

MEDIA RELEASE

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'OUR MOON'S MISSION' FAMILY BUILDS ARMY OF FACEBOOK FUNDRAISERS TO CURE THEIR PRECIOUS DAUGHTER OF RARE GENETIC DISEASE THIS #GIVINGDAY

In only 24 hours, a Queensland-based family has rallied an army of friends, family and supporters to run mini-Facebook fundraisers to help cure their baby girl of a rare genetic disease. **In just 24 hours they have already raised over \$26 000 and are shooting for the moon.**

In May 2020, one year old, sparkly eyed Tallulah Moon Whitrod lost her ability to walk, talk or even hold up her head. She was later diagnosed with Hereditary Spastic Paraplegia Type 56, a rare degenerative brain disease that continues to worsen with time. Tragically, there is no known cure or treatment.

Despite the heart breaking and vague prognosis of this progressive disease, the Whitrods have been compelled to find a better outcome for their daughter. They have sought out a cure for this so-called "incurable" disease to give their daughter the life she deserves.

"We loved our life in Darwin where our kids were born and our son Finn was just starting pre-school, but we moved to Queensland to give Tallulah the early intervention support she needs: intensive specialist paediatric physiotherapy, speech therapy and occupational therapy," Tallulah's mum, Golden Whitrod said.

"Tallulah literally has a full-time job with therapy every day, struggling to keep her disease at bay".

While Tallulah combats the disease with therapy, her parents are combating the disease with research. In June they established a team and began research with world renowned genetic researchers at the University of Queensland and Griffith University, including **2017 Australian of the year, Emeritus Prof Alan Mackay-Sim.**

"When Chris and Golden first proposed looking for treatment for Tallulah, my first thought was: 'It's possible for us to do that'," Prof. Mackay-Sim said.

"If we found a drug for Tallulah, we could take to other kids around the world who've got a similar mutation," he said.

"Philanthropic funds are essential to get this work going. If it gets going well, it can lead to other competitive sources like government funds," Prof. Mackay-Sim said.

The Whitrods initiated the research with their own funds. Now, to keep funding the research, this week the family has launched their charitable foundation Genetic Cures for

Kids Inc. This volunteer-led charity has one mission: to raise awareness and funds to continue these dedicated research projects and find a cure for SPG56.

“We aim to raise \$1.5 Million over 1.5 years and we know that’s a big plea to make,” Tallulah’s dad Chris Whitrod said.

“We want people to join our mission and to feel great being part of this epic journey of hope, discovery and success. That’s how we came up with the idea of starting ‘Tallulah’s Army’ of mini-fundraisers,” he said.

The family put out a plea on Facebook for people to start mini-fundraisers, ahead of their campaign’s official launch on Tuesday 30 November, International #GivingDay.

“We’ve been overwhelmed by the response in just one day, and we are so grateful that people want to join us on this mission to cure SPG 56 and save our daughter,” said Golden.

“We can’t thank the community enough. To our donors and to #TallulahsArmy, we love you to the moon and back.,” she said.

“The long-term success of our mission is reliant on philanthropy: in kind contributions, partnerships and sustained funding opportunities. If you know of anyone who you think would be aligned to what we are doing, please reach out.”

You can watch the film that captures Tallulah’s story [here](#).

To donate head to www.ourmoonsmission.org/donate/

To start a Facebook Fundraiser, go to www.TallulahsArmy.Org or www.facebook.com/fund/ourmoonsmission/

Our Moon’s Mission is committed to finding a cure for SPG56 through dedicated, results-driven research.

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