



CFCinternational

Cardio-Facio-Cutaneous Syndrome

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No Stone Unturned

By Melinda Wolford

The birth of a couple's first child is almost always exciting, but Eric (known by most as "Wolf") and I faced immediate challenges after our son Stone was born. The first sign was an inability to move his neck, and then we realized his vision was severely impaired, to the point where he was all but blind until he was six months old. He had difficulty feeding, and seemed unable to gain weight.



The Wolford Family

Then he was diagnosed with a heart condition known as pulmonary stenosis. Every time I would take him to a doctor for one concern, I left that doctor's office with more. For just

over two long years and consultations with over 40 specialists in multiple fields, we found no definitive answers. Finally, we were hit with the devastating news that Stone had a genetic condition called Cardiofaciocutaneous Syndrome (CFC Syndrome).

After a number of genetic tests, we finally received confirmation of Cardiofaciocutaneous Syndrome (CFC Syndrome). It was interesting. So many of my close friends and family said, "You must be relieved." To be honest, I was mortified, I was horrified and I was devastated. Any hope left that my baby would "grow out of this" was shattered and now I had to live with the reality that his issues were not going away. I grieved again. My husband grieved again. We grieved together. Then something almost magical happened. We began to realize how blessed we really are. We started verbalizing to each other how much our lives had changed because of Stone and how

very much we have learned throughout this experience. We have a completely new perspective on life. One day, Wolf said to me, "Has Stone been happy? Has he brought us joy? Has he changed our lives for the better?" The answer to all of these questions was and is a resounding 'YES.' Then my incredible husband made a profound statement. He said, "I will take every day that I can with him."

Raising a developmentally challenged child is one of the greatest challenges parents will ever face, yet Wolf and I feel God has prepared us for the task, and we view our son as a gift. Stone will never grow up to have a "normal" life and play football with his dad, but Stone is his father's motivation in life. Stone is what drives him, he gives him more focus.

Stone's dad, Wolf is currently the head football coach at Youngstown State University in Youngstown, OH. Wolf's career as a football coach brought him many challenges that perhaps prepared him for what he would one day face with his son. During his first year coaching at the University of Arizona, one of the players he recruited died in his arms the first day of practice. The next year, one of his "big time" recruits was shot. Though the player's football career was over, Wolf's commitment to nurturing the player and his family through the aftermath of that violent act had just begun. It has also helped that my husband grew up in a family that was very committed to each other.

No Stone Unturned continued on page 10.

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Forging a path to improve lives through family support, research and education.



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We offer information, support, newsletters, an address directory, brochure and Parent's Guide. Our mission is to assist those whose lives are touched by CFC Syndrome and to improve lives through family support, research and education. The group is self-funded. Contributions are gratefully accepted and will help the next family to receive information about CFC Syndrome.

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Message from the President

It is an extremely rewarding experience when a brand new CFC family approaches us, desperately seeking information and guidance on how to raise their CFC child. I think the hardest thing in the beginning with this diagnosis is finding that you are not in control. Parents struggle to get a handle on the whole syndrome and how it will impact their child or grandchild's life. Often, with time and experience, family members slowly reach out to other families and offer assistance and words of support. Sometimes, reaching out may just be a quick answer to a post on the CFC listserv. If you are not connected to the listserv and wish to be, please visit our website and click the Join button. Our listserv is private for only our CFC families. Some families come forward at our conference and offer their help wherever needed. Still others pull together fundraising events. It is wonderful to see how talents are shared within our organization.

Next summer we will all meet again at the family conference and medical clinic program in the Chicago, Illinois area. In addition to this event, the Costello and Noonan syndrome organizations will also be at the same hotel and workshops on Saturday will be shared since the concerns are often the same with our "cousins" on this pathway. A Scientific meeting is also in the planning stage similar to the event held in California last summer. If you have concerns and questions about CFC syndrome then this is the place to be! Keep checking our website for more conference details as they become available. If you wish to attend and will be requesting any free clinic exams or wish to use the professional child care please be aware that you must have mailed in the CFC Registry along with the genetic and cardiology records no later than May 1st. Clinic exams are set up on a first come first serve basis for only families who have sent in the Registry and reports. The Registry can be found on our website so you can easily print it and mail it in.

I am looking forward to meeting up with all our families again. In the meantime, I have knee surgery scheduled and hope to be bouncing back and active again by next July.

Brenda Conger

E-mail: bconger@cfcysndrome.org

Donations

Thank you!

CFC International is grateful to its supporters for their generosity. We extend our deepest thanks to the contributors listed below for their kind donations.

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In memory of:

Harley Crawford

CFC Cookie Fundraiser

My name is Luke Catania and I am one of 13 cousins. Unfortunately, my youngest cousin, Nola Iacobelli, was born with the genetic disorder CFC. It took a long time for her to be diagnosed, and I remember the first year of her life no one knew exactly what was wrong with her. I never heard of C.F.C. before, but I knew it meant that Nola was going to have difficulty eating and maybe some delays in her growth. The first time I saw my Aunt Jenny and Uncle Darin feed her through a feeding tube, I knew I had to do something. But what can a 14 year-old cousin do?

After much thought, I created Cookies For Cousin; a fundraiser in which I sold bags of homemade chocolate chip



Luke Catania

cookies. All of the profits went directly to C.F.C. International. I wanted to raise awareness of C.F.C. because

no one really knows that much about it and I wanted my cousin Nola and others like her to have the best treatment available. I created and distributed fliers giving information about C.F.C and advertising Cookies For Cousin. It didn't take long until the orders came piling in. This is when I realized there were so many people out there who never met Nola, but loved her just the same.

I had to bake a ton of cookies! Since I am not a good cook, this was especially difficult for me. I sometimes burned myself, and I worked real slowly. Whenever my friends wanted to hang out, I would have to say, "Sorry, I have to bake cookies." As soon as I was done with one order, my mom would come tell me, "Luke, I just got four more orders." Sometimes I would say to myself that it was too much work to be baking all of these cookies. But then I remembered why I was doing it, and that kept me going. I would look at Nola's picture and I just knew that one day she would get better; and maybe my project would have a part in her progress!



Nola Rose

Packaging and delivering the cookies to my customers were my favorite parts of the project. And no, it wasn't because I got to eat the pieces of the broken cookies or watch my brother salivate because he gave up chocolate for lent. It was because as soon as one of my customers bit into a cookie, their facial expression changed

dramatically. I would get praises like, "That was the best cookie I've even eaten," and "Oh my goodness, this is delicious!" Then, they would order more cookies and I would have to start baking again. It was basically a cycle of baking, packaging, delivering and then baking again. But this meant more money for C.F.C. International. In total I have raised over three hundred dollars for C.F.C. International.

I was invited to attend and sell my cookies at the C.F.C. Fundraiser in New York. I know that being invited to the event is a great honor and I am very lucky to be able to go. I am also lucky that I have had the chance to help all people who have been diagnosed with C.F.C. As you can see, my

story of helping Nola and raising awareness of C.F.C. has been a great experience.

By Luke Catania

Doyle Family Chili Bowl Fundraiser

We hosted the annual CFC Chili Bowl in Medina, Ohio on Saturday, February 27. It was a great event, as just over 200 family and friends joined us at the Medina Eagle's banquet room. Giant Eagle was a sponsor again this year donating most of the extra food and beverages. Jim Shields covered the evening's beer tab and Pete Effinger supplied the cheese. Kristine Effinger, Carol Ryland and many other great friends made delicious desserts and cornbread. Our family covered the rest of the incidental expenses so the total amount from sponsors, donations, admission, chili entries, big screen TV raffle, raffle prizes, and silent auction items went directly to CFC International. This year's total amount was just over \$17,000!

The chili competition was as hot as ever. 21 cooks entered for a chance to win the Chili Bowl's top spot. For the first time ever we had a tie for 1st Place; first time placing, Karen Salmoni and first time entry Lindsey Boosinger shared top honors. They both very graciously donated back their winnings. 2nd Place also went to first-timer, Patrick Evans. There was also a tie for 3rd Place, Stacy Bonitz, a returning winner and first time attendee and aunt to Michael, age 17, who has CFC, Tammi Pavilonis. Congratulations to all of this year's winners!



Chili Bowl winners with the best recipes

We appreciate everyone who donated raffle prizes and silent auction items. We had a great selection again this year and the most ever. A special thanks goes to Patty Palombo who helped out getting donations for the silent auction. The 46" LCD TV raffle was big hit again this year. Stan and Rosemarie Pavilonis, Michael's parents, hauled it all the way back to Chicago. Good thing they drove!



Kaci Smith, Jack Doyle, Michael Pavilonis, Natalie Hayek, & Victoria Palombo

Jack had a great night. He was busy again this year passing out his artwork. Even though there are only about 300 cases of CFC in the world, we were so fortunate to have four affected kids join us. Michael, age 17, and his family came in from Chicago, Victoria, age 12, and her family came in from Butler, PA, Kaci, age 15, from Massillon joins us every year and Natalie, age 2 and newly diagnosed, came with her parents from Euclid. Next year's date will be Saturday, February 26. Mark your calendars and join us in beautiful Northeast Ohio in the middle of the winter.

Tim, Judy, Maddie, Sally and Jack Doyle

8th Annual Toast the Angels

The April 7th Toast the Angels dinner and wine tasting turned out to be the Conger family's largest fundraiser ever. One hundred and sixty-two guests paid \$55 per person for the annual festivities at the Kalurah Shrine Center in Endicott, NY. It was an evening filled with wine from Chateau LaFayette Reneau and delicious food from chef Rodriguez and his staff at Orlando's Restaurant at En-Joie.

The Iacobelli family from Long Island drove up with their extended family members. They even stopped along the way at the Fashion Institute of Technology in NYC and

picked up Clifford's sister Paige and a college friend so they could be part of this family event. Two-year-old Nola Rose Iacobelli charmed the guests with her beautiful smile and personality. Her cousin Luke sold more of his home baked cookies to help raise money for CFC International. A grand total of \$9,200 was raised thanks to family and friends who support this community event.



Clifford helping clear tables

Welcome to Awez (aka CFC Land)

You are going about living your life in a beautiful Metropolitan city, let's say, in Kansas. You decide that what would make your life complete is a beautiful baby with whom you can share the opera (school recitals) and ballet (dance class) with. So you and your significant other embark on this great and marvelous journey to becoming a threesome (or foursome, or fivesome, you get it).

Nine months later you are presented with a beautiful (if not quite healthy) child. Doctors swoop in (strangely resembling flying monkeys) darting this way and that, throwing ideas and sometimes accusations. It is all quite overwhelming, but you learn to tuck and roll dodging the bad ideas and every once in a while you get in a good throw yourself. You decide you must continue on this path (is that road yellow?) until you find the most enlightened doctor, a wizard of sorts, is what you seek.

It feels like you trudge this road forever, and some of us nearly do, when finally you are there in front of the curtain with the booming voice, and boom it does "Your child has CFC Syndrome".

Before you have time to digest this statement, from out of nowhere a tornado zips in and picks up your family and the next thing you know you're in Awez (Pronounced Oz), Ohio.

Where you say? EXACTLY. Whoever heard of Awez, Ohio?

You step out onto the dimly lit streets and try to get your bearings.

As you venture into this unknown city, you are surrounded by a troop of the most adorable curly haired short people. They tear at your heartstrings with their lopsided grins and expressive eyes. Some are quiet, some are singing their own tune, and some are talking your head off, but all are adorable. Maybe Awez isn't so bad after all.

Unfortunately, there are flocks of evil witches in this land, these witches bear a strong resemblance to regular members of society until they open their mouths, or twist their face in disgust. You must try to avoid the witches, they will do you harm if you let them. Try picturing a house landing on them, it helps!

Thankfully in this place there are good witches too, the good witches organize tours to show you around Awez. They also introduce you to the mayor who is constantly trying to improve Awez. They introduce you to other townsfolk who are raising money to implement the improvements and even hold grand parties in honor of the curly headed ummmm, we'll call them munchkins.

All in all, this is a strange but inviting city. Unfortunately, because it is so remote, most of your old friends, and even some family members have trouble finding their way around Awez and are lost. The good news is you will make new friends in this city. They will be some of the smartest, most caring, and extremely courageous friends you will ever meet. You will begin to feel that this is HOME.

Still, you will find yourself, like all the other citizens of Awez searching for those ruby slippers. The magic slippers, that will make life so much easier for your special munchkin and others like him.

And sometimes, in your sleep deprived mind, you'll find yourself thinking:

"I don't think we're in Kansas anymore"

Michelle Smith
Massillon, Ohio

Noonan/LEOPARD/Cardio-Facio-Cutaneous/Costello Syndromes

Comprehensive Noonan Syndrome Resequencing Array Ras/MAPK pathway related disorders

Testing for Noonan syndrome and related disorders (CFC) is now offered as a **low-cost and time-effective** test (\$1,500). The custom-designed resequencing array includes 8 genes of the RAS/MAPK pathway, which are sequenced simultaneously. Testing also includes mutation specific analysis for the Ser2Gly SHOC2 (Noonan) gene mutation using bi-directional dideoxy-based DNA sequencing. The presence of a mutation is confirmed by bi-directional dideoxy-based DNA sequencing or another appropriate method. Once a mutation in the proband is identified, mutation-specific testing in relatives and prenatal testing is available. **ANY** of these genes can also be ordered individually as a separate test.

Inheritance pattern: Noonan, LEOPARD, CFC, and Costello syndrome belong to a genetically heterogeneous, group of signaling pathway autosomal dominant disorders related at the molecular-biologic level. Most cases are sporadic and due to de novo mutation; however, familial cases, particularly of Noonan syndrome and rarely of CFC syndrome have been described.

Noonan Syndrome: Approximately 65% - 78% of individuals with a clinical diagnosis of Noonan Syndrome are expected to have a heterozygous mutation in one of four genes, PTPN11, SOS1, RAF1 or KRAS.

Noonan-like with loose anagen hair: The Ser2Gly mutation in the SHOC2 accounts for approximately 5% of all patients with a Noonan-like phenotype and negative results for analysis of the PTPN11, SOS1, RAF1, and KRAS genes. This mutation typically has a distinct clinical presentation, including features of Noonan syndrome and loose anagen hair, in association with one or more of the following features: distinctive hyperactive behavior, mitral valve dysplasia and septal cardiac defects.

LEOPARD Syndrome: Germline mutations in PTPN11 have been found in almost 90% of patients with LEOPARD syndrome. In one recent study, 2 out of 6 patients with a clinical diagnosis of LEOPARD syndrome and hypertrophic cardiomyopathy harbored a mutation in the RAF1 gene.

Cardio-Facio-Cutaneous Syndrome: In CFC, a study of 56 patients revealed an overall mutation detection rate of over 62% when BRAF, MAP2K1, MAP2K2 and KRAS were analyzed.

Costello Syndrome: 82% to 92% of patients with Costello syndrome are expected to have a missense mutation in the HRAS gene.

ATTENTION: For any person who had testing for any of these disorders, which was started before July 7, 2009 and who has already incurred \$1,500 or more in expenses, analysis of the remaining genes present as a part of the resequencing panel is available for \$500.

For more information on gene testing please visit Gene DX at: www.genedx.com . If you would like to speak to a genetic counselor at Gene DX you may contact Brad Williams at: 301-519-2100 x 6103

CFC Child Reaches out to the Depths of the Sea

I recently had the pleasure, and a real pleasure it was, to meet Jessie and her parents, Rocky and Judy, from Darwin, Australia. One morning they participated in my Dolphin & Whale Watching Expeditions eco-tour here at Moorea, an island next to Tahiti in French Polynesia. Jessie was wearing a CFC t-shirt, and from Rocky and Judy I learned about CFC, Jessie's and her family's lives, and your organization.

With over 20 other people we were in my eco-tour boat looking for dolphins and whales. In spite of fairly rough seas, Jessie was enjoying herself and was so enthusiastic. I was sitting next to Jessie and her parents when we first found the whales. They were rather close to our boat, and Jessie exclaimed with pure joy and glee, "They're BIG!" and indeed they were! But rather than express fear or insecurity (which other people have sometimes done) Jessie expressed wonder and excitement. It was one of the most wonderful experiences I've had. It was so real, so pure, so natural. And that was just the start of what was simply a marvelous morning together. Jessie was a special blessing to every one of us.

I told Rocky and Judy that I would look up CFC on the net, and now having learned a little more about it, I have decided to make a small contribution of \$250 USD to your organization, in honor of Jessie; a US check will be mailed to your office. It's not much (even here in our South Pacific paradise, the economic crisis is felt), but it's given in the best of faith, with hope that Jessie and other children like her can be helped in some way.

Please feel free to forward a copy of this email to Jessie, Rocky, and Judy. I wish your organization, and the scientific research it supports, every possible success.

Fa'aitoitito ("Be encouraged and carry on"),

Michael Poole, Ph.D.
Marine Mammal Research Program
and
Dolphin & Whale Watching Expeditions
BP 698 Maharepa, Moorea
FRENCH POLYNESIA



Jessie with her dad
on a boat watching
the whales



Photo Gallery



Meg Young age 12



Clara Edwards in her rice and beans therapy bucket, Raleigh, NC



David Jud, Switzerland



Brennan Skipper at his 13th birthday party



Eli dancing at our yearly school May Day program, Hawaii

Jenna Braun on her 10th birthday



Danielle Davis, age 14 months with her cool Florida shades



Emerald, 15 months from Virginia.



Fleur Hoedjes, age 7, playing with shaving cream



Kaci and Steven Smith at Steven's senior year choir concert



Kimberly Luntsford at Easter sharing her Easter Basket with her beloved siamese cat!



Lahnon Moore, age 8



Scott Quirion's winning race car with the CFC logo.



Nancy Newton loves motorcycles

Isabella Misita, age 9



No Stone Unturnedcontinued.

I grew up facing daunting circumstances that helped prepare me for the challenges we would face with Stone. My parents were missionaries in Africa, and my mother died in childbirth, giving birth to her fifth child. At the age of ten, I was faced with the responsibility of raising my four younger siblings, including a newborn. My father remarried, and I helped raise my two new two step-siblings as well. My childhood prepared me for being a coach's wife, as well as for raising Stone. I was used to moving around, used to getting into new environments, used to doing things on my own. I had faced daunting challenges in life before Stone came along.

My husband's relationship with our son contrasts with what people see of Wolf on the football or practice fields. We see that he is this passionate, very energetic person. The picture I'm thinking of is a picture of him that was published in the newspaper, of him screaming. You can see every muscle in his face. When he walks in the door, with Stone he is a soft, gentle giant. He handles him very well. He loves him with all of his heart, and Stone is his motivation in life. He is a very generous person and that's

how he is with Stone. A lot of men have difficulty dealing with a child who has a disability. He has been there, and he has supported me, even though he is not home because of his job requirements.



Stone

Stone can't eat solid food, so we have him on "as nutritious a liquid concoction as we can come up with," things like PediaSure, Instant Carnation Breakfast, etc. We have invented a smoothie that includes whey protein that Stone can drink through his special bottle. Many children who have CFC are on a feeding tube but we have been able to avoid a feeding tube by using a 4 ounce drop in Playtex. I X cut the nipple to provide a faster flow. As a result of my profession, I have been able to consult with the best for good advice. I have a PhD in School Psychology with a minor in neurological disorders of childhood and have specialized in working with kids with autism and other disabilities. Because of what I have learned from the health specialists I worked with side-by-side to treat my patients, I have learned how to be able to feed Stone as we do, and not be forced to put him on a feeding tube. I believe that Stone may actually be healthier than some CFC children because he is able to get nutrition in that way.

Stone has difficulty communicating and has just a few words he can say. He also has limited motor skills, which limits his ability to use sign language. There are times he communicates just fine though. His fourth birthday was November 26. Wolf said to him, "I love you!" And Stone said, "Luff! Luff!" It absolutely melted him when his son said I love you back. Stone loves movies and music. He loves to dance (in circles). He is a very happy boy, his spirit is always shining. When I walk into his school, everybody knows "Stone Man." Not sure where it started, but head football Coach Ron Zook called him that at the University of Illinois, called him Stone Man. He adores people, and plays well together with his younger sister Marlee. He loves her, and constantly hugs her. Stone is a very special little soul. He appreciates everyone and spreads joy as if it is abundant. On our many trips through the hospital halls his little voice rings out to everyone we pass with a tiny, but very clear "Hi". He oozes cuteness and brings smiles to those we pass in wheelchairs, those in pain and some that just don't have anything to smile about. He is such a blessing to us on so many levels and allows us to experience life on a plane that many will never know. We meet and experience people that we would have never had the chance to meet. We have learned lessons that could not have been possible without him.

Moving from Arizona to Illinois, to South Carolina and recently to Youngstown, Ohio has been difficult, especially with the support system needed for Stone, and the myriad of doctors and health professionals he needs as part of his care, but, amazingly, the communities have been supportive and the medical staff have been wonderful overall.

We also have a healthy 2 year old daughter Marlee, whom Stone adores. I have been able to return to work, with Stone attending a special education class for half a day, where he is doing well in school, and making amazing progress.

We have started a foundation called "No Stone Unturned," dedicated to supporting research, raise awareness, and to help other families facing similar challenges to what we face. We also are dedicated to local organizations that provide support for the families involved who have children with disabilities and provide scholarships to families who have children with outstanding medical and mental needs. You can learn more about the No Stone Unturned Foundation at www.nostonefoundation.org.

We have had two fundraisers in the past year. We held the first Wildcat Legends for Charity Golf Tournament in Manhattan, Kansas last July and intend to make it a tradition. Wolf attended Kansas State and was a starter all five years for the Kansas State Wildcats under Coach Bill Snyder. We are planning to continue the tradition and will be hosting the 2nd annual Wildcats Legends for Charity in Manhattan, KS again this coming July.

The other fundraiser held this year was a Pancake Breakfast at a local restaurant in Columbia, SC. It was initiated by a small act of kindness by a local restaurant manager while we were still in Columbia, South Carolina. With Wolf's busy schedule it's difficult to find family time together, so we try to have a family dinner out once a week. One evening we went into Fatz Café, a local restaurant for dinner. Stone cannot sit still and cannot eat food. He is interested in food, and likes to lick it, but he tends to crunch it and it ends up on the floor. He was laying on the floor there in the restaurant, food everywhere, and over walked the manager! I hurried to clean up the mess, telling the manager how sorry I was. I told him that Stone has "special needs". The manager, Jonathan Tuten smiled and told me, "Don't you worry about it. Get up off that floor and stop cleaning up. That's what we do! Typical kids do the same thing."

Not too long after that, Ron Morris of The State newspaper in Columbia wrote a story about Stone and the "No Stone Unturned Foundation," and Tuten saw it. He contacted us and volunteered to have a fundraiser at the restaurant for the foundation. The fundraiser was a successful event. No Stone Foundation and Fatz Café were able to raise over \$6000. With the money, No Stone was able to give out family scholarships, support Family Connections of South Carolina and CFC International.

We would like to invite you to join us in our journey to make differences in the lives of children and families who face the uncertainties that come when a child suffers from various health issues and don't know which way to turn. We deeply feel that our Foundation, with your assistance, will truly leave "no stone unturned" in efforts to change lives.

Melinda Wolford

Remembering The Siblings Of a Special Needs Child

The birth of a child with a disability or chronic illness has an extensive and usually lifelong effect on the family. Other children in the family must adjust to a brother or sister who may require a large portion of the family resources such as money, along with time and attention from the parents. It is important to any family that the sibling of the special needs child adjust in order to foster a nurturing environment for the family as a whole.

The positive and negative aspects of sibling relationships and among all family members may be influenced by some or all of the following factors:

- family's resources
- family's lifestyle

- family child rearing practices
- type and severity of the disability
- number of children in the family
- age differences between children in the family
- coping mechanisms and interaction patterns that exist within the family
- supports services available in the community

Each child's reaction to having a sibling with a disability will vary depending on his/her age and developmental level. The feelings of the sibling toward their disabled brother or sister generally will not stay the same, but will change over time due to their adaptation to the situation as well and in day to day realities, in addition to maturity levels and exposure of family life over time.

Generally the focus of the family lies within the special needs child. Family life changes dramatically and the needs of the siblings are often overshadowed by the obvious physical, mental and emotional needs of the child with a disability.

Some suggestions for ways to resolve the potential feelings of alienation on behalf of the child without a special need would be to:

- provide accurate, age appropriate information regarding the special need
- explain the disability and what to expect
- tell them about their sibling's strengths and weaknesses
- teach ways to interact with their brother/sister with special needs
- avoid making comparisons between siblings, even if the comparisons are positive, as doing so can make the child feel less unique
- remember to provide attention to the non disabled child's developmental and emotional needs
- give recognition of the non disabled child's accomplishments
- allow for time alone with their parents(s)
- take advantage of support networks such as sibling support groups, school counselors and physicians

It is important for families and professionals to utilize the positive resources in order to cope with a variety of special circumstances, and to adapt them to meet individual needs as they change and develop over time. Together, families and the community must strive to accent the "abilities" of disabilities, not only for a brother or sister with this disability, but for the entire family.

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2011 CFC International Conference

~~ Save the Date ~~

The 6th International CFC Family Conference & Clinic Program

*July 28-30, 2011
The Westin O'Hare
Rosemont, Illinois*

Join us at the beautiful Westin O'Hare Hotel in Rosemont, Illinois where we host our 6th International CFC Syndrome Family Conference and Clinic Program.

We are grateful and excited to share our conference again with researchers and scientists from around the world. You will also have the chance to meet families and individuals affected by Costello Syndrome and Noonan Syndrome whom we share the same genetic pathway with. They are our CFC cousins!

See you in Illinois in July 2011!

The Westin O'Hare Hotel is conveniently located and just minutes from O'Hare International Airport. They provide complimentary airport shuttle service that departs the hotel approximately every 30 minutes and the train station is only 2 blocks away into downtown Chicago.





CFC International Annual Report 2009

Caring, Facilitating & Connecting

To Our Families, Friends and Donors:

We felt such sorrow this year from the loss of two of our children and grieved with their parents as a whole community. We are a family united by this rare syndrome that is present in each and every cell of the person's body. We care deeply about each other. We give each other the strength, courage and hope to live, to laugh and to face whatever may come each day, knowing that we are not alone. Our mission is ... **“Forging a path to improve lives through family support, research and education”**. I know that we have made a huge difference in the world through our services to families and by promoting extraordinary new research on this rare condition.

2009 was also a difficult year with the global economy for all non-profit communities. CFC International tightened its belt and made the decision to move our BioBank from the Genetic Alliance to the National Disease Research Interchange (NDRI). Our BioBank served us well and was instrumental in the gene discoveries. Now as we look to the future and treatments, it is clear that donated tissue is crucial for research. The transfer of our DNA to the NDRI will also result in approximately a \$20,000 per year savings for CFC International.

Our accomplishments over this past year could not have occurred without the generosity of our supporters. So many of you have contributed through the United Way to our organization. We have loving grandparents, aunts and uncles, friends and many others who send in donations after each newsletter or in honor of a child's birthday. You keep us focused and inspire all of us to keep working harder with researchers to find treatment programs for all the children. Thank you for your faith and support!

Brenda Conger

President & Executive Director

CFC International 2009 Accomplishments

Family Services *(Led by Molly Santa Cruz and Judy Doyle)*

Family Service representatives contact and care for our families, giving them the strength, knowledge and tools to care for their own. The latest census shows that CFC International has grown to a total of 177 registered families from around the world. When new families reach out to CFC International, Molly Santa Cruz and Judy Doyle are there to welcome and support them. Many of our newer families tell us that they were anxious about contacting us for the first time, not knowing what they would find. Those who do find a warm voice and a gentle introduction to a new family. Judy Doyle connects them with the private family listserv—our global lifeline on the internet and the place where no question is too small, answers come quickly and everyone understands. Molly ships them out the new parent package with a note to contact her with any questions.

CFC International produces a fact sheet, Parent's Guide, brochure, and private family address directory. We ship new family packages out to all regions of the world. In 2009 42 packages were shipped out to new families.

Individuals Registered With CFC International

Australia 5	England 16	Hong Kong 1	Mexico 2	Scotland 3	USA 122
Belgium 1	France 1	Ireland 2	Netherlands 3	South Africa 1	
Canada 8	Germany 1	Israel 2	New Zealand 1	Scotland 2	Total 177
Denmark 2	Greece 1	Malaysia 1	Samoa 1	Switzerland 1	

As much as CFC International is an internet community, there is nothing like the opportunity to spend time together. Our families can't wait to attend a conference and meet others they have chatted on line with.

CFC Conference *(Board of Directors)*

The 5th International family conference and clinic program was held in Berkeley, California from August 2nd – 4th. Forty-two families from eight different countries attended along with clinicians, researchers, and workshop speakers which contributed to our largest conference event ever. Clinic stations for evaluations and advice included genetics, cardiology, ophthalmology, dermatology, dental, and orthopedics. We held our traditional Mom and Dad's night out where each night one parent was able to go to an evening mixer with other mothers or fathers for some relaxed socialization. For many parents this was a first time for them to just hang out with other parents who are raising a special needs child.

Science and Medicine

BioBank & Clinical Registry program *(Led by Brenda Conger, Molly Santa Cruz and Amy Hess)*

Our original BioBank program was focused on DNA collection and storage. In late 2009 we joined the Rare Disease Biospecimen Alliance at the National Disease Research Interchange (NDRI). We have transferred all DNA and are looking ahead to enroll participants with tissue donation. Our next big focus for research is to obtain tissue samples when individuals go in for surgery or if an individual passes away and the family wishes to contribute tissue. Our clinical data collection has continued with all newly enrolled CFC children. Reports are scanned in and CD's full of data are then shipped out for approved research projects.

Research Projects

Collecting medical reports (clinical data) on CFC individuals since 2002 has continued to help drive research projects. Our families really do care to make a difference! Years ago we asked parents to only send in their child's genetics reports along with the CFC Registry. As time went on we gradually asked for **all** medical reports that families could get their hands on. The reports encompass cardiology, genetics, ENT, ophthalmology, orthopedic, endocrinology, neurology, and any other specialist the CFC person met with. The years and years of extreme data collection have brought about extensive research projects in 2009:

1. Biomarker Identification for Future Treatment - UCSF Comprehensive Cancer Center
2. Cardiac Abnormalities in patients with CFC – Children's Hospitals and Clinics of Minnesota
3. Effects of Germline Mutations within the Ras Pathway on Bone Remodeling – University of Utah

Scientific and Medical Meetings

2009 was the second time that a scientific meeting was coordinated. In early 2007, Dr. Kate Rauen from UCSF stepped up to the plate to represent all the disorders on the RAS/MAPK pathway and embarked on non-stop grant writing to pull together a first time USA Scientific meeting for CFC, Costello, Noonan and Neurofibromatosis (Ras/MAPK pathway disorders). This meeting was held in conjunction with the family advocacy group meetings in Berkeley, CA. Researchers from around the world came together to share their individual research and proposals for future studies to help this complex pathway of disorders.

Contributions

CFC International raised \$63,781 from contributors including our fundraisers in 2009. These financial supports are so vital to the continued survival and progress of CFC International. Without your contributions, none of the important programs described above would be possible. Your donations fund advances in research. You fund physician awareness and the cost of operating and maintaining our Biorepository, website and listserv—such vital links for our families and physicians.

Our conferences and medical clinics held every 2 years are costly and we could not host them with professional childcare without your support. Equally critical are the families and friends who led the fund raising efforts that raised this money. People don't give to institutions or charities; they give to a cause they have come to believe in. A rare and obscure disorder like CFC syndrome is not a high profile cause. There are no government or corporate grants or celebrities endorsing CFC syndrome, and most people have never heard of it let alone known someone who is affected. *Except our donors.*

Every one of them knows someone with CFC syndrome personally or has been told the story by a good friend who does. Every donor was asked to donate to CFC International by someone. These are our heroes. The ones who ask. The ones who tell their friends and family of the challenge of CFC syndrome and the hope of CFC International. The ones who understand that without financial support, progress stops. So our thanks go to our donors and we ask you to please keep CFC International at the forefront of your generosity, even in these difficult economic times. But we reserve our highest praise and deepest appreciation for our fund raisers, for they keep the lights shining... literally!

- = Judy and Tim Doyle's annual chili cook off held in Ohio — Each year the Doyle family bring their community together to sample the best chili in their region. The silent auction, donations, TV raffle and chili samples raise money for CFC International at this very popular event.
- = NYC Triathlon – Nola Rose's uncle Danny Hojnowski competed in this triathlon to raise money for CFC International. This was his first triathlon event!
- = Each year Matt Brockwell has sent a letter with CFC syndrome information and updates on his daughter Kate's progress to a list of coworkers at PricewaterhouseCoopers to appeal for consideration of donations earmarked to CFC International during the United Way Campaign. This appeal continues to raise thousands of dollars each and every year. A simple letter from the heart is making a huge difference!
- = Car club president, Ron DeHaus and the Binghamton, NY Cruisin' Buddies Rod and Custom car club love to get out and raise money for local charities. Each year the club shows off their cars at an annual Memory Cruise. Again they chose CFC International as one of their charity to support for their annual fall cruise.
- = 7th Annual "Toast the Angels" – Brenda and Cliff Conger host this fabulous wine tasting and dinner year after year to honor all CFC children here and those who have passed. Friends continue to support this huge event and start asking about the next date right after the first of each year since it is a sure hit and reserved on many a calendar.
- = Valley Bash – The Getts Family from Connecticut chose CFC International as the benefactor for their annual community event. A remarkable event that involves many people from Oxford, Connecticut.
- = Ten Bucks for Ten Years! Newsletter appeal. Vice-President Molly Santa Cruz came up with the catchy slogan for the organization's 10 year anniversary.

CFC International is a member of the Genetic Alliance and an Associate member of the National Organization for Rare Disorders

CFC International Income and Expenses 2009:

INCOME 2009		EXPENSES 2009	
Conference Registration fees & sales	\$21,649	Berkeley Conference	\$45,752
Fundraiser Income	\$30,253	Research	\$17,785
Contributions	\$31,048	General Administrative Expenses	\$8,469
Interest & Dividends	\$6,257	Payroll	\$10,000
Total Income	\$89,207	Total Expenses	\$82,006



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Our vision is a world in which no one will be isolated from appropriate diagnosis and treatment.

Would you like to contribute to CFC International?

Your donation and support will help:

- families to receive information about CFC syndrome;
- publish our newsletter;
- fund the biannual International CFC Family Conference & Clinic Program;
- maintain the CFC Tissue and Biobank, which is critical to future research.

Enclosed please find a check in the amount of \$ _____

Gift in Honor of _____

Gift in Memory of _____

Please make checks payable to CFC International & mail to the address above.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____