. Include present membership on any advisory committee.				
<b>Honors and Awards</b>				



CFC International  
8720 W Bent Tree Drive  
Peoria, AZ 85383  
(623) 248-7992 | [info@cfcsyndrome.org](mailto:info@cfcsyndrome.org)

## BIBLIOGRAPHY

**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.

Name of Co-Investigator	
Position/Title	
Institution	
Email	

Name of Co-Investigator	
Position/Title	
Institution	
Email	

Name of Co-Investigator	
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.
- 2.
- 3.
- 4.
- 5.

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

NAME	INSTITUTION	JUSTIFICATION

## APPLICATION CHECKLIST

**Deadline for Initial Applications: July 31, 2020**

<b>Application summary</b> (page 3)	
<b>Biographical sketch and bibliography</b> (templates provided on pages 4-5)	
<b>List of co-investigators, if applicable</b> (page 6)	
<b>Reviewer information, optional</b> (page 7)	
<b>Abstract of the proposal</b> (maximum one page)	
<b>Brief budget outline.</b> Funding can be used to cover expenses such as staff salary, technical assistance, supplies, and small equipment. Indirect cost requests cannot exceed 10%.	
<b>Cogent reasons why CFC International's funding is essential</b>	

To receive notification of future funding opportunities through CFC International, send email to:  
[info@cfcsyndrome.org](mailto:info@cfcsyndrome.org)

CFC International  
8720 W Bent Tree Drive  
Peoria, AZ 85383  
(623) 248-7992 | [info@cfcsyndrome.org](mailto:info@cfcsyndrome.org)