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FOR IMMEDIATE RELEASE

Parents using viral video to overcome the single obstacle in the way of saving their son's life: \$3 million

Columbia, SC (Oct. 16, 2020) - The parents of Connor Dobbyn, Marisa DiChiacchio and Mike Dobbyn, are using a viral "Save Connor" video to fundraise \$3 million for a clinical trial for Sanfilippo Syndrome that could save their son's life, but lacks funding. People from around the country and world, most of whom are strangers, are watching the video, which launched Oct. 16 during the Chelsea Film Festival, and are donating to help the clinical trial happen and give Connor a chance at life.

"Simply put, Sanfilippo Syndrome is like Alzheimer's in children," said Glenn O'Neill, President & Co-Founder of Cure Sanfilippo Foundation and father to a daughter with Sanfilippo Syndrome. "It is a rapidly-degenerative brain disorder that will steal Connor's ability to talk, swallow, and walk. He will develop seizures and movement disorders. He will suffer pain and severe dementia. And then he'll die. All before his parents' eyes."

There is currently no FDA-approved treatment or cure for Sanfilippo Syndrome. However, gene therapy has shown in pre-clinical models that it can stop the disease. Researchers are ready to conduct the first-ever gene therapy clinical trial for Connor's type of Sanfilippo Syndrome which they hope will show the same therapeutic benefits in children. But the trial lacks funding.

The "Save Connor" viral video aims to raise \$3 million to fund the gene therapy clinical trial, for which required pre-clinical work is already underway. This trial will treat many children. Viewers of the video are asked to donate and share the video with others to keep spreading Connor's story.

"'Save Connor' is an example of the power created when people come together," said Connor's mom Marisa DiChiacchio. "Thousands of people, each lending a hand amidst their normal busy day, can change fate. Viral videos have inspired people to raise millions to save other children's lives. It can for Connor. This is his only chance."

"The emotional and uplifting video especially resonates with parents, who see their children in Connor's smile, kindness, and laugh," said O'Neill. "They feel the tragedy of money being what will determine whether Connor has a chance at life. They want to do whatever they can to help, so they donate and then share the video far and wide. These kind and generous people want Marisa and Mike to wake up one day and know that money will not stand in the way of Connor getting to live."

Watch the video and learn more about Connor at SaveConnor.com.

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Cure Sanfilippo Foundation is a 501(c)3 nonprofit dedicated to advocating and funding research to bring about treatments and/or a cure for Sanfilippo Syndrome. Cure Sanfilippo has funded 25+ research grants around the world which has helped three clinical trials get underway, to date, treating children with Sanfilippo Syndrome. The Foundation creates and explores innovative and breakthrough research to ensure multiple promising paths are being explored in the effort to save children and better their quality of life. Learn more about Sanfilippo Syndrome and the Foundation at CureSanfilippoFoundation.org.