**Barth Syndrome Awareness Day**

**Social Media Toolkit**

April 5 is Barth Syndrome Awareness Day. We’re taking the opportunity to raise awareness about this condition – and that we are not too rare to care about.

*Ways to Support & Advocate*

* Like, share, and engage with Barth Syndrome Foundation posts on social media.
* Use and/or customize the suggested language below in your own social media posts or when you share BSF posts.
  + Use hashtags #BarthSyndromeAwareness and #NotTooRareToCare.
* Share the Barth syndrome factoid graphics posted daily on Facebook and Instagram
* For those who have “personalized story” social media graphics from Rare Disease Day, please consider sharing those again on your social media channels.
* For those who have recorded a video on the Not Too Rare to Care site, please consider sharing it again on your social media channels.
* Change your profile picture to the BSF-provided graphic below.

*Suggested Social Media Language*

Please feel free to customize the language below so it highlights your perspectives, stories, and voice.

* April 5 is #BarthSyndromeAwareness Day! Barth syndrome is a serious, progressive heart disease that affects ~300 people worldwide. The disease may be rare, but it affects [me/my son/my nephew] so to our family, it is everything. We are #NotTooRareToCare about.
* Barth syndrome is an ultra-rare, life-threatening genetic disease caused by a mutation in the TAFAZZIN gene, also called G4.5. For this reason, April 5 (4/5 in the U.S.) is #BarthSyndromeAwareness Day! #NotTooRareToCare
* Those affected by #RareDiseases need and deserve good treatment options just as much as those with more common diseases. On #BarthSyndromeAwareness Day – and every day – I advocate for our small but resilient and strong community living with this progressive ultra-rare disease. #NotTooRareToCare
* Barth syndrome is a life-threatening, genetic #RareDisease that primarily impacts males. The most common causes of death include cardiac issues (arrhythmia, heart failure) and sepsis (unable to fight lethal infections due to low white blood cell counts). This is the reality my [family/community/son] lives with every day. #BarthSyndromeAwareness #NotTooRaretoCare

