

Barth Syndrome Foundation  
Fundraising Toolkit  
Media Relations



Barth Syndrome  
Foundation

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# Media Relations

You don't have to be a seasoned public relations professional or publicist to capture the attention of editors and reporters. However, you have a better chance of getting your event "covered" with some proven methods of generating media interest. It often takes lots of friendly follow-up and persistence to break through the clutter in a newsroom. Your biggest strength is your passion and enthusiasm for – and accurate knowledge of – the importance of raising Barth syndrome research dollars.

## Research: Know Your Local Reporters and Their Beats

As with any form of communication, know your audience. Before you send a pitch letter, press release, or pick up the phone, compile an accurate media list. Find the names of editors and reporters who report on related topics, such as community, health, or science-related topics. In other words, find out their beat. You can often find their contact information (phone, fax, email) and instructions for submitting a story idea to the publication as well.

Here are some reporters most likely to cover your story:

- Daily newspapers – Features Editor, Calendar Editor, Health Reporter, Metro Desk
- Weekly newspapers - Features Editor, Calendar Editor, Health Reporter, Metro Desk
- Television stations – Assignment Desk, News Desk or Health Reporter
- Radio news station – News Desk

## Pitch: Tell Your Story

A "pitch" is used to make an editor or a reporter take an interest in your story. It can take the form of a one-page letter or a phone call. The two most important things to remember: keep it brief (it's a teaser) and give them a compelling reason why they should cover your story. For instance, why would your event or your personal story be of interest to their readers or viewers? Why are you hosting a fundraising event? At the end of the letter or conversation, offer to send them more information in the form of a press release. We have included a **Sample Pitch Letter** to help you get started.

## Talking Points

### About BSF

BSF is the only worldwide volunteer organization dedicated to saving lives through education, advances in treatment and pursuit of a cure for Barth syndrome. Our Foundation strives to accelerate progress through collaboration between families and scientists.

## What BSF Does

- **Fund high-impact research:** funds research projects identified by the Scientific Advisory Board as strategic priorities for advancing the development of possible treatments for Barth syndrome.
- **Provide critical resources:** creates, collects, stores, and distributes the information and biological materials that researchers need in order to study Barth syndrome and develop new treatments.
- **Connect researchers:** connects physicians and scientists from across the world to share information and collaborate on projects they can only achieve together.
- **Support families:** help patients and families from initial diagnosis and beyond.

## About Barth Syndrome

Barth syndrome (BTSH) is a life-threatening, X-linked genetic disorder, primarily affecting males. It is caused by a mutation in the *tafazzin* gene (TAZ), resulting in an inborn error of lipid metabolism. Barth syndrome is a genetic condition, usually transmitted from mother to son. A mother who is a carrier of a Barth syndrome mutation shows no signs or symptoms of this disorder herself.

### Barth Syndrome Facts:

- **Cardiomyopathy**  
A weak heart muscle usually associated with enlargement of the heart.
- **Neutropenia (Chronic, Cyclic, or Intermittent)**  
A reduction in “neutrophils,” a type of white blood cell that is most important for fighting bacterial infections. Neutropenia may predispose an individual to mouth ulcers, fevers and bacterial infections such as bacterial pneumonia and skin abscesses.
- **Underdeveloped Skeletal Musculature and Muscle Weakness**  
All muscles, including the heart, have a cellular deficiency which limits their ability to produce energy. Muscle weakness and increased fatigue are characteristic findings in BTSH.
- **Growth Delay**  
During childhood most affected individuals are below-average in height and weight.
- **Exercise Intolerance**
- **Cardiolipin Abnormalities**  
A failure of BTSH mitochondria to make adequate amounts of tetralinoleoyl-cardiolipin, an essential lipid (fat-like molecule) for normal mitochondrial structure and energy.
- **3-Methylglutaconic Aciduria, Type II (MGA, Type II)**  
(Typically a 5- to 20-fold increase in an organic acid that can be measured in urine)  
A result of abnormal mitochondria (the “powerhouses” or primary energy producers in cells) function. However, there have been reports of normal levels of 3-methylglutaconic acid (3MGA) in confirmed cases of BTSH.

Historically, boys died of heart failure or infection by 3 years of age, but with improved diagnosis, appropriate medical treatment and monitoring of all symptoms, the survival rate and future of these individuals is much brighter.

## Things to Keep in Mind When Talking to the Media

### Be prepared.

- Know the five “Ws” of your event: who, what, when, where, why (and how) .
- Be familiar with a publication and its audience.
- Have BSF’s mission statement and key messages with you for reference.

### Be truthful and direct.

- Make your key points as simply and as often as possible.
- Have engaging examples or anecdotes to back up your key points. Tell your personal story.
- If you don’t have the answer to a reporter’s question, admit it and offer to get the information for the reporter as soon as possible. (Be sure to follow up!)

### Be confident and relaxed.

- You know your story and what you are doing.
- A successful interview is often a conversation, not an inquisition.

### Be sure you understand the question before you answer.

- If you’re not sure what the reporter is asking, say so.
- It’s OK to ask a reporter to back up and rephrase a question.

### Be aware of saying things “off the record”

- It doesn’t exist; what you say can be quoted.

### Never say “no comment.”

- Give a reason for why you can’t discuss certain topics or issues.
- There are many ways to give a “non-answer.” You can redirect the conversation by saying, “I can’t discuss that, but what I can tell you is that the this program is successful because...”

### Don’t be afraid to show emotion.

- This is a very emotional topic for you and your family...and for many other families out there who may really connect with your message and be inspired by your story.

### Silence, or long pauses, is OK.

- When you’ve made your point, stop speaking. Don’t feel like you have to keep talking. People often speak nervously to fill the silence, which may dilute their original, well-articulated point.

### Remember, you have control over what you say in an interview.

- The editor has ultimate control over what finally appears in print or on the air.

### Press Release:

BSF has written a **Sample Press Release**. It contains key points and messages with spaces for you to fill in and distribute to the media. It’s suitable for all types and sizes of events – from letter writing campaigns, to bake sales, to dinners. Any and every event counts and we want as many people as possible to know about it.

After you've personalized your press release, you're ready to send it to the contacts on your media list. Be mindful of publications' deadlines. In some instances, they need to be notified six weeks before the event in order to be included in the calendar listing.

### **Follow up: be friendly, yet persistent**

After you distribute your press release to your media list, be sure to follow up. Editors and reporters are typically under deadline and have a lot going on, so give them a few days to get to it. Then pursue your first-round of follow up with a call or email. We suggest that you ask if they received the release, gauge their interest in covering the story, and stress that you are available to help.

Don't be discouraged if it takes you several attempts to reach an editor or reporter. Follow up, whether it's the first round or third round, is a great opportunity to stay in a reporter's mind and build a relationship. Sometimes just a friendly, informative 30-second conversation can go a long way.

### **Press Placement**

Please send us your press release and any placement for our records.

### **Final Outcome**

Please do not be discouraged if your story does not get placed. Your efforts are still worthwhile; we appreciate all the time you've spent

## Sample Letter for Letter Writing Campaign

Date

Name

Address (city,state,zip)

Dear ,

\*Insert person's name and relation, such as "John, my 8-year-old son," was diagnosed with a rare disorder called Barth syndrome. Barth Syndrome is a rare and serious multi-symptom genetic disorder. Symptoms include: weakened and enlarged heart, an inability to fight infection, growth delay, and muscle weakness. Historically, boys with the disorder died of heart failure or infection by three years of age, but with improved diagnosis and appropriate medical treatment, the survival rate and future of these individuals is much brighter.

This has meant [insert a bit of information about your personal situation, or that of your friend/family member – multiple surgeries, relapses, or we've been lucky. Tell your story here.]

While the course of this disorder can be unpredictable, one thing is for sure: effective treatments are needed. BSF is the only organization dedicated to finding a cure for this devastating disorder.

Scientists are making great progress each day, but there is still more that needs to be done. Won't you please help by making a gift of \$ to BSF today? [It is often more effective to ask for a specific dollar amount. Remember not to ask for too little. People can always give less, but might not think to give more.] A check can be sent to: PO Box 582, Gretna, NE 68028 OR visit [www.barthysyndrome.org](http://www.barthysyndrome.org) to make a donation and to learn more about the Foundation.

I know that, with your help, we can find a cure! Thank you for supporting me.

With appreciation,

(Personally Sign)

## Pitch Letter to Reporter

[Date]

Editor or Reporter's Name  
Newspaper or other publication  
Address (City, State, Zip)

Dear \*Editor or Reporter's Name+:

I am writing to suggest a story idea to raise awareness about a rare and devastating disorder. Barth syndrome is a serious X-linked genetic disorder, primarily affecting males. It is caused by a mutation in the *tafazzin* gene (*TAZ*), resulting in an inborn error of lipid metabolism.

[Person's name and relation, such as "John, my 8-year-old son," was diagnosed with Barth syndrome in [year], and [his] life may depend on research to find new treatments. The Barth Syndrome Foundation (BSF) is the only organization dedicated to finding a cure for this devastating disorder.

On [date of event], I am hosting a [type of event] to raise awareness about Barth syndrome and to raise funds for BSF. We ask that you consider covering our event. You could help your readers gain invaluable information about Barth syndrome. You'd also be giving your readers a great way to support our efforts on behalf of BSF. Please help us in our fight against Barth syndrome.

Sincerely,

[Your name]  
[Your phone number]  
[Your email]

P.S. A press release is available upon request.



## Sample Press Release (Could be modified for pitch)

**For Immediate Release**  
September 4, 2013

**For more information, contact:**  
Shelley Bowen  
Phone: 850-273-6947  
E-mail: [info@barthsyndrome.org](mailto:info@barthsyndrome.org)

### ***NKFA & Dayton's S.W.O.R.D. Team Up for Barth Syndrome Fencing Fundraiser***

**Local father and fencing coach, Ned Kalapasev found a unique way to honor his son living with an ultra-rare disease called Barth syndrome which affects fewer than 200 individuals worldwide.**

Dayton's S.W.O.R.D. academy and the NKY Fencing Academy (NKFA) have teamed up to host the Blades Battling Barth Syndrome Open Fencing Fundraiser on Sept. 14<sup>th</sup> at the S.W.O.R.D. venue. The event kicks off at 9 am and will feature competitions in Sabre, Foil and Epee. All proceeds will benefit the Barth Syndrome Foundation.

William DeVan, owner of S.W.O.R.D., and NKFA owner Ned Kalapasev, whose young son Milosh is affected by Barth Syndrome organized the event. Barth Syndrome is a rare and serious multi-symptom genetic disorder. Symptoms include: weakened and enlarged heart, an inability to fight infection, growth delay, and muscle weakness. Historically, boys with the disorder died of heart failure or infection by three years of age, but with improved diagnosis and appropriate medical treatment, the survival rate and future of these individuals is much brighter.

Kalapasev opened the Erlanger-based NKFA in March 2011, not long after Milosh was diagnosed with Barth Syndrome and listed for a heart transplant. "Fencing is a family friendly sport, and when Milosh was healthy enough, he also attended many fencing tournaments held at S.W.O.R.D.," Kalapasev says. "Milosh's personality and his amazing life makes him instantly popular with everyone. One tournament in which I was refereeing, I was wearing Milosh in a baby carrier. While the rules of fencing state fencers must salute their opponents and referee at the beginning and ending of the bout, it was quite touching when they each gave a salute to Milosh."

When Kalapasev mentioned to DeVan his desire to hold a charity fencing tournament in honor of Milosh and to raise money and awareness for the Barth Syndrome Foundation, DeVan immediately offered to have S.W.O.R.D. host the event. Their hope is to make the Blades Battling Barth Syndrome the premier fencing event in the Midwest.

The cost for participation is \$25 for one weapon, \$40 for two and \$50 for three. There will also be t-shirts, raffle prizes and a silent auction. S.W.O.R.D. is located at 813 Leo St in Dayton. For more information about the event, please visit [www.s-w-o-r-d.com](http://www.s-w-o-r-d.com) or check it out on Facebook at <https://www.facebook.com/events/405010406264921/>. For more information about the Barth Syndrome Foundation, visit [www.barthsyndrome.org](http://www.barthsyndrome.org).

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