

## TNAA President's Report AGM 2023

The year has passed by so quickly and so much has been achieved by so many.

Our achievements since last year's AGM June 2022 have been astounding and the impact of all the hard work is seen every time a sufferer is provided hope.

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The Association recognised the importance of attracting new volunteers and we have highlighted the volunteer opportunities in every newsletter and ENEWS publication. This approach has bought wonderful rewards with five volunteers stepping forward to run train to become Support Group Leaders.

- August 2022 Kim O'Donnell for The Lockyer Valley Support Group Kim runs an online meeting fortnightly and everyone is welcome.
- September 2022 Gay Roberts took over the Adelaide Support Group from Graham Boyer and is also running online meetings for regional sufferers and everyone is welcome.
- December 2022 Jodie Schneider stepped forward to run the Townsville Support Group which is in its fledging stage.
- February 2023 a new member Camille Scarf expressed an interest in setting up a Support Group in the Northern Rivers area of NSW.
- March 2023 a new member Michael Byron expressed an interest in assisting Gaye Roberts in South Australia.



The Association launched its online training module to enable all volunteers to learn the skills and knowledge required to become a **support group leader**, **committee member** and some psychology training aids to assist in understanding mental health impacts.



I would also like to thank both **Shane Thein** in Sydney and **Emelye Lovell** in Melbourne for their many years of volunteer service as Support Group Leaders for their cities. Each has made a huge difference for trigeminal neuralgia sufferers, providing education, practical options when seeking a treatment plan and most importantly, support and hope.

We are now searching for volunteers to fill their shoes, and the configuration can be many things. Perhaps several people could share the responsibility by committing to hosting one or two

meetings a year. Perhaps an online meeting every quarter, or a mixture of face to face and online options.

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Our Association is run entirely by volunteers, we value each and every one of you, and want to ensure if you choose to volunteer for our Association, it is a positive experience.

Remember – we do not ask you to commit to a life time of service, we ask that you consider your personal and family commitments and consider if you can give us the gift of

"a period of time"

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The Association achieved a great showing for International Trigeminal Neuralgia Awareness Day on 7<sup>th</sup> October when we worked with 11 cities around the country to light up a council building or landmark to highlight the needs of all trigeminal neuralgia sufferers. We received great support from members, face group members, and family to take pictures and record the event. Unfortunately, not many news outlets picked up the story, but a special mention to MYGC who ran an

online story, and Townsville News who printed an article about Townsville woman Haley Plaza and her struggle with trigeminal neuralgia.

In 2023 we are encouraging individuals to contact their cities to join the Awareness Day. We have made available on our website, the words you may like to use and a media release to send to your local news outlet. Our committee would love to run this process but unfortunately, we really do not have the capacity. However, the saying "many hands make light work" is very apt.

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In 2022 we established that our constitution, which was written in 2002, was no longer fit for purpose. Changes and advancements in the digital world meant we needed to create a constitution inline with how our Association now functions.

I would like to extend my heartfelt thank you to our Vice President Helen Tyzack, who applied all of her business acumen to reviewing, researching, rewriting and presenting the updated document. This document has been reviewed by a lawyer and is the subject of our Special Resolution today. This piece of work was a massive undertaking and we are very lucky to have these skills within our committee.

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In August 2022 following our webinar presented by Pain Specialist Prof Arun Aggarwal, we

Present this card at the **Emergency Department** "Pain Management advice endorsed by the



Medical Advisory Board Trigeminal Neuralgia Association Australia"

I suffer from TRIGEMINAL NEURALGIA which causes NEUROPATHIC FACIAL PAIN characterised by SHARP, STABBING and **ELECTRIC SHOCK-LIKE** pain

designed and produced our Emergency Department Card, highlighting the treatment options for sufferers who found they needed to present to their Emergency Department. Every new member receives this card as part of their membership, and cards can also be purchased on the website. This innovation has already reaped benefit to users who have had to use it during a pain breakout.

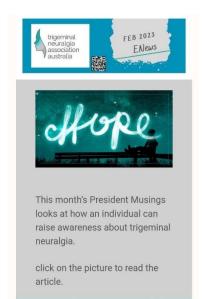
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During the year we have presented 3 webinars

- Prof Arun Aggarwal What to do when pain becomes too much
- Lyn Donnelly a presentation covering the projects the committee worked on
- Dr Jeremy Russell what to do when MVD is ruled out

A special thank you to A/Prof Liam Caffrey who continues to support us in our digital endeavours. We hope to continue our program of special webinars. All past webinars and a great deal of other content can be found on our website. Don't forget to regularly check under the <u>News</u>, <u>Research</u> and <u>Pain Management and Quality of Life</u> sections of our website.

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The Association launched ENEWS a monthly digital newsletter which is sent to non member subscribers and our membership. We try and have a monthly theme, with links to stories on our website. To stay near the top of the Google search engine stats we must ensure regular activity and user interaction, so we thank you all for the part you play. Every time you click on a link and engage with our website, the better chance new Australian sufferers have in finding our website and support network. We are competing with millions of articles loaded to the internet. We want to ensure sufferers have access to first class and verified education.

## *"Every click shines a beacon of light and hope via our website"*

## How do we know we are making a difference?

Our membership numbers tell us that we are reaching those who need our help. We have increased our membership by more than 200% and now we need to work hard to retain every new member and encourage everyone to renew their annual membership. Together with you our members, who support our work financially, we can achieve much more. I thank every member for allowing the committee to provide our services to those that need it.

## "Sometimes making a difference for just one person is enough"