"Mission: Hide and Help" - Sanfilippo Awareness Campaign

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Abstract

Mission: Hide and Help (MHH), an awareness campaign for Sanfilippo Syndrome. Sanfilippo Syndrome (MPS III) is a rare genetic disease caused by the deficiency of one of four lysosomal enzymes required to breakdown the glycosaminoglycan, heparan sulfate. There is often a delay in diagnosis, families may be stuck in the diagnostic odyssey for years or go misdiagnosed for decades, often times as Autistic. **However, by the time the child is two, they have distinctive facial features characteristic to Sanfilippo which include: progressive coarsening facies, prominent eyebrows, and frontal bossing. Behavioral issues and cognitive delays are also evident**. There currently is no approved treatment for Sanfilippo Syndrome, but many companies and academics are working on one. The earlier a child is treated the better the outcome. We currently do not have newborn screening. So how do we reach those on the front lines of diagnosis and educate them to the signs and existence of Sanfilippo Syndrome? Co-Founder of Jonah's Just Begun, Jill Wood turned to her friends in advertising to help come up with a unique and creative way to raise awareness. "Mission: Hide and Help" is a social experiment designed for viral attention through social media. The campaign is inspired by Pokémon, a trading card, video game and most recently a downloadable app. Pokémon has special ultra-rare characters, these cards are coveted by their owners. Doctors offices are the places where children with ultra-rare syndromes are discovered. The home is where children begin to present with symptoms and parents become suspicious. In our poster we will demonstrate how children will use their ultra-rare cards to inspire their parents and pediatricians to make ultra-rare diagnoses. MissionHideandHelp.org

Introduction

Newborn Screening is the best option for finding new patients for any rare disease. However, a test for a disease has to have a treatment already available. Once a treatment is approved, advocates have to lobby state by state to add their test to a newborn screening panel. To date there are 34 core diseases and 26 secondary diseases but there is no guarantee a state will test for it even if its on the panel. In order to develop treatments for rare diseases we need to find patients. To motivate companies to develop treatments we need to find patients. We have a classic chicken and egg scenario here. Without newborn screening we are never going to find the patients to justify a treatment. We propose trying to break out of the proverbial egg and educate those on the front line, such as pediatricians and parents to look for signs that a newborn child may have a rare disease. We have been involved in leveraging multiple approaches, raising awareness using an innovative social experiment is described here.

Visit us at Booth # 513

Approach

Mission: Hide and Help leverages social media accounts, press and supporters to create a buzz and inspire action.

Recruited MHH troopers (kids) are directed to wrap their *favorite* rare card in a paper sleeve, available on the MHH website, then hide the card and sleeve at their doctors office or early intervention clinic.

MHH is a huge undertaking, but what life saving mission isn't? To put it in perspective- do you know how many MPS IIIC or D children were diagnosed asymptomatic in the U.S. last year? The educated guess is zero. But you do know that the earlier a child is treated the better the outcome. The science is here now, clinical trials have finally started for MPSIII. If the efforts of MHH can help identify one Sanfilippo toddler in each of the 50 states then we have done our job.

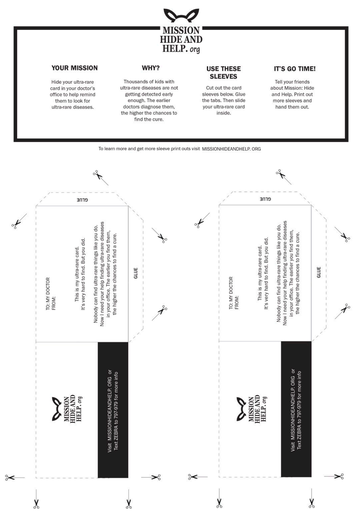

Fig. 1 Downloadable sleeve

Fig. 2 One sheet for doctors

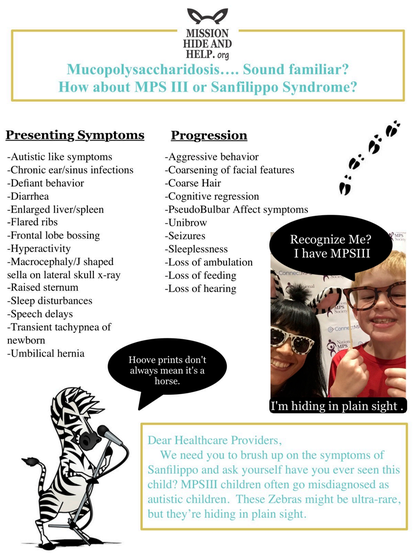

Fig. 3 Viloh, MPS IIIC Finland

Fig. 5 Alec, MPS IIIC Australia

Fig. 4 Jonah, MPS IIIC USA

Fig. 6 Mohamed, MPS IIIC Pakistan

Find them all

In the absence of Newborn Screening, how do we diagnose Ultra-Rare Diseases?

Kids, Parents, & Healthcare Providers can join the mission.

- Watch the video and help kids download the sleeve
- Children hide card at their Doctors office
- Doctors find the card and are directed to information on diagnosis

Text "Zebra" to 797-979

Can your Ultra-Rare trading cards help a doctor diagnose an Ultra-Rare disease?

Let's find out!

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