



Angel Foundation

Damian's Story



January 2009: Angel of the Month

Written by: **Angel Mom, Sarah**

As the Mother of a child who did not receive expanded newborn screening, I've often thought that the "other side of the fence" might be greener for those families who received a diagnosis, shortly after the time of their child's birth. And for the most part, it is "greener".

Per statistics, most children who are born with a metabolic disorder and is detected at birth, 75 to 90% of them avoid a crisis, which can prevent them from severe developmental delay, mental retardation, disability or death (among other things). So it's a good thing when a parent knows ahead of time, and the child's Doctors can follow a care plan of action, along with the parents, to keep the child in the best of health.

Amidst all the good, there still is the fear that if the child does not get proper nutrition or has a sudden or unknown illness, dependant on the condition and the child, they can still have a crisis. This to me, is quite scary!

Imagine having to weigh food every day, medicating them, balancing protein and other parts of their formula to perfection, and watching them every minute when they are ill, because there is always that chance, in the blink of an eye, that something could still happen.

I have learned a lot from **Laura Larks**, mother of our January BBAF Angel, **Damian Larks** who is eight months old and has **3-methylcrotonyl-CoA carboxylase deficiency**, also a metabolic disorder.

Damian received screening at birth and since his diagnosis, Laura has to be extremely vigilant in his care to prevent the complications I mentioned above. Laura is a wonderful Mom, who feels that caring for Damian has taught her so much, and made her a "different person" altogether.



Below in her own words, is Damian's story:

Damian was born on April 27, 2008 at 3:41 pm and weighed a healthy 8 lbs. 9 oz. He is our sixth child and all our children had been perfectly healthy so when the nurse took him to do his first newborn screening test, we really didn't give it a second thought.

And I didn't have to give it a second thought until Damian was five days old. That's when the pediatrician called us personally at 7:00 pm. I instantly knew something was wrong.

She told us that Damian's newborn screening had come back abnormal for 3mcc. I was in such a state of shock that I didn't really ask her any questions.

She asked us a few questions about how he was doing (was he sleeping too much, difficult to wake, any vomiting, etc.) and we had to take him to our local children's hospital to get a second screening as well as some other lab work done.

After my initial shock wore off, I immediately got on the internet and began researching 3mcc. I was overwhelmed with devastating information and very sad stories.

After getting the tests done, we went to see the pediatrician. She explained that the horrible things I found on the internet were what could happen to a child who had 3mcc and was not diagnosed early. Diet, supplements and special precautions can prevent all those things from happening.

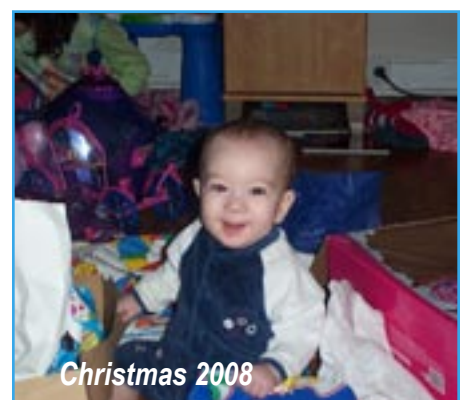
She told me not to worry too much until we got the results from the second newborn screen and lab work. But of course, I worried about it every minute of every day!

After about a week, the results came in and again confirmed the 3mcc diagnosis. The doctor ordered some more follow up tests, which in another week came back with the same thing, Damian had 3mcc.

Admittedly, we had a very hard time accepting this. We had five other children who were completely healthy and it just felt unbelievable that we could carry such a genetic disorder. It was a lot to deal with initially. Time has helped us to realize that his early diagnosis was a blessing, as we now have the best chance at preventing the complications associated with his disorder.

The journey we've been on since Damian's diagnosis has had its ups and downs, but has already taken us amazing places. We have met some of the most wonderful families and some of the kindest people we've ever come across in our lives.

Damian is an adorable, strong little guy that has truly changed our family. We have learned to see the blessings in everything, even in times when life is really difficult. When life feels overwhelming I learned to just take things day by day, hour by hour, or even minute by minute." – Laura Larks



Thank you for taking the time to read Damian's story, and have a wonderful new year!

Best Wishes,

Sarah