



REST ASSURED RESPITE

CHARITABLE TRUST

TRUST-LINK NEWSLETTER

April 2019 Issue 1



Hello to all our Trust Supporters,

My name is Liz Carmine-Dick. I am on the working committee of the RARCT Trust. As the Trust moves forward this year, we would like to keep you up to date with our progress and aspirations, therefore I will be making sure to include all that information in this, our **Trust-Link** newsletter.

The donations we have received from private individuals and funding agencies mean a huge amount to us and are vital to our progress, as are the volunteers who help us in so many ways. *Thank you all for your involvement and interest. We would get nowhere without you!*



The Trust AGM in October 2018

It was decided at the AGM that trust priorities for this year would be:

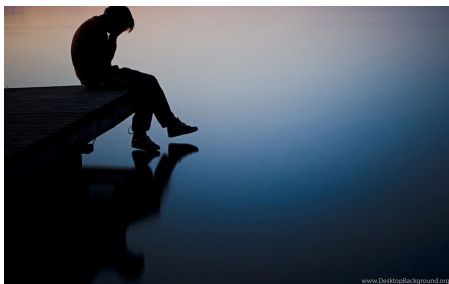
- 1 Awareness Events - to grow awareness and visibility for RARCT
- 2 Social Media - to update our progress on Facebook & other sites
- 3 Website - to keep our website current with stories & research
- 4 Membership - to have a database of members that are interested in being kept up to date with what we are doing

We welcome Adrienne Frame who has come on board as a Trustee. Adrienne has a background in fundraising and business management and a thorough understanding of ME/CFS. She supports our current Trustees, Phil Letford and Wendy Matthews.

We are at present advertising for a Manager via Seek. Our Manager Kate Donley has been unable to help us this year. She did an amazing job of getting us up and running, was professional as well as very empathetic. We are now looking for someone with the same passion we have, to take us to the next level and help us bring the help that is so urgently needed. If you know of anyone suitable please share this information. Applications need to be made through Seek - here is the link [Seek](#)

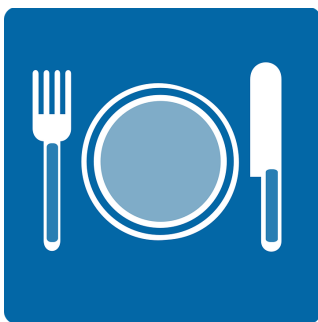
Respite Progress

We are continually reminded through our contact with those who have ME/CFS that a place for care is vital. The aim of the respite will be to give carers and those with the illness time out in a place that understands their needs. It will be primarily for those who have ME/CFS but also for those who have similar illnesses.



Recently a community worker rang looking for day stay options for someone having surgery who lived alone. A mother rang looking for a place for her son in his 20s who needed respite. Another wanted respite to give her aged and exhausted parents a break. We know of others who desperately need accommodation and care. *We are committed to establishing such a place!*

Our MEals Programme



We worked hard to find a meal supplier last year, designed the logo for MEals (right) and researched many options. Finally finding one company who at reasonable cost would supply us with meals tailored to varied diets. The company unfortunately

stopped trading so we are exploring other options. The funder has allowed us to re-allocate the money - still along the lines of providing food for those that need help - and we will be looking at the best way to do that.



The Awareness Event 23rd March - Whitford Auckland

Our aim was to get as much awareness and information as possible out into the community about ME/CFS.



The award winning Movie '**Unrest**' by Jennifer Brea was screened to a large public audience. (We suggested a 15+ age restriction on the movie due to the sensitive nature of some content).



The movie was followed by speakers;

Dr Ros Vallings - GP specialising in ME/CFS

Richie Barnett - NZ Rugby League Captain who had ME/CFS

Both the movie and the speakers were excellent. There was a Question and Answer time with Dr Ros Vallings and Richie after their talks.

Andrew Bayly - MP for Hunua, spoke briefly after the movie and endorsed our efforts.

The speakers were live streamed to our Facebook page where you are still able to view them. We are waiting on a video that was taken of the event and will pop that onto our website as soon as it is available. That will have Adrienne's introduction on it, explaining the purpose of the trust.

Around 40 came to the event. The feedback we received after it was very positive. Many felt validated by the movie and those who went said it had been an invaluable event. It educated those with the illness, as well as those who came with them and helped them to understand the illness more. Some who had a very new diagnosis found it explained many of the symptoms they had, which they didn't know were even related to ME/CFS. We felt we reached a lot of people through our advertising, and those who couldn't come were able to take part in real time, via the facebook page.

Our grateful thanks to the **Whitford Community Trust** who funded the event and all who worked hard behind the scenes to make that happen and those who made the huge effort to come.

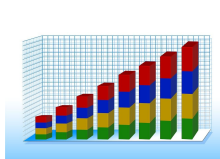


Givealittle Champion!! Neon Challenge in Wellington



Sam Fernando ran for his wife Victoria who has ME/CFS. He found it a gruelling event and opted not to do the last leg. On reflection he said he was glad he didn't. He had really needed to listen to his body and drop out - that was so in keeping with what many with the illness face everyday in real life. Continually making choices on how to use the little bit of energy they have or risking a "crash". Thank you Sam!!! We were really proud to have your support and very grateful for the donations you raised. If people would like to support Sam Fernando's mammoth effort at the Neon challenge in Wellington you can make a donation on Rest Assured Respite Trusts Givealittle page.

Surveys



We have learnt a lot along the way through our contacts and online surveys. Thank you for helping us if you have completed those. The surveys are still open on our website if you would like to participate. These help us provide valuable information to funders we approach, as well as adding to our knowledge base. Link to surveys <https://restassuredrespitetrust.org/respite-surveys>

We would love to hear from you if you have ideas or feedback to share. We hope you have found this newsletter informative and look forward to sharing more with you as we progress through 2019. Thank you for being part of our team!!

Kindest Regards

Liz Carmine-Dick

Rest Assured Respite Charitable Trust
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 To download our brochure about the trust click this link [Brochure](#)



We would like to thank all those who have helped us so far and especially over this last year.

Staff:

Kate Donley - Manager

Dave Bartle - Fundraising Manager

Trustees

Phil Letford

Adrienne Frame

Mel Mason - Mel has stepped down to look after his health but still advises us.

Funders:

Stevenson Village Trust

Foundation North

Milestone Foundation

Whitford Community Trust

Businesses:

McVeagh Fleming - especially Matthew Tetley-Jones Lawyer and Denise Ryder. And Brent Jones for his help in accessing this.

Pinc Printing

Nic Butterworth Design

Banner Express

Volunteers:

Alicia Fu

Farah Jafar

Working Committee

Liz Carmine Dick

Rajiv Sondhi - Rajiv has taken up an appointment in Malaysia and we wish him all the best.

Paul O'Brien - Business Mentor

To those who worked so hard to make our ME/Awareness Event at Whitford a success:

Dr Ros Vallings, Richie Barnett and Andrew Bayly MP for speaking to us. Taking time out of very full schedules to support us.

Please take the time to watch their videos.

Trustee Adrienne Frame for hours of tireless preparation, managing the event and making sure everything was as it should be.

Peter Morton who gave up his day off to deliver, set up sound equipment, put out chairs etc and live stream our event to Facebook.

Andrew Perry for help setting up and videoing the event.

Peter Matthews for helping with anything else that anyone needed help with.

Nic Butterworth for volunteering a lot of his time to design our banner, footpath sign, brochure and other material.

Banner Express who discounted our banner cost.

Pinc Printing who gave us a huge discount on the cost of our printing.

The local papers that ran editorials and gave us free advertising. The rural posties who delivered all our flyers for free.

And the Whitford Community Trust for funding the event.

Phil Letford Trustee and Liz Carmine-Dick on our Working Committee for all they have done to keep things running in the background and sharing our event with their networks.

Thank you to all who came and joined us on the day, or who got involved with us by tuning in to Facebook.

Warmest regards

Wendy Matthews - Chair Rest Assured Respite Charitable Trust

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