



EMBARGO: RELEASE AFTER 2PM Eastern Time, Thursday, January 26, 2006.

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Gene for Rare Syndrome Found with Help of Families CFC genes linked to cancer

[*Vestal, NY- January 26, 2006*]- A genetic support group of approximately 100 families from the United States and abroad worked together to promote research to better understand a rare condition known as **cardio-facio-cutaneous syndrome** or CFC syndrome. Today, CFC International announces their collaboration with US researchers to identify three genes that begin to explain this complex developmental disorder. The findings are being reported today in Science Online: www.sciencenews.org/.

This is only the third time that a genetic advocacy group has co-authored a gene discovery. Since 2003, the families of CFC International have worked collaboratively to collect medical reports, photographs, and most critically, provided the DNA of family members diagnosed with this condition. The collection of DNA was managed through the CFC International BioBank. CFC International and six other genetic advocacy groups founded the BioBank through the Genetic Alliance. This BioBank serves to bring researchers to the families who have critical input into potential research questions and studies.

“Through the formation of the CFC BioBank, research ignited at a rapid pace” says Brenda Conger, who is president of the group. The Congers spent years searching for a diagnosis for their son. Brenda tirelessly led the group to raise awareness among physicians and researchers. The group’s determination to promote gene discovery and by taking a leadership role in forming the BioBank has opened many new doors for research. This has brought these families closer to treatment.

The CFC BioBank is the largest collection of DNA and clinical data to date that is available to researchers. The information and DNA samples allowed Dr. Katherine A. Rauen and her colleagues at the Comprehensive Cancer Center, University of California, San Francisco to quickly find three genes, BRAF, MEK1 and MEK2. These three genes are part of a complex pathway called Ras/MAPK that has a central role in cell growth. Disruptions to this pathway can lead to tumors. The gene discovery is the first step to learning more about the genes and their role in CFC and more fully appreciating the complexity of tumor development. Dr. Rauen has stated “From the basic science viewpoint, CFC is going to help us to learn more about this ancient pathway in human development and how the pathway functions in cancer. This, in turn, will assist us in understanding more about this syndrome, and help us start moving forward on possible therapeutic options for these children.”

Gene discovery for CFC is an important milestone in the groups’ effort to forge a path to improve lives through family support, research and education. Dr. Rauen explained that, “Discovering these genes will allow medical geneticist to be able to provide a molecular diagnosis to families”. The next step for CFC International is to identify ways that families from all over the world may have access to the new gene test for CFC. This gene discovery continues to provide a model of collaboration between individuals and families with genetic conditions and researchers. This working model gives hope to hundreds of other genetic support groups who are seeking answers for the conditions that challenge their families.

To learn more: www.cfcsyndrome.org

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Brenda Conger is available for interviews about her role in organizing families with CFC and their efforts to focus research efforts in the complex disease. Ms. Conger started her efforts in 1997 and connected with families from all over the world. She is available for print, audio, or video interviews.

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