



Barth Syndrome  
Foundation









## Strategies of Educational Advocacy

For a Child Diagnosed with Barth Syndrome

*An Educators' Handbook*

*The Barth Syndrome Foundation  
Third Edition  
2019*

## Table of Contents

 Introduction	3
 What is Barth syndrome?	5
 Physical Challenges	8
 Some Neurodevelopmental Challenges Faced by Students	13
 Social and Emotional Challenges	15
 Suggestions and Advice for Educators	18
 Warning Signs of Physical Distress and Tips for Care	28
 Resources	22

---

## Introduction

---



**The purpose of this handbook is to inform teachers and school administrators about Barth syndrome (BTHS) and how they can best advocate for a student with BTHS in the educational environment.**

Two handbooks have been created. One handbook has been written for the parents of students who live with BTHS, and another handbook has been written for educators of a child with BTHS. Each of these resources represents the collective wisdom, knowledge, and stories of the families and educators who have worked closely with students diagnosed with BTHS. It is the hope of the Barth Syndrome Foundation that these handbooks will help families and educators to manage the child's educational journey with less anxiety, more happiness, and greater success.

Both of these handbooks are living documents which have been updated many times over since 2003. The credit for the original research and writing, on which this project rests, goes to expert Jon Rosenshine, M.A, M.Ed., with very helpful input from Eileen Juico, M.A., M.Ed., Joan Stoner, Ed.D., Jaclyn Butera, M.S.W., C.S.W., M.Ed., Jules Spotts, Ph.D., P.C., Raghad Schroeder, O.T.R./L and Paula Geigle, P.T., Ph.D. The Barth Syndrome Foundation is very grateful for dedication of these professionals in devoting their time and expertise to our cause. It is through their guidance that parents and teachers have this invaluable resource to make school a success for those who have BTHS.

As part of the initial research for this handbook, a number of the Barth Syndrome Foundation (BSF) families were surveyed about their experiences in the education with their children who live with BTHS.

**Some important patterns in Barth syndrome (BTHS) students' experiences emerged from the research.**

-  Every individual who has BTHS lives with daily fatigue. The degree of fatigue is highly variable but nevertheless debilitating
-  Each individual who has BTHS must deal with the social challenge of not only feeling different but also being perceived as different by his classmates. Almost all students with BTHS must have some form of adjusted academic schedule with adjusted expectations from the normal curricular guidelines. Otherwise, they simply could not be expected to keep up.

The greatest educational obstacle facing students who live with BTHS is their serious medical condition, but **the greatest cause of educational stress for these students comes from their schools' not understanding how BTHS affects them.** BTHS is a rare and complicated condition, so it is entirely understandable that most educators have no idea what it is.

One way of looking at the current situation for students with BTHS is they are often square pegs being fit into round holes. BTHS manifests itself so differently from other illnesses, and indeed from individual-to-individual. Parents often simply try to find educational solutions where their child(ren) can comfortably *fit*. With parents and educators working together and with this handbook and the resources it offers, BSF hopes to give educators what they need to help guide a student with BTHS through his education with the care and support that every individual deserves.

---

## What is Barth syndrome?

---

Barth syndrome (BTSH) is a rare, life-threatening genetic disorder, which primarily affects males. It is caused by a mutation in the **tafazzin gene (TAZ, also called G4.5)**, resulting in an inborn error of phospholipid metabolism, affecting many systems of the body.

Historically, boys died of heart failure or infection by three years of age, but with improved diagnosis, medical therapy and monitoring, survival has been extended, with many survivors now into their adult years. Survivors of BTSH, however, almost always live with extremely compromised physical health, and those few who enjoy relatively good health live every day with medical conditions that can become life-threatening with little or no warning. Someone with BTSH will likely suffer with varying degrees of BTSH symptoms.

### Cardiac Aspects of Barth Syndrome

Cardiomyopathy (heart muscle weakness) is generally worse in the left side of the heart. The left side of the heart pumps oxygenated blood to the entire body. The heart muscle wall can be **dilated** (thin) and/or **hypertrophic** (thick), in either case the left side of the heart is too weak to push the blood out to the body. As the function of the left side of the heart worsens the right side of the heart has to work harder to push blood from the body into the left side of the heart. This causes the left side of the heart to become larger with the muscle, thinning the muscle wall of the left side of the heart even more. When the right side of the heart fails blood builds up in the body causing swelling in the abdomen and extremities. **In basic terms when the heart can't pump enough blood to meet the body's needs it is known as heart failure. Heart function can significantly deteriorate very suddenly and unexpectedly.**

About half of the people diagnosed with BTSH have **left ventricular noncompaction**, which is a condition that causes deep trabeculations (crevices), generally at the apex of the heart. Blood will pool in these trabeculations, which leads to the formation of **blood clots**. Dislodged clots can lead to **stroke**. Heart muscle cell abnormalities also place the individual with BTSH at an increased risk of having an **arrhythmia** (abnormal heart rhythm). Arrhythmia can lead to abrupt loss of heart function altogether. This is known as **cardiac arrest**. Without intervention the individual will face certain death. **Life-threatening arrhythmias can occur, even when the heart function is in normal range.**

## Neutropenia

Neutropenia is a condition where the individual with BTHS has very low and sometimes zero white blood cells called neutrophils. The neutrophils are the most abundant white blood cells in the body. A person who does not have adequate numbers of neutrophils are unable to fight bacterial infections. **Neutropenia places the individual with BTHS at an increased risk of acquiring serious infections such as bacterial pneumonia and skin abscesses.** This can lead to **sepsis**. It is not always possible to predict when the person with BTHS is neutropenic. Some people experience neutropenia at regular intervals; this is known as **cyclic neutropenia**. Some people are always neutropenic; this is known as **chronic neutropenia**. Some people experience neutropenia with no predictability whatsoever; this is known as **intermittent neutropenia**. **A common cold can be life-threatening for someone with BTHS when they are neutropenic. A rectal temperature should NEVER be taken on the individual with BTHS.** Death in BTHS is most commonly due to **sepsis from neutropenia and heart failure**.

## Low Muscle Mass and Fatigue

All muscles, including the heart, have a cellular deficiency which limits their ability to produce energy. **This causes extreme fatigue during any endeavor that requires strength or stamina (e.g., walking, reading, writing, and growing and thinking).** **Low muscle mass significantly limits the individual's ability to tolerate periods of fasting.** Even during brief periods of time, they are at risk of becoming **hypoglycemic**. Serious hypoglycemic crisis situations have occurred in BTHS. Any symptoms of low blood sugar (e.g., onset of excessive weakness, change of pallor, excessive sweating) must be taken seriously.

Given their diminished body stores, **BTHS individuals often tolerate illnesses poorly, especially those that include diarrhea or vomiting.**

## Failure-to-Thrive and Growth Delay

Most individuals with BTHS are below-average in weight and height, often substantially so. **Short stature in early years is often followed by an accelerated growth pattern during mid-to-late phase of puberty.** **Poor growth is often assumed to be evidence of poor nutrition, but this is not the case.** Fortunately, the older boys with BTHS have grown to average and above average heights, but their growth takes longer to come to completion than their peers.

## Exercise Intolerance

Symptom severity of BTHS is highly variable, even in families where there is more than one person diagnosed with the condition. Amongst those who have BTHS, some have weaker hearts than others, some have weaker immune systems than others, and some have slower physical developmental rates than others. However, **almost all individuals with BTHS suffer from muscle weakness and a general fatigue, which significantly limits their ability to perform normal life activities.**

It should be noted again that relatively good health in someone with BTHS offers no indication of disease severity in the future. Therefore, educators need to understand that a student with BTHS wakes up every morning and goes to sleep every night with a life-threatening condition. Some students are underweight, frail, easily fatigued, and easily identifiable as "*sick*," while others have appeared healthy and strong for years only to suffer sudden illness.

In order to fight their symptoms, individuals with BTHS must be carefully monitored by doctors, so they will likely miss school for doctors' appointments more often than other students. Many of the students

take medications, which treat some symptoms of their condition but might also complicate other areas of their well-being. Furthermore, some students have to experiment with medications before finding successful combinations, and these periods of trial and error can be painful and traumatic for them.

Ultimately, in addition to focusing on the intellectual development of students with BTHS, **educators must always be sensitive to their medical conditions and physical needs.**

---

## Physical Challenges

---

One physical challenge that all students with Barth syndrome (BTHS) share is fatigue. <sup>xii, vii, i.</sup> **Almost every boy who lives with BTHS faces the educational challenge of an exhaustion that debilitates him on a daily basis.** One youth described his daily experience of fatigue as a painful exhaustion in every limb, in the marrow of his bones, in every cell of his body. This physical challenge for students with BTHS is one of the largest obstacles to their gaining a normalized education. Regardless of the strategies employed to help combat an individual student's fatigue, his educational progress will almost certainly be slower than his classmates' as a result of his inability to work at a pace that most people consider normal.

The first step to coping with the effects of fatigue on students is making the distinction between true fatigue and laziness. Adolescents, whether they have BTHS or not, have the occasional tendency to indulge in natural adolescent behavior, but, as a general rule, **when a student with BTHS says he is tired and needs a rest, he needs to rest.** There simply will be no productive activity out of an individual suffering from such fatigue, **so immediate accommodations must be made for a tired boy to regain his energy.**

Many students with BTHS have arrangements with their teachers that allow them to seek out the rest they need when they need it. In some circumstances, boys are allowed to put their heads down on their desks for five minutes to regain some energy, and in other cases, students are allowed to excuse themselves to the nurse's office where they can lie down for a short nap. Some students have identified particular points in the day when they become tired, so they are able to schedule a rest/nap time on a formal basis. It would be helpful for parents to provide the teacher with a window of times when their child is at his best and better able to focus as well as windows of time when the child is most fatigued. With a sense of the average time the student is able to work before the need to rest, parents and teachers can plan lessons more effectively.

Students with BTHS who go to school in buildings with several floors often are allowed to use elevators, if they exist. Many older students have scooters to help them get around large buildings and campuses and/or extended time between classes to help them get from one class to the next. Most have multiple copies of schoolbooks that are left in different locations, so that they do not have to carry the books with them during the day nor back home in the afternoon.

Eric Storch, Ph.D. reported a significant need for academic accommodations for the 34 individuals with BTHS who participated in his research study. Specific accommodations included classroom seating changes, rest periods, schedule adjustments, note takers, extra books for home use, alternative assignments, extra tutorials, recordings and peer mentors<sup>ii</sup>.



The **physical education and sport elements of education must be modified dramatically for all students living with Barth syndrome (BTHS)**. At some point, almost every student has needed a reduced physical education requirement, and it almost goes without saying that most competitive sports are unfortunately not a possibility. Still, some creative solutions have been found to allow students the opportunity to participate in athletic endeavors. When actually participating in a sport, a student with BTHS could play in the goalie position or some similarly less strenuous role. Some students with BTHS with a love for sports have found it rewarding to be a timekeeper and record the plays and game statistics and these are all important, challenging, and fun activities in sports such as basketball, baseball, and football. Conversely, **resistance non-aerobic exercise is suggested to improve muscle strength** for those who have BTHS<sup>iii</sup>.

Activity, Tai Chi is a soft martial art that not only improves both balance and strength but also improves health issues such as diabetes, arthritis, heart disease, and problems with the immune system. As Tai Chi can be performed in a wheelchair or even in bed, it is particularly well-suited for individuals living with BTHS. For a brief overview of this Chinese meditative martial art check out the [Fung Loy Kok Institute of Taoism](#) website. This site also offers a world directory of Tai Chi instructors, and you might be especially interested to explore the link for “health benefits.”

Some students with BTHS have an **assigned aide at school** who watches him during lunch or recess or during a fire drill when there are many students around. At these times, the potential for a student with BTHS to be accidentally injured is higher than normal, and the extra pair of eyes on the student can be a tremendous help in keeping him away from the crowded and sometimes jostling hallways and stairwells. Parents of young children with BTHS have reported increased anxiety about being left behind or perception of increased vulnerability in an emergency situation.

Children who live with BTHS often have **difficulty with fine motor skills**—usually defined as the coordination between the eyes and the hands/fingers. Holding pens correctly and using scissors can be much more complicated, strenuous, and fatiguing for a student with BTHS than for his classmates. **Visual spatial skills can be compromised** in an individual with BTHS<sup>vii</sup>. In order to improve their fine motor skills, many children with BTHS receive Occupational Therapy (OT) at some point in their early education. Occupational therapists help students not only learn how to manipulate their hands but also configure their environment in a way that will best suit them. For instance, an OT might help make sure that a student has a desk that is best fitted for him and pens that he can hold most effectively. To learn more about what OT is and how it might be appropriate for an individual with BTHS, parents can easily check out the [American Occupational Therapy Association](#) website.

Children with BTHS also have **difficulty with gross motor skills**<sup>iv</sup>—usually defined as the activities done by the arms, legs, and large muscle groups of the body. Running, jumping, and carrying large objects can be a challenge for a student with BTHS. Between general fatigue and the delayed development of the body of a child with BTHS, some individuals cannot take even walking long distances for granted. To meet these needs, many students with BTHS receive Physical Therapy (PT) to strengthen their bodies. Published case reports about such rehabilitative

therapies further promote the benefit of such therapies<sup>v,vi</sup>. To learn more about PT and how it might be appropriate for an individual with BTHS, check out the [American Physical Therapy Association](#) website.

Because the vast majority of students with BTHS would benefit from some form of PT and OT, it is recommended that all individuals with BTHS be screened for PT and OT needs. Furthermore, parents might seek consultations with PT and OT specialists whenever their child faces new physical challenges.

Some parents also note that their children receive speech therapy at a young age. Again, considering the developmental delays caused by BTHS, it is not surprising that boys would begin speaking late and would need some extra help to catch up with their classmates.

**In the Barth Syndrome Registry study**, 30 of 60 males older than age three years reported delay either in first words or in putting words together; 31 of 67 participated in speech therapy. **Sensory issues** related to feeding and eating are common, and many patients have a strong preference for salty, cheesy, and spicy foods while having an overall restricted repertoire of foods. Some issues such as a strong gag reflex manifest early in development<sup>vii</sup>.

As mentioned above, almost all students living with BTHS have **severe difficulties with handwriting**, and this is probably the result of both fatigue and compromised fine motor skills. A student with BTHS should learn how to type as soon as he can in order to ease the burden of using his hand for writing. The Diana Hanbury King [Keyboarding Skills](#) method of teaching typing to the young is a highly praised approach for teaching dyslexic students keyboarding skills. Another method for teaching keyboarding is called [Type It](#) by Joan Duffy.

A student with BTHS might also explore the option of a voice recognition to written transcription program. If you are unfamiliar with such apps, check out side-by-side reviews and comparisons on sites such as [Business.com](#). There are numerous leads and reviews for **assistive technology** available on [Noodle.com](#).

Not all schools have school nurses. **A school that has a student with Barth syndrome (BTHS), however, must have a school nurse on site. Furthermore, all teachers who work with students with BTHS should be trained in the use of cardiopulmonary resuscitation (CPR) as well as in the use of an Automated External Defibrillator (AED).** Furthermore, for those students who have an Internal Cardiac Defibrillator (ICD), schools should have the essential information about how to care for a student should he have a medical emergency. Teachers are sometimes nervous about taking on such responsibilities, but a child with BTHS should be around adults who can react appropriately in a crisis. All teachers and school administrators in contact with a student with BTHS should be educated in the physical warning signs that a student might be in distress.

**For some students, absences from school present the biggest obstacle to their education.** There have been cases in which students have missed 50%, 60%, 70% or more of the school days in a year. Nearly half of the parent respondents to the educational survey rated the level of

seriousness of absences as a 5 out of 5. A quarter of the parents, however, rated the seriousness of absences as a 1 out of 5 (and another quarter of the parents rated absences as a 3 out of 5), so again, we can find few patterns that apply to all students with BTHS.

There exist little data to help us understand when students are more likely to miss a lot of school, but many parents have noted that in the periods of extreme challenges with health and stamina during periods of accelerated growth. For students who miss a significant number of consecutive school days due to illness, schools might help the family explore the options of home tutoring when it is appropriate.

In preparation for each school year, schools should encourage parents to fill out an updated **Care Plan for School Age Children with Barth syndrome (BTHS)**. This form is easily downloaded from the Barth Syndrome Foundation website and in addition to providing the school with essential medical and contact information, it lists the warning signs of problematic symptoms, offers tips for caring for a child with BTHS, and outlines some of the important academic issues facing students.

One of the most effective methods for teachers and administrators to learn about the serious physical and medical realities of a child with BTHS is through **direct contact between the child's doctor(s) and the school**. Either through a letter or a phone call (or both), a doctor's instructions lend validity and immediacy to the special needs of students who have BTHS. If parents do not suggest it first, educators might reach out to begin this important communication.

---

## Some Neurodevelopmental Challenges Faced by Students

---

Despite the lack of consistency in the intellectual experiences of students with Barth syndrome (BTHS), schools would do well to prepare for the kinds of neurodevelopmental and learning issues their student(s) with BTHS *might* face. Some of the issues could be direct results of the symptoms of BTHS, and some of the issues might be caused by the medications the students have to take.

**Regardless of the causes of the academic challenges facing students with BTHS, a school would do well to have a student with BTHS tested on a reasonably regular basis in order to monitor his learning style.**

Students with BTHS often **struggle to stay focused** in classes when there is much movement and noise to distract them. Some teachers have noticed dramatic improvements in learning when students go from distracting classrooms to one-on-one lessons. **Staying on task** is another commonly noted challenge for students. Teachers should keep students with BTHS close to the front of the room where they can keep an eye on their progress on assignments and where the distractions are reduced.

A significant percentage of individuals with BTHS struggle with **short- and long-term memory issues**. Such problems might very well be a consequence of fatigue, but another possible cause for memory difficulties could be found in the effects of the medications that many students with BTHS take. Schools can always consult with a student's parents or doctors to learn about the possible side effects of medications on an individual's memory and other cognitive functions. Ultimately, however, there are no clear answers yet for the cause of memory difficulties in individuals with BTHS.

**Reading comprehension and retention** are also noted by some parents as challenges for their children. Again, for many students, challenges in reading might be caused more by fatigue than by discernible learning difficulties, but some students do seem to have weaknesses in the verbal area. In the United States, once students with BTHS are identified as *other health impaired*, they are able to receive special education services, and this allows them to receive recorded texts through mobile apps such as [Learning Ally](#).

Listening to readings through an app, as opposed to reading the texts directly, usually takes longer, but easily fatigued students might expend less energy in getting the work done. Each student needs to explore his options and choose the method of reading or listening to the text that best the student's style.

**Mathematics** is an area of difficulty for many students with Barth syndrome (BTHS), but very little data exist to explain why this is. Possibly, it stands to reason that students with inconsistent

attendance and with focus and short-term memory difficulties will struggle with the logical sequencing necessary in mathematical operations.

Dr. Michele Mazzocco began investigating cognition patterns in BTHS in 2000. She published a preliminary paper in 2001<sup>viii</sup> that discussed the first evidence ever found that boys with BTHS might share some learning patterns as a result of BTHS. Further research demonstrated those with BTHS to have **age appropriate cognition**, vocabulary skills, and reading skills<sup>ix</sup>.

Dr. Mazzocco and her team characterized those with BTHS to have **below-average performance in mathematics** and selective difficulties in visuo-spatial skills that is not linked to impaired motor functioning from myopathy. Math difficulties are not evident in preschool but do emerge in most during kindergarten<sup>x</sup>. **In the Barth Syndrome Registry study**, twenty-two of forty-six males older than age seven years reported some form of “*learning disability*”<sup>xi</sup>. An estimated 33% of those diagnosed with BTHS require some type of **educational accommodations**<sup>xii</sup>.

---

## Social and Emotional Challenges Faced by Students

---

A child who lives with Barth syndrome (BTHS) will usually contend with significant emotional challenges as the child learns to cope with his condition. The unpredictability of the course of the symptoms makes it impossible for the individual and his family, even in times of good health, to stop being aware every day of the potentials for illness. When possible, a school and a family should work together to figure out how to cope in a healthy manner with these difficulties.

**Almost all school age individuals with BTHS must contend with being significantly smaller than their classmates**, and this understandably leads to self-esteem issues in some. In one of the ugliest anecdotes gathered during the research for this handbook, a parent conveyed the story of her son's enduring threats from classmates who picked on him because of his size and went so far as to knock him down violently enough that he ended up in the hospital. Fortunately, this boy was quickly taken out of the school system that had failed to protect him, and his self-esteem has suffered no significant damage. The potential for serious emotional harm, however, is great in school age children whose psyches are so delicate. It should go without saying that teachers and administrators must be vigilant to watch over the physical and emotional health and safety of *all* students. Students with disabilities or a chronic illness are more likely to be victimized by bullying than their peers<sup>xiii, xiv, ii</sup>. A student with BTHS especially needs many sets of sensitive and watchful eyes to protect his safety in the school setting.

The experience of living with Barth syndrome (BTHS) seems to bring out many complicated and mixed developmental issues. **On the one hand, those with BTHS tend to exhibit an attachment to their parents that their classmates have left behind.** One mother shared a story about her 2<sup>nd</sup> grade son, who would run to her for a hug whenever he saw her in school. The other children in the class, however, who were becoming more socialized with their peers and less dependent on their parents, were uncomfortable with the boy's enthusiasm for his mom. It is unlikely that other young children can understand how living with BTHS forges uncommonly strong bonds between parent and child.

On the other hand, children who live with a life-threatening and often times life-limiting condition such as BTHS appear to have a wisdom that goes far beyond their age. They live with a host of medical conditions that can threaten their lives, and they have had experiences and overcome adversities that most people cannot imagine. So, in many ways, individuals with BTHS are often both older and younger than their peers.

**Falling behind in schoolwork and being unable to keep pace with classmates present emotional challenges to many children.** Under normal conditions, students often feel that the pace of school is overly burdensome; they long to slow down and take time off from their studies. Students with Barth syndrome (BTHS), however, often have an extremely different experience: they find themselves unable to keep up with the workload and wish that they could do more, that they could be more like their classmates. As discussed earlier, a student with BTHS must learn to accept his own capacity for completing work. Just as a runner with severe asthma must

pace himself in order to complete a marathon, a student with BTHS must make adjustments that his classmates will not have to make. One high school student observed that two days of missed school required him to work doubly hard with a quarter of the energy on the remaining days. So, even if he worked on his studies over the weekend, it was simply impossible to catch up.

**Parents, educators, and the individual with Barth syndrome (BTHS) should discuss how much and when his classmates should be told about the condition that affects him.** Most children can quickly recognize that their classmate is special. He is smaller, often misses more class, and does not participate in all of the activities that everyone else does. With younger children, it might not be necessary to clarify for them the details of BTHS, but they might very well ask questions about their classmate's differences. Teachers and children should be prepared in advance for how they would like to handle these questions. In one instance, the classmates of a student with BTHS innocently misunderstood neutropenia (a deficiency of the immune system) to be related to another immune deficiency syndrome, AIDS—it is not. Ultimately, disclosing the details of BTHS to a classroom of students must be handled on a case-by-case basis, depending largely on the coping mechanisms of each individual child and the support services in the school. Some students (especially the older ones) might prefer to address their classmates directly, while other students might need a teacher to explain BTHS to their classmates. Under the best circumstances, the school will have a mental health professional—social worker, guidance counselor, or psychologist—who can offer advice and possibly even facilitate a discussion in the classroom if one needs to happen.

**Almost all students who have positive experiences in school have dedicated educators who advocate for them.** All students, pre-Kindergarten through high school, should have at least one person in the school who has taken the responsibility to look out for their best interests. Sometimes this advocate can be an academic advisor, a guidance counselor, a school psychologist or social worker, a Coordinator of Special Education, a dean, or even a principal. This person often fields questions from the parents, spots difficulties the student might be having, communicates with the team of teachers working with the student, directly communicates with the student, and conveys information back to the parents in a timely manner.

In addition to having an educator advocate, **a student with Barth syndrome (BTHS) would have a significant way of helping himself if he could self-advocate in the school environment.** As far as his own health and safety are concerned, no one knows the state of his body better than he does, and he should feel both the right and the responsibility to clarify to his teachers (and to his classmates, if need be) when he is not feeling well or not feeling safe in a given situation. Even if the situation is as simple as needing a break to put his head down or needing to be excused to go to the bathroom, a student needs to be encouraged and trusted by his teachers to speak up for himself.



---

## Suggestions and Advice to Educators








---

**Be Proactive in Teaching Other Educators About Barth Syndrome (BTHS).** In almost all parents' experiences, the responsibility has been solely on them to educate their child's school about the nature of BTHS. Certainly, they are uniquely qualified to do so as they understand BTHS and its effects on their child better than anyone else.

Teachers and school administrators, however, sometimes see parents as unreliable sources of information. Parents of boys with BTHS are especially susceptible to being perceived by teachers as overly protective. From their points of view, teachers often see a boy who needs to be less dependent on his mother and more socialized to his peers. He needs to get out and eat more and exercise more! They do not understand the life-threatening conditions of the boy's weakened heart, of his weakened immune system, and of his extreme fatigue, so they see the parents as unreasonable in their demands for accommodations for their child.

These miscommunications create stress for the parents, for the teachers, and most of all for the students themselves. If parents have allies in the school committed to educating others by validating the seriousness of BTHS, the student will be able to face his considerable challenges without being caught between contradictory expectations.

**Assemble a Team.** One of the best ways to ensure a student with BTHS is well cared for in the academic setting is to put together a team of educators who are dedicated to helping him negotiate the challenges of school. Depending on the nature of the school and the resources available, this team might consist of the following people:

-  *the student's advisor, advocate, or guidance counselor*
-  *a learning specialist*
-  *a special education coordinator*
-  *a mental health specialist*
-  *the school nurse*
-  *all teachers working directly with the student*
-  *the dean of students or the administrator directly responsible for the student's academic experience*

In a public school in the United States or Canada, such a group of people will likely exist already in the team that writes the student's Individualized Education Plan (IEP), but this team should be ready to meet together on a more informal basis than the IEP meetings.

One of the purposes of this team is to share information with each other. In order to respond quickly to the needs of a student with BTHS, teachers need to have up-to-date information about the student's physical health, emotional well-being, and academic developments. Teachers often need to be coached about when and how to accommodate the special needs of a student whose disabilities can seem vague and confusing to someone not intimately aware of how BTHS manifests itself.

For instance, a particularly complicated academic situation discussed during a Barth Syndrome Foundation Conference concerned a young student who suffers from both BTHS and ADHD. The hyperactivity makes his classroom experience a challenge for himself, his classmates, and his teacher, but the student also suffers from the fatigue and exhaustion that comes when his cells fail to produce the energy he needs to stay focused or even to keep his head up at times. The teacher was reasonably baffled by the student's claims to be too exhausted to work—shortly after he was bouncing off the walls. Because she did not fully understand his condition, she regularly refused to make accommodations for a student who was suffering under a collection of physical conditions that were beyond his control.

The health of an individual with BTHS can change dramatically, compromising the regularity of his education. At these times, the team needs to assemble to discuss how best to approach his new situation. Some of the most emotionally traumatic moments for those with BTHS come when they finally return to school after a period in hospital or after being homebound only to be handed a test that they had missed while they were away. While a teacher assumes that the student could have been studying while away from school, he feels defeated at the very moment that he has overcome a serious infection, or heart failure, or any one of the medical conditions that threatened him.

If naming and bringing together a team around a student with BTHS is beyond the capacity of a school, at the very least, the administration might assign at least one educator to be the student's advocate. This person should be charged with the responsibility to field questions from the parents, spot difficulties the student might be having, communicate with the teachers working with the student, communicate directly with the student, and convey information back to the parents in a timely manner.




**Keep Neuro-Developmental Testing Updated.** Because an individual with Barth syndrome (BTHS) can suffer from general growth delay, he often suffers from neuro-developmental delays as well as the more obvious physical developmental delays. In order to best serve his needs, his school should carefully monitor his academic development.

It should be noted here that **the vast majority of students with BTHS have Individualized Educational Plans** if they are in the United States or the Canadian public-school systems or

**Statements of Special Needs** if they are in the United Kingdom. Whether a student qualifies for this protection due to a specific learning disability or due to “**Other Health Impairment**,” this formal protection of the student’s rights is extraordinarily useful to the student and to his teachers in helping the student negotiate his education from kindergarten through to the end of high school.




**Help Parents Keep a Master File.** The Barth Syndrome Foundation has advised parents to keep a master file at home with all of the records, letters, evaluations, test results, and reports that pertain to their child’s education. This master file will help parents communicate effectively and objectively with their child’s school. The parents and the school can best work together to find solutions for a child with disabilities when they share information and when they base their decisions as much as possible on objective facts. A school can help parents keep this file by providing a copy of the student’s complete school file and by making sure that the parents have updated copies of all documents.

**Think Creatively When Finding Solutions.** Some of the most successful educational solutions for students with Barth syndrome (BTHS) have been found way outside the box of the traditional educational experience.

-  *Some students have been enrolled in schools but have their schedules amended to allow them to be in school only half days.*
-  *One school paid for home tutoring but allowed the student to audit some classes at school so he could maintain his friendships and social development.*
-  *One high school student found a balance by taking some classes at school, receiving home tutoring for another class, and rounding out his curriculum online*

Most importantly, a student with Barth syndrome (BTHS) will have to approach his education on his own terms and at his own pace. For all students, health and safety are of paramount importance, but for a student with BTHS, health and safety affect educational choices far more than for the vast majority of his classmates.

**Consider sending a School Representative to the Barth Syndrome Foundation (BSF) Biennial International Conference** where families, doctors, scientists, and educators come together to:

-  *share information necessary in guiding the search for treatments and a cure for BTHS*
-  *educate and support physicians*
-  *create a caring and informed community for affected families*

By sending a teacher, an advisor, or a school nurse to this conference, a school will have an expert who can most effectively lead the team of teachers and administrators in caring for and educating their student with BTHS.



---

## Resources *(click the cap)*

---







### *Americans with Disabilities Act (Section 504)*

---

-  Difference between section (504) and (508) of the Americans With Disabilities Act explained ~ Office of Civil Rights
  -  Wright's Law provides a robust list of resources on this topic
- 

### *Assistive Technology*

---

-  Assistive Technology for Kids with Learning and Attention Issues: What You Need to Know / Understood
  -  Assistive Technology for Kids with Learning Disabilities: An Overview  
*Kristen Stanberry and Marshall H. Raskind*
  -  Best Voice Recognition Software of 2019 | Business.com
  -  Dictation (Speech-to-Text) Technology: What It Is and How It Works  
*Jamie Martin*
  -  Text-to-Speech: The First Assistive Technology for Special Learners  
*Jamie Martin*
  -  Back-to-School Guide: Must-Have Apps for Dyslexic Students  
*Jamie Martin*
- 





### *Attention Disorders*

---

-  Learning and Attention Issues | Understood
- 


### *Audio Book Apps*

---

-  Bookshare
  -  Homeschooling with Dyslexia Audio Book Review
  -  Learning Ally
  -  Learning Specialist Materials Blogspot Side-by Side Comparison of Audiobook Apps
- 

### *Back to School Tips*

---

-  Connecting with Your Child's School Counselor for a Successful School Year | American School Counselor Association
-

---

## **Blogs**

---



LD Resources



WrightsLaw Blog



Rasmussen College Education Blog



Your Therapy Source

---

## **Books**

---



Complete IEP Guide | NOLO



The Core Strengthening Handbook



ESP Publishers



Find Resources in Libraries and Bookstores Near You | WorldCat



From Emotions to Advocacy | Harbor House Law Press



LD Online Book Recommendations by Subject

---

## **Bullying**

---



Kids Against Bullying



Teens Against Bullying

---

## **Charter Schools**

---



Public vs. Private vs. Charter Schools | GreatSchools.org

---

## **Classroom Accommodations**

---



Seating and Positioning for Children with Sensory Issues or Other Special Needs ~  
eSpecialNeeds



Teaching Children with Attention Deficit Hyperactivity Disorder: Instructional  
Strategies and Practices

---

## **Free and Appropriate Public Education (FAPE)**

---




What Is and Isn't Covered under FAPE | Andrew M.I. Lee, JD

---

---

## *Inclusion*

---


 Inclusive Schools Network


 Special Education in the Least Restrictive Environment | Inclusion?


---


## *Individuals with Disabilities Education Act (IDEA)*

---

 Center for Parent Information and Resources

 National Center for Learning Disabilities

 PACER Center is a Minnesota based nonprofit that provides advocacy resources to assist families and special needs children throughout the US


 United States Department of Education Individuals with Disabilities Education Act

---

## *Individual Education Plan*

---

 United States Department of Education IEP


 What is the difference between an IEP and a 504 Plan? | University of Washington


---


## *Keyboarding Techniques*

---

 Diana King Method for Touch Typing

 Keyboarding Skills 2<sup>nd</sup> edition “alphabet method” to teach keyboarding skills to students of varying ages.


 Type it by Joan Duffy

 Write makes Right: Type is Hype | Diana Hanbury King

---


## *Policy and Advocacy*

---

 Americans with Disabilities Act with Updated Revisions (select Law/Regulations on option on ADA website)


 British Dyslexia Association

 Council for Exceptional Children

 From Emotions to Advocacy Website

 International Dyslexia Association

 Laws and Guidance ~ US Department of Education

 National School Boards Association

---


---

 [United Kingdom Kent County Council Learning Disability Resources](#)


---


### *Professional Resources*


---


 [American Occupational Therapy Association](#)


 [American Physical Therapy Association](#)


 [American Speech-Language-Hearing Association](#)


 [Back-to-School Tips for Special Education Teachers | Kandace Wernsing and Reading Rockets](#)


 [Center for Autism Research “CAR Autism Roadmap”](#)

 [Canadian Accredited Independent Schools \(CA<sup>+</sup>IS\)](#)

 [Institute of Education Sciences](#)

 [Digest of Educational Statistics / National Center for Education Statistics](#)

 [National Association of Independent Schools](#)


 [Teach Junkie](#)


---

### *Types of Schools*


---

#### *Homeschooling*


 [Best Homeschooling Websites and Resources / K12 Learning Liftoff](#)

 [Homeschool.com](#)


#### *Magnet Schools*

 [Magnet Schools of America](#)


#### *Private Schools*


 [Council for American Private Education \(CAPE\)](#)

#### *Private Special Education Schools*

 [Fifty Best Private Special Needs Schools in the United States](#)

#### *Reggio Emilia Schools*

 [Five Facts about Reggio Emilia](#)

 [North American Reggio Emilia Alliance](#)


---

#### *Traditional Public School Resources*

---



---

 ED Facts Consolidated State Performance Report of Public Schools |  
US Department of Education

---

 Public School Review

---

*Virtual Schools*

---

 Facts about Public Virtual Schools


---

 Florida Virtual School

---

*Vocational Rehabilitation*

---

 Vocational Rehabilitation PACER Transition Resources

---

*Waldorf Schools*


---

 Association of Waldorf Schools of North America


---

*Videos/Webinars*


---

 A Little Book for Children | Barth syndrome in a child's terms

---

 Meeting the Needs of Special Learners | Barth Syndrome Foundation |  
*Julie Floyd*


---

 Barth Syndrome in Simple Terms | A video to explain Barth syndrome to younger  
children

---

*Barth Syndrome Foundation*

---

 Tools for School

---



### Contact Parent(s)

- Call parent immediately to report any change in behavior or appearance



### Limited Walking

- Locker assignment on same floor of classes
- Multiple locker assignments if it is not possible to assign locker on the same floor as classes
- Drop off and pick up near school entrance
- Use of scooter, motorized wheelchair



### Extra Time

- Extra crossover time between classes
- Early dismissal from class to avoid fall risks between classes
- Additional time to complete tasks, tests and assignments



### Limited Lifting

- Assistance with carrying heavy items
- Limit weight of book bag to less than one tenth of the student's body weight, if possible purchase a book bag with wheels



### Books

- Extra set of books for home and if classes are on separate floors of the school



### Accessibility

- Wheelchair accessible
- Arms on desk chairs and in lunchroom for body stabilization and ease of positional changes
- Handicapped accessible restroom
- Schedule classes on the same floor to reduce fall risks and fatigue when climbing stairs
- Permission to use elevator (if available) rather than stairs
- Schedule classes on the same floor to reduce fall risks and fatigue when climbing stairs
- Permission to use elevator (if available)



### Meals and Snacks

- Time for snacks during class or between class to avoid hypoglycemia
- The child should NEVER be prevented from eating or drinking or forced to eat or drink



### Physical Education

- Self limiting physical exercise, competitive sports should never be forced and could be potentially harmful, discuss with parents. Never force the individual to participate in physical activities



### Assistive Technology

- Text to speech software, dictation (speech-to-text) and word prediction, electronic worksheets
- Audible text books to reduce reading fatigue
- Electronic Worksheets
- Calculators, tablets, laptops, other electronic/mobile devices



### Rest

- Student should have a quiet place to rest when needed Parent should be notified and child should be monitored until parent arrives



### Restroom

- Student should be allowed to go to the restroom upon request and never be penalized or disallowed to use the restroom when needed



### Supervision

- Cool environment, sensitive to overheating
- Setting free of mold, mildew and kept away from other students who appear ill
- Classroom seating preference, close to the front of the class to avoid distractions
- Closely monitored in crowds, low muscle tone, and poor balance increases risk of falls

# Medical Condition

## Barth Syndrome



**Description:** Barth syndrome is a rare but serious genetic disorder that affects males. The characteristics (signs and symptoms) of Barth syndrome consist of the following in varying degrees:

♥ **Neutropenia:** Weakness in the immune system, specifically a reduction in the number of “neutrophils”, a type of white blood cell that is most important for fighting bacterial infections. Neutropenia places Barth boys at an increased risk of acquiring serious infections such as bacterial pneumonia and skin abscesses.

♥ **Cardiomyopathy:** Enlarged heart and heart pumping weakness

♥ **Arrhythmia:** Abnormal life threatening and potentially fatal heart rhythm

♥ **Muscle Weakness and General Fatigue:** All muscles, including the heart, have a cellular deficiency, which limits their ability to produce energy, causing extreme fatigue during activities requiring strength or stamina, from walking to writing to growing.

♥ **Small Stature:** Most children with Barth syndrome are also below average in weight and height, often substantially so. The poor growth of Barth boys is often due to the secondary effects of a chronic illness.



### Contact parent if any of the following symptoms appear:

- |                       |                      |                          |                                |
|-----------------------|----------------------|--------------------------|--------------------------------|
| ♥ Grey pallor         | ♥ Vomiting or nausea | ♥ Signs of heart failure | ♥ Persistent cough             |
| ♥ Extreme fatigue     | ♥ Chest pain         | ♥ Fever                  | ♥ Persistent sweating          |
| ♥ Tightening in chest | ♥ Diarrhea           | ♥ Increased irritability | ♥ Signs of potential infection |

### NEVER:

- ♥ Force child to eat: Forcing child to eat may worsen child's condition.
- ♥ Forbid child to contact parents when he states he does not feel well: Child knows his own body and will be at a heightened awareness of symptoms that may not be apparent to others.
- ♥ Prohibit child from going to restroom: Medications and actual condition may cause child to have BM or urinate more frequently than his peers.
- ♥ Force child to participate in physical exercise

### Tips for Care:

- ♥ Child should be kept in cool environment. Child will worsen when overheated.
- ♥ Child should be kept away from other children who appear to be ill. Children who have Barth syndrome are at increased risk of infections. A common cold can be catastrophic to a child with Barth syndrome.
- ♥ Those who have Barth syndrome appear deceptively healthy, even in times when they are very ill.

# Modifications and Accommodations

## Recommendations For Special Learner with Barth Syndrome



### In the Classroom



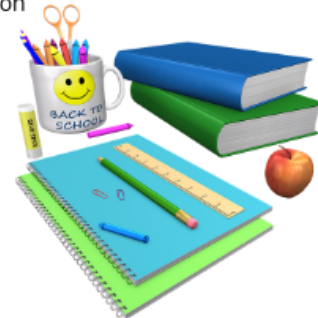
- Modified desk / seating with adjustable height to support posture
- Reduce visual and/or auditory distractions
- Increase space between desks and avoid proximity to children with apparent illness
- Student should not become overheated or too cold

### Tests and Schoolwork

- Break down large assignments into smaller parts
- Extra time to complete assignments
- Have "buddy" take notes for the student
- Allow student to answer questions out loud
- Don't reduce grade for poor penmanship
- Incomplete assignments should be sent home with child permitting additional time after rest for completion

### Technology

- Speech-to-text dictation apps
- Text-to-speech reading apps
- Allow use of laptop or tablet in class
- Audible text books
- Recordings of lessons



### Parent Teacher Communications

- Close contact when child is out ill
- Parents should be kept abreast of testing dates, syllabus of course study and progress reports
- Recommended Timeline for Parent-Teacher conferences: Month prior to start of school year, Mid-term of each session, mid-year report of student's progress or delays, year end meeting with current teachers, advisors, parents, student and recommended teachers for the following year
- Parents should be notified immediately if teacher sees change in behavior patterns in class

### Activity

- Modified Physical Education
- Allow student to rest when he is tired
- Allow child to be excused when he says he needs to go to the restroom
- Self limited activities may be allowed, should **NEVER** be forced to participate in competitive sports
- Reduced walking and stair climbing/ ability to use elevator (if available)
- Early dismissal from class to avoid fall risk
- Extra books for home use
- Classes scheduled on same floor (if possible)
- Locker assignment on same floor as classes



## Bibliography

- <sup>i</sup> Spencer CT, Byrne BJ, Bryant RM, et al. [Impaired cardiac reserve and severely diminished skeletal muscle O<sub>2</sub> utilization mediate exercise intolerance in Barth syndrome.](#) *Am J Physiol Heart Circ Physiol.* 2011;301:H2122–9.
- <sup>ii</sup> Storch EA, Keeley M, Merlo LJ, et al. [Psychosocial functioning in youth with Barth syndrome.](#) *Child Health Care.* 2009;38(2):137–156.
- <sup>iii</sup> Bittle AJ, Bohnert KL, Reeds DN, et al. [Reduced muscle strength in Barth syndrome may be improved by resistance exercise training: A pilot study.](#) *JIMD Rep.* 2018;41:63-72.
- <sup>iv</sup> Jarvis M, Garrett P, Svien L. [Gross motor development of a toddler with Barth syndrome, an x-linked recessive disorder: A case report.](#) *Pediatr Phys Ther.* 2001 Winter; 13(4):175-81
- <sup>v</sup> Finsterer J, Frank M. [Haematological features in Barth syndrome.](#) *Curr Opin Hematol.* 2013;20(1):36–40.
- <sup>vi</sup> Singh HR, Yang Z, Siddiqui S, et al. [A novel Alu-mediated Xq28 microdeletion ablates TAZ and partially deletes DNL1L in a patient with Barth syndrome.](#) *Am J Med Genet A.* 2009;149A(5):1082–1085.
- <sup>vii</sup> Reynolds S, Kreider CM, Bendixen R. [A mixed-methods investigation of sensory response patterns in Barth syndrome: A clinical phenotype?](#) *Am J Med Genet A.* 2012;158A:1647–53.
- <sup>viii</sup> Mazzocco MM, Kelley RI, [Preliminary evidence for cognitive phenotype in Barth syndrome.](#) *Am J Med Genet.* 2001 Sep 1;102(4):372-8.
- <sup>ix</sup> Mazzocco MM, Henry AE, Kelley RI. [Barth syndrome is associated with a cognitive phenotype.](#) *J Dev Behav Pediatr.* 2007;28(1):22–30.
- <sup>x</sup> Raches D, Mazzocco MM. [Emergence and nature of mathematical difficulties in young children with Barth syndrome.](#) *J Dev Behav Pediatr.* 2012;33(4):328–335.
- <sup>xi</sup> Roberts AE, Nixon C, Steward CG, et al. [The Barth Syndrome Registry: Distinguishing disease characteristics and growth data from a longitudinal study.](#) *Am J Med Genet A.* 2012;158A(11):2726–2732.
- <sup>xii</sup> Clarke SL, Bowron A, Gonzalez IL, et al. [Barth syndrome.](#) *J Rare Disord.* 2013;8(23):1–17
- <sup>xiii</sup> Sentenac M, Gavin A, Arnaud C, et al. [Victims of bullying among students with a disability or chronic illness and their peers: A cross-national study between Ireland and France.](#) *J Adolesc Health.* 2011 May;48(5):461-6.

---

<sup>xiv</sup> Storch EA, Heidgerken AD, Geffken GR, et al. [Bullying, regimen self-management, and metabolic control in youth with type I diabetes.](#) *J Pediatr.* Jun;148(6):784-7.