

**MARCH 2015** 

# **RARE STARS 2015**

**OUR MISSION IS TO** PROVIDE LIFE CHANGING SUPPORT AND CHAMPION THE STORIES OF THOSE LIVING WITH RARE DISEASES

# WELCOME TO 2015 - OUR 10<sup>TH</sup> YEAR CELEBRATIONS

"We're honoured to partner with two of Australia's most prestigious organisations to host a once-in-a-lifetime experience." Grange on the Range" is brought to Sydney for the first time in fifteen years by the Steve Waugh Foundation bringing together Penfolds Grange, NSW Golf Club with the support of Treasury Wine Estates to create a unique golf day. We're grateful to teams playing at one of our signature fundraising events for 2015 and thank everyone involved for their support and generosity."

STEVE WAUGH AO

### **RARE STARS**

Rare Star Day is an exclusive Foundation event, part of our movement to raise awareness for rare diseases around World Rare Disease Day, the last day of February, each year. It allows our grant recipients and their families a chance to connect, make new friends and share stories in an experience that can't be valued in dollars - a day they can for a moment forget

hardships, enjoy themselves and shine. Over 200 quests including 29 families, 18 flown in from all around Australia courtesy of Virgin, joined Foundation staff, supporters and volunteers at Sydney's Taronga Zoo February 25th - for a fun day out. Taking home cameras and priceless family photos courtesy of major event partners Canon.

THANK YOU TO ALL EVENT PARTNERS AND SUPPORTERS FOR HELPING US LET OUR FAMILIES KNOW THEY ARE NOT ALONE



**BASIL SELLERS** 





#### **MEET ONE OF OUR RARE STARS - TAMARA**

## 23 YEAR OLD TAMARA LOVES ART, DESIGN, ARCHITECTURE, ASTROPHYSICS AND PHILOSOPHY!"

"Rare Stars was fantastic, I held a snake which was pretty rad! Being from interstate, SWF was exceptional organising logistics of our stay. They've been great financial support, funding a new power wheelchair and physio, fundamental to my health and well-being. It's great to see a Foundation supporting and raising awareness of an overlooked minority 'niche'. The fact so many families seek support from SWF highlights a broader systematic problem of resources and funding for rare diseases and disabilities. SWF is doing something that directly and instantaneously betters these people's lives. I truly appreciate what SWF has done for me. I'm able to continue my life without stresses of finding or raising considerable funding needed."

Tamara has completed a university degree in architecture and will be starting an internship with an architecture firm this year.

Tamara's rare disease: Selenoprotein N mutation myopathy, primarily affects muscles for movement (skeletal muscles), mutations included muscle weakness, spinal rigidity, restrictive respiratory syndrome, and related health problems mild to life-threatening.



STEVE WAUGH FOUNDATION IS THE ONLY FOUNDATION OF ITS KIND IN AUSTRALIA SUPPORTING CHILDREN AND YOUNG ADULTS WITH RARE DISEASES.



In just 10 years we are one of Australia's most respected charities, and make a conscious effort to work with partners who are socially responsible & enthusiastic, engaged but not demanding. 'Strength of Character' is at the core of what we do, from the people we support to the people who help. We work with partners who embrace that characteristic, share our vision and our goals.

# BE PART OF OUR 10TH YEAR CELEBRATIONS - JOIN IN UPCOMING EVENTS.



#### **FOREVER GREEN**

**DATE: 10 OCTOBER 2015** 

JOIN US AT THE STAR SYDNEY FOR A WORLD CLASS LINE UP OF ENTERTAINMENT FOR ONE NIGHT ONLY.

A fine dining experience, premium wine and beer and 10th Anniversary memento.

Forever Green is our bi-annual major fundraising event -personalised by an audience of high end individuals, corporate support, world renowned entertainment, unique productions, stylish locations and engaging experiences.

LIMITED PLACES FOR TABLES OF 10

**BOOK YOUR SPOT** 



#### **CITY2SURF**

**DATE: 9 AUGUST 2015** 

CITY 2 SURF IS THE BIGGEST ANNUAL FUN RUN IN THE WORLD - WHY NOT BE PART OF TEAM WAUGH!

We're calling on as many people as we can to join Team Waugh to celebrate our 10th year, adding to 1400+ people who've already run for us in our 'Baggy Lime Green' caps.

OUR TARGET: 500 PEOPLE RUNNING FOR OUR TEAM.

YOUR GOAL: PLAY TWENTY/20 - ASK 20 FRIENDS TO SPONSOR YOU \$20. SIMPLE.

SIGN UP FOR TEAM WAUGH TODAY.



#### **SYDNEY 2 BYRON**

**DATE: 1 NOVEMBER 2015** 

NEVER SHY FROM A CHALLENGE, JOIN OUR BIGGEST FUNDRAISER YET - A BIKE RIDE FROM SYDNEY TO BYRON BAY.

The Captain's Ride will take riders through the spectacular NSW Hinterlands, include food, accommodation, guest speakers and drop-in celebrities along the way.

An entry fee to join, and riders will also be encouraged to raise \$10,000 as part of the peleton and chance to ride with Steve and crew. Full details to come soon.

REGISTER YOUR INTEREST WITH US TODAY

THINK YOU'RE UP FOR THE CHALLENGE?

UP TO 1 IN 10 PEOPLE IS LIVING WITH OR AFFECTED BY A RARE DISEASE - NUMBERS SIMILAR TO DIABETES.

To date we have

- Helped 634 grant recipients & their familie
- Funded 28 Respite Camps; and
- Supported over 150 different rare diseases

## **ALL WE ASK**



The Foundation has produced a video called #Allweask to raise awareness and shine a light on people living with rare disease. We'd love your support spreading this message across your networks on Facebook, Instagram or Twitter.

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

CHECK OUT OUR NEW WEBSITE LAUNCHED MARCH 2015 TO WATCH THE VIDEO! WWW.STEVEWAUGHFOUDATION.COM.AU THANKS IN ADVANCE FOR YOUR SUPPORT!



For further information email us at info@stevewaughfoundation.com.au or phone 1300 669 935