



Barth Syndrome Foundation

www.barthsyndrome.org

ADVOCACY

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Building the skills of BSF

The Barth Syndrome Foundation recognizes the need for parental-advocacy on the behalf of those affected by Barth syndrome. Our commitment to those affected by Barth syndrome serves as a focal point for all programs. In this section you will learn about the initiatives of BSF to assist you in becoming an effective advocate for your child.

Each Board member has a specific area where we focus. By delegation of these programs each member is able to focus on specific needs of the group. We are constantly seeking resources to assist us in ways to become better informed and opportunities to build our skills for this organization. Each of our programs are centered around our desire to improve the lives of those who have Barth syndrome. The programs fall into five primary categories:

1. Awareness
2. Progression and Succession of BSF
3. Family support
4. Science and Medicine
5. Development

Programs for these specific areas are continually evolving as BSF grows. We look to our members to provide us with for a guideline in each of the aforementioned areas.

Development for each of the program goals are enhanced by outreach to other model organizations, professionals and expert advisors. Building the existing skills of each BSF board member is crucial to the future of this organization. We are able to stay on task by:

- Holding monthly committee meetings keeping us accountable to fellow board members for progress
- Holding quarterly board meetings (Posts of those minutes can be found on the BSF website); holding us accountable to our constituency for maintaining progress
- Affiliate with organizations of like-minded focus such as:
 - Genetic Alliance
 - United Mitochondrial Disease Foundation
 - American Heart Association
 - National Organization of Rare Disorders
 - National Heart, Lung and Blood Institute
 - Office of Rare Disorders
 - National Institute of Neurological Disorders and Stroke

BSF is always seeking out ways to expand the base of our expert advisors. When expanding upon a program we seek out qualified professionals who have expertise and skills in each of the program specific

areas. One such example of this commitment to quality is the assembly of world-class scientists on our Scientific Medical Advisory Board.

Our BSF newsletter, listserv and monthly updates to our members serve as a resource tool to share current information about BSF, related topics and posts about recent scientific breakthroughs. BSF is committed building skills and programs for those we serve. We encourage and support participation of our members. It is the goal that through education, encouragement and development of programs BSF will grow the community of involved members.

Committees and sub-committees expose members to the mission minded focus of each program. The future of BSF depends on the involvement of our constituency. Growth of the group through expert advisors and family members is fostered and continually encouraged. Each of the program goals have several initiatives that all members can take a part in to ensure the future of this group.

BSF's mission and vision is based upon concerns shared by all of our families.

Vision Statement:

Today, Barth Syndrome is a rarely understood, frequently fatal, genetic disorder affecting boys. The Barth Syndrome Foundation's vision is a world in which not one more child will suffer or perish from this condition.

Mission Statement:

The Barth Syndrome Foundation's mission is to guide the search for a cure, to educate and support physicians and to create a caring community for affected families.

We value the input of our family members, friends and professionals who support our group. Without their input our organization would not evolve. It is particularly important for us to hear about our members interests, needs and strengths. This assists us in seeking out a wider network of support for our group. Through contact with our members we are able to learn about coping strategies that may have a positive impact on other members. Keeping first in mind, those affected by Barth syndrome and being receptive to how others would like to approach helping those affected by Barth syndrome keeps the greater vision of BSF on track.

Knowing our members concerns:

The BSF registry serves as a resource for a comprehensive base of knowledge about those affected by Barth syndrome. The registry reflects the medical history, social issues and pedigree of those who have Barth syndrome. Because Barth syndrome affects so few individuals the collaborative effort to share experience with this disorder serves as a base for the group as a whole.

As BSF grows the needs are becoming more fully realized of the individual members and reflection of how these similar issues relate to the group as a whole. Being an advocate for our members requires tenacity and perseverance. Through our registry we are able to learn how best to support our members through identification of their needs.

Other tools such as the listserv serve as a compass point for the group. Encouraging dialog between families, clinicians, scientists, educators and therapists provides a balance for understanding the needs of our group.

Building the Skills of BSF Families:

One in ten people are affected by a rare genetic condition. It takes an average of three to five years to obtain a diagnosis of a rare disorder¹. Most of our families are all too aware of this statistic. The average time reported for an accurate diagnosis of Barth syndrome is three years². Currently BSF supports 49 individuals and families living with Barth syndrome around the world.³ We are aware of at least 150 individuals who have Barth syndrome globally. While this is a small number it is suspected that there are

more individuals who have Barth syndrome but have not been diagnosed. We also support around 50 families who have lost children due to Barth syndrome.

BSF is committed to assisting our members in becoming effective advocates for their child we have and are equally committed to promote awareness about our group and our desire to support all affected by Barth syndrome around the world. More often than not our members are miles apart from one another. The distance between members makes the Internet the ideal forum for family support.

BSF recognizes the need for our family members to be educated about the disorder that affects their respective child as well as being empowered with the tools to improve their child's life. We understand that each family came to know Barth syndrome not by choice but by circumstance.

Become an advocate for your child⁴

1. **Targeting:** The process of identifying individual or family needs and the service agencies, if any, responsible to address these needs.
 - a. Consider all possible needs. You must first identify when a problem exists. As your child's advocate you must ask yourself this question:
 - i. Who else would be more appropriate than you to deal with a problem your child may be having?
 1. The answer is no one!
 - b. If you feel your child is not receiving the services he requires you also must ask yourself several questions.
 - i. Are you satisfied with the way your son is receiving services or being treated?
 - ii. What specifically is needed to help? Now? In the future?
 - c. When targeting, it is important to consider all of your son's possible needs: Medical, self-help, social, recreational, educational, future living arrangement, support, financial needs.
 - d. Once you have identified what it is your son needs, make a list of those areas and things that would improve his life. Prioritize those items.
 - e. Write down all of the questions you have about what services he needs. This is the time wherein you decide whether or not you are satisfied with how your son progressing with Barth syndrome and what specifically is needed to help his quality of life improve. It is a time in which you seek out support and advice to help identify and obtain needed services.
2. **Preparing:** The process of preparing to participate with service professionals (physicians, educators, physical therapists, etc.) in decision making sessions on how best to meet identified needs.
 - a. You have identified the problem, the desired solution and the parties involved. Now you begin to gather the information and carefully consider the approach or strategies and the skills necessary to begin your action. The preparation phase of the advocacy cycle is probably the most important. The following questions need to be answered:
 - i. What is the problem?
 - ii. Why does the problem exist?
 - iii. What or who is the target to help me solve the concerns I have for my child?
 - iv. What action strategies should be considered?
 - v. What is the desired outcome?
 - b. This is the time when you learn all the information needed to communicate with professionals or other decision makers. It is also a time to become familiar with the laws pertaining to rights, insurance benefits, educational choices and healthcare options. You have documented all the information necessary to make your case.
 - c. Remember accurate, organized record keeping is one of the most important factors to keep in mind. It is a way to organize vital information, medical records, test results, lab tests, diagnostic records, school records, etc. Take files along to meetings so that officials will be aware of all relevant background information. A file also provides information to professionals when a new service is started or if your son changes physicians. Keep copies of every letter, correspondence you write and you receive, copies of reports, notes you take at meetings and assessment results.

- d. You now decide what approach you are going to take. Action can involve any of the following: a letter, telephone call speaking directly to a person or persons targeted, speaking at a public hearing such as a school board, etc. The type of approach obviously depends on the issue, the degree of resistance, and the level of change desired. Skills involved include: ability to communicate clearly, assertively, and persistently. The ability to persuade, convince, negotiate, and compromise when necessary. Ability to evaluate your own plan and progress and make necessary revisions to achieve the desired outcome.
 - e. There are several steps and considerations to take in preparing for your contacts:
 - i. Remember you are building and maintaining good relationships with the persons with whom you are working. Practice through role playing.
 - ii. Come prepared to be POSITIVE, leave feelings of resentment or defensiveness at home. Don't allow yourself to be categorized as an irrational parent.
 - iii. Get to know agency personnel, school board members, the school psychologist, legislators, insurance commissioners etc. Find out their names, addresses and telephone numbers so that you may contact them to seek help and information. It is important to follow the chain of command. It is important not to become known as a pest. You want those you are approaching to improve your child's life to understand that you have followed the chain of command to get to each respective level. For example, don't go to the Superintendent of the school board on an issue that could be resolved at the teacher's level.
 - iv. Know your child's rights prior to requesting assistance from an agency.
 - v. Be aware if the agency's services are offered on a mandatory or a voluntary basis. Does your child meet the eligibility criteria? What documentation should you have to substantiate your request for service. What is the agency's application process? What is the appeal process?
3. **Influencing Decision Makers:** The process of influencing decision makers within service agencies to adopt the parental-advocate's desired approaches for addressing individual and family needs.
- a. The most important things needed by advocates are good communications skills. It is just as important to know HOW to say something as it is to know what to say. It is also important to know when to LISTEN. Having good communication includes give and take and knowing how to develop empathy, i.e., to see the issues from the agency person's perspective. It also includes being assertive, as expressed through eye contact, posture, facial expressions, timing, and voice tone, which communicates seriousness of intent. Remember aggressive behavior puts people off assertive behavior gets things done. Always keep in mind there is a thin line between assertive and aggressive behavior. There are several ways to do effective advocacy: telephone, letter writing or face-to-face.
 - i. **Advocacy through the telephone:** The telephone is the easiest, most effective advocacy tool to advocate. The following are some suggestions for using telephone advocacy:
 - 1. Always have a note-book, pad of paper, pen at hand when you make the phone call. Write down the date, time and the number you are calling and the person you are trying to reach. Also keep track of the amount of time you are on hold, the number of times you have been transferred, the number and names of the people with whom you have spoken. KEEP THOROUGH NOTES!
 - 2. Find out who you are speaking with in order to avoid repeating your story.
 - 3. Identify yourself and specifically state the purpose of your call
 - 4. Be prepared. Have records available and encourage immediate action.
 - 5. Be goal oriented. Know exactly the purpose of your call and stay on that purpose until it has been achieved.
 - 6. Be assertive, yet positive and polite. One thing is for certain, if you insult the person from whom you are seeking assistance it is likely you will not receive it and your child will suffer.
 - 7. If you're unsatisfied, ask who else you may speak to. Ask to speak to a supervisor, or director.
 - 8. Communicate a sense of teamwork. "How may we make that happen"

9. Know exactly what, when, and where your next steps are before hanging up.
 10. Confirm name, title, address, phone number of the person with whom you have been speaking.
 11. Send a follow up letter, which thanks the individual and confirms the agreements which, have been reached and the follow up and who will be doing what and what are the next steps.
- ii. **Advocacy through Letter Writing:** letter writing is another tool for advocacy:
1. It is a way to reach otherwise unreachable people.
 2. Document important interactions such as a request for service, or a meeting, or expressing a complaint, filing for due process hearing or appeal.
 3. Document time lines and deadlines.
 4. Build accountability. Letters create pressure for a written response. If the person whom you write fails to respond within a reasonable time frame or refuses to consider your request, write again with a copy of your original letter attached. If you still do not receive an affirmative response, write to their supervisor, or the director of the agency with copies of your previous letters attached and continue this chain of letters until you get an affirmative response or have exhausted the agency's levels of administrative ladder, i.e., have written at least two letters to the chief administrator and chairperson of the agency's board of directors. Your final recourse, aside from court action which is time consuming and costly, is to contact the agency's funding sources and perhaps local legislators or council members. Be sure to attach copies of all previous letters when contacting each person in a "paper trail" communication sequence.
- iii. **Advocacy through Face-to-Face Meetings:** Face-to-face meetings is another strategy for advocacy. The most important thing needed is good communication skills. It is important to be aware of your personal presentation when meeting in person. Personal presentation includes body postures, facial expressions, dress, and interaction style. Most agency personnel react best to people who look and act like other agency personnel, i.e., people who dress neatly and control their outward emotional reactions. Being an advocate does not demand an artificial presentation style, but we all have within us the ability to produce a variety of effects, to transmit many different messages. Non-functional behaviors are not effective: Any type of temper tantrum, emotionalism, screaming, rudeness, empty threats, name calling, treating someone as your enemy, endless complaints, outrageous demands, trying to resolve too many issues simultaneously, trying to resolve an issue when a crucial person is absent. It is important when advocating to communicate a sense of self-confidence, personal competence, and determination. Be prepared with well-organized reports, documentation and questions in advance. Know what it is you want. While at the meeting, it is important that you take notes. Note taking is an advocacy tool.
1. Note taking is a tool that provides a written record of what happened at a meeting or during a phone conversation. Note taking signifies to others that you are an active participant in what is occurring. When you are taking notes people around you are more likely to feel accountable. They become more productive and responsible and pay more attention to you. Take notes at every meeting, conference, that you attend and of every phone call that you make so that you can keep a record and document everything.
 - a. Helpful hints on note taking:
 - i. At the beginning of your notes for a meeting list the names and roles of all those present, and list the dated, place, and time of the meeting. State the primary purpose of the meeting in one or two sentences.
 - ii. Group the information into blocks according to topic so it will be organized for you when you reread your notes.

- iii. Use an outline format
 - iv. Write key words and abbreviations rather than long sentences. The fewer the words written, the more time available for thinking and actively participating.
 - v. Leave space along the left-hand margin for filling in answers to questions and for clarifying points, which are not initially understood. Ask the speaker to clarify what is being said.
 - vi. Use a colored felt tip pen to underline notes.
 - vii. It is sometimes helpful to organize information according to the questions asked and the various responses of each person at the meeting.
 - viii. Before you leave a meeting, review your notes, be sure they are dated, and ask for any clarification that is needed.
 - ix. File your notes in a home file or notebook.
4. **Following Up:** The process of checking to be certain that the agreements made by parental-advocates and service professionals are carried out.
- a. It's up to you as the advocate to check and see if the services, which you worked hard for your child to get are being delivered. Do they meet the specifications, which were stated during decision-making meetings? This is the time that involves an assessment of the services, which are being received to assure quality outcomes. The mere fact that an agency or an individual agrees to provide a needed service does not always mean that the service will be provided in the promised manner. You should periodically visit the services which are being delivered to see if they meet the specifications which were stated during decision-making meetings and to make sure both sides are living up to the agreed upon plan. Always bring along a note pad and your copy of the program plan.

Becoming the “Expert Parent”

When initially told that our child is ill we all face the similar emotions in varied degree. No one comes to parenthood equipped to care for a child with special needs. Even physicians find themselves feeling helpless when confronted with the knowledge their child is ill. All parents have the joyful expectation of bearing a healthy child. As parents we have the determination of a dragon-slayer to do all we can for our children but knowing that special skills are now required to care for this child is often times quite intimidating. A new language of medical terms are now being introduced. Difficult decisions are put upon our shoulders. After the initial cycle of working through the emotional shock we come to the point of reality that our child has a chronic illness. Our BSF parents have reported an average of three years to obtain an accurate diagnosis. During that time families struggle to understand why and what is happening to their child. By the time a child receives a diagnosis of Barth syndrome families have expressed they almost felt a sense of relief to finally have a “name” to the disorder their child has been battling. Sometimes families obtain a diagnosis almost immediately. Regardless of where a parent is in this process the need for education is universal. The fact remains; regardless of life-skill preparation it is now left up to the parent to become an expert in Barth syndrome and all the components involved therein.

Recently initiatives have begun to assist the needs of people who are affected by chronic disease by implementing ways to empower individuals to improve services and care.⁵ Recognizing the varied experience of people with chronic disease in using health services it has been noted that better services need to be provided in giving advice and information and addressing questions in dealing day-to-day with a chronic disease. BSF is committed to assist families in becoming the best advocate for their child and thereby reducing the costs of healthcare. Statistics have proven that individuals who are informed about the condition that affects them, in our case Barth syndrome, affects the reduction in quantity of medications used, reduction in symptom severity, improved social function and overall improvement in quality of life.

Giving our members the skills to manage their child's illness can have a major beneficial impact on their lives. Providing knowledge and empowering our members to use the experience of their child's illness,

and that of BSF peers, can help and support our members to develop the confidence necessary to become active in the parental management of the children affected with Barth syndrome.

According to a study conducted by the Arthritis Self-Management Course (ASMC) by Kate Lorig and her colleagues at Stanford University a reduction in physician visits of 42 – 44% can be achieved, and significant cost savings made by using information gleaned by association with volunteer based groups such as BSF, rather contacting a health professionals on every detail encountered in the management of care. This study does not suggest groups such as BSF take the place of healthcare professionals moreover it suggests that increased knowledge provides the caregiver with the ability to discern when it is necessary to contact a physician for access to care as opposed to management of care at home. There has been strong evidence that some of the people involved in groups such as BSF enhances the quality of doctor/patient relationships. Those who are informed about the condition affecting them report improved communication with physicians and other health care providers. Collectively these studies suggest that, rather than becoming more demanding, “expert” patients are in general more likely to make more effective use of available services.

1. Parental-management has real value

- ❖ Parental-management helps those affected with a long-term medical condition to take responsibility for their child’s life. It addresses the “whole person” and not just the condition. It is about people with chronic disorders such as Barth syndrome becoming able to gain greater independence and empowering them to assist their child in gaining greater independence and live a better quality of life and confidence in making decisions.
 - ❖ Parental management could help reduce visits to physicians and better equip parents to manage their child’s condition with appropriate professional support.
- a. The need to become an “expert” parent is important to our members
 - i. It is particularly important to reach those members who have difficulty in gaining access to services:
 - ii. Members living in rural locations
 - iii. Members whose ethnicity, culture or language may present barriers
 - iv. Members with low education or literacy levels
 - v. Members who might not see themselves as able to be partners in their child’s care
 - b. The right messages about parental management need to be sent
 - i. Information should be appropriate and accessible. Delivery tools include
 1. List-serve
 2. BSF Newsletter
 3. BSF Website
 4. Access to informed expert care providers
 5. BSF Family/Scientific Conference
 - c. Partnerships between Parents/Patients and professionals are essential
 - i. Education about the concept of parental-management is important throughout all stages of empowering our families.
 1. Undiagnosed (Searching for a diagnosis for a child)
 - a. Direct new contact to http://www.barthsyndrome.org/diagnose_barth_syndrome.html for access to expert guidance on diagnosis and quality of diagnosis
 2. Newly diagnosed
 - a. New family packet including but not limited to “Practical Tips on Being a Barth Parent”
http://www.barthsyndrome.org/PRACTICAL_TIPS_FOR_BARTH_PARENTS.pdf
 3. BSF members
 - a. Involvement in Listserv
 - b. Mailing list for BSF Newsletter

- c. Email ring for BSF monthly updates
 - 4. Seasoned BSF members
 - a. Greater involvement in the execution of program implementation for our members
- 2. Access to information about Barth syndrome is offered from the BSF website. Availing our members with resource and journal articles, ways to diagnose Barth syndrome and information on a variety of ways to become better informed about the disorder that affects their child. Continued development of our programs are required to keep our members as informed and involved in the process of understanding more about Barth syndrome
 - d. BSF's goal is to assist in the vital role in creating the partnership of our members as "expert parents" and the healthcare providers of their children
 - e. BSF has demonstrated the innovation and development of programs to assist our members (scientific and families)
 - f. Because BSF is a parent- scientific based volunteer group we have a good understanding of, and commitment to, assuring the constant of our programs
 - g. Through BSF we offer our families and attending physicians access to a large pool of information BSF offers access for professional-to-professional partnerships as well as family-to-family involvement
 - h. BSF offers effective networks and partnerships to support our families.
 - i. Through our commitment to access of quality information we offer every family the ability to better understand the disorder that affects their child regardless of socio-economic basis. Our computer-donation program avails access to this information for families who otherwise would be isolated.

3. BSF assistance

- a. Information about Barth syndrome and access to information is offered to all those affected by this disorder
- b. BSF recruits involvement from "Experts" in a variety of areas to assist our members
 - i. Education
 - ii. Neurology
 - iii. Cardiology
 - iv. Genetics
 - v. Psycho-Social
- c. Through our List-serve we offer access to training, encouragement and access to evolving research
- d. Joint work with other groups and voluntary lay advocacy groups make our programs widely known within all sections of the community
 - i. Genetic Alliance
 - ii. American Heart Association
 - iii. NORD
 - iv. UMDF
- e. BSF does not offer medical advice to the care of a child, nor does BSF endorse any medical advice offered through any forum offered by BSF. Moreover BSF offers access to information to empower our members to become "expert" partners in the care and management of their child's condition.

4. BSF Understands

- a. The expertise of our families as a largely untapped resource in the effective management of their child's chronic illness
- b. Our families must become an integral part of the design and functioning of BSF programs. Increased involvement of our members is crucial in ensuring the future of the evolving process of addressing our members concerns. Ways to become more involved in this process:
- c. Participation in the BSF Registry

- d. Increased involvement in BSF programs
- e. Remaining informed about Barth syndrome and participation in sharing personal experiences in addressing issues pertaining to the care of a child with Barth syndrome that have been successful as well as those that have not been successful
- f. Member involvement serves as the principal route for creating a new generation of “expert” patients that can evolve to tutor new families in the steps required to become an effective advocate for their child.
- g. By increasing involvement of our scientific professionals and family members BSF is better able to insure the sustained evolution of programs that are now in place and the as well as the future of BSF
- h. Recognizing the need for a “whole child” approach BSF offers forums for new provisions in the management of care in a variety of areas are integrated with the work of providers in a variety of areas such as:
 - i. Education
 - ii. Neurology
 - iii. Cardiology
 - iv. Genetics
 - v. Psycho-Social
- i. Feedback, evaluation and assessment of outcome of BSF programs are sought out as a routine part of the operation and development of program initiatives.

5. Things you can do

- a. BSF parents can and should expect to become “experts” in their child’s condition and effective partners in their child’s overall management in education, healthcare and general well-being
- b. Take advantage of the programs offered by BSF and become more involved in the evolving process of the execution of these programs. By doing this you will develop a greater confidence, knowledge and skills to better manage your child’s condition, thereby gain a greater measure of control and independence to enhance the quality of your child’s life
- c. Recognize and express barriers you find in the evolution of becoming an “expert” parent. You may not be alone in facing these barriers and partnership with other family members may better assist you and future members in effective ways to overcome these obstacles
- d. Encourage your child’s healthcare providers, educators, therapists to contact BSF “expert” advisors in the management of care for your child. Expanded involvement will better equip your child’s provider of care in making informed decisions and general Barth syndrome awareness in approach to the management of care

¹ National Organization of Rare Disorders

² BSF 2000 Survey

³ BSF Registry

⁴ Mental Health Association of MD, Inc.

⁵ The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century