



RESTRICTED FUND DESCRIPTIONS

BSF FAMILY SERVICES FUND

Gifts to the BSF Family Services Fund (Fund) are restricted to uses that support the Barth Syndrome Foundation (BSF) programs for affected individuals and their families as well as helping to mitigate particular financial challenges experienced by these individuals and their families due to the disease.

Anticipated and Accepted Uses

Donations to the Fund will be used exclusively to support a variety of BSF programs that bolster the Barth syndrome affected community and their families. This includes, without limitation, supporting Barth families through every stage of the disease from pre-diagnosis through bereavement following a death. Its purpose encompasses, but is not limited to, educational materials, communications, programs of varying sorts (as well as the ability for families to participate in them), and avenues for advocacy regarding Barth affected individuals and treatment development for their disease. In addition, these monies will help fund the BSF Emergency Relief Program which provides our families financial assistance when they struggle with basic living expenses as a result of the financial enormity of living with or caring for a loved one with Barth, through a fair and objective program that is open to all who are eligible. All of these endeavors will support our affected individuals and their families as well as expand their participation and engagement, thus strengthening our collective voice, knowledge and power.

BSF SCIENCE AND MEDICINE FUND (“THE SCIMED FUND”)

Gifts to the BSF Science and Medicine Fund (Fund) are restricted to uses that help support Barth Syndrome Foundation (BSF) efforts to advance scientific understanding of our disease (or any of its components) and/or medical knowledge pertaining to the care of patients with this ultra-rare disease.

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Anticipated and Accepted Uses

Donations to the Fund will be used exclusively to support the advancement of both scientific knowledge about the causes of Barth syndrome as well as medical care available to Barth syndrome affected individuals. This includes, without limitation, funding basic scientific, clinical, and translational research as well as supporting the creation, curation and maintenance of resources and tools (such as, Barth syndrome animal models, biological samples, human gene variants, natural history data, and treatment guidelines, etc.) made broadly available to accelerate the work of Barth syndrome researchers, scientists, and clinicians. In addition, endeavors to grow the number and supplement the expertise of those involved and/or to convene scientists and clinicians in order to propel, acknowledge and accelerate the advancement of Barth syndrome scientific and medical knowledge may be supported by the Fund. The form of support for each of these purposes can be varied, including but not limited to, grants, contracts, or investments.

BSF THERAPY DEVELOPMENT FUND (“THE THERAPY FUND”)

Gifts to the BSF Therapy Development Fund (Fund) are restricted to uses that support Barth Syndrome Foundation (BSF) efforts to advance potential therapies and other interventions for our disease with the goal of developing and making accessible safe, effective therapies and/or standards of care that lead to better health outcomes.

Anticipated and Accepted Uses

Donations to the Fund will be used exclusively to support endeavors intended to advance or facilitate the development of therapies to treat people with Barth syndrome. This includes, without limitation, finding and encouraging the participation of researchers or companies to advance strategic Barth syndrome R&D efforts; early-stage de-risking of promising therapeutic pathways; hiring expert consultants when warranted to augment BSF’s knowledge in specific areas relevant to therapy development; facilitating and/or funding translational and clinical research; clinical trial development and support; and/or licensing agreements. The Fund also may be used to address regulatory affairs, payor interactions, and post-approval access issues. The form of support for each of these purposes can be varied, including but not limited to grants, contracts, or investments.

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