



OUR MISSION

Our mission is to fund and support the research and education necessary to accelerate a cure for rare neurodegenerative genetic diseases that affect children and currently have no cure.



NEWBORN SCREENING

Niemann Pick Type C can be detected in newborns with a simple blood test commonly referred to as newborn screening. In 2017, The Firefly Fund initiated and is leading a national effort to add NPC to newborn screening lists at the state and federal levels. #fireflyfund #shiningalightonnpc1 #newbornscreeningsaveslives



MEDICAL RESEARCH

The Firefly Fund supports translational research and applied science with the goal of accelerating a cure for NPC1. In an effort to not duplicate important scientific and medical research being supported by other NPC Foundations, the Firefly Fund strictly focuses on translational research in an effort to test potential therapies and move them to the clinic expediently. #fireflyfund #shiningalightonnpc1 #jointheflight



PATIENT ACCESS FUND

The objective of the Firefly Fund's Patient Access Fund is to financially support the burdensome medical cost and travel costs required for most NPC patients. Doctors familiar with treating patients diagnosed with NPC are often far from where families live, which can present a logistical and financial burden for many families. Our goal is to remove barriers so patients seeking treatment can gain timely, necessary and improved access. #fireflyfund #shiningalightonnpc1 #jointheflight