



Strategies of Educational Advocacy

For a Child Diagnosed with Barth Syndrome
A Parents' Handbook

*The Barth Syndrome Foundation
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Introduction

This handbook offers suggestions and ideas as to how families can better advocate for their children in school settings. It is a living document which has been updated many times over since 2003. The credit for the original research and writing, on which this project rests, goes to experts Jon Rosenshine, M.A, M.Ed., Eileen Juico, MA, 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, PT, PhD. 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 Barth syndrome.

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 Barth syndrome (BTHS).

Some important patterns in BTHS (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.

Possibly, the most significant point this handbook can make, however, is that **parents need to assess each child and each educational context on a case-by-case basis.** A goal of this handbook is to offer simple solutions that might be good for ALL students with BTHS, but the varied realities of the students and the varied school systems they attend makes many generalizations inaccurate. The students exhibit such a range of personal and academic strengths and weaknesses. What works for one, may not work for another. Some students have been tested and found to have significant neurodevelopmental learning difficulties while others have been tested and found to be free of any diagnosable learning challenge (other than the physical trials of living with BTHS). Furthermore, school systems—including all the variations of public and private offerings—are so different from region-to-region and indeed, from town-to-town, that there is no way to recommend for all students one solution that could be appropriate for each of them.

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*. Schools need to be willing to open their programs in more flexible

ways to accommodate the student with BTHS. With parents and educators working together, the individual with BTHS should find himself solving the educational challenge more and more successfully.

Section II Developmental Issues will first lay out **the physical, neurodevelopmental, social, and emotional issues as they have been experienced by BTHS students** and then discuss some of the solutions (successful and unsuccessful) that families have tried.

Section III Protection of Students with Disabilities offers **an overview of the laws that apply to students with BTHS** in the United States of America. This section will unfortunately not be very helpful for families living outside the United States. Hopefully the discussion of these laws might give some guidance for families living in other countries of the kinds of laws they might look for in their own country.

Section IV Choices of Educational Environments addresses the **different choices of educational environments** families have tried as well as the successes and disappointments they have encountered.

Section V Preparing the Master File and **Section VI Communicating with Schools** address **the strategies that parents can use to advocate successfully for their children** in any educational environment. Fortunately, we *can* generalize about these approaches because they are well-proven to be effective for parents who must deal with teachers and school administrators.

Section VII Resources provides a **variety of tools that might be helpful for parents**. Included is information for printed materials, websites, blogs and many other useful resources to provide parents with knowledge of the topics this handbook discusses.

Developmental Issues

When to Begin School

One of the first questions facing parents of children with BTHS is when to enroll their children in school. In the United States, most children begin their school experience in nursery school or pre-school at three or four years of age. Their more formal educational career begins in kindergarten, typically around five years of age. Because BTHS significantly delays the growth rate, many parents have found their children are behind their own age group physically, intellectually, and socially.

It stands to reason that if one of the symptoms of BTHS is *growth delay* then the individuals who have BTHS will be late not only in the development of weight and height but also, possibly, in the development of the neurodevelopmental system¹, which controls the cognitive and learning experience of each person. Therefore, some advocates of students with BTHS strongly argue for parents to consider enrolling their child(ren) a year late in order to compensate for the child's developmental delays. It must be noted, however, that no strong evidence exists to suggest that

all students with BTHS should be delayed in their school enrollment, but some anecdotal evidence suggests both that the question should remain open for further discussion and that each parent should consider the possibility for their child.

One parent spoke about having her son tested and finding that he was significantly below average in most cognitive categories. After adjusting the analysis of the boy's scores for a child two years younger than his chronological age, the tester found all of the boy's scores easily fit into the *average* range. The conclusion from this one example is if the child were delayed in his enrollment in school, his physical and intellectual development might have been similar to that of his classmates. Furthermore, almost without exception, individuals with BTHS tend to experience delayed puberty. They are generally significantly behind their peers in height and weight. As a result, they constantly struggle with the characteristic of being physically smaller than their peers. With these points in mind, some members of the BSF community have advocated that parents consider delaying school enrollment for a year to allow the child to be developmentally at the same age as his peers.

The next question that arises is, "If delaying the student is a good idea, at what age/grade level should the parents make the adjustment in their child's education?" Should parents simply delay their child's enrollment in kindergarten, or should they allow their child to try keeping up with his peers and have him repeat a grade level only when the time comes that he needs the extra year to catch up? In answer to this, some advocate holding the student back very early, so that the child will not have to suffer the social complication of watching his friends advance while he stays behind. At the same time, however, one argument against holding a student back for a year before beginning kindergarten is that the medical and academic challenges of BTHS with each child tend to be quite unpredictable. If a student begins his school career a year late, he has no guarantee that he will not face a year of serious academic or medical challenges later on, challenges that might hold him back from completing a year of school on time. Under these conditions, a student who is already a year older than his classmates might be faced with the need to repeat a school year and then have classmates who are a full two years younger than he.

One good piece of advice to keep in mind at this point is that despite the considerable social pressures of adolescence and despite an individual's goals for his own academic career, **a student with BTHS will simply have to complete school on his own schedule and in a manner that is most appropriate for him.** The academic experience is a secondary consideration after health and safety. If an individual student faces the prospect of graduating from high school at nineteen or twenty years of age, with classmates who are eighteen years of age, his parents need to be prepared to support their child through the experience. A student with BTHS faces challenges unimaginable to anyone else; therefore, if possible, parents should help their child(ren) attach their self-esteem to their own efforts in the context of their own lives and not in the context of their classmates.

Ultimately, the lack of patterns in the experiences of the various individuals with BTHS makes a general recommendation on the matter of when to enroll in school impossible. While some students have the challenge of neurodevelopmental delays, some of which might be well-

addressed by a delay in school enrollment, other students have learning difficulties that would not be eased by keeping the student back a year. Still, others have no diagnosable neurodevelopmental learning difficulties at all.

Developmental Issues

Some Neurodevelopmental Challenges Faced by Students

Despite the lack of consistency in the intellectual experiences of the students with BTHS, parents would do well to prepare for the kinds of neurodevelopmental and learning issues their child(ren) *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.

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 sizable portion of parents who responded to the educational survey noted that their children struggle with **short and long-term memory issues**². Such problems might very well be a consequence of the fatigue, which would place a strain on anyone's capacity for retaining information. Another possible cause for memory difficulties could be found in the effects of the medications that many students with BTHS take. Parents should always consult with their children's doctors about the possible side effects of medications on their child'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 suits him. Easily distractible students might have an even harder time digesting material that comes to them orally as opposed to material that they read themselves.

Mathematics is an area of difficulty for many students with BTHS, but very little data exist to explain why this is. Possibly, it stands to reason that students 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 2001³ 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 skills⁴.

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 kindergarten⁵. **In the Barth Syndrome Registry study**, twenty-two of forty-six males older than age seven years reported some form of “*learning disability*”⁶. An estimated 33% of those diagnosed with BTHS require some type of **educational accommodations**⁷.

If parents find that their child is having substantial difficulty with any part of the learning process, they should consider having their child tested for his cognitive learning styles, strengths, and weaknesses. The testing does not commit parents to any course of action, but the results could supply helpful information as well as essential evidence as parents work with educators to find the best educational environment for their child. There are two options for parents in the United States: parents have the right to ask their local public school to test their child at no cost, or parents can find a private psychologist to do independent testing, which might be covered by insurance. Costs for a comprehensive round of tests and a full written analysis is generally thousands of dollars. So, it pays to be the squeaky wheel to try to get these costs covered through school or insurance.

If significant cognitive challenges are found in the testing, a student in the American public school system might be eligible for legal protection under the [Individuals with Disabilities Education Act](#) (IDEA). Protection under the IDEA supplies a student with an Individualized Education Plan (IEP), which is a written plan that outlines how the school is going to best meet the needs of an individual student. Sometimes, parents are afraid of having their child *labeled* as different, but these protections are more about providing students with accommodations than they are about labeling students. The vast majority of parents who filled out the educational survey noted their child had an IEP in place for his education.

Developmental Issues

Physical Challenges

If a student with BTHS is in a public school system in America and if he does not already have protection under the IDEA, his health issues will almost certainly make him eligible for legal protection under Section 504 of the Rehabilitation Act of 1973 (504) as well as under the [Americans with Disabilities Act](#) of 1990 (ADA). Because of the physical challenges that most students with BTHS face, they will likely need some of the special accommodations discussed below. The legal protections are often necessary to ensure a student with BTHS is fairly treated in the educational environment.

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 BTHS¹¹. 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 Barth syndrome also have **difficulty with gross motor skills**⁸—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^{9,10}. To learn more about PT and how it might be appropriate for an individual with BTHS, check out the [American Physical Therapy Association](#) website.

OT and PT specialists diagnose students' challenges, help students strengthen their muscles in order to overcome their challenges, and prescribe solutions for students who need accommodations, tools, and special technology in order to function independently. Because the vast majority of students with BTHS need some form of PT and OT, all those diagnosed with BTHS should be screened for PT and OT needs as soon as they are diagnosed with BTHS. Furthermore, parents should seek consultations with PT and OT specialists whenever their children face new physical challenges, and they should be proactive with their children's schools in requesting PT and OT aid for their children.

Some parents also noted that their children received speech therapy at a young age. Again, considering the developmental delays caused by Barth syndrome, 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 development¹¹.

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 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](#).

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 Barth syndrome. 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 periods.

For students who miss a significant number of consecutive school days due to illness, public schools in the U.S. can sometimes offer tutoring better known as **hospital homebound** programs at no cost to the parents. For children who are in private schools, parents might still obtain this home tutoring by enrolling their child in the public-school system for the period that he is not able to go to school. It may be possible for him to begin attending classes at the private school after ending his enrollment in the public-school system.

A common problem faced by students with BTHS is the need to leave class to go to the restroom beyond set allowances. **Often teachers may limit the number of restroom breaks students may take in a given day.** However, some students with medical issues such as BTHS must be excused from these restrictions. Because of his medical condition and occasionally as a result of his

medications, a student with BTHS must be allowed to excuse himself to the bathroom when he requests it. Teachers and administrators should be alerted to this situation before students are caught in the position of having to explain their needs or worse—being unable to excuse themselves. If possible, it would be best, if the student could be permitted to leave the room without need calling attention to himself, particularly in grades beyond primary school. It is important for the teacher not to assume abuse of breaks with increased frequency to the restroom. Something far more serious may be occurring. The parent and teacher should have a discussion when increased frequency of bathroom breaks occur. The parent should also advise teachers when a change in medication occurs which may lead to changes in behavior and habits.

One physical challenge that all students with Barth syndrome share is fatigue.^{7,11,12} **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 Barth syndrome 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 their 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 need 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.

Eric Storch, PhD 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 mentors¹³.

The **physical education and sports elements of education must be modified dramatically for all students living with 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 time keeper and record the plays and game statistics and these are all important, challenging, and fun activities in sports such as basketball and baseball and football. Conversely, **resistance non-aerobic exercise is suggested to improve muscle strength** for those who have BTHS¹⁴.

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 parent respondents to the educational survey shared their child was **assigned an 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.

Not all schools have school nurses. **A school that has a student with Barth 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 for 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, and the BTHS Foundation handbook for faculty and administrators will outline these warning signs. Still, parents should provide a simple handout of the warning signs of medical problems to share with all educators who come into contact with him.

In preparation for each school year, parents should make sure that they have filled out an updated **Care Plan for School Age Children with Barth syndrome.** 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 of clarifying for teachers and administrators the serious physical and medical realities of a child with BTHS is through **direct contact between the child's doctor 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. One parent noted her child's school did not originally have a nurse, but a letter from her son's doctor forced the school to commit the resources to have a full-time nurse on site. With few exceptions, every parent who has already initiated contact between their child's doctor(s) and their child's school has noted that the letters or the phone calls were extremely helpful in directing the school to best care for the student.

As a final note on the physical challenges faced by students with Barth syndrome, significant anecdotal evidence suggests that as individuals approach their high school years, they should be prepared for greater health and fatigue issues. The demands on high school students tend to be greater than the demands on them in the elementary grades, and furthermore, students in high school are often experiencing their final growth spurts. All teenagers experience fatigue as their bodies take the energy to grow, but individuals with Barth syndrome suffer considerably more than their peers at these times.

Developmental Issues

Social and Emotional Challenges

A child who lives with 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 family would be well-served to seek some kind of support in learning how to cope in a healthy manner with these difficulties. The individual with BTHS, as well as his family, could benefit from therapy specifically designed for coping with chronic illness, and parents could benefit from counseling just for themselves.

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^{15, 16, 13}. 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 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 2nd grade son, who would run to her for a hug whenever she 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 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 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; 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 often wonder how much and when the classmates of a student with BTHS should be told about the condition that affects their classmate. 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. 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 a teacher, 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, models good behavior for him, and conveys information back to the parents in a timely manner.

In addition to having an educator advocate, **a student with BTHS should learn over time how to 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 to speak up for himself.

On the educational survey, parents overwhelmingly noted their children, regardless of age, were not strong at advocating for themselves. Self-advocacy presents a significant challenge to students who have no desire to draw attention to themselves and wish, instead, to be treated no

differently from their classmates, but it is a skill that parents should try to foster in their children, nevertheless. It should be stressed to a student with Barth syndrome that his right to advocate for himself must never be abused; when he says he needs to go to the bathroom, he should never go instead to talk with friends, and when he forgets to do his homework, he should never come into school the next day and explain that he was too tired to complete his work the night before. If a student can agree to these terms and recognize that self-advocacy is both a right and a responsibility, then he might feel more comfortable speaking up for himself when he truly needs to do so.

Federal Protections of Students with Disabilities

Overview

BSF has member families from all over the world, but the majority of the families are currently in the United States. In order to keep this discussion of legal protections as readable as possible, the focus here will be on the laws of the United States federal government. Certainly, other countries have different laws and some variations on the laws below. Also, each state and local school district in the U.S. has its own specific laws that might add to, but not take away from, the protections discussed below. While the following discussion offers a simplified and readable version of the kinds of laws that protect students with Barth syndrome in the public-school system in the United States, it is hoped that parents from other countries will find some guidance in this section.

If parents are interested in reading a more thorough discussion of the legal protections discussed in this section, they should get a copy of an outstanding book called [*From Emotions to Advocacy – The Special Education Survival Guide, by Pam and Pete Wright*](#). Chapters 13-20 cover the legal issues that a parent would want to learn about. Basically, all parents of students with Barth syndrome could benefit from having this book, and its complete bibliographical information will be in the resources section of this handbook.

Lastly, if parents are truly interested in learning about the laws that protect their child with BTHS, regardless of what country or state they live in, they **should seek out professional advice and support**. In the U.S. one's local public-school district will have educators who are responsible to explain the laws fully to parents if parents ask for guidance. Furthermore, parents should not hesitate to reach out to BSF for additional assistance.

No book, guide, or handbook can replace the direct advice that a parent needs when dealing with these potentially complicated but powerful laws that can make the difference in a child's education and development. Still, it helps to have a written explanation of the laws to use as a reference.

At a Glance: Which Laws Do What?

Three federal laws protect the rights of individuals with disabilities, which can include people with learning and attention issues. Here's what these laws do.



IDEA

Individuals with Disabilities Education Act

An education law that requires schools to provide special education and related services to kids with disabilities who need them

Section 504

Section 504 of the Rehabilitation Act

A civil rights law that prohibits discrimination on the basis of disability at schools that receive federal funding

ADA

Americans with Disabilities Act

A civil rights law that prohibits discrimination on the basis of disability in schools, workplaces and public spaces

WHAT IT PROVIDES	IDEA	504	ADA
Legal rights for people with disabilities, which may include accommodations	✓	✓	✓
Special education and related services (such as speech therapy or counseling) that meet the individual needs of students	✓		
An Individualized Education Program (IEP) for eligible students	✓		
A requirement that public schools identify and evaluate, at no cost to parents, kids suspected of having a disability	✓		
Education funding for schools	✓		
A requirement that schools give prior written notice before making changes to students' services	✓		
A "stay put" provision, which keeps students' services in place while parents and schools resolve IEP disagreements	✓		
Freedom from discrimination in the workplace (with the exception of workplaces with fewer than 15 employees)			✓
A free and appropriate public education (FAPE) in the least restrictive environment (LRE)—usually a general education classroom—for kids with disabilities	✓	✓	
Procedural safeguards to protect the rights of students with disabilities (and their parents), including informed consent, access to school records, the right to appeal and timelines for certain actions	✓	✓	
Due process for resolving disagreements between parents and schools	✓		
Freedom from discrimination at private schools (including colleges and universities) that receive federal funding		✓	✓
A 504 plan for eligible students		✓	

Understood
for learning & attention issues

For more tips and resources, go to [understood.org](https://www.understood.org)

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A student with BTHS in the U.S. will almost certainly be eligible for special accommodations in his education under one or a handful of United States federal laws. **Parents should not be afraid that their children will be harmfully “labeled” if they take advantage of these protections.** The protections are far more important than the usually misplaced fears of labels. **Furthermore, parents should not be afraid that their children will immediately be placed in “special education” classrooms if they take advantage of these protections.** Being protected as a student with a disability does not necessarily mean that a student will have to be educated apart from non-disabled students.

Schools in the United States have the legal responsibility to identify and evaluate students with disabilities. If a public-school has not made the decision on its own to evaluate a student with BTHS (possibly because the student attends a private school), his parents have the right to ask the local public school system to conduct, at no charge to the parents, an evaluation of the student’s potential physical and/or cognitive disabilities. Furthermore, if the parents do not agree with the school’s evaluation of their child, they have the right to have their child tested by an independent evaluator. Some school districts can be reluctant to perform these evaluations, but parents should not allow a school to win this argument. Parents might be able to find professional student advocates in their area to help in this endeavor, and they can always call on the BSF for help and advice.

Parents (in America and in countries with similar public education systems) may find it helpful to call the department of education in their state/region and ask to speak to someone in special education who is assigned to their home district. This call should be made *before problems arise*. When the parent speaks with the individual assigned to their school, they can explain more about BTHS (and arrange for a BSF Educators’ Handbook to be sent to the individual) and ask questions about testing, accommodations, and services. During this call, parents can ask for their child to be tested. Through this call, parents make a valuable contact with an individual charged with protecting the rights of their child. By asking if they

can call the individual back some time in the future for more guidance, parents can help assure that the special education person will be checking in with the local school.

Federal Protections of Students with Disabilities

Section 504 of the Rehabilitation Act of 1973

If no learning disabilities are found, the evaluation of a child with BTHS will certainly identify the physical limitations that he lives with. Under these conditions, a student will likely be eligible for protection as *other health impaired* under Section 504 of the Rehabilitation Act of 1973 (504). **A student has a 504 disability if he has a physical or mental impairment that substantially limits one or more major life activities such as learning, walking, writing, reading, performing manual tasks, etc.** The physical and neurodevelopmental issues discussed in Section II of this handbook make clear that a student with BTHS is likely to be limited in his ability to perform at least one of these major life activities.

With 504 protection, a student in a public school will have a “504 plan” that clarifies his impairments as well as the necessary and appropriate accommodations put in place to assure the student has access to the same public education as his classmates. Some of the kinds of 504 plan accommodations that a school might make for a student with BTHS include (but are certainly not limited to) the following:

-  *Making the school accessible to a wheelchair*
-  *Modifying physical education requirements*
-  *Making technology available for a student to do his writing and other assignments computer*
-  *Providing physical therapy, occupational therapy and speech therapy*

The public school is responsible to make these accommodations free of charge to the parents, but it should be noted again that while Section 504 applies to public schools, it generally does not apply to private schools.

It should be noted that if a student has only a 504 plan and not an Individualized Education Plan (discussed below), the school has the responsibility only to assure that the student with BTHS have the same access as his classmates have to an education. Ultimately, the school has many fewer responsibilities to follow special procedures and make special arrangements for students with 504 plans than they have for students with Individualized Education Plans (IEP).

Federal Protections of Students with Disabilities

Individuals with Disabilities Act, IDEA

If the evaluation of a student with BTHS also finds evidence of a recognizable learning disability and if the student needs special education as a result of his learning disability, then he will be protected under the Individuals with Disabilities Education Act, amended in 1997 (IDEA). This federal law provides many more protections than Section 504 provides, so a student who is already protected under the IDEA does not have to worry about having a 504 plan. Under the IDEA, a student with disabilities will have an Individualized Education Plan (IEP), which details how the student will be accommodated for his disabilities in each element of his education. This document legally binds the school district to provide the protections and accommodations they promise to provide. (Some provinces in Canada also have IEP's protecting students with disabilities, and the British government has a similar protection called a Special Educational Needs policy.)

An excellent book for parents who have students with IEP's or for parents who are thinking about having their children protected under the IDEA is called [*The Complete IEP Guide: How to Advocate for Your Special Ed Child*](#) by Lawrence M. Seigel. This book offers all that a parent could need in learning the basics and the specifics of the IEP process.

One of the purposes of the IEP is to provide protections that a student with disabilities will be educated, as much as possible, with non-disabled students in regular classrooms. In legal terms, the student should be educated in the *Least Restrictive Environment* possible. At the same time, the school has the responsibility to take the student out of the regular classroom for special education or one-on-one instruction when such methods are necessary for the student to actually benefit from his education. Parents often are concerned about the extent to which their child will be labeled as a *special education student* and separated from the general student body, but parents should be equally concerned if their child with disabilities are unable to learn in a regular classroom. Finding the balance between special education and mainstreamed education is a challenge the parents and the school will work toward in the writing of the IEP.

An IEP includes the following information:

-  *A statement of the student's present levels of educational performance*
-  *A statement of measurable annual goals and objectives*
-  *A statement of the special education, aids and related services to be provided by the student*
-  *A statement of the program modifications or supports for school personnel to be provided for the student*
-  *A statement that explains the ways in which the student might be educated separated from non-disabled students in regular classrooms*
-  *Communicating with Schools*

The school must evaluate the student once every three years in order to keep the student's records up to date, and the IEP must be reviewed (and possibly revised) at least once a year. **An IEP team made up of educators and the child's parents is responsible for the writing and the reviewing of the IEP.** Parents do not have the final say in how their child will be educated, but the law provides protections that the parents, as members of the IEP team, will have a significant say in how their child will be placed and accommodated. In order to have a meaningful say in the creation of an IEP, parents need to be educated in how to read their child's evaluations and test scores.

When disagreements between parents and educators arise concerning the education of a student with an IEP, the school has many legal responsibilities to work with the parents to find a solution that everyone will accept. If parents make a request for accommodation that the school does not wish to offer or if the school plans to make an adjustment to a student's IEP, the school must inform the parents in writing. This letter is called *prior written consent*, and it not only must explain exactly how the school came to its decision but also must be written in a language that the parents can easily understand. Furthermore, if the parents cannot read and write in the language that the school uses in its letters and communications, the school must provide an interpreter to assure that the parents understand the IEP process.

If, after reading the prior written consent letter, parents wish to have the school reconsider its position, they may ask for mediation, and if mediation fails, parents may request an impartial *due process hearing*, otherwise known as a *Fair Hearing*. Most student advocates, however, will argue that these hearings are rarely fair and are usually biased towards the school districts. **Essentially, a Due Process hearing is something to be avoided when possible.** Certainly, parents would need considerable expert help and advice before they should consider such a strategy.

In the rare cases when the parents wish to continue their fight beyond the due process hearing, they have the right to appeal their case to the state or federal courts. This kind of legal battle often costs an enormous amount of money in legal fees, and the battle takes years to finish. **The best way to solve a dispute between parents and schools regarding a child's IEP is through mediation** (see Section VI of this handbook for more discussion about mediation and due process hearings.)

In summary, here are some points to remember regarding students with IEP's:

-  *A student with an IEP does not also need a 504 plan*
-  *Schools must allow parents to examine all records pertaining to their child*
-  *Schools must give parents the opportunity to participate in all meetings pertaining to how their child will be educated*
-  *Schools must allow parents to have their child independently evaluated*

- ④ *When disagreements cannot be resolved between schools and parents, schools must pay for mediation sessions between administrators and parents*
- ④ *If parents do not accept the terms offered in mediation, they have the right to take their case to a due process hearing*
- ④ *If parents are not satisfied with the outcome of the due process hearing, they have the right to appeal their case to a state or federal court*

Federal Protections of Students with Disabilities

Free Appropriate Public Education (FAPE)

Under the IDEA, a student with a disability is assured the right to a Free Appropriate Public Education (FAPE). If a student's local public school system cannot meet the special education needs of the student—in other words, if it cannot offer an appropriate education to the student in the public school—then the public school system must provide the student with other means to an education free of charge to the parents. Under such circumstances, the public school might pay for the student's tuition at a private school better suited to meet the student's needs, or the public school might pay for personalized home tutoring for the student. The cases in which this happens tend to be rare, but if the public-school system cannot educate a child appropriately, then parents have the right (and the school has the responsibility) to find an effective means of educating their child.

If a student with an IEP is homebound and cannot attend school due to his own health, the local public-school district has the responsibility to pay for homebound tutoring. Such circumstances often leave the parents with little control over the quality of the tutors sent to work with their child, but homebound tutoring might very well turn out to be a successful, if only temporary, solution for many individuals with Barth syndrome.

Federal Protections of Students with Disabilities

Family Educational Rights and Privacy Act (FERPA)

In the U.S., families have the legal right to access to all educational records pertaining to their child. **Parents have the right to inspect their child's records**, and if they need copies of the files in order to be able to inspect them fully, then the school has the responsibility to make those copies for a reasonable copying fee (or for no fee at all if the parents cannot afford the fee). Regardless of whether the parents actually need the copies made, schools will usually be helpful in making copies for the parents if the parents simply make a written request to the appropriate school administrators. Schools are legally bound to keep all records for at least five years, and furthermore, the school is responsible to explain the significance of any records the parents are having difficulty understanding on their own.

Some of the kinds of records available to parents under FERPA include the following:

-  *Transcripts and recordings of IEP Meetings*
-  *Due Process decisions*
-  *Psychological testing evaluations*
-  *Grades and teacher evaluations*
-  *Testing materials*

Federal Protections of Students with Disabilities

Americans with Disabilities Act (ADA)

The Americans with Disabilities Act of 1990 (“ADA”) is another federal law that protects students with disabilities. Because it is extremely similar to Section 504 of the Rehabilitation Act of 1973, parents should concern themselves with either the 504 or the IDEA for the purposes of protecting their child with BTHS in the public-school system. Since the ADA might come up as a topic when discussing the legal protections for students with BTHS, however, parents should know of its existence as another law written to protect individuals with disabilities in the United States.



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

Choices for Educational Environments

Each family of a child living with Barth syndrome (BTHS) wrestles with the decisions of how best to educate their child, and students with BTHS have experienced a considerable range of schooling options. Ultimately, however, the actual choices available to an individual student vary greatly with the circumstances of any given family and region. The following are some of the educational environments that students with BTHS have experienced:

-  *Public School*
-  *Private*
-  *Parochial School*
-  *Vocational School*
-  *Homeschooling*
-  *Home Tutoring (Hospital Homebound)*
-  *Virtual School*

One important piece of advice for parents to follow is that flexibility is essential. It is common for individuals with BTHS to revise their educational situations at least once throughout their educational career. Because the course of BTHS in an individual can change dramatically, parents need to be willing to revisit and rethink their child's schooling choices when his condition changes. The high school years can be particularly challenging with increasing academic demands coupled with changing health conditions.

PUBLIC SCHOOLS

The local public-school system is a common choice of parents to educate their children with disabilities. In order for a student with disabilities to take advantage of the laws that protect him, he must be enrolled in the public-school system, and the financial cost of other educational options is often far too much for families to consider seriously. Also, because the laws in the United States require public schools to provide a Free Appropriate Public Education for all students with disabilities, they are often the best equipped to educate students with disabilities.

The downside of relying on the local public-school system is that parents have less control over the quality of the school. Unless parents have the financial flexibility to move into a neighborhood with a public school that is ready and willing to educate their child, they have to hope that the local public school will be a safe and accessible place for their child. If the school is reluctant to learn about and to recognize the seriousness of BTHS, if they use the bureaucracy

and the paperwork of the school system to make it difficult for parents to participate in their child's education—in short, if the school administrators do not make themselves good partners with the parents in educating a child with BTHS—then parents and students have a long road ahead. Many public schools have educators who are truly dedicated professionals; they understand the legal protections of students with disabilities, they make sure that parents understand their rights, and they do their best to meet the needs of their students. At the same time, however, very negative stories of experiences with the public-school systems have been reported by BTHS parents. Each local public school is different from the next.

PRIVATE SCHOOLS

For some parents, private schools (otherwise known as independent schools) are the best answer for their students with Barth syndrome (BTHS). Because private schools are not bound by many of the regulations that govern public-schools, they have far more flexibility to think creatively in meeting the needs of a student with BTHS. Parents can work with school administrators to create flexible schedules, expectations, and evaluation techniques; and some private schools are specially designed to meet the needs of students with disabilities. Parents do not have to participate in IEP meetings, and they will usually find the process of working with their child's school a far easier process than working with a public-schools.

The downsides of enrolling a child in a private school can be significant, however. First of all, the cost of private schools often costs well over ten thousand dollars per year¹⁷. Many schools offer extremely generous financial aid packages, therefore, families should not dismiss private schools outright because of tuition costs. Still, the cost of a private education can often be too much for many families. Also, while the parents of a private school student do not have to worry as much about daunting paperwork, intimidating evaluation meetings, and occasionally complicated IEP's, private schools are not bound by Section 504 or the IDEA. In giving up the protection of the laws for disabled students, parents must rely on the individual private school to be able to supply their child with an education. They have no legal guarantee apart from their particular enrollment contract with the school, however, that the school will be able to succeed in this endeavor. For more information about private schools in America, parents can begin their research by visiting the website for the [National Association of Independent Schools](#).

PAROCHIAL SCHOOLS

Parochial Schools (often Catholic or other religious schools) are a good solution for many families of students with disabilities. Parochial Schools have the same kinds of freedoms that independent schools have, but tuition, even at half the cost of a private school per year, parochial schools may still be unaffordable to the average family. Also, most faith-based schools do not restrict enrollment to students of the school's faith. Many Parochial Schools do offer generous financial assistance to students. Parochial Schools should not be ruled out based upon assumption of cost. If families are comfortable with the school's religious identity, students can often get an excellent and affordable education in addition to the spiritual and ethical instruction.

VOCATIONAL SCHOOLS

Every state in the U.S. has Vocational Rehabilitation Services offices. Students over 16 years of age can receive vocational testing to help them identify possible options and career paths. A vocational school, however, might have requirements for its students to take certain classes, such as shop and mechanics classes, that might pose physical challenges to students with BTBS. Under these circumstances, parents must work out with the school the appropriate requirements and expectations for their child. Often times funding and services are available through Vocational Rehab that would not be available to meet the students' IEP needs. **Parents should explore potential services available through Vocational Rehab.**

HOSPITAL HOMEBOUND HOME TUTORING

One way to take advantage of many of the homeschooling advantages without the parents' having to take on the responsibility of educators is home tutoring. With home tutoring, professional educators come into the home to teach a child. This would obviously be an extremely expensive option if parents were to pay for private tutors, but some state and local school districts provide teachers for students who are home-bound. Under the requirements of FAPE, a student with an IEP might be able to receive home tutoring paid for by the school district if he cannot attend school enough to receive an appropriate education. If the local school system does not supply home tutors, parents might consider contacting a nearby university to find a student who could provide home tutoring, and some parents have also relied on retired educators to provide tutoring in the home for their child.

Home tutoring, of course, does not provide a perfect solution. Students will still need opportunities to socialize with peers, and when relying on outside tutoring coming into the home, parents must depend on the reliability, flexibility, and skills of individuals who might not be very reliable, flexible, or skillful. As always, these solutions must be considered on a case-by-case basis.

HOMESCHOOLING

Some parents make the choice to homeschool their children for at least part of their educational career, and for the purposes of a child with BTBS, the homeschooling option allows for incredible flexibility. The student can function on a schedule best geared to his physical and neurodevelopmental needs. He has constant access to the people who can best care for him. He does not have to deal with the stresses of being different from his classmates. Furthermore, the homeschooling option can be very inexpensive compared with other forms of non-public schooling options.

The challenges of homeschooling, however, can be considerable. The parents of a child with BTBS are usually working full-time to support and care for their child under *normal* circumstances; most parents have neither the expertise nor the time to be the primary educators for their children. Another challenge to the parents of a homeschooled child is how to offer him appropriate opportunities to socialize with peers. Homeschooling, while it presents many attractive solutions for the education of a child with BTBS, is not a simple solution. If parents are interested in exploring what homeschooling entails, they might visit the [Homeschooling Community](#) website. [Learning Liftoff](#) is another great website for homeschooling families.

VIRTUAL SCHOOL

One relatively new option that is worthy of consideration for a student with BTHS is virtual school. For students in high school, internet academies offer the flexibility of homeschooling along with the expertise of professional educators. Furthermore, these educators do not have to come into the home as with home tutors, and the internet schooling experience is often especially geared towards students who work at different paces than students in regular classrooms. For instance, [the Florida Virtual School](#) (FLVS), which has been attended successfully by a student with BTHS, has the motto, “*any time, any place, any path, any pace*”. Florida residents do not have to pay to attend FLVS. The school does offer a global school with affordable tuition to students in all states and to students in more than 65 countries around the world.

CREATIVE COMBINATIONS

Lastly, parents have the opportunity to develop creative solutions to educating their child with BTHS. The course of BTHS is different for each person. Sometimes they have periods of relatively good health, and sometimes, unfortunately, they have periods of extreme fatigue and illness. These periods can last for short or for prolonged amounts of time, so it can be difficult settle on one educational program throughout a student’s academic career.

The following are a few of the creative solutions that parents have come up with to educate their children who have BTHS:

-  *Some parents homeschool their child and offer him the opportunity to socialize with peers through taking music and art courses in his regular school*
-  *Some students are homeschooled with an option to audit classes at a local public school*
-  *Some students have combined home schooling, hospital homebound tutoring with virtual school*
-  *Students can enroll in a public-school system on a part-time basis and supplement his education with internet- based classes*

Ultimately, parents should think creatively and explore options when searching for the educational environment that best meets their child’s needs.

Preparing the Master File

Much of the information in the following two sections comes from Chapter 9 of [*From Emotions to Advocacy – The Special Education Survival Guide*](#), by Pam and Pete Wright. This is a very reader-friendly and well-organized guide that gives parents far more helpful information than a handbook can supply.

Parents cannot rely solely on their personal knowledge of their child if they want to advocate properly for him. In order to convey to others (teachers, administrators, tutors, etc.) what they know of their child and what kinds of services he needs to be successful in the educational environment, parents have to be *experts* and deal with professional educators as if they themselves were professionals in the field of their child.

Just as it is critical for parents to keep complete medical records in order to support their child's healthcare, it is also essential for educational advocacy to keep **a complete master file on a student's educational experience**. If parents can keep a well-organized and detailed master file of all educational records, reports, evaluations, letters, and even verbal communications, then they have a powerful means of convincing others not only to take them seriously but also to do what is best for their child. Putting together such a file takes time, patience, and careful organization. Many parents are so busy taking care of their children on a day-to-day basis that the creation and maintenance of such a file seem daunting. The importance of this file, however, must be stressed: If parents do not have a careful record of their child's academic experiences, they will have a significant disadvantage when they try to advocate for him in an academic setting.

In putting together this master file, parents should know the following: **Under FERPA (see Section III of this handbook), parents have the right to inspect all documents that pertain to their child's education, and under most circumstances, schools will be willing to provide the parents with copies of these records**. Parents should send a letter to the school or schools their child has attended and ask for full copies of their child's file including all confidential information. It is a good idea to specify that nothing in the school's file should be omitted from what they copy and send. Similarly, parents should send letters to all relevant agencies and individuals who have worked with their child and ask for copies of their child's files. Schools and agencies might ask parents to pay photocopying fees, but these fees should be reasonable.

Whether the document is a doctor's note, a report card, or a correspondence between parents and school, **every document should be dated and put in a binder in chronological order**. Pam and Pete Wright suggest filing with earliest in front and most recent in back, but some argue that accessing the most recent documents is easiest when those papers are in front and the rest move backwards to the earliest at the back of the binder. Filing papers by category can lead to confusion because some documents do not fit easily into a single category. The goal is for parents to be able to access all relevant documents at a moment's notice. When sitting in a conference in a principal's office trying to convince teachers to change their approach to a child, parents are

likely to be nervous. They will have control and confidence, however, if they can quickly access the support for their points when they need it.

Some tips for the file:

-  *Keep your documents in a three- ring binder*
-  *Original copies of documents are valuable sources. When you have them, do not give them away, do not share them and do not mark them up.*
-  *When using a hole punch make sure the holes do not ruin important information*
-  *Use sticky notes if you need to mark up a specific document*
-  *Keep a list of professionals and agencies that have added to your child's file in the binder*
-  *Include files from doctors, mental health providers, teachers and administrators*
-  *Make sure documents are dated*
-  *Maintain a well organized log of notes that you might need to reference later*
-  *Keep a copy of all letters and written correspondence, including copies of written documents requesting copies of records*
-  *Keep file current and file important documents as they are received*
-  *It is a good idea to scan and keep a virtual copy of any written copy available on the cloud. Think carefully before destroying written documents.*

TIP: When buying a three-ring binder seek a silent D clip binder rather than a round clip binder. Papers are less likely to become torn or ripped in this type of notebook

In order to know what is in the file and in order to find each document with ease, parents might keep what Pam and Pete Wright call a **Master Document List**. Essentially, this list is a table of contents for the master file, but it should include the date of the document, the source and writer of the document, the type of document, and whatever significance the document might have to the student's education. With this list of the documents in the file, parents should be able to access quickly the papers they need without confusion.

If parents can find the means to do so, it is a very good idea to **make a copy of the master file**. With so much importance placed on one collection of papers, the risk of losing the file or of having it destroyed in some way is too great, even if it is treated with special care. Parents should make a copy of the master file and as the file grows, regularly continue making copies of the recent additions. If possible, keep the copy of the master file in a different place from the one you use on a regular basis.

Communicating with Schools

In this section, the handbook makes the assumption that the reader is a parent who has a child in a school rather than in a homeschooling environment. Still, because those parents who homeschool their children still need to communicate about their children with other individuals and agencies, the following advice should still be relevant and helpful to them. And again, much of the information in this section is given far more detailed development in the Pam and Pete Wright book, *From Emotions to Advocacy*, Chapters 21-27.

Possibly the single most important rule for parents who wish to advocate successfully for their children is that successful relationships between parents and schools lead most effectively to healthy educational environments for the students. In case after case, parents have told how their success stories were due to their having open lines of communication with teachers and supportive school administrators dedicated to caring for a student with BTHS. And in almost every unsuccessful educational experience, parents found themselves in negative relationships with teachers and administrators in their son's school.

To be sure, parents cannot always control the nature of their relationships with educators, especially when an educator seems reluctant to care properly for their child. Still, the primary piece of advice that this handbook can offer is the following: **parents must try very hard to cultivate positive, friendly, and mutually supportive relationships with the people in their child's school.**

Communicating with Schools

Document Everything

Parents should keep a record and a paper trail on every contact with schools, agencies, and individuals as they pertain to their child's education. Every phone call, every letter, every evaluation, report, and consent form should be carefully documented. Actual paper documents will be easy to save in the master file discussed in Section V of this handbook. Phone calls and direct conversations, however, need to be recorded in a journal on the day they happen. If a dispute with a school arises and parents wish to refer to a meeting or a phone call that took place three months earlier, they will be on strong ground if they can refer to the notes they took immediately after the conversation happened. If, in the stressful context of a dispute, they rely only on their memory of the conversation, the strength of their position and the accuracy of their recollections are greatly reduced.

If parents follow every significant phone conversation and meeting with a letter to the school detailing their understanding of the agreements or disagreements discussed, they will have an even more convincing piece of evidence to rely on in the master file. Furthermore, **follow-up letters can be a valuable means of avoiding conflict in the future.** When parents allow a school to review in writing their impressions of a verbal discussion, the school is able to respond and clarify their position if they need to and thus avoid miscommunications that might have occurred before those miscommunications turn into problems. This strategy spares the parents and the school the energy they might spend arguing, and more importantly, this strategy spares the student the stress of being caught between conflicting demands and expectations.

Communicating with Schools

Communicate Effectively

In the educational survey created in preparation for this handbook, parents were asked to rate the degree to which they felt that the burden was on them to educate their child's school as to the nature of BTHS. Not surprisingly, nearly 100% of the respondents answered the question with a 5 out of 5, saying that the burden was fully on them to educate the school about BTHS. The next question asked parents to rate the degree of their success in educating their child's school as to the nature of BTHS. Three quarters of the respondents rated their degree of success a 4 or 5 out of 5, a statistic that suggests that parents are already very good at communicating with educators and that educators are often open to learning about the special needs of individual children. Still, the guidelines below might offer parents some helpful tips and strategies.

A good rule for all meetings and correspondences with teachers and administrators is **to keep it simple**. Try to remember that teachers usually work at 110% capacity and that school administrators are often responding to many significant challenges at the same time. If parents can simplify their issues to one or two clear and essential points, they will make it easier for the school to respond positively to their concerns.

Furthermore, parents cannot be effective advocates for their child if they are perceived by the school as being a problem parent. Throughout any letter and throughout any meeting, parents should use a calm tone and remember that they are working *with the school* to educate their child, not against the school in an adversarial relationship. **If a negative and angry relationship develops between the parents and the school, everyone will suffer, but the student will suffer the most because he will not receive the care he needs at school.** Even when parents believe that the school has acted unfairly towards their son, they must try to avoid blaming the teachers or administrators directly. If teachers and administrators feel blamed for mistakes, they will dig in their heels on issues, and they will not make adjustments.

Parents should avoid making demands even when they see a course of action that the school should take with regards to their child. Educators are professionals, and it is not their job to answer directly to parents. The best course of action is for parents to know their rights, their child's rights, and their child's needs and then to calmly work with educators towards the best solution for the student. BSF parents especially should know that they are not alone and that they can contact any of the BSF advisors (see Section VII) for help before disagreements turn into ugly conflicts.

Parents should keep in mind that for the most part, teachers and administrators of schools are good people who have every desire to do what is best for their students. There are very few teachers in the world who would knowingly tolerate a situation that could hurt a child physically or emotionally. Parents should remember that teachers often have so many students in class

that it is difficult to remember the needs of each and every individual child. If they are willing to help educators learn about the nature of Barth syndrome as well as about the particular needs of their child, parents can help teachers be better teachers for their children.

Before a parent communicates with a teacher or school administrator about an incident that occurred in school, the following rule should be kept in mind: **Parents do not see clearly what happens in the classroom and teachers do not see clearly what happens at home.** Parents and educators can best help the student by working together to discover facts and share perspectives without blame, without demands, and without anger.

The educational survey gathered some hopeful statistics regarding how schools have responded to the needs of students with Barth syndrome (BTHS). When asked to rate how accommodating school administrators have been regarding the special needs of their children, 75% of the parents gave the administrators a 4 or 5 out of 5, and when asked how accommodating children's teachers have been regarding the special needs of their children, over 80% of the parents answered that the teachers' were a 4 or 5 out of 5 in making accommodations. Certainly, there are too many stories of schools that fail to care properly for children with BTHS, but these numbers suggest that by and large, parents can reasonably expect that schools will make appropriate accommodations for their children.

Communicating with Schools

Identify Interests Over Positions

An essential strategy in any conflict resolution situation is the identification of interests over positions. In a conflict, the parents take one position, and the school takes another position, but as long as everyone stays focused on their respective positions, there will be no way to satisfy both parties.

If the parents decide to express *why* they hold their position, however, they might stand a better chance of clarifying to the school why the school should make an unusual or even an unprecedented accommodation for a student. Furthermore, if the parents listen to the needs and interests of the school, rather than simply to their negative answer, they will be far less angry and far more likely to appreciate the school's position. Once both parties are working together, listening to each other, and trying to find creative solutions that suit their respective needs, the relationships stay positive, and there are few problems that cannot be resolved.

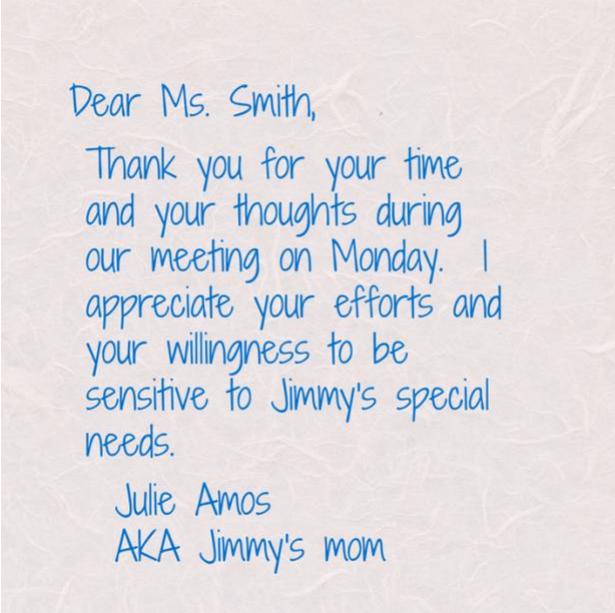
An unfortunately common problem faced by students with BTHS concerns permission to go to the bathroom. Teachers are often doubtful about students who ask to go to the bathroom more than usual, so in order to maintain control, they limit the students' permission for leaving class. An individual with BTHS, however, sometimes has needs to use the bathroom more regularly than his peers. After their child comes home, upset that he was not allowed to use the bathroom when he needed it, parents would do well to clarify for the teacher their son's needs and validate the teacher's perspective as well before they work together to find a solution to the problem.

Another common problem faced by students with BTHS concerns what activity the school offers a student who is excused from physical education or who cannot play with his peers on the playground. When a school decides to have a boy in a wheelchair sit outside and watch his friends play at recess, the parents need to help the school find a more appropriate solution by sharing their own interests for the use of their child's time and by listening to the school's interests for the supervision of the students.

Communicating with Schools

Show Appreciation

After every substantial meeting or phone conversation with teachers or school administrators, parents should be kind enough to express appreciation for the time that they have been given. Even after conversations that do not go as well as parents might have hoped, it is good to remember that the educators in the conversation either arrived at school early, stayed late, or simply used time in the school day that might have used in other productive ways. In addition to writing a follow-up note that clarifies a parent's understandings of meetings (discussed above under "Document Everything"), parents should follow formal meetings with thank you notes to the participants. These notes do not have to be long and developed. Unless you have the urge to write a more extended message, a simple, short, and nice note is all that is necessary:



Dear Ms. Smith,
Thank you for your time
and your thoughts during
our meeting on Monday. I
appreciate your efforts and
your willingness to be
sensitive to Jimmy's special
needs.
Julie Amos
AKA Jimmy's mom

If parents actually do appreciate the help they have received from a teacher or from an administrator, they have all the more reason to write a note or make a phone call or simply say something to the individual's supervisor in the school.

Communicating with Schools

Prepare for Adversity

If parents are able to communicate effectively and if the school personnel are caring professionals, parents and educators will usually be able to resolve disputes informally and comfortably. Nevertheless, when parents see a problem in their child's education, they need to prepare for a possible dispute. If the school is ultimately willing to make the adjustments the parents ask for, then the preparation was simply insurance; if the school decides to fight the parents on the issue, however, the parents will be ready for the next step.

When parents are facing a potential conflict with the school, their master file (see Section V) will be a major asset to them because it will have objective evidence speaking to the needs of their child. In addition to making sure that the master file is in order, parents might benefit greatly from reading chapters 21-26 in the Pam and Pete Wright book *From Emotions to Advocacy*. These chapters describe in detail the successful strategies for dealing with adversity when parents have to face off against a school.

Most importantly, however, parents should seek help as early as possible and certainly before the conflict begins to weaken (or worsen) the relationship between themselves and the school.

Communicating with Schools

Control Emotions

This point has been made already several times, but it is important enough to make note of one more time. One of the biggest *disadvantages* that parents have in the advocacy of their children is their emotions. Professional educators will rarely get angry because even though they are dedicated professionals, they simply have less invested in any given decision than do the student and his parents. Once parents give way to their anger in a meeting or in a letter, they immediately reduce their chances of successfully advocating for their child. Imagine the following scenario:

A student with Barth syndrome in a 6th grade public school, has missed several days of school recently because he has not been feeling well. Despite his exhaustion, he has asked his parents to take him into school for his last period English class and so he could see some of his friends on the bus ride home. When he comes in the house later, he is depressed and refuses to talk. He finally tells his parents at dinner that his teacher said to him in front of his classmates that since he had missed so many classes, he should miss the discussion today to sit outside the classroom in the hall to make up the quizzes he had missed. He has an IEP that specifies that he will be allowed to use a computer to type his responses because he cannot sustain handwriting for long without his hand becoming painfully tired. His computer, however, has a virus and is being fixed, so he did not have his computer with him.

His teacher said, *“Well, you are allowed to use a computer, but you are not allowed to simply miss the quizzes given in this class. If you don’t have your computer, you’ll just have to handwrite like everyone else in the class. Please sit outside and let us know when you are done.”*

He was able to write for 5 minutes before his hand ached. He sat in the hall and tried to write a few more times until the class ended. He knew he had failed the three quizzes, and he felt entirely defeated.

“I should never have gone into school today,” he said.

At this point, any parent (any decent person!) should be ready to explode in anger. This teacher not only had been terribly cruel, but also had clearly violated the student’s rights as they are protected by federal law. It would be understandable if the parents were in the principal’s office *screaming* at 8:00 am the next morning, demanding that apologies be made and that disciplinary measures be taken against the teacher. Such a tactic, however, will only lead the principal to consider first how to protect the teacher from irate parents.

Consider, on the other hand, the following course of action on the part of the parents:

They assure the child that he has been unfairly treated and that they will speak to his school about the matter first thing in the morning. When he goes to bed, the parents vent their anger to each other, to friends, and to the Barth Syndrome Foundation Listserv. They let off a lot of steam and hurt in safe ways. Then, when their anger subsides a little bit, they use their energy to write a calm letter to the principal describing their version of the events in school that day as well as their child's reaction. **They leave out any references to their incredible anger.** They refer to their student's IEP and ask the principal to look into the incident. They write a letter to ask if it would be possible for their son to receive an apology for his treatment, and they ask if the principal could offer assurances that the child will not have to suffer such treatment again. The next morning, they hand deliver the letter directly to the principal and politely ask her to give them a response as soon as she is able, for the matter is serious and important to them. They thank the principal for her time and leave the school, allowing her to read the letter at her leisure.

Such a tactic gives the parents the greatest chance of winning the sympathy of the principal. By stating the facts clearly and by leaving their anger out of their communications with the school, the parents keep the principal from going into defensive mode. Furthermore, by not attacking the teacher, the parents also allow for him to learn that his treatment of the child was unacceptable. Possibly, the teacher will come to understand the nature of Barth syndrome better after the incident. Possibly, he will be made a better teacher from what he learns. These are certainly best-case scenarios, but what is certain is that if the teacher feels attacked, he will do little but defend himself. If he feels the need to defend himself, he will not be able to listen to the other side of the story, and he will not learn anything from the incident. And the student will be the one most hurt if this is the case.

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 2nd 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⁺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 US

Reggio Emilia Schools

 Five Facts about Reggio Emilia

 North American Reggio Emilia Alliance

Traditional Public School Resources

 EDfacts 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

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.

Barth Syndrome Foundation Care Plan for School Age Children
<https://www.barthsyndrome.org/barthsyndrome/familyresources/toolsforschool/>

What is Barth Syndrome



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



Barth Syndrome Foundation Care Plan for School Age Children

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