Jonah's Just Begun-Foundation to Cure Sanfilippo Inc. (JJB)Announces Awareness Campaign: Mission Hide and Help

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JJB is attempting to break the diagnostic odyssey for Sanfilippo Syndrome also known as Mucopoysaccharidosis (MPS) type III

Brooklyn, NY, September 19, 2017 (Newswire.com) - Jonah's Just Begun-Foundation to Cure Sanfilippo Inc. (JJB) announces the launch of "Mission Hide and Help"-(https://missionhideandhelp.org/ A social media campaign designed to reach parents; their pediatric and early intervention practitioners who are unknowingly caring for a child afflicted with Sanfilippo Syndrome (MPS III). MPS III is an insidious genetic syndrome that often goes undetected for years. In the preschool years children don't meet their milestones. Parents start to suspect something is wrong and the diagnostic odyssey begins.

Founder of JJB, Jill Wood comments: "Most doctors see cognitive delay and assume autism, the catch all for I don't know what's going on with this child. Many parents accept their doctor's diagnosis. Parents and practitioners start to second guess the autism diagnosis when the child presents with symptoms uncharacteristic to autism such as: cognitive regression, sleeplessness, aggressive behavior and loss of motor skills. The diagnostic odyssey can take years if not decades to come up with MPS III."

Today there is no FDA approved treatment for Sanfilippo Syndrome. Non-Profit organizations like JJB are in the midst of changing that. Sanfilippo Syndrome is caused by a single gene defect, which takes some of the guesswork out of a potential treatment. The scarcity of known patients is a hindrance for pharmaceutical companies to support and commercialize treatments.

" People might think that there are lots of orphan drugs being developed so there is no problem, but they could not be more wrong. There are so many ultra-rare diseases with well understood biology and science and yet there is no active development happening on treatments because they are just too few people affected. And yet for many of these ultra-rare diseases there are so many undiagnosed patients wandering without treatment or insight as to why they are sick. Finding these lost patients and making the diagnosis is the

first step to getting the numbers needed to develop treatments and make a treatment available to all." Emil Kakkis, CEO Ultragenyx

Mission Hide and Help is inspired by kids finding rare cards in their Pokemon collections. If they could use these rare cards to help doctors uncover a rare disease, they could really make a difference. Mission Hide Help is calling on families to download a card sleeve from missionhideandhelp.org; placing their rare card in the sleeve and hiding it at their next doctors visit. The sleeve has a message for the doctors: "Nobody can find ultra-rare things like you do. Now I need your help finding ultra-rare diseases in your office. The earlier you find them,
the higher the chances to find a cure."

"There's this idea in medicine that sometimes diagnosis doesn't matter. That it only matters if we can do something about it today. But especially for rare conditions, the more we diagnose the more we learn, and the more we learn the better we will be able to someday treat and prevent these terrible disorders in the first place." Patricia Dickson, Chief, Devision of Medical Genetics, Harbor UCLA Pediatrics

Sanfilippo Syndrome has distinctive facial features often described as 'coarse'. Please refer to jonahsjustbegun.org for more information.

"Mission Hide and Help creator Steve Lundberg says: I understand JJB's dilemma, this posed a major challenge to my creative partner, Eduardo De La Herran and I. We wanted to get our message directly into the offices of pediatricians. To do this, we needed the help of kids. With a shoe string budget, getting their help via social media and a grassroots effort was the best solution. Now we need everyone's help...and ultra-rare cards... to make Mission Hide and Help a success."

About Jonah's Just Begun

JJB was formed in 2010, when parents: Jill Wood and Jeremy Weisharr received the diagnosis of MPSIII C, for their 2 year old son, Jonah. JJB's primary focus is to raise funds for MPS III research. JJB has co-founded the only global MPS registry, ConnectMPS.org, and the first Natural History Study for MPS III C and D. JJB is currently aiding Face2Gene in training their facial recognition software to identify children with Sanfilippo Syndrome.

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Source: Jonah's Just Begun

Related **Files**

- HideandHelpSleeves(1)

Additional **Links**

- Jonah's Just Begun
- National MPS Society

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