



Zach's Story



August 2009: Angel of the Month

Zach Fisch has an amazing story to tell. Zach is 17 years old has Short-chain acyl-CoA dehydrogenase deficiency, known as SCAD. As the mother of a metabolic child, I was eager to talk to Zach and ask him questions. In a way, it was like getting to peek into the mind of my child 16 years from now. I was anxious to hear Zach's experiences and perspective. Zach is in a unique position to be able to be a 'voice' for our children. To answer questions that our children are too young to have experienced yet, or are just a matter of concern for us when thinking about the future. His maturity and positive attitude are amazing, and he was wonderful to talk with.

After his younger brother Matthew, was diagnosed, Zach, his sister and parents were all tested for SCAD. In June of 2004, the day after his 12th birthday he learned of his diagnosis.

So often when our children are diagnosed through Newborn Screening, we as parents go through denial and refusal to believe that our child actually has what the doctors are telling us. Zach, since he was able to understand, went through a similar process. A process that I can only imagine was incredibly difficult for him. Although his mother Jill had found out on Zach's birthday, she decided to wait to tell him until the next day. Zach had a good understanding of what SCAD was, because of Matthew's diagnosis and watching all that had been going on. Zach compared himself to his brother, and because he was so much older and did not have as many of the same problems, he felt that he simply was not as affected by the disorder. He went through a significant period of denial, and battled with Jill over issues like diet and medication. Despite all this, Zach did share with me that the diagnosis did make sense to him. There were symptoms and complications that SCAD had caused for him, but until the diagnosis no one knew the cause. As a young child, Zach had been hospitalized on a number of occasions related to minor illnesses in addition to the issue of his growth. Learning of the metabolic disorder made those pieces of the puzzle fit into place.

Of all the complications that arose from the SCAD, the main problem for Zach was that he did not grow properly. At age 12, he was only about 4 feet tall and weighed only 60 pounds. It has taken growth hormones and several years for Zach to reach the 5 feet 11 inches he is now. His size caused the most issues for Zach, especially among his peers. He was often singled out or ridiculed because of his small stature. His self-esteem has increased significantly since the use of growth hormones has helped him grow.

As Zach's self-esteem grew and he became older, he became more independent which presented new challenges in managing his disorder. Zach was able to share with me his experience, when he was 15 and he ate a large amount of ice cream with his friends. While it did make him feel horrible and he was incredibly sick, he learned the importance of not overdoing it with "off-limit" foods. Zach says that there never was a specific time that he began managing his disorder for himself (and he admittedly does eat some things that he should not).



Attempting to get Zach to consistently take his medication, Carnitor, also became a larger challenge. When he initially began taking it, it caused some severe stomach issues for Zach, so he simply would stop taking it rather than giving his body the opportunity to adjust to the side effects. When I asked Zach about his medication, he was very honest and shared that he does not take it as he should. I learned that it is not that he does not understand its importance, but that the pill form of the medication he takes simply presents a challenge to his routine. The pill can not be left out at all, which means that he would have to take the pill around in it's special packaging, which is not convenient to him, or simply can't be done depending on his activities that day. Of course this, from a parent's perspective, should not even be an issue; you have to take it so take it! But from the perspective of a teenager it is quite different.

From reading the forum and speaking to families, I know that many parents wonder how their child's disorder will affect them in many areas. We discussed issues such as peer relationships, physical activity, illness avoidance and his feelings about his parents and their care for him. Zach does share about his disorder with friends, although how open he is about it does vary depending on that relationship. Other than the occasional person that asks a million questions about SCAD, he has not encountered any issues from his peers regarding his disorder. The only negativity resulted from his short stature prior to his diagnosis and receiving proper treatment. Zach does feel like he has a responsibility to share about SCAD, to raise awareness.

Zach did not play many sports when he was smaller because they were so physically challenging. Those he did play, he found tired him easily. Even before his diagnosis he had issues with severe joint pain. Zach now plays golf which he enjoys very much but which is not as physically demanding.

On the topic of illness avoidance, he said that he is probably more careful than most teenagers his age with hand washing and simply avoiding others who are sick. I was very curious as to how Jill handled germs and illness when he was younger and how he felt about it. Jill was extremely cautious with germs, as most of us are, but Zach seemed to genuinely understand her concerns and had no issue or complaints with anything she has ever done. That was wonderful to hear that since so many of us are the same way!

So many parents dedicate a great deal of time and energy in our advocacy efforts following our child's diagnosis and I have often wondered how my children will feel about that. Zach has an exceptional respect for his mother Jill and her advocacy efforts for Expanded Newborn Screening in her role as President of the Save the Babies Through Screening Foundation. Having the opportunity to see Jill through Zach's eyes, as he discussed her care for both Matthew and himself was a unique and amazing experience. She is so obviously a fantastic, caring and loving mother who does so much for her children, and for all our children in her efforts to promote and raise awareness for NBS.

When I asked Zach what the one piece of advice he would offer to parents of children affected by these disorders, his answer was simple yet eye opening. He said, "Don't remind us that we have a metabolic disorder." Day-to-day, we get so caught up in the requirements of managing our children's disorders; the gram counting, the attempts to prevent illness, the overall worry that never quite leaves your mind. While that is completely understandable, I see the importance and perspective of what Zach said. Just as we never forget the disorder, our children do not either.

From the parent perspective of caring for a teenager with a metabolic disorder, Jill offered some exceptional insight. She credits their metabolic specialist with truly helping Zach accept and deal with having SCAD. When choosing a metabolic specialist, we need not only address how we feel about them and that our needs as parents are addressed, but also consider how our future teenager will be able to connect to them. Having a doctor that is willing to allow our children to be part of their care and plan of care is a crucial part of helping them to learn responsibility for their care, especially as they become more independent. Having this type of support for your child from their specialist can help them get good advice on sensitive topics like drugs, alcohol and pregnancy. This are topics that many teenagers will shy away from their parents on, so, especially for a teen with a metabolic disorder, it is very important that they have a doctor they can connect with and trust.

When it comes to drugs and alcohol, Zach's specialist has explained to him that there are even more risks for him than an unaffected individual. As a high school student, drug and alcohol use by his peers (which, of course, brings along peer pressure) is something he has to directly deal with. He takes the position of simply being honest, and saying that due to SCAD, he simply can not do it. He feels that he is and would be respected for his position, and if he were not then he'd simply have to re-evaluate that relationship.

Thank you for taking the time to read Zach's story, and I encourage you to look for him on the forum so he can offer us more insight and perspective into our care of our children!

*Angel Den Mother,
Laura*

A Note from BBAF:
Laura, you did an incredible job on Zach's story, and gave a level of insight that is invaluable in so many ways. Thank you for sharing your talent and energy with us all. We look forward to many more great stories in the year to come!

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