

Barth Syndrome Foundation Annual Confidentiality Acknowledgement and Pledge

I, _______, acknowledge that in my capacity as a volunteer or employee of the Barth Syndrome Foundation, I may see, become aware of or possess information of a private or confidential nature to BSF, families affected by Barth syndrome, researchers, physicians or donors. Any information related to the identity, health, treatments or condition of an individual or family affected by Barth syndrome should be considered private and confidential, as should any unpublished information related to research, the identity of physicians who may be treating someone affected by Barth syndrome, and any information related to donors to BSF.

I recognize that I and others working for and on behalf of BSF may have a legitimate need to know and make use of confidential or private information in the course of fulfilling our responsibilities on behalf of BSF. I also understand that I have a special obligation to protect against the inappropriate or unauthorized use or release of this information.

I pledge to use my best efforts and judgment in identifying and protecting information that might be considered private and confidential. I promise to limit my access to and use of confidential information only to that which I need to perform the tasks assigned to me by BSF. If I am uncertain, I promise to ask an officer of BSF to clarify for me whether information should be treated as confidential and under what circumstances, if any, it may legitimately be revealed or released to anyone other than an officer of BSF. Should I be asked by an officer of BSF to return or destroy all copies of confidential information I posses or have access to, I promise to do so promptly.

Signed and Acknowledged on _____

[Date]

[Please print name]

[Signature]