

Autumn/Winter 2014



Rare Words with Steve

As with any organisation we've evolved since day one. The one thing that's not changed is the calibre of people who make up Team Waugh - they share character, courage, integrity, credibility and are part of something unique and significant.

We are the only Foundation of our kind in Australia supporting children and young adults affected by rare diseases. Delivering life changing support to those we help, we fight on behalf of those who have nowhere else to go. The Steve Waugh Foundation is 'somewhere to turn'.

Earlier this year we launched a new Foundation logo as part of looking closely at our values, how we want to work moving forward and ongoing focus on being the best we can be as a charity and for the kids and families we support.

At our core we represent and stand for 'strength of character. Kids and families

impacted by a rare disease feel abandoned, isolated and alone. They share bravery and determination to meet everyday challenges; and do so with courage, tenacity, perseverance and incredible endurance. These kids and their families inspire us every day.

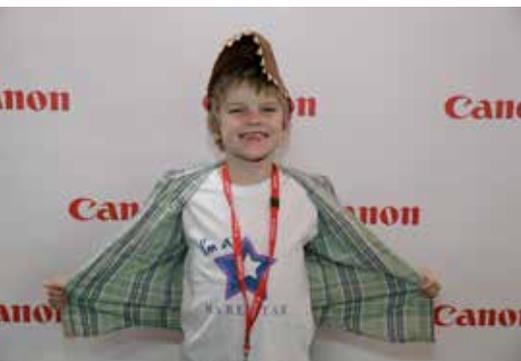
Our work is personal, about connections and results. Collaboration is essential. I'm eternally grateful for the incredible support of our First XI Patrons, major corporate partners, colleagues, and friends all of whom have and continue to show tremendous faith in the vision that Lynette and I have for the Foundation and outcomes we aim to achieve.

Supporters and funding are the lifeblood and the backbone of the Foundation that enable us to pursue our goal of changing lives for the better in a real and committed way. This is the result of a loyal group of extraordinarily generous individuals and companies.

We're a team that strives for excellence every day with 'strength of character' - from the children who live with rare diseases, to the people who help us.

Thank you for your incredible support.

**Always 100%
Steve Waugh AO**



Rare Stars – Shining Bright

Rare Star Day was an idea - a thought of hope that would inspire.

200 guests, including 125 grant recipients and their families from NSW, VIC, QLD, SA, TAS and WA were invited to our first Rare Stars event. A free fun day out for the whole family at Luna Park in Sydney on World Rare Disease Day 2014 – February 28th, - a rare day for our kids, families and supporters to 'shine'.

No amount of rain could dampen excited children as they chatted and squealed with laughter from rides, faces being painted and crazy dress up photos taken by Canon. No screams louder than after having been lent a camera by Canon for a 'star photo challenge', everyone was told they got to keep their camera!! Thanks Canon!

Rare Stars is our first national event with families from around Australia coming together, made possible by the generosity of Patron Basil Sellers, major event partner Canon, and Virgin Airlines.

Rare Star Ambassador Georgie Parker, Founders Steve and Lynette Waugh, Board Members, Deb Thompson representing Basil Sellers, The Canon Collective Team, with support agencies Ogilvy PR and Leo Burnett, Foundation Supporters, Event Volunteers and staff all took a rare break to raise awareness of rare diseases, share their stories, meet Team Waugh and other families in a similar position, have fun, and enjoy a once in a life time rare day out for the whole family.

Happy, weary kids and families all left smiling, with parents saying they had an unbelievably good time and no longer feel like they are in it alone. If happiness was measured in smiles – they were bigger than the Luna Park Clown's smile!

The day was wrapped up with 50 guests hosted by the Foundation at the 'A Rare Night Out Ball'. Major partners AVJennings, SNUG Program and Medical Health Advisory Committee representatives, parents of grant recipient families, and the Foundation team enjoyed a great night out and danced the night away.

Our World Rare Disease Day 2014 Media & Social Media :

- 114 pieces telling real stories
- Reached 7,500,000 Aussies
- 46 regional papers, 2.6 million readers
- 6,048 visits to the Foundation website

World Rare Disease Day 2014

For the past 5 years the Foundation has led the way with the generous support from Patron Basil Sellers who shares our vision of a national coordinated approach to rare diseases in Australia. World Rare Disease Day 2014 was celebrated by 84 countries & 410 events worldwide!



“Being a part of the Steve Waugh Foundation means you're a part of a remarkable group of people. Not only the grant recipients and their families, but all the people who help make the Foundation's work possible. I love World Rare Disease Day, partly because we get to see all of our families, but we also all get a chance to talk, share stories and laugh. This year was exceptional, what on earth can we do to top Luna Park??”

Georgie Parker – Rare Star and Foundation Ambassador

Thank you to our fantastic Sponsors



Ogilvy Public Relations

BASIL SELLERS
AM



All the way from WA

You have lifted our spirits, recharged our patience batteries and made us feel special and supported despite living so far away on the other side of Australia.

Holly couldn't get enough of the sensory stimulation of fast rides, and has always been an extreme daredevil. We were green and exhausted keeping up with her, but well worth it to see her excitement and hear her squeals and giggles.

More than anyone else, this trip meant the world to Archie. Our little man has adjusted

to so many changes over the past year and is in 'continual-compromise-mode' for his sister. Along with Holly he felt special at Luna Park thanks to the bubbly Canon crew, and Duncan who might not know he made Archie's day by talking Big Bash and sharing some pictures. Archie only just took his Rare Star hat off today to go back to school.

Feeling supported and having hope has set us on a positive path for Holly's lifelong journey with CDG. Thank you for keeping us connected, and may you continue to help many more families to come. With love and gratitude.

Rachel, Mark, Holly & Archie (WA)



Luna Park was magical!

Endless wealth exists for the person who could harness the extraordinary passion that exists when parents of children with special needs connect.

The Hayes Family (NSW)



Thanks to the sponsors, particularly the Canon crew. Watching them with the kids was amazing, they're able to put smiles and get plenty of laughs out of all the kids with their energy and funny spirits they brought to the day.

The Eagan Family (VIC)

It was great to meet your team and to hear about experiences of other young adults. We've taken many photos of our time in Sydney with the camera that was gifted by Canon, it has already come in use for my Architecture course! Thanks for a wonderful weekend!

The Baksheev Family (VIC)



It was our first year as part of what feels like a great extended family! Our girls had a lot of fun and loved being part of the video. We really enjoyed meeting other parents and sharing stories and information (so much to learn!) Favourite moment - Eden's ride on the Wild Mouse with Steve!

Eden, Neve, Jessica and Geoff Chester (NSW)





RENEE II Sold!

With shovels in hand and plenty of plants, AVJennings staff rolled up their sleeves with Steve Waugh and Ambassador Renee Eliades to create the garden of the Renee II at AVJennings' award-winning Lyndarum development in Wollert – the first Victorian home, and second of the partnership between AVJennings and the Foundation.

Over 12 months building the Renee II, AVJennings hosted 3 events; a Suppliers Thank You; Community Garden Party; and more than 100 people attended the Auction 1st March 2014, with all proceeds from the profit of the sale donated to the Foundation.

AVJennings CEO Peter Summers said the AVJennings staff, suppliers and local communities have embraced this partnership over the few years to make a difference. "As a company whose foundations are in the creation of communities, we feel it is important to have a strong sense of community within the company, within our people and how we relate to our market and customers. To that end, we have proudly partnered with the

Steve Waugh Foundation," he said. "We are delighted with how many staff, suppliers and friends have raised their hands to help out in the creation of The Renee II."

AVJennings staff raise additional funds as a group and through individual efforts such as bike rides, community cricket matches, and workplace giving.

AVJennings®

You can watch time lapse vision of the building of the Renee II on our Foundation YouTube Channel: <http://www.youtube.com/user/SteveWaughFoundation>



"The auction was so exciting; especially with so many people attending to bid and see what AVJennings had created. AVJennings picking me to name the house after makes me feel special and unique. It's such a huge honour to be part of such a remarkable experience. AVJennings do such a great job for the community and the Foundation!"

**Renee
Foundation and AVJennings
House Project Ambassador**



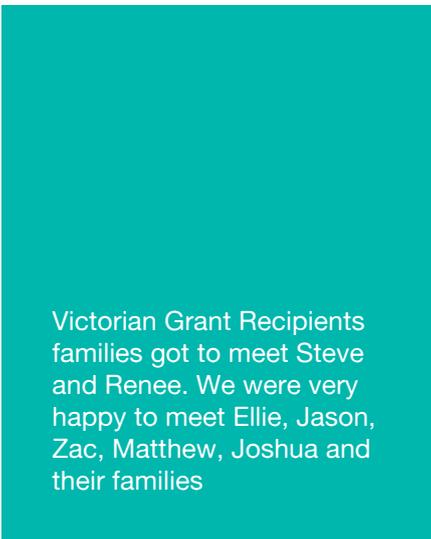
Rare Stars!
AV Jennings
 Founding Corporate
 Partner



Peter Summers and Peter Vlitas of AV Jennings with Paul Russell, Steve Waugh and Renee from the Foundation



Janet Dejong purchased the Renee II



Victorian Grant Recipients families got to meet Steve and Renee. We were very happy to meet Ellie, Jason, Zac, Matthew, Joshua and their families



Steve and Renee leave the home by Harley Davidson for the Garden Party.





Grants ‘Somewhere to turn’

Over the past 6 months, 65 individual grants have been approved to provide life changing support to children and their families.

Generous donations to the Foundation go directly to providing: hope, medicine, treatment, specialised equipment and supporting information, education and research, as well as specific projects and programs, including items that improve the quality of life for children, young adults and families affected by rare diseases 0 - 25 years of age.

Respite Camp milestone - 100 families!

Since the inaugural camp in 2009, we have funded 25 SNUG (Special Needs Unlimited) Camps, recently reaching the milestone of 100 families having attended these free residential respite camps.

While holidaying, families see clinicians, complementary therapists for massage, play and music therapy. Parents exchange ideas and inspiration, while students from the Newcastle University work as volunteer staff. The siblings from all the families share a bond that comes from having a brother or sister with a rare disease. Respite as a whole family is often rare in itself, and can help build the family unit again.

The next camp will be in May 2014 and are managed by The Family Action Centre, Faculty of Health and Medicine, The University of Newcastle.



LOOK who got to meet the Royals while in Sydney! Grant Recipient Sienna & her family at Bear Cottage.

SNUG Camp kids and their families



Jihad with his twin brother, Amir and younger brothers Abdul & Mohammad

Grant Recipient - Jihad

Standing Tall – I feel like I can achieve anything!

Jihad is a 15 year old who says “all my brothers play football. I wish I could play too.”

There are lots of activities Jihad says he'd love to do but is restricted by his rare neurological condition, Ataxia Telangiectasia (A-T).

A-T is a rare childhood neurological progressive disease that causes degeneration in the part of the brain that controls muscles, movement and speech. Symptoms are a lack of balance, delayed development, uncontrollable movement and slurred speech. Children are eventually confined to a wheelchair, there's no cure or way to slow down the disease. Jihad can no longer walk without falling all the time.

The Canterbury League Club teamed up with the Foundation to approve a grant to

cover the gap of \$20,000 for Jihad's new 'transformer' power wheelchair.

With a special standing function, it allows Jihad to be independent and manoeuvre around without help. He can now stand and reach for things up high which he's never been able to do before.

“I want to thank the Foundation and Canterbury League. Because of your support, you have allowed me to be able to stand up tall and feel like I can achieve anything!” said Jihad.

We'd like to express our sincere appreciation for the support from the Canterbury League Club to our Individual Grant Program.



443 families have their say!

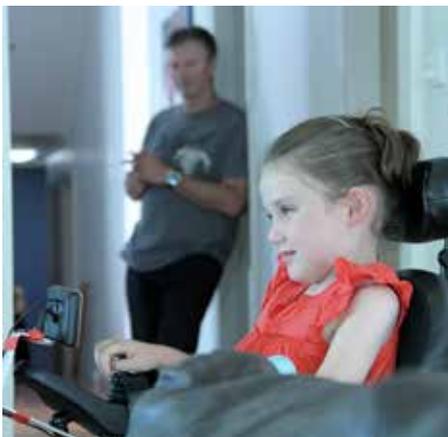
The Foundation joined with the Australian Paediatric Surveillance Unit (APSU) to research and study the psychological and economic impacts of rare diseases on Australian children, families and health professionals.

The aim to provide evidence of the future support we all need to improve the often forgotten area of rare diseases in health and medicine in Australia. Learning new important information to support advocacy for better health services is critical.

443 families have so far completed the survey. In the last 12 months these families accounted for:

- 4,000 visits to specialists
- 10,000 visits to allied health professionals
- 250 of the children had an admission to hospital

Results are being compiled – we look forward to sharing more from the final results of this Australian Research Linkage Grant.



Rare 'Good' Sports

Join Team Waugh in this year's City2Surf – registrations open!

Team Waugh has had a team in the Sydney City2Surf since 2010. We'd love you to join us again, or for the first time this year on Sunday 10th August 2014.

One of this year's groups is Team Bianca in memory of Bianca Caltabiano who passed away October 2013 at 18 from secondary hemophagocytic lymphohistiocytosis (HLH), a rare cancer-like blood disorder of the immune system. Brother Daniel and best friend Michelle have formed Team Bianca to get people together to fundraise to ensure that others with rare diseases like Bianca do not have to face their battle alone. Read more of Bianca's inspirational story on Daniel's fundraising page and "Do you know whatcha gotta do, when life gets you down - just keep swimming, just keep swimming" - a quote from Finding Nemo that Bianca that inspired Bianca her during

the battle with her rare condition.

Read more at: <https://city2surf2014.everydayhero.com/au/daniel-caltabiano>

Our Gold Charity Ticket holders have committed to raising a minimum of \$1,000 each.

Be a rare 'good' sport, join Team Waugh and help us give kids and families 'somewhere to turn'.

Registrations are open, they fill fast. Contact Nikki in the office to find out how you can join the team – don't miss out!

Join Team Waugh now - register online at: <https://city2surf2014.everydayhero.com/au/team-waugh>

A few more of our 'good' sports...

Spartan of Fundraising

Rob Wallis of the Menai District Physiotherapy & Sports Injury Centre has been raising funds for the Foundation for a few years – but not the easy way! First was the Tough Bloke Challenge, most recently 21km and 5 hours of torture in the Spartan Race considered the toughest, most competitive obstacle race in the world.

Every year Rob tests his endurance while raising funds. The courage of kids with rare diseases inspire us every day - so does Rob!



Master of Surf

Longtime volunteer Jock Campbell has been training and coaching surf lifesaving athletes for 20 years. A fitness guru Jock is a stickler for his athletes training on sand, and through sandhills, whether they're cricket stars of the past such as Steve Waugh or present-day Olympic runners.

So it was only fitting Jock won the recent 2014 Australian Surf Life Saving Championship over 455 two-kilometre race. Congrats Jocko!



'All we Ask'

Through event partner Canon, this year's World Rare Disease Day campaign 'star' feature was a short video 'All we Ask' produced by Leo Burnett.

7,748 views and counting – help us spread the word!

www.youtube.com/user/SteveWaughFoundation



Making the video has been an inspirational experience for everyone involved.

Special thanks to our grant recipients: Daniel, Caoimhe, Marley, Eden, Renee, Alysha, Tristan, Liam, Bradley and Thomas and their families for letting us and a production crew of 13 take over their homes and being part of 'All we Ask'.

Now we are asking YOU to help by simply sharing the video with as many people as you can to give those with rare diseases a voice. Children and young adults with rare diseases aren't asking for much - Only that you know about them.



Steve Waugh has been involved in the launch of Canon's latest project, #canonshine, talking about what matters to him highlighting rare diseases through the story of Daniel Michel. See his story and get involved by sharing what matters to you at canon.com.au/shine.

Shine a light on what matters to you



For further information or to donate contact Steve Waugh Foundation

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