



Barth Syndrome
Foundation



Talking About Barth Syndrome

Talking Points for School Age Children

Parents often feel conflicted about whether to share or not to share information about Barth syndrome with their child's school peers. It is important to be open about Barth syndrome at the level the parent and the child feels comfortable. It is generally best if the child with Barth syndrome does not feel he is singled out in telling others about himself. A good approach is to ask the teacher if all the students would be allowed to introduce themselves in such a way to share something they are very good at and things they struggle with. Giving the child with Barth syndrome the opportunity to share what he is comfortable sharing instills self-advocacy skills at an early age. Here are a few talking tips that have been recommended.



I was born with Barth syndrome, don't worry it is not contagious



I don't look sick



I get sick easily, so I have to avoid being around people when they are sick



I get tired really easily



Talk about special needs (use a scooter, leave school early, use the elevator, etc.)



I can't do some things that require a lot of energy



I still like doing some of the things that other kids my age like to do



I like spending time with my friends



I like doing (list of things the child enjoys doing)



I have an AICD in case my heart isn't beating properly