

WAUGH CRY

The newsletter of the
**STEVE WAUGH FOUNDATION
AUSTRALIA**

Summer 2010



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TEAM WAUGH RUNS FOR RARE KIDS



Little Liam's big smile and fist punching the air as he crossed the finish line with his mate Steve Waugh said it all!

Crossing the City2Surf finish line is a feat in anyone's book. But for Liam Titterton and Thomas and Bradley Farrell (pictured above) it was extra special. They are just three children that the Foundation supports through the generosity of those who join Team Waugh in events like the 2010 40th Anniversary of the City2Surf.

Steve Waugh joined over 600 team members, including 16 corporate teams, who together raised \$103,456.00, an amazing result in only our second year in the event.

in the crowd. Families, work colleagues, Olympians and friends walked, jogged and ran from the Sydney city to Bondi Beach gathering in the Team Waugh Marquee to enjoy a well earned sausage sizzle and cold drink with team mates and children and families they ran to support.

The Foundation has already allocated \$53,246.00 of funds raised through grants to children and families affected by rare diseases for items like specialised wheelchairs and communication devices—the efforts of everyone who were part of Team Waugh City2Surf 2010 is already changing lives!

**THANK YOU TO EVERYONE THAT MADE
A CONTRIBUTION TO THESE CHILDREN
AND THEIR FAMILIES.**



'SOMEWHERE TO TURN'

Lime Green Team Waugh hats stood out

CITY2SURF 2010

CONGRATULATIONS TO OUR TOP CORPORATE FUNDRAISING TEAMS

1. CBA \$21,230.00
2. AV Jennings \$8,696.60
3. Bank of America Merrill Lynch \$7,925.00
4. AHM \$5,000.00
5. CBRE \$4,452.00
6. Cricket NSW \$3,405.00
7. Morgan Stanley \$2,860.00
8. Life7 \$2,640.00
9. UBS \$2,029.00
10. Abergeldie \$1,450.00
11. Navitas \$1,105.00
12. Komatsu \$650.00

CONGRATULATIONS TO OUR FIRST XI INDIVIDUAL FUNDRAISERS

1. Keith Stubbs \$12,980.00
CBA
2. Charlie Woodcock \$4,675.00
Merrill Lynch
3. Sandra Vogiatzakis \$3,610.00
AVJennings
4. Matthew Griffin \$2,190.00
Life7
5. Matthew Unsworth \$2,180.00
Merrill Lynch
6. Sally Hetherington \$2,050.00
Team Waugh
7. Andrew Glover \$1,985.00
Team Waugh
8. David Jenkins \$1,571.00
Team Waugh
9. Tony and Julie Fort \$1,445.00
Team Waugh
10. Gregory Jenkins \$1,422.00
Team Waugh
11. Dale Marment \$1,375.00
Team Waugh

"THANK YOU FOR A WONDERFUL DAY ON SUNDAY AND IT WAS A PLEASURE TO MEET THE KEY PEOPLE INVOLVED IN THE FOUNDATION AND WHOM MAKE IT A SUCCESS. MYSELF AND MY FAMILY WILL BE SUPPORTING THE FOUNDATION FOR MANY YEARS TO COME, SO YOU CAN COUNT ON THE MARMENT FAMILY FROM THE GOLD COAST AS PART OF THE GIVING TEAM"

DALE MARMENT Member of City2Surf Team Waugh, 1st XI fundraiser and supporter of the Foundation since 2007

WINNERS ARE GRINNERS!



CBA Backyard Cricket Winners



Some of our First XI Fundraisers enjoying the Sydney FC vs Newcastle Jets soccer game

On Saturday 6th November and Sunday 7th November 2010 the Foundation hosted 2 functions for the winners of the City2Surf Corporate Challenge and First XI Individual Fundraisers.

The Commonwealth Bank of Australia were the winners of the Corporate Challenge raising over \$21,000 for the Foundation in the City2Surf. Approximately 30 invited guests and their families joined Steve Waugh and Gavin Robertson at the Sydney Cricket Ground to participate in a range of cricket skills training activities put on by David Lawson and his team at Cricket

NSW. Steve Waugh and Gavin Robertson joined the drills and parted with some of their experiences as members of the Australian Cricket Team.

After the training, the guests enjoyed an exclusive guided tour around the Sydney Cricket Ground.

Even the weather couldn't keep the guests from having a great time and experiencing this unique opportunity.

The following day the Foundation hosted 25 guests in a private suite at the Sydney FC vs Newcastle Jets soccer game at the Sydney Football Stadium.

Our top fundraisers were treated to a fantastic afternoon of sport with the final one day cricket match Australia vs Sri Lanka shown on the televisions as well as a tight match of soccer being played out on the field.

At the half time break Steve Waugh thanked the guests for their amazing support of the Foundation through their City2Surf fundraising efforts and presented Jack Atley, SWF Photographer, with the Volunteer of the Year award.

We would like to thank all of our team and individual fundraisers who supported us in the City2Surf and we look forward to your continued support in 2011.

TEAM WAUGH CITY2SURF'ERS 2010



Photography courtesy Jack Atley

WE WOULD LIKE TO SINCERELY THANK ALL OUR EVENT SUPPORTERS, VOLUNTEERS AND CORPORATE SPONSORS WHO ASSISTED US WITH THE CITY2SURF. YOUR GENEROSITY ENABLES US TO DO WHAT WE DO AND FOR THAT WE ARE MOST APPRECIATIVE.

..... CITY2SURF 2010 SPONSORS AND SUPPORTERS

**CES CATERING
EQUIPMENT
SPECIALISTS**

**MEDICAL CENTRE CAFE
BANKSTOWN**



**MENAI CENTRAL
FRUIT WORLD
& WHOLESALE**



SONY
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SHIRE FOODS



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**A GIFT
IN KIND**

The Steve Waugh Foundation would like to acknowledge and thank Sony for their support through the provision of Sony digital cameras and video cameras for use by the Foundation. These cameras will be used for capturing the memories of the Foundation activities.

The Steve Waugh Foundation would also like to thank the ongoing support of Bernie Brookes and Myer for providing gift cards for our volunteers and key supporters.

MYER
SONY
make.believe

PATIENT STORY

SARAH WALKER



chronic nature, severely impacts Sarah's growth and development.

Sarah has been critically and chronically ill since birth and has spent much of her early childhood in and out of intensive care. Although her lung condition is improving, Sarah is almost constantly attached to an oxygen machine and receives most of her nutrition by the creation of an artificial external opening into the stomach called a gastrostomy (PEG).

The Steve Waugh Foundation has been able to help Sarah and her family by providing them with a portable oxygen container, an above ground swimming pool for Sarah to

Sarah is a fun loving, outgoing and vivacious 2 and a half year old who loves singing along to the Sound of Music, swimming and teasing her 2 older siblings.

safely undertake her lung development therapy, and a baby video monitor allowing Sarah's parents to continually check on her from their own bed.

Sarah has a very rare condition called Children's Interstitial Lung Disease affecting approximately three in 1 million children in the world. This disease causes constant low levels of oxygen in her blood and due to its

With the help of this equipment, Sarah's condition will improve however the long term damage that has been done to Sarah's lungs may mean she will require a lung transplant and ongoing treatment.

WHAT IS CHILDREN'S INTERSTITIAL LUNG DISEASE?

Interstitial Lung Disease in Children (ChILD) is a group of rare lung conditions that causes chronic lung disease and affects 3 in a million children. It is usually diagnosed within the first year of life with low oxygen, fast breathing, cough and failing to grow properly. Some genes have recently been discovered which cause the disease. These genes are responsible for producing surfactant; surfactant acts by keeping the small air sacs (alveoli) in the lung open to

ensure there is adequate oxygen in the body. However, in half the cases the cause is not known. The diagnosis is usually made by lung biopsy. Treatment is with steroids, oxygen and breathing support and sometimes lung transplant. Some children get better with treatment, however some children will unfortunately die from this disease.

Dr Adam Jaffé,
*Paediatric Respiratory Consultant,
Sydney Children's Hospital, Randwick*

STEVE WAUGH FOUNDATION GRANTS

The Foundation is currently accepting applications for grants for individual and families affected by very rare diseases. For more information about the Foundation's application process and our criteria please go to www.stevewaughfoundation.com.au/content_common/pg-Grants.seo

VOLUNTEER PROFILE



SALLY HETHERINGTON

Sally Hetherington first got involved with the Steve Waugh Foundation through her association with Sydney City Rotaract. While she had no idea who Steve Waugh was or what the Foundation stood for, she decided to help out at our 'Sounds of Sydney' event at Star City a few years ago. It was the first time Sally had volunteered but knew straight away she was hooked and has since helped us on many more wonderful events.

This year Sally was a Family Host to the Farrell family for the City2Surf and the experience turned out to be a life changing one for her. Bradley and Thomas Farrell were born with Arts Syndrome - a rare genetic condition causing muscle weakness, hearing and visual impairment, severe mental disability as well as an increased risk of infection.

"I saw the demands and pressures that are put on families with children with disorders, and how they make it a way of life. They learn to deal with it, they don't complain, and they appreciate life more than most people. It was so inspiring to meet the Farrell family, and to witness the bond that Bradley and Thomas have with each other," explains Sally.

"I like to live my life by the quote: 'Make it a rule, never to lie down at night without being able to say I have made at least one human being at least a little wiser, a little happier, or a little better this day'. My involvement with the Steve Waugh Foundation enables me to ensure I achieve that goal. Whether it is by raising funds, volunteering at events, or promoting the Foundation, I am able to make a real difference. And I owe the utmost gratitude to the Foundation and it's recipients for enabling me to do so."

WORLD RARE DISEASE DAY IS A GLOBAL EVENT HELD ANNUALLY ON THE LAST DAY OF FEBRUARY.

The main objective of World Rare Disease Day is to raise awareness of rare diseases and their impact on not only the kids living with them and their families, but also on the wider community as a whole.

We invite you to join Steve Waugh and the Steve Waugh Foundation at a rare and exclusive evening at the prestigious Sydney Opera House for a 'Dinner & Show,' Monday 28th February 2011.

The day's activities for the Foundation culminate at the Opera House with an exclusive dinner, high end networking, and Billy Connolly show with Steve Waugh,



colleagues, associates and Foundation supporters – 220 guests only.

Join an exclusive group in a high end pre-show dinner with Steve Waugh and major corporates and supporters followed by the Billy Connolly Show and after show drinks at the prestigious Sydney Opera House.

Mix with Steve Waugh, Australia's elite corporate networks and have an enjoyable evening, while helping the Steve Waugh Foundation give children and families affected by rare disease 'somewhere to turn'.

**For further information please contact the Foundation on 1300 66 99 35
or at forevergreen@stevewaughfoundation.com.au**

2010 FUNDRAISER OF THE YEAR AWARD



Congratulations to Kerry Johnston who single handedly raised over \$22,000 for the Foundation and for kids with rare diseases. Kerry and her husband Gary are founding Patron members of the Steve Waugh 1st XI and have been very supportive of the work of the Foundation from the beginning.

Kerry organised a unique fundraising

opportunity for an exclusive group of friends and work colleagues. On Saturday 22nd of May 2010 approximately 120 guests dressed in clothing from the 1930's, 1940's and 1950's boarded a Steam train locomotive at Central Station in Sydney called the Steve Waugh Express bound for Robertson in the Southern Highlands.

WELL DONE, THANKS KERRY

2010 VOLUNTEER OF THE YEAR AWARD

Congratulations to Jack Atley for winning this year's Volunteer of the Year Award. Most of our readers will be familiar with Jack's work through his role as the Foundation's official photographer. Jack's outstanding work appears in our newsletters, publications and promotional material. Jack has an amazing way of working with the families and children the Foundation supports and has an incredible knack of capturing the expressions and feelings of those he photographs.

Jack has been an outstanding member of the Foundation team since the start and has been the Foundation's official photographer since 2007. Jack's friendship with Steve and Lynette goes back to the days when Jack was a professional photographer with Getty Images and touring with the Australian Cricket Team. Jack is one of Australia's multi award winning corporate photographers. He has won the Australian Press Photographer of the Year Award and has been commissioned by the Sydney Opera House Trust to photograph their Fine Art Photographic poster range. Jack has also recently set up a shop which exhibits his work at the International Terminal at Sydney Airport.

You can view Jack's work by visiting his website www.jackatley.com

CONGRATULATIONS JACK

"I WAS TRULY HUMBLLED TO RECEIVE THIS AWARD FROM THE STEVE WAUGH FOUNDATION. IT'S AMAZING ENOUGH TO BE INVOLVED WITH THE FOUNDATION AND TO GET THIS AWARD WHEN THERE ARE SO MANY PEOPLE WHO CONTRIBUTE TO IT IS INDEED AN HONOUR."



THE FOUNDATION WISHES EVERYONE A

Merry Christmas
AND A Happy New year

RARE WORDS WITH STEVE WAUGH

Thank you to everyone who joined Team Waugh City2Surf this year, it was a magnificent team effort. We're looking forward to building on this year's success in the coming years.



The City2Surf has come and gone, but the challenges that kids and families with rare diseases face every day hasn't.

On September 15th one of our many special recipients, Keziah De Guia passed away. Our thoughts are with her family and friends.

Keziah, 18 suffered a rare syndrome of progressive bone marrow failure with pulmonary complications, malignancy and liver problems. We were pleased to be able to provide Keziah with a Interx Interactive Neuro Stimulator machine which limited hospital admissions and provided significant relief from her painful condition.

I spent time with Keziah over the 10 days before her passing. She was an inspirational young lady, in her own words... "I've learnt

to use my condition as a way for people to know that even if times get really tough there's always a light at the end of the tunnel and that you should always smile and just be happy with what you have."

It is Foundation moments like this that are important to share. It makes us even more resolved to improve the quality of life for children and families affected by rare diseases.

Thank you for being such a valued part of our Foundation and what we do. Your support and contribution is very important and most truly appreciated.

Lynette and I wish you and your family a blessed and Merry Christmas with loved ones.

STEVE WAUGH AO

FUTURE EVENTS

28TH FEBRUARY 2011

World Rare Disease Day Event

28TH FEBRUARY 2011

Forever Green 2011

14TH AUGUST 2011

City2Surf 2011

HOW YOU CAN HELP

The rare disease patient is the orphan of the health system, often without diagnosis, without treatment, without research and therefore, without reason to hope.

The Steve Waugh Foundation is 'somewhere to turn'
- Your gift of a donation to help Team Waugh is appreciated. The Volunteers Committee is always looking for supporters

who are able to help us out with upcoming events and fundraising drives.

If you would like further information, to donate or register to become a Foundation Volunteer, please contact us on 1300 66 99 35, via email on info@stevewaughfoundation.com.au or visit our website.

IF YOU'D PREFER TO RECEIVE THIS NEWSLETTER BY EMAIL OR WOULD LIKE MORE INFORMATION PLEASE CONTACT AMELIA LUCCITTI ON 1300 669 935 OR aluccitti@stevewaughfoundation.com.au



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