Investors Bank Supports Barth Syndrome Foundation

Grant to Help Fund Research on Rare Disease

SHORT HILLS, New Jersey – Investors Bank, through the Investors Foundation and Roma Bank Community Foundation, recently provided the Barth Syndrome Foundation (BSF) with $2,000 in grants to support its research, community awareness, and family services programs.

Barth syndrome is a serious X-linked genetic disorder, primarily affecting males, caused by a mutation in the *tafazzin* gene (*TAZ*, also called G4.5), which results in an inborn error of lipid metabolism. Barth syndrome usually is transmitted from mother to son; a mother who is a carrier of a Barth syndrome mutation shows no signs or symptoms of this disorder. According to BSF Executive Director Lindsay Groff, the cardinal clinical characteristics of Barth syndrome are cardiomyopathy (enlarged heart), neutropenia (reduced levels of white blood cells that fight infection), underdeveloped skeletal muscles and muscle weakness, growth delay, exercise intolerance, abnormalities in Cardiolipin (a lipid critical for mitochondrial function) and 3-methylglutaconic aciduria (metabolic abnormalities in the blood and urine).

Groff said that although there are no formalized population studies of Barth syndrome, the organization is made aware of approximately 10 individuals diagnosed with Barth syndrome each year worldwide. BSF hosts an international registry to collect clinical data on those who have a confirmed diagnosis of Barth syndrome; currently BSF is aware of fewer than 500 living or deceased individuals with Barth syndrome.

BSF applied for the grants from the Investors Foundation and Roma Bank Community Foundation; Roma Bank became part of Investors Bank in December 2013. The foundations support non-profit organizations that enrich diverse communities served by Investors Bank.

“The Barth Syndrome Foundation is grateful to Investors Bank and its foundations for these grants. This is a very rare, little known disease,” explained Groff, “and this money will help us fund the research so desperately needed to help our boys, and to provide support and ease the suffering of their families. Our boys are not forgotten, and it is so wonderful that Investors Bank cares.”

The grant checks – each for $1,000 – were presented by Investors Bank’s Angela Venti, Assistant Vice President/Branch Manager – Marlton Office. “Investors Bank does care,” said Venti, “and we recognize how debilitating Barth syndrome is, not only for the boys who suffer with this disease, but for their families, who must feel so isolated and alone. Investors hope these grants will assist BSF in its research efforts.”

(More)
Currently there are no specific treatments for Barth syndrome, nor is there a cure. Not all patients exhibit all of the symptoms at any one time; cardiomyopathy, neutropenia, neuromuscular weakness and associated comorbidities are treated as they arise. Careful attention and monitoring for symptoms is advised. Early, accurate diagnosis is key. Historically, Barth syndrome was considered uniformly fatal among boys in infancy, but improved diagnosis, treatment, and management has provided a higher survival rate and prospects of a brighter future.

Photo Caption: Investors Bank recently presented two checks totaling $2,000 to the Barth Syndrome Foundation (BSF), including one for $1,000 from the Roma Bank Community Foundation, to further its research and family services programs. Investors Bank’s Angela Venti, Assistant Vice President/Branch Manager – Marlton Office (right) presented the check to BSF Executive Director Lindsay Groff.

About Investors Bank
Investors Bank is a full-service community bank that has been serving customers since 1926. With more than $20 billion in assets and over 135 retail branches in New Jersey, New York City and Long Island, Investors Bank delivers personalized services and products tailored to the needs of its customers. Investors’ consumer banking services include complete deposit products, online banking, home equity loans and lines of credit and a full array of mortgage loans. Serving the business community, Investors provides deposit accounts, cash management services, business loans and lines of credit, and commercial real estate financing solutions to small and middle market companies, professional services firms, municipalities and other businesses. Investors Bank. Member FDIC and Equal Housing Lender.

About the Barth Syndrome Foundation
The Barth Syndrome Foundation (BSF) is an international organization raising awareness among physicians, scientists, and the general public about Barth syndrome, a rare, serious, X-linked genetic disorder of lipid metabolism primarily affecting males. The Barth Syndrome Foundation's mission is saving lives through education, advances in treatment and finding a cure for Barth syndrome until the ultimate vision of ending suffering and loss of life due to Barth syndrome has been achieved. There is no specific cure for Barth syndrome at this time, but the BSF is funding research for interested scientists and physicians in hopes to further their understanding of the clinical and biochemical abnormalities seen in this disease. In addition to funding research, the BSF provides a caring, educational community for affected families.