THE OFFICIAL
PATIENT'S SOURCEBOOK
on

TRIGEMINAL
NEURALGIA

JAMES N. PARKER, M.D.
AND PHILIP M. PARKER, PH.D., EDITORS

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Dedication

To the healthcare professionals dedicating their time and efforts to the study of trigeminal neuralgia.

Acknowledgements

The collective knowledge generated from academic and applied research summarized in various references has been critical in the creation of this sourcebook which is best viewed as a comprehensive compilation and collection of information prepared by various official agencies which directly or indirectly are dedicated to trigeminal neuralgia. All of the *Official Patient's Sourcebooks* draw from various agencies and institutions associated with the United States Department of Health and Human Services, and in particular, the Office of the Secretary of Health and Human Services (OS), the Administration for Children and Families (ACF), the Administration on Aging (AOA), the Agency for Healthcare Research and Quality (AHRQ), the Agency for Toxic Substances and Disease Registry (ATSDR), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the Healthcare Financing Administration (HCFA), the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the institutions of the National Institutes of Health (NIH), the Program Support Center (PSC), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In addition to these sources, information gathered from the National Library of Medicine, the United States Patent Office, the European Union, and their related organizations has been invaluable in the creation of this sourcebook. Some of the work represented was financially supported by the Research and Development Committee at INSEAD. This support is gratefully acknowledged. Finally, special thanks are owed to Tiffany LaRochelle for her excellent editorial support.

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Dr. James N. Parker received his Bachelor of Science degree in Psychobiology from the University of California, Riverside and his M.D. from the University of California, San Diego. In addition to authoring numerous research publications, he has lectured at various academic institutions. Dr. Parker is the medical editor for the *Official Patient's Sourcebook* series published by ICON Health Publications.

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Philip M. Parker is the Eli Lilly Chair Professor of Innovation, Business and Society at INSEAD (Fontainebleau, France and Singapore). Dr. Parker has also been Professor at the University of California, San Diego and has taught courses at Harvard University, the Hong Kong University of Science and Technology, the Massachusetts Institute of Technology, Stanford University, and UCLA. Dr. Parker is the associate editor for the *Official Patient's Sourcebook* series published by ICON Health Publications.

About ICON Health Publications

In addition to trigeminal neuralgia, *Official Patient's Sourcebooks* are available for the following related topics:

- The Official Patient's Sourcebook on Amyotrophic Lateral Sclerosis
- The Official Patient's Sourcebook on Brachial Plexus Injuries
- The Official Patient's Sourcebook on Brown Sequard
- The Official Patient's Sourcebook on Chronic Inflammatory Demyelinating Polyneuropathy
- The Official Patient's Sourcebook on Orthostatic Hypotension
- The Official Patient's Sourcebook on Paresthesia
- The Official Patient's Sourcebook on Peripheral Neuropathy
- The Official Patient's Sourcebook on Primary Lateral Sclerosis
- The Official Patient's Sourcebook on Reflex Sympathetic Dystrophy Syndrome
- The Official Patient's Sourcebook on Shy Drager
- The Official Patient's Sourcebook on Spinal Cord Injury
- The Official Patient's Sourcebook on Syringomyelia
- The Official Patient's Sourcebook on Tethered Spinal Cord Syndrome
- The Official Patient's Sourcebook on Thoracic Outlet Syndrome
- The Official Patient's Sourcebook on Transverse Myelitis
- The Official Patient's Sourcebook on Whiplash

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INTRODUCTION

Overview

Dr. C. Everett Koop, former U.S. Surgeon General, once said, "The best prescription is knowledge."[1] The Agency for Healthcare Research and Quality (AHRQ) of the National Institutes of Health (NIH) echoes this view and recommends that every patient incorporate education into the treatment process. According to the AHRQ:

> Finding out more about your condition is a good place to start. By contacting groups that support your condition, visiting your local library, and searching on the Internet, you can find good information to help guide your treatment decisions. Some information may be hard to find—especially if you don't know where to look.[2]

As the AHRQ mentions, finding the right information is not an obvious task. Though many physicians and public officials had thought that the emergence of the Internet would do much to assist patients in obtaining reliable information, in March 2001 the National Institutes of Health issued the following warning:

> The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading.[3]

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[1] Quotation from **http://www.drkoop.com**.

[2] The Agency for Healthcare Research and Quality (AHRQ): **http://www.ahcpr.gov/consumer/diaginfo.htm**.

[3] From the NIH, National Cancer Institute (NCI): **http://cancertrials.nci.nih.gov/beyond/evaluating.html**.

Since the late 1990s, physicians have seen a general increase in patient Internet usage rates. Patients frequently enter their doctor's offices with printed Web pages of home remedies in the guise of latest medical research. This scenario is so common that doctors often spend more time dispelling misleading information than guiding patients through sound therapies. *The Official Patient's Sourcebook on Trigeminal Neuralgia* has been created for patients who have decided to make education and research an integral part of the treatment process. The pages that follow will tell you where and how to look for information covering virtually all topics related to trigeminal neuralgia, from the essentials to the most advanced areas of research.

The title of this book includes the word "official." This reflects the fact that the sourcebook draws from public, academic, government, and peer-reviewed research. Selected readings from various agencies are reproduced to give you some of the latest official information available to date on trigeminal neuralgia.

Given patients' increasing sophistication in using the Internet, abundant references to reliable Internet-based resources are provided throughout this sourcebook. Where possible, guidance is provided on how to obtain free-of-charge, primary research results as well as more detailed information via the Internet. E-book and electronic versions of this sourcebook are fully interactive with each of the Internet sites mentioned (clicking on a hyperlink automatically opens your browser to the site indicated). Hard copy users of this sourcebook can type cited Web addresses directly into their browsers to obtain access to the corresponding sites. Since we are working with ICON Health Publications, hard copy *Sourcebooks* are frequently updated and printed on demand to ensure that the information provided is current.

In addition to extensive references accessible via the Internet, every chapter presents a "Vocabulary Builder." Many health guides offer glossaries of technical or uncommon terms in an appendix. In editing this sourcebook, we have decided to place a smaller glossary within each chapter that covers terms used in that chapter. Given the technical nature of some chapters, you may need to revisit many sections. Building one's vocabulary of medical terms in such a gradual manner has been shown to improve the learning process.

We must emphasize that no sourcebook on trigeminal neuralgia should affirm that a specific diagnostic procedure or treatment discussed in a research study, patent, or doctoral dissertation is "correct" or your best option. This sourcebook is no exception. Each patient is unique. Deciding on appropriate options is always up to the patient in consultation with their physician and healthcare providers.

Organization

This sourcebook is organized into three parts. Part I explores basic techniques to researching trigeminal neuralgia (e.g. finding guidelines on diagnosis, treatments, and prognosis), followed by a number of topics, including information on how to get in touch with organizations, associations, or other patient networks dedicated to trigeminal neuralgia. It also gives you sources of information that can help you find a doctor in your local area specializing in treating trigeminal neuralgia. Collectively, the material presented in Part I is a complete primer on basic research topics for patients with trigeminal neuralgia.

Part II moves on to advanced research dedicated to trigeminal neuralgia. Part II is intended for those willing to invest many hours of hard work and study. It is here that we direct you to the latest scientific and applied research on trigeminal neuralgia. When possible, contact names, links via the Internet, and summaries are provided. It is in Part II where the vocabulary process becomes important as authors publishing advanced research frequently use highly specialized language. In general, every attempt is made to recommend "free-to-use" options.

Part III provides appendices of useful background reading for all patients with trigeminal neuralgia or related disorders. The appendices are dedicated to more pragmatic issues faced by many patients with trigeminal neuralgia. Accessing materials via medical libraries may be the only option for some readers, so a guide is provided for finding local medical libraries which are open to the public. Part III, therefore, focuses on advice that goes beyond the biological and scientific issues facing patients with trigeminal neuralgia.

Scope

While this sourcebook covers trigeminal neuralgia, your doctor, research publications, and specialists may refer to your condition using a variety of terms. Therefore, you should understand that trigeminal neuralgia is often considered a synonym or a condition closely related to the following:

- Fothergill Disease
- Fothergill's Neuralgia

- Tic Douloureux
- Trifacial Neuralgia

In addition to synonyms and related conditions, physicians may refer to trigeminal neuralgia using certain coding systems. The International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) is the most commonly used system of classification for the world's illnesses. Your physician may use this coding system as an administrative or tracking tool. The following classification is commonly used for trigeminal neuralgia:[4]

- 350.1 trigeminal neuralgia

For the purposes of this sourcebook, we have attempted to be as inclusive as possible, looking for official information for all of the synonyms relevant to trigeminal neuralgia. You may find it useful to refer to synonyms when accessing databases or interacting with healthcare professionals and medical librarians.

Moving Forward

Since the 1980s, the world has seen a proliferation of healthcare guides covering most illnesses. Some are written by patients or their family members. These generally take a layperson's approach to understanding and coping with an illness or disorder. They can be uplifting, encouraging, and highly supportive. Other guides are authored by physicians or other healthcare providers who have a more clinical outlook. Each of these two styles of guide has its purpose and can be quite useful.

As editors, we have chosen a third route. We have chosen to expose you to as many sources of official and peer-reviewed information as practical, for the purpose of educating you about basic and advanced knowledge as recognized by medical science today. You can think of this sourcebook as your personal Internet age reference librarian.

Why "Internet age"? All too often, patients diagnosed with trigeminal neuralgia will log on to the Internet, type words into a search engine, and

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[4] This list is based on the official version of the World Health Organization's 9th Revision, International Classification of Diseases (ICD-9). According to the National Technical Information Service, "ICD-9CM extensions, interpretations, modifications, addenda, or errata other than those approved by the U.S. Public Health Service and the Health Care Financing Administration are not to be considered official and should not be utilized. Continuous maintenance of the ICD-9-CM is the responsibility of the federal government."

receive several Web site listings which are mostly irrelevant or redundant. These patients are left to wonder where the relevant information is, and how to obtain it. Since only the smallest fraction of information dealing with trigeminal neuralgia is even indexed in search engines, a non-systematic approach often leads to frustration and disappointment. With this sourcebook, we hope to direct you to the information you need that you would not likely find using popular Web directories. Beyond Web listings, in many cases we will reproduce brief summaries or abstracts of available reference materials. These abstracts often contain distilled information on topics of discussion.

While we focus on the more scientific aspects of trigeminal neuralgia, there is, of course, the emotional side to consider. Later in the sourcebook, we provide a chapter dedicated to helping you find peer groups and associations that can provide additional support beyond research produced by medical science. We hope that the choices we have made give you the most options available in moving forward. In this way, we wish you the best in your efforts to incorporate this educational approach into your treatment plan.

The Editors

PART I: THE ESSENTIALS

ABOUT PART I

Part I has been edited to give you access to what we feel are “the essentials” on trigeminal neuralgia. The essentials of a disease typically include the definition or description of the disease, a discussion of who it affects, the signs or symptoms associated with the disease, tests or diagnostic procedures that might be specific to the disease, and treatments for the disease. Your doctor or healthcare provider may have already explained the essentials of trigeminal neuralgia to you or even given you a pamphlet or brochure describing trigeminal neuralgia. Now you are searching for more in-depth information. As editors, we have decided, nevertheless, to include a discussion on where to find essential information that can complement what your doctor has already told you. In this section we recommend a process, not a particular Web site or reference book. The process ensures that, as you search the Web, you gain background information in such a way as to maximize your understanding.

CHAPTER 1. THE ESSENTIALS ON TRIGEMINAL NEURALGIA: GUIDELINES

Overview

Official agencies, as well as federally-funded institutions supported by national grants, frequently publish a variety of guidelines on trigeminal neuralgia. These are typically called "Fact Sheets" or "Guidelines." They can take the form of a brochure, information kit, pamphlet, or flyer. Often they are only a few pages in length. The great advantage of guidelines over other sources is that they are often written with the patient in mind. Since new guidelines on trigeminal neuralgia can appear at any moment and be published by a number of sources, the best approach to finding guidelines is to systematically scan the Internet-based services that post them.

The National Institutes of Health (NIH)[5]

The National Institutes of Health (NIH) is the first place to search for relatively current patient guidelines and fact sheets on trigeminal neuralgia. Originally founded in 1887, the NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States. At any given time, the NIH supports some 35,000 research grants at universities, medical schools, and other research and training institutions, both nationally and internationally. The rosters of those who have conducted research or who have received NIH support over the years include the world's most illustrious scientists and physicians. Among them are 97 scientists who have won the Nobel Prize for achievement in medicine.

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[5] Adapted from the NIH: **http://www.nih.gov/about/NIHoverview.html**.

There is no guarantee that any one Institute will have a guideline on a specific disease, though the National Institutes of Health collectively publish over 600 guidelines for both common and rare diseases. The best way to access NIH guidelines is via the Internet. Although the NIH is organized into many different Institutes and Offices, the following is a list of key Web sites where you are most likely to find NIH clinical guidelines and publications dealing with trigeminal neuralgia and associated conditions:

- Office of the Director (OD); guidelines consolidated across agencies available at **http://www.nih.gov/health/consumer/conkey.htm**
- National Library of Medicine (NLM); extensive encyclopedia (A.D.A.M., Inc.) with guidelines available at **http://www.nlm.nih.gov/medlineplus/healthtopics.html**
- National Institute of Neurological Disorders and Stroke (NINDS); **http://www.ninds.nih.gov/health_and_medical/disorder_index.htm**

Among the above, the National Institute of Neurological Disorders and Stroke (NINDS) is particularly noteworthy. The mission of the NINDS is to reduce the burden of neurological disease—a burden borne by every age group, by every segment of society, by people all over the world.[6] To support this mission, the NINDS conducts, fosters, coordinates, and guides research on the causes, prevention, diagnosis, and treatment of neurological disorders and stroke, and supports basic research in related scientific areas. The following patient guideline was recently published by the NINDS on trigeminal neuralgia.

What Is Trigeminal Neuralgia?[7]

Trigeminal neuralgia, also called tic douloureux, is a condition that affects the trigeminal nerve (the 5th cranial nerve), one of the largest nerves in the head. The trigeminal nerve is responsible for sending impulses of touch, pain, pressure, and temperature to the brain from the face, jaw, gums, forehead, and around the eyes. Trigeminal neuralgia is characterized by a sudden, severe, electric shock-like or stabbing pain typically felt on one side of the jaw or cheek. The disorder is more common in women than in men and rarely affects anyone younger than 50. The attacks of pain, which

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[6] This paragraph has been adapted from the NINDS: **http://www.ninds.nih.gov/about_ninds/mission.htm**. "Adapted" signifies that a passage has been reproduced exactly or slightly edited for this book.

[7] Adapted from The National Institute of Neurological Disorders and Stroke (NINDS): **http://www.ninds.nih.gov/health_and_medical/disorders/trigemin_doc.htm**.

generally last several seconds and may be repeated one after the other, may be triggered by talking, brushing teeth, touching the face, chewing, or swallowing. The attacks may come and go throughout the day and last for days, weeks, or months at a time, and then disappear for months or years.

Is There Any Treatment?

Treatment for trigeminal neuralgia typically includes anticonvulsant medications such as carbamazepine or phenytoin. Baclofen, clonazepam, gabapentin, and valproic acid may also be effective and may be used in combination to achieve pain relief. If medication fails to relieve pain, surgical treatment may be recommended.

What Is the Prognosis?

The disorder is characterized by recurrences and remissions, and successive recurrences may incapacitate the patient. Due to the intensity of the pain, even the fear of an impending attack may prevent activity. Trigeminal neuralgia is not fatal.

What Research Is Being Done?

Within the NINDS research programs, trigeminal neuralgia is addressed primarily through studies associated with pain research. NINDS vigorously pursues a research program seeking new treatments for pain and nerve damage with the ultimate goal of reversing debilitating conditions such as trigeminal neuralgia. NINDS has notified research investigators that it is seeking grant applications both in basic and clinical pain research.

For More Information

For more information, contact:

American Chronic Pain Association (ACPA)
P.O. Box 850
Rocklin, CA 95677-0850
ACPA@pacbell.net

http://www.theacpa.org
Tel: 916-632-0922
Fax: 916-632-3208

National Chronic Pain Outreach Association (NCPOA)
P.O. Box 274
Millboro, VA 24460
ncpoa@cfw.com
Tel: 540-862-9437
Fax: 540-862-9485

Trigeminal Neuralgia Association
2801 SW Archer Road
Suite C
Gainesville, FL 32608
tna@csionline.net
http://www.tna-support.org
Tel: 352-376-9955
Fax: 352-376-8688

National Foundation for the Treatment of Pain
1330 Skyline Drive
#21
Monterey, CA 93940
mgordon@mbay.net
http://www.paincare.org
Tel: 831-655-8812
Fax: 831-655-2823

More Guideline Sources

The guideline above on trigeminal neuralgia is only one example of the kind of material that you can find online and free of charge. The remainder of this chapter will direct you to other sources which either publish or can help you find additional guidelines on topics related to trigeminal neuralgia. Many of the guidelines listed below address topics that may be of particular relevance to your specific situation or of special interest to only some patients with trigeminal neuralgia. Due to space limitations these sources are listed in a concise manner. Do not hesitate to consult the following sources by either using the Internet hyperlink provided, or, in cases where the contact information is provided, contacting the publisher or author directly.

Topic Pages: MEDLINEplus

For patients wishing to go beyond guidelines published by specific Institutes of the NIH, the National Library of Medicine has created a vast and patient-oriented healthcare information portal called MEDLINEplus. Within this Internet-based system are "health topic pages." You can think of a health topic page as a guide to patient guides. To access this system, log on to **http://www.nlm.nih.gov/medlineplus/healthtopics.html**. From there you can either search using the alphabetical index or browse by broad topic areas.

If you do not find topics of interest when browsing health topic pages, then you can choose to use the advanced search utility of MEDLINEplus at **http://www.nlm.nih.gov/medlineplus/advancedsearch.html**. This utility is similar to the NIH Search Utility, with the exception that it only includes material linked within the MEDLINEplus system (mostly patient-oriented information). It also has the disadvantage of generating unstructured results. We recommend, therefore, that you use this method only if you have a very targeted search.

The Combined Health Information Database (CHID)

CHID Online is a reference tool that maintains a database directory of thousands of journal articles and patient education guidelines on trigeminal neuralgia and related conditions. One of the advantages of CHID over other sources is that it offers summaries that describe the guidelines available, including contact information and pricing. CHID's general Web site is **http://chid.nih.gov/**. To search this database, go to **http://chid.nih.gov/detail/detail.html**. In particular, you can use the advanced search options to look up pamphlets, reports, brochures, and information kits. The following was recently posted in this archive:

- **Trigeminal Neuralgia Association**

  Source: Barnegat Light, NJ: Trigeminal Neuralgia Association. 6 p.

  Contact: Available from Trigeminal Neuralgia Association. P.O. Box 340, Barnegat Light, NJ 08006. (609) 361-1014; FAX (609) 361- 0982. Price: Free.

  Summary: This brochure briefly explains trigeminal neuralgia, the history of the Trigeminal Neuralgia Association, their objectives and methods, and their goals. Included is a form to send for more information about the disorder or to offer contributions.

- **Trigeminal Neuralgia: A Primer for Physicians and Patients**

  Source: Barnegat Light, NJ: Trigeminal Neuralgia Association. 200x. 9 p.

  Contact: Available from Trigeminal Neuralgia Association. P.O. Box 340, Barnegat Light, NJ 08006. (609) 361-6250. Fax (609) 361-0982. E-mail: tna@csionline.net. Website: www.tna-support.org. Price: Single copy free.

  Summary: Trigeminal neuralgia (TN) is a chronic disorder that usually affects people in middle or late life and is characterized by excruciating pain around the eyes, nose, lips, jaw, forehead, or scalp. This brochure provides an overview of the causes, diagnosis, medical treatments, and surgical options for trigeminal neuralgia. TN is believed to be caused when a blood vessel presses on the trigeminal nerve (vascular compression) and causes the covering (myelin sheath) to deteriorate. This deterioration causes the nerve to send abnormal signals to the brain which can cause a soft touch or simple facial movement to feel painful. TN can be easily diagnosed by a dentist or physician familiar with its pain and symptoms. There is no specific test to confirm TN. Many patients find that TN can be effectively managed with medication, usually on an ongoing basis (at least four to six weeks on medications, then a gradual tapering off if the pain stays in remission). The most commonly prescribed medications for TN are anticonvulsants, which work by suppressing the abnormal signaling activity of the trigeminal nerve. Surgical options can include radiofrequency rhizotomy (or electrocoagulation), glycerol rhizotomy, balloon compression, microvascular decompression, and stereotactic (or gamma knife or LINAC) radiosurgery. The brochure concludes with information about the non profit Trigeminal Neuralgia Association (TNA), a group that sponsors support groups, a national patient network, and educational outreach (www.tna-support.org). 1 figure.

- **Trigeminal Neuralgia Association: A Nonprofit Voluntary Organization**

  Source: Barnegat Light, NJ: Trigeminal Neuralgia Association. 199x. 2 p.

  Contact: Available from Trigeminal Neuralgia Association. P.O. Box 340, Barnegat Light, NJ 08006. (609) 361-1014; Fax (609) 361-0982. Price: Single copy free.

  Summary: This brochure describes the Trigeminal Neuralgia Association (TNA), a nonprofit organization established to provide the opportunity for TN patients to share experiences, to receive support, and to obtain current information on the treatment of this disorder. The Association has an Educational Outreach Program directed to medical and dental practitioners, TN patients, and the general public; the program is intended to increase public and professional awareness of the disorder and the modes of treatment available. The brochure lists the goals of the TNA and includes a form with which readers can join or contribute to the organization. The back panel of the brochure lists the Board of Directors and Medical Advisory Board of the TNA.

The National Guideline Clearinghouse™

The National Guideline Clearinghouse™ offers hundreds of evidence-based clinical practice guidelines published in the United States and other countries. You can search their site located at **http://www.guideline.gov** by using the keyword "trigeminal neuralgia" or synonyms. The following was recently posted:

- **Guidelines for outpatient prescription of oral opioids for injured workers with chronic, noncancer pain.**

  Source: Washington State Medical Association/Washington State Department of Labor and Industries.; 2000 May 1; 17 pages

  http://www.guideline.gov/FRAMESETS/guideline_fs.asp?guideline=001835&sSearch_string=Trigeminal+Neuralgia

- **The management of chronic pain in older persons.**

  Source: American Geriatrics Society.; 1998 October

  http://www.guideline.gov/FRAMESETS/guideline_fs.asp?guideline=001113&sSearch_string=Trigeminal+Neuralgia

The NIH Search Utility

After browsing the references listed at the beginning of this chapter, you may want to explore the NIH Search Utility. This allows you to search for documents on over 100 selected Web sites that comprise the NIH-WEB-SPACE. Each of these servers is “crawled” and indexed on an ongoing basis. Your search will produce a list of various documents, all of which will relate in some way to trigeminal neuralgia. The drawbacks of this approach are that the information is not organized by theme and that the references are often a mix of information for professionals and patients. Nevertheless, a large number of the listed Web sites provide useful background information. We can only recommend this route, therefore, for relatively rare or specific disorders, or when using highly targeted searches. To use the NIH search utility, visit the following Web page: **http://search.nih.gov/index.html**.

Additional Web Sources

A number of Web sites that often link to government sites are available to the public. These can also point you in the direction of essential information. The following is a representative sample:

- AOL: **http://search.aol.com/cat.adp?id=168&layer=&from=subcats**
- drkoop.com®: **http://www.drkoop.com/conditions/ency/index.html**
- Family Village: **http://www.familyvillage.wisc.edu/specific.htm**
- Google: **http://directory.google.com/Top/Health/Conditions_and_Diseases/**
- Med Help International: **http://www.medhelp.org/HealthTopics/A.html**
- Open Directory Project: **http://dmoz.org/Health/Conditions_and_Diseases/**
- Yahoo.com: **http://dir.yahoo.com/Health/Diseases_and_Conditions/**
- WebMD®Health: **http://my.webmd.com/health_topics**

Vocabulary Builder

The material in this chapter may have contained a number of unfamiliar words. The following Vocabulary Builder introduces you to terms used in this chapter that have not been covered in the previous chapter:

Anticonvulsant: An agent that prevents or relieves convulsions. [EU]

Carbamazepine: An anticonvulsant used to control grand mal and psychomotor or focal seizures. Its mode of action is not fully understood, but some of its actions resemble those of phenytoin; although there is little chemical resemblance between the two compounds, their three-dimensional structure is similar. [NIH]

Chronic: Persisting over a long period of time. [EU]

Clonazepam: An anticonvulsant used for several types of seizures, including myotonic or atonic seizures, photosensitive epilepsy, and absence seizures, although tolerance may develop. It is seldom effective in generalized tonic-clonic or partial seizures. The mechanism of action appears to involve the enhancement of gaba receptor responses. [NIH]

Cranial: Pertaining to the cranium, or to the anterior (in animals) or superior (in humans) end of the body. [EU]

Facial: Of or pertaining to the face. [EU]

Glycerol: A trihydroxy sugar alcohol that is an intermediate in carbohydrate and lipid metabolism. It is used as a solvent, emollient, pharmaceutical agent, and sweetening agent. [NIH]

Lip: Either of the two fleshy, full-blooded margins of the mouth. [NIH]

Neuralgia: Paroxysmal pain which extends along the course of one or more nerves. Many varieties of neuralgia are distinguished according to the part affected or to the cause, as brachial, facial, occipital, supraorbital, etc., or anaemic, diabetic, gouty, malarial, syphilitic, etc. [EU]

Oral: Pertaining to the mouth, taken through or applied in the mouth, as an oral medication or an oral thermometer. [EU]

Phenytoin: An anticonvulsant that is used in a wide variety of seizures. It is also an anti-arrhythmic and a muscle relaxant. The mechanism of therapeutic action is not clear, although several cellular actions have been described including effects on ion channels, active transport, and general membrane stabilization. The mechanism of its muscle relaxant effect appears to involve a reduction in the sensitivity of muscle spindles to stretch. Phenytoin has been proposed for several other therapeutic uses, but its use has been limited by its many adverse effects and interactions with other drugs. [NIH]

Recurrence: The return of a sign, symptom, or disease after a remission. [NIH]

Remission: A diminution or abatement of the symptoms of a disease; also the period during which such diminution occurs. [EU]

Vascular: Pertaining to blood vessels or indicative of a copious blood supply. [EU]

CHAPTER 2. SEEKING GUIDANCE

Overview

Some patients are comforted by the knowledge that a number of organizations dedicate their resources to helping people with trigeminal neuralgia. These associations can become invaluable sources of information and advice. Many associations offer aftercare support, financial assistance, and other important services. Furthermore, healthcare research has shown that support groups often help people to better cope with their conditions.[8] In addition to support groups, your physician can be a valuable source of guidance and support. Therefore, finding a physician that can work with your unique situation is a very important aspect of your care.

In this chapter, we direct you to resources that can help you find patient organizations and medical specialists. We begin by describing how to find associations and peer groups that can help you better understand and cope with trigeminal neuralgia. The chapter ends with a discussion on how to find a doctor that is right for you.

Associations and Trigeminal Neuralgia

As mentioned by the Agency for Healthcare Research and Quality, sometimes the emotional side of an illness can be as taxing as the physical side.[9] You may have fears or feel overwhelmed by your situation. Everyone has different ways of dealing with disease or physical injury. Your attitude, your expectations, and how well you cope with your condition can all

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[8] Churches, synagogues, and other houses of worship might also have groups that can offer you the social support you need.

[9] This section has been adapted from **http://www.ahcpr.gov/consumer/diaginf5.htm**.

influence your well-being. This is true for both minor conditions and serious illnesses. For example, a study on female breast cancer survivors revealed that women who participated in support groups lived longer and experienced better quality of life when compared with women who did not participate. In the support group, women learned coping skills and had the opportunity to share their feelings with other women in the same situation.

In addition to associations or groups that your doctor might recommend, we suggest that you consider the following list (if there is a fee for an association, you may want to check with your insurance provider to find out if the cost will be covered):

- **American Pain Society**

  Address: American Pain Society 4700 West Lake Avenue, Glenview, IL 60025-1485

  Telephone: (847) 375-4715

  Fax: (847) 375-4777

  Email: info@ampainsoc.org

  Web Site: http://www.ampainsoc.org

  Background: The American Pain Society (APS) is a not-for-profit organization dedicated to serving people in pain by advancing research, education, treatment, and professional practice. Established in 1978, APS recognizes that its goals can best be accomplished by a joint and interactive effort among basic scientists and health care professionals. APS consists of 3,200 members and six chapters in the United States. Educational materials include a quarterly journal called 'Pain Forum,' a pamphlet entitled 'American Pain Society,' and a directory entitled 'Pain Facilities Directory.' The Society also conducts an annual Scientific Meeting. APS maintains a web site at http://www.ampainsoc.org.

  Relevant area(s) of interest: Reflex Sympathetic Dystrophy Syndrome, Trigeminal Neuralgia

- **Rombergs Connection**

  Address: Rombergs Connection 4106 West 87th Street, Chicago, IL 60652

  Telephone: (773) 838-1243

  Email: rombergs@hotmail.com

  Web Site: http://www.geocities.com/HotSprings/1018/

  Background: The Rombergs Connection is a self-help group dedicated to locating individuals and families whose lives are affected by Parry-Romberg Syndrome and offering appropriate support. This is