

## ABOUT TNA UK

The Trigeminal Neuralgia Association UK (TNA UK) is a support group for people suffering from this severely painful neurological condition. It was formed in 1999 by a patient (Elisabeth Boulot) and a doctor specialising in treating TN (Prof Joanna Zakrzewska) to offer support and encouragement to sufferers. The Association was run by a handful of people until January 2001, when the founder returned to live in France and several members responded to the call for help as the membership grew. That group formed the Association's Executive Committee elected at the first AGM on 7 July 2001. The Constitution was adopted at that meeting and the Association was granted charity status in July 2002.

The aims of the Association are to continue to provide information and offer support to members, and to raise awareness of TN amongst medical professionals as well as the general public. The TNA UK is dependent on donations and annual membership fees in order to continue its work; all the officers of the Association give their time voluntarily. The membership fee is £10 annually; and there is now contact with well over 1,000 TN patients.

When joining TNA UK, members can sign up to one of our Regional Support Groups so that they can meet and talk to other members in their geographical area who understand exactly what they are going through. They receive a quarterly newsletter featuring articles about TN and updates on treatments, and have access to detailed information on all aspects of TN. They can also call the dedicated members' telephone helpline. Our website [www.tna.org.uk](http://www.tna.org.uk) has personal histories as well as all kinds of information about TN and the Association. The site is regularly updated and linked with other useful sites including the British Brain and Spine Foundation, whose Face Pain booklet has a good overview of TN.

The Association's Medical Adviser, Prof Joanna Zakrzewska, Consultant/Hon Professor, Facial Pain Lead, Division of Diagnostic, Surgical and Medical Sciences at Eastman's Dental Hospital, is a worldwide authority on trigeminal neuralgia. She speaks regularly at medical and dental conferences and has written numerous papers on trigeminal neuralgia drug treatments and surgical outcomes. Her publications include: *Trigeminal Neuralgia* published in 1995 and several chapters in books on facial pain, including *Epidemiology of Facial Pain* (with P. Hamlyn) and regular contributions to various medical and dental journals. Her book *Assessment and Management of Orofacial Pain* was published in January 2003.

As a result of meetings with patients in the UK and US, Prof Zakrzewska organised a survey of patients' views on trigeminal neuralgia management and this has now been published and draws attention to the need for more support for these patients. Prof Zakrzewska has also drawn together a team of medical and surgical specialists, all of whom have considerable experience in treating trigeminal neuralgia, to form the Medical Advisory Board of the Association.

The members of the Medical Advisory Board currently are as follows:

*Dr Anish Bahra* Consultant Neurologist  
*The National Hospital, London*  
*Mr Peter Bullock* Consultant Neurosurgeon  
*King's College Hospital, London*  
*Dr Sam Chong* Consultant Neurologist  
*King's College Hospital, London*  
*Prof Hugh Coakham* Consultant Neurosurgeon  
*Frenchay Hospital, Bristol*  
*Dr Alex Crighton* Consultant, Oral Medicine  
*Glasgow University Dental Hospital*  
*Mr Paul Eldridge* Consultant Neurosurgeon  
*The Walton Centre, Liverpool*  
*Mr Neil Kitchen* Consultant Neurosurgeon  
*The National Hospital, London*  
*Mr Nigel Mendoza* Consultant Neurosurgeon  
*Charing Cross Hospital, London*

*Prof Turo Nurmikko* Consultant Neurologist  
*The Walton Centre, Liverpool*  
*Mr Owen Sparrow* Consultant Neurosurgeon  
*Southampton General Hospital*

## Information available

Our leaflet *Trigeminal Neuralgia, Information and Support for Patients* has been distributed to neurological specialists, GPs and dentists to be given to patients when they have been diagnosed with TN. Following the first approach by patients, the Association sends out a letter outlining its objectives, an application form, a Gift Aid form and an informative booklet. Other information booklets and leaflets, all of which have been endorsed by the Association's Medical Adviser, are available to members as appropriate after joining the Association:

***Treating Trigeminal Neuralgia with Medicine  
Considering Surgery for Trigeminal Neuralgia  
Microvascular Decompression  
Glycerol Injection and Thermocoagulation  
(Radiofrequency Lesioning)  
Gamma Knife Treatment for Trigeminal Neuralgia  
Multiple Sclerosis and Trigeminal Neuralgia  
Post-herpetic Neuralgia  
Glossopharyngeal Neuralgia  
Strategies for Coping with Pain  
Caring for Someone with Trigeminal Neuralgia***

We also have a list of hospitals which provide the full range of treatments for trigeminal neuralgia and medical professionals who have extensive experience in dealing with this area of neurology. Almost all of our Regional Support Groups in the UK and Eire (Dublin) have a neurological consultant at a nearby hospital to support them.

Trigeminal neuralgia is an agonizing and debilitating condition and TNA UK is committed to exploring all avenues in order to provide help and hope to people who are afflicted by it.

## Access to TNA UK

Access to TNA UK is available through the internet, by email, by post and by telephone (main number and separate members' helpline number).

The Association has its own dedicated website at [www.tna.org.uk](http://www.tna.org.uk) which carries basic information on TN and the treatments available, as well as some personal histories. Other websites with similar aims and areas of knowledge provide links to our website. Various professional medical and healthcare websites have links to the TNA UK site or provide information about the Association, among many others: *NHS Direct, The British Dental Association, the Brain and Spine Foundation; the American Trigeminal Neuralgia Association.*

## Plans for the future

We have regularly appeared across the country with our display stand and literature at exhibitions and meetings of healthcare professionals such as the Society of British Neurological Surgeons, the Association of British Neurologists, and the British Pain Society, and will continue to do all we can to promote the Association and the plight of TN patients. We aim to target GPs and dentists to ensure that patients receive faster diagnoses, the appropriate initial medication, and advice on available surgical procedures where appropriate.

As our membership grows, we are able to collect more information from patients that is valuable to the medical profession, and which will hopefully open up avenues of research. Our Medical Advisory Board is helping us to compile a comprehensive database of TN specialists throughout the UK and as our local support group network expands we will be better able to offer our members guidance as to their best course of action and where to go for treatment.

**The TNA UK was established to provide support and information to people affected by trigeminal neuralgia and we regret that we are unable to provide medical advice. The information contained in this booklet is for educational purposes only, to enable you to make informed decisions about your care in consultation with your physician. It should not be regarded as advice on diagnosis or treatment.**

*All information leaflets issued by the Trigeminal Neuralgia Association UK have been endorsed by the Association's Medical Adviser*

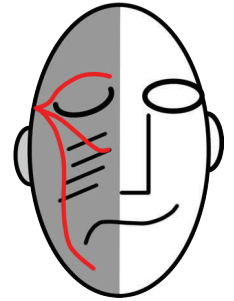
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[www.tna.org.uk](http://www.tna.org.uk)

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Facing pain together

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