From Diagnosis to Conference: Our Family’s Journey

Our sweet Isaiah was born in May of 2013; our first child and we were smitten. Within eight hours of Isaiah being born, he was whisked off to the NICU where he remained for 42 days. Isaiah came home on a NG feeding tube (which would later become a g-tube), still vomiting most of his feeds, taking very little by mouth and crying 20+ hours a day – just to name a few of the struggles. There were endless hours of therapy, numerous visits to specialists, constant testing, two exhausted parents, and a stumped medical team.

Isaiah was referred to a geneticist and she was convinced that all of these issues had a genetic cause and possibly in the area of Noonan’s Syndrome, but each time the genetic tests came back negative. We had resigned ourselves to the fact that we may never know why he struggled so much.

It had been a while since we made a trip to the geneticist, so last fall we set up an appointment to follow up. As soon as the geneticist walked into the appointment, she immediately noticed the head of curls (he was still practically bald last time she had seen him). We had been wondering where those curls came from since it is not a family trait. The doctor mentioned the name CFC and that one of the traits is the distinct curly hair. It was recommended to do one more genetic test to see if we could indeed confirm. After four years of watching other children excel in therapy at walking, talking, eating, etc., there was progress to be seen in Isaiah, but just not in the same ways as the other children. Many days it was challenging not being able to meet and connect with anyone who understood all the complexities. Then the call came, we had an answer – we had a diagnosis, and the last four years finally made sense. Everything Isaiah has and has been through had a place. I think I am still picking my jaw up off the floor. Who knew that three little letters – CFC – would open up a whole new wonderful (and scary) world! What did the diagnosis do? It gave us instant community. After finding the CFC International website and Facebook group, we quickly realized we happened to be in a conference year. How could we miss an amazing opportunity to meet others who know this road better than those who struggle so much.

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CFC International Welcomes New Board Member: Jeff Kohler

Jeff and his wife Linda had a daughter, Stephanie, with CFC syndrome. Stephanie passed away in 2011 at age 24. In honor of Stephanie, Jeff and Linda started a scholarship fund. The fund assists families with a financial need to attend a CFC conference.

Jeff is a CPA and recently retired from the accounting firm PricewaterhouseCoopers, where he was a tax partner. Prior to that, he worked for General American Life Insurance Company.

Previously, Jeff has served on several other boards of directors, including DAKOTA (an organization to foster further involvement of dads in the activities of their children with disabilities), the St. Louis Public Schools Foundation, St. Joseph Home for Families, and Ride on St. Louis (therapeutic horsemanship for children with disabilities).

Jeff resides in St. Louis, Missouri, and is looking forward to serving on the CFC International Board.

CFC Conference and 20th Anniversary Gala
Tampa Bay, Florida
July 10-13, 2019

More information to follow!

To improve the quality of life through family support, research and education.

Continued on page 3
CFC International

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www.cfcsyndrome.org

We offer information, support, newsletters, brochures and educational resources. Our mission is to assist those whose lives are touched by CFC syndrome and to improve lives through family support, research and education.

Contributions are gratefully accepted and will be used to help more families receive information, support and resources.

Please note, CFC International is not a medical facility and cannot give medical advice. CFC International and any associated parties will not be held responsible for any actions readers take based on their interpretation of published or disseminated materials. Please review medical treatments and decisions with your medical team.

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Message from the Executive Director

Hello! I started my new role as Executive Director in January, and had the pleasure of working alongside Brenda for several months in preparation of our Texas conference to get familiar with the planning process of the biennial conference. I extend my thanks to Brenda for showing me all the tricks of the trade in putting on these amazing events! We sincerely hope that you all enjoyed attending, learning, and connecting with each other and the medical experts.

We absolutely could not have accomplished the success of this conference without the support of an amazing network of volunteers. We had numerous returning families, staff from Baylor College, and other community volunteers sign up to assist us with registration, obtaining donations for tote bags and auction items, set up our projectors and laptops, facilitate workshops at the conference, and so much more! We are so grateful for the support of volunteers. For all those who helped out in Sugar Land, another heartfelt thanks to you!

Over the past year, we have added 48 new families to the CFC International family! As our organization continues to grow, we hope to engage more volunteers to help to advance our mission to improve the quality of life through family support, research, and education so that we are able to serve more families. We are always looking for talented, committed volunteers to assist us with raising funds, marketing, or outreach. We also need assistance with providing support to affected families who may be newly diagnosed or newly registered with CFC International. If you are interested in becoming a Family Liaison volunteer and offering this type of support, please contact me.

Additionally, we need parent volunteers who speak other languages to assist in connecting with families as well as helping with translation services.

There are many exciting new ideas and projects planned for the upcoming months, so please check our website for more information on how to get involved. We are glad to work around your availability and interests to create a volunteer experience that best meets your needs and wishes.

Thank you again for your ongoing support!

Gina Peattie

“The meaning of life is to find your gift. The purpose of life is to give it away.” —William Shakespeare
From Diagnosis to Conference: Our Family's Journey (cont.)

who ARE we? So, we packed our bags and off we went to Sugar Land, TX for the 2017 CFC Conference.

To say our lives were changed forever may sound cliché, but they really were. I think my husband and I knew it would be a “good experience” to meet other families and the team of specialists, but I don’t think anything can prepare you to be in a room filled with parents who just GET IT. Parents who know your struggle because they probably just had the same struggle five minutes before in the elevator ride down to the next gathering. Not only are you meeting special needs parents, but you are meeting CFC special needs parents. You could even say, an “elite group”!

After all, most of us haven’t slept since the day our precious children were born. We now know more medical terms than we ever dreamt possible, and have turned into an army of OT’s, PT’s, and around the clock nurses.

Within minutes of arriving to the conference, you can’t help but feel like you are home. With just one smile to another family you say so much without speaking a word. When we first met Brenda Conger’s husband, Cliff, he said, “Get to know everyone because this is your family now.” He was right – everyone becomes instant family. Friendships were made that will always remain special and unsurpassable.

Having the opportunity to meet the doctors who take the time to come and meet with the families is truly a gift. These are doctors who have actually laid their own eyes on a person with CFC, which for many of us, our own children will be the only CFC person our main providers will ever see. To be able to sit down and speak with a doctor and not have to inform them about CFC but to have them teach YOU about CFC is a wonderful thing. We were so fortunate Isaiah was able to meet up with a couple of the doctors during the Sugar Land Conference. The knowledge gained on how to further care for Isaiah was immensely helpful to take to his current providers, as well as the knowledge to know what to look for in the future.

Not only did we get to meet with specialists but we were able to take part in research! I know for us, in the beginning years, it would have been amazing to have the data to present to the medical team in treating Isaiah. As we all know, our precious children do not follow the normal patterns.

There was so much knowledge to be gained from the doctor visits, to the lecture times, and small group discussions. Just being in the presence of other families and getting to know what works for them or what didn’t work for them is so helpful. Unfortunately, there is one awful part of the conference – the day it ends and you have to go back to the “real world.” A few tears (ok, several) are shed because you realize you are going to miss the environment and the dear relationships. The conference is a place where your CFC child/adult can be themselves, and parents can relax and know it’s a safe setting to let our guard down and breathe.

How do I sum up what the CFC Conference 2017 meant to our family? Two words: life changing. It will be impossible to keep us away in 2019. Mark your calendars, because I want to see you all in sunny Tampa Bay!

–Jennifer Huber,
Lincoln, Nebraska

Conference Recap!

In June, we held the 9th CFC International Family Conference in Sugar Land, Texas. We had a total of 82 families attend! Of those, 27 were first time attendees. There were nine different countries represented, as well as 33 states (US). It was an amazing, educational, inspiring, supportive event!

For the first time, we incorporated a “Day of Caring,” which focused on activities to provide support and relaxation to families and caregivers. Siblings participated in a Sib-Shop, grandparents attended a Grandparents’ Tea, families attended field trips to the Fort Bend Discovery Center and the movies, and caregivers got to participate in yoga and receive massages, among other wonderful agenda items.

We also incorporated a memorial ceremony to honor and remember those CFC children and individuals who we have lost. Paper doves with each name of the CFC child were placed on a lighted tree in a ceremony, and the tree remained displayed during the conference. This ceremony will remain an important piece of future conferences as a reminder that those who have passed, remain on our minds and in our hearts.

It is our hope that attendees left the conference recharged, with both new connections and renewed friendships with other CFC families. Hopefully through consulting with expert medical professionals and attending the medical lectures, families learned new information about the syndrome or suggestions for managing their child’s medical care in consultation with their doctors.

Thanks again to our CFC families in attendance, as well as our medical experts, researchers, sponsors and volunteers. We couldn’t have done it without all of your support! We look forward to seeing everyone in Tampa Bay, Florida, for our 2019 conference and 20th anniversary gala of CFC International!

Photos of conference on pages 4, 5, and 11.

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THE CFC CHRONICLE: September 2017
Sugar Land, TX ★ June 28 – July 1, 2017
Gone from our sight, but never from our memories

Gone from our touch, but never our hearts...

Remembering Claudio Ferretti
May 26, 2012 – May 25, 2017
A few hours less than five years.

So long has last the earthly mission of our sweet Claudio, who dispensed love, gathered people, and taught so much to everyone.

On an Autumn Sunday, in my hometown of Pisa, I watched the hot-air balloon of Campo dei Miracoli; it stood there anchored to the ground and led the tourists to see the square as an elevator, up and down, forty feet above and then back to the soil. It made me somehow sad.

And so is how Claudio lived: with many limitations as a captive hot-air balloon. Then at some point the moorings are loosened and he now flies happily. He has returned to Paradise, where he will not suffer any more and will look after his brother Alberto (7), his parents, his grandparents and all his friends.

Life is often so: mocking, ironic, ruthless. The overwhelming attestations of closeness, affectionate thoughts and the many hugs received are of real comfort for Marco and I.

We know that Claudio now runs free and happy, better than he could ever do.

–Monica De Giovanni, Italy

What Medical Experts Are Saying About the Conference...

“As a researcher, I view coming to the CFC International meetings as an essential activity to be able to advance our scientific understanding of this condition. Because CFC is so rare, attending the meetings is the only way that researchers in some disciplines can successfully study CFC – it allows us to meet with many children/families and gather loads of information in a short span of time. This year I enjoyed seeing quite a few familiar faces and also many new families! I also had a great time sharing about some of our research findings and ideas in the workshop session.”

–Rene Pierpont, Ph.D., L.P., University of Minnesota

“I loved the conference for several reasons. First, it is truly an honor to be able to help so many individuals affected by CFC and their families. The doctors who are there, myself included, are passionate about that. Second, I learn so much from the families who are generous in sharing their personal CFC journeys. That, in turn, makes me better able to help the next affected person whom I will encounter in my practice or who will just reach out to me for advice from across the world. Third, we have so much fun! Being together for meals and at so many other moments during the meeting allows us to interact person-to-person in ways that are not readily achieved in an examining room or at a hospital bedside.”

–Bruce Gelb, M.D., Mount Sinai

“Typically medical geneticists will only see a couple of individuals with CFC in their clinic, but when one attends the conference, one gains a much larger perspective that I think translates to better clinical care. I truly think that the conference is an important meeting for both new and seasoned families that can help improve quality of life.”

–David Stevenson, M.D., Stanford University

We are so grateful to the medical experts who share their time and expertise with our group! The conference wouldn't be a success without them. It's wonderful that we have such great partnerships with experts who truly value and enjoy attending our conferences!
Samantha’s Walk-a-Thon

On April 22, 2017, Samantha Colleran held her annual Walk-a-Thon for CFC in honor of Nola Iacobelli. The April showers held off long enough for a sizeable crowd to make their presence known along Rockaway Beach Boulevard. This year’s event raised over $6,000!

The event garnered not only monetary support for CFC but also raised awareness in ways it had not done before. Samantha was asked to speak at a local Rotary Club meeting about CFC. She focused on why helping to fund research and provide support to the families who are dealing with CFC is important to her. No one on the board had ever heard of CFC and they were all eager to learn more and to support Samantha in her campaign. The local paper also ran a story on Samantha’s efforts, advertised the walk in the paper, and sent a reporter on the day of the event to do a follow up piece and to take photos. They were able to speak with Nola and her dad, Darin, as well. Additionally, the local news channel came to the walk and aired the story a number of times, giving many who would not normally know about CFC a chance to learn more.

Samantha was excited about the money raised this year, as it was her highest amount to date. More importantly, the increase in awareness about CFC was an added bonus to this year’s event. She is already looking forward to next year!

Car Show

Amelie was chosen as the beneficiary of a grand reopening of a local car dealership and its 1st annual car show. We decided to have the proceeds donated to CFC International. There were over 60 vehicles and motorcycles entered in the car show. There were food trucks, fun jumps and face painting. The winner of the car show fell in love with Amelie and even allowed her to sit in his car. T-shirts were sold to also help raise money. The Melvin family also joined us and Rene and Chris Melvin helped with Amelie’s care that day. We are so lucky our community cares about giving back! —Libby Airhart

Kinley Klassic

On Monday, May 22, Coby and Shelly Greenhaw hosted the 3rd Annual Kinley Klassic, benefitting CFC International. The event was held at Tour 18 Rose Creek Golf and Country Club in Edmond, Oklahoma, welcoming approximately 192 golfers and 100 additional lunch attendees. With the support of family and friends, as well as a great amount of help from fellow CFC International families, the golf tournament, luncheon and auction brought not only community awareness to CFC syndrome and services provided by CFC International, but also raised approximately $40,000 in funds toward furthering our organization’s mission.

Several of our CFC community families were in attendance, including Machelle Sims and La’Tara Blankenship (mom and aunt to Brody Sims), Jeff and Linda Kohler (parents to Stephanie Kohler), Sunny, Alice, Caleb, Rebekah and Jacob Thomas, Sherri and Meg Young and Fred and Karen Holland (parents to Amanda Holland).

Coby and Shelly are grateful for our CFC community and look forward to many more years of the Kinley Klassic! More information can be found at www.kinleyklassic.com.
The 5th International RASopathies Scientific Symposium: Making Connections and Engaging Research – Orlando, FL, July 2017

I attended the “5th International RASopathies Symposium: When Development and Cancer Intersect” hosted by the RASopathiesNet group, as a presenter and representative of CFC International. It was an amazing experience, and it made me feel so grateful to have so many dedicated researchers working on our genetic pathway in such varied ways. I am excited to share this experience with the rest of our CFC community.

The Symposium began with a poster session, where my job was to talk about one of my favorite topics, my daughter Gloria. Many researchers stopped by, and we discussed Gloria’s mutation and her experience with CFC syndrome. Many researchers are in awe of seeing an actual person with the mutations that they give to fruit flies and zebrafish through the course of their research. We all reflected on Glo’s life and demeanor and what we hope to gain from the research people are doing. We talked about seizures, feeding difficulties, and aging in the RASopathies.

The second day of the Symposium was a clinical day that kicked off with a panel on aging in the RASopathies including representatives of: Noonan, Costello, Neurofibromatosis 1, and myself representing the CFC group. We discussed what was a challenge and what got easier with age in the RASopathies. We fielded questions from researchers, and it was a great way to start the day – putting a face to the syndromes for all those in attendance. Then the researchers presented, focusing mostly on clinical issues. There was an introduction to the genetic pathway and a session on cancer and the RASopathies.

As far as we know right now, but one of the big reasons for research is that by alleviating the issues caused by mutations in this pathway it may unlock a way to treat and/or cure certain cancer types. As the title of the Symposium suggests, RASopathies are often related to cancer. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens at our syndrome.

The final day of the Symposium was focused on the Biomolecular aspects of RASopathies and therapeutic drug development. Drug development is highly dependent on having a medical registry that is filled with affected individuals. If we ever want to find treatments for our loved ones, we must all get into the medical registry. We still have fewer than one in five affected individuals in our organization in the registry. Joining the registry is one of the most important things we can do to help our loved ones. To join the registry, click on research on the CFC homepage and then click on join the CFC Registry. The good news is there are treatments on the horizon, and having a medical registry has paid off for other RASopathies already: NF1 is in final stage clinical trials for a medication that significantly reduces some debilitating bone tumors, while an aggressive form of leukemia called JMML that affects some individuals with Noonan syndrome has a treatment in development called Rigosertib. The day ended with a short session with Drs. Gelb, Shankar, and Rauen. We were able to debrief and discuss issues that arose from the conference. The emphasis of that meeting is how encouraged the researchers and doctors were by the amount of focus on treatments, but also wanted to make sure we understood many of these are far off and that having a robust registry was critical to attaining treatments.

The take away from the conference that hit me the most is how very lucky we are to have so many dedicated researchers looking at our syndrome. Many rare diseases are lucky to have one or two researchers, if any, working on their syndrome – we have dozens over focused on our syndromes. The obvious next question is why? As the title of the Symposium suggests, RASopathies are often associated with cancer. Many cancerous cells have mutations in the Ras/Mitogen-activated Protein Kinase pathway. Again, this does not mean that the risk of cancer is exceedingly high for CFC syndrome as far as we know right now, but one of the big reasons for research is that by alleviating the issues caused by mutations in this pathway it may unlock a way to treat and/or cure certain cancer types.
These treatments are already being utilized in some cancer treatment protocols like MEK inhibitors being utilized in Melanoma (skin cancer) treatments.

I want us to be able to find treatments for the symptoms of CFC that impair our loved ones’ lives, and seeing the successes of other syndrome groups gives me hope. It is in our hands. If we fill out our medical registry and participate in research, we have a group of researchers ready to help us. We need all families to participate in the medical registry, and there is no better time than now to fill it out, and check that you have up-to-date information. In the next year we hope to move forward with research that will require us to have our registry filled with CFC-affected individuals. The Symposium reaffirmed my conviction that having a registry with as many CFC-affected individuals as possible is one of the best things we can do to help our loved ones and to support finding treatments for our community.

–Les Rogers, CFC International Board Member, Roseburg, OR
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Phone: _________________________ Email: ________________________________