

## WELCOME, New Barth Family Member!

### The following is very important; please read this entire message!!

For each new family who has joined BSF and also for our more seasoned families who have been members for sometime, below you will find a list of Listserv Rules that should be followed by **all** members!

New members will soon realize how valuable the BSF Family Listserv is and how much information is shared and gained by all that contribute.

### Please read each article below!

If you have any questions or comments about the Listserv rules please [contact](#) us. Thank You!

## RULES

1. Respect others privacy and do not forward messages from the Barth Listserv to anyone. This is a private listserv for members only! If you have a family member or friend who would like to become a member, please feel free to have them [contact](#) us to join.
2. Do not forward messages to your child's physician. These messages could be taken out of context. If your physician is interested in knowing more about BTHS or be involved with the group, the BSF Doctors Listserv is an ideal option. There are fewer messages on this listserv. This is a professional peer-to-peer list. No parents are permitted on this list. This is the perfect forum to exchange clinical ideas or collaborative research opportunities.
3. Refrain from making diagnostic recommendations or giving medical advice over the listserv. Please note all information provided on the listserv is for informational purposes only. Nothing posted on the listserv is meant to serve as a diagnosis or recommended treatment. Only the physician treating the individual can truly make a diagnostic judgment to recommend treatment.
4. Attachments cannot be posted over the listserv. These sometimes contain viruses and also require additional administrative response. If you have a document that is relevant to a topic on the listserv please [contact](#) Michael Hope and he can set up a link to the document.
5. Refrain from personal comments posted over the listserv that would be best posted on an individual basis. Refrain from sending "Way to go" and "Me too" comments. Those should be posted on an individual basis. There are physicians and scientists who volunteer time on the listserv. Please be courteous of their time and attention. If there is a post pertaining to the care of a child please feel free to post the concern over the listserv.
6. Sending chain type emails or jokes to the listserv is not acceptable! Please remember this listserv is used for Barth syndrome information only. If it does not relate or pertain to Barth syndrome, please refrain from making the post.
7. Refrain from sending any religious or political messages or comments to the listserv. Speaking about religious beliefs could be great on a religious or political chat line, however when dealing with families from all over the world that practice a variety of religious doctrines this is not acceptable.
8. Refrain from making judgment calls on physicians or anyone else over the listserv. Please don't be judgmental over the listserv. If you have a strong opinion about something please feel free to share it personally with the appropriate person. BSF cannot risk the liability of slandering someone's good name or assuming to diagnose a child.
9. Please remember this listserv is archival! Every post is archived, so please refrain from making statements that you may later regret. Remember you are talking to people. In cyberspace you are not always able to hear the tone of voice, see expressions or understand how your comments will be communicated. It is easy to communicate the wrong message.

10. Go to the archives to see if there is information you are seeking. Do your homework. Every question on the listserv offers a better view of Barth syndrome. By reading the archives you may come up with a question that could enlighten the group. The listserv is the perfect place to exchange expertise with Barth syndrome. Share what you know! The archives are a wonderful resource. Take advantage of them and learn.
11. Make yourself look good online. Spell check your messages before pressing send. Proof the document you are sending for errors in grammar. Remember it goes in the archives. Check your facts. Don't state something as fact if indeed it is not.
12. **Always** properly name your message and make certain the appropriate heading is listed in the subject field. It takes time to sort through emails. Please be courteous and make it very clear what your message is about. If you catch a post that does not have a subject heading that you would like to correct with your thread please take the liberty to add a subject that you feel best describes the topic of the post.
13. Try when possible to thread messages. If you would like to make a comment on a previous post please thread that post by selecting reply. This will make navigation of the archives much easier.
14. Please post any pictures over the MSN site. To join or post pictures to the BSF MSN Photo site, please [contact](#) us.
15. Please understand if someone makes a mistake or does not follow the BSF Listserv rules, they are first warned behind the scenes unless a message is potentially dangerous to future viewers then it will be threaded. On the second warning the person will be warned openly on the listserv. The third warning will result in being removed permanently from the listserv.

Thank you for your attention to the BSF Listserv Rules. The Barth Syndrome Foundation, Inc. appreciates your cooperation!

**The Barth Syndrome Foundation, Inc.**