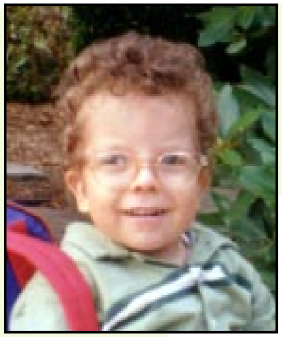

Jack

CFC International Mission

- To strive to help each other cope with the challenges of raising a child with a rare and often medically involved disorder.
- To act as a clearing house of information on all aspects of Cardio-Facio-Cutaneous Syndrome.
- To publish newsletters, address book and CFC Parents Guide for all registered families.
- To educate the general public, the medical profession and government agencies by disseminating information on CFC Syndrome.
- To facilitate research on this very rare syndrome.

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Caring, Facilitating & Connecting

Medical Advisory Board

- Dr. Judith Allanson
  Medical Geneticist, Children's Hospital of Eastern Ontario, Canada
- Dr. Maria Ines Kavamura
  Medical Geneticist and Dermatologist, Universidade Federal de Sao Paulo, Brazil
- Dr. Giovanni Neri
  Medical Geneticist, Universita Cattolica, Rome , Italy
- Dr. Jacqueline Noonan
  Pediatric Cardiologist (Retired), University of Kentucky, Lexington, Kentucky
- Dr. John Opitz
  Medical Geneticist, Primary Children's Medical Center, Salt Lake City, Utah
- Dr. Terri Young
  Opthalmologist, Genetic Research Center, Children's Hospital, Philadelphia, Pennsylvania

CFC international

CARDIO-
FACIO-
CUTANEOUS
Syndrome

Cliffy

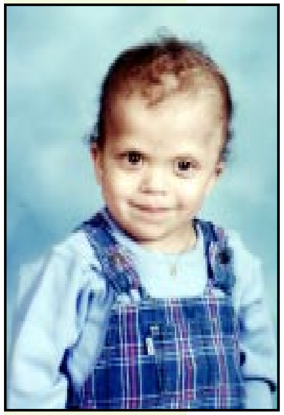
Our hope...

... is for families to feel less isolated and more confident about raising their special child.

A rare genetic disorder

Cardiofaciocutaneous (CFC) is a rare genetic disorder characterized by:

- a distinctive facial appearance;
- unusually sparse, brittle, curly hair;
- skin abnormalities;
- heart malformations present at birth (congenital heart defects) or developing later;
- growth delays;
- varying degrees of developmental delays.



Brittany

Individuals with the disorder typically have distinctive malformations of the head and facial (craniofacial) area including an unusually large head (macrocephaly), early in life, a prominent forehead, and abnormal narrowing of both sides of the forehead (bitemporal constriction); a short, upturned nose with a low nasal bridge; and/or prominent external ears that are abnormally rotated toward the back of the head. The ear canals are often small and filled with excessive wax, which may interfere with hearing. In most cases, affected individuals also have downwardly slanting eyelid openings, widely spaced eyes, drooping of the upper eyelids, eye muscle inbalance, and/or other eye abnormalities. In addition to having unusually dry brittle, curly scalp hair, affected individuals also often lack eyebrows and eyelashes.

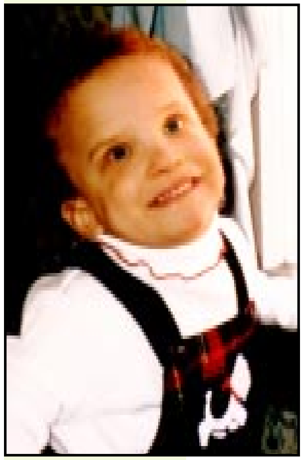
Individuals with CFC Syndrome may also have a range of skin abnormalities, varying from areas of skin inflammation to unusually dry, thickened, scaly skin over the entire body. In addition, most individuals with the disorder experience growth delays, mild to severe mental retardation, and abnormal delays in the acquisition of skills requiring the coordination of muscular and mental activity (psychomotor retardation). In some cases, additional abnormalities may be present.

CFC facts

- To date there is no clinical test to diagnose CFC Syndrome.
- Affected individuals may have behavior problems, learning difficulties and many other anomalies.
- Currently, there are between 150–200 known cases of CFC individuals in the United States.

About our services

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, its membership has grown from 21 families in the USA to now include persons from all around the world.



Elizabeth

We are involved with networking individuals, families, doctors and therapists for the purpose of education, medical treatments and knowledge. We publish a newsletter, a parent's guide, address book, and letters written by families. Each year we become closer finding strength and courage in each other, knowing that we are a growing genetic family whose connection lies at the very core of human existence. If you are interested in membership or further information please contact us.