

For Immediate Release
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Contact: curesff@gmail.com



Cure Sanfilippo Foundation welcomes new Executive Director

The Board of Directors for Cure Sanfilippo Foundation is pleased to announce that Glenn O’Neill has assumed the position of Executive Director, as of September 5, 2016. Glenn co-founded the Foundation shortly after his daughter, Eliza, was diagnosed with Sanfilippo Syndrome in July of 2013. He previously led the Foundation for the past 3 years in a volunteer position.

Glenn brings with him more than 15 years of experience in Management and Consulting in the private sector, where he had success negotiating for Global Fortune 500 companies. He has a track record of delivering creative, customized, and strategic solutions to drive Return On Investment for clients across various categories. During his 3-year tenure on the Cure Sanfilippo Foundation Board of Directors, he helped the Foundation raise \$3.2 Million to support research to treat or cure Sanfilippo Syndrome. Glenn also was invited and spoke at Rare Disease conferences for the National MPS Society, NORD (National Organization of Rare Disorders), and Rare Genomics Institute. In recognition of his work both at the Foundation and in the area of rare disease awareness, Glenn, along with his wife Cara, were awarded the Portraits of Courage Honor by NORD in 2015.

“We are very proud of the direction Cure Sanfilippo Foundation has taken since its inception in 2013. Glenn O’Neill has always unofficially guided our mission since co-founding the Foundation with his wife, Cara, and we are excited for him to take on a more official role. We believe that the establishment of the Executive Director position will allow the Foundation to take the next step in nonprofit development: to grow, to become sustainable, and to raise the awareness and funding necessary to accelerate research and treatments for children afflicted with Sanfilippo Syndrome. We know that Mr. O’Neill brings the commitment, passion, energy, and ideas that will help guide us on our mission,” shared the Board in a joint statement.

The Cure Sanfilippo Foundation is a 501(c)(3) not-for-profit organization dedicated to advocating for and funding research directed towards a cure and treatment options for patients with Sanfilippo Syndrome. Sanfilippo Syndrome, also called MPS III, is an inherited disease of metabolism that means the body cannot properly break down long chains of sugar molecules called mucopolysaccharides or glycosaminoglycans (i.e., GAGs). A genetic defect passed on from each parent results in missing or poorly functioning enzymes needed for cells to work normally. Without these enzymes, cells are unable to break down and recycle cellular waste. Over time, this waste builds up causing cells to act abnormally and then to die. Children with this genetic disease face a progressively debilitating and rapid decline in physical and intellectual abilities, leading to an early death.

For more information on the Cure Sanfilippo Foundation and Sanfilippo Syndrome, please visit CureSFF.org. Contact Cure Sanfilippo Foundation at curesff@gmail.com.