

SUFFOLK COUNTY LEGISLATURE

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MEDIA RELEASE

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Pictured from left to right: Superintendent of Schools James Polansky, Huntington High School Principal Brenden Cusack, Eli Mollineaux, Legislator William R. Spencer, M.D., Ellen Mollineaux, Sam Mollineaux, Josh Mollineaux, Ilene Messina

Eli's Law Brings Awareness to Mitochondrial Disease

Huntington, NY - In honor of Huntington native Eli Mollineaux, the Suffolk County Legislature has passed a resolution designating every September Mitochondrial Disease Awareness Month. Born with a rare type of Mitochondrial Disease known as Pearson Marrow-Pancreas Syndrome, Eli faces many physical challenges, but he perseveres with his optimistic spirit and positive energy. On Wednesday, September 30th, family, friends, and community officials gathered at Huntington High School to celebrate Eli and raise awareness about this debilitating disease. "Eli's Law", sponsored by Suffolk County Legislator William R. Spencer, M.D., will honor this courageous, kindhearted young man.

Eli, who is currently a high school freshman, has a reputation throughout the community for his great sense of humor, optimism, and sunny disposition. His positive attitude is contagious, and he serves as an inspiration

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to everyone he meets. "Since first meeting Eli this summer, I could immediately tell that this young man has an amazing way of inspiring others." said Huntington High School Principal Brenden Cusack. "His humor and positive demeanor are magnetic, and I've seen the effect of this on our whole school community. Kids gravitate toward him and rally around him like nothing I've ever seen. He's the Mayor of Huntington High School."

There are several different kinds of Mitochondrial Disease. Pearson Marrow-Pancreas Syndrome and related Kearns-Sayre Syndrome, an extremely rare variety caused by a deletion of mitochondrial DNA and characterized by a form of anemia, pancreas dysfunction and other ailments. Treatments are based on the types of symptoms and organs involved in each particular case. For Eli it has been a slowly progressive multi-system disease that has affected his brain, heart, muscles, vision and hearing. Despite all this, Eli's dedication to bettering the community and to making people laugh holds strong as he and his family battle this condition.

"Eli is incredibly special. He inspires those who know about him and forever changes those who are lucky enough to know him. He bounces out of bed every morning with a smile and a hug. He navigates his way through his day with all of his mounting challenges with not only a smile but also a determination and grace that most of us can't muster on our best day." said Eli's mother, Ellen Mollineaux.

"Eli is the kindest, sweetest, most courageous boy I know. He is truly a gift, and I am blessed to be able to work with him and to be a part of his life." said Ilene Messina, Eli's Aide.

Mitochondrial Disease results from failure of mitochondria, the compartments inside cells which are responsible for providing the energy needed for the body to sustain life and support growth. Mitochondria fuel all cells in the body except red blood cells and when they fail, less and less energy is generated, which results in cell injury and cell death. Mitochondrial Disease often presents itself at birth, but it can occur at any age, and can be fatal.

While certain variations of mitochondrial disease are very rare, every 30 minutes, a child is born who will develop some form of the disease by the age of 10. Known as the "notorious masquerader", mitochondrial diseases are often misdiagnosed for other illnesses due to symptomatic similarities and lack of understanding of the disease. As research has progressed, it appears that mitochondria may play a far greater role in our health than realized before. Surprisingly, new developments have found that mitochondrial dysfunction is at the core of a variety of common illnesses and conditions, some of which include: type 2 diabetes, Parkinson's disease, atherosclerotic heart disease, stroke, Alzheimer's disease, and cancer. This new information is a promising opportunity for research and development of treatment and therapeutic options for those suffering from this incapacitating illness.

"With currently no cure or highly effective treatments, it is crucial that we raise physician and public awareness about the signs and symptoms, and the need for further research and education." said Legislator William R. Spencer, M.D. "Eli's spirit is bringing this disease to light. He gives us hope and is an inspiration to others going through their own difficult times. Together, we can create the energy needed to advocate for thousands of families who are living the reality of mitochondrial disease each day."

To learn more about Mitochondrial Disease and to find out how you can help promote awareness, visit the United Mitochondrial Disease Foundation website at www.umdf.org, or call 1-888-317-UMDF.

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