



FocusFAA

Two Precious Reasons to Consider Giving

October 21, 2011 – *FAAers Kristen and Justin Bouchard in the Southwest Region wanted to share their personal story to create awareness about one of the CFC charities that has been of tremendous help to their family.*

On May 4 and July 22, 2008, we lost our identical twin daughters, Corynne and Cathryn, to Niemann-Pick Disease Type C (NPC). NPC is a rare metabolic disease that currently has no cure, and it is always fatal. Cathryn and Corynne were diagnosed with this disease shortly after their first birthday, and they both died before reaching the age of two. We have made it our family's mission to spread awareness about NPC, as it continues to take the lives of children.

One of the CFC charities, the National Niemann-Pick Disease Foundation (CFC #10121), was instrumental in helping us to cope with this devastating diagnosis for our precious twins. The foundation is an invaluable resource to families who cope with this awful disease on a daily basis.

Because NPC is so rare, it is difficult to find people who know what it is like to take care



Justin and Kristen Bouchard with their daughters, Corynne (left) and Cathryn.



The Bouchard twins, Cathryn (left) and Corynne.

of a child with Niemann-Pick Disease — even doctors typically do not have any experience in treating children with the disease. Parents have to become experts on the disease and the primary advocates for their children. The foundation puts families in contact with each other to share what has worked best in caring for their children. They also hold a conference every year to address current research, provide grief support, and meet other needs that families may have.

The National Niemann-Pick Disease Foundation also supports and promotes research to find treatments and a cure for Niemann-Pick Disease. Its vision is a world where

Niemann-Pick Disease is no longer a threat to a full and productive life for patients and their families.

There is nothing our family would like more than to see an effective treatment, and eventually a cure, found for NPC so that other families will not have to experience losing a child (or in our case, two children) to this horrible disease.

Thank you for taking the time to consider contributing to the CFC this year, and for considering a donation to the National Niemann-Pick Disease Foundation. We can personally say that your donation will make a difference in the lives of the children and families facing this terrible diagnosis.

If you are interested in learning more about Niemann-Pick Disease, you can visit the website above, or Cathryn and Corynne's website at www.angeltwins.org.

Read additional FocusFAA People CFC testimonials:

FAA Combined Federal Campaign News

Sep 26—The need has never been greater. Just ask FAAer Karen Alden.

CFC Makes a Wish Come True

Oct 11—Fighting cancer, the daughter of an FAAer received a trip to remember-and a new lease on life.

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