



Quote of the Day:

“As a Senior Undergraduate Student at Wayne State University and under the mentorship of Amit Joshi and Dr. Greenberg, I was given the privilege to attend the BSF conference this past July. I am incredibly grateful for the support that the BSF community has shown me as I pursue my research and learn more about Barth syndrome. ...The perseverance, care, and unified nature of the BSF community is astounding, and has inspired me to continue diligently on my career path. I do hope that I have the opportunity to work with all of you in the future.” ~ Naomi Fei, Senior Undergraduate Student, Wayne State University, Detroit, MI

Featured Story: My Barth Syndrome Essay

By Derek, BTHS Diagnosed Individual, Age 19, New York



Derek (2012)
Photo courtesy of Amanda Clark

I personally have this disease. Living with Barth syndrome has its hard points but you have to work through it and be strong. Life is never smooth sailing. One good thing about having Barth syndrome is not having to do gym; not that I'm lazy, but no one wants to do the mile long run and sweat like crazy! One difficult thing is not being able to run around and keep up with friends.

If I was given a million dollars and I could not spend it on myself or my family, I would give it to the Barth Syndrome Foundation. Barth syndrome is a very rare heart disease. This specific disease has many side effects. Two of the most life threatening components are cardiomyopathy and neutropenia. Cardiomyopathy is anything to do with the heart. Neutropenia has to do with white blood cells which fight off bacterial infections. If you don't have enough white blood cells you have to get a shot called G-CSF, or Neupogen. If you can't fight off bacteria

you can end up in the hospital easily. Most people have the right amount of neutrophils; but if you don't you have to be careful.



In December 2011 I received my G.E.D. I took classes for auto mechanics. I would also like to take auto body refinishing which is putting body kits on cars, etc. I did have a part-time job, but am currently not working. These are two things I can do with Barth syndrome.

Donations would be good for the Barth Syndrome Foundation because it could really speed up the discovery of new information or even a cure. Plus they can hire more doctors to do more studies on the people who have Barth syndrome.

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