



*World Rare Disease Day  
28 February 2015*



**ALL**

## **WE ASK**

This Saturday, 28 February, is World Rare Disease Day and we want to shine a light on those living with a rare disease.

For every share of our #AllWeAsk video, Foundation partner Canon Australia will donate \$1 to the Steve Waugh Foundation, up to a total of \$10,000.

Please help us share the link directly from [YouTube](#), or from our posts on [Facebook](#) and [Twitter](#).

Children and young adults with rare diseases aren't asking for much - only that you know about them.

Give those with #raredisease a voice. [Watch now and share.](#)

### **Steve Waugh AO**

## Always 100%

### 'RARE STAR' DAY

Our second annual **Rare Star Day** was held this week and once again it didn't disappoint.

We had 31 of our grant recipients and their families from all around Australia attend our 'Safari Party' at Sydney's Taronga Zoo. A rare chance to connect, meet and learn from others in the same boat, share stories with each other and the people who support them and most importantly to enjoy a rare day out for the whole family that is all about them!

It is with much gratitude that we thank Foundation Partner **Canon Australia** for helping us coordinate and host this event, as well as the team at **Virgin Australia**, who provided 72 flights to fly families to Sydney so they could be part of the day; **Ogilvy PR Agency** for managing our media campaign; and **Industrie Clothing** for gifting outfits to the kids and their siblings. Not least, a special thank you to **Patron Basil Sellers AM** for his continued support of Rare Disease Day Australia and the Foundation. Truly amazing supporters.

Check out more images on our [FB gallery](#).



### RECIPIENT PROFILE

#### Meet Marley

**CONDITION:** TRISOMY CHROMOSOME 5q33 (long arm),  
MONOSOMY CHROMOSOME 11q24.2 (long arm)

Lifelong intellectual and physical disability, feeding difficulty, slow growth, congenital heart disease & astigmatism. Marley is tiny! At the age of 4 she looks the size of a 1 year old.

**In 2013, the Foundation provided Marley with a double Electric Bed that also acts as a cot.** After two years of Marley waking up to 10 times a night to be settled, her parents can now settle Marley and leave her without fear she'll injure herself. Bed is now a place Marley feels safe and likes to go to relax.

*"The result has been enormous for us all. We're extremely grateful and feel a bit more like a "normal" family now Marley's more settled throughout the night. Being part of the Steve Waugh Foundation, for the first time, we feel as though we belong somewhere. 'Belongingness' is something we all strive for in life, a rare disease can often result in isolation." Simon, Marley's dad.*



### SOCIAL-ISE WITH US!

Keep up to date with all things SWF across Social Media. We'll be sharing our news and your stories via @SWFAustralia on Instagram and Twitter, as well as on Facebook. Give us a follow, tag and share your images using #allweask and #stevewaughfoundation.

Check it out.



For further queries email us at [info@stevewaughfoundation.com.au](mailto:info@stevewaughfoundation.com.au) or phone 1300 669 935



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STEVE WAUGH FOUNDATION

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