

# Rare Health Equity Workplan



**CFC International**  
Cardio-Facio-Cutaneous Syndrome

# THE APPROACH



## **ENGAGEMENT STRATEGY**

Examined past engagement and we learned that we have no targeted past engagement.

So, we began making contact through:

- Email
- Direct contact through social media
  - Phone calls
  - Social media posts
  - Newsletter posts

# STAKEHOLDER MAPPING

- Caregivers/Parents of color
- Caregivers/Parents of an individual of color that has CFC syndrome
- Of color designated as: Black, LatinX, Asian or Pacific Islander, Native American.
- Researchers
- Medical Professionals
- CFC International Committees





## CFC INTERNATIONAL HEALTH EQUITY SESSIONS AND ADVISORY COUNCIL

BECAUSE WE CAN'T WAIT ANY LONGER TO  
BUILD HEALTH EQUITY FOR OUR FAMILIES

**CFC International has been working to identify funding and opportunities for us to examine equity barriers to our programs for our patients, families and caregivers. We are proud to be a recipient of the 2021 Rare Patient Impact Health Equity Grant from Global Genes.**

We are engaging our families and caregivers who represent patients of color in a deeper conversation about how CFC International can do better, create more equitable programs, and improve ways we assist our families and caregivers of loved ones with CFC syndrome.

We cannot do this work without listening to you!  
Your participation will assist us in being better and doing better, by knowing better.

### 1 What are we doing?

We are asking you to join with other parents and caregivers in at least one of three conversations led by our consultants, Vicki Clark and Chela Sanchez. We'd like to host these 3 discussions in the months of September, and you can participate in as many of these conversations as you'd like.

### 2 How does it work?

In recognition of your time, we are offering parents or caregivers a \$100 stipend for each listening session you can participate in.

Parents or caregivers should be representative of patients in communities where health equity has been marginalized - Black, Asian Pacific Islander, Native American, Latina and Latino patients.

### 3 What will change?

These sessions will inform needed changes in our programming, conferences, and communications. What you share will improve our existing programs and direct us in adding new programs.

Over the course of the next year, we'll add listening sessions to better understand and work toward overcoming the challenges you present. You will direct how we advocate change, and provide recommendations to improve diagnosis and care for families of color.

You will also be invited to join as an **inaugural member of our Health Equity Advisory Council** - a team of caregivers, clinicians and researchers that will lead equity work at CFC International.

### 4 How can you participate?

Please email Tuesdi Dyer [tdyer@cfcsyndrome.org](mailto:tdyer@cfcsyndrome.org) to participate. You will receive a listing of all sessions, and we will accommodate listening session times that work best for you.





## **PREPARATION**

- Executive Director phone calls
- Establishment of Session Timeline
- Sessions led by consultant, Chela Sanchez
- Attendee stipends
- Development of Health Equity Advisory Council

# ENGAGEMENT



7 PHONE DISCUSSIONS  
Executive Director



3- 1 HOUR SESSIONS  
Executive Director, Board  
President, Consultant



## COMPLETED WORK BY THE NUMBERS:

- 10 HOURS OF ENGAGEMENT WITH KEY STAKEHOLDERS
- 6 HOURS OF HEALTH EQUITY TRAINING FOR EXECUTIVE DIRECTOR AND BOARD PRESIDENT
- OVER 20 HOURS OF ENGAGEMENT WITH HEALTH EQUITY CONSULTANT ON KEY WORK TO BE DONE.

# IMPACT

Estimated 189 patients;  
337 parents/caregivers

Added an additional Medical Advisory Board  
Member

Created Advisory Council as a Committee  
of the Board of Directors



## WHAT WE HEARD:

- Parents feel equity is really based on the state they live in.
- We have parents making major sacrifices to live in states where there are better service outcomes for families of color, despite financial challenges or having to move away from family members.
  - We need more people of color in leadership roles.
- We need to have a member of the black medical community on our medical advisory board.
- Doctors representing the same racial demographic as their family can advocate for them better than doctors who are not.
  - They need more from us (CFC International) when it comes to understanding what programs we have that can benefit patients.
- Parents of color, or of patients of color want to be more than a voice, they want to be leaders for the organization.

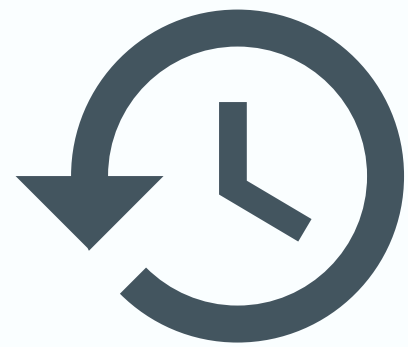
## ORDER OF MOST IMPORTANT PROGRAMS:

1. CFC Family Medical Conference
2. Family Liaison Program
3. Transition Resources
4. Family Meetups

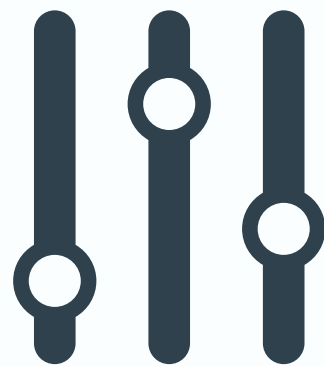


# ACTION PLAN

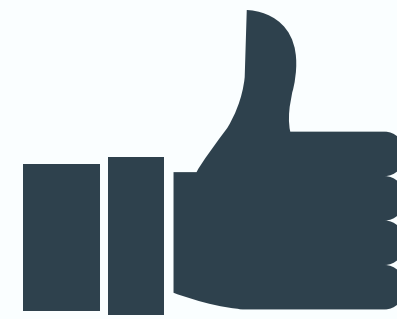
## What our Families Said they Need Most!



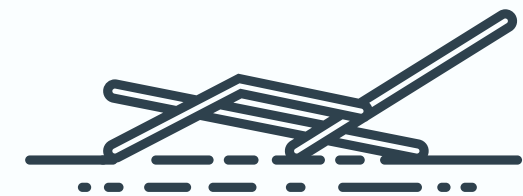
In-person  
meetups



Better  
understanding of  
what we offer



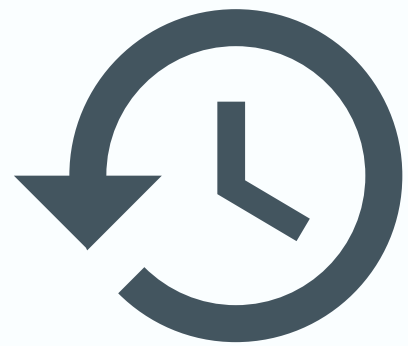
Coping skills



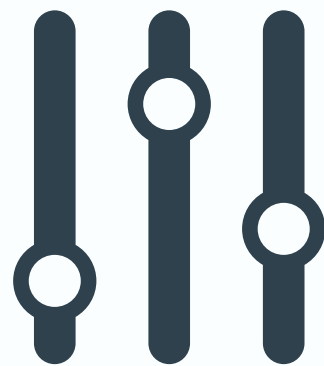
More translation

# ACTION PLAN

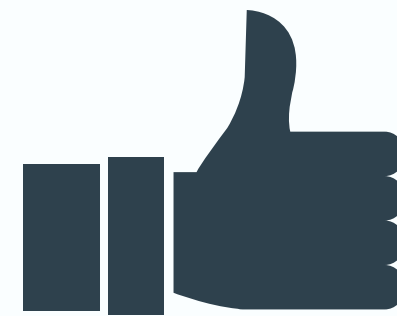
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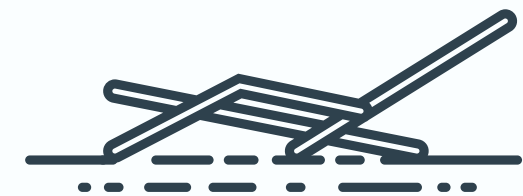
Help accessing  
public services



More information  
about transitions



More interaction  
with other CFC  
caregivers



Better  
understanding of  
where to find  
things at CFC  
International

# ACTION PLAN

## What we are going to do!



### PHASE 1 AUGUST-SEPTEMBER 2021

- Conduct individual listening phone calls with caregivers
- Host 3, 1-hour group listening sessions
  - Develop HE Advisory Council
  - HE Council Application period
- Create 3 minute video explaining CFC International Program
- Collect testimonials about conference
- October 28: Ambassador meeting on new diagnosis onboarding and timeline for current family engagement.



### PHASE 2 OCTOBER- NOVEMBER 2021

- First HE Council meeting
- Develop Council Position Statement
- Evaluate 3 new communications platforms that can transition families to stronger community interaction.
- Adjust current Zoom support groups to be topic specific.



### PHASE 3 DECEMBER 2021 - FEBRUARY 2022

- Work with partners to:
- Offer a multi-lingual zoom support group
  - Transform Zoom groups to meet age group needs.
  - Increase translation of services
  - Create "Knowing You're Not Alone" video.
  - Develop "checklist" cards for caregivers



### PHASE 4 BEFORE DECEMBER 2022

- January: Implement new communications platform
- Expand opportunity to attend conference.
- Create meetup opportunities among Ambassador regions.

What did we learn about  
doing this work?

