


# Town Hall Meeting

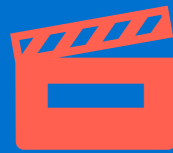


 A few housekeeping tips before we start...

 Check your speakers so you can hear us

 Having trouble? Contact Cristy Balcells  
[communications@barthsyndrome.org](mailto:communications@barthsyndrome.org)

 Submit your questions through the chat section of Go To Training Control Panel.  
Questions will be addressed at the conclusion of the meeting

 This call is being recorded. To optimize sound quality of this recording, attendees who are joining the call will be muted.

 Reach out to us from the website at [www.barthsyndrome.org](http://www.barthsyndrome.org)

Barth Syndrome  
Foundation



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# Town Hall Meeting

## Spring 2019

June 11, 2019

Shelley Bowen, Director, Family Services and Advocacy

Emily Milligan, Executive Director

Matthew Toth, PhD, Science Director

Lynda Sedefian, Executive Assistant

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*



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# Family Services

Shelley Bowen, Director, Family Services and Advocacy



*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*

# Family Services and Advocacy Update

- Care Management Toolkit
- Emergency Department Guidance
- Medical Binder
  - Medical Record Forms
  - Health History
  - Contacts
  - Laboratory Test Results
- Barth Syndrome by System
  - Function of systems primer
  - Resources to learn more (general and Barth syndrome specific)

# Emergency Department Guidance

*The local emergency department doctors are unfamiliar with Barth syndrome. I wish I had something I could just hand to the doctors that says DO THIS!*

## Diagnosis: Barth Syndrome ICD# E78.71

This patient has been diagnosed with Barth syndrome and should be triaged as soon as possible upon arrival in the emergency department, even if he does not appear to be ill. Decompensation and death may occur rapidly. Early and aggressive intervention may reduce complications and stop further deterioration or death.

Barth syndrome is a rare genetic, life-threatening disorder caused by a mutation in the tafazzin gene (TAZ, also called G4.5), resulting in an inborn error of phospholipid metabolism.

## Cardinal Characteristics of Barth Syndrome

- Cardiomyopathy
- Neutropenia
- Low Muscle Mass and Muscle Weakness
- Exercise Intolerance
- Growth Delay

## Additional Clinical Problems of Barth Syndrome

- Heart failure
- Sepsis
- Arrhythmia
- Thrombosis
- Hypoglycemia

Date:	
Patient Name:	First Last MI
Date of Birth:	
Street Address:	
City, State, Postal Code:	
Phone:	
Corresponding Documents	Medications, Allergies, Healthcare Providers, My Health History

### BARTH SYNDROME FOUNDATION

2005 Palmer Avenue #1033, Larchmont, New York 10538, Phone (914) 303-6323, Fax (518) 213-4061 [www.barthsyndrome.org](http://www.barthsyndrome.org)

Name	Date of Birth
Equipment/ Device Type	Manufacturer/ Make
Model Name/ Number	Serial Number
Date Received / Implanted	Customer Service Telephone
Doctor's Name	Doctor's Telephone
Doctor's Fax	Doctor's Email
Manufacturer Support Telephone	Website
User Name	Password
Additional Information (ie, paced rate for AICD)	

# Medical Records

*A short pencil is far more reliable than a long memory.*

### My Personal Information

My Name \_\_\_\_\_

My Address \_\_\_\_\_

Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_

Birth Date \_\_\_\_\_ Age \_\_\_\_\_ Marital Status \_\_\_\_\_

Living Will  Yes  No Healthcare POA  Yes  No Organ Donor  Yes  No

Primary Language \_\_\_\_\_

### Emergency Contact #1

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Address \_\_\_\_\_

Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_

### Emergency Contact #2

Name \_\_\_\_\_ Relationship \_\_\_\_\_

Address \_\_\_\_\_

Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_

### Emergency Contact #3

First Name \_\_\_\_\_ Last Name \_\_\_\_\_ Relationship \_\_\_\_\_

Address \_\_\_\_\_

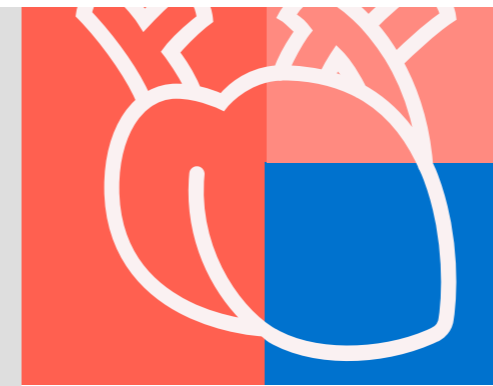
Home Phone \_\_\_\_\_ Work Phone \_\_\_\_\_ Cell Phone \_\_\_\_\_

# Contacts

*80% of the population loses 80% of their cognitive thinking in an emergency situation. You don't know if you are that person until you are in that situation. Be prepared!*

# Barth Syndrome by System

*There is so much to learn. My greatest fear is that I won't know what I don't know when I need to know it the most.*

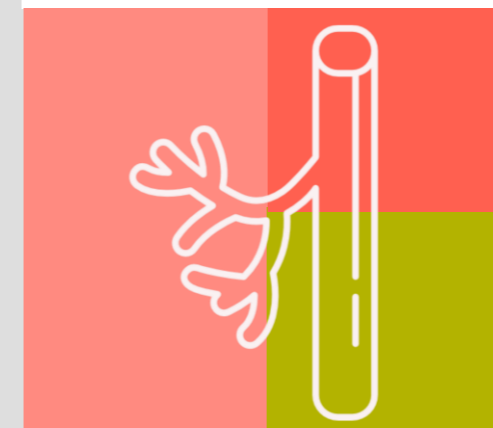
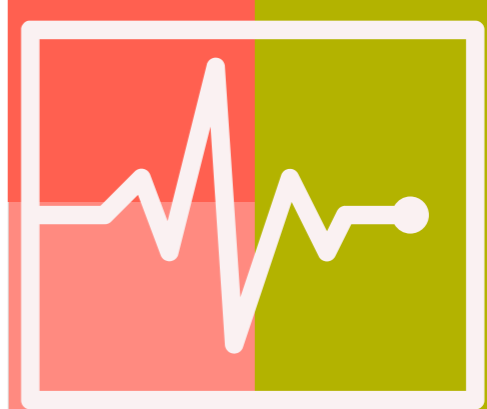


## Heart Muscle

The left side of heart and right side of heart are divided by the heart's septum. The left side of heart consists of two chambers; **left atrium and left ventricle**, and two heart valves; **mitral valve and aortic valve**. In contrast, right side of heart consists of two heart chambers; **right atrium and right ventricle** and two heart valves; **tricuspid valve and pulmonary valve**. Oxygenated blood flows through the left side of heart while deoxygenated blood flows through the right side of heart. The walls of left side of the heart are thicker than the right side walls.

## Heart Conduction

The heart's cardiac conduction system coordinates the rate and rhythm of the heartbeat cycle. The **electrical signal pathway** starts in the upper portion of the right atrium the travels through a series of impulses to synchronize the heartbeat cycle. **Ions** such as sodium, potassium, chloride and calcium are released through voltage channels which regulates cardiac output. Epinephrine, norepinephrine and thyroid and elevated calcium levels cause the heart to beat faster. Elevated potassium, decreased calcium, dehydration, poor nutrition and acidosis cause decreases heart rate



## Blood Vessels

Blood is carried through the body via blood vessels. An **artery** is a blood vessel that carries blood away from the heart, where it branches. Eventually, the smallest arteries, vessels called **arterioles**, further branch into tiny **capillaries**, where nutrients and wastes are exchanged, and then combine with other vessels that exit capillaries to form **venules**, small blood vessels that carry blood to a **vein**, a larger blood vessel that returns blood to the heart.

## Blood

Blood is a connective tissue made up of cellular elements and an extracellular matrix. The cellular elements include **red blood cells (RBCs)**, **white blood cells (WBCs)**, and cell fragments called **platelets**. The extracellular matrix, called **plasma**, makes blood unique among connective tissues because it is fluid. The primary function of blood is to deliver oxygen and nutrients to cells throughout the body and to remove wastes from body cells. Other important blood functions include defense, maintaining body temperature, keeping the the body stable.



## Cardiovascular Disease



What is Barth Syndrome?

How to Diagnose >

Newly Diagnosed

Family Resources >

Clinician Resources

International Affiliates

Meet Our Community >

Female Carriers

Families Affected by Barth Syndrome

Care Management Toolbox

FACT Sheets

# Barth Syndrome International Conference

SAVE THE DATE



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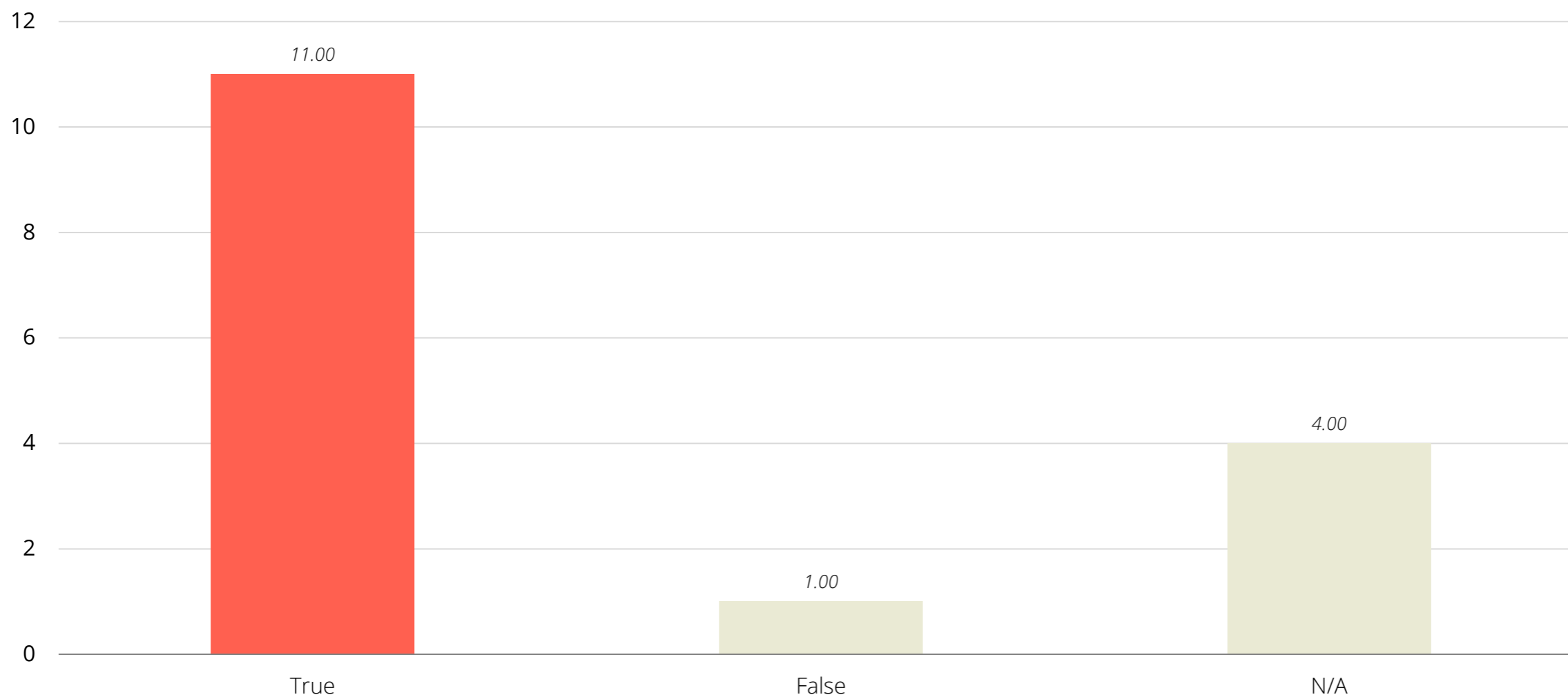
# Coming Soon

Laboratory Test Results  
Filtered by date and by finding  
Charts to map trends

I have some questions for you.

*Ready Set Poll!*

I use the **LISTSERV** to share questions and concerns when communicating with others in the BSF community.



Mean : 1.562 | Confidence Interval @ 95% : [1.125 - 2.000] | Standard Deviation : 0.892 | Standard Error : 0.223

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*

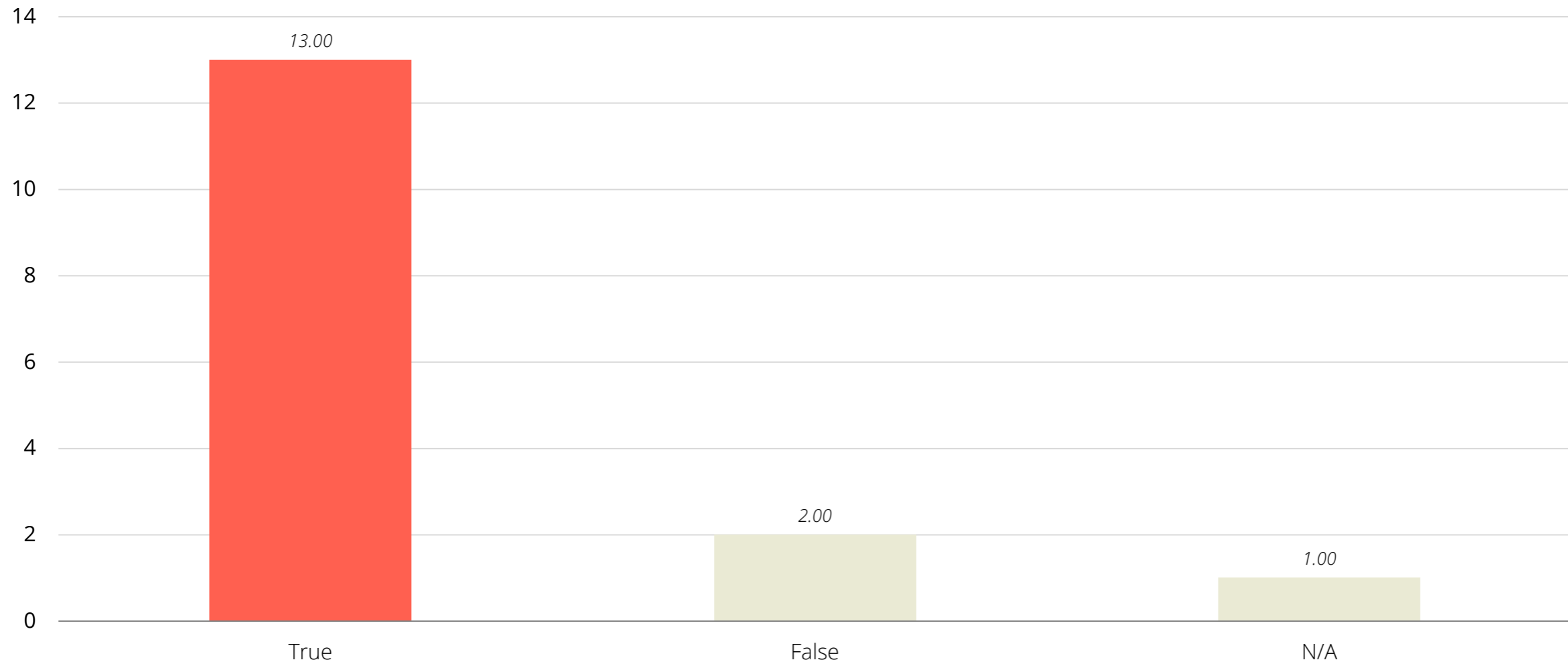
I use the **FACEBOOK GROUP PAGE** to share questions and concerns when communicating with others in the BSF community.



Mean : 1.938 | Confidence Interval @ 95% : [1.519 - 2.356] | Standard Deviation : 0.854 | Standard Error : 0.213

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I consider the Barth Syndrome Foundation Website as the "go to" source for reliable information about Barth syndrome.



Mean : 1.250 | Confidence Interval @ 95% : [0.967 - 1.533] | Standard Deviation : 0.577 | Standard Error : 0.144

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*



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# Behind the Scenes at BSF

Lynda Sedefian, Executive Assistant

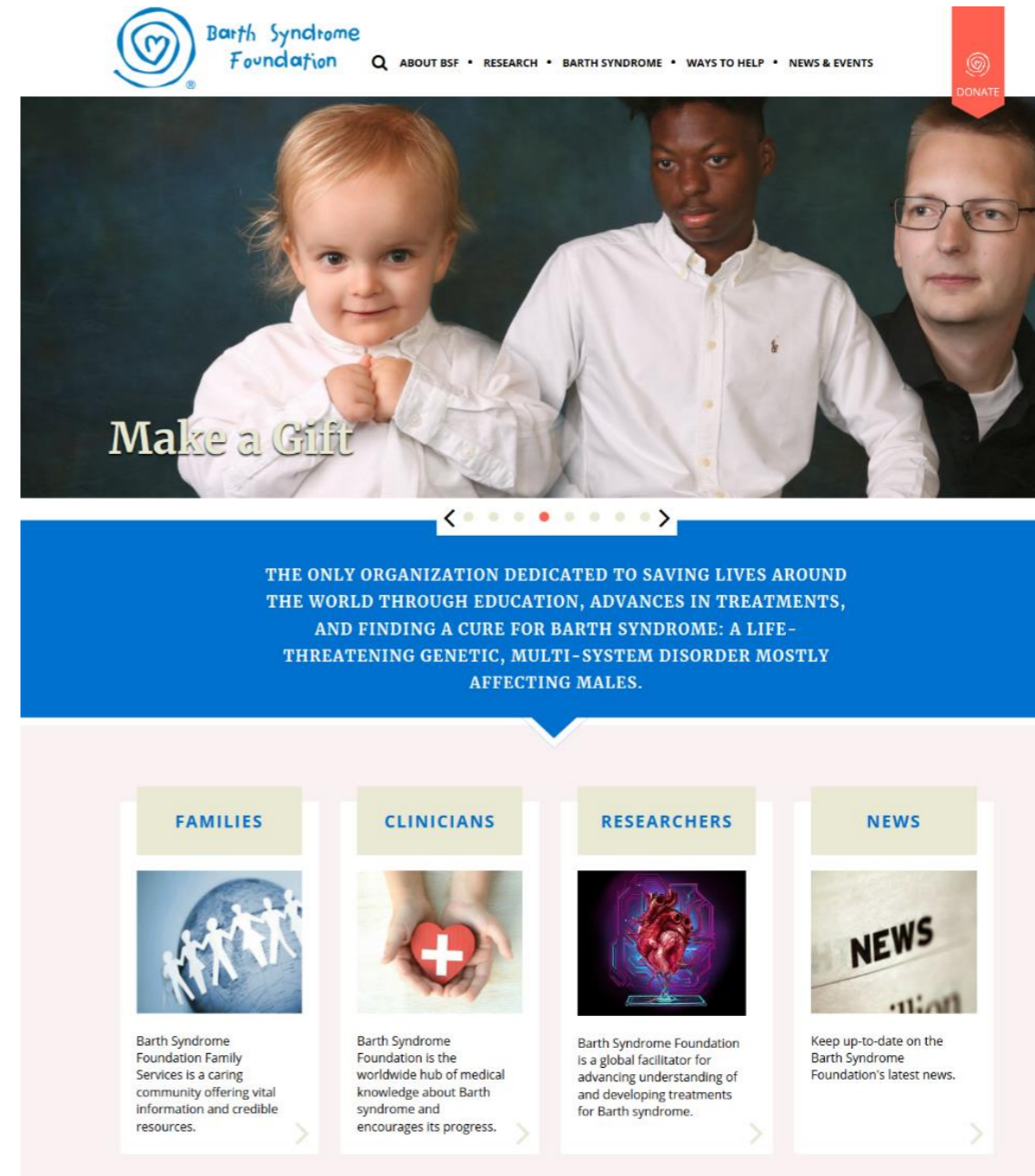


# Branding Initiative

New look and feel across all BSF communications:

- Website
- BSF Beat
- E-News
- Transition to new email/donation platform

# S





# BSF Beat

- A NEW newsletter for everyone in the BSF community
- Distributed May 2019
- Includes a summary of the latest E-News over the past several months
- Sent by email and by postal mail to families and donors
- Check it out on our website News & Events /Newsletter →

**Did you receive your BSF Beat?  
Contact  
[bsfinfo@barthsyndrome.org](mailto:bsfinfo@barthsyndrome.org) for  
your copy!**



## BSF breaking boundaries in research, advocacy

In the past, I always felt a little more hopeful in the spring. The promise of new beginnings, the opportunity for growth -- these ideas seemed to be most relevant at a time when the earth was also newly blooming.

This year, however, is different. Over the past 12 months as I have integrated into the Barth syndrome community, I have learned the importance of being both resilient yet compassionate, to stand strong for individuals yet serve as the shared voice of our BSF family, to listen and bend to the needs of our community while also planting strong roots for future partnerships. I have learned that hope is important, but action is critical.

As seasons change, so does the world around us. You'll see in this newly designed newsletter a fresh look for Barth Syndrome Foundation as we share just a few of the incredible endeavors taking place around the globe over the last few months. BSF listened to you and took action. Beginning this year, we will begin to communicate with you more often -- to showcase the work of our researchers -- and

emphasize the strength in our community -- to deepen BSF's relationship with you and hopefully your engagement with BSF.

We intend to be both efficient and cost-effective through electronic newsletters. Please keep in touch with us more often online. In the spirit of spring, BSF encourages you to go green. For those who prefer print communications, we also intend to share our progress with you more often and in a dynamic format.

We are working to modernize our look and method of communicating. However, the mission of BSF and you, our community of families, donors, and scientific contributors, remains tireless and true to saving lives and ending suffering caused by Barth syndrome. Thank you for everything you personally do to help BSF achieve our mission.



From the desk of  
**Emily Milligan MPH**  
Executive Director

## Advocacy in Action

### BSF presents Voice of the Patient report to FDA

March 20, 2019, marked another monumental milestone as BSF spent time with representatives from U.S. Food and Drug Administration (FDA) near Washington DC to present the "Voice of the Patient: Barth Syndrome" summary report. Officials conducted a listening session with BSF to learn about the types of therapies that would address the urgent unmet medical needs from Barth syndrome.

Last July, BSF earned the distinction as the 14<sup>th</sup> organization to ever host an Externally-Led Patient-Focused Drug Development (PFDD) meeting. The event took place during BSF's biennial international conference to share with officials at FDA and other stakeholders from academia and industry the perspectives of people living with Barth syndrome, its impact on their daily lives, and their

Continued on Page 2



1

# E-News

- Barth Syndrome Research Brief
- News from Executive Director

**Are you receiving E-News?**

Visit our website to manage your email preferences.

- Research Brief
- News from Executive Director
- Advocacy Alerts
- Donation Opportunities
- Family Heartbeat Newsletter

[www.barthsyndrome.org/gogreen](http://www.barthsyndrome.org/gogreen)



Connect with us!   




From the Desk of  
Emily Milligan, MPH, Executive Director



Dear Friends,

March 20, 2019, marked another monumental milestone for Barth Syndrome Foundation (BSF). On Wednesday of this week, BSF spent time with representatives from U.S. Food and Drug Administration (FDA) near Washington DC to present the *Voice of the Patient Report* to officials and educate regulators on the types of therapies that would address the urgent unmet medical needs from Barth syndrome. I was joined in this meeting by other members of our Barth family including Stacey and Kevin Woodward, Amanda and Tim Maksin, Andrew Buddemeyer, and Susan McCormack. In addition, the "Patient-Focused Drug Development Meeting Resource" toolbox, which BSF helped to co-author, was published on [FasterCures.org](http://FasterCures.org). Finally, in the ongoing spirit of advocacy, collaboration and tireless efforts to champion on behalf of those who have Barth syndrome and other rare diseases, we are working with NORD to Take Action to support the Orphan Drug Act, and need your help.



Connect with us!   

For 16 years, the BSF Research Grant Program has strategically funded research projects to improve the scientific and medical understanding of Barth syndrome, creating a pathway towards potential therapies. The recent 2018 cycle continues to showcase that legacy, a legacy that led directly to the **CARDIOMAN** clinical trial in 2019 and more than 25 awards from NIH to advance research about Barth syndrome.

**Discovery of viable therapies to alleviate suffering and prolong life for individuals affected by Barth syndrome is the impetus behind the therapeutic research strategy employed by BSF.** To that end, the 2018 research grant recipients demonstrated innovative and scientifically-rigorous approaches to addressing knowledge gaps in three key areas:

1. Gene Therapies
2. Modification of Cardiolipin
3. Improving Mitochondrial Function



From the desk of

**Matt Toth, PhD**

*Research questions?*

*Suggestions for future newsletters?*

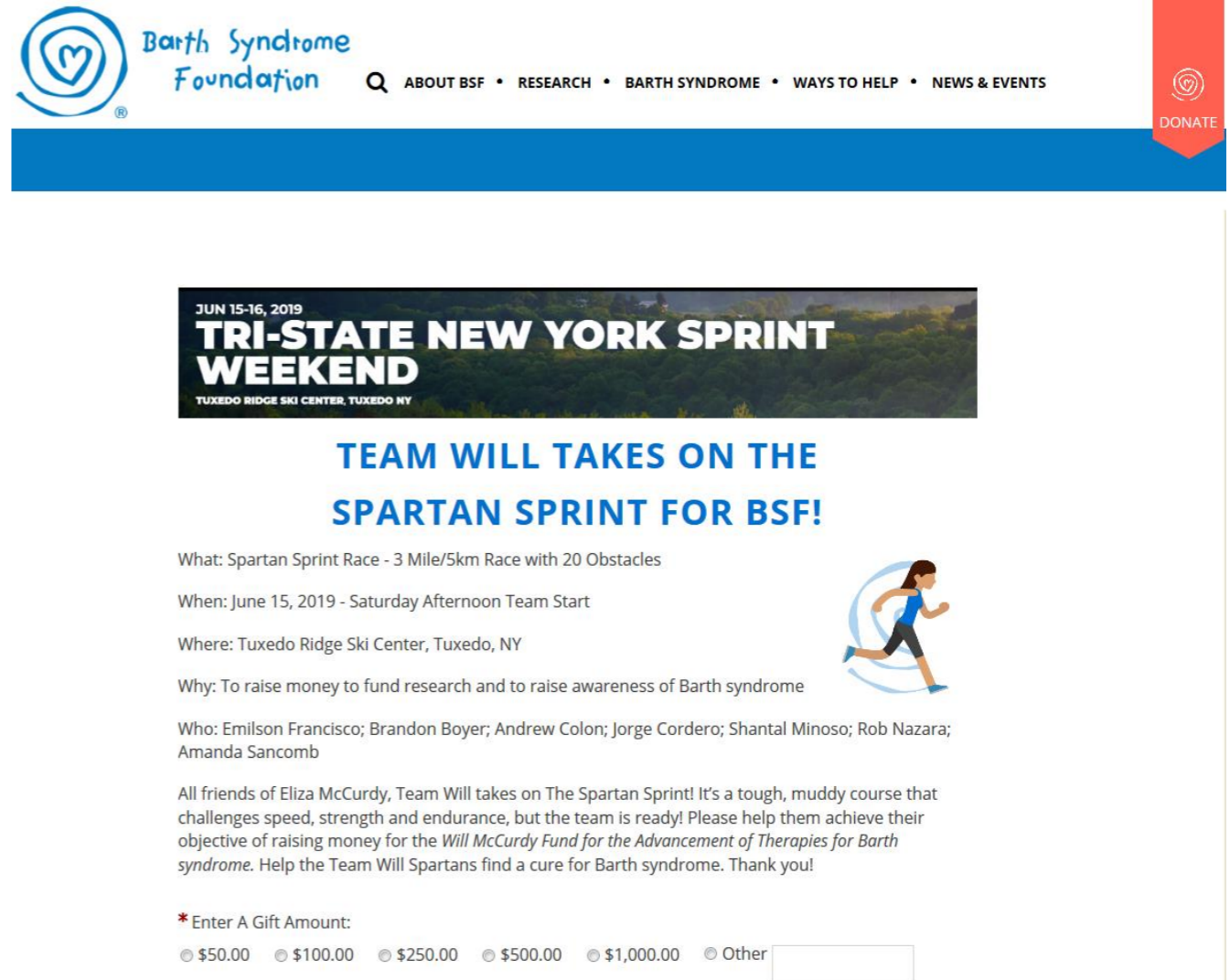
*Email me!*

**Support  
BSF Research**



# Transitioning to a New Platform

- Newly created donation forms
  - General
  - Tribute
- Autoresponders automatically sent to donor
- Ability to send Ecards to honoree when making a donation in honor/memory



**Barth Syndrome Foundation** ABOUT BSF • RESEARCH • BARTH SYNDROME • WAYS TO HELP • NEWS & EVENTS

**JUN 15-16, 2019**  
**TRI-STATE NEW YORK SPURT WEEKEND**  
TUXEDO RIDGE SKI CENTER, TUXEDO NY

**TEAM WILL TAKES ON THE SPARTAN SPURT FOR BSF!**

What: Spartan Spurt Race - 3 Mile/5km Race with 20 Obstacles  
When: June 15, 2019 - Saturday Afternoon Team Start  
Where: Tuxedo Ridge Ski Center, Tuxedo, NY  
Why: To raise money to fund research and to raise awareness of Barth syndrome  
Who: Emilson Francisco; Brandon Boyer; Andrew Colon; Jorge Cordero; Shantal Minoso; Rob Nazara; Amanda Sancomb

All friends of Eliza McCurdy, Team Will takes on The Spartan Spurt! It's a tough, muddy course that challenges speed, strength and endurance, but the team is ready! Please help them achieve their objective of raising money for the *Will McCurdy Fund for the Advancement of Therapies for Barth syndrome*. Help the Team Will Spartans find a cure for Barth syndrome. Thank you!

\*Enter A Gift Amount:  
 \$50.00  \$100.00  \$250.00  \$500.00  \$1,000.00  Other

**Look for an email asking you to update your profile this month!**

# New Fundraising Tool called TeamRaiser Coming Soon!

## Luminate Online – TeamRaiser

- A new, interactive platform for fundraising!
- Create your own personal fundraising page, send emails and share the link, receive donations from families and friends, and even integrate with Facebook
- Looking for a few volunteers to help us test the platform – contact Lynda If you are interested in setting up your page in June
- [barthsyndrome.org/donate](http://barthsyndrome.org/donate)

# New Fundraising Tool called TeamRaiser Coming Soon!

The screenshot displays the website's header with the Barth Syndrome Foundation logo and navigation links: HOME, DONATE, START FUNDRAISING, and HOW THIS WORKS. A LOGIN button is also visible. The main banner features a smiling child with a red heart on their cheek and a large red balloon, with the text "How do you support #TEAMBARTH". Below the banner are two buttons: "GET STARTED" (create your fundraising page) and "DONATE" (in support of a participant's fundraiser).

**SEARCH PARTICIPANTS**

First Name  
Last Name

**SHARE**

**Together we will create a world where Barth syndrome no longer causes suffering or loss of life.**

Your support today will help to save the life of someone born with Barth syndrome. Barth syndrome is a rare, life-threatening, genetic mitochondrial disorder. People with Barth syndrome, usually boys, often suffer from serious medical complications including heart failure, muscle weakness, debilitating fatigue and infection.

The mission of Barth Syndrome Foundation is to save lives through education, advances in treatment and finding a cure for Barth syndrome.

**Joining #TeamBarth and getting started is easy!** Simply sign up for a free awareness and fundraising Team Barth page, personalize it and invite your friends and family to make donations. Every dollar raised supports the work we do to end suffering caused by Barth syndrome. We need your help!

**#TEAMBARTH PROGRESS**  
Goal: \$100,000

0% of Goal      \$0 Raised

MAKE A GIFT!

Want a sneak peek? → [TeamBarth.barthsyndrome.org](https://TeamBarth.barthsyndrome.org)

# New Fundraising Tool called TeamRaiser Coming Soon!



LOGIN

HOME DONATE START FUNDRAISING HOW THIS WORKS ▾





Create a Personal Fundraising Page in support of Barth Syndrome Foundation

- 1 Select Options
- 2 Provide Details
- 3 Review
- 4 Make Payment

Thank you - we're grateful for your support!

\* Indicates Required

\* Please tell us about your fundraiser:

-  **Have a Barth Birthday! - No Fee**  
In lieu of unwrapping packages this year, dedicate your birthday to Barth Syndrome Foundation and collect donations that will make a difference in the lives of our friends and family with Barth Syndrome! Not only do community donations support research and family services provided by BSF, your birthday fundraiser raises much needed awareness about Barth syndrome.
-  **Create your own fundraiser! - No Fee**  
Create your own personal fundraising page in honor of or in memory of someone with Barth syndrome. Use this tool to customize your page with photos, your personal story, and set a fundraising goal. You can include a live event in your community as well, from a lemonade stand to a community run or a book club, or you can simply share your personal page and ask for donations to BSF to support research and family services for people with Barth syndrome.
-  **Go Blue for Barth! - No Fee**  
Challenge your friends to raise a specific amount and when the goal is met, you agree to do something funny or exciting! You can dress as a superhero or cartoon character for a day, dye your hair blue, take a cold plunge, or anything else that you wouldn't NORMALLY do! Raise awareness for Barth syndrome by setting up a challenge fundraiser!
-  **Run for BSF! - No Fee**  
Are you participating in a marathon, a race, triathlon or a physical challenge event? Create a fundraising page to collect donations in SUPPORT of each step, mile or obstacle you will have to overcome. Your hard work on the course can further the mission of Barth Syndrome Foundation!

Set your Personal Fundraising Goal:

\$1,000.00

Want a sneak peek? → [TeamBarth.barthsyndrome.org](https://TeamBarth.barthsyndrome.org)



I have some questions for you.

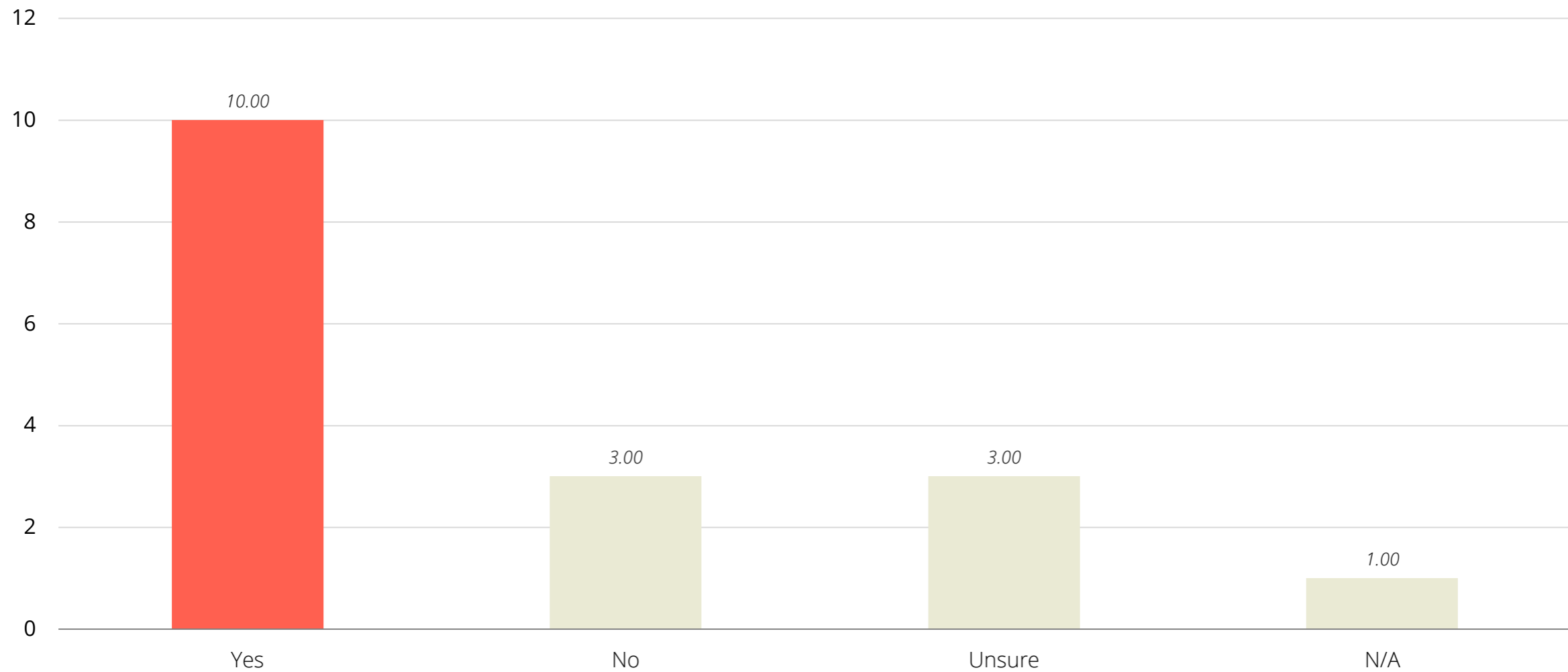
*Ready Set Poll!*





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## Are you receiving E-News updates from BSF?

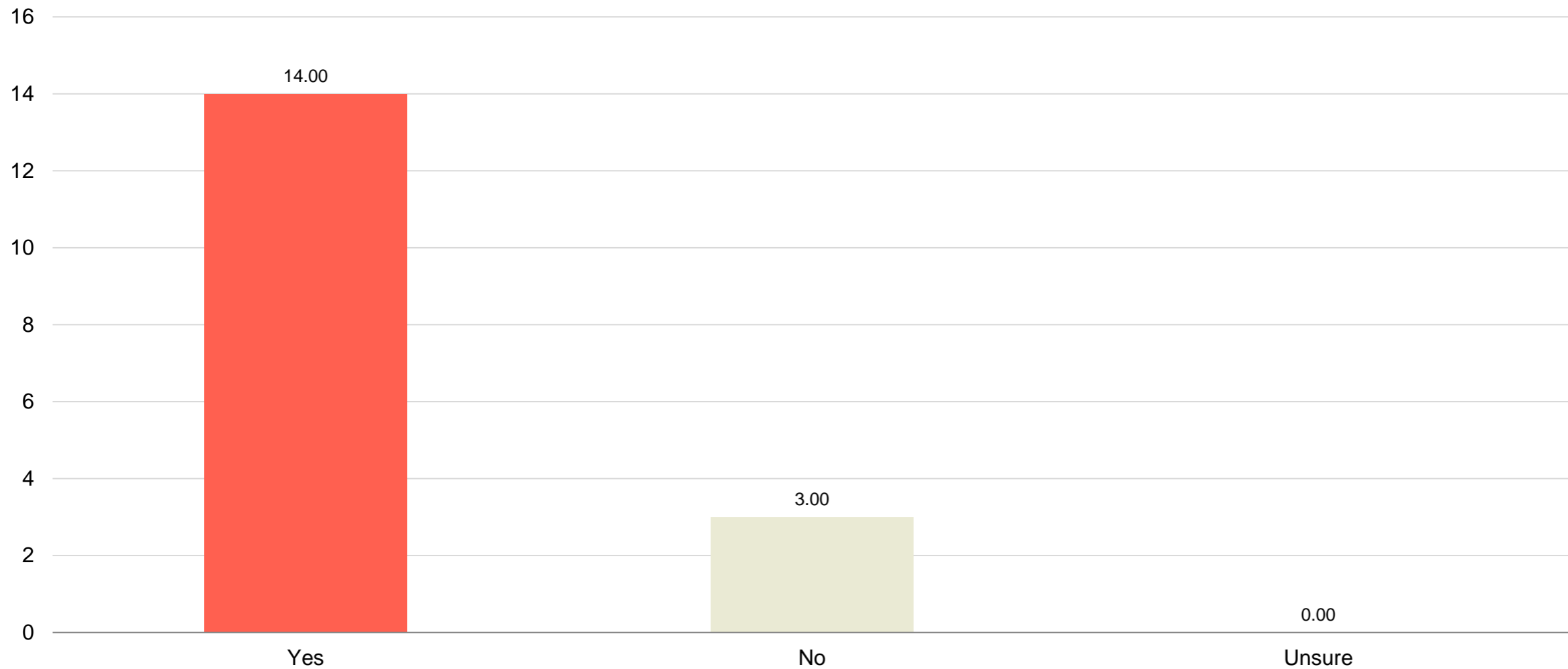


Mean : 1.706 | Confidence Interval @ 95% : [1.238 - 2.174] | Standard Deviation : 0.985 | Standard Error : 0.239

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*



Have you visited our website recently to view the new look and feel of branding?



Mean : 1.176 | Confidence Interval @ 95% : [0.990 - 1.363] | Standard Deviation : 0.393 | Standard Error : 0.095

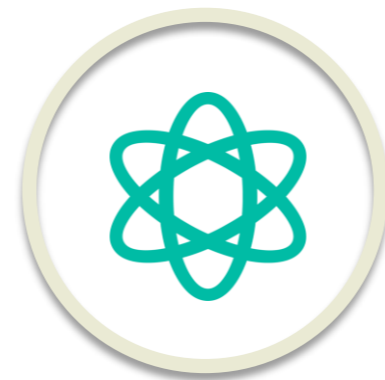
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# Research

Matthew Toth, Science Director



*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*

# Portfolio Review – June 19<sup>th</sup>

- BSF Board members
- SMAB members
- Three presentations on near-term clinical trials
  - Gene therapy—Drs. Byrne and Pacak
  - Enzyme replacement therapy—Dr. Chin
  - ALCAT1 inhibitors—Dr. Shi
- Four external reviewers
  - Dr. Philip Johnson, former CEO of CHOP, CSO of Limelight Bio
  - Dr. R. Mark Payne, Indiana School of Medicine
  - Dr. Charles Venditti, NIH/NHGRI
  - Dr. Adam Chicco, Colorado State University

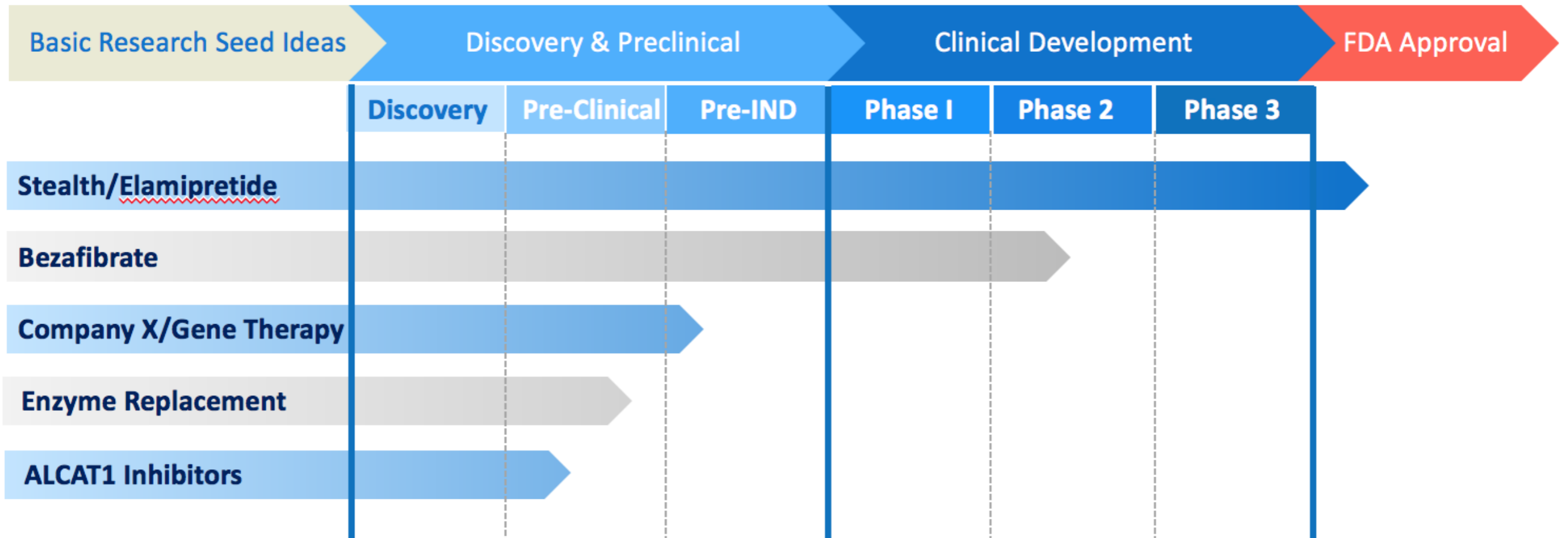
# Purpose

- BSF has reached an important milestone in our mission to accelerate treatments and find a cure for Barth syndrome.
- Presently, 3 therapeutic ideas are at the cusp of clinical trial implementation.
- BSF seeks to understand specific ways that we can strategically advance the following clinical candidates within the next 1-3 years.
- Our goal is to translate scientific and business considerations of clinical candidates into future actionable steps through strong cross-sector collaboration.

# Format

- LOCATION: Boston, MA
- Speakers will present for 40-minutes on topics ranging from technical considerations to partnering and financing challenges that may impact clinical development of potential therapies.
- Each presentation will be followed by question and discussion with BSF's Reviewers and SMAB members.
- The day will wrap up with a guided discussion among the Reviewers, SMAB, and BSF Board.
- Meeting debrief will take place on June 26<sup>th</sup> at which time the Board will evaluate next steps.

# Therapeutic Pipeline Grows to 5 Clinical Candidates



I have some questions for you.

*Ready Set Poll!*



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# 2019 Strategic Vision

Emily Milligan, Executive Director



*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*



# ADVOCACY IN ACTION

**2018 - JULY**

## **PFDD Meeting**

BSF launches agenda to advocate for the approval of therapies and overcome the unmet medical need of individuals living with Barth syndrome.



**2018 - SEPTEMBER**

## **Preferred Partnering in R&D**

BSF joins NORD's membership and speaks to peer organizations about best practices for partnering with industry to advance therapies.

**2019 - FEBRUARY**

## **FasterCures PFDD Guidance**

BSF co-authors guide for non-profit sector on common practices, lessons learned, and considerations for planning PFDD meetings to shape R&D.



**2019 - FEBRUARY**

## **The Power of BSF's Registry**

BSF invited to speak on a distinguished panel during World Rare Disease Day in Bethesda to champion the importance of patient registries.

**2019 - MARCH**

## **Voice of the Patient (VOP) Report**

BSF publishes the summary report that reflects the perspectives of patients and caregivers who participated in the July 18<sup>th</sup> public meeting.



**2019 - MARCH**

## **FDA listens to BSF**

BSF meets with more than 20 regulators to deliver VOP report and educate FDA on challenges of living with or caring for someone with Barth syndrome.

**LATE 2019 (?)**

## **NDA pre-submission meeting**



# BSF Strategic Plan 2017-2020

1. Expand science and medicine program to further encourage finding treatments or a cure
2. Enhance the capacity of Barth Syndrome Foundation to better meet its mission
3. Build confidence and trust in Barth Syndrome Foundation's community and resources

## ORGANIZATIONAL GOALS 2019



**Develop and promote BSF's therapeutic strategy and research priorities**



**Successfully implement and adopt tools to broaden and deepen engagement in BSF's mission**



**Establish BSF as the premier organization advocating for therapies and policies that positively impact individuals affected by Barth syndrome**

# BSF Impact Assessment

## ↑ ORGANIZATIONAL GOALS 2019

1. Develop and promote BSF's therapeutic strategy and research priorities
2. Successfully implement and adopt tools to broaden and deepen engagement
3. Establish BSF as the premier organization



- ❑ Portfolio review successfully executed
- ❑ BSF publicizes therapeutic vision
- ❑ Contract negotiations initiated for new strategic partnership



- ❑ Family e-news launched
- ❑ Communications platform implemented and adopted by Q3
- ❑ Development committee holds 1<sup>st</sup> meeting



- ❑ BSF invited member of  $\geq 2$  working groups
- ❑ VOP report published to FDA.gov
- ❑ Meetings with  $\geq 20$  new companies and academic institutions to cultivate partnerships

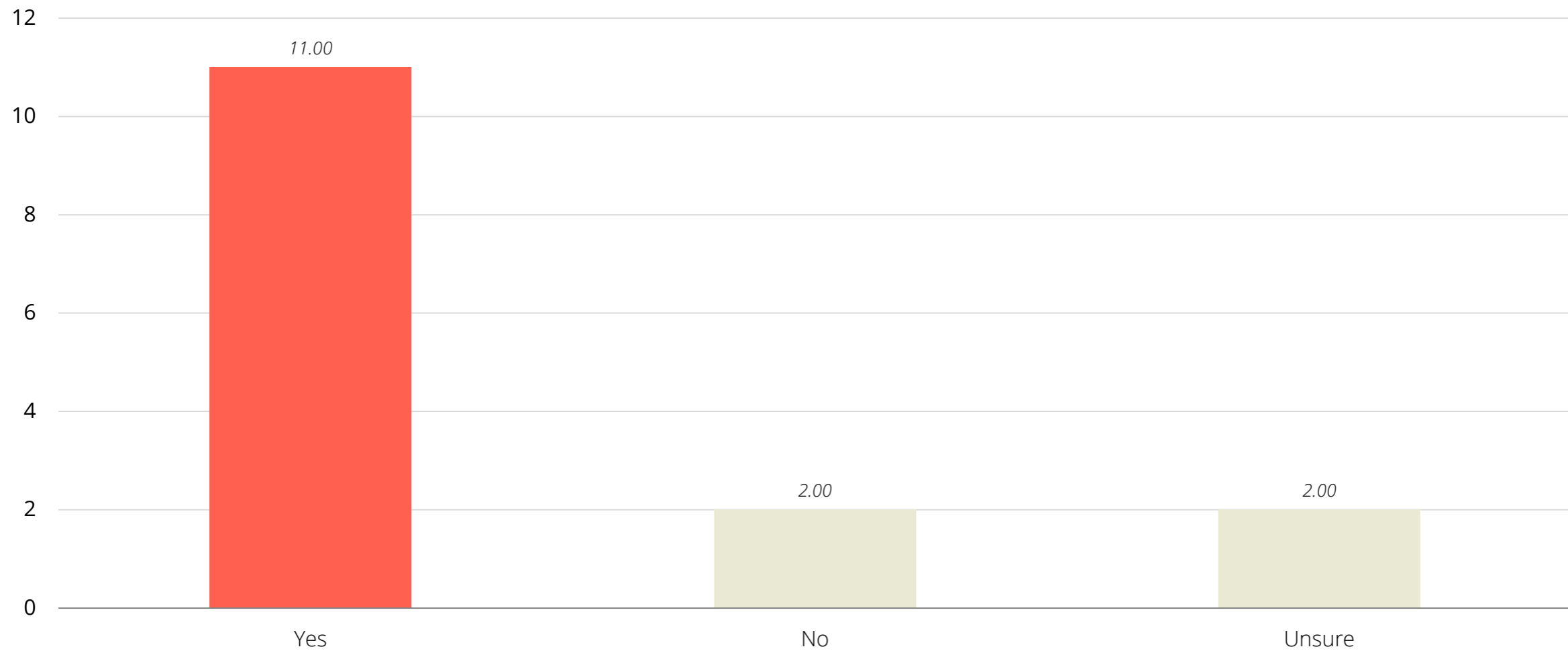
I have some questions for you.

*Ready Set Poll!*

Have you read any of the “Research Brief” Monthly newsletters through email?



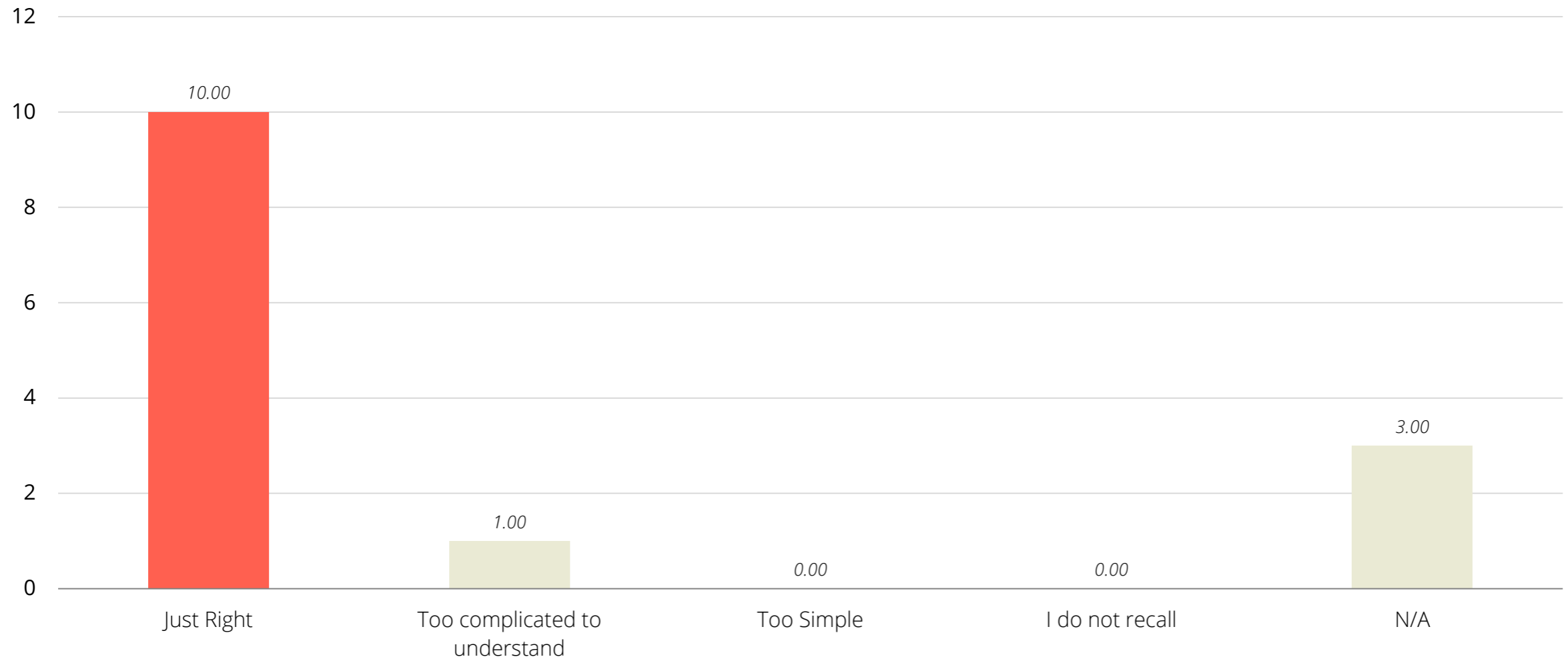
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Mean : 1.400 | Confidence Interval @ 95% : [1.027 - 1.773] | Standard Deviation : 0.737 | Standard Error : 0.190

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How would you describe the reading level content within the "Research Brief" newsletters you have received through email?



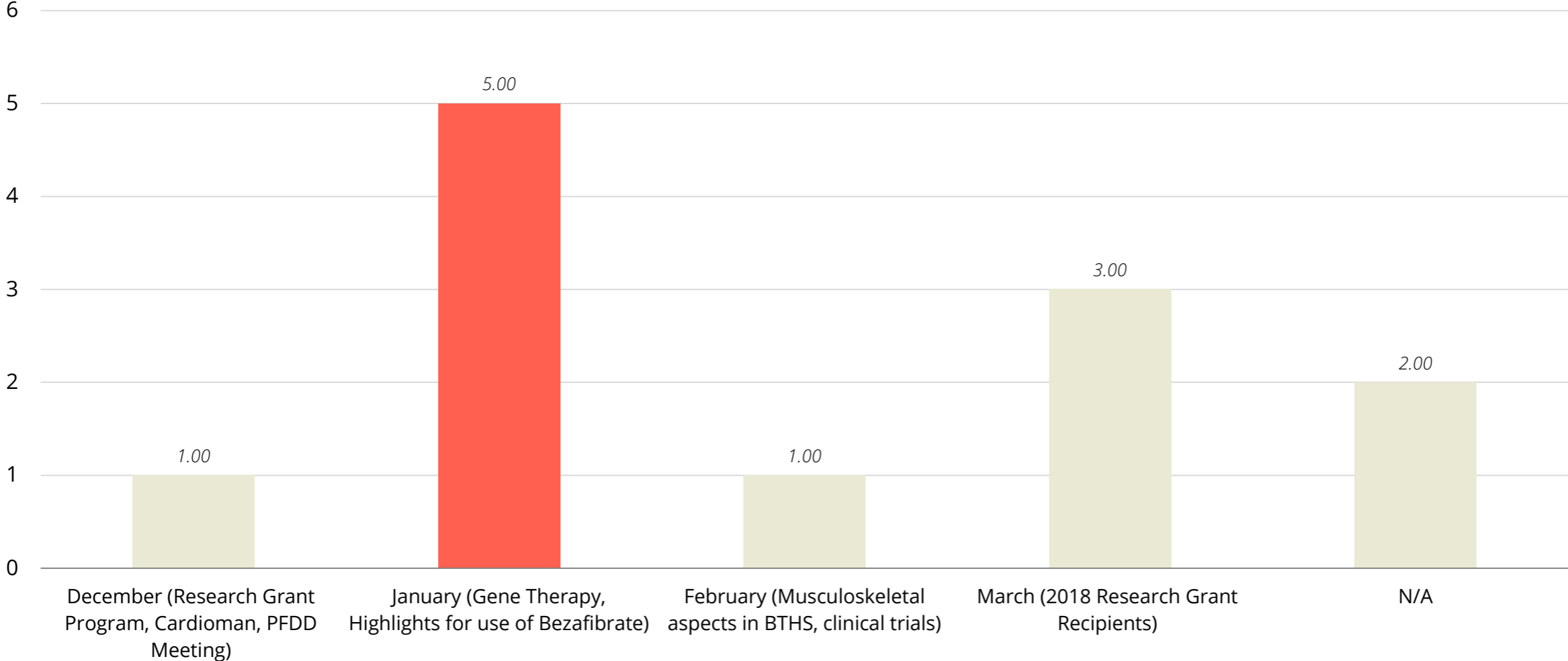
Mean : 1.929 | Confidence Interval @ 95% : [1.046 - 2.811] | Standard Deviation : 1.685 | Standard Error : 0.450

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*

# What monthly "Research Brief" newsletter interested you the most?



Barth Syndrome Foundation



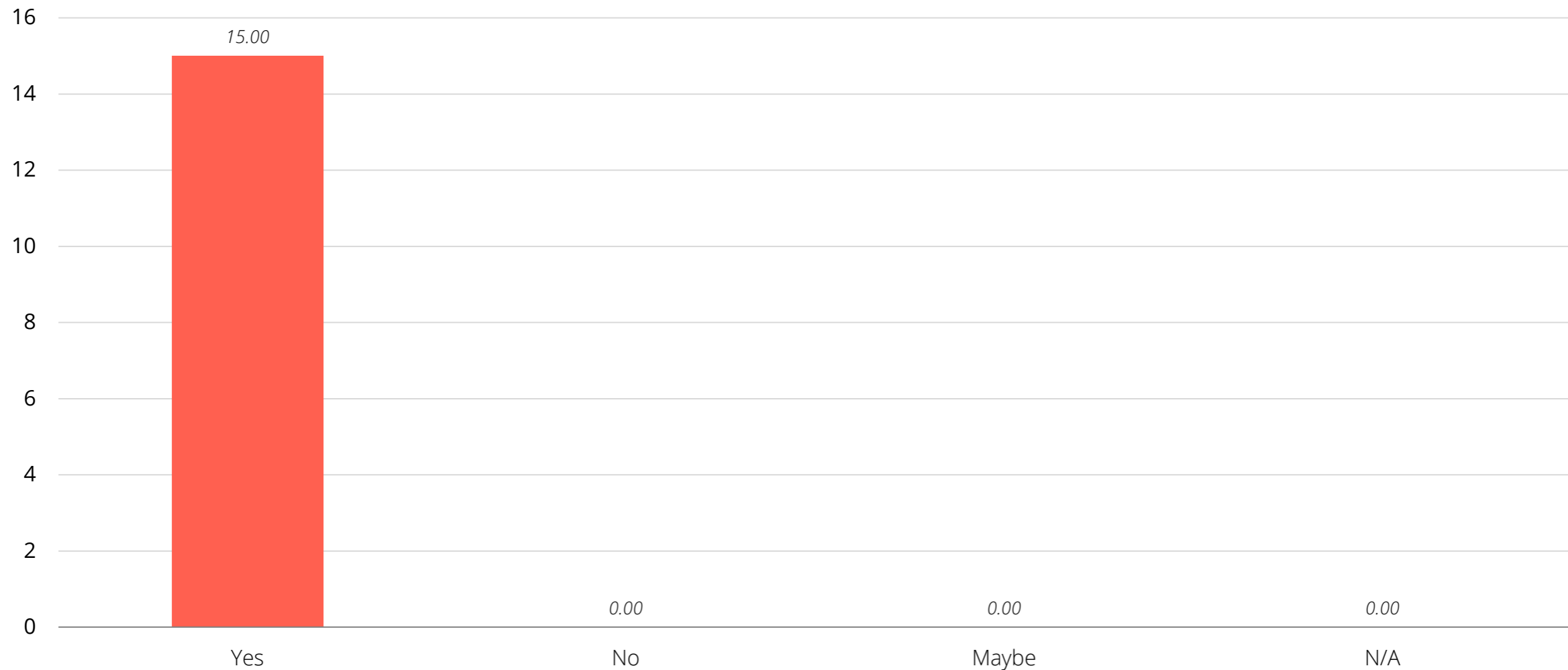
Mean : 3.000 | Confidence Interval @ 95% : [2.237 - 3.763] | Standard Deviation : 1.348 | Standard Error : 0.389

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*

Do you want to see the monthly "Research Brief" newsletter about RESEARCH to continue?



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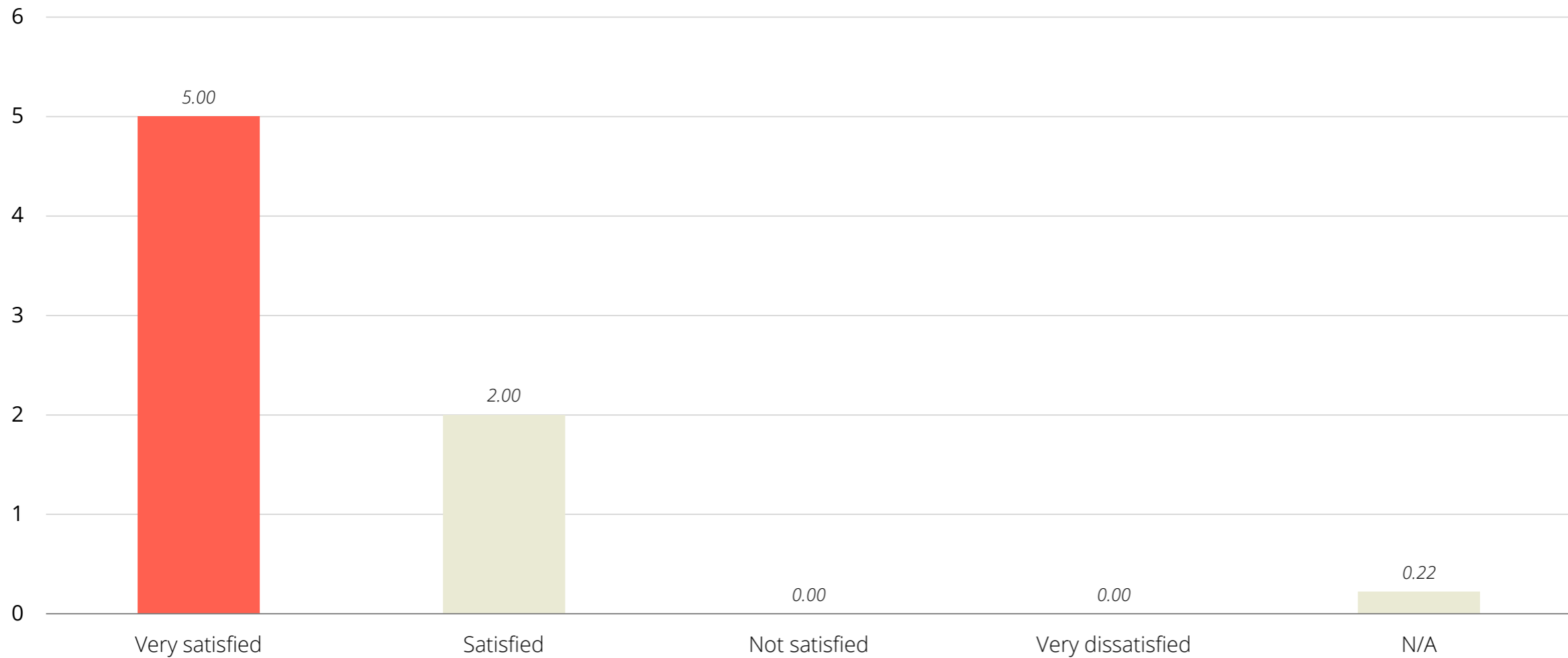
Mean : 1.000 | Confidence Interval @ 95% : [1.000 - 1.000] | Standard Deviation : 0.000 | Standard Error : 0.000

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*



What's on your mind?

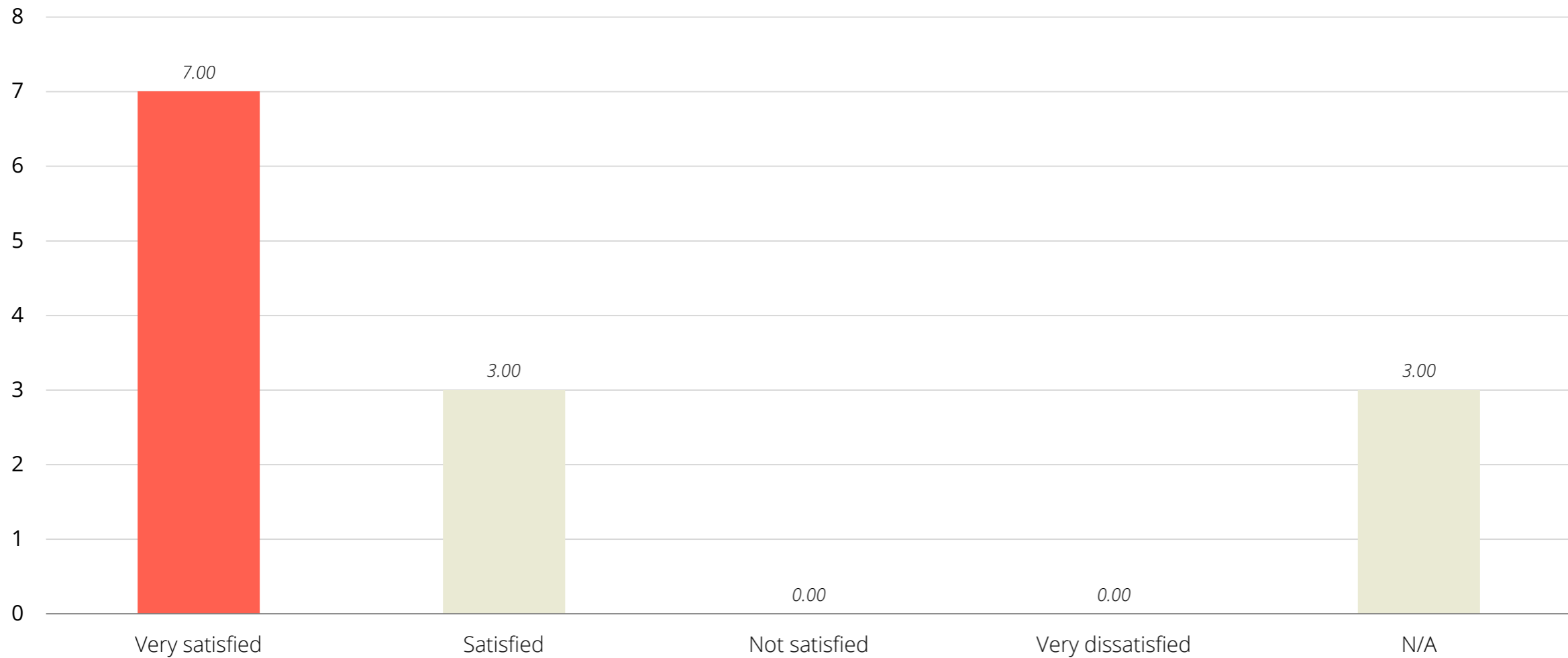
How satisfied are you with BSF representing your needs, interests, goals and desires in the area of **ADVOCACY**?



Mean : 2.111 | Confidence Interval @ 95% : [1.006 - 3.216] | Standard Deviation : 1.691 | Standard Error : 0.564

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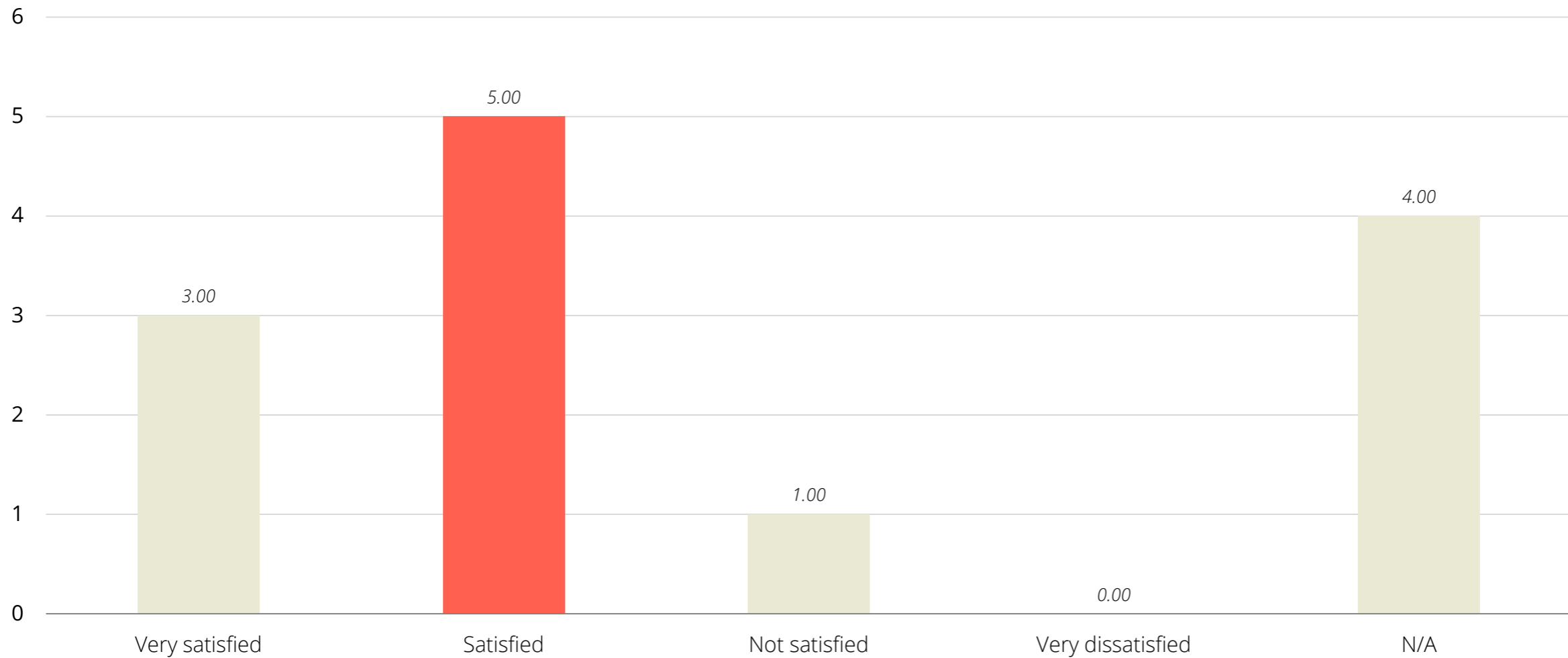
How satisfied are you with BSF representing your needs, interests, goals and desires in the area of **RESEARCH**?



Mean : 2.385 | Confidence Interval @ 95% : [1.455 - 3.314] | Standard Deviation : 1.710 | Standard Error : 0.474

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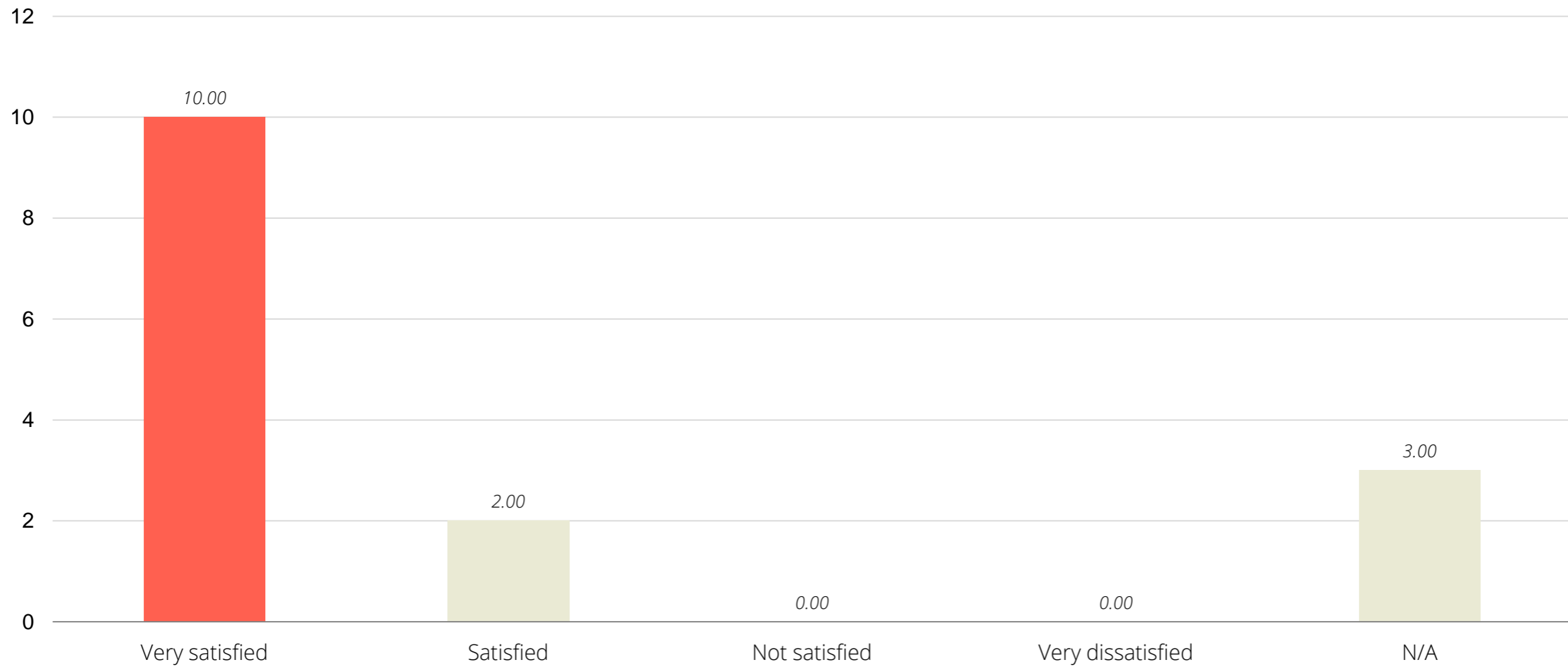
# How satisfied are you with BSF representing your needs, interests, goals and desires in the area of **FAMILY SUPPORT**?



Mean : 2.769 | Confidence Interval @ 95% : [1.877 - 3.661] | Standard Deviation : 1.641 | Standard Error : 0.455

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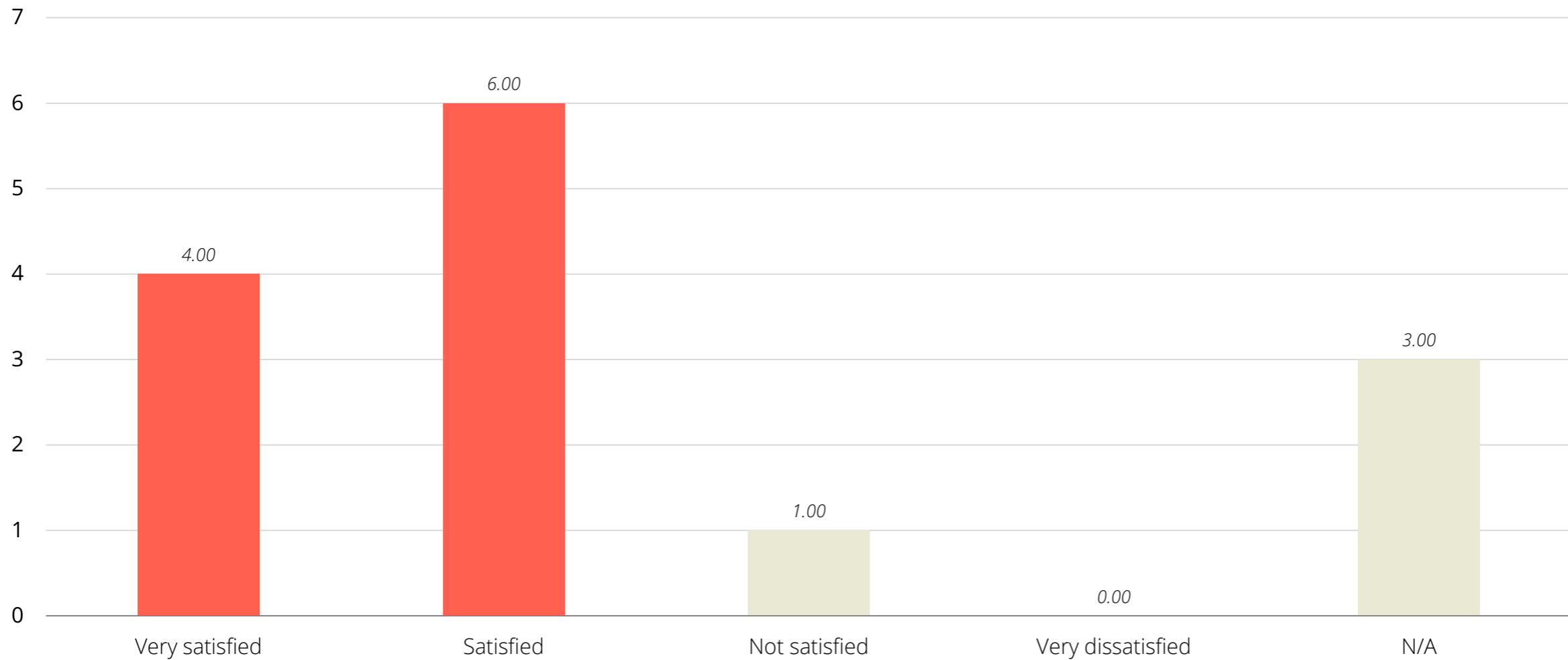
# How satisfied are you with BSF representing your needs, interests, goals and desires in the area of **FAMILY EDUCATION**?



Mean : 1.933 | Confidence Interval @ 95% : [1.111 - 2.755] | Standard Deviation : 1.624 | Standard Error : 0.419

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*

# How satisfied are you with BSF representing your needs, interests, goals and desires in the area of **HEALTHCARE PROVIDER EDUCATION/AWARENESS**?



Mean : 2.429 | Confidence Interval @ 95% : [1.589 - 3.269] | Standard Deviation : 1.604 | Standard Error : 0.429

*Saving lives through education, advances in treatments and finding a cure for Barth syndrome*

# THANK YOU!

