

Stroke Recovery Trial Fund Newsletter 2016 (2): August 2016



The Stroke Recovery Trial Fund LTD is a registered Australian Health Promotion charity. Our activities are to educate the community about how to protect the brain from avoidable injury, and to educate people who experience brain injury and their families on how to ease suffering and distress from the symptoms of the brain tissue injury. In addition to providing online information about prevention, symptom management and carer support, the SRTF will, amongst other things, provide community education programs in person or in the media, and support research into new treatments for stroke and brain injury.

Website: <http://strokerecoverytrialfund.org/>

Email: strokertf@gmail.com

Facebook: Stroke Recovery Trial Fund (1307 followers!)

Postal: P.O. Box 478, Darling Heights, 4350, QLD

What a busy few months it has been! Thank you all for your continuing support!

TOWNSVILLE EVENTS

Our work continues and we have had a couple of major events including the Townsville Public Meeting in June 2016 which was well attended and was followed up by a Channel 7 Townsville news story which so far has had over 27,000 views and was shared on Facebook almost 300 times!

On the same day we held the SRTF Townsville Fundraising Ball, which was attended by around 150 locals as well as our special guest speakers, Professor Ian Clark, Dr Coralie Graham, Krystal Reynolds and Paul Harris. A special guest performance by Happy Feet and music by A14 made the evening extra special. The Ball was hosted by Glenn (Minty) Mintern who generously donated his time. There were a number of fundraising activities at the gala event including a charity auction and raffles which raised almost \$40,000! A special thanks to our Director Susan Graham-Ryan for all of her hard work in organising both very successful events!

And along with continuing regular donations from generous people, brought our funds raised to close to \$AUD 125,000 to date!

For those wishing to continue to assist the SRTF with our work, please encourage others to make their tax-deductible (Australia only) donations (\$2 and over) on our website:

<http://strokerecoverytrialfund.org/>



Townsville Ball: Back : Krystal Reynolds, Glenn (Minty) Mintern, Professor Ian Clark,
Front: Susan Graham-Ryan, Coralie Graham and Paul Harris.

The health promotion aspect of the SRTF has also continued, with Managing Director Dr Coralie Graham being invited to speak at a number of local organisations including the Toowoomba Orchid Society, TomNet, a Toowoomba business networking event and others. If your organisation would like Coralie to come and talk to your members about Stroke , causes, how to avoid them and Perispinal Etanercept treatment- please send an email to organise a time.

WELCOME!

We have also welcomed a new addition to our membership with our Director Susan and her husband John, welcoming baby Joseph Thomas Ryan (Joey) into the world on 3 August 2016!

Congratulations to you all!



PERISPINAL ETANERCEPT TREATMENT PATIENT SUCCESS

We are regularly contacted by people seeking Perispinal Etanercept treatment for themselves or a family member, and they continue to report back with their improvements after treatment at the Institute of Neurological Recovery (INR) in the USA which is wonderful. The INR continues to treat stroke and brain injury patients in the Boca Raton office in Florida. The office details are available on their Facebook page and website: <http://www.nrmed.com>

CLINICAL TRIAL NEWS

And the question on everyone's lips is – what about the Griffith University School of Medicine Perispinal Etanercept clinical trial for Stroke patients which is being funded by the SRTF? When is it starting? It has been incredibly frustrating waiting for the official start date. As the result of work by the scientific team who are working on this exciting project, there has been a revision of the inclusion criteria to improve the scientific rigor.

This is part of an email which was sent to people at the start of July 2016 who had expressed an interest as a potential participant in the clinical trial:

“The study trial at this stage is in the final process of being modified to focus on a particular group of stroke patients with anatomically well-defined problems and clinical characteristics - namely those who have right hemisphere stroke with left sided hemiparesis (weakness of left arm and left leg). This is in order to give it the best chances of success in the trial. These represent a specific subgroup of stroke patients who have had a stroke in the territory of the right middle cerebral artery (right MCA stroke). This type of stroke affects the left side of the body, causing left-sided weakness.

The reason for this focus is because these patients have characteristic neurological dysfunction that can be evaluated for a particular set of outcomes in a more straightforward manner, comparing before and after treatment. Thus, left hemiparesis will be a specific inclusion criteria for entry into the study. Hence, post-stroke subjects with these specific characteristics are the only ones who will be eligible for the proposed study. We expect that our trial should be underway in the next few months. Please await further advice, which will be sent out at that time. Please also understand that we are not calling for applications at this time for the trial and do not have the staff available to respond to individual inquiries made either by phone or email, in the meantime.”

From my conversations with the research team, they are awaiting final approval from the Australian Stroke Trials Network which should be received any day. I understand that the Griffith research team is in the final stages of preparation for this clinical trial.

We will email an update as soon as we have the official word of a start date!

UPCOMING FUNDRAISING EVENTS

BENDIGO BANK CHARITY GOLF DAY – TOOWOOMBA

One of our major sponsors Bendigo Bank is organising a charity golf day at Middle Ridge Golf Club in Toowoomba on 23 September 2016. It is being held on the last day of the Toowoomba Carnival of Flowers so the gardens will be beautiful, the weather will be amazing and if you are thinking to visit us from out of town – there are lots of other great things on in Toowoomba!

Please see the flyer later in this newsletter for details. You need to nominate your team soon so please call the numbers on the flyer or contact SRTF strokertf@gmail.com

It will be a great day – with great prizes!

2016 SRTF CHRISTMAS RAFFLE

We are also holding the SRTF Christmas Raffle again – with tickets on sale from 23 September 2016 – and drawn 8 November 2016. Tickets \$5 each – to purchase tickets or to offer to sell some please contact us: strokertf@gmail.com

Prizes Include:

1st Prize – Total Value \$3000: Medium car trailer (unregistered), electrical goods, framed artwork, non-perishable Christmas items and various other prizes

2nd Prize – Total Value \$1035: family portrait package (\$785), Handmade Camilleri patchwork quilt and \$50 gift voucher Blue Mountain Hotel

3rd Prize: - Total Value: \$620: photography gift certificate (\$340) and a copper floor lamp

Thanks to generous prize donors including

Ralph Buck Agencies/A.L.B. Distributors <http://www.ralphbuckagencies.com/>

Betta Electrical Wilsonon <https://www.betta.com.au/wilsonon-betta-home-living.html>

Frontier Voice & Data <http://www.frontiervoice.com.au/>

Dr Tobinick (INR) <http://www.nrimed.com>

Peter Rickards Photography <http://www.rickardsphotography.com.au/>

LilyFern Photography <http://www.lilyfernphotography.com.au/>

Blue Mountain Hotel <https://www.bluemountainhotel.com.au/>

Beacon Lighting <http://www.beaconlighting.com.au/beacon-lighting-toowoomba.html?store=beaconretail>

Margaret Camilleri (family member)



You're Invited

The Bendigo Bank branches of Toowoomba invite you to attend the 4 person ambrose

Stroke Recovery Trial Fund Golf Day

Hosted by Bendigo Bank – Toowoomba

Date	Friday 23 September
Time	11.00am Sausage Sizzle followed by 12 noon Shotgun Start – 4 Person Ambrose
Venue	Middle Ridge Golf Club 235-323 Rowbotham Street Toowoomba, Q, 4350
Dress Code:	Appropriate Golf Attire
RSVP	Please visit your local branch or contact to Sammie & Bendigo Bank Team on 4687 7677, 4633 7066 or 4632 8099. \$55 Per Person, Sausage Sizzle lunch provided. Sponsorship opportunities available. Payments required to confirm booking, contact branch for details.



We look forward to seeing you there.

Bendigo and Adelaide Bank Limited. ABN 11 068 049 178 AFSL 237879. (S54741) (03/16)



www.bendigobank.com.au/business

Thank – you also to our sponsors and those businesses and individuals who have generously donated to the SRTF in any way – please support these businesses whenever you can!

