

BSF Community Petition

FDA & STEALTH BIOTHERAPEUTICS: ALLOW INDIVIDUALS WITH BARTH SYNDROME ACCESS TO ELAMIPRETIDE

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Introduction

Barth Syndrome Foundation (BSF) and constituents support access to elamipretide to individuals with Barth syndrome. The enclosed citizens petition prompts action by FDA to urgently review this request.

Advocating for Access to Elamipretide

A copy of the petition as provided in its entirety to BSF constituents, including background and rationale as published at <u>barthsyndrome.org/petition</u>.



Comments from the BSF Community

A compilation of qualitative comments from individuals living with Barth syndrome, parents, and caregivers of both living and deceased individuals, healthcare providers, researchers, and members of the community.



Signatures

Responses organized by first name and last initial to protect privacy.

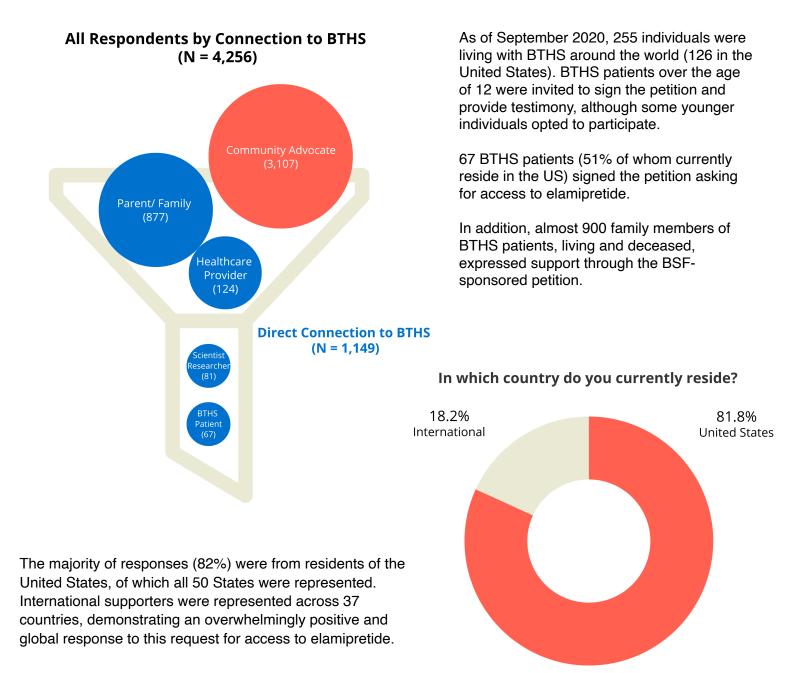
BSF's mission

Barth Syndrome Foundation (BSF) is the only global network of families, healthcare providers, and researchers solely driven by the mission to save lives through education, advances in treatment, and finding a cure for Barth syndrome. Introduction

4,256 unique signatures were gathered by Barth Syndrome Foundation (BSF) in September 2020 in an effort to demonstrate BSF community-wide support for allowing BTHS patients access to the drug elamipretide.

This petition was generated in response to FDA's request of Stealth BioTherapeutics (drug sponsor) to conduct additional clinical trials for the study of elamipretide in Barth syndrome (BTHS) prior to submitting a New Drug Application (NDA). This move would dramatically delay, if not close the door to, individuals' access to the potentially life-altering therapy, a drug that has already been proven to have a high safety profile.

Given the high death rate and rarity of BTHS as well as the positive safety profile of elamipretide, we are asking FDA and Stealth to grant access to elamipretide to BTHS patients as soon as possible.



Advocating for Access to Elamipretide

The following is an exact copy of the information provided to the community via an electronically distributed petition. Between September 15 and 30, 2020, BSF published this information and gathered signatures at barthsyndrome.org/petition. Efforts were made to represent all information and views on which the petition relies.

FDA & STEALTH BIOTHERAPEUTICS: ALLOW INDIVIDUALS WITH BARTH SYNDROME ACCESS TO ELAMIPRETIDE

Elamipretide, produced by Stealth BioTherapeutics, is an experimental drug that has been shown to reduce debilitating fatigue and potentially improve important baseline health measures in people with the ultra-rare disease Barth syndrome. Given the risk of life-threatening cardiac complications in this population, individuals with Barth syndrome cannot wait for additional studies of elamipretide before receiving access.

FDA has repeatedly signaled the importance of incorporating the "patient voice" in drug development. This is especially critical in rare diseases. The 21st Century Cures Act requires sponsors to include and FDA to consider the patient perspective. The voice of affected individuals and organizational advocacy is critical in communicating to FDA the extreme unmet need in Barth syndrome. In 2018, the <u>externally-led Patient-Focused Drug Development</u> meeting on Barth syndrome revealed that 100% of patients experience fatigue, 90% (based on cardiomyopathy occurrence) have heart failure or other life-threatening cardiac complications related to their disease, and 100% of patients surveyed would like access to therapies that improve quality of life even if they do not reverse disease.

As of today, there are only 126 known affected living individuals in the United States. In a very small clinical trial like <u>TAZPOWER</u>, it is very challenging to see compelling clinical data that reach statistical significance. The majority of trial participants experienced improvements in fatigue, strength, and quality of life. The patient voice becomes particularly critical in this setting. We are asking FDA and Stealth to work together to provide access to elamipretide to people with Barth syndrome as soon as possible.

Background

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In the open-label extension portion of the Phase 2/3 TAZPOWER study, treatment with elamipretide resulted in a <u>27% increase in average cardiac stroke volume</u>, or the amount of blood pumped by the heart's left ventricle per contraction. Most patients with Barth syndrome have underlying heart disease, often leading to heart failure and death. Even a modest improvement in heart function could potentially represent an opportunity for longer and improved quality of life for an individual with Barth syndrome.

People with Barth syndrome who were enrolled in the open-label extension of the TAZPOWER clinical trial for one year showed positive changes in functional assessments such as fatigue, muscle strength, and endurance. Compared to natural history information (data collected from patients not receiving an experimental treatment), patients receiving elamipretide showed an average improvement of 116.92 meters on their six-minute walk test compared to 1.73 meters for those in the natural history group over the same period of time. Improvements were also seen in muscle strength and sit-to-stand assessments. Quality of life for people with Barth syndrome is of utmost importance and can be improved by access to therapies that increase the individual's strength and endurance as well as reduce fatigue.

The trial also showed elamipretide is generally safe and well-tolerated, which builds upon Stealth's experience testing this experimental drug for other, more prevalent conditions.

Rationale

Barth syndrome is a serious and life-threatening genetic disorder, primarily affecting males. It is caused by a mutation in the *tafazzin* gene resulting in an inborn error of lipid metabolism. Cardinal characteristics of this multi-system disorder often include combinations and various degrees of cardiomyopathy, neutropenia, muscle weakness, growth delay, fatigue, and exercise intolerance. These symptoms limit the day-to-day quality of life for people with Barth syndrome, and often lead to life-threatening complications and early death. In the last 12 months, the ultra-rare global Barth syndrome population has lost seven patients to complications of the disease. Given that there are currently 255 in the world living with this disease, this means that nearly 3% of the world's cohort has succumbed in the last year, predominantly due to cardiac-related causes. Although improved diagnosis, symptom monitoring, and symptom management have improved the survival rate, heart disease (cardiomyopathy, sudden cardiac death, heart failure) remains the primary cause of premature death in the Barth syndrome population.

Given the results of the trial, Stealth BioTherapeutics and FDA must give patients with Barth syndrome, who currently have no other choice for treatment, access to elamipretide. FDA has emphasized the importance of the patient voice, especially for rare conditions without FDA-approved treatment options. As summarized in the <u>"Voice of the Patient: Barth Syndrome"</u> report, people with Barth syndrome experience compromised quality of life caused by fatigue and other symptoms. Affected individuals and families deserve the right to have access to elamipretide in order to potentially experience improvements as seen in the clinical trials.

Data from the clinical trial evaluating the use of elamipretide in Barth syndrome demonstrate meaningful potential benefit and low risk, particularly evidenced by people who participated in open-label extension and have used elamipretide for over one year. Individuals with Barth syndrome have been informed during the course of elamipretide clinical trials and are willing to accept the potential risks given the potential for benefit and the absence of any other FDA-approved therapies.

Therefore, we ask Stealth and FDA to address this issue with urgency by submitting and approving an NDA for elamipretide in Barth syndrome based on existing evidence from clinical trials.

Individuals with Barth syndrome have a reduced quality of life and many are dying. We need treatment choices now.

Allow Individuals with Barth Syndrome Access to Elamipretide

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* 1. Your Name (First & Last)

* 2. Email address

- * 3. In what country do you currently reside?
- ^C United States
- Other (please specify)

4. US residents, in what state or U.S. territory do you live?

* 5. Connection to Barth syndrome: (please choose one)

- C Living with Barth syndrome
- Parent or family member of an individual with Barth syndrome
- [©] Parent or family member of an individual who died with Barth syndrome
- ^C Community advocate, friend or volunteer
- ^C Healthcare provider
- ^O Other scientist or researcher

6. If you or your immediate family member has or had Barth syndrome, please provide comment to the question below, with specific examples if possible.

How would the availability of elamipretide, potentially the first-ever FDA-approved drug for Barth syndrome, impact (or have impacted) the life of you, your child, and/or your family member?

Comments from the BSF Community

INTRODUCTION The following are direct, unedited quotations provided by BTHS patients, parents and caregivers of both living and deceased patients, and clinicians who are directly involved in the care of these individuals. As demonstrated below, the qualitative comments from the community reflect an overwhelming desire to increase longevity and improve quality of life.

Name	Quotations
Alfie Lennon A.	The biggest advantage for me would be to not be fatigued constantly. I would be able to be more independent, see friends without knowing that I would be physically exhausted for the next 4/5 days. My brother who is only one year older than me has lived away from home for the last three years at university and I wish I could do that but my fatigue is too much. I have to study part time, get driven to and from university and still have stay at home, therefore I am still so dependant on others. I would love to believe there was a medicine that would help and offer me some independence as a young man. I don't have many friends now as they have all moved on with their social lives which I cannot keep up with, moving into their own homes, having relationshipsall things I would love to do but I do not have the energy for. I want to be more independent and not rely on my parents and brother for every aspect of care in my life. I know this drug is for use in America and may not be available for us here in the UK but I would love if others in America could have the opportunity to have access to a medication that could potentially be life changing.
Allanna A.	I know, see and watch the massive day to day impact that Barth takes on my son. I would love the approval of elamipretide as a treatment for our individuals. The approval would be huge and life changing. Cardiac function is always a huge concern, my son also suffers from rhythm issues too. Muscle weakness and fatigue is huge for my son, doing things that people wouldn't even consider as a thing would make such a difference to him. Things like showering/cooking/being able to stand for a period of time/being able to walk for more than a few minutes without being exhausted. For him to able to spend time with friends without knowing that this will wipe him out physically for the next 4 days. My son wakes in the morning tired and goes to sleep tired, it's draining for him. My older son is only 1 year older and does not have Barth, he has lived away from home the last 3 years while at university and I know that my son who has Barth would love to be able to do something like this but due to his fatigue this is not possible. He is currently in his 3 year studying at university but has to stay at home and be driven to and from university so that he can reserve any energy he has for his studies. He wants to teach chemistry, we have always encouraged him to reach for his dreams however I have no idea if he will ever be a reality for him due to his fatigue. My son wants to be a contributing member of society, he wants to be independent, he wants to live his life to the best of his abilities and a drug that offers him some hope of this is a wonderful thing.

Ashley A.	It would help save a friends son who is only 7 months old.
Brandy A.	I was the childcare provider for a child with barths, the impact would be great on this child if he could walk, run or jump with his classmates or his little brother.
Cross A.	I would be able to hang out with my friend more often.
Holly A.	My child died from Barth Syndrome. Due to the limited drugs available to treat the symptoms of Barth Syndrome elapretide would greatly assist in greater treatment options.
Isabel A.	It would give hope to the child and families to have a happy, normal and wholesome life.
Jay A.	My brother [A] has Barth Syndrome and suffers from severe fatigue, a treatment which could potentially alleviate some of this burden would be incredible to his daily life. Simple activities such as washing / cooking would make him feel so much more independent which would give him a greater opportunity to lead a better and more sociable life.
Jenn A.	It could save a life of a deserving little boy, and give his family a chance to watch him grow up into a man.
Jim A.	It would help my nephew with his symptoms and my neice with the stress of taking care of my nephew.
Josanne A.	It would have a life saving impact on the life of my son.
Julianne A.	Would help my friend's son survive!
María A.	Will give quality of live and longer life. The patient will be very healthy and independent
Richard A.	[A] would benefit immensely, by giving him the energy he needs to carry out his hobbies interests and employment to a much higher level. And greatly improve his quality of life
Shaun A.	It would be a potential to the debilitating fatigue! Please push this through for hope to individuals living with Barth Syndrome.
Shirley A.	It would help my nephew to deal with his disease. It would alleviate the stress upon my niece and nephew.
Tal A.	my child [T] has barth syndrom, and we hope it will help him with the fatigue, he suffer from.
Tandi A.	Quality of life
Tiffini A.	It could help give my son a better quality of life. He would possibly be able to participate in activities for a longer period of time.
Tina A.	Would have helped my son in so many ways. Build strengths.
Tommy A.	My son suffers from severe fatigue due to Barth Syndrome this stops him living a normal life compared to his peers and as a parent it is heartbreaking watching and supporting this on a daily basis. If my son was not as fatigued he would be much more socially active which I believe would lead to a whole new outlook for him as he is severely restricted at the moment and suffers for days if he has a day which exhausts his energy which is very hard to stop as he just wants to mix with his peers.
Vigdis A.	He might not have needed the Berlin Heart wich broke down and took his life

Abby B.	It would increase his quality of life and provide an opportunity for him to do things he wouldn't be able to do otherwise, opening many doors and opportunities for him
Alanna B.	Both of my brothers struggled with fatigue; this drug could have helped them have more energy and maybe get to do more activities that their peers enjoyed.
Alex B.	Better, more energetic life for my son
Alysha B.	Anything to help my family member have a chance to live a longer more normal life.
Alyssa B.	Could help save my nephews life!
Amanda B.	It would help my friends' 2 year old who lives with Barth Syndrome.
Amy B.	Elimipretide offers a better quality of life for my grandson.
Andrew B.	If elampretide would make even a moderate difference in energy level it would be a game changer. An improvement of one to two hours a day or even a week could make a substantial difference in quality of life. There is rarely a day that goes by where I do not have to be conscious of my fatigue and manage my energy levels. As a result, it has impacted my career and personal life in significant ways. A chance to mitigate those issues and to gain a semblance of normalcy in life would be greatly appreciated.
Benjamin B.	This could potentially cure him or at the very least help him live a easier more normal life.
Bianca B.	I wish my nephew will have opportunity as other Barth boys to take this medicine and feeling better
Bill B.	It could change [H]'s life.
Bly B.	Knowing that there's something I could take to help with my endurance, energy, heart function and overall wellness is very exciting!
Bonnie B.	I had the child as a student in my classroom with this syndrome when he was very young, having this available would have helped increase his stamina and endurance, but have an even greater impact now. He has so much potential and deserves to try to achieve it.
Brenton B.	My older brother has been affected by Barth syndrome since a young age and he had a heart transplant due to complications. This drug could possibly be a life changer in my brothers life and other people affected with barthsyndrome. It has the potential to increase the energy of anyone with barthsyndrome wich could make an astounding difference in everyday life for them.
Camilla B.	Hope for the future
Carrie B.	All people who need a medication to combat a known medical condition should have access.
Claire B.	Fatigue has often affected day to day activity and what my nephew has been able to do. After simple short walk to the postbox, he had to ring his dad to carry him back home. Nobody, especially children should have to suffer the effects barth syndrome has on their day to day lives and jumping though hoops to get a drug that may offer to combat such common symptoms is heartbreaking too.
Cynthia B.	It would help the child regain strength to play baseball again and play with friends more actively.

Daniel B.	Saving the life of a love one or friend, in general anyones life, it would impact many with Barth Syndrome
Danielle B.	My son and brother have Barth Syndrome
Daryl B.	It will save my life and many more to come!
Dave B.	Could save his life
David B.	May save the lives of 2 of our grandsons that have [Barth syndrome]!
David B.	Let's get r done!!
Diane B.	It would be the life saving drug in insuring my grandson a long and healthier life! Please please please!
Donna B.	This would help greatly for a little 3 year old friends son who has Barth. He so needs to trial it
Edwin B.	Will improve quality of life
Elena B.	Very important
Elizabeth B.	It would provide my friends son a treatment that wasn't an option in the past. This would be huge for their family.
Ella B.	They will have a better quality of life with increased energy. [E] will be able to enjoy his life with his friends and family so much more with the help of this drug.
Gretchen B.	Extreme muscle weakness. Unsteady gait. Weakened heart.
Haley B.	This could help my coworker little one beat the odds of Barth Syndrome!
Helen B.	I have a niece who died and her twin who is living with barth. Anything to aid and assist, would be a god send
Jasmine B.	My friend [A] has Barth syndrome and struggles with tasks that the rest of us take for granted. Access to elamipretide would change his life immeasurably. As friends we do a lot of outside activities and [A] would be able to join us on all our escapades without getting tired and suffering from fatigue. It would also give him the opportunity to start a full time job which I know he would absolutely love.
Jason B.	Give my son a chance to live. He is a good kid. We need more good people in this world to make it a better place. It would also relive some stress that my family carries every day. It would give us hope. Hope can do great things.
Jeanne B.	Could save the lives of our 2 Grandsons that are living with [Barth syndrome]!
Jessica B.	The approval of elamipretide could CHANGE [L]'s LIFE.
John B.	Son is constantly fatigued

John B.	My son [H] is 8 years old and has Barth syndrome. [H] fatigues very easily and it effects his every day life. It is very hard as a parent to see him lag behind his peers on the playground, at PE, or even a simple walk from the classroom to the library. Since he is 8 years old, it is difficult to know how all of this makes him feel physically, emotionally, and mentally. It impacts the way he feels about himself and his self confidence. Hearing from a grown man like [W] with Barth syndrome, was extremely emotional and touching for me. When [W] said he did not want to go back to the old [W], I felt like he was speaking for [H], and communicating to me how bad life is for [H]. To think that [W] got a glimpse of what a body without Barth syndrome should feel like (or at least some fraction of that), something completely different that all he has known his whole life, brought me an immense amount of hope for the future of the boys and men affected by Barth syndrome. Please help.
Joseph B.	My nephew is at risk for the complications of Barth's Syndrome. This treatment can help him safely live a more normal life.
Judith B.	The approval of this drug, elamipretide, could CHANGE our Family Member's LIFE for the better!
Kara B.	Potentially save the life of my friend's son!
Kelsey B.	It could potentially change our sons life. It could help him be able to live his life to the fullest without the devastating symptoms and draw backs that Barth syndrome creates; such as fatigue. He needs all potential options available to live a wonderful life he so much deserves!
Kerry B.	The availability of elamipretide means the chance of a life that I dreamed of for my son. The life that I worked so hard to give my son but was stolen from us by this syndrome. Seeing the statistics from the trial and the participants comments, it brings me such tears of joy and hope for the future. It gives me faith which is something I lose often with no cure for Barth syndrome. This medication could help my boy be a boy! It's a chance. It's an opportunity. To me it likes hitting the lottery. The availability of elamipretide will be an absolute god sent to this community. I hope the evidence is obvious as to how badly these boys need elamipretide. Thank you.
Kevin B.	It could give me the energy to live a more normal life.
Leah B.	It has improved the quality of life by increasing muscle strength and stamina throughout the day.
Linda B.	Give my grandson the chance to live & thrive especially in school since he tires easily, needs fine & large muscle skills to learn reading & writing, enjoy normal socialization w peers. Barth is such an all system disorder that could take him from us in an instant. He didn't cause it, can't control it, nor can he cure it. However, this drug may improve his quality of life why not give all our beloved Barth boys the chance ? You can always stop it, for thousands of Barth family members & friends PLEASE give our fellas a chance.
Mark B.	Life changing. [Simple]
Marykate B.	Giving my brother the opportunity to continue his path towards health!
Matt B.	Only 255 boys live with this very rare terminal disease, while effected group is small the for cure is everything to massive. Please help

Matthew B.	The availability of elamipretide would allow Barth-affected individuals to live fuller, more active lives, with less pain and fatigue.
Matthew B.	Elamipretide would drastically improve my brother's conditioning and allow him to participate in more family/friend activities.
Meg B.	More resources for family
Megan B.	More energy, better quality of life!
Megan B.	Reduce symptoms and side effects Barth syndrome and improve quality of life
Megan B.	Having access to a treatment would be LIFE CHANGING for our family, specifically for my son living with Barth syndrome. Although he is currently 8yrs old and not old enough for the drug at the moment, we are super hopeful that it could be available to him in the near future, as Elamipretide has greatly improved the quality of life of the individuals that have been on the drug. I also feel that the approval of Elamipretide would open doors for potentially more treatments options for Barth syndrome in the future. Approval would provide so much HOPE!
Melissa B.	Give him a better chance at normal life and a chance at a longer life than what he currently has
Michelle B.	A friend of mine, her son passed away earlier this year. He had Barth syndrome.
Nancy B.	Would potentially save his life.
Nicholas B.	Brother has Barth syndrome, being able to even slightly reduce fatigue would result in a major quality of life improvement. Regularly does he have to miss out on activities, traveling, due to fatigue. For instance we regularly have to make trade offs on what we want to do/go see and what we realistically to not over assert himself.
Nicole B.	This drug would change my nephews life. Be able to keep up with his brothers and friends and not constantly be tired. Help maintain a better baseline for his heart.
Noelle B.	My friend who is a registered nurse whom just had her first child, is unable to truly enjoy all the endearing things about first time motherhood. She was a very strong woman from the mother I met her, but now with her Barth baby life has just been one up and down of doctor appointments and constant worries, meanwhile she has to watch our other friends enjoy all the typical wonderful milestones with their non-Barth children. I would love for her to just feel one inch of normalcy if this medication could provide it.
Oliver B.	Having Barth is a struggle everyday, being able to do anything is a struggle and illness is a constant battle, if there is a drug that even remotely help any aspect of struggling day to day then it's going to help
Olivia B.	This should be available to help all with Barth syndrome in anyway possible.
Pam B.	Great impact for the health of our grandson
Pamela B.	As an extended family member of a child I loved who lived and died with Barth Syndrome, I ask that you give all Barth patients access to elamipretide. As a nurse, I expect both leadership and compassion from the FDA to give Barth kids a shot at better quality of life. How much they need it would take Shakespeare to express. I cannot help them. You can. You must.
Rachel B.	Help my friends son immensely.
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Rachelle B.	My step son had this disease and Every day I wish I could help him so if there is a drug out there to help these patients then they should be allowed To have access to it
Rebecca B.	Will help a friend with fatigue.
Richard B.	I think it could help my grandson.
Rosemary B.	Increase in energy level despite heart condition would be life changing, elevating quality of life to a level never attained before.
Sara B.	Our son participated in the drug trial. His energy level and subsequently his quality of life has improved significantly. The drug has been truly life changing. I look forward to the day his nephew who is affected with Barth syndrome has the opportunity to take the drug. Thank you.
Sarah B.	Gives more treatment options
Sasha B.	Two of my younger cousins have barth syndrome so this is something that is close to my heart as I love them both dearly. I hope this drug is approved and becomes available to those living with Barth Syndrome to increase life expectancy and also quality of life.
Sharron B.	Hopefully help my g grandson.
Shawn B.	Confidence
Shelley B.	Availability to a specific therapy for Barth syndrome would have sped up the diagnosis process because doctors would have had a reason to search for a diagnosis. It could have made a difference in my children's quality of life. And they might still be here. When asked why he chose to participate in research My son responded "Because the research that [i] participate in might one day save my life. If it doesn't it will make a difference in the lives of others." If he were here he would be advocating for the opportunity to try.
Sherri B.	LIFE for [W]♡
Simon B.	Improve their quality of life
Stephanie B.	Improve his muscle stamina to give him better quality of life
Susan B.	Greatly needed! [H] is a child and this drug would greatly improve his longevity
Tallon B.	Although my child is only 5 months old and we've yet to see any complications, despite the fact he was diagnosed with Barth in the womb, availability of any drug that could help a child will Barth syndrome would be especially beneficial. Should my son start having complications down the road, I'd want access to every possible aid that could help him.
Terry B.	My cousin [L]'s grandsons have this disease. Anything that can help the boys is good. We are talking about two boys 2 yrs and 6 mon.
Tracy B.	We have two boys with Barth syndrome, so the impact is even greater. One specifically struggles with reduced heart function and has been in heart failure multiple times. To have more peace of mind with his heart function and increased energy would be life changing. Day to day tasks require a lot of energy for our boys, so any kind of help would be greatly noticed. Their quality of life would improve so much. Whether it's handwriting or walking, both take everything within our boys to achieve. Less falls and accidents due to fatigue and muscle weakness, would be so incredible!

Veronica B.	My niece has a son with Barth Syndrome. His quality of life could be greatly improved. Please help him!
Vivien B.	improved cardiac function, muscle endurance and fatigue improvement.
Walker B.	As a participant in the TAZPOWER study. If I were to describe my results I would say, "I HAD Barth Syndrome". As I don't live with the symptoms of Barth Syndrome anymore. I've also described the changes to Dr. Vernon using terms like the "old [W] " vs the "new [W]" as I truly feel like a new person. I also look forward to seeing how much the study drug can help others.
Warner B.	Son in trial with very promising results. Grandson will benefit from drug as same mutation as son. Grateful for Elamipretide.
Wendell B.	Improved quality of life
Whitney B.	Hopeful if results and data are promising .
William B.	It will reduce debilitating fatigue and potentially improve important baseline health measures (which have been affected by Barth Syndrome, including LVNC cardiomyopathy).
Abby C.	It would help my cousins immensely. It would improve his way of life and help to lesson the worry upon his parents.
Alex C.	It would drastically improve his quality of life!
Angela C.	Energy levels are increased granting my sons a chance at a more normal existence.
Angela C.	it may ameliorate the function of skeletal muscle and reduce fatigue
Ann C.	More energy and hopefully live a longer life.
Bonita C.	Would help dramatically and others need the help too
Brian C.	I am 46 years old and living with Barth Syndrome. I suffer from extreme fatigue, weakness, dilated cardiomyopathy and many other symptoms common to Barth. I have a lower quality of life and my length of life is considerably shortened. Given the safety profile and potential benefit of elamipretide as demonstrated in the clinical trial and open label extension, I greatly desire the opportunity to use this drug. I understand that the drug may not help me with my Barth Syndrome, but that it is worth approval because of the potential benefit to other people in the Barth community.
Brie C.	My 10-y-o son suffers every day from Barth Syndrome. He has had 2 heart transplants, many hospitalizations and debilitating muscle weakness and fatigue. There is nothing more I would love than to see my son participate more fully in life, no longer needing a wheelchair because of overwhelming fatigue. I want him to have the energy to leave the sidelines and join his friends in the games. He deserves that. Every person affected by this iniquitous disease deserves the opportunity to live their best life. Please consider offering the off label use of elamipretide to patients with Barth Syndrome. Please let them live their best lives. Thank you.
Cari C.	Has considerably helped a friend living with Barths.
Carly C.	Save [H]'s life.
Christy C.	Help [H]!!!

Claudia C.	I would literally have moved heaven and earth to improve my son's quality of life (after 13 months of desperately searching for a diagnostic) and when I found him [F] had his first hospital stay a week and passed away at 15 months. I was looking for a pill to help him with a treatable disease, and I came across a multi-systemic disease that doesn't even have a palliative yet to improve symptoms. We need elamipretide, the kids with Barth and their families suffer too much, in memory of my son and all the children of the community that is no less important as a child.
Darla C.	It would give him quality of life he does not have now. He would feel stronger and better every day and have some normalcy in his young life.
Donna C.	I'm not family, but the people I know are like family. They live next door to me. We are called nanny and papa to the little one we know with Barth syndrome! We were at the hospital when he was born, we watched all the problems that went on with [C], we were there when the team from Vancouver children's hospital came in and prepped him to fly him back to Vancouver hospital, with dad by his side. Their other son and I watched the helicopter leave with his daddy and little brother in it. Momma did not even get to hold her baby boy. She had to be taken by ambulance on the ferry to children hospital where the whole family stayed for months while they tried to figure out what was wrong with [C]. We went over a few times to be with them and the family. It's very hard to watch a new born with tubes come out of him, and being monitored by a nurse every second he lives, being told that he is not going to live, and if he does how long will he live for. Then for momma and daddy having to learn how to feed him, change him, give him meds every day, shots all the time, having to take him to the doctors constantly, and watch him grow just a little bit at a time, see him not walking very well, having to wear walking braces, breathing problemsa long list of problems I could rym off. All the while, wondering if this is his last breath, is he going to live a long life, are we going to have to say goodbye to early, is he going to get sick by your common cold or flu and not get better, or have to struggle for weeks or months to get over it. Or in the summer when it's to hot, having to make sure he doesn't over heat, washing how He wants so bad to play and keep up with his brother, cousins, and friends, then getting so tired that he has to go nap to rest his poor little heart. How he will be if and when he goes to school. He is such the sweetest and smartest little guy you ever want to meet. This new meds would hopefully make a big difference for [C] and his loving family. Maybe he could live a long beautiful life. Maybe he could
Doug C.	This could be life changing!
Edith C.	It would give my son [J] age 15 a better quality of life, I believed he deserves to live in the fullest and enjoy as much as he can his daily activities.
Eleanor C.	It would potentially improve his quality of life and alleviate symptoms of fatigue which impact on his quality of life daily.
Eva C.	Significantly. Every day is a challenge. The stress level being the parent's of a child with bartg syndrome is like no other daily. Any possible assistance in helping family child and extended family would be a much welcomed relief

Francisco C.	Disponer de la seguridad de que la salud de mi hijo será más fuerte en un futuro y de que su calidad de vida se puede equiparar a la de la gente sin problemas de salud crónicos. Ahora mismo, mi hijo se cansa al andar un poco y a lo largo de sus 18 años de vida no ha podido practicar ningún deporte. Me gustaría tener la tranquilidad de que sus problemas de fatiga se reducen y de que su calidad de vida es buena en un futuro. Machine translation: To have the assurance that my son's health will be stronger in the future and that his quality of life can be compared to that of people without chronic health problems. Right now, my son gets tired from walking a bit and throughout his 18 years of life he has not been able to play any sports. I would like to have the peace of mind that your fatigue problems are reduced and that your quality of life is good in the future.
Frank C.	The approval of this drug, elamipretide, could CHANGE our friend's LIFE.
Gale C.	Elamipretide should be available to every Barth Syndrome Most importantly, they suffer from fatigue all the time and elamipretide has been proven that it can improve and provide the energy needed to just make it thru the day. This will greatly improve the quality of their lives. My son suffers from many symptoms of Barth and complains daily of fatigue and no energy and gets tired walkimg up and down stairs and after walking just a block3. He regularly takes naps because exhaustion and migraines. I believe this drug will increase his energy level enough to
Genesis C C.	it would have helped my son's life in the future had he lived passed 7.5 months.
Gerald C.	Personal family friend will benefit from the drug
Guadalupe C.	possibly my grandson would still be alive
Helen C.	This could help any one of our boys, please help us support them more than we can!
lan C.	My son died of heart failure at age 18. We would naturally have lived to have seen him enjoying a better, longer life. He was a inherently happy person despite a problematic heart function, along with muscular-skeletal issues.
Isabel C.	Es positivo para todos los miembros Barth Syndrome, para su fatiga.
Jack C.	I have persistant and chronic mitochondrial myopathy and the approval and availability of Elamipretide could greatly relieve these symptoms.
Janet C.	improve his quality of life
Jasmine C.	My child is severely affected by low muscle tone and fatigue. This would be life changing for him.
Jason C.	I believed this would be beneficial for me and all the others that have Barth. The limitations that I have, hold me back to do things that I would like to do.

El hecho de mejorar mis capacidades físicas podría aumentar mi valor para trabajar en la disciplina que estoy estudiando: técnico en emergencias sanitarias. Además, también podría mejorar mis accesos a algunas localizaciones ya que cuando subo escaleras me canso mucho. También podría verme con la capacidad de realizar algún deporte, hecho que no he podido llevar a cabo debido a la enfermedad. Finalmente, el hecho de confiar más en mí mismo y saber que tengo unas capacidades físicas mayores y que mi resistencia es mayor también proporciona una estabilidad emocional que tendría un gran impacto en mi nivel de vida. Automatic translation: Improving my physical abilities could increase my courage to work in the discipline I am studying: emergency health technician. In addition, it could also improve my access to some locations since when I climb stairs I get very tired. I could also see myself with the ability to do some sport, a fact that I have not been able to do due to illness. Finally, trusting myself more and knowing that I have greater physical capabilities and that my stamina is greater also provides an emotional stability that would have a great impact on my standard of living.
[J] who passed away in 2004 from Barth syndrome he would have been eighteen next year. His sister are having children of their own and possibly could be affected themselves. We will be doing testing on them this week to find out if they're positive for Barth syndrome. Which means their children will have to be tested, one is a boy and one is a girl. So for me it would make a big impact on my family, grandchildren and future grandchildren to come.
My nephew has Barth syndrome
Stay much more calm about my brother health.
I would not have lost my Grandson. My Grandson was 7 months of age when he passed away because of Barth Syndrome we need to find. Cure or something that will aid in a longer life
the difference would be amazing
Any chance to help my precious nephew to have relief from any one of many complications due to Barth Syndrome has to be taken. This shows promise to help this amazing child who has suffered, while still smiling, for his entire life. Please help to give him hope for some relief of fatigue and give him a chance to walk and play with his family in a way he's not been able to.
Cousin
It could save our friends life!
It could save his life and give him the chance to be a normal little boy.
It will save a little boys life
Extend his lifespan
It would potentially save/ extend my best friends nephews life!
Less fatigue, better quality of life to endure school and other activities.
Es un bien para los miembros Barth Syndrome, para apaliar la fatiga que tienen.
If elamitpretide were to be approved it could have impacted my sons quality/duration of his life.

Melissa C.	It would significantly help my friends child quality-of-life.
Michael C.	This drug has changed the life of those who have taken it by drastically improving their quality of life!
Michael C.	Fatigue impacts my quality of life on a daily basis. The opportunity of having a medication that could reduce these symptoms would have a positive impact on my quality of life.
Michelle C.	His quality of life could or may be better.
Nancy C.	I have witnessed, first hand, the positive effect of this drug on a young man in my community.
Niamh C.	This would enable my friend to live a better quality of life, giving him more opportunities to day to day activities that he struggles with.
Paola C.	We wish giving to our son this hopeful opportunity for getting up his quality of life
Pat C.	It would help my grandson with his fatigue and energy level.
Paul C.	My best friend lost their son to Barth.
Peter C.	Our 14yr old son has weakened heart muscle and fatigue. Elamipretide may improve his quality of life and ability to work.
Rhiannon C.	My 2 year old son was in heart failure and currently takes 4 cardiac medications to keep his heart functioning. This medication could help improve his function.
Robert C.	This drug would give him a better quality of life and hopefully make him stronger to be able to cope with the physical challenges he faces every day.
Samuel C.	I feel that this drug could truly help with day to day life
Sharon C.	Our son has heart failure, muscle weakness and fatigue and struggles on a daily basis. Having the opportunity to improve those disabilities would enable a better quality of life
Stephen C.	Our son was diagnosed with left ventricular cardiomyopathy with non - compaction at four months old. Subsequently, he was diagnosed with Barth Syndrome. He suffers from muscle weakness and general fatigue during the school day. Any improvement in strength, stamina and obviously cardiac output is an incredible development and one our son woud hugely benefit from physically and also mentally. Things like not relying on a wheelchair, keeping up with friends in the playground, on the beach and generally lasting the day along with the rest of us would mean so much to him and us. Please take this opportunity to help so individuals and families.
Terasa C.	My Nephew
Tonja C.	could save his life give him a better benfits for life
Tony C.	A good friend of mine has [Barth syndrome] and this product helped him immensely!
William C.	increased energy levels and increased recovery rates after exercise
Abderrahmane D.	will probably save my son

Abram D.	Having elamipretide as a treatment option could mean a new lease on life. Maybe with elamipretide it would give me enough energy so that I could run outside, even walk around the block maybe with my brothers. Right now I can go a few feet or a block on a good day. I'd be able to chase my baby brothers, further and more outside of the living room, and have more energy to play sports like baseball. Because right now, I can't play any sports, I don't have the energy even for modified sports. Having elamipretide as an option means perhaps I wouldn't have to ride an electric scooter at school to get to my next class just down the hallway. I could fix myself a snack, like cutting cheese off a cheese block, instead of opting for a processed wrapped cheese slice from the fridge, because this takes less energy and sometimes I'm simply too fatigued to even cut a slice of cheese. If elamipretide gave me more energy I would feel more like participating in school because even raising my hand and conversations fatigues me. I go to school part time because of this. Elamipretide as an option could give me a chance to participate in life instead of having to sit on the side and be an observer to the class, to kids on the playground, to friends playing sports and running around the neighborhood, to my family playing ball in the back yard, to my brothers blowing bubbles, to knowing I could attend events and make it through rather than leaving early and exhausted, such as a teen dance once made me feel for four days afterward. I'd love to participate in life more than I am able to now.
Aldo D.	Elamipretide would decrease my fatigue levels enabling me to walk further or even run. Elamipretide would increase my muscle strength enabling me to lift heavier objects and help out more around the house. Elamipretide may not work for every affected Barth individual but, if it can help even a few, I believe it is worth being made widely available. Seeing as it greatly increases muscle strength, Barth individuals like myself may not ever need to worry about heart transplantation or re-transplant seeing as the heart is a muscle. I greatly believe this drug, Elamipretide, has the potential for great use as the first treatment ever, specially designed at treating Barth Syndrome. Please approve this drug. Thank you.
Anna D.	Could save my friends sons life!
Anna D.	Anything that works to provide a better quality of life or safe a life is instrumental to our boys with Barth and their families.
Brandi D.	I firmly believe it would improve my son's quality of life by improving his cardiac function, his strength, and his endurance. He is almost 5 so we are only at the beginning of this journey and we are already keenly aware of the continued impact Barth Syndrome will have in limiting his life. We desperately want our son to have the opportunity of a limitless life. One that doesn't involve countless medical and therapy appointments, one where he can thrive with his peers, and, honestly, one where we aren't always concerned in the back of our minds that he will most definitely die prematurely. No child, adult, or parent should live with that if there are potential therapies available. I humbly ask that you please consider approval of elamipretide to include pediatric use. We would be excited to try it, injections and all, to give our son the chance at a limitless life.

Brianna D.	My boyfriend is affected by Barth. It impacts his stamina and his ability to work or do other things. It can impact our schedules and when he is sick/hospitalized it can be a great stressor and has an outsized effect on our lives. Any treatment that could reduce or help diminish some of the symptoms would have a significant impact on both of our lives.
Bryan D.	I am the father of a boy affected by Barth Syndrome. I have been following Elamipretide very closely since we first heard of it's potential treatment for my son. It seems very safe and has been used for other disease treatments before for years. It would greatly benefit my son's quality of life and give him more energy to get up and out of the house. He currently only has enough energy to walk up to the street corner and back (approximately 125 meters) and he is wiped out the rest of the day and sometimes part of the next day. He is on ACE inhibitors, cardiac glycosides and has been on Lasix. Elamipretide could possibly replace these medications if his cardiologists and hematology see a significant improvement and with fewer side effects. He is taking pills 3 times a day and a stool softener twice per day. It is not just these boys skeletal muscle that is affected it is EVERY muscle in their bodies which includes his cardiac and digestive system. This makes it difficult to plan a trip away from home and attend school as he can't hold it when he does need to go to the bathroom. He often has diarrhea or constipation, nothing in between or what's considered normal stool. He is often nauseous after eating and eats very little as it is a chore for him to chew his food up fine enough to swallow. He has had OT, PT and speech therapy since he was a toddler and continues to have trouble eating certain foods and speaking clearly. Please approve Elamipretide for use in our boys. I believe it would greatly enhance their quality of life and help their self-esteem by allowing them to do more things for themselves by becoming stronger and having more endurance. Thank you!
Carla D.	Better quality of life
Carmen D.	We need to find a medicine.
Cassie D.	It would help my little buddy lead a better life.
Charlotte D.	My son is 14years old and only recently diagnosed with Barth Syndrome. He's lived 14yrs in the shadow of his friends and sisters because he's struggles to do normal activities due to exhaustion and pain. Holidays, days out and even meals out are a challenge as he gets tired and irritable and this effects the whole family. School is tough as days are tiring and it's not just physical tiredness, his tiredness is like no other and stress can tire him out. His body just doesn't function in a normal way and for there to be something that could help with this and give him a quality of life would be totally life changing for him and our family. I want him to have a normal life and be able to live his life to the full.
Christy D.	Hopefully a friend's son will receive some relief, as she has already had a don die from the disease.
Colt D.	I could have had another brother in law. I am hoping the drug will simplify the life of the other.

Danielle D.	It's a struggle every day to have to be super mom, it's a constant worry and I just want this to be treated like all other syndromes, it's serious and there should be no reason why it shouldn't be
Deborah D.	Please help these families. These children need your help now.
Deborah D.	A dear friends son passed away due to Barth Syndrome.
Diego D.	Probably will be the life saver of my son
Edward D.	Life changing and life extension.
Frank D.	Greatly because it is such a life or death thing with the boys all over the world that have this!
Gissela D.	I have a brother who passed away from Barth Syndrome in the early 2000s. In 2003 my 2nd brother with Barth Syndrome was born. His was detected super early. He is now 16 years old! Even though he is on 4 different medications, he still suffered from fatigue, muscle pain and just not being able to physically keep up with other "normal" kids his age. Elamipretide would be of great benefit for my brother and everyone else who suffers from Barth Syndrome.
Henry D.	[M] could have lived a more active life.
Jacqueline D.	A family member of mine who is 8 months old has barth and is in need of assistance
Jim D.	I cannot yet answer specifically how it would affect us.
Jules D.	I hope this drug will improve the everyday life of patients with Barth Syndrome. I think it is important to have access to it.
Justin D.	It could save their life
Kevin D.	Hope, a product that has shown any quality of life improvement is a must. These children live with little or no support except through the barth family network. Hope is all we and the children have that miracles can happen. The current lack of any direct therapeutics for this affliction means an ongoing deterioration of meaningful and productive life for these children and most certainly an early death. As a parent the crushing day to day reminder of your child's condition is paralyzing and heart breaking. Please give us some remanence of hope.
Kim D.	Could of helped my friends son live past 11 years old.
Kim D.	It could save my grandsons life
Kimberly D.	A child's life could be prolonged or saved
Kristen D.	Quality and extension of life
Mandy D.	Will provide the chance of a potential successful treatment to the person we love
Mark D.	The hope is that it would provide relief to some of the devastating symptoms of the condition including the strong fatigue felt by most patients with Barth Syndrome.
Mary Alice D.	It would hopefully improve my grandson's quality of life by alleviating his fatigue and muscle weakness.
Michaela D.	Elamipretide may have given our son that extra bit of energy needed to have a more normal life - to go to university, get a job, have an independent life

Nicholas D.	The most debilitating symptom of Barth syndrome for me is fatigue and muscle weakness. I'm unable to do many things that I want to do, things that most people don't even consider to be things. Taking a shower, preparing food for myself, and basic household chores are absolutely draining. Nothing I do has any effect on my fatigue. My cardiac meds keep my heart function more or less stable, my GCSF keeps my neutropenia under control but nothing I do helps this fatigue. I know I'm at risk of a sudden cardiac arrest and death from Barth syndrome and any medication that could reduce that risk would be wonderful. But I don't actually think about the cardiac aspect every day. The thing that holds me back from doing the things and being the person I am inside, the person I would like to be, is the fatigue and weakness. I'd love to be able to go out with friends without them wondering why I'm so lazy, slow and unfit, without having to ask them to wait for me and without literally being left behind. For as long as I've known, this fatigue has just been something that I've had to accept, there has never been anything that can help. It's hard to think of things I would want to do because it hurts too much to think about things I feel I can never have. Having access to a medicine like elamipretide could open a door for me, one that would allow me to achieve my goals - an independent life, a stable career, the ability to support myself without the help of my parents or the state. I live in the UK and so FDA approval is unlikely to mean that I personally get access to the drug. I wish it did. But this drug could help so many people like me, so many of my Barth brothers. I would do daily injections of elamipretide for a year to even see a small improvement. Even a small improvement would make a big difference.
Nick D.	It would drastically change my son's ability to have a somewhat normal life
PALASH D.	My only son has barth syndrome. He has dilated cardio myopathy. FDA approved drug will save his life .
Patricia D.	It would allow them to live a healthy & normal life!
Robert D.	I have the pleasure to be an uncle of one of THE RAREST collectors in the game. [L] is an incredibly smart and compassionate big brother with an ultra-rare disease that affects the heart called Barth's Syndrome. Only 126 cases in USA. Now is the time our families have been waiting for, they've found a medication that can prevent the debilitating fatigue.
Robyn D.	Having this drug approved could save a small child in my communities life with Barth syndrome.
Sara D.	Wow, any help for our grandson would be wonderful. He currently has to isolate frequently to avoid infections.
Siska D.	Every person who has been diagnosed [Barth] Syndrome, should have te right to choose if he wants to use the new medicin[e] or not to improve the quality of his live.
Sonja D.	It would give the patients the choice and possibility to gain a higher quality of life
Tabitha D.	It could potentially help our friend have the energy to do basic daily tasks, be more productive, & have a better quality of life.
Tammy D.	It could improve quality of life, for our [L]
Teresa D.	It would give my grandson more energy to live a better life. Thank you.

Tiffany D.	It would help his over all day to day Life He gets tired walking out of our driveway He gets tired writing a paragraph for school He gets tired eating Something to help with fatigue could help with this I would hope
Wes D.	Hopefully for the better.
Whitney D.	It could potentially save my nephews life!
Alex E.	Although I don't suffer from the serious effects of Barth I still suffer from fatigue so I think that anything that can help with that would be [of] great help during day-to-day life.
Daune E.	We need this drug to help improve their quality of life; they need to mitigate the debilitating effects of this rare disease
leuan E.	As a sufferer of Barth Syndrome, I think it's important to not just sustain life, but also improve the quality of life where possible. This treatment will make it possible for individuals such as myself to do more for longer, and could mean I could at last have a worthwhile job. It may also mean that I am better placed to overcome & recover from medical episodes in the future.
lsabel E.	As a mother of 2 boys who suffer with Barth Syndrome I see that the effects that extreme fatigue Has impacted on their lives. The improvement shown in the treatment of the drug could mean the difference between life or death should heart failure or other medical emergency arise.
Jessica E.	Life saving, helpful, much needed!!
Joseph E.	Help tremendously
Kayla E.	It could greatly improve the life of my cousin [A].
Linda E.	Anything to save a life.
Lynn E.	We would like to have the option to try elamipretide to help our affected son with daily energy, muscle weakness and and daily health issues associated with Barth syndrome.
Ralph E.	The most debilitating side-effect of Barth Syndrome in my opinion is the chronic fatigue that carriers suffer; separate from the various medical regimes followed to counter-act the serious musclo & skeleto-myopathy, low white blood cell count and intravenous feeding tubes etc., the most difficult issue to face is the dis-connect between the hopes and aspirations of those diagnosed with this Syndrome when faced with the reality of chronic fatigue. In many cases, fatigue could be the difference between being able to function to an acceptable standard in a preferred field or area, or being able to keep pace with one's peers academically. Alternatively, this could result in having to choose a different, less preferred career path, or losing engagement and interest academically and losing ambition. Although from a scientific viewpoint the results to date show a 'marginal' improvement, to the affected individuals there was a marked difference in their overall well-being, which if the treatment is now withdrawn would have a detrimental impact not only on those directly affected, but also those hoping to be able to have access to this treatment in future.
Rowena E.	Improves muscle [strength] pls allow access to this medications by pts with barth syndrome
Angelo F.	Quality of life

Caitlin F.	Could potentially save the life of a lovely boy that I know who sadly has Barth syndrome. Anything that can be done should be done to help these people affected by it no matter the economic cost to Governments/Pharmaceutical companies.
Caitlin F.	It could potentially help those suffering from Barth Syndrome and save the lives of many lovely people
Carl F.	Could help
Cheryl F.	It could save my nephews life and give him a chance to live a more normal life without constant fatigue.
Christine F.	Could increase his lifespan.
Connie F.	It would improve [T]'s quality of life.
Don F.	Help family friend
Dorothy F.	It could extend this little boys life
Elisa F.	My grandson [M] might have had a longer life than 8 years old.
Elizabeth F.	This opportunity would have given us hope and priceless time vs Heart transplant and may have prevented such an early death for both my nephews . The Barth families currently need that hope and this may very well give it to them as well as precious time against this rare disease .This may be just one stepping stone towards finding a cure and we as families want to step forward and need this approved to do so . Approval may save 1 or more lives even just one life is everything
Grace F.	It would give my friend's brother a fighting chance.
Hayley F.	Life changing
Jacob F.	The drug has shown promising results and would help the lives of those that live from Barth Syndrome. This would be very beneficial to the organization in it's search for a solution to the problem of Barth Syndrome.
Joani F.	To help my nephews quality of life. He greatly enjoys outdoor activities. He deserves a childhood without so many side effects of this horrible disease.
Johan F.	When elamipitede would have improved the functioning of my mytochondria I would probably have less issues with fatigue in my daily life. I would also have more strength for activities like cycling or walking stairs and so on. And not at least I am convinced it could have a positive effect on the level of my heart faillure. To put it short: This medicine might potentially have a huge combined positive impact on my life. If neccessary i am also willing to take part in clinical trial if this helps me and others to get closer to a cure for Barth Syndrome.
Julie F.	Give opportunity for this drug to help live a full life without excess fatigue that has constantly been a problem for my son
Julie F.	More strength
Kay F.	Families are willing to try anything to improve life quality for any disease. Let them make informed decisions
Kylee F.	Give [C] a heart.
Lawrence F.	Give some hope and drive. Save a poor child the embarrassing experience of needing someone to carry his backpack just one example

Louise F.	The options above wouldn't allow me to chose both that are applicable iewe are parents to our six year old daughter living with Barth, and we are parents to her sister who died of Barth at the age of 3. I hope that statement speaks for itself. We have list one child to Barth and do not want to lose our other daughter. A drug that could improve her quality of life and those of others affected by this devastating disease, is a must.
Mary F.	It would give my Friend's Grandson, a life of being able to get out of his wheelchair and be able to play with his friends and live a much better life, PLEASE MAKE THIS DRUG AVALABLE TO ALL WHO SUFFER FROM BARTH'S SYNDROM. The availability of elamipretide would be a God's blessing, for Barth syndrome sufferer's, i pray every day of my life for a cure, please !! let this made available, to all who suffer from Barth's
Mary Jo F.	Quality of life and longevity
Michelle F.	This drug could have improved my son's quality of life. He would have been able to participate more in school and life without getting so exhausted and having to sleep and recover for several hours. He almost died at a year and half due to heart failure.
Nicole F.	It could be life saving for a sons friend.
Rachel F.	Reduction of fatigue
Sharon F.	All help is greatly appreciated.
Stefan F.	It would be an immeasurable benefit to get access to this drug for all people with Barth. It would help children and adults lead a better life where they could do the things they could only dream of before.
Catalin G.	Is very important for our boy, give us hope for a better life
Christine G.	It would have a very important impact on our step grandsons life. The impact would be huge. Giving him great chance to live a longer and healthier life.
Danielle G.	It would help alot
Don G.	It would help save our friends son. Please make it available ASAP! They need help!
Emily G.	The availability of elamipretide for a son who has Barth Syndrome would be life changing. Barth Syndrome is already life altering, and the thought of my son being offered something that could help him live his best life, brings me to tears! It means it's a chance at a life that we dreamed for our son, but was ripped away after our diagnosis. Seeing the statistics from the trial, and how much it's helped, brings me so much hope for the future! It would mean my son could enjoy life and feel close to "normal". It would mean my son wouldn't have to take days to recover, from one day of fun. It would mean my son would have the chance to exercise and not feel so tired out afterwards. He could do physical therapy, and have the opportunity to build up muscles that he doesn't have. This medication could give my son the opportunity to really live life like a boy and do all the boy things! We are praying that there is enough evidence to show how badly the Barth Boys and Men could benefit from this drug! I can't imagine what it's like living with Barth Syndrome like my son does, and how much it alters his life every day, but I do know we want to give him every chance in life to live it as "normal" as possible. Please consider approving this for our community, it would mean the world to all of us!

Eva G.	Relieve symptoms of Barth Syndrome
Jacob G.	I have Barth Syndrome
Jennifer G.	This helps with quality of life for those living with Barth Syndrome
Jill G.	Give an important member of our family a chance to live an improved life
Joan G.	it would reduce my grandson's fatigue
John G.	Any improvement to my sons heart function that he may receive to improve his life expectancy will be a blessing.
Joyce G.	Anything that can help my grandson live a better life! It's so difficult for the entire family to see his daily struggles. Just to have more energy and not being so exhausted would help him fit in with his peers. Children that don't understand his struggles to keep up with them is heartbreaking to not only him but his family as well.
Kathleen G.	[H] would have a higher chance of living a long life and a life where he could participate in normal activities that other kids get to do day-to-day! Also, when a sibling comes home sick from school, the parents would not have to be concerned that it would be life threatening for him!
Kristen G.	My cousin's 8 year old is living with Barth and this drug could mean a much longer, healthier life for him.
Laura G.	It would give my nephew the chance to live a more normal life in comparison to others his age and participate in activities that may require more physical exertion.
Linda G.	It would keep other families from experiencing the loss of their child.
Lisa G.	It would help my son have less fatigue abd therefore be able to participate in life more.
Michael G.	I could have saved one childs life
Michelle G.	I have a family member who has participated in the trial. His muscle strength and stamina has been increased throughout the day while taking the drug as a trial.
Mitchell G.	I would like it to allow me to have the energy to go to university and hold down job.
Nada G.	It will help my son to restore and release his cells energy, this lead to improve his heart and immunity functions. Will decrease the life threatened for many boys who live with Barth syndrome.
Rob G.	Improve quality of life
Robert G.	May extend the life of my grandson.
Rudy G.	A stronger heart , better muscle tone and the better life and possibly of a longer life.
Rudy G.	Mu nephew had barth. If he had had access to this then he may still be with us. My family suffered the largest loss of my 41 years of life. We watched my nephew suffer and be in the hospital for over a month while trying to help him every day. The pain and suffering was almost unbearable. We made it thru but my nephew didn't. Even 8 years later it's still hard to deal with his loss. If this would help others to not have to endure the same hurt and pain then I would do anything to help others. Please help other families and individuals with barth.

born in heart failure, and required a heart transplant to survive. We are very grateful that his new heart is doing well, but every part of his life remains impacted by Barth Syndrome. More specifically, his quality of life. As an eleven year old, he struggles in school, fatigues easily and has very low muscle tone. His body does not sweat. So, he often misses recess, and the important bonds and lessons that happen on a playground. He can't just run down the street for a game of pick-up basketball in the summer. It is too hot and his body is unable to cool itself. It breaks my heart to see his dissolving passions because his body just can't keep up safely. I am hopeful that elamipretide may one day help bridge the gap between his stamina and strength and that of his peers. I also wonder if elamipretide could have prevented him from even needing a heart transplant. Donor hearts are finite, precious gifts. Could this be the thing that makes just a few less children need them? It is my deep hope, and faith, that elamipretide will be an available treatment for Barth Syndrome. It has already been approved for another mitochondrial disease, so it must not be detrimental. Although there are very few people who live with this disease, they are not just numbers, they are real people. These boys and men matter. If your brother or son was diagnosed, he would only be one person. But, wouldn't he matter?	Sandra G.	It would have improved his quality of life.
Syndrome, I have seen it with my own eyes. My brother is a patient in the elamipretide study. I have seen him develop into a stronger, happier, more confident person since beginning the trial. He has chosen to tell a very limited number of people about his participation. Yet, several lifelong friends have noticed a change in him. He now has the physical and emotional energy to want to participate in all that life has to offer. Before elamipretide he barely had enough energy to do the bare minimum. As a child, he was very well liked and respected by his peers. Enough so, that he was elected the president of his senior class. But, there were no friends coming over to our house. As much as he wanted them to, he just didn't have the energy. Even as a young sports enthusiast, he did not have the stamina or muscle tone to play. Our father once pointed out that he could not run. He was not strong enough to get both feet off the ground at the same time. I can't remember a single time that our parents had to tell him to go to bed, he was always exhausted. He was unable to work while in college. Although he would have liked to, he could not have done so while maintaining his grades. Even after graduation, he struggled making friends because he didn't have the energy to get together after work. Since beginning the elamipretide treatment, he smiles more. He has the energy to enjoy life. He enjoys exercising, and wants to any. He is showing up, and participating fully. My son also has Barth syndrome. He was born in heart failure, and required a heart transplant to survive. We are very grateful that his new heart is doing well, but every part of his life: As an eleven year old, he struggles in school, fatigues easily and has very low muscle tone. His body does not sweat. So, he often misses recess, and the important bonds and lessons that happen on a playground. He can't just run down the street for a game of pick-up basketball in the summer. It is too hat and his body is unable to cool itself. It breaks my heart to see his	Santos G.	It will help him tremendously
		I do not have to wonder if elamipretide will impact people with Barth Syndrome, I have seen it with my own eyes. My brother is a patient in the elamipretide study. I have seen him develop into a stronger, happier, more confident person since beginning the trial. He has chosen to tell a very limited number of people about his participation. Yet, several lifelong friends have noticed a change in him. He now has the physical and emotional energy to want to participate in all that life has to offer. Before elamipretide he barely had enough energy to do the bare minimum. As a child, he was very well liked and respected by his peers. Enough so, that he was elected the president of his senior class. But, there were no friends coming over to our house. As much as he wanted them to, he just didn't have the energy. Even as a young sports enthusiast, he did not have the stamina or muscle tone to play. Our father once pointed out that he could not run. He was not strong enough to get both feet off the ground at the same time. I can't remember a single time that our parents had to tell him to go to bed, he was always exhausted. He was unable to work while in college. Although he would have liked to, he could not have done so while maintaining his grades. Even after graduation, he struggled making friends because he didn't have the energy to get together after work. Since beginning the elamipretide treatment, he smiles more. He has the energy to enjoy life. He enjoys exercising, and wants to attend sporting events after work. He is no longer ashamed to be the man his 20's that needs to go straight bed after work. He doesn't leave family events to go nap. He is showing up, and participating fully. My son also has Barth syndrome. He was born in heart failure, and required a heart transplant to survive. We are very grateful that his new heart is doing well, but every part of his life remains impacted by Barth Syndrome. More specifically, his quality of life. As an eleven year old, he struggles in school, fatigues easily and has
Shawn G. It would improve the quality of life for those with Barth syndrome.		•
Shea G. It would allow my friend -a child!- a better quality of life!	Shawn G.	It would improve the quality of life for those with Barth syndrome.

Shirley G.	It would help them live a better & longer life I hope.
Steven G.	Decrease Fatigue, Increase heart function and blood flow, decrease shortness of breath.
Suzy G.	My son could enjoy a social life alongside his peers and hold down full time paid employment without the need to feel different or explain why he can't do full time or limit his dreams and ambitions.
Toni G.	If it was available then maybe my grandson wou li dnt have been in the hospital for so long. It could help him by giving him more pressure to write with a pencil instead of markers. Maybe he would be able to run with no problems. It would be Great for Families to have this available and not so heartbreaking.
Travis G.	It would help many others, and possibly myself.
Tyler G.	I would have more energy and have a better quality of life
Alicia H.	It would impact my child's life by helping him live a more comfortable life. A more active life. An easier life.
Amie H.	My son was in the trial for elamipretide and he definitely felt that it improved his life and made him feel better.
Amy H.	It would allow my son to live more of a [normal] life with less restrictions.
Anne-Marie H.	Ensure a better quality of life
Audrey H.	It would have improved quality of life
Audrey H.	My brother-in-law, [B], has Barth Syndrome. Being on this drug has greatly improved his strength and stamina, allowing him to start playing golf, which he loves. [B]'s brother, [C], passed away at 14 months old from Barth Syndrome. My family has been greatly affected by this disease, so the approval of a drug that would improve [B] and the other young mens lives would be amazing.
Ben H.	It's impacted my life so much I can keep up with my friends and not get so tired
Bridget H.	Elamipretide could save the life of my friend's son.
Brittny H.	I hate 2 nephews diagnosed with Barth and their quality of life could be significantly improved if they had any increase in strength and endurance. Especially if their cardiac functuon can be improved. They just want to be able to walk up the stair without becoming short of breath or tired. Or be able to play with friends at recess (they're ages 10 and 8).
Carter H.	Benefit in this syndrome outweighs risks as alternate therapeutic options not available in my opinion as a Physician of 45 years!
Christiane H.	Better cardiac function, higher energy level, general overall improvement in ability to function and enjoy life.
Corry H.	My son would have more energy to perform a normale job, [better] acces [to] the job market. Less tired.
Craig H.	It would certainly improve the quality of life for our family member.
David H.	A friend of mine has a child with Barth Syndrome, which has had very favorable results from this drug, promising to give him a better quality of life.
Doug H.	Most of all our nephew, it would give him a better quality if life and hope for the future. As of us, it will give more opportunities for being able to let him experience more in life.
Drena H.	It would be life changing for our entire family!

Gina H.	Improve quality of life
Greg H.	My son participated in the study, and has continued to take the drug afterwards. He has experienced a significant increase in his energy levels and stamina throughout the day. Taking the drug has been a great improvement to his quality of life.
Harry H.	Improve the quality of life and perhaps prolong his life
Jack H.	I feel it would be an exciting opportunity to try this drug. If it works, it could be an incredible breakthrough for our foundation.
James H.	My son is in the study and it has helped him immensely.
Jennifer H.	It's life or death
Jennifer H.	Better quality of life
Jeremy H.	Could optionally save the life of a childz
Jeremy H.	Help him be normal kid and not get picked on
Jessica H.	Huge impact
John H.	This is a rhetorical question of course it would be positive
Joshua H.	Any opportunity for the improvement to the quality of life is always appreciated.
Judy H.	My friend told me it could change her son's life.
Keli H.	My son is in the elamipretide trial now. He has significantly improved his is energy level and stamina since starting elamipretide. If this drug was not approved, I feel that his quality of life would be not as great as it is now.
Kenneth H.	Let's go for it if it will help all those Kids that have it like my Grandson Go for it !!!!
Kenzy H.	My domestic partner and his brother have [barth] syndrome and if it could help either of them it would make their life easier.
Kim L H.	It would give my grandchild the opportunity to live without worry of not being here someday :(
Leigh H.	Have a huge impact would help them out greatly. Make their life less stressful with every day to day life
Liz H.	It would be very positive
Louise H.	it would greatly improve the quality of life for this family member
Mackenzie H.	Greatly help a good friends child
Marcia H.	My nephew would love to have more energy to play with his friends. He uses a scooter to get around. All he wants is to be "normal".
Megan H.	This could give important treatment to my friends son, who lives with Barth syndrome. Please pass this drug!
Michael H.	Make my son to be able to do more and have a more normal life.
Mike H.	Improve quality of life and be more active.
Nickolous H.	It would make me feel better
Obed H.	Entresto also helps me.
Pam H.	Quality of life for people with Barth syndrome is of utmost importance and can be improved by access to therapies which increase the individual's strength and endurance as well as reduce fatigue.

Robert H.	It could potentially allow me to accomplish more during the day than I otherwise would have.
Rogier H.	To be honest I really dont know, but am sure it helps much Barth [patients].
Ron H.	It is currently being used by my grandson and is working well for him.
Serena H.	My dear little friend is 13 years old. His name is [A]! He has Barth Syndrome! For him to be able to take this drug, he would be able to have the strength to do just small daily things at home and for school without getting completely worn out! It is hard watching him struggle everyday just to have the strength to live! He has small brothers he would love to play with! But that is not possible at this time! Please make this drug available to those who are struggling with this awful disease, so that their lives can be more productive for them! Why would you withhold this good from them?
Sharon H.	The possibility of a young child being able to play with his siblings
Shelbi H.	This drug has been such a help to my brother, [B]. He has more stamina as a result of the drug trial. It would give him more energy to do the things he loves!
Stacy H.	[It] would change lives
Stephanie A H.	My brother in law has Barth. In fact, my husband lost his older brother to this disease too (so two boys in his family have/had it). Please give access to this medication.
Suniora H.	Please keep this drug!!!
Susan H.	If my son could have access to this drug and it helps with his fatigue, it could give us more time to do family activities. Currently he needs at least 11 - 12 hours of sleep a day. With having to get up at 7 am to go to his day program, that means he needs to be in bed at 8, 9 at the very latest. This means as a family, if we go anywhere we need to leave early. We miss a lot of things and are constantly apologizing for having to leave early. As he also has cerebral palsy, it is not possible to just lay him down to rest anywhere. He needs special equipment. Our other children have had to miss out on things or we don't go as a family - only one parent goes and the other stays home with our son. Also, if his fatgue level decreased, I am hopeful that it would give him more energy to use his hands to use a communication device.
Tammy H.	A relative has had this drug for Barth and it has helped him. My relative has also lost a son to this disease.
Tara H.	To help them live a healthy life
Teisina H.	Signing to help a friend who's family member suffers from the fatigue of the disease.
William H.	I was on the elamipretide for over a year and had great results than I was put on another medication that can cause allergic reactions to other medications and I started to have a reaction to the elamipretide once I'm off of the other medication I want to go back on the elamipretide. The elamipretide gave me more energy and just a all around better feeling of health as far as being able to do things worh my friends and have a normal job.
Fala I.	Extend his life. Improve the function of his heart. Allow us to keep him alive as long as possible. Please, we need to be given the opportunity to have this.
Josh I.	It would help tremendously and save lives
JUSIT I.	

Mariana I.	This would have given our cousin a better quality of life and an additional treatment option.
Rachael I.	It would improve fatigue levels, quality of life, and enable engagement in activities and education. Thus achieve educational aspirations, contribute to society, and enable enjoyment in leisure pursuits. These are basic things to those without this condition, and surely a human right.
Scott I.	It would allow him a longer life with us by helping his heart and function. These boys need a chance to improve their heart with this medicine if agreed Upon by their doctors
Alex J.	He would have a chance to have more energy and less cardiac complications, hopefully live a long happy healthy relatively 'normal ' life.
Anna J.	He would be able to continue the activities that he has come to love but slowly can no longer enjoy because of muscle weakness and fatigue. He could be a happy child.
Annie J.	it could save my sweet nephews life
Ashley J.	It will help my cousin live a productive life and be able to play and ride a bike like any other child
Carrie J.	It would help my son's best friend.
Chavez J.	My son is 15 years. It would mean the world to us to have some hope.
Deloris J.	Give him better health and a longer life.
eneida J.	have not been impacted by it but curious as to how it would help
Kami J.	Friend
Kimjuanna J.	It may help my child live a normal life something I've been wishing for from the day he was diagnosed
Lawanda J.	Help greatly
Lisa J.	Save my friends life
Melinda J.	It may save this child's life. Please approve!
Orione J.	Could maybe give me a better life
Ronda J.	Quality of life
Brenda K.	It will make the lives of all involved so much better the family has been through so much.
Bridgette K.	My husband's beloved cousin has Barth Syndrome. His health is worsening and this is the only treatment that could be available soon. We are eager for him to be able to see if it improves his debilitating fatigue. Please consider approving access to Elamipretide for Barth Syndrome boys.
Catherine K.	It would have changed his life
Chalaye K.	[A] France
Chelsey K.	It would give people with Barth syndrome a chance at a better fun filled life.
Christie K.	Elamipretide would be very useful as it might reduce fatigue, improve muscle strength and assist with some cardiac aspects of Barth Syndrome.

Cynthia K.	My grandson was diagnosed with dilated cardiomyopathy when he was a few months old. This was later diagnosed to be caused by Barth Syndrome. He is now 3 years old. I have been involved with the Barth community for the last 2 years. I have watched these boys and young men suffer with heart damage and fatigue. To have a medication available that will help with the fatigue associated with this syndrome would most welcome.
Eleanor K.	This drug could substantially improve the life of my friend's grandchild.
Ernest K.	It would hopefully improve his quality of life.
Hannah K.	Help save kids life
Izayla K.	A friend of a friend is suffering !! No child should have to suffer if there is a cure or remedy ready and available!! Come on help this family out !!
Jessica K.	It would help save or prolong my friends sons life
John K.	It gives them hope to have a treatment option that does not exist now.
Joy K.	My friends baby has Barth Synd of course it would help her baby boy! Please make it available, so difficult & a heartache on the parents.
Joy K.	Please make available to these children!
Leslie K.	Hopefully give him a much much longer healthier life
Lois K.	Quality of life is priceless. As a board certified pediatric RN, I have treated several of these kids during my career. If this drug can give an increased quality of life, then its worth its weight in gold.
Mary K.	It would give them a chance to live a fuller life- something everyone deserves.
Megan K.	Help improve the duration and quality of life for a friends son, with little to no side effects. Thank you.
Ned K.	Improve overall quality of life. Increase in energy to be able to do simple daily tasks
Theresa K.	If it helps we shouldn't even have to sign a petition! Our country is struggling with right & wrong! Our babies need it & it works give it to them!
Andrea L.	positively
Audrey L.	it would make life so much better for him
Carole L.	Waiting so long for this time The dream to save the child would come true
Cheryl L.	hugely improve his daily life!
David L.	My very good friend and her husband have a young boy with Barth. She worries constantly about his health and his future. Being able to try this drug would do wonders for their hope and outlook. And hopefully, would also increase her boy's test scores when she takes him in for his frequent evaluations, giving him a better chance for a longer and fuller life. Thank you for considering this petition.
Denise L.	It would mean the world to me. I have been donating and praying for a cure for these wonderful boys and men who suffer from this difficult disease. This would be an answer to a prayer Whatever we can do to help improve the life of these boys/men is so worthwhile. They deserve a chance at life as much as any other person living with a disease.
Doreen L. 32	It would change the outlook for their son and my nephew and his wife. Please reconsider for the sake of little [C] and all other boys who are living with this awful syndrome.

Erin L.	[E]
Gaylord L.	At the very least, it would have improved their quality of life. It might also have extended their life.
Ghent L.	This drug has the potential for improving quality of life by improving heart stroke volume and, therefore, cardiac output. This in turn would allow those with Barth Syndrome to be less bedridden, and more participative in life in general.
Ginger G. L.	There appears to be some improvement in heart parameters. Also, it seems to be helping with over all quality of life, energy etc
Irina L.	This drug will make better life for son of my best friend. He had Barth syndrome, and I want him to live long and happy and healthy
James L.	It would be amazing
Karine L.	I signe[d] this petition, because my 4-year-old nephew died on june 8,2020 from Barth syndrome, which had Just been diagnosed, only 3 months between the announcement of the disease and his death, we cannot recover 😢
Kathy L.	Strengthen muscles
Laceia L.	More love to give
Linda L.	Save children's liives.
Lori L.	I am a Speech Language Pathologist who works with a child who has Barth Syndrome. I feel access to this drug could be life changing for him with his Oral motor strength for feeding as well as his overall body strength for Occupational Therapy. Please consider this.
Maike L.	It would have [P] allowed to play with his friends. He was always tired and had not the strenght to do the same games as a healthy child. It would have given him more confidence and inproved his quality of life. [P] would have been less exhausted.
Nancy R L.	LIFE !!
Scott L.	Everybody should have access to life saving medication!
Taylor L.	It would help keep our friends child around longer and improve his life.
Valerie L.	make everyday life better
Yolanda L.	Allow them to live with a better quality of life.
Alexis M.	It could save his life
Allie M.	My friends 4 year old has Barth syndrome and lives such a tough life. This drug could help change that and give him a better future
Alyssa M.	It would be life changing.
Amanda M.	Longer life
Amanda M.	Any possible thing to help my son feel even the slightest bit better on a daily basis is worth so much.
Amie M.	our dear friend has barth syndrome and this would greatly improve his quality of life.

Anita M.	We have two grandsons with Barth Syndrome. We watch them daily struggling to do even the simplest of activity without getting tired and short of breath. The availability of elamipretride would improve their quality of life by increasing their cardiac function and improve their exercise tolerance. It would be a blessing to see them run and play with other children without struggle or without stopping to rest.
Annick M.	Improvement in heart function as well as improved and better quality of life all round for my grandson.
Antonia M.	Disponer de la seguridad de que la salud de mi hijo será más fuerte en un futuro y de que su calidad de vida se puede equiparar a la de la gente sin problemas de salud crónicos. Ahora mismo, mi hijo se cansa al andar un poco y a lo largo de sus 18 años de vida no ha podido practicar ningún deporte. Me gustaría tener la tranquilidad de que sus problemas de fatiga se reducen y de que su calidad de vida es buena en un futuro. Machine transaltion: To have the assurance that my son's health will be stronger in the future and that his quality of life can be compared to that of people without chronic health problems. Right now, my son gets tired from walking a bit and throughout his 18 years of life he has not been able to play any sports. I would like to have the peace of mind that your fatigue problems are reduced and that your quality of life is good in the future.
Ashton M.	Quality of life for our family friends!
Benjamin M.	I was born with Barth syndrome and have lived and suffered for 23 years with heart problems, severe fatigue, poor appetite, tiredness, no energy, low immune system. My low muscle tone and fatigue has kept me from doing normal things like sports, hiking, just climbing small hills, my entire life. Some days I stay in bed all day because I don't have the energy or stamina to move around. Unfortunately I was not able to participate in the Elamipretide trial because I was participating in another trial that the Barth Foundation sponsored, which was an exercise study with [Researcher]. So it knocked me out of doing the Elamipretide trail. I understand that this medicine has helped other Barth syndrome guys and helped improve there fatigue, muscle strength and heart improvements. BSF has been working my entire life to find a treatment for Barth. For the first time in my life this medicine could help me feel better and improve my quality of life. I am asking that the FDA give me and my other Barth brothers a fair chance to have this medicine and improve our lives. We deserve to feel better and have more energy and have a better quality life. Please Do Not Deny Us this chance for a Better Life. I want to someday have a family of my own and have the energy and stamina to hold down a job to provide for them. You can help me by approving this drug to treat Barth Syndrome. Thank you.
Brantley M.	I don't, nor do my family members, have Barths Syndrome, but I know how important this is. My most dear friends have a son/brother that needs a cure to become reality. He is a light to the world and must be cured, no matter the cost.

Cecilia M.	My friends 2 year old would have the opportunity to be more active and like his peers. As an oncology mom, I know how heart wrenching it is when a medical condition keeps your kid on the sidelines of their life. He is 2! He should get every opportunity to grow and develop with kids his age.
Colette M.	He would be able to wake up in the morning and not be fatigued, live daily life without being exhausted all the time. He would be able to potentially have a career, own a home and drive. It would make life so much better for him and those around him.
Constance M.	He might have been able to HAVE a childhood. Instead he suffered enormous fatigue therefore could not participate in normal social interaction with his peers.
David M.	1: As a parent, it will always be an emotional task to explain why our sons, brothers, cousins and friends with Barth Syndrome have passed away. 2: It will never be an easy discussion with your son who is affected with Barth Syndrome about how long HIS heart will last or how long he may live with his condition. 3: As a parent, you NEVER want to outlive your child. 4: Summary; We (Barth Syndrome) are a rare disease with many heart beats that need support and a cure. 5: We could use a cure. 6: Thank You
Ed M.	Elamipretide can change the life style of our 2 grand children with Barth, it can improve their ability for healthier cardiac function and be life changing for young boys that are unable to do many simple task and exercises that "normal" boys can do. It can greatly increase their caridic so they can live more of a normal life style. Their current abilities are so limited, they are unable to function with boys of their own age and size, they withdraw and have to rest all the time. They just want to be able to function as a normal boys.
Edwin M.	It might have saved the life of a friend's son who died of complications of Barth syndrome.
Elizabeth M.	It would mean everything. If my brother were alive, everything would be better. Now we will never know if elamipretide could have saved him, but I don't want that fate for others with Barth.
Florence M.	It would improve my son's quality of life, especially by lowering is fatigue
Greg M.	Positively
Greg M.	It would potentially make their life much better.
Jamie M.	It would potentially give my nephew the energy to be able to keep up with his cousins when they spend time together - he might be able to remain at the table with his family for the entire Holiday meal, he may be able to swim more with his cousins on our family vacations, and he may be able to take longer walks with his cousins and play at the park with them!
Jason M.	It is helping a [young] child that we are friends with. He feels much better and his muscle stamina has greatly increased.
Jennifer M.	My brother experienced fatigue, strength issues, and endurance issues throughout his life. Help improving these factors would have greatly improved quality of life and allowed him to do more with the time.
Jill M.	It could possibly save my nephew's life and definitely give him better quality of life with less fatigue.

John and Joanne M.	Make his live much easier
Kate M.	Our son passed away from BTHS at age 28. He was chronically exhausted and felt completely "depleted" all the time. He also spent a great deal of time in the hospital. It would have made a HUGE difference to him to be less medically vulnerable and to have a little more energy so that he could engage more fully in school, with family and friends and in a productive life. Thank you for your efforts on behalf of those who have no treatments right now.
Kathryn M.	Having increased energy and stamina would allow my school-aged child to keep up with his peers and have enough energy to last through the entire school day. It would also allow him to engage more with his younger, non-Barth brother. My son feels left behind both by his peers and by his younger (by five years!) brother, and is experiencing depression about not being able to keep up both physically and emotionally. No young child should ever experience depression. I believe this treatment would greatly impact his quality of life and give him a much brighter outlook on life.
Kellie M.	Our three year old grandson has Barth syndrome and and would greatly improve his quality of life and his ability to interact more with his peers
Kirt M.	Hopefully would give my grandson [A] more normal teenage life
Kristin M.	Greatly
Laura M.	Made life less terrifying due to reduced hospitalizations
Lesley M.	improve quality of life 100%
Leslie M.	help my nephew with his fatigue
Lisa M.	Help build muscle mass and help with fatigue.
Lynda M.	Two great grandchildren with Barths. 3 yrs 7years Especially older one - weakness and fatigue.
Lynne M.	Anything that supports my friends son with all that he needs is vital.
Mariam M.	We need to try and have a medication that would help with you complications of such a rare syndrome. In my country is very hard to medically help patients with breath syndrome which makes daily life quite hard for the patient and is challenging for medical staffs
Mario M.	Hello, My son [M] has Barth Sindrome and He had on febreaury two clots that His heart release, the first one went to the femoral artery and he had to be in surgery in the next hours or he would miss his rifht leg. The second one was even worse because the clot went to the medium cerebral artery and caused Him a cerebral stroke, He lost congnositive brain functions, his left part of the body is paralized and his heart function is 39% now. Thats only one example of what [M] is been going on in his life. This is a cruel desease and it has to be sttoped, nobody deserves to live like this. Regards !
Martha M.	My grandchild would be able to live a more normal life, increase his ability to be productive, struggle less with the devastating consequences of BARTH Syndrome, give him a better chance at living longer and healthier, and continue to bring joy to our family.
Matthew M.	If it has a even the slightest possibility of saving, or even lengthening the life of these individuals, it would be a huge impact. And a necessary one at that!

Mayoung M.	Greatly
Mike M.	It would save lives
Mike M.	My brother would have been given a chance at an improved quality of life if this was available to him to try
Parker M.	Friend of family has shown exponential results such is wished on all who battle with Barth.
Patricia M.	The drug would potentially expand a child' life.
Paul M.	Helping a friend out
Paul-Antoine M.	It would change everything for the son of my friends!
Pietro M.	I really wish improve my capabilities, strength, and fatigue resistance. I wish I have a life in which I can provide to myself and my beloved. Elamipretide gave opportunity having more energy to a lot of my barth brother: please, consider giving this opportunity to all of us!
Rachel M.	This drug could potentially improve the quality of life of my child.
Rosa M.	My grandson [B] has lived with Barth syndrome for 23 years. He has struggled with heart failure, muscle fatigue, poor appetite, no energy, weak immune from birth. We have been heart broken to watch him live with this daily. He has also witnessed many of his Barth friends die of this terrible disease. It is our understanding that the new drug Elamipretide has been used in a trial for Barth individuals and has shown to improve fatigue, muscle tone and also heart improvement and overall improvement in quality of life. [B] deserves a chance to use this medicine and improve his quality of life. We are asking that the FDA give Immediate Approval for Elamipretide to be used by All Barth Individuals. We can not lose another Barth Individual Life! Please approve this drug for use in Barth syndrome. Thank You, Grandmother to [B].
Rosemary M.	This would be a life saver an absolute game changer to the lives of these boys.
Sandt M.	A treatment such as this will potentially improve my son's quality of life, be able to keep up with his peers in many ways and feel better about himself and his abilities.
Sarah M.	It would improve the quality of life for my son, and hopefully increase his life expectancy.

Shelia M.	My son has been living with Barth Syndrome for 23 years now. We have watched [B] struggle all his life with all the complications of this terrible disease. He was failure to thrive at birth, couldn't meet his childhood milestones. In heart failure at 6 weeks of age. Couldn't walk till he was 2 yrs of age. The fatigue and muscle weakness his entire life has kept him from playing sports like normal children his age. He still fatigue's just walking short distances. He tires super easy and has to rest and sleep most of his day. He can only work for short period of time due to fatigue. He has lived his entire life taking 5-8 drugs for his heart and immune and muscles. I am asking the FDA approve this drug Elamipretide for all of our Barth boys/men to use and improve their quality of life. It has shown great promise in the trial to improve fatigue, muscle strength and heart stroke volume. My son and all Barth individuals deserve a chance at a better quality life. He deserves to feel better and want to do things he has never had the stamina to do like hike, swim, run, play ball, just walk in our neighborhood. He wants to be able to work a full time job and have a family of his own someday. Please give him and all Barth individuals this drug to better their health. We have lost 7 Barth individuals in the last 12 months alone. Me and my family and [B] have witnessed losing our Barth boys/men and friends to this terrible disease. I DO NOT want to LOSE MY SON or another Barth individual. It is devastating to our family to hear about another loss! Please give our son a fighting chance to improve his quality of life. PLEASE FDA APPROVE ELAMIPRETIDE FOR Our son and all Barth affected individuals use. Thank you.
Sherrie M.	Save a life
Stacy M.	Hopefully would help our nephew
Stef M.	Studies so far have shown it to improve day to day quality of life. What an amazing thing that would be for Barth affected people
Stephanie M.	it would give hope for one sweet boy
Stephen B M.	I believe, based on the results reported to date that [W] would have experienced much less of the debilitating fatigue that destroyed his life. I do not know if he would have lived longer, but I believe his life would have been more enjoyable.
Susan M.	As the mother of a teen daughter who is a known carrier, I worry about my future grandchildren, who may be born with Barth syndrome. Knowing that there are no viable treatments is daunting, to say the least. I've heard first hand from more than one of the TAZPOWER participants who have had a life-changing experience on this drug. I pray that FDA allows our community access to elamipretide.
Suzanne M.	My cousin's son would have a chance at a better life

Taylor English M.	My brother [B] is 23 years old and has had Barth Syndrome his whole life. I have watched him grow up with this disease and have watched how it has impacted his life. Going through life with this disease has taken anyway many things he has wanted to succeed at, including sports and hobbies in school, being active with his friends, and applying for multiple careers he has wanted to try, but wasn't able too because of his weakness and fatigue. Watching my brother live a life with Barth Syndrome has shown me that it even makes him sad and depressed some days because he has to live his life around this disease. Any medication that could help make him feel better each day and not have to live life this way is a chance he is willing to take. It would impact is life greatly if it meant it gave him more energy to get out of bed for the day and live a normal happy life without being fatigue, in pain, or worried that his health could spiral down any day. I don't know what it's like to live with this disease, but I can see how it affects my brother everyday, and any thing that can be a step to helping my brother and the rest of the Barth boys is a step we are willing to fight for. I am asking the FDA to approve Elamipretide for Immediate use in Barth syndrome. Thank you.
Teri M.	It could give him a long normal life.
Timothy M.	Help a child in need.
Tonya M.	Alot
Vincent M.	This could impact him and his family wonderfully. These boys and men deserve to have the best quality possible to live their lives.
Wyatt M.	I would love to have more energy. I want to play with my friends and not have to stop because I'm tired. I want to be able to run in baseball. I would want to try it and see if it can help me .
Ana N.	Will improve [H]'s life
Carolina N.	My grandson nothing would make me happy to see him better and have a better quality of life. Thank you
Cindy N.	It would allow him to get more muscle mass so he can keep up with his friends better. It would also make him a happier child.
Dana N.	It could give a little boy the ability to simply play with his friends and play a sport he loved to play.
Gabe N.	I'm almost 8 years old and weigh 46 lbs. I have Barth. My doctor just increased my medications again this month because my heart is not working the way it should. I get very tired and have to rest when I try to walk and keep up with other kids. I don't get to play any sports. I hope this medication is approved so it can help me have more energy and help my heart work better.
Jill N.	Elamipretide would greatly help the lives and quality of life of children living with Barth syndrome.
Jon N.	[L]
Joshua N.	This could give more normality to my son's life.
Laura N.	Improved quality of life with energy and strength. Thank you!
Rovena N.	After my grandson had a heart transplant and was subsequently diagnosed with Barth Sydrome any way however small to help him lead a 'normal ' life is

	to be applauded and encouraged to be made available to all Barth Sydrome suffers
Tiffany N.	Improve quality of life for my friends son
TINA N.	Life for my nephew 🔍 🖤
Casie O.	Having access to this drug would increase the quality of life to individuals affected by Barth and their families. We have lost five boys in our family and now we currently have a four month old. We don't have time to wait. Time is not on our side.
Char O.	Making it readily available to those suffering from Barth Stndrome
Jeremy O.	Save a kids life!!
Kristi O.	My brother is participating in the trial and it has been a tremendous help to improve his quality of life.
Nicholas O.	It would make my friend life so much better and easier to not suffer
Oscar O.	It would definitely improve their life
Sherly O.	Its been challenging but my sisters baby is doing good
Sonja O.	It has positive results with barth syndrome people
Susan O.	My cousin [W] struggled for years with acute fatigue and I would Hope Elamipretide could be useful.
Tracey O.	It would of made life better
Allene P.	I wish my nephew had had access to this drug. It could have had a very positive impact on his quality of life.
Alma P.	It would help a family friends child receive treatment.
Andrew P.	Showing the good this drug can do for the Barth boys in America would show our government the worth of it so it could get approved for our boy. Thanks.
Angelique P.	my first child died of barth syndrome.I wish my second child, who has barth syndrome, could have a better life and cope better with fatigue in order to make their daily life easier. He deserves to have his health improved.
Chloe P.	save [R]
Christopher P.	Barth Syndrome makes me feel sick all the time. It makes me feel tired. I can't keep up with my friends. Anytime I go do something fun, it wipes me out. No matter how many Epsom salt baths I take or tubes of deep muscle cream I use I can never get rid of the stress my body feels from doing anything physical. It would help me a lot if I could have a chance to try this medicine.
Cynthia P.	Better quality of life
Don P.	Give them the cure and hope they deserve.
Eliana P.	So much
Erin P.	My nephews were both born with Barth. One passed at 6 months. The other is 9 and struggling.
Heather P.	Without an approved drug my nephew may not survive
Jen P.	Greatly improved health and fitness and an ability to socialise and mix with friends and family. Less stressful visits to the hospital

 and. has never been able to catch-up to his peers from coloring to running, he has always been very behind due to his hypotonia and chronic fatigue in his body. School, physical sports, or just walking around the grocery store proves so difficult for him. His overall myocardia function, moderate mitral valve regurgitation, and lower than normal and during activity is when he struggles with that the most. My youngest son is 3, he has Barth Syndrome as well and his symptoms have been declared more severe side on the Barth Patient spectrum; [M] suffers from numerous cardiac symptoms of BTHS such as Dilated Cardiomyopathy. Hypertophic Cardiomyopathy, Left Ventricle Non-Compaction, Superventricular Tachycardia, Moderate Mitral Valve Regurgitation, Neutropenia, Hypotonia, Developmental Delays, Chronic weakness and fatigue. The TAZPOWER trial is a promising trial for my sons and the approval of this drug would be absolutely life changing for my sons and their overall quality of life. Please approve this. Thank you. Jose P. UJ Kelsi P. This could immensely help my child live the life he wishes he could One of the greatest barriers of living life normally for our son affected by barth syndrome is the extreme fatigue associated with just living normally day to day This could potentially be life changing in regards to the quality of his life. Krysten P. It would save my cousins life Laurel P. Both my boys have Barth Syndrome now—recently diagnosed. Since elamipretide has shown no dangerous side effects and/or since studies have shown the drug can improve the quality of life of Barth syndrome patients, there seems to be no reason NOT to allow patients access to the drug and every reason to allow that access. Patients with rare diseases—and the parents of children born with rare disease=-are at a grave disadvantage in terms of children born with area disease affect hundreds, thousands of peopleand l, for one, would hope that this d		
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Lisa P. It could change their life!	linda P.	
	Lisa P.	
	Lorraine P.	Impact them greatly

Mandy P.	It would help my small cousin be able to walk more than 30 steps without feeling exhausted and have to use his wheel chair as much. It would give him a better quality of life.
Mary P.	Maybe they would still be alive
Maureen P.	Would increase his quality of life providing him with the strength and endurance to fulfill his potential and enjoy his life to the full x
Mindy P.	It gives them a new start at a wonderful life
Miranda P.	Better living
Penny P.	A chance to improve life and its expectancy for my friend's daughter
Rhonda P.	Our family in [State] need [M] to be healthy. If this medication offers hope, please dispense it immediately.
Richard N. P.	Opportunity to benefit from a treatment that other patients have found to benefit from. While their experience is anecdotal, it is also supported by the best available evidence, and by a logical scientific reason it should help. As an orphan disease, better evidence is not going to be available. Please approve this application!!!
Sarah P.	Life saving drug. This could alter the lives of many people with Barth syndrome and their families and friends!
Sharilyn P.	It could give hope to a family dealing with two children with Barths!
Valerie P.	Hope it would help my great nephew to become a healthy little boy
Vanessa P.	Afectaría el fármaco Elamipretide positivamente en mi hijo [D], ya que podría reducir su fatiga.
Veera P.	We will be able to spend more time outdors
Veera P.	I won't live in a constant fear to find my son dead in bed in the morning.
Will P.	It could improve lives.
Adam R.	My son died at 1 week old. This drug could have potentially prolonged his life. 3 of my nephews also have barth syndrome and if there is a chance it can improve their quality of life they should be allowed access to it.
Allison R.	Life saving.
Amer R.	This drug HAS had an immensely positive impact on 2 of my boys with Barth, as it has given them an increased appetite and energy!
Ashlynne R.	It will give him the opportunity to have the best quality of life possible and hopefully give him a chance for a longer life.
Brie R.	Save a life
Catherine R.	help my grandson to have more energy help him with his dilated cardiomyopathy and hopefully extend his life
Cheryl R.	Hopefully would of helped with the fatigue. Which I think would help with daily life. Simple things were tough on my boys.
Curt R.	Improve it
Dalene R.	Well it would help others my family has lost 2 family members both my grandsons first one 16 days old and the other who had had heart transplant was 16 months so hopefully another family doesn't go through what we did

Diane R.	It has shown great promise in helping the boys/men grow muscle mass and increase strength, and endurance. Our friend [C] fights the affects of low muscle tone and extreme fatigue which will continue to increase as he gets older. This drug could be a game changer!
Emily R.	Giving my son a chance to have increased stamina and less fatigue would be life changing.
Eric R.	Hope and optimism on a cure or at best, a better quality life
Jay R.	My child has benefitted immensely from being on the study for elamepretide. This drug should be available to all
Jenny R.	Friend has it and has impacted her family immensely.
Karen R.	My 2 great nephews have Barth syndrome. Seeing them live a somewhat normal life would be amazing.
Laura R.	Better quality of life .
Lauriane R.	Family member
Lori R.	It could have saved the lives of 5 children in our family who died plus a 4 month old who currently has it.
Mason R.	It would significantly increase the quality of life for my family member and allow him to carry on a much more normal life style than without the drug.
Nicole R.	It would give my friend's son a better chance to have a normal and enjoyable life. It could potentially allow him to engage in things Barth Syndrome could hold him back from. He deserves to live life to its full capacity and this drug could provide that to him.
Olivia R.	it would help save my friends brothers life
Paul R.	Might well have allowed him to extend his schooling and thus his useful life
Paula R.	It would change their life!
Phil R.	It will not impact me but will help someone in need
Richard R.	This is a terrible life limiting disease and hearing from this that took the trial and how they felt it helped and improved their overall well-being is something is the biggest factor here. Living with the varied limiting conditions associated with Barth is hard enough so anything that is proven to help is gold dust for all those suffering and family members affected.
Robert R.	It could save lives and let people live normalized lives without worry about the effects of the disease
Adam S.	It would allow them to have more freedom and live a more normal life.
Adrienne S.	It could save the life of our dear friend, [H].

Alex S.	The list of things this drug would help me with is forever growing even as i type. A good first example the muscles used in my fingers are already slightly aching from being used. Sitting, the muscles used to posture up are aching and fatiguing. I currently do not work and can not do the work i would like to do because of fatigue and tiredness. I could potentially live a normal working life with access to this. With this drug i would be able to thing such as, Drive - My legs would not begin to ache and fatigue so quickly causing hazards to myself and others, giving me independence. Walking - I would be able to walk greater distances, keep up with friends and just not point blank be in pain while doing the most simple exercise. I live with my Fiancee, in a small one bedroom Bungalow, it is not very big and on one ground level due to the fact stairs daily tire me out, cleaning a bigger home is exhausting and unfair to put the entire housework weigh on my partner. With this drug i could potentially move into a bigger home and not worry over these things because i would have the energy to have a good paid job to afford a bigger house and the energy to take care of it. I am a huge MMA fan, i simply can only dream of training for real one day, with this drug i potentially could go to the local club, be "Normal" and keep up with others. I have friends who like to go for light jogs, I could possibly do this if my fatigue is managed by this drug. I am a big Football (soccer) fan, since i can remember i have dreams of playing just at a local weekend club, Barth syndrome put that to a halt many years ago. With this new Drug that could be a possibility for me. Aside from of course hobbies, working life, home life and so many other things that i could make this list go on and on, My fatigue, Tiredness. a tiredness that when so bad can make me feel physically ill, i can wake up one morning after sleeping 11 hours and stand up dizzy, fatigued and exhausted and nothing could fix it. This new drug could be that fix, It could ch
Alexis S.	If/when our son does into heart failure it would be a relief to know there's something else we could try to save our baby boy's life. We need this, please.
Amanda S.	My nephew has Barth syndrome and this would potentially give him a chance
Andrew S.	for a better and longer life. Help nephew
Angie S.	This could help save the son of my friend.
	This would impact my friend's child in a positive waycreating not just a
Candice S.	quantity of days but a quality of life.

Carolyn S.	My grandson [B] has lived with Barth syndrome his entire life. His heart failed when he was 6 weeks old. He has always had very low muscle tone and the fatigue he deals with daily is sometimes unbearable. He sleeps a lot or stays in bed a lot. He can't work a full time job because he doesn't have the energy. If this drug has shown to help with fatigue and improve muscle and help his heart function improve please approve it immediately for his use and for use by all Barth individuals. [B] deserves to feel better and have more energy and stamina for daily functions. I am asking for Immediate Approval from the FDA for Elamipretide to be used by Barth individuals. Thank you.
Catherine S.	This would help my nephew god bless 🙏 xxx
Chad (CJ) S.	I get very tired when I play with other kids. I'm almost 11 years old and weigh 40lbs. I have hardly any muscles. I can't take the physical education classes like the other children because I get too tire. I can't do any sports. I wish I had more energy and muscles. If this medication will help me feel better then I hope it is approved.
Cherie S.	My nephew may have had the energy to play with his sisters longer or his toys on Christmas because just unwrapping them was strenuous enough. He may have been stronger to withstand hot summer days better, and play with his dog in the yard. If we were going to only have him for a short period of time . We would've loved to see him enjoy life to the fullest. Having options for medication to improve quality of life is a tremendous gift. Even his cry was weak, we would've loved to hear a loud strong cry from him, for this sweet beautiful boy to have the chance to share his emotions in a loud and strong way. I could list pages of reasons why these boys/men should have the chance to improve they way they feel. But mostly if you ask this aunt that held her baby nephew with so much love in her arms but times this little boy didn't have the strength to hug me back please give them a chance a choice
Christian S.	We hope it will decrees fatigue and improve general life quality
Cody S.	Friends child has this and wants to have access for her child to help his health struggles
Collin S.	I have Barth. This would help improve fatigue
Daniel S.	It would be life changing
David S.	Make life easier for the individual
Denise S.	Save a life!
Derek S.	It would affect my life for the better. I'd have more energy.
Desmond S.	Anything that improved my young nephews health would in turn improve my health because I worry about him , and everyone in our feel the same way ,
Diana S.	Quality of life
Diane S.	We are always desiring for the best life available to any individual. If medical intervention allows for a better life then that medicine should be made available.

Donna S.	My son is now 22yrs old. Since his diagnosis we have lived with the hope of a treatment that would lessen the symptoms of Barth Syndrome and make his life easier. He is currently trying to complete a University degree and fatigue is one of the biggest obstacles he faces on a daily basis. Fatigue not only makes it difficult for him to do physical activity, it also impacts his ability to concentrate and absorb information. This makes studying very difficult. He is very concerned about his ability to hold down full time employment due to the extreme fatigue he experiences. He desperately wants to be able to support himself and be a contributing member of society. Elamipretide, could potentially allow him to achieve all he aspires to and reduce the daily debilitating fatigue he faces.
Elise S.	What does this mean for [M]? More energy to do basic daily tasks, like walking, playing, and learning! [M] uses his wheelchair every day to get around outside. Wouldn't it be wonderful to be able to walk for more than 30 steps and not be exhausted?
Elizabeth S.	It could potentially help in the treatment of my cousin's 2 boys with Barth syndrome.
Ellen S.	Based on what I have read about elamipretide, I believe that this drug would positively impact the life of not only my little brother, but of hundreds of boys and men throughout the world living with Barth syndrome. I have seen countless times how fatigue can affect my brother. A drug that could help this and provide increased endurance and strength would be life-changing for individuals with Barth syndrome.
Eric S.	May have saved family members lives if it was around and approved.
Erik S.	As a dad of 2 adolescent boys having Barth syndrome I think that Elamipretide should be available to all Barthpatients to let them decide on their own if they want to try it or not to ameliorate their quality of life. It has worked for some patients so we cannot take away the hope for other Barth patients to try it too. We cannot leave them without prospects.
Erin S.	We have family friends with 2 boys with the disease. Please help save them.

Erin S.	Availability of elamipretide would allow our son to join us in family activities. He becomes too fatigued for walks, sports, leisure activities such as swimming or bike rides. He can't go to school full time, he has a part time schedule due to fatigue. Elamipretide would allow him to play with his toddler brothers without wearing out after only 5 minutes. Elamipretied would potentially allow our son to have play dates and join other friends who go out walking around the neighborhood, to join in dance at a school dance, to be able to attend a sports or musical event without navigating handicap accessibility and planning with the event how [A] will be able to be a spectator. I believe Elamipretide could help [A] go on vacations with his family and be able to attend sightseeing and other vacation activities in which in the past the entire family has not been able to do because he could not be left alone, nor would we want to leave him behind while out vacationing. Elamipretide could potentially give [A] energy to make it through a typical day without having to have a rest and miss out on events of a typical or not so typical day. There is so much that he misses out on due to fatigue and his need to rest. We ask for his sake, for the family's sake, for the sake of the boys with BArth Syndrome to please allow for Elamipretide to be an option to try and to give "life" back to the boys. As one boy stated, "I would rather die than stop taking the medication (elamipretide)". This is the proof that Elamipretide is life changing for at least one. I beieve, it could be more.
Gabrielle S.	My baby cousin has Barth syndrome and it would drastically change his life
Genevieve S.	We have studied the effects of elamipretide on failing heart tissue and we have found that it helps mitochondrial function profoundly with no effect on healthy mitochondria.
Jacqueline S.	This would allow my great nephew a chance to participate in life instead of just observing.
Jacquelyn S.	My son is a 10 year male living with Barth Syndrome, he is a fairly active child but becomes fatigued after minimal activity. This prevents him from engaging in a lot of activities with his peers which frustrates him. Access to elamipretide would improve his quality of life by providing him with the energy to complete tasks and explore new things.
Jaroslav S.	I would be happy, if my nephew [V] could have gotten elamipretide, so that he could have better life (but died six weeks ago). He was happy child and very clever, but fatigue was a big issue for him. We could see, that his gross motor skills were very bad in comparison with children of the same age. He died because of heart failure and this might not have happened if he could be treated wiht elamipretide.
Jason S.	He could possibly still he alive with us!!!!!
Jef S.	I think we as Barth patients should all have access to elamipretide because if it is a potentially beneficial therapy we should have the choice to try it or not. So many peers are having so much troubles in life because of the lack of energy for so many years already. They are entitled to a better life, a normal life. If there is something existing that might help them, they should have access to it to try. I would want to have access to it if and when the time comes that my situation worsens.

Jeffrey S.	Some of the symptoms of Barth Syndrome that impacts my stepson life is muscle weakness, fatigue, exercise intolerance and heart issues. These things impact his overall daily and quality of life. These impacts his ability go to school for a full day and is expected to prevent him from being able to work 40 hours a week, in which he will most likely never be able to live on his own. If he has several activities going on during a day he has to choose which ones as he usually doesn't have the energy level to participate in them. These items impact how he interacts with others. He is limited in how he can interact/play with kids. He isn't able to run around (literally cannot run as fast or as long), ride bikes (doesn't have the muscle tone to balance on a bike or push the peddles up a hill), play sport with kids, etc. Not only does this frustrate and sadden my stepson it also limits/prevents him from being able to make new friends and makes it hard to keep existing ones as they lean more towards active past times. Having friends is such an important part of growing up and these items make it very difficult for him because it takes away a lot of that opportunity to do so. These items also limit his interaction with family. He has brothers that are 3 years old and they already outrun him, out last him energy wise, and are stronger. He wants so badly to play with them, but he can't physically keep up. He also struggles to pick them up properly and or maintain his body to lean in and give them a kiss and this causes his brothers to get upset with him at times when all he is trying to do is give them some affection. Just like he struggles physically keeping up with other kids this applies to his cousins that are around his age and that he is close to. Kids with Barth Syndrome are impacted in so many ways that any improvement to the above items mentioned will make a huge impact to their overall quality of life, which they deserve help with.
Jessica S.	My brother has shown an increase in his since being on the medical trial. I want that for all the individuals affected by this horrible disease.
Jill S.	It would allow him to have more strength and endurance, less fatigue.
Jordan S.	My brother may finally feel more normal in his ability to travel, exercise, study and live everyday.
Judy S.	Make the lives of my dear friends immeasurably improved forever them and their son.
Julie S.	Our friend's son has participated in a clinical trial of this drug and it has helped his Barth Syndrome symptoms.
Kari S.	Two members have died from Barth syndrome. This medication could have helped them live longer. One family member has Barth Syndrome at this time and would be beneficial in increasing his stamina and overall health.
Kirsten S.	Please provide access to this potentially life saving drug for those who suffer with Barth. It is a small community but the lives you will affect are very very real. Thank you!
Leah S.	We need options for treatment to improve my son's quality of life. Those living with Barth Syndrome deserve the best quality of life we can give them!
Leah S.	The family member is a baby. It could help him live longer and be more healthy.

Lidiya S.	elamipretide gives great hope! I hope that Barths syndrome patients in USA will be able to receive the drug to improve their condition sooner. I hope someday this will happen in Russia.
Mara S.	helps our friends son have an option to live.
Marc S.	My son [R] was born in 2005, went into severe heart failure at four months old, and was diagnosed with Barth Syndrome right before his first birthday. Despite some early struggles, [R] heart and overall health rebounded to allow him to live a relatively normal and quite happy childhood. My family and I became members of the Barth Syndrome Foundation soon after [R]'s diagnosis, and I became a member of the Board of Directors for the Barth Syndrome Foundation, and served as chairman of the Board from 2013-2018. I was very excited when we learned of elamipretide and its potential therapeutic value for persons with Barth Syndrome, and I was involved in coordinating with Stealth for the trial that was conducted with Barth patients. Based on what I knew about the biochemistry associated with Barth patients. Based on what I knew about the biochemistry associated with Barth individuals and the mechanism of action of elamipretide, this potential treatment always stood out to me as one that "should" have a good chance of making a positive difference (as compared to many others where we "hope" for some positive impact). My son was 12 years old and too young and small to participate in the Stealth trial. At the time [R] was a personable straight A sixth grade student and accomplished chess player, despite suffering from the cardiomyopathy and muscle weakness/fatigue that afflicts Barth boys. [R} had great plans for all he wanted to accomplish in high school and beyond, and we had great hope that eventually a therapeutic option might help him achieve all of those goals. Tragically, the world as we knew it, and [R]'s life, ended on [date]. [R] passed away from a sudden arrhythmia. A life with so much promise lost in an instant. [R]'s loss deeply impacted his family and friends, and many of us still reel from his loss over two years later. I sit here today wondering what might have beer if [R] had been old enough to participate in the elamipretide trial, or if it had been approved as a treatment option for him to take. We kno
Mariko S.	It could save my grandson's life! We won't have to live with a fear of losing the baby.
Matthew S.	It will give my nephew a chance at a more normal life.
Maureen S.	Would provide hope.
Melissa S.	It could change a friend's child's life
Michael S.	It would enable my friend to live a more fulfilling life, being able to take part in sports activities and go on long walks.

Michelle S.	This drug would help 2 boys of a friend live a longer life and for the whole family not to always be on eggshells over cold and flu season especially. And to know that there is something being done to help their boys and others that fight this Barth Disease every day. Let's do something about i!			
Michelle S.	It has given my son the ability and energy to go out of the house and enjoy life without being totally exhausted			
Michelle S.	Any hope to help our kiddos			
Mike S.	Opportunity. Give this child an opportunity at life			
Misty-Lee S.	This would assist in improving the quality of life of my loved one. He is a beautiful young man and deserves to life a happy and fulfilling life for as long as he has.			
Nancy S.	This would allow my friend's child to have more energy to do normal kid things. Walk, play, learn, etc.			
Patricia S.	Give parents peace of mind to do all they can			
Rae Ann S.	I have seen such great improvement in [W]'s health, both physically and emotionally, since he began the treatment, I feel it would be almost criminal to take it away.			
Rhonda S.	I believe it would have a positive impact on anyone with this disease			
Rhonda S.	My two grandsons might still be alive			
Rod S.	My grandson [B] has lived with Barth syndrome for 23 years. His fatigue and poor heart function and poor muscles keeps him from living a normal life. He sleeps a lot or stays in bed a lot. He can't work a full time job because he doesn't have the energy. If this drug has shown to help with fatigue and improve muscle and help his heart function improve please approve it immediately for his use and for use by all Barth individuals. [B] deserves to feel better and have more energy and stamina for daily functions. I am asking for Immediate Approval from the FDA for Elamipretide to be used by Barth individuals. Thank you.			
Ruth Ann S.	It would improve the quality of life for people with Barth Syndrome			
Sara S.	Provide a true quality of life. Providing sustainable energy, activity, social attraction and a more positive outlook! A possible game changer for kids who deserve a fighting chance.			
Saskia S.	My firstborn would maybe be alive. My two other boys (9 and 3) could live a better life with less fatigue, more options, better. connection with other children,			
Shari S.	They should all have a choice.			
Sharon S.	My grandson passed away two years ago but if this drug were available, he might be here today. Please save someone the grief we have had to endure. Give these Barth children a chance for life!			
Shawana S.	My son has been diagnosed with barth syndrome since February 2016. He had a dilated heart and got his donor heart June 2nd 2016. Since that time he's been blessed with having 7 cardio biopsies without a rejection. If his heart was to possibly fail, I believe this drug could help him.			
Sheila S.	Give them a treat option			

Solomon S.	Good friend's son has Barth Syndrome and drug would greatly benefit his quality of life!			
Sonja S.	More energy, less social isolation, improved quality of life, decreasing the risk of severe heart complications like heart failure.			
Stacey S.	It has the potential to greatly increase [A]'s quality of life.			
Stephanie S.	Have a dear friend who's 11 yea old [son] suffers from Barth , she's been fortunate to see him make it to his age , would love her to have more time , [G] is a spectacular little boy			
Susan S.	It could save the life of my best friend's son who has Barth Syndrome			
Susan S.	My best friend has a young grandson who has Barth syndrome. Please allow this child access to this medication to enhance his precious time/ life. Thank you!			
Susan S.	Help a very close family friend have an opportunity for participation in the clinical trial for elamipretide that could help him & others have an improved quality of life.			
Susan S.	An improvement in the quality of life for the child !			
Thomas S.	This may enable my son to overcome fatigue and lead a more normal in terms of physical activity.			
Tuur S.	I want elamipretide to be available for all the Barth patients because if it works for some, it might also work for another. We all should have the right to have the option to try. Everybody has the right to function normally, to try being able to be independent in life, to exercise a job, to get a life just like everybody else. It would be terrible not having access to medication that might help Barth patients with this.			
Viktoriya S.	Such a drug is not used in Russia			
William S.	It would be good to boost daily energy levels.			
Zdenka S.	If my son [V] was still alive (died at the age 2.5 years 6 weeks ago due to sudden heart fibrillation), I'd definitely try to give him Elamipretide to increase his quality of life. Fatigue was a big topic for us: although [V] was a happy boy, he was always much more tired than kids of his own age and he did not have much opportunities to explore the world from an age-appropriate perspective. When he died at 2.5 years, his verbal skills and intelligence was at ~ 3 years old (based on what professionals told us), but his gross motor skills were at 10 months - he was still crawling at 2.5 years. His energy for moving around was even less than 10 months old babies. Often after only few hours awake, he was just lying on his back reading a book, when other kids of his age were running around. [V] also had serious chronic heart failure during his whole life (spongious cardiomyopathy, EF around 40) and died by sudden heart fibrillation, elamipretide could have also improve his heart function.			
Alyssa T.	My godson (4) was diagnosed with Barth Syndrome 3 years ago and I want a brighter, stronger future for him. This drug would have a positive impact on his quality of life. As an occupational therapist, I treat the whole person holistically and I understand that fatigue can be debilitating, preventing individuals from participating in daily activities that give their lives meaning, value, and purpose. Thank you.			

Atsuhito T.	I have two patients having TAZ mutation. Cardiomyopthy is the most serious problem in these patients. I hope that elamipretide will overcome heart failure in patients with Barth syndrome.			
Beth T.	It would improve the quality and prolong the life of my friend's son.			
Carol T.	It will help him to breathe easier so he can get out to do more things with family and friends, as now he doesnt have enough energy.			
Chris T.	Our friends with a Barth child wouldn't have the anxiety that they experience every day watching for symptoms that to other children wouldn't matter, but could be life threatening and cause their Barth child to need emergency care.			
Daniel T.	Dramatically			
Diana T.	It might help			
Harish T.	To see hope for people you need it .			
Jacob T.	Would change the life of my friends boy. The emotion distress it has caused as well.			
Jeanette T.	My child could possibly have survived this disease and gone on to live a full and healthy life			
Margaret T.	This drug would make a positive improvement to the quality of life to Barth syndrome sufferers.			
Matěj T.	Simply said, it will help me to feel confident in that I will have chance to do wha I love with people I love in far future.			
Naomi T.	First promising treatment.			
Nigel T.	My son may have survived to live a long and healthy life			
Shirlan T.	Better quality of life			
Tracy T.	It would allow him to have more energy to do the things that he enjoys.			
Will T.	Treatment would change our lives.			
Brittney U.	Freedom and the ability to have a more purposeful life!			
Ben V.	My grandson [B] has lived with Barth syndrome for 23 years now. We have watched him struggle with this disease for far to long. He is always fatigued and hasn't had a chance to live a normal life. If this drug has shown to help with fatigue and improve muscle and help his heart please approve it immediately for his use and for use by all Barth individuals. [B] deserves to feel better and have more energy and stamina for daily functions. I am asking for Immediate Approval from the FDA. Thank you.			
Crystal V.	Improve the health of kids of friend of a friend living with Barth Syndrome.			
Ethan V.	It will alleviate the pain of a friend, which is all I care about.			
lvadell V.	My grandson [B] has lived with Barth syndrome for 23 years now. We have watched him struggle with this disease for far to long. He is always fatigued and hasn't had a chance to live a normal life. If this drug has shown to help with fatigue and improve muscle and help his heart please approve it immediately for his use and for use by all Barth individuals. [B] deserves to feel better and have more energy and stamina for daily functions. I am asking for Immediate Approval from the FDA. Thank you.			

Jan V.	I have 2 brothers and 2 cousins with Barth syndrome. As a general practitioner I realize very well what "quality of life" means! So , for me it's very important that everybody with Barth syndrome should have the possibility to choose for elamipretide : the results of TAZPOWER are convincing !!		
JoAnn V.	Anything that gives a better life to another, even if only one person, should be a given, please consider as if it was your child.		
Judy V.	It can keep my nephew alive. He has been battling this for over 30 years. There are few options left. He has participated in every testing program possible to find a cure for this heartbreaking issue. Please move to approve it for Barth boys before more are lost		
Julia V.	My brother, a Barth syndrome patient, has seen great improvement on the drug. I don't have any children, but I am carrier for Barth syndrome. This FDA approval gives me great hope for future children with Barth Syndrome.		
Karel and Magda V.	As parents and grandparents of 4 still living Barth patients we want Barth patients to have access to elamipretide because of the potential benefit to some people in the Barth community. The disease doesn't affect everyone in the same way but the patients need options to try medications that could potentially improve some of the symptoms. They already have to live with a life-threatening disease, they should at least have the chance to ameliorate their quality of life. Deeply sadly we lost three sons probably due to Barth syndrome which was unknown in those days. Now science has improved and we have the chance to act. We should not leave Barth patients alone in their battle.		
Karen V.	Extra Quality of life		
Michael V.	My wife is a carrier for Barth Syndrome. Her brother has been taking this medication and it has made a world of difference for him. I would like to have my own children some day, but this is not something we want to pass on to our children with the current treatment options available. The impact to me is that I wouldn't have to see my family members struggle with this syndrome as much, nor will I have to see my wife feel so hopeless as we move forward into parenthood.		
Paul V.	It would be a big step forward for all the patients with barthsyndrome, they all have right to live a normal life, and if it's possible with elamipretide. The availability of elamipretide is very important becourse every patient with Barth syndrome has right to live a normal live, if it's possible with this [medicine], it would be a big stap		
Peter V.	Would help a lot.		
Peter V.	Fatigue is more limiting than any healthy person could even imagine. It leads to many practical problems, severe depression and even suicidal thoughts at time. Saying that my quality of life is current low would be an understatement. Hardly having a life would be more accurate. The question therefore isn't how much elamipretide can improve quality of life. It can give me a life and even a chance of that is worth almost any risk.		
Tiffany V.	I have a friend who's son participated in the trials. it's improved his quality of life by increasing his muscle strength and stamina throughout the day.		
Tom V.	made it better - dumb question		

Veerle V.	Our seriously Barth loaded family history has shown many different degrees of the disease so there will always be the fear of deterioration of the health of my 2 sons and 2 brothers having Barth. It is crucial to have access and availability to potentially beneficial therapies. It is urgently crucial for all the Barth peers who we have seen struggling for 19 years already. Having lack of energy as a child is already very difficult, not being able to keep up with peers, not being able to follow fulltime school. Having lack of energy as an adult means additional serious problems: how exercising a job, how maintaining a family when already insurance companies refuse you because of a life-threatening diagnosis. Not having the option for access to potentially beneficial treatments which could, even just a bit, improve quality of these lifes would be emotionally and physically unbearable for the patients as well as for their families.		
Abigail W.	I would like my uncle to have the opportunity to be less tired		
Adrianne W.	Giving the family hope		
Amy W.	Tremendously! Helps with fatigue. My son was able to go to school and work after school due to this medication. We need access to this drug for every affected individual! Let us have the choice of using this please.		
Amy W.	It would greatly help my son life in so many ways. This needs to get approved, my sons life depends on it. Please!		
Angie W.	Would help save the life of family member		
Ashlee W.	This would be a life changing drug for a Barth syndrome kiddo in my area, who has been fighting his entire life to stay alive! Please please approve this drug for this rare disease and make these kids healthier!!		
Brenda W.	[B]		
Brittany W.	It will give me my husband longer. It will improve his health.		
Charles W.	Assist a dear freind		
Christopher W.	It could greatly improve my quality of life.		
Corey W.	It would give me the ability to perform everyday functions, play with my children, go to work and exercise without being extremely limited. I give anything to have as much of a normal life as possible		
Cory W.	Help a lot		
Craig W.	Give him the life he is deserves		
Deborah W.	Increase their lifespan and ease symptoms		
Deborah W.	Improve ability to function, perform ADLs, decrease hospitalizations		
Dillon W.	If it stopped me being tired it could change my life. I could concentrate at		
	school and my dream of being a farmer might come true if I havent got to have things adapted to help me		
Dodie W.			
Dodie W. Gerald W.	things adapted to help me		
	things adapted to help meGrandson has Barth & this drug will improve the quality of his lifeMy nephew, [J], has Barth Syndrome. He's an amazing person whom we all		
Gerald W.	things adapted to help meGrandson has Barth & this drug will improve the quality of his lifeMy nephew, [J], has Barth Syndrome. He's an amazing person whom we all love dearly and want only the best for him.This drug has the potential of changing the opportunities available for my		

Jessica W.	This could give my brother more energy and give him a better quality of life, he wouldn't need to sleep so much.
Jessica W.	My brother is one of the oldest living people with Barth syndrome (he is 38) and we can see his health declining. His fatigue makes it difficult for him to do hobbies he used to enjoy, he struggles to get up from a chair, he has a tremor, and he just doesn't feel well. I am very worried that he is going to die soon, which is heartbreaking - so his ability to access this drug could mean a literal difference between life and death. Please, please, please approve this drug. My daughter, who is 9, loves her uncle [J] dearly, and I want him to be able to see her graduate from high school, go to college, get married, etc. We are all extremely close, and the availability of this drug could make all the difference for him and our family (and everyone affected by Barth). Thank you.
JoAnna W.	Increase quality of life got my friend who has Barth
Joanne W.	Hopefully help him become more active and continue make the world a better place!
John W.	I participated in the clinical trail and had to stop taking the drug because of an adverse reaction. We have sorted out the issue and I feel comfortable restarting Elamipretide. I believe I was on the drug during the first half of the trial, then had the placebo, then went back on drug for the OLE. I would like to see if I stayed on drug for a longer duration. The fatigue I have is debilitating. I am unable to work at all now and I would give anything to be able to have a job and work. I would love the opportunity to go back on the drug and try again Thank you very much for your consideration.
Johnathan W.	Save lives
Julie W.	If my son wasn't so tired so quickly he might have been able to join in more in primary school and been able to make friends. He might be able to concentrate more in school and not be so far behind. He wants to be a farmer as his grandad was but has to have so many things adapted for him it is incredibly expensive and he would have to rely on others to help him as he does get so tired. It has been very hard trying to help him without him losing his independence and him getting angry with us. People look at him using his wheelchair and wonder why when he can walk, which makes him very self conscious. These are just a few of the things that we have struggled with and there are so much more
Kathleen W.	Grandson could get out of wheel chair
Kathryn W.	This will help [C] tremendously.
Katie W.	My friends son has Barth syndrome
Kerry W.	This drug could ease a child's suffering!
Kevin W.	Our older son, [C] (10) suffers from Barth syndrome and the approval of elamipretide could give him endurance, more strength to be able to do all the things he currently cannot do like ride a bike, swim, play sports, and countless other activities. Thank you for the consideration.

Kim W.	My Grandson has had to deal with so many of the issues Barth Syndrome causes but what truly breaks my heart, is watching him grow up with no friends and being bullied because hes different. I'm referring to [his] extreme fatigue and constant aching. He can't keep up with the other kids. Nobody wants to play with him, he holds them back and therefore is made fun of. If there is a chance for him to fit in among peers it would mean the world!			
Krista W.	My son could benefit from getting fatigued, every so often.			
Kristen W.	Would much improve the quality of life for him.			
Lauren W.	Friend suffers from this.			
Lucinda W.	it will make the lives of my two sons better and increase their quality of life.			
Marilyn W.	Any medication that can possibly improve heart function can be life-saving.			
Marvin W.	Hopefully it would help my son [J] feel like he'ss normal! That's all he wants in life!			
Michael W.	Family member participated in elamipretide trial.			
Patricia W.	It would provide an opportunity for a little boy to live his best life even better, just like all little boys should !!			
Robert W.	Would help our grandson who has Barth live a longer life			
Ron & Lori W.	Give both of our Grandsons hopefully a better quality of life.			
Ryan W.	It would finally provide a treatment for my best friend's soon who is suffering from Barth Syndrome. Please approve this drug. This is the hope they have been praying for!			
Scott W.	Would help with school and work life to achieve more and not have to depend on other people as much .			
Shannon W.	This would help a friends little boy			
Sophie W.	One of my closest friends [A] has the condition. We have an overseas friendship so in person i can not see the effects but i hear about them from time to time, from hospital visits and check up to due with his condition. Daily grievances such as feeling fatigued and ill that day and his body just not behaving, Not being able to do the same activities as his friends and how aggravating it is for him. Work which he applys for but ends up not being able to do due to his condition. Many daily factors could be improved in his life with this drug and i believe it is in his and everyone else best interest that this gets the go ahead. It could change their lives completely.			
Stacey W.	There are no words. To be able to see my 10-year-old son have the strength and energy to keep up with school and his peers would be life-changing.			
Steven W.	It can hopefully give [C] (my godson) more strength and stamina			

Susan W.	My son is 38 years old. Barth syndrome has negatively and sometimes dangerously affected his life since his birth. Two examples of many are that he was not able to attend high school in person and it took him 6 years to complete a community college 2 year degree program due to the extreme and devastating fatigue caused by Barth syndrome. His dream is to be able to have a job to support himself. He cannot do this because of Barth syndrome. It basically has robbed him of the life he hoped for. As he ages, the fatigue is getting even worse; climbing one set of stairs is difficult and he avoids it when possible, without a handrail it is impossible., he has an electric scooter to make it possible for him to manage distances more than a few blocks or he just stays home. Elamipretide offers the possibility of hope for my son and all the other individuals suffering with this disorder. Please make Elamipretide accessible for all who have Barth syndrome! It could be life changing in ways large and small for people in the Barth community and even the small improvements can make a huge difference for people when so many things are so hardjust the basics of life Please give those suffering with Barth syndrome the opportunity to try this drug to see how it might improve their quality of life and maybe even slow the progression of the disorder. Thank you for your consideration.	
Tracy W.	It would give my son more energy and therefore a much better quality of life	
Virginia W.	Give this child a chance at a better and longer life.	
Cassidy Y.	If would be the answer for a close friend's son that they have been hoping to be approved	
Cathy Y.	i belive this should be provided for chrildren with barth	
David Y.	Hope extend the life of his Heart	
Lucy Y.	We have friends for many years through our church and they list their son to Barth Syndrome. In 2014.	
Mary Anne Y.	It strengthens muscle strength and stamina throughout the day.	
Alicia Z.	It would allow my son to participate in activities with children his age as they do - he would not have to sit out because he cannot physically keep up.	
Anne and Bill Z.	Our grandson, [B], age 8, suffers with Barth Syndrome which also caused the death of his brother, [R]. Had a treatment been available perhaps [R] would still be with us. [B] is a very bright boy who struggles to keep up physically with his younger brother, [R] (age 3) who is unaffected. Treatment of his symptoms would allow [B] to participate more fully and normally in activities with family and friends, alleviating much of his frustration and disappointment and giving him an opportunity for a much happier and hopefully longer life.	
Emily Z.	My little cousin is 3 years old fighting Barth syndrome! This could change his life forever!!	
Eric Z.	Elamipretide would help give my 12 yo son, [G], more sustainable energy. He could study better. He could be more independent. He could begin thinking about jobs. It would greatly improved his quality of life. Thank you.	
Kelly Z.	My great nephew [C] has Barth Syndrome. He is 3 years old and has struggled to survive since the day he was born. Please help. Thank you.	
Taja Z.	It's for my cousin 💙	
Canon	It could be life saving for the son of a friend!!	

Anonymous	[M], notre petit fils est atteint du syndrome de Barth, il a 2 ans et demi		
Charity	I have been blessed to know [C] his entire life he is my little neighbor and friend I'm praying and hoping but he can have access to this medicine he's a bright beautiful child very intelligent and kind our world is a better place because he is in it and anything that will better the quality of his life I will do anything that y'all need me to do I will get as many people as we need to get to sign this petition for him I have known his mother since she was a young girl she's one of the strongest mothers I've ever known and I know she will do anything to help her child they're a wonderful family and this medication could increase the quality of their lives		
Collet	[S]		
Courtney	Give them energy to keep up with their family.		
Jodi	Help friends son and others		
Renee	My best friend's 1st born passed away right after birth from Barth's and her son also has Barth's. We would all do anything for him.		
Serena	Obvious impact of potentially saving a child's life and providing the families much needed support.		



BTHS Patient

Alfie Lennon A. Andrew B. Bly B. Daryl B. Kevin B. Oliver B. Valerio B. Walker B. Brian C. lack C. Jason C. Javier C. Michael C. Samuel C. William C. Abram D. Aldo D.

lason D. Jules D. Justin D. Nicholas D. Alex E. leuan E. lacob F. Johan F. Jacob G. Mitchell G. Steven G. Steven G. Travis G. Tyler G. Ben H. lack H. Nickolous H.

Obed H. Robert H. Rogier H. William H. Orione I. Jeremiah A L. Benjamin M. Lyem M. Mario M. Pietro M. Samantha M. Wyatt M. Gabe N. Christopher P. Kareim P. Alex S. Cameron S.

Chad (Cj) S. Collin S. Derek S. lef S. Tuur S. William S. Matěj T. Paul V. Peter V. Peter V. Christopher W. Corey W. Dillon W. Jason W. John W. Rupert W.

Parent or Family of BTHS Patient

Collet Courtney	Jim A. Josanne A.	Amy B. Anna B.	Danielle B. Dave B.
Heligon	María A.	Anne B.	David B.
Katelynne	Marian A.	Ashley B.	David B.
Olga	Mary A.	Benjamin B.	Deirdre B.
Sherry	Miriam A.	Barbara B.	Diane B.
Allanna A.	Shirley A.	Bianca B.	Dominique B.
Ashley A.	Tal A.	Bill B.	Donna B.
Chalaye A.	Tiffini A.	Blaine B.	Elena B.
Émilie A.	Tina A.	Brenda B.	Ella B.
Emily A.	Tommy A.	Brenton B.	Emily B.
Florence A.	Vigdis Á.	Brian B.	Francesca B.
Gerald A.	Yessenia A.	Camilla B.	Geoff B.
Guégan A.	Abby B.	Carl B.	Gretchen B.
Holly A.	Alanna B.	Carlo B.	Helen B.
lan Á.	Alex B.	Christine B.	Isabella B.
Isabel A.	Alysha B.	Claire B.	Jade B.
Jay A.	Alyssa B.	Courtney B.	James B.
Jean A.	Amanda B.	Daniel B.	James B.

lan B. Jason B. lennifer B. Jérémy B. John B. John B. John B. Johna B. Joseph B. Joseph B. Judith B. Kelsey B. Kelsi B. Kerry B. Kimberly B. Kristen B. Leslie B. Linda B. Loyce B. Marissa B. Marita B. Marykate B. Mathieu B. Matt B. Matthew B. Meg B. Megan B. Megan B. Megan B. Michael B. Nancy B. Nicholas B. Nick B. Nicole B. Noémie B. Olivia B. Pam B. Rachelle B. Richard B. Richard B. Rosemary B. Roy B. Sally B. Sandra B. Sara B. Sarah B.

Sasha B. Serena B. Shananne B. Sharon B. Sharron B. Shaun B. Shawn B. Shelley B. Shelley B. Sherri B. Simon B. Steven B. Susan B. Suzette B. Tallon B. Tamara B. Ted B. Thomas B. Tom B. Tracy B. Veronica B. Warner B. Wendell B. Whitney B. William B. Abby C. Alexis C. Amandine C. Anderson C. Angela C. Benjamin C. Bonita C. Brie C. Carly C. Cassandra C. Claudia C. Coralie C. Darla C. Dawn C. Doug C. Edith C. Eleanor C. Elizabeth C. Ellen C. Elodie C. Fairilee C.

Francisco C. Gale C. Genesis C C. Guadalupe C. Helen C. Héléna C. lan C. Isabel C. Jasmine C. lennifer C. leremy C. Joey C. Joseph C. loyce C. Juan C. Karen C. Karen C. Katelyn C. Kerri C. Kevin C. Korey C. Kristi C. Kristina C. Lodé C. Malissa C. Mannes C. Marc C. Mark C. Marlene C. Mckenna C. Michael C. Michelle C. Nelson C. Paola C. Pat C. Paul C. Penelope C. Peter C. Ouevin C. Rhiannon C. Riccardo C. Robert C. Roseann C. Sharon C. Simona C. Stephen C.

Tasha C. Terasa C. Tom C. Tonja C. Abderrahmane D. Alana D. Anna D. Brandi D. Branislav D. Brooke D. Bryan D. Carla D. Carmen D. Catherine D. Chandler D. Charlotte D. Danielle D. David D. Diego D. Drew D. Edward D. Elizabeth D. Elizabeth D. Frank D. Fred D. Gissela D. Gunther D. Henry D. Jacqueline D. Jason D. lim D. Katelynn D. Kati D. Kevin D. Kim D. Kimberly D. Kristen D. Laura D. Lisa D. Maggie D. Mandy D. Marcia D. Mark D. Mary Alice D. Michael D. Michael D.

Michaela D. Michaela D. Nick D. Palash D. Patricia D. Penny D. Rachelle D. Rebecca D. Robbe D. Sara D. Sarah D. Sherry D. Siska D. Sonja D. Susan D. Teresa D. Tiffany D. Tori D. Whitney D. Anyssa E. Daune E. Diane E. Elizabeth E. Isabel E. Kate-Marie E. Kayla E. Linda E. Lynn E. Madeline E. Marc E. Ralph E. Renee E. Angelo F. Carl F. Cheryl F. Chris F. Dorothy F. Elisa F. Elizabeth F. Emily F. Hayley F. Ioani F. Julie F. Iulie F. Kristen F. Kylee F.

Louise F. Mary Jo F. Michelle F. Rachel F. Rebecca F. Serenity F. Sharon F. Stefan F. Steve F. Sylvie F. Alex G. Amanda G. Angela G. Annette G. Antonio G. Bradon G. Candy G. Catalin G. Chalave G. Christine G. Daisy G. Emily G. Fraser G. Henry G. Holly G. Iría Laura G. lill G. Joan G. Joel G. John G. Joyce G. Karen G. Kathleen G. Kristen G. Launa G. Laura G. Linda G. Linda G. Lisa G. Lois G. Lorraine G. Matt G. Michela G. Michele G. Michelle G. Nada G.

Rob G. Robert G. Roy G. Rudy G. Rudy G. Sandra G. Santos G. Sara G. Shannon G. Shirley G. Suzy G. Syd G. Tiffany G. Tina G. Toni G. Alicia H. Amie H. Amy H. Angélina H. Annette H. Audrev H. Audrey H. Aurelia H. Betty H. Brittny H. Candace H. Cecilia H. Chris H. Christiane H. Christine H. Christy H. Corry H. Courtney H. Craig H. Doug H. Drena H. Elissa H. Erica-Lynn H. Gina H. Greg H. Harry H. lames H. lennifer H. lennifer H. lennifer H. Jeremy H.

lessica H. John H. Joshua H. Joshua H. Keli H. Kelsev H. Kenneth H. Kenneth H. Kenzy H. Kim L H. Leigh H. Leonie H. Linda H. Lisa H. Liz H. Louise H. Marcia H. Mary H. Megan H. Michael H. Mike H. Monica H. Nicole H. Olivia H. Pam H. Peggy H. Peggy H. Richard H. Ron H. Shayli H. Shelbi H. Stephanie A H. Susan H. Sylvia H. Tammy H. Fala I. María I. Mariah I. Mariana I. Rachael I. Ryuya I. Scott I. Yukie I. Annie J. Ashley J. Beaudouin J.

Brian I. Chavez I. Deloris I. Eneida J. Kimjuanna J. Lawanda I. Allis K. Amanda K. Ann K. Brenda K. Bridgette K. Catherine K. Chalaye K. Christie K. Cynthia K. Ernest K. Geri K. Giovanna K. len K. Jess K. John K. John K. Kathy K. Lakin K. Laurie K. Lecubin K. Leslie K. Maria K. Mary K. Matt K. Nancy K. Ned K. Pamela K. Valerie K. Annemarie L. Brenda L. Brooke L. Carmela L. Carole L. Caroline L. Christie L. Deborah L. Denise L. Doreen L. Garrett L. Gaylord L.

Ghent L. Ginger G. L. lason L. Jenny L. Kathy L. Keri L. Maike L. Megan L. Melissa L. Michelle L. Michelle L. Nancy R L. Palmer L. Randie L. Sarah L. Sladkevitch L. Victoria L. Alexis M. Amanda M. André M. Anita M. Ann M. Ann M. Annick M. Antonia M. Belinda M. Carmela M. Celeste M. Chris M. Claudio M. Colette M. Constance M. Corinne M. Craig M. Cynthia M. David M. Debra M. Denise M. Ed M. Elizabeth M. Elizabeth M. Florence M. Greg M. Greg M. Inès M. Jamie M.

lasmine M. lennifer M. lennifer M. lill M. Jill M. John And Joanne Μ. Joseph M. Kate M. Kathryn M. Kellie M. Kirt M. Kristin M. Kvle M. Laura M. Laura M. Les M. Leslie M. Lvnda M. Lynn M. Mariam M. Marina M. Mario M. Martha M. Mary M. Mary M. Matthew M. Mayoung M. Mike M. Patty M. Patty I. M. Rachel M. Rebecca M. Rosa M. Roxanna M. Sandt M. Sarah M. Shannon M. Shelia M. Sheryl M. Spencer M. Stacy M. Stef M. Stephanie M. Stephen B M. Suzanne M.

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Heather P. Inez P. len P. lo P. loe P. lordan P. lustin P. Kelsi P. Kristi P. Krysten P. Mandy P. Mannes P. Mary P. Oksana P. Rhonda P. Richard P. Richard N. P. Suzanne P. Valerie P. Vanessa P. Veera P. Megan Q. Adam R. Alicianne R. Alvina R. Amer R. Ashlynne R. Babette R. Brie R. Brittany R. Carolyn M. R. Catherine R. Cedar R. Cheryl R. Dalene R. Danielle R. Darlene R. Desiree R. Emily R. Erin R. Eunice R. Hannah R. Harold R. Jay R. Joann R. Jose R.

Karen R. Kim R. Lauriane R. Leah R. Lori R. Margaret R. Mason R. Megan R. Melodie R. Nina R. Paul R. Richard R. Alexis S. Alice S. Amanda S. Amanda S. Anatoly S. Andrew S. Anne S. Annie S. Camchung S. Carolyn S. Catherine S. Cherie S. Christian S. David S. Denise S. Desmond S. Diane S. Donna S. Elizabeth S. Ellen S. Eric S. Erik S. Erin S. Gabrielle S. Gail S. Garrett S. Gary S. Jacqueline S. Jacquelyn S. Jaroslav S. Jason S. Jeffrey S. lens S. Jessica S.

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Marvin W. Melissa W. Michael W. Michelle W. Nancy W. Paige W. Patricia W. Rebecca W. Rhiannon W. Robert W. Ron & Lori W. Samantha W. Sara W. Scott W. Sharon W. Stacev W. Steve W.

Steven W. Susan W. Suzanne W. Tracy W. Virginia W. Cathy Y. David Y. Margaret Y. Mary Anne Y. Alicia Z. Anne And Bill Z. Emily Z. Eric Z. lanice Z. Kelly Z. Shiva Z. Taja Z.

Community Advocate

Amy
Ana
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Ashlee
Canon
Cecile
Charity
Donna
Dubreuil
Erin
Irving
Jennifer
Jodi
Kirstin
Makayla
Marsico
Michael
Michael
Obringer
Renee
Scott
Serena
Teddy
Vincent
Alice A.
Amanda A.
Anahi A.
Anastacia A.
Andrew A.
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Anne A.
Ashley A.
Ashley A.
Astrid A.
Ben A.
Brandy A.
Cauchy A.
Cecilia A.
Chris A.
Courtney A.
Cross A.
Dandre A.
Danielle A.
David A.
Dawn A.
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Dea Ann A. Denise A. Donna A. Elizabeth A. Emily A. Eric A. Estelle A. Flavia A. Garry A. Gary A. Gilet A. Haley A. Heidi A. lackie A. Jamie A. lamie A. Janelle A. Jayson A. lean A. lenelle A. lenn A. Jenny A. Jillian A. lohn A. Joleen A. Jolene A. luan A. Julianne A. Kali A. Karen A. Katey A. Keely A. Kelli A. Kelly A. Keri A. Kim A. Kim A. Kristi A. Laura A. Leona A. Linda A. Lisa A. Lyndal A. Mandy A. Margaret A. María A.

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Aidan B. Alan B. Aleese B. Alessandro B. Alex B. Alexis B. Alice B. Alicia B. Alisha B. Allison B. Allison B. Allyn B. Alyssa B. Amanda B. Amanda B. Amanda B. Amanda B. Amanda B. Amandine B. Amber B. Amber B. Amy B. Amy B. Ann B. Anne B. Annie B. Annie B. Antoine B. Ash B. Ashley B. Avis B. Barbara B. Barbara B. Becky B. Becky B. Benny B. Beverly B. Bonnie B. Brandy B. Brenna B. Brittan B. Brittney B. Caitlin B. Camilla B. Carianne B. Carin B.

Carley B. Carol B. Carrie B. Cassidy B. Catherine B. Cathlyne B. Chelsea B. Chelsea B. Christea B. Christine B. Christy B. Claire B. Cleo B. Cody B. Colleen B. Connie B. Connie B. Connie B. Coralie B. Cynthia B. Cynthia B. Cynthia B. Daniel B. Daniel B. Daniel B. Daniel B. Daniel B. Daniel B. Daniel B. Daniel B. Debra B. Debra B. Debra B. Debra B. Debra B. Debra B. Diana B. Diana B. Diana B. Diana B. Diana B. Diana B. Diana B. Diana B. Diana B.	Emily B. Emma B. Erica B. Erika B. Erika B. Francesca B. Gail B. Gina B. Greg B. Greg B. Greg B. Haley B. Hannah B. Heather B. Hannah B. Heather B. Heidi B. Ilah B. Jacob B. Jamie B. Jamie B. Jamie B. Jamie B. Jamie B. January B. Jared B. Jasmine B. Jasmine B. Jenn B. Jenn B. Jennifer B.	John B. Johni B. Josephine B. Judith B. Julia B. Julia B. Julie B. Kara B. Kara B. Karla B. Kathy B. Kathy B. Kathy B. Kelley B. Kelley B. Kelly B. Kenneth B. Kimberly B. Kimberly B. Kimberly B. Kisa B. Kristin B. Kristin B. Kristin B. Kristin B. Lacey B. Lacey B. Lacey B. Laura B.	Mary B. Mary B. Mary B. Maty B. Matt B. Matt B. Matthew B. Matthew B. Megan B. Meghan B. Melinda B. Melissa B. Melissa B. Melody B. Michelle B. Michelle B. Michelle B. Michelle B. Monica B. Monica B. Nancy B. Nancy B. Nathalie B. Nathalie B. Nathalie B. Nathalie B. Nathal B. Nikki B. Nisha B. Noelle B. Paige B. Patrice B. Patricia B. Paul B
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Dina B.	Jeremy B.	Lexandria B.	Rachael B.
Donna B.	Jesse B.	Linda B.	Rachael B.
Donna B.	Jessica B.	Lindsey B.	Rachel B.
Donna B.	Jessica B.	Lisa B.	Raydeen B.
Edwin B.	Jessica B.	Lorenzo B.	Rebecca B.
Elaine B.	Jessica B.	Lorna B.	Rebecca B.
Eliana B.	Jessica B.	Louise B.	Rhae B.
Elisabeth B.	Jessica B.	Lynne B.	Rhonda B.
Eliza B.	Jill B.	Mandy B.	Rick B.
Elizabeth B.	Jo B.	Maria B.	Robin B.
Elizabeth B.	Jody B.	Marie B.	Rodney B.
Ellecia B.	Joe B.	Mark B.	Ryan B.
Emily B.	John B.	Mary B.	Samuel B.

Sarah B. Sarah B. Savannah B. Schyler B. Shane B. Sharon B. Sharron B. Shelley B. Sherri B. Sherry B. Sophie C. B. Stacey B. Stefania B. Stefano B. Stephanie B. Stephanie B. Stephanie A. B. Steve B. Stewart B. Sue B. Sue B. Susan B. Susan B. Tammy B. Tammy B. Tawny B. Teresa B. Teri B. Terry B. Terry B. Thomas B. Thresa B. Tiffany B. Tim B. Tim B. Tina B. Tracy B. Trey B. Vanessa B. Velinda B. Vince B. Virginia B. Vivien B. Wendy B. Woodrow B. Zoe B.

√Âmilie C. Abigail C. Adrienne C. Alex C. Ali C. Alice C. Alice C. Allison C. Amanda C. Amanda C. Amanda C. Amanda C. Amy C. Andrea C. Andrew C. Andrew C. Andrew C. Andria C. Angela C. Anissa C. Ann C. Anna C. Anna C. Annah C. Anne C. Anthony C. Anthony E. C. Antonio C. Barbara C. Bonnie C. Bourreau C. Brandi C. Brandon C. Brandy C. Brenda C. Brenda C. Brittany C. Calvin C. Camilla C. Cari C. Carla C. Cathey C. Celia C. Charles C. Charley C. Cheri C.

Chris C. Christian C. Christy C. CI C. Claudio C. Coleen C. Connie C. Courtney C. Courtney C. Crystal C. Crystal C. Cynthia C. Dan C. Dave C. David C. Debbie C. Debra C. Diane C. Diane C. Dianne C. Donna C. Dotty C. Doug C. Dusty C. Elena C. Elizabeth C. Elizabeth C. Erica C. Erin C. Eva C. Evelyn C. Francesca C. Françoise C. Frank C. Geamileth C. Gerald C. Gregorio C. Heather C. Heather C. Helen C. Hélène C. Hillary C. Ila C. Ilaria C. James C. James C.

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Lauren C. Lauren C. Leah C. Leigh C. Leroy C. Letourneau C. Linda C. Linda C. Lisa C. Loretta C. Loretta C. Manuel C. Marcy C. Marie C. Marti C. Mary C. Mary C. Mary C. Mason C. Matthew C. Matthew C. Megan C. Meggan C. Melissa C. Melissa C. Melody C. Melvin C. Meredith C. Micaela C. Michael C. Michelle C. Mike C. Molly C. Monica C. Monica C. Monika C. Nancy C. Natalie C. Niamh C. Nicholas C. Noel C. Patricia C. Patricia C. Patty C. Paula C. Phillip C.

Rachel C. Ray C. Regnault C. Renee C. Ron C. Sam C. Sarah C. Sarah C. Sarah C. Sarah C. Savannah C. Sharon C. Shelly C. Sherry C. Sierra C. Sondra C. Stacie C. Stan C. Stephanie C. Stephanie C. Steven C. Susan C. Taralee C. Terri C. Terry C. Theresa C. Tiffanv C. Tiffany C. Tony C. Tonya C. Traci C. Veronique C. Vikki C. Wanda C. Whitney C. Zain C. Adam D. Alicia D. Alix D. Amanda D. Amanda D. Amy D. Amv D. Anastasia D. Anna D. Arnaud D.

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Robin E. Ryan E. Sandra E. Sarah E. Sheena E. Shelby & John E. Susan E. Susan E. Teresa E. Terri E. Tyler E. Aimee F. Aimee F. Alison F. Amanda F. Amanda F. Amanda F. Amaury F. Amy F. Ann F. April F. Aprile F. Armando F. Barbara F. Belen F. Benedicte F. Bernadette F. Brian F. Caitlin F. Candice F. Carey F. Carrie F. Cecilia F. Chrissy F. Christine F. Cindy F. Connie F. Crystal F. Crystal F. Dara F. Debbie F. Debbie F. Don F. Donald F. Ellen F. Ellen F.

Ellie F. Emily F. Emily F. Felice F. Gaye F. Gertrude M F. Grace F. Hannah F. Heidi F. lames F. lana F. lane F. lane F. lanice F. Jayme F. lean F. Jeremy F. lessica F. loanne F. Jon F. Julie F. Julie F. Karina F. Kathy F. Katie F. Kay F. Kaylynn F. Kristy F. Lawrence F. Marcella F. Marilyn F. Mark F. Mark F. Martha F. Mary F. Matthew F. Micah F. Michelle F. Milena F. Mya F. Nancy F. Nancy F. Nancy F. Nicole F. Nicole F. Nicole F.

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Health Care Provider

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