

Trigeminal Neuralgia Association UK

Chairman's Report 2014

Introduction

This report must begin on a personal note as I am sad to say that a number of factors, including my own health, have conspired to force me to stand down after just one year as Chairman. It is with regret that I feel I must do this but, apart from various other factors, my TN has grown significantly worse in recent months. I have been able to identify a number of risk factors for my own TN and travelling to meetings and working on a laptop are just two of them. Short of relocating to Surrey and asking my partner to take dictation, there is little I can do about either of those things. The Association is actively engaged in recruiting a new Chairperson and until we have found a replacement, I will continue as nominal Chairman with the assistance of Jillie, Mike and the other very able Trustees, to whom I am extremely grateful.

The Association is in good health, on the other hand. After two years' operation with a CEO, Naomi Gilbert, we have been able to review the way we work and provide the services our membership demands of us. This has meant prioritising our activities to minimise the dissipation of effort and to concentrate on streamlining the organisation to increase its appeal to prospective sponsors. To that end, we have improved the efficiency of our office functions and have achieved the Information Standard, which demonstrates that our publications, both printed and on-line, are of high quality.

Associations and Affiliations

It is in this area that we could be considered to be stretching ourselves too thinly, as there are many organisations on which we have representation, but arguably too few Officers to attend them. I have attended both the European Federation of Neurological Alliances (EFNA) General Assembly in Dublin, as well as Pain Alliance Europe (PAE) in Brussels. Both of these are worthy bodies, but EFNA has a number of delegates that represent single organisations rather than national Neurological Alliances, making the representation somewhat lopsided. Of course, to have TNA UK's 'foot in the door' of a European body should be considered highly advantageous, but the cost-benefit equation should be considered. Likewise, PAE has the ear of the European Parliament – indeed, its office is within the same building – and would seem a natural place for us to make a contribution, so continued membership should be without question, but once again we must weigh up the relative costs and benefits. It should, however, be pointed out that both

these organisations receive European funding and attendance should incur no monetary cost to TNA UK.

On the domestic front, we attend numerous conferences, usually with the TNA UK stand, to provide information and literature to delegates. We have looked hard at the number and nature of the meetings we attend, as some are expensive and of questionable benefit. I personally have attended the OUCH (Organisation for the Understanding of Cluster Headache) Regional Conference in York as a delegate and Jillie has attended a similar meeting in Shrewsbury. I found this a useful and interesting meeting, as Cluster Headache sufferers has many similarities with TN, although the aetiology of the condition and its treatment are different. I also attended the British Pain Society's Annual Scientific Meeting in Manchester with the TNA UK stand, with help from the Cheshire Local Support Group organiser, Helen Clayton. As a so-called trade attendee, we had to pay to have the stand there. The full list of meetings attended is attached at Appendix 1. It is noteworthy that fees for our exhibits at medical conferences have increased from £2635 in 2012/13 to £2830 in 2013/14. Likewise, our affiliations have increased from £1002 in 2012/13 to £2548 in 2013/14.

Officers' Reports

Medical Advisory Board

Professor Joanna Zakrzewska continues in her invaluable role as Chair of the MAB and maintains the profile of Trigeminal Neuralgia through her publications and presentations, as well as TNA UK through media involvement. She has been on Dr Mark Porter's BBC Radio 4 programme alongside Anne Eastman, as well as in the BBC Health News, interviewed by Paula McGrath. Professor Zakrzewska was also interviewed by the Daily Mail for a case study on TN.

Her peer-reviewed publications include a chapter in Wall and Melzack's Textbook of Pain (6th Edition) as well as four articles in the British Medical Journal and the British Journal of Anaesthesia.

She is actively involved in research, including a trial for a new sodium channel blocker which has been successful. The drug company is now raising funds for a large international study so that the drug can meet approval. She is also continuing with a study to determine outcomes after gamma knife surgery, as well as working with a team in the US to research the genetics of TN.

Finance

The Treasurer, Mike Gibbard, continues to do sterling work to keep the finances of the Association in good order and we owe him a debt of gratitude for his excellent work. Although our cash reserves are down, owing to the employment of a CEO for two years, our income has achieved record levels in terms of donations and renewals and we are in a strong position. We still

seek substantial new funding to enable us to carry out the projects that are on hold, and this remains a major goal. The accounts will be presented at the AGM .

Helplines

Many thanks to Jan Bruten who continues to co-ordinate both the telephone and email helplines in an expert fashion. She reports that the Telephone Helpline Team now consists of 6 volunteers following the successful recruitment of Francine Tyler and Jeanette Kinder. The team's stints have been reduced from 2 weeks to 1 week, proving less arduous for the volunteers. The number of calls received averages 4 per day but increases significantly following media publicity. The team is collecting a slimmed down set of data from the calls, which is being collated in spreadsheet fashion. The email helpline is rather harder to manage effectively, as enquiries cover such a variety of topics. One common enquiry is if we know of any 'TN-friendly' dentists, and we hope to be able to compile a list of those recommended by other sufferers. If you have or know a dentist who is understanding of the particular difficulties faced by TN sufferers, please let us know.

Local Support Groups

Owing to the patchy provision of Local Support Groups, The Executive Committee has decided to discontinue actively promoting LSGs – at least for the time being – but will continue support of those currently active.

Volunteer Recruitment

Fiona Twitchen has, with the assistance of our outgoing CEO, produced a Volunteer Recruitment Pack designed to streamline the recruitment of volunteers in a consistent and reliable manner. In the first instance, we have advertised for a Chairman via the Oxted volunteer centre, and although we have not received any applicants for that role we have interviewed a person who we believe could take on the responsibility for IT and communications strategy. Other roles to be filled are office administration and fundraising.

Special Projects

Jillie Abbott is the Special Projects Officer who has been involved with a couple of projects this year. The aim of the first is to collect evidence showing that TN is often not recognised by dentists, sometimes misdiagnosed and often inappropriately treated by GPs. We hope to be able to use this information for educational purposes as well as for fund-raising. The second project focuses on narratives and the language used by people with facial pain; it is also hoped we might identify people with familial TN who may have a genetic predisposition to neuropathic pain from differences in their sodium channels. Jillie is also looking at a range of other subjects to

investigate, including: the cognitive side effects of the drugs, long-lasting TN attacks and complications following surgery – all worthy areas of research. In addition to her special projects, Jillie has also been very active in attending meetings and liaising with other bodies.

Summary

Finally, I would like to thank all the Trustees and other volunteers for their exceptionally hard work throughout the year and for their invaluable support. Without their time and effort, the Association simply would not exist. I would also like to thank Clare Whitfield, the Office Manager, who is neither a Trustee nor a volunteer, but who runs the office with great efficiency.

Appendix

Meetings Attended by EC Members

NHS England Improving Dental Care & Oral Health – A Call to Action Conference. This event was attended by over 220 professionals, including the majority of the top officials in the NHS dental services. **JA**

All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD) – Inquiry into Headache Services in England. In December and January, the APPGPHD, which is chaired by TNA UK member Jim Fitzpatrick MP, organised two sessions at the House of Commons, collecting written and oral evidence for this inquiry. **MS, JA & JZ**

e-Pain Launch at the College of Anaesthetists, run by the Faculty of Pain Medicine **JA**

Pfizer Workshops on Commissioning **JA**

OUCH UK Regional Meeting in Shrewsbury. **JA**

European Federation of Neurological Alliances (EFNA) General Assembly in Dublin **MS**

Pain Alliance Europe (PAE) in Brussels **MS**

OUCH (Organisation for the Understanding of Cluster Headache) Regional Conference in York **MS**

British Pain Society Annual Scientific Conference **MS & JZ**

TNA Scientific Conference, San Diego (two presentations) **JZ**