Minutes of the 2022 Annual General Meeting of the Trigeminal Neuralgia Association UK held on Saturday 14 January 2023 held at The Copthorne Tara Hotel, London

Executive Committee Members Present:

Anne-Marie Poynor [Chair], Robert Jackson [Treasurer], Kirsten Cooper, Deborah Edwards, Tony Williams,

Apologies for absence: Lorraine Woolley MBE,

Officers:

Aneeta Prem [Chief Executive Officer {CEO}], Heather Morris [Office and Finance Manager]

Welcome from the Chair

- Anne-Marie Poynor welcomed everyone to the meeting, thanked the members for attending and introduced the Trustees, CEO and the Office and Finance Manager.
- The Chair then made reference to how unfortunate it was that the original date of 26 November 2022 for the AGM and Conference had to be cancelled due to the national rail strike, and she was particularly grateful to Members for attending and showing understanding and flexibility.

Approval of the Minutes of the AGM 2021

Proposer: Norman Rutterford Seconder: Harry Smith There were no matters arising from last year's minutes. **Carried Unanimously**

Approval of the Minutes of the AGM 2019

Note: Due to COVID there was no AGM in 2020 There were no matters arising Proposer: Harry Smith Seconder: Norman Rutterford **The proposal was carried Unanimously**

Presentation of Annual Report from The Treasurer

- Robert Jackson, Treasurer, firstly congratulated our CEO, Aneeta Prem, on recently receiving an MBE for her services and dedication given to the 'Freedom' Charity of which she was a founder.
- Robert then gave his report and thanked members for reading the accounts. These will be passed to our newly appointed auditors, Hains and Watts.

There were member questions about the breakdown of the balance sheet which was answered in the treasurer's statement of financial activities; difficulty in finding the reports on the website; a query on the amount spent on research. A query as to whether we could look at better investment on our deposits was completely accepted and explained that this is already being looked at.

Accounts Proposal

- To accept the 20221/2022 set of accounts as posted on the website and circulated to members who do not have an email account
- Proposer: Daniel Smith

Seconder: William Marshall

The proposal was carried with 47 in favour and one abstention

Ordinary Resolutions

- 1. To Appoint Haines Watts as Auditor to TNA UK They will hold office until the next general meeting at which annual accounts are laid before TNA UK
- 2. To Authorise the Charity Trustees to determine the remuneration (if any) of the Auditor of TNA UK
- 3. To re-elect the following Trustees: Kirsten Cooper, Deborah Edwards, Robert Jackson, Ann-Marie Poynor Tony Williams, Lorraine Wooley

Proposer: Daniel Smith

Seconder: Nadine Fronek

The above ordinary resolution proposals were carried unanimously

Special Resolutions

To Adopt an Amended Constitution for TNA UK as presented at the meeting

A copy of a red line version showing changes from the existing constitution of TNA UK accompanied this notice:

- 1. Article 3 to enable TNA UK to campaign for research funds
- 2. Article 11 (5) to reduce the quorum for general meetings TNA UK to three members
- 3. Article 13 to permit the removal of a charity trustee in the event that a majority of the then existing trustees vote in favour of such a removal

Question: A member queried non receipt of the AGM documents and accompanying red line document detailing the proposed changes

Reply: An email containing a link to the to all the documents on the website was sent to all members prior to the meeting. The email was opened by 1,615 members. A further question was asked to members present as to how many had received this email link. Of the 48 members present, 45 raised their hands to say they had received the link and 3 said they did not

Question: Regarding article 3, should there be a member of the Medical Advisory Board on the Board of Trustees

Reply: The CEO reported that this is already in hand

Question: In article 3, why was there a need to reduce the quorum to three when voting on general meetings

Reply: This is necessary when a quick decision is required in order to protect the association from the huge costs associated with the cancellation or postponement of a general meeting due to circumstances beyond our control e.g., train strikes. (We are acting under advice from our Lawyers)

Question: In article 3, a member was not happy with the addition of 'Face Pain' being added to research as believed it muddied waters and diluted the message of TN **Reply:** The Chairs of the Medical Board believe it will enhance our chances of receiving funds, as TN being such a rare condition it is unlikely to receive significant funding on its own. This will in no way will dilute our research

Voting on the Changes to the Constitution

Article 3 – to enable TNA UK to campaign for research funds This proposal was carried 46 in favour, 2 against and no abstentions

Article 11 (5) – to reduce the quorum for general meetings TNA UK to three members **This proposal was carried 39 in favour, 5 against and 4 abstentions**

Article 13 – to permit the removal of a charity trustee in the event that a majority of the then existing trustees vote in favour of such a removal **This proposal was carried 45 in favour, 2 against and 1 abstention**

Report from CEO

Aneeta Prem began by thanking Joanna Zakzrewska and previous trustees for all of their dedication and hard work in the past.

She also thanked Heather Morris (Office and Finance Manager) for all that she does for the association as she rarely goes off duty and is always there to lend a hand or an ear to members.

Aneeta, then gave her report reviewing the past year's activities which have included:

- 'Face of TN' campaign for National TN Awareness Day a film make-up artist showed the branches of the TN nerve and visually displayed the pain through images of shards of glass. Some members painted their faces to depict this
- **Tea for TNA** members and supporters hosted tea parties around the country. We now have Tea for TNA packs with cake stands and bunting etc. The first events raised over £5,000
- **Regional Support Groups** The new London support group is well under way and we are looking at new ways to attract new groups and make the groups more dynamic with outside speakers
- Webinar Series These bi-monthly webinars have proved to be hugely successful and well supported
- **1,000,000 Steps for TNA** A new initiative to raise much needed funds and improve physical and mental health
- Improving Accessibility 20 tablets and Wi-Fi dongles have been obtained from two charities for those members who had no technical access. We have also successfully bid for new smartphones for some helpline volunteers
- **Fundraising** we have engaged a scoping officer who has helped us raise over £14,000. We have also submitted bids to cover a Support Services Coordinator and training for Regional Support Groups. We also wish to apply for research funding.

Have engaged in a will writing service and working to secure future legacies. We have set up an 'In Loving Memory' fundraising initiative

- **Public Affairs and Communications** Met with the Secretary of State for Work and Pensions re PIP benefits for TN sufferers
- Website Have been working with developers to provide a non-static and up to date website.
- **Social Media** Hugely increased TNA's social media presence and have started filming for a YouTube channel
- **Global Health Summit in Glasgow 2022** Aneeta was invited to be a keynote speaker and was able to raise awareness of TN globally
- Behind the Scenes -
 - Strengthening financial management of the organisation
 - Developing ongoing relationships with other facial pain and neurological organisations
 - > Working with pro bono lawyers to develop policies and use of legal services
 - Looking at new pain relief/coping strategies such as medical cannabis and mindfulness
 - Developing our helpline by sourcing funding for training, introduction of freephone and a Samaritans option

In short, a hugely successful year.

Close of Meeting

Anne-Marie Poynor thanked members for attending and all volunteers for their hard work for the charity over the past year.

Meeting closed at 10:10am