Resource Summary Report

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CFC International

RRID:SCR_004174
Type: Tool

Proper Citation

CFC International (RRID:SCR_004174)

Resource Information

URL: http://www.cfcsyndrome.org/index.shtml

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Description: CFC International is a volunteer, not-for profit, self-help support group for persons and families dealing with Cardio-Facio-Cutaneous Syndrome. Incorporated in 1999 in the state of New York, its membership has grown from 21 families in mainly the USA to now include persons from all around the world. Our mission is to strive to help each other cope with the challenges of raising a child with a rare and often medically involved disorder. We act as a clearinghouse of information on all aspects of CFC Syndrome. We publish a quarterly newsletter, produce a brochure and CFC Parent""s Guide, private address book, host a private family computer list serve and also host a website. We host International family conferences and clinics open to families from all over the globe. Our goal is to educate the general public, the medical profession, and government agencies by disseminating information on CFC Syndrome. We work to facilitate research on this very rare syndrome. We have a medical/scientific advisory board consisting of doctors from different regions of the world who have a committed interest in our CFC children. We maintain the most extensive registry for CFC Syndrome patients in the world. The Registry provides resources for the study of CFC Syndrome. It maintains centralized information records on CFC Syndrome cases from around the world. Confidentiality of personal information regarding incidence, genetics, clinical course, and prognosis is provided to professionals and families. The Registry also serves to improve communication of ideas among interested researchers, and to assure rapid distribution of any new information that may benefit patients or their families. As part of this medical registry we are founding members of the Genetic Alliance BioBank. The BioBank contains the largest collection of DNA and tissue samples from CFC patients and their parents.

Abbreviations: CFC International

Resource Type: data or information resource, disease-related portal, feed, listserv, meeting resource, narrative resource, patient-support portal, portal, topical portal, training resource

Keywords: cardio-facio-cutaneous syndrome

Resource Name: CFC International

Resource ID: SCR_004174

Alternate IDs: nlx_20087

Record Creation Time: 20220129T080223+0000

Record Last Update: 20260919T195034+0000

Ratings and Alerts

No rating or validation information has been found for CFC International.

No alerts have been found for CFC International.

Data and Source Information

Source: SciCrunch Registry

Usage and Citation Metrics

We have not found any literature mentions for this resource.