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A Voice for People with Migraine and Headache Disorders
From the National Headache Foundation

Game Changer

Miami Heat forward
James Jones brings
migraine awareness
to the NBA

Lights Out
"Boxer's disease" leads
to headache, dementia

Give And Take
The tradeoffs of
migraine prevention

4

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If you think a headache is just a headache, think again. Millions of Americans suffer from migraines, cluster headaches and other serious headache disorders. Chances are, headache disorders affect you or someone you love.

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and help advance headache advocacy,
education and research



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or call 1-888-NHF-5552.

FEATURES

24

The Downward Spiral of Chronic Traumatic Encephalopathy

Once dubbed the boxers' disease, this degenerative condition is creating havoc and headaches among athletes and soldiers.

30

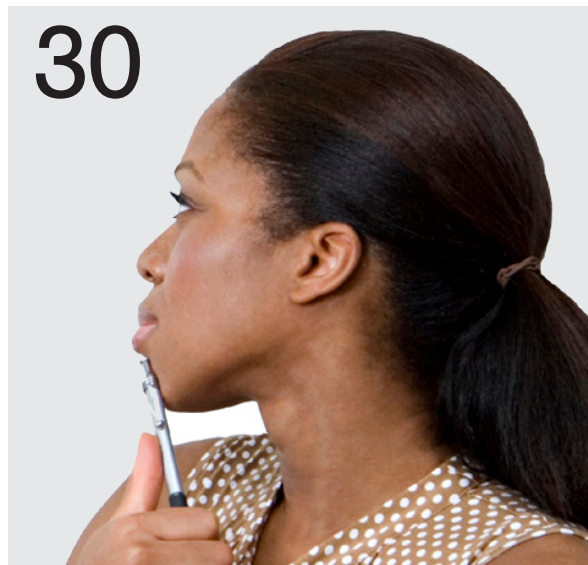
The Upsides and Downfalls of Topiramate

It is now considered one of the most effective preventive treatments for episodic migraine. But topiramate comes with both benefits and risks.

36

Bringing the Heat

NBA superstar James Jones discusses the migraine that kept him out of Game 1 of the 2012 Playoffs and why it's important for male athletes to talk about the condition.



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Mission

The National Headache Foundation exists to enhance the healthcare of individuals with headache. It is a source of help to their families, physicians and allied healthcare professionals who treat them, and to the public. The NHF accomplishes its mission by providing educational and informational resources, supporting headache research, and advocating for the understanding of headache as a legitimate neurobiological disease.

Vision

The National Headache Foundation is the premier educational and informational resource for individuals with headache, their families, physicians, allied healthcare professionals, and health policy decision makers. The NHF advocates for those experiencing headache. The organization employs the most effective means to disseminate information and knowledge about headache.

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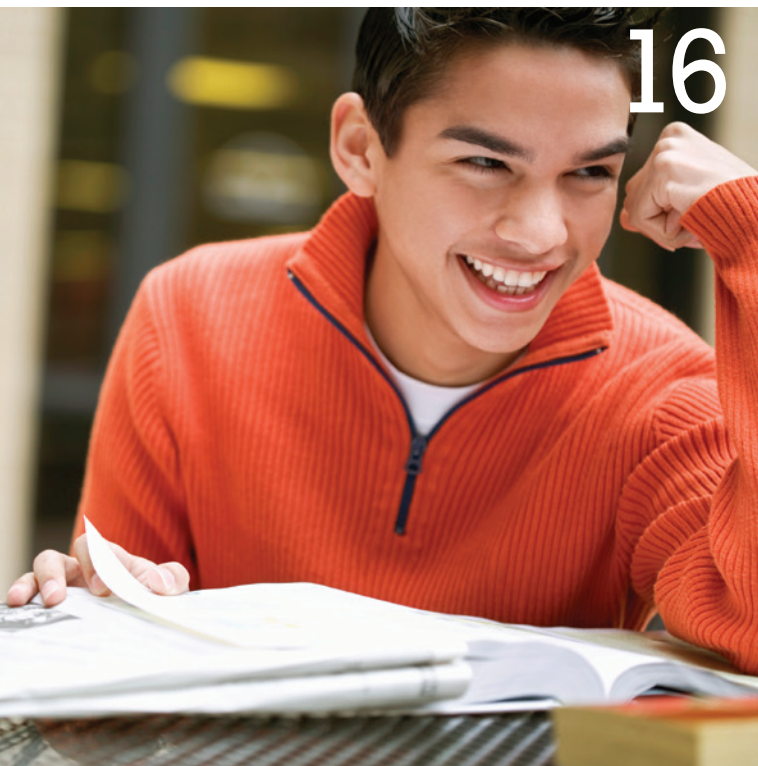
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IN EVERY ISSUE

- 4 NHF news**
Learn what's happening in and around the National Headache Foundation.
- 6 reader mail**
You ask. We answer. Get expert advice from leaders in the field.
- 9 book review**
Knock Out Headaches Vincent Martin, MD, reviews *Knock Out Headaches*, a new book written by Gary Ruoff, MD.

- 10 research**
Find the latest information on neurostimulators, migraine prevention and how headache is portrayed in popular music.
- 13 ask the pharmacist**
See what our expert has to say about emergency room treatments.
- 40 wise words**
Read how migraine and headache sufferers are living life to the fullest.



DEPARTMENTS

- 14 invisible wounds**
REPEAT CONCUSSIONS SIDELINE SOLDIERS
When military servicemen and women endure multiple concussions, the neurological damage and related headaches can be serious and long-lasting.
- 12 know your trigger**
HOW SLEEP DISORDERS IMPACT HEADACHE
Learn about four sleep disorders that are tied to headache—plus find five tips for better rest.
- 16 kids' korner**
WHEN HEADACHES DON'T GO AWAY
A. David Rothner, MD, describes chronic daily headache's impact on children and programs for rehabilitation.
- 22 self help**
HOW TO ORGANIZE YOUR MEDICAL HISTORY
A clear picture of your medical history can help you get the most from your physician visit.

COVER PHOTOGRAPHY BY JOSHUA PREZANT



DID YOU KNOW?

Migraineurs have taken to YouTube in recent years to help their friends and family understand visual aura. The video forum now contains multiple amateur simulations of aura, from videos demonstrating tunnel vision to clips with flashing lights and scintillating scotoma. Visit YouTube.com today and search for "migraine aura simulation."

The Bruxism Connection

On a recent visit to an oral surgeon for a dental extraction, I had an interesting discussion about the condition known as bruxism. The word “bruxism” is derived from the Greek word “bruch,” which means “to grind the teeth.” It is described as a clenching of the teeth, which is associated with forceful or jutting jaw movements. These actions result in rubbing, gritting or grinding together of the teeth, usually during sleep.

While I waited for the local anesthetic to start deadening my nerves, the oral surgeon inquired about my earlier career in headache medicine. I explained that I had done original work with the tricyclic antidepressant amitriptyline for somatic disorders and eventually continued my research with amitriptyline and chronic headaches.



To my surprise, the oral surgeon remarked that he and numerous dentists, for many years, had successfully treated bruxism with amitriptyline.

Following the procedure and while recovering at home, I did some research and noted several citations in the scientific literature on the use of amitriptyline in other disorders, including temporomandibular joint dysfunction (TMJ). Amitriptyline and other tricyclic antidepressants have served as a source of relief over the years for many headache and headache-related disorders. The effectiveness of the tricyclic antidepressants may be due to their actions on the serotonin receptors. It is refreshing to know that some old standard therapies are still acknowledged for their efficacy.

—Seymour Diamond, MD
Executive Chairman and Founder

Volunteer as a Patient Advocate

Headache disorders are one of the most pervasive neurological issues seen by health care professionals worldwide. According to the World Health Organization, tension-type headaches alone affect about 70 percent of adult males and 80 percent of adult females.

In contrast, the National Headache Foundation (NHF) has just six employees and 13 board members. To bridge this numbers gap and connect with the millions of headache sufferers who are desperate for information about the spectrum of headache disorders, the NHF is calling on community-based volunteerism (or patient advocates).

“Migraine impacts the community as a whole, whether through lost time as a parent, spouse or friend, or loss of profits from a sick employee,” says Heather Zanitsch, St. Louis patient advocate coordinator for the NHF. “I would like to see the community work with migraineurs peacefully instead of rolling their eyes every time someone must necessarily ‘complain’ of an attack and go home to rest or wait for their medications to take effect.”

The NHF is looking for more volunteers to help spread the word about headache disorders. This can include helping at patient education

events, working with insurance companies or reaching out to headache sufferers with positive support and encouragement.

“I think it’s important to build a relationship with the public that is geared toward patients as active participants in their own care and knowledge,” Zanitsch says. “That’s what we need—a patient base that stands firm in their knowledge of what they are dealing with.”

If you want to become an NHF patient advocate, contact the NHF at (888) NHF-5552 or e-mail info@headaches.org.

2013 Benefit: Fête de Masque

The National Headache Foundation (NHF) will host its twenty-seventh annual fundraising benefit, Fête de Masque, Saturday, May 4, 2013, at the Ritz-Carlton (160 E. Pearson St., Chicago, Ill.). The benefit will include a raffle as well as live and silent auctions.

If you would like to attend, contribute an auction item or volunteer, please contact the NHF at 312-274-2670 or e-mail info@headaches.org.

Chat with a Headache Specialist

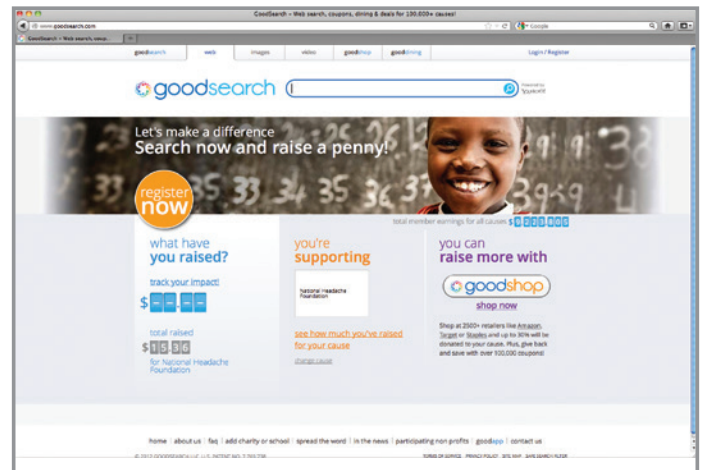
The NHF is hosting several live chats in 2012, offering members and visitors to the NHF website a chance to interact with headache specialists online. Since the first chat in December 2011, NHF has hosted more than 15 live chats on topics such as hormones and headache, post-concussion headache, depression and headache, and more.

Each chat is assigned a topic and a headache specialist who answers questions in real time. To see a list of upcoming chats and to register, visit the NHF website at www.headaches.org/content/nhf-webinars. On that page you will also find links to transcripts and podcasts from previous chat rooms. If you have ideas for new chat topics, send an e-mail to info@headaches.org.



Helping Hand

If you or someone you love has a headache disorder and doesn't know where to turn, try the NHF Physician Finder at www.headaches.org/physicians. The database allows headache sufferers to search for a headache specialist by name, location or certification.



Search and Rescue

You already spend a good portion of your day online. Why not make it count? GoodSearch.com can help you turn your everyday searches and shopping sprees into donations to the NHF—or any other nonprofit organization you wish to support.

GoodSearch is a Yahoo-powered search engine that donates half of its sponsored search revenue to user-designated charities, nonprofit organizations or schools. It works just like any other search engine, and it is free for users.

All you have to do is visit the GoodSearch home page and select the NHF as your favorite cause. Then, whenever you search or shop online, 50 percent of the revenue generated by sponsored search advertisers will go to the organization.

Turn your searches into NHF donations at www.goodsearch.com.



Tired of searching the Internet for answers? It's time to learn from those in the know. In every issue of *Head Wise*, our experts respond to reader-submitted questions about migraine and headache disorders.

SENSE AND SENSITIVITY

Many of my migraines will last days, even with medication. After the pain has subsided, I will have soreness all the way down the side of my face, neck and back. Does that mean I'm really having tension-type headaches? What can I do to stop the soreness?

—Lori N.

It sounds like you are probably experiencing what is called “allodynia.” Cutaneous allodynia is hypersensitivity to touch or temperature, a common condition that may feel like skin, scalp or muscle soreness. Given the muscle factor, I understand why you would think it's due to tension-type headache; but this soreness is more often the result, not the cause, of a headache attack. This sensitivity is seen in some patients with a chronic tension-type headache but is more frequently a component of migraine. Following a severe migraine, many patients will often report discomfort from

pressure applied to the head and neck, and some even complain of their hair or teeth hurting.

I look at migraine as a three-stage process: Stage 1 of migraine responds nicely and completely to medication; Stage 2 is more severe, with medication providing significant relief of the headache without clearing it completely; and Stage 3 is when nothing you do will turn off the migraine and it just needs to run its course and burn out. Once the migraine has hit Stage 3, as you mentioned, it will go on for days and you may be left with soreness. The longer the headache lasts and the more intense it is, the more soreness you will experience. Instead of your muscles being sore from running, a brain workout generally manifests as hypersensitivity of the nerves and soreness of skin and muscles connected to those nerves. This most often happens in the face and neck, but can sometimes extend down into the limbs.

You want to be aggressive with treatment if you're a person who can get an attack lasting several days. It's imperative that you catch your migraine within one or two hours with fast-acting, strong migraine medication. If you can, go with migraine-specific medication like injectable triptans. In such situations, a combination of a migraine medication and a nonsteroidal anti-inflammatory drug (NSAID) can often be helpful in aborting the migraine.

—Robert G. Kaniecki, MD, University of Pittsburgh, Pittsburgh

SEEING RED

My boyfriend has been having migraines for the past three years and finally went to the emergency room (ER). The ER physicians did a computed tomography (CT) scan and found a cyst on his brain. After many visits to all kinds of physicians, they told him it wasn't the cyst that was causing the migraines—but it's funny that he never had migraines until that cyst popped up. His headaches

The National Headache Foundation has a list of headache specialists who may be of help. See www.headaches.org or call 888-NHF-5552.

are so bad that his left eye becomes blood-red (not bloodshot, I mean real blood covering the white part) and then the skin under his eye turns black, yellow and green. Why is this happening and what can he do for his migraines? He has tried all kinds of medications and they haven't helped.
—Jennifer D.

It is important to know that the definitive brain imaging technique is magnetic resonance imaging (MRI), rather than the CT scan. There is a huge difference in the accuracy of these techniques, and important decisions should not be made because of a single CT scan.

Because a CT scan was performed in response to the headaches, there is no way of knowing whether the cyst appeared at the same time as the headaches (unless there was prior testing). Many people are born with cystic changes in the brain, and the term “cyst” could mean many things. For example, an area of the brain that was damaged at birth is known as a porencephalic cyst, where there is an absence of brain matter and the space is filled with cerebrospinal fluid. Cystic structures in the brain are not uncommon and usually do not cause headache. One type of cyst that might cause headache is known as an arachnoid cyst, but only if it is expanding and exerting pressure on the brain itself. Small arachnoid cysts are a common incidental finding and do not require treatment unless they change in size. They need to be monitored over time. Again, without knowing the details of the cyst, additional testing such as MRI and magnetic resonance angiogram (MRA) might be helpful.

It is not entirely clear by your description, but one type of headache that produces extreme redness in the eye is known as Short-lasting Unilateral Neuralgiform headache attacks with Conjunctival injection and Tearing (SUNCT syndrome). These are very brief attacks and are accompanied by tearing and redness, but that would not explain changes in the skin below the orbit. At this point, a careful neurological evaluation with appropriate testing would be in order. Unusual headache patterns are best treated by headache specialists who are certified in headache medicine.

—Edmund Messina, MD, Michigan Headache Clinic, East Lansing, Mich.

DAILY DISTRESS

Is there any hope at all for someone with a diagnosis of hemicrania continua? The pain never stops and I discovered I'm allergic to indomethacin, the typical treatment. What can I do?

—Anthony T.

Hemicrania continua is an ongoing, one-sided headache that is sometimes accompanied by watery eyes, a runny nose, etc. It is certainly difficult to treat someone with hemicrania continua when the use of indomethacin is not an option. However, we have treated some people successfully using celecoxib (e.g., Celebrex®), topiramate (see page 30), or verapamil (e.g., Covera®). Some have responded to onabotulinumtoxin A (Botox®) and some improved with C2-C4 medial branch and facet nerve blocks. You should discuss these options with a headache specialist.

—Mark Green, MD, Mount Sinai School of Medicine, New York City

“WHAT IS THERE LEFT TO DO?”

I am 29 years old and have suffered with migraines since 1995. I also started experiencing fibromyalgia two years ago. Around 2001 during my senior year of high school, the migraines became daily, and I am still experiencing daily migraine. They are throbbing and aching, located in the forehead and temples, and sometimes make me nauseous. I have seen three headache specialists and four neurologists. I've taken dozens of different preventive and abortive medications with no relief; most recently I was on Zonigran® (zonisamide), Lyrica® (pregabalin), and nadolol for migraine prevention. I have also tried Botox® (onabotulinumtoxin A) and nerve blocks without success. What is there left to do? I feel absolutely debilitated.

—Jackie S.

It is common for migraine and fibromyalgia to coexist in many patients. Although the majority of chronic migraineurs can gain at least some relief from onabotulinumtoxin A injections, a good number of people do not respond.

I am a strong believer in carefully evaluating migraineurs in the context of their other medical conditions. The approach to chronic headaches must include careful evaluation of behavioral problems such as anxiety and depression, sleep disorders such as sleep apnea (see page 12), and other conditions, including systemic illness such as autoimmune diseases and connective tissue disorders. Everything is important.

Patients commonly tell me that, when it comes to medication, they've been on "everything." It is important to know whether those treatments matched the headache diagnosis. We also need to know whether the optimal dose of an appropriate medication was used for an adequate length of time, whether appropriate medications were used in synergistic combinations, or whether certain combinations of medications actually neutralized each other or produced side effects that led to their discontinuation. Often, medications are switched too quickly, before the medication has had a chance to work. It sometimes takes many weeks to know whether the medication will be beneficial. Keep at it, and don't give up!

—Edmund Messina, MD, Michigan Headache Clinic, East Lansing, Mich.

A CHILLING EFFECT

I take Premarin® (conjugated estrogen tablets) for post-menopausal reasons. I've had pre-menstrual migraines throughout my adulthood while menstruating. Recently I took Premarin before bedtime and woke up the next morning with a severe migraine and cold sweats, followed by uncontrollable nausea. Could the Premarin have triggered a migraine? Why am I having cold sweats?

—Linda J.

Migraines are often made worse by fluctuations in estrogen levels. Estrogen levels drop before menstruation, triggering migraines in some women. This

is not the case in all women, but two out of three women stop having migraines after menopause when estrogen levels drop and remain stable. Taking Premarin causes estrogen levels to fluctuate again, resulting in recurrence of migraines. According to the manufacturer, 26 percent of women taking 0.625 mg of Premarin have headaches as a side effect. Cold sweats and nausea are also known side effects of Premarin.

—Alexander Mauskop, MD, New York Headache Center, New York, N.Y.

GOING OVERBOARD?

My 79-year-old mother has been experiencing severe headaches for 11 years. My theory is that she is addicted to paracetamol (an acetaminophen). She takes six to eight each day and has done so as long as I can remember. She gets the shakes when she is due for the tablets and, if she misses a dose, the headache completely consumes her. Her physician is happy to have her continue with the paracetamol as he says it is harmless, but I'm not so sure that she should be taking it this regularly and for an incredible length of time. Could she be suffering from medication overuse headache? If so, what can we do to help her?

—Julia W.

When someone has medication overuse headache, the longer it exists, the harder it is to treat. With paracetamol, we also worry about its effects on the liver.

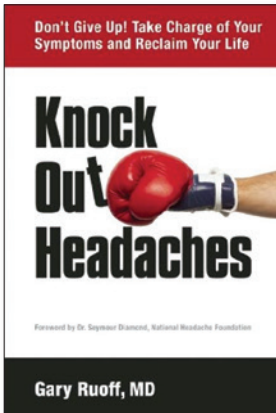
There are various strategies for substituting a preventive headache medication for overuse of an acute headache medication. It often requires hospitalization, and it's always a long, deliberate process that needs to be done under the care of a headache specialist.

—Mark Green, MD, Mount Sinai School of Medicine, New York City



Do you have a question or comment for NHF? Send it to info@headaches.org.

Knock Out Headaches



The book *Knock Out Headaches*, written by Gary Ruoff, MD, is a “must read” for individuals who suffer from migraine.

Dr. Ruoff is a primary care physician who has spent more than 30 years caring for patients with migraine. He takes a primary care approach

to headaches in this book, discussing not only their management, but also modification of lifestyle habits, the importance of correct posture and treatment of other disorders that often co-occur in headache patients. Such a “holistic” approach to the management of headache makes this book unique among educational books about headache disorders.

The book is particularly well written and easily understandable to the lay reader. It is divided into interesting chapters with titles to which the reader can relate. For example, one of the chapters is entitled, “Not all headaches are created equal” and another is entitled, “The patient-doctor partnership.” Throughout the book Dr. Ruoff empowers the patient with information that will enable them to get their headaches under control. He stresses the importance of the doctor-patient relationship and the need for the patient to take an active role in the management of their headaches.

The book also contains “real life” stories of patients who have encountered headaches and how they have tried to manage them. These stories will connect with patients and make the book more interesting and readable. The tables and figures are excellent and serve to illustrate important concepts raised in the text of the book. Overall, I was quite impressed with this book and would recommend it

for any patient who is having problems controlling their headaches. Dr. Ruoff has truly hit a home run with this book or in his words “knocked out headaches.”

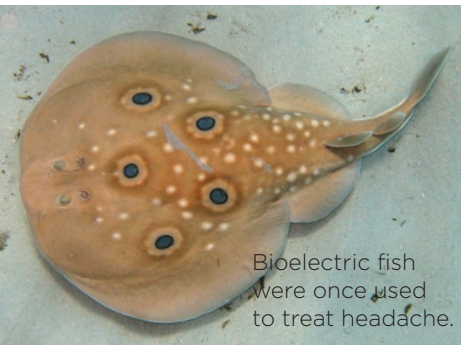
VINCENT T. MARTIN, MD, is professor of medicine at the University of Cincinnati College of Medicine and vice president of the National Headache Foundation.

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Portable Neurostimulation on the Horizon?

By Jackie Walker Gibson



Bioelectric fish were once used to treat headache.

IN 46 AD, Scribonis Largus (court physician to the Roman emperor Claudius) wrote that he could “permanently cure” a headache through the use of bioelectric fish placed on the area of pain. Today, electricity is used to reduce head pain through a procedure called neurostimulation.

That procedure typically involves surgery in a physician’s office. But a new trial could turn neurostimulation into an affordable, at-home treatment for migraine relief.

HEADACHE AND PAIN SIGNALS

Neurostimulation for headache involves sending electrical impulses through the nerves to affect the signals those nerves send to the brain. The thinking behind the procedure is that if you can stop the nerves from sending pain signals or if you can change the way the brain processes those signals, then you can stop the feeling of pain. Since its introduction to the headache world in 1977, neurostimulation has been used to reduce the pain associated with cluster headache, migraine and other headache conditions.

Neurostimulation comes in many forms, depending on the area of the body that is stimulated. For example:

- **Percutaneous electrical nerve stimulation** involves insertion of needle probes into the skin.
- **Transcranial holocephalic stimulation** involves the use of electrodes placed about the skull.
- **Peripheral nerve stimulation** involves the applica-

tion of electrical impulses to branches of afferent nerves, which conduct sensory neurons.

- **Vagal nerve stimulation** involves wrapping an electrode around the vagus nerve in the neck.
- **Occipital nerve stimulation** involves the application of electrical impulses over the occipital nerves, located in the spine in the upper neck.
- **Deep brain stimulation** involves placement of electrodes through the skull, into structures in the brain.^{1,2}

Because neurostimulation usually involves surgery—and because surgery always carries risks—headache specialists generally advise that individuals with headache only use neurostimulation as a last resort.

A PORTABLE BREAKTHROUGH?

A new clinical trial, which began in Summer 2012 at the University of Kent, seeks to change the need for invasive surgery as part of neurostimulation. The researchers hope to discover a type of neurostimulation device for migraine that would be portable and cheaply manufactured.³

“Over the last 30 years, numerous acute and preventive therapies for headache and migraine have evolved,” says Seymour Diamond, MD, executive chairman of the National Headache Foundation and founder and director emeritus of the Diamond Headache Clinic. “It should be noted that there is a subset of patients who are resistant or not helped by these ‘welcome’ innovations. Personally, I applaud and am hopeful that newer treatments, such as portable neurostimulators, will provide relief to these recidivist patients.” **HW**

1. Jenkins et al. “Neurostimulation for Primary Headache Disorders, Part 1: Pathophysiology and anatomy, History of Neuromodulation in Headache Treatment, and Review of Peripheral Neuromodulation in Primary Headaches.” *Headache*. 2011;51:1254-1266.
 2. Jenkins et al. “Neurostimulation for Primary Headache Disorders, Part 2: Review of Central Neurostimulators for Primary Headache, Overall Therapeutic Efficacy, Safety, Cost, Patient Selection, and Future Research in Headache Neuromodulation.” *Headache*. 2011;51:1408-1418.
 3. ScientistLive. “US-Kent Research Aims to Find a New Treatment for Migraine.” www.scientistlive.com/European-Science-News/Drug_Discovery/US-Kent_research_aims_to_find_a_new_treatment_for_migraine/25640/

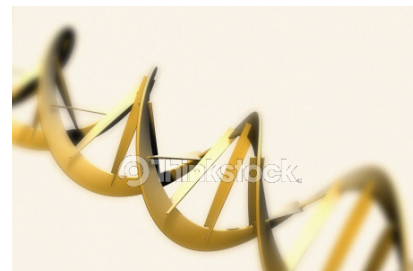
RESEARCHERS EXAMINE AGENTS RESPONSIBLE FOR MIGRAINE

It's an ever-frustrating issue: Migraine researchers have never been able to pin down the true cause of migraine. Yet year after year, researchers continue to look into the agents responsible for the condition. Two possible triggers, a migraine gene and a brain chemical, have received added attention in recent months as researchers focus on their contributions to migraine pain.

Researchers once thought the restriction of blood vessels triggered migraine, leading many to believe migraine was a vascular disorder. Today, many believe that migraine has far more to do with the brain than the blood vessels, pointing to the dysfunction of pain signals or to cortical spreading depression (see page 32). Two neurotransmitters—substance P and calcitonin gene-related peptide neurotransmitter (CGRP)—could also be responsible for activating pain signals in the brain.¹ CGRP made headlines recently when *The Wall Street Journal* covered its contributions

to migraine. According to the newspaper, several companies are conducting studies to develop drugs that could prevent CGRP from triggering pain.²

In addition to this chemical, a potential “migraine gene” has also made headlines in recent months. In June 2012, Finnish researchers at the Institute for Molecular Medicine Finland and Wellcome Trust Sanger Institute reported they had discovered four new genes that predispose people to migraine without aura and had confirmed the implication of two other genes previously thought to play a role. The study, published in the June issue of the journal *Nature Genetics*, compared the genetic data of 4,800 migraineurs to 7,000 non-migraineurs.³ The gene identification could bring researchers one step closer to understanding the basis for migraine.



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1. Nicolodi et al. “Sensory Neuropeptides (Substance P, Calcitonin Gene-related Peptide) and Vasoactive Intestinal Polypeptide in Human Saliva: Their Pattern in Migraine and Cluster Headache.” *Cephalalgia*. 1990;10(1):39-50.
 2. Wang. “Fresh Target in Hunt for a Migraine Cure.” *The Wall Street Journal*. Aug. 7, 2012.
 3. Isau.de.net. “Researchers Found Four Gene Loci Predisposing People to the Most Common Migraine.” Nov. 6, 2012.
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Switch Triptans to Relieve Headaches?

Maybe your insurance company only allows you to use a specific triptan, or your physician wants to try supplementing your triptan prescription with a nonsteroidal anti-inflammatory drug (NSAID) to see if you improve. Whatever the reason, many migraineurs switch from one triptan to the next or take a combination of medications to treat their head pain. But does it help?

Richard B. Lipton, MD, and Dawn C. Buse, PhD, of the Albert Einstein College of Medicine in New York recently explored this question. They reviewed data from the American Migraine Prevalence and Prevention study, which was sponsored by the National Headache Foundation. The researchers discovered:

- Switching from one triptan to another triptan did not improve headache disability.
- Switching from a triptan to an NSAID, opioid or barbiturate worsened headache disability for people with high-frequency episodic migraine or chronic migraine.
- Adding an NSAID to a triptan worsened headache disability for people with high-frequency episodic migraine or chronic migraine.
- Switching medication regimens had less of an impact on people with low-frequency episodic migraine or moderate-frequency episodic migraine.¹

This may sound discouraging to people with high-frequency episodic migraine, for whom triptans are not working. However, physicians who attended the annual American Headache Society meeting where the results were released noted that all triptans are not created equal and some patients may find headache relief by switching medications.

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1. London. “Studies Examine Scenarios of Changing Triptan Regimens.” *Family Practice News*. July 3, 2012.

How Sleep Disorders Impact Headache

Sleep complications could trigger headache attacks during or following a night's rest.

“SLEEP IS NATURE’S WAY of treating almost any headache disorder,” Roger Cady, MD, said in a recent National Headache Foundation chat room.

But what happens to that headache disorder when sleep is disrupted by insomnia, fidgety legs or difficulty breathing?

Just as painful headaches can keep a person awake at night, a lack of sleep or disrupted sleep can trigger headaches. To achieve better sleep and decrease associated headaches, it is important to first understand the underlying sleep disorders that could be triggering your headaches.



4 SLEEP DISORDERS THAT TRIGGER HEADACHE

Research shows that many common sleep disorders are associated with headaches:

- **INSOMNIA** is considered a risk factor for tension-type headache. Research suggests this is also a bidirectional phenomenon: the pain of a tension-type headache or the use of sleep at odd hours to relieve a headache could keep sufferers from sleep at nighttime; conversely, that inability to sleep at regular intervals could lead to new headaches.
- **PARASOMNIAS**, characterized by events during sleep that do not disrupt sleep (e.g., snoring, sleep-walking and sleep-talking), are more common among children with migraine and headache than children who do not experience headache. This connection has been

observed, though researchers have not yet studied the reasoning behind this connection.

- **RESTLESS LEGS SYNDROME**, characterized by a crawling or fidgety sensation in the legs during rest, is more prevalent among migraineurs. Researchers have proposed a number of theories for this connection, blaming the relationship on iron deficiency or comorbidity with depression, among other aggravating factors.
- **OBSTRUCTIVE SLEEP APNEA** involves the collapse and obstruction of airways during sleep. People with sleep apnea frequently complain of morning headaches and, rarely, of headaches during sleep. But research suggests the condition could also trigger cluster headache; chronic paroxysmal hemicrania, a severe, frequent, one-sided headache and hypnic headache, a regular headache that may awaken the sufferer from sleep and generally affects elderly people.

For people with sleep disorders and headache, treating the underlying sleep disorder could help improve an associated headache condition. **HW**

5 TIPS FOR BETTER SLEEP

1. Schedule eight hours in bed every night and commit to a regular bedtime.
2. Turn off devices at least one hour before bed.
3. Avoid eating within four hours of bedtime.
4. Don't sleep in.
5. Treat sleep disorders.

1. Mitsikostas et al. "Sleep and Headache: The Clinical Relationship." *Headache*. 2010;50(7):1233-1245.

Emergency Treatment

Q What kind of treatment can I expect from the ER?

HEADACHE IS THE FIFTH most common reason for a visit to the emergency department, and migraine is the most frequent headache diagnosis made in the emergency room (ER).¹ In fact, 6 percent of Americans with migraine visit an ER annually for migraine-related pain or complications. Of that 6 percent, one-third visit the ER two or three times a year and one-fifth visit four or more times per year.²

Emergency physicians are not the ultimate resource for long-term headache management. It is best to discuss headaches with your primary care provider or schedule an appointment with a headache specialist who has more training and daily experience helping patients with difficult-to-treat headache disorders. That said, if your physician is not available, the ER is a reasonable place for expedited diagnosis and treatment, particularly if you're experiencing a thunderclap headache (the most sudden and intense headache you've ever experienced) or severe headache with fever (which could be indicative of a ruptured aneurysm or meningitis).

It is common practice in the emergency room to administer intravenous (IV) fluids for acute migraine. The nausea and vomiting that accompany migraine often dehydrates the patient. Plus, IVs just seem to make patients feel better.

To ensure medication is absorbed into your system quickly, an ER physician may administer a drug via an injection, intravenous catheter or rectal suppository. These delivery systems bypass the gastrointestinal tract, which is particularly useful if associated nausea and vomiting are a problem.

Often, emergency physicians will treat headaches with migraine-specific agents such as Imitrex® (sumatriptan), nonsteroidal anti-inflammatory drugs such as Toradol® (ketorolac), and antiemetics

such as Compazine® (prochlorperazine) or Reglan® (metoclopramide), which ameliorate the migraine and treat associated nausea and vomiting.

Demerol® (meperidine) or Dilaudid® (hydromorphone), two types of opioids, are the most commonly used to treat migraine in emergency rooms (they also happen to be the most commonly used opioids in general). However, some emergency physicians are reluctant to use these as a primary option for fear of exacerbating the underlying headache disorder.³ Opioids are also highly addictive.

Occasionally, patients who require stronger medication (such as opioids) may clash with their emergency physician over this issue. For this reason, people who experience frequent headaches and may need to visit the ER should maintain strong relationships with their primary care physicians or headache specialists. Those physicians can advocate for patients in these situations.

Keep in mind that if your headaches are so severe that you are making regular visits to the ER, it is time to see a headache specialist for a more proactive treatment plan that addresses both preventive and abortive means.

If you do need to go to the ER, alert your headache specialist that you are going. The specialist can advise the ER physicians about which medications work for you. It may also be worthwhile to have your physician help you create a contract documenting your headache history and detailing your treatment plan and goals so that you can take that information with you to the ER. These actions should help decrease the scrutiny you might otherwise receive. **HW**

BENJAMIN W. FRIEDMAN, MD, MS, FAAEM, is associate professor of emergency medicine at Montefiore Medical Center and the Albert Einstein College of Medicine in the Bronx, NY.

1. Evans et al. "Headache in the Emergency Department." *Headache*. 2011;51(8):1276-1278.

2. Friedman et al. "Use of the Emergency Department for Severe Headache. A Population-based Study." *Headache*. 2009;49(1):21-30.

3. Vinson. "Treatment patterns of isolated benign headache in U.S. emergency departments." *Annals of Emerging Medicine*. 2002;39(3):215-222.

Repeat Concussions Can Sideline Soldiers

When the risks are this high, prevention and recovery are of utmost importance.



IN THE MILITARY, a concussion can temporarily keep a soldier out of a war zone. When that concussion is followed by another concussion, the effects can be devastating.

Concussion is one of the most common injuries impacting today's military. Among servicemen and women with exposure to combat in Iraq and Afghanistan, 15 to 20 percent experience traumatic brain injury; of those, 85 percent are mild concussions, the result of exposure to blasts.¹

Although likely underreported, repeat concussion (or "cumulative concussion") seems to occur among a smaller segment of the military population. One study found 113 reports of repeat concussion among 14,653 servicemen and women who served in Operation Iraqi Freedom from 2004 to 2008. Among those, 20 percent suffered the second trauma within two weeks of the first; another 87 percent experienced the second

trauma within three months of the first concussion.²

"We are seeing more of this in the military because the head becomes more vulnerable with the type of combat occurring in the world today," says Roger Cady, MD, associate executive chairman of the National Headache Foundation and founder and director of the Headache Care Center, Inc. in Springfield, Mo.

Despite the smaller population, the risks are more significant for individuals who suffer repeat concussions than for those who suffer a singular concussion. Research indicates that recovery is slower, neurological damage is prolonged and susceptibility to additional brain injuries increases after repeat concussions.³ To avoid complications, military servicemen and women must make every effort to avoid concussions and take time to heal after trauma occurs.

FROM CONCUSSION TO CHRONIC HEADACHE

A single concussion can trigger post-concussion headache in the form of tension-type headache, episodic migraine, chronic daily headache or a combination. Those who already had headaches or a family history of headaches prior to trauma are more likely to experience some form of post-concussion headache.

For soldiers who already experience headache, repeat concussions can take an episodic condition and turn it into a chronic, daily problem, says Alan G. Finkel, MD, FAAN, FAHS, a contractor for the Henry Jackson Foundation/Defense and Veterans Brain Injury Center at Fort Bragg, N.C. and co-founder of

1. Rigg and Mooney. "Concussions and the Military: Issues Specific to Service Members." *PM&R*. 2011;3:S380-S386.

2. MacGregor et al. "Repeated Concussion Among U.S. Military Personnel During Operation Iraqi Freedom." *Journal of Rehabilitation Research & Development*. 2011;48(10):1269-1277.

3. Defense and Veterans Brain Injury Center. "Cumulative Concussions." www.dvbic.org/cumulative-concussions

the Carolina Headache Institute.

“Repeat concussions appear to make it more likely that these headaches will become intractable,” Dr. Finkel says.

THE RISK FOR PERMANENT DAMAGE

In addition to extending a headache condition, repeat concussion can also turn other concussion side effects (e.g., memory and concentration deficits, sleep disorders and balance difficulties) into more serious and longer-lasting concerns.

Perhaps even more alarming, repeat concussion can lead to permanent brain damage, including the potential for a progressive degenerative disease called chronic traumatic encephalopathy (CTE). Although CTE was once known as a boxer’s condition and is receiving media attention for its effects on football players, it can affect anyone with multiple head traumas. The condition, which leads to brain atrophy and nerve cell damage, can cause progressive memory and cognition deficits, long-term personality changes, suicidal behavior and dementia.⁴ (Turn to page 24 to learn more about CTE.)

Repeat concussion can also trigger second-impact syndrome (SIS), a rare complication in which the brain swells rapidly, leading to death or severe disability. SIS can develop if a second concussion occurs before symptoms of an earlier one have subsided.

Unfortunately, researchers don’t yet know how many concussions are too many and which concussion might lead to permanent damage. The threshold may vary from person to person, depending on differences in genetics, the environment and the dynamics of the injury, according to Dr. Cady. Uncertainty aside, physicians do agree that prevention and early treatment can help reduce concussion risks.

THE IMPORTANCE OF DOWNTIME

Helmets and protective gear can help reduce the risk of head trauma to an extent. Dr. Finkel suggests it would also be helpful for the military to train soldiers “to avoid situations where head injuries are more prevalent.” But

ultimately, Dr. Finkel and Dr. Cady agree that, given the way wars are fought today, there is really no effective way to prevent a concussion.

“The military provides sophisticated protective gear and training to help soldiers in combat prevent injury,” Dr. Cady says. “However, the magnitude of an assault like that of an improvised explosive device is beyond the limits of this protection.”

To optimize recovery following a head injury, early diagnosis and treatment of post-traumatic headache is essential. Further, military servicemen and women must be offered an environment in which the brain has time to recover from the assault, Dr. Cady says.

“When adequate time and proper environment for recovery are not provided, this can lead to more disabling headaches and other symptoms associated with concussion,” Dr. Cady says. “Also, when the brain is concussed, reaction time and cognition may be affected, which increases the risk of re-injury.”

To fully recuperate, military personnel may need to take time off from active duty. While this may seem initially disruptive, it can lead to a healthier life in the long-term and the maintenance of a functional deployed status. With proper conservative care and a gradual return to regular activities, most brains recover from injury, even after repeat concussion, Dr. Cady says.

Unfortunately, with the risk of a disrupted tour of duty, soldiers may be reluctant to seek treatment. But military leaders are increasingly urging servicemen and women to seek treatment instead of downplaying their symptoms. In an effort to reduce the side effects of traumatic brain injury, the U.S. Army developed new guidelines that require troops caught within 165 feet of a blast to be removed from the battlefield for at least 24 hours and examined for evidence of a concussion.⁵ Soldiers sustaining three concussions in one deployment are required to undergo a more detailed evaluation before being cleared to return to combat.

If implemented successfully, the latter effort combined with adequate downtime could save many soldiers from carrying home the insidious effects of concussion. **#W**



Learn more about concussions at www.besmartbewell.com/tbi.

4. Stern et al. “Long-term Consequences of Repetitive Brain Trauma: Chronic Traumatic Encephalopathy.” *PM&R*. 2011;3:S460-S467.

5. Zoroya. “More Troops’ Concussions Diagnosed Under New Rules.” *USA Today*. October 28, 2010.

When Headaches Don't Go Away

Children and teens can follow these tips to manage chronic daily headaches.



HEADACHE IS COMMON AMONG THE PEDIATRIC POPULATION—so common that it affects up to 51 percent of children during their elementary school years.¹ The more frequent or serious headaches only affect 17 percent of children, but these can impede a child's daily activities and a family's function. Among the

more severe headache types is chronic daily headache (CDH), which affects 2 percent of children.

CDH is a daily or near-daily headache in which the headache is present for three months or longer, occurs at least 15 days a month, and lasts at least four hours per day. The more severe form occurs 24 hours a day, every day of the month. Girls tend to experience chronic headache more than boys, and it seems to increase with age.²

While it would be simpler to put a singular face on the condition, CDH comes in many forms. Holistic treatment that involves both traditional medications as well as lifestyle and dietary changes is necessary to keep a child in school and away from over-the-counter medications that can exacerbate the situation.

CHARACTERISTICS OF CHRONIC DAILY HEADACHE

CDH occurs in primarily four varieties:

- CDH can be a tension-type headache that's evolved into a

daily or near-daily problem, where migraine is not present.

- CDH can start as migraine and evolve into daily or near-daily tension-type headache accompanied by a few migraines a month. This is sometimes called CDH with episodic superimposed migraine, transformed migraine or mixed headache.
- One form of CDH is New Daily Persistent Headache, in which an infection or other trigger causes a child to awaken with their first headache one day and continue to experience that headache from that day forward.
- Post-concussion headache can turn into a chronic issue among children who had few or no headaches prior to the concussion.

For some children, CDH can be traced to an event such as a concussion or an infection. However, for most children, the reason for the new onset or long-time occurrence is still unknown.²

We do know that stress, inadequate sleep or diet, and medication overuse can play a role in exacerbating a headache condition. When a child with CDH misses an excessive amount of school (some have missed years of school) or overuses over-the-counter medications, this complicates the condition and diminishes the quality of life for both the children and their families. For one, overuse of over-the-counter medications can exacerbate a headache condition, turning a headache condition that might otherwise have been treatable into a chronic condition. With

1. Lopez et al. "Pediatric Headache." Medscape Reference. May 14, 2012.

2. Gladstein et al. "Chronic Daily Headache in Children and Adolescents." *Seminars in Pediatric Neurology*. 2010;17(2):88-92.

schooling, children may miss school because they are anxious or because parents are afraid to send their children to school with headaches. Unfortunately, this merely keeps children from their daily activities and does not address the root of the problem (the headaches or any underlying stress). It is best to keep children in their normal environments, keep them working on school-related activities and prepare them to manage their headaches in the real world. Headache specialists cannot truly help children with CDH unless the patient stops overusing over-the-counter medications and moves forward with school and daily activities.

TREATING ALL ASPECTS OF THE CHILD'S LIFE

The treatment program for CDH should involve a holistic approach, addressing everything from lifestyle to diet. Medication is only part of the equation.

First, it should be noted that all teens have stress, and this might be especially prevalent among teens who put pressure on themselves to be straight-A students or the best in their activity. Many children also encounter stress at home or bullying from their peers. Because stress can trigger headache, it should be managed; a stress management program might incorporate cognitive behavioral therapy or biofeedback.

Other aspects of the child's lifestyle should also be addressed. This includes ensuring the child receives eight hours of sleep each night, drinks six to eight glasses of water per day, has a routine eating schedule with no skipped meals, reduces over-the-counter medication usage to no more than two days per week, does cardio exercise three times a week for an hour each time, and returns to school. A specific diet may also be helpful. This should exclude food additives, caffeine, chocolate, lunch meat, aged cheese and MSG (which can be found in everything from Ramen noodles to Doritos).

MEDICATION, ONLY PART OF THE EQUATION

Headache specialists typically prescribe both rescue medications and preventive treatments. Rescue medications can help the child abort a particularly severe headache or migraine. For CDH patients with tension-type headache and migraine, a headache specialist may advise the use of Zofran® (ondansetron), used for the treatment of nausea and vomiting. To help the child

abort a severe attack, the medication can be combined with a cold compress, a quiet place to rest, Benedryl® (diphenhydramine) to help the child sleep, and Aleve® (naproxen) to help with the pain (the dosage will depend on the child's weight). This approach should not be used more than two days a week, to avoid medication overuse headache.

Preventive medication can also effectively reduce the number of headaches and can be prescribed based on comorbidities. For example, for anxious or depressed patients, Elavil® (amitriptyline) may be prescribed; for thin patients who have trouble sleeping, Periactin® (cyproheptadine) can be effective as it improves sleep and increases appetite; and for obese or overweight patients, Topamax® (topiramate) can both reduce the headaches and decrease appetite (see page 30). Many physicians start treatment with a low dose and increase the dose slowly to avoid side effects and to find the lowest dose possible that benefits the child. Regardless of the dose, the child will probably need to use the medication for 6-8 weeks in order to see improvement.

Medications like propranolol (e.g., Inderal®) are used less frequently. Propranolol can cause depression or lower heart rates in teens, thereby reducing the teen's ability to increase their heart rate to the level needed for competitive sports.

Complementary therapies can be effective in CDH patients, in addition to traditional treatments. Complementary therapies include biofeedback, cognitive behavioral therapy, acupuncture, yoga, and vitamins and minerals (e.g., magnesium, riboflavin, butterbur and coenzyme Q10). An inpatient rehabilitation program can also be beneficial for children who are missing excessive amounts of school and are overusing medication. Inpatient programs focus on treatment as well as teaching the child to cope with headaches and lead a normal life.

Today's children are tomorrow's adults. Preparing them now to manage daily headaches amid their circumstances and within their everyday environment will empower children to become productive adults who can advocate for their own health. **HW**

A. DAVID ROTHNER, MD, is director of the Pediatric/Adolescent Headache Program, chairman emeritus of Child Neurology at the Cleveland Clinic in Cleveland, and a member of the *Head Wise* editorial board.

How to Organize Your Medical History

Optimize your next physician appointment by bringing a clear, complete picture of your medical history.

By Kelly Rehan

A VISIT TO THE DOCTOR IS LIKE A JOB INTERVIEW: You have a limited amount of time to get your point across and may leave feeling like there were a million other things you should have said.

Although a first-time appointment may last longer, many checkups only last 15 to 30 minutes. To use your time wisely and leave with the best possible treatment plan, it is important to bring a complete medical history and a list of current symptoms. In this way, your medical history becomes your resume, a document that helps you quickly offer a complete picture of your experiences and helps the physician make a well-informed decision.

“There’s no test made exclusively for headache—it’s all based on history,” says Edmund Messina, MD, Director of the Michigan Headache Clinic, East Lansing, Mich.

While it might take time to build this history on paper, headache specialists recommend patients err on the side of too much detail.

“My experiences range from patients who present with no information to an engineering professor who created a PowerPoint presentation with color-coded graphs,” says Wade Cooper, DO, Director of the Headache and Neuropathic Pain Program at the University of Michigan in Ann Arbor, Mich.

“A detailed history is always preferred to ensure an accurate diagnosis and development of an effective treatment plan.”

On the other hand, not all physicians will have time to sift through stacks of old family records. To optimize time with your physician, organize your medical history in a clear, complete manner and bring a printout to your appointment.

DOCUMENT EVERYTHING CLEARLY

When you’re in pain and have a limited amount of time to articulate your history and current symptoms, it can be overwhelming and you could be easily sidetracked. The key to a successful appointment is to organize your thoughts in advance.

Your medical history should answer a number of key questions (see sidebar) and should also contain any speaking points you want to convey or any questions you want to ask. You should also plan to include:

- A list of all medications used for headache or headache prevention and the doses (a printout from the pharmacy may be helpful), and a list of all vitamin supplements or alternative treatments used
- Copies of any diagnostic records (e.g., magnetic resonance imaging scans, CT scans, neck X-rays, etc.)
- A headache diary that details when you had your headaches in recent months and any known triggers



Want more tips for communicating with your physician? Go to www.headaches.org, click “Resources” and select “Tools for sufferers.”

What Should I Document?

AS YOU BUILD YOUR MEDICAL HISTORY, BE SURE TO ANSWER THESE QUESTIONS IN YOUR DOCUMENT:

- When did you begin having headaches that impacted your quality of life?
- Explain the frequency and severity of your headaches.
- What are the symptoms associated with your headaches (e.g., paralysis, nausea, vomiting, sensitivity to light and sound)?
- What is the typical duration of your headaches?
- Do you experience visual aura (e.g., blind spots or flashing lights) or paralysis before the pain starts?
- How often are you using pain-relieving medication and how much do you take?
- If female, do you find that you have headaches around the time of your menstrual period?
- What treatments have you tried, and what was the outcome of using those treatments? Did you experience side effects?
- Do you experience sleep disorders, such as insomnia, excessive daytime sleepiness or sleep apnea?
- Do you experience personal stress (work, marital, etc.)?
- Do you have a family medical history of pain syndromes (e.g., fibromyalgia, cluster headache, migraine)?
- What hobbies, interests or exercise programs do you enjoy? (These could be used as part of your treatment plan.)

Note: This is a general list and you should customize it to fit your condition.

The headache diary is a vital component of your medical history. If you've kept an accurate, consistent record of every time a headache started and ended, what you were doing when it started, what foods you consumed prior to the headache and any associated symptoms (e.g., nausea, vomiting, sensitivity to light and sound), this can help you and your physician identify patterns, investigate triggers and determine if treatments are working. Be as detailed as you can and don't hesitate to mention seemingly minor symptoms or reactions. Dr. Messina says one of the mistakes many patients make is only noting major migraine events, omitting mention of low-grade daily headaches and less-intense migraines. It is important to make note of all headaches as the number and type of headaches could impact your diagnosis and treatment.

Plan to also include a list of questions that you'd like to ask once you receive your diagnosis and treatment plan, including questions about medication dosage, prevention strategies and any special instructions.

FIND HELP CRAFTING YOUR HISTORY

Pertinent information compiled in an organized manner (e.g., a ring binder or folder) allows your physician to access data when needed, Dr. Cooper says. Ideally,

you should bring this information to every clinician encounter to allow your medical team to have access to your medical records when needed.

If you aren't sure how to get started, Dr. Messina recommends using Arbor Medicus™, a tool he developed to help patients think through important questions before their appointments. The tool requires a login, allowing you to keep your information confidential. After logging in, a "video nurse" will walk you through several questions, building a history that you can then e-mail to your doctor or print a copy to bring to your visit. To access the tool, go to www.ArborMedicus.com.

While documentation is significant, keep in mind that it will also be important to communicate effectively during your appointment. Before your appointment, practice discussing how headaches have affected your quality of life and how the pain is impacting your daily activities.

"The biggest challenge for many patients is the feeling that their symptoms are not being taken seriously," Dr. Messina says. "A decent doctor presented with the right information is going to act on it. If you feel the physician is not listening, you need to find another doctor." **HW**



THE
DOWNWARD SPIRAL
OF CHRONIC TRAUMATIC
ENCEPHALOPATHY

THE DEGENERATIVE BRAIN DISEASE CALLED **CHRONIC TRAUMATIC ENCEPHALOPATHY (CTE)** HAS LED TO HEADACHE, DEMENTIA, LAWSUITS AND SUICIDE.

BY LESLEY REED

IN THE FINAL MONTHS before retired football player Dave Duerson committed suicide in 2011, he complained of headaches, blurred vision and a deteriorating memory.¹

For most of his life, he'd been met with remarkable success. In college, he was an All-American defensive back at Notre Dame. During his 11-year National Football League (NFL) career, he won Super Bowls with the Chicago Bears and the New York Giants.² After he retired in 1993, he had a successful career in the food-services industry.¹ He earned an economics degree from the University of Notre Dame and a certificate from Harvard Business School's Executive Education program.³

Then things began to fall apart. Outwardly, his marriage ended, his business failed and he went bankrupt. Inwardly, he feared he was suffering from symptoms of a brain disease called chronic traumatic encephalopathy (CTE), a form of dementia that shares similarities with Alzheimer's disease.⁴ Just before he shot himself

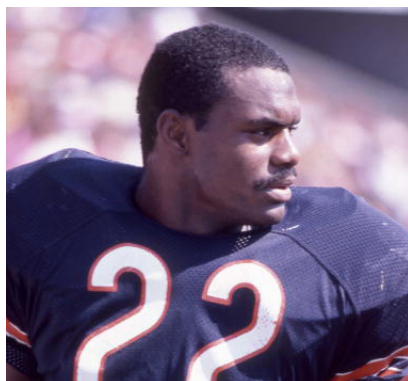
in the chest, Duerson sent text messages and wrote a note to his family with this request: "Please, see that my brain is given to the NFL's brain bank."¹

That brain bank is Boston University's Center for the Study of Traumatic Encephalopathy, which has examined dozens of former football players' brains for the telltale signs of CTE. The Center autopsied Duerson's

brain and did, indeed, diagnose him with CTE. In fact, they've found CTE in the majority of the players' brains they've examined.⁵

CTE is a degenerative disease found in individuals with a history of repeated mild head injuries. For decades, it was believed that only boxers were susceptible to CTE. The disease was first described in a 1928 article titled "Punch Drunk," written by pathologist and medical examiner Harrison Martland, MD.⁶ Dr. Martland wrote that he found the condition in "nearly one-half of the fighters who have stayed in the game long enough." These boxers were nicknamed "punch drunk" for the tremors and signs of dementia that can occur in the later stages of

Duerson exhibited such worsening cognitive and social functioning that led to problems with his relationships and poor money management.



1. Schwarz. "Duerson's Brain Trauma Diagnosed." *The New York Times*. May 2, 2011.
2. Munson. "Duerson Case Could Set Precedent." ESPN.com. July 16, 2012.
3. Garriott. "NFLPA Mourns Loss of Legend Dave Duerson." NFLPlayers.com. February 18, 2011.
4. Mayo Clinic. "Dementia." Mayoclinic.com. Apr. 16, 2011.
5. BU Center for the Study of Traumatic Encephalopathy. Press release. Dec. 6, 2011.
6. Martland. "Punch drunk." *JAMA*. 1928;91(15):1103-1107.

the disease. It was later termed “dementia pugilistica,” meaning dementia of a fighter.⁷

But the symptoms of CTE—including painful headaches—are not exclusive to boxers. They’ve been reported in football players, hockey players, professional wrestlers, soccer players, jockeys, soldiers exposed to blasts and even a frequent parachutist.⁸ Further, head trauma isn’t exclusive to professional athletes. *The New York Times* recently reported that a Tulane University football player broke his neck in September during a tackle, and countless other high school athletes are likely enduring concussions that could result in long-term decline.⁹ To account for this widespread impact of head trauma, dementia pugilistica was renamed “chronic traumatic encephalopathy” (i.e., a chronic disease of the brain caused by trauma) in the 1960s. Fifty years later, CTE research remains in its infancy and there is still much to be learned about the disease. Prevention is currently the only way to avoid the downward spiral.⁷

CHRONIC HEADACHES AND SIGNS OF DEMENTIA

Matthew McCoyd, MD, remembers being shocked by the news of Duerson’s suicide but says Duerson’s history was “fairly characteristic of the disease.” Dr. McCoyd is a Notre Dame alum himself and a neurologist at Chicago’s Loyola Medical Center where he runs a concussion clinic for athletes.

The downward spiral of CTE can start years or even decades after the head trauma. In athletes, symptoms

typically emerge in mid-life, after they’ve retired from sport. In the first phase of CTE, individuals notice problems with concentration and memory, disorientation, dizziness and chronic headaches. Over time, those individuals become more irritable and confused, may show aggressive or violent behavior, and may have speech disorders.⁸

Family and friends often speak of a change in personality. Duerson exhibited worsening cognitive

GOVERNMENT, ATHLETICS SUPPORTING CTE RESEARCH

CTE research has grown exponentially in recent years.⁷ On September 5, 2012, the NFL donated \$30 million in funding to the Foundation for the National Institutes of Health for research into brain injuries and degenerative diseases.²⁰

In addition to studies among athletes, the Veterans Administration (VA) is researching CTE among veterans.

“Imagine someone who just had an improvised explosive device set off near them: first, there’s the actual blast and then there’s a wind that can be upwards of a few hundred miles per hour,” Dr. McCoyd says. “You can imagine the type of force that’s going to put on the brain.”

The VA recently performed a neuropathological analysis to compare the brains of four military veterans exposed to blasts or concussive injury with the brains of football players and a wrestler who had experienced repetitive concussive injuries. Published in the May 2012 issue of *Science Translational Medicine*, the study found that all four veterans had tau tangles indicative of CTE, similar to the CTE indications found in the brains of the four athletes.²¹ (Learn more about repetitive concussions on page 14.)

In the same study, the researchers immobilized the head of a mouse and found that such immobilization protected the mouse from brain injury during a blast. NASCAR has tried a similar approach to prevent head injuries by mandating better seatbelts and harnesses for racecar drivers.²² “If you could do the same thing for football, you’d probably reduce the risk of concussion,” says Dr. McCoyd, “but then you can’t play the game.”

7. Saulte et al. “Chronic Traumatic Encephalopathy: A Review.” *Rehabilitation Research and Practice*. 2012:816069.

8. McKee et al. “Chronic Traumatic Encephalopathy in Athletes: Progressive Tauopathy Following Repetitive Head Injury.” *Journal of Neuropathology and Experimental Neurology*. 2009;68(7):709-735.

9. Cook. “Dying to Play.” *The New York Times*. Sept. 11, 2012.

and social functioning that led to problems with his relationships and poor money management. Among all CTE sufferers, there's a high frequency of depression, drug overdose and suicide.

In the final phase of CTE, individuals can develop loss in motor functions that, as Dr. McCoyd describes, "looks something like Parkinson's disease," and they may also develop dementia.

In all stages of the disease, chronic headaches (in particular, chronic migraine or chronic tension-type headaches) seem to be common, Dr. McCoyd says. This is what sets CTE apart from Alzheimer's disease. "The pathology is similar to what we see in Alzheimer's, but the Alzheimer's patients don't seem to have headaches," Dr. McCoyd says.

It isn't clear why headaches are connected to CTE, Dr. McCoyd says. Then again, much of CTE is still a mystery.

UNDERSTANDING THE CTE BRAIN

CTE is difficult to understand in large part because, currently, it can only be diagnosed after a person dies by doing an autopsy of the brain. Pathologists look for tangled threads of tau, a protein that accumulates in the brain tissue of people with CTE and other illnesses that cause dementia. "Your body can't get rid of the protein, so it stores it in nerve cells," Dr. McCoyd says. "This clogs up the nerve cells, which makes them unable to work properly or pass messages along."

Tau build-up is present in both CTE and Alzheimer's, yet the tangles are more uniformly widespread in Alzheimer's disease. In CTE, tau is typically found in high-density

Did You Know?

More than 3,500 former NFL players have filed lawsuits against the NFL for head injuries.²³ Most recently, former Chicago Bear Shaun Gayle sued the league, fearing he suffers from CTE and alleging that the NFL did not do enough to prevent head injuries. The lawsuit also noted that Gayle suffers from headaches and short-term memory loss associated with CTE.²⁴

clumps close to the interface between the blood vessels on the brain's surface and the brain itself.¹

"When you're getting hit in the head repetitively, your brain is shaking and may be bouncing up against these rigid blood vessels," Dr. McCoyd says.

Chris Nowinski, 34, a former professional wrestler with World Wrestling Entertainment, is on a mission to help the research community better understand the CTE brain. Repeated concussions left Nowinski with severe headaches and depression and ended his sports career. Headaches were a rare event before his sixth—and last—concussion, which he sustained during a wrestling match. After that day he began experiencing short-term mem-

ory loss and a constant, dull-aching headache that lasted for five years. Nowinski says medications didn't make a dent in the pain. Time was the only healer, he says, noting that he



Christopher Nowinski and actress Sigourney Weaver at the Brain Trauma Foundation 2011 gala.

only experiences one or two headache days a month now.

Currently there is no cure for CTE; physicians can only treat the symptoms. Nowinski also hopes that will change through the work of his Sports Legacy Institute in Boston (which seeks to advance the study, treatment and prevention of brain trauma in athletes) and through its collaboration with Boston University through the Center for the Study of Traumatic Encephalopathy. Nowinski has persuaded a number of families to donate the brains of deceased athletes for research, including the family of former NFL player Andre Waters, who committed suicide in 2006 at the age of 44.¹⁰ The neuropathologist who examined Waters' brain, Bennet Omalu, MD, determined that Waters had developed CTE.¹¹

When, in 1994, Waters was asked by the *Philadelphia Inquirer* how many concussions he'd sustained, he said, "I think I lost count at 15." He also admitted to ignoring the concussions, sniffing smelling salts and returning to the game.¹¹

Waters' story illuminates one thing that researchers do know about CTE: it takes repeated head injuries to trigger the disease. "But only a small number of people have been diagnosed with CTE and there are still many questions: How many hits do you need? Why do some people seem to have long careers with histories of head injuries and not get it? Is it a combination of the

MEASURING IMPACT

To help coaches and trainers determine whether an athlete can return to play after head trauma, many teams now use the ImpACT® (Immediate Post-concussion Assessment and Cognitive Testing) evaluation system. ImpACT is a 20-minute, computerized tool that walks the user through several concussion-related tests including attention span, reaction time and working memory. Athletes must take the test prior to a concussion to set a baseline score. Once head trauma occurs, the athlete then takes the test again to see how their score aligns with the baseline and normative data. A licensed health care professional interprets the data and makes a decision about return-to-play.

A majority of U.S. professional football and soccer teams—and all national hockey league teams—use the ImpACT test. When it comes to high schools and universities, it depends on whether the state and/or school has made ImpACT use mandatory. For a list of states, schools and teams using ImpACT, go to <http://impacttest.com/clients/page/all>.



number of hits and being predisposed?" Dr. McCoyd says.

Genetics may be a factor that makes some people susceptible. A gene variation seen in Alzheimer's has been found in approximately 57 percent of individuals with CTE.¹² Dr. McCoyd hypothesizes that other health problems (e.g., hypertension, diabetes) or age might influence the process.



Learn more about your headaches and interact with specialists in the NHF Chat Room at www.headaches.org/content/nhf-webinars.

10. Bialik and Fry. "Eagles Fans Mourn Death of Andre Waters." *The Wall Street Journal*. Nov. 21, 2006.

11. Schwarz. "Expert Ties Ex-Player's Suicide to Brain Damage." *The New York Times*. Jan. 18, 2007.

12. Gavett et al. "Chronic Traumatic Encephalopathy: A Potential Late Effect of Sport-related Concussive and Subconcussive Head Trauma." *Clinical Journal of Sports Medicine*. 2011;30(1):179-xi.

“Younger athletes might be more at risk because they aren’t as strong and their skulls aren’t as thick as older athletes,” Dr. McCoyd says.

Indeed, CTE has been discovered in the brains of two football players who died young, one at age 21 and the other at age 18.^{13,14} In one study using a system called HITS™, Stefan M. Duma of the Center for Injury Biomechanics installed sensors in the helmets of seven- or eight-year-old football players.¹⁵ His research showed that the players averaged more than 100 head impacts during the course of about nine practices and five games. Some hits exceeded a force equivalent to a big hit in college football.¹⁶

REDUCING THE RISK

In June 2012, Pop Warner, the nation’s largest youth football organization, announced new rules of play, including prohibiting contact for two-thirds of each practice. The new policy may help the largest group of vulnerable players (more than 285,000 children ages 5 to 15) in the country. Adult leagues are also making moves to reduce the risk. Both the NFL and Ivy League college teams have reduced the number of full-contact practices. The NFL imposed stiffened penalties for hits to the head and neck, requiring athletes be barred from returning to play on the same day of a concussion if they exhibit any symptoms.^{17,18} Helmet technology has also improved, with the addition of more padding and helmets that are designed to better distribute the force of impact.¹⁹

Such prevention is critical. An estimated 1.6 to 3.8 million sports-related concussions occur annually in the United

States.⁷ Once a person suffers one concussion, they’re more likely to sustain another (see page 14). It is this accumulation of concussions that is of utmost concern. By the time an NFL player has played through high school, college and 10 years of pro football, he could have been hit 18,000 times, according to HITS data.

Still, as Dr. McCoyd says, “football is a contact and collision sport designed to run into people. You’re never going to take the hits out of the game completely.”

Thus, while prevention is key, it is also important for people who experience head trauma to report it and seek help right away. Unfortunately, in sports and the military where strength and a fighting spirit are celebrated, Dr. McCoyd says many people won’t report their symptoms.

“[In athletics], most players know that if they develop symptoms that are suspicious for concussions, they’re going to get pulled from the game and they’re not going to be able to play,” says Dr. McCoyd.

Therefore it is also important for people to police one another. Coaches should be alert for concussion symptoms among their players, parents should ask their children if they’ve been hit in the head during practice, etc. If mild or severe head trauma is found, it should be reported and treated promptly to avoid worsening of symptoms and new blows to the head. An environment where people feel safe to report their symptoms and where coaches, trainers, parents and fellow soldiers work to prevent trauma could go a long way in reducing the risk for CTE and the number of people lost to the degenerative disease. **HW**

13. Faris and Hinman. “Football’s Risk Factor: Brain Injuries Raise New Concerns for Young Athletes.” ABCNews.go.com. May 24, 2012.

14. BU Center for the Study of Traumatic Encephalopathy. “18 Year Old High School Football Player.” www.bu.edu/cste/case-studies/18-year-old/

15. Farrey. “Study: Impact of Youth Head Hits Severe.” ESPN.com. Feb. 22, 2012.

16. Daniel et al. “Head Impact Exposure in Youth Football.” *Annals of Biomedical Engineering*. 2012;40(4):976-981.

17. O’Connor. “Trying to Reduce Head Injuries, Youth Football Limits Practices.” *The New York Times*. June 13, 2012.

18. Schwarz. “NFL Issues New Guidelines on Concussions.” *The New York Times*. Dec. 2, 2009.

19. Malone. “Football Turns to Helmet Technology to Tackle Head Injuries.” *Reuters*. Apr. 2, 2012.

20. NFL.com. “National Football League Grants \$30 Million to National Institutes of Health.” Sept. 5, 2012.

21. Goldstein et al. “Chronic Traumatic Encephalopathy in Blast-exposed Military Veterans and a Blast Neurotrauma Mouse Model.” *Science Translational Medicine*. 2012;4(134):134ra60.

22. Aumann. “Safety Improvements, Changes Define Racing Eras.” Nascar.com. Feb. 16, 2011.

23. Fenno and Rosiak. “NFL Concussion Lawsuits.” *The Washington Times*. June 21, 2012.

24. Grogg. “Shaun Gayle Joins NFL Concussion Lawsuit.” NBCCChicago.com. July 11, 2012.

The Upsides and Downfalls of Topiramate

Topiramate is now among the drugs considered effective for migraine prevention—**but is it safe?**

TWELVE YEARS AGO, the American Headache Society (AHS) and the American Academy of Neurology (AAN) released a set of guidelines to rank the effectiveness of various medications for prevention of episodic migraine. Drugs such as amitriptyline, divalproex, propranolol and timolol made the top tier.

Topiramate, a common migraine preventive drug, had not yet been approved by the U.S. Food & Drug Administration (FDA) for prevention of episodic migraine. The medication was placed in the third tier in the 2000 AHS/AAN guidelines, as a drug that “may” be considered for migraine prevention.¹

In the 2012 update to the AAN/AHS guidelines,

topiramate graduated to the top tier of migraine preventive meds. According to a summary of the guidelines, clinical trials in the past 12 years have established the drug as effective for prevention of episodic migraine (i.e., migraines that occur six to 14 times per month).² One could conclude that the FDA’s approval of topiramate for episodic migraine in 2004³ as the reason for the upgrade, but this is not the case: “Assignment of drugs to levels was based solely on grading by quality and the strength of clinical trial evidence,” says Elizabeth Loder, MD, MPH, lead author of the guidelines summary.

Topiramate’s recent advancement in the guidelines could lead more headache specialists to prescribe the medication.

1. Silberstein. “Practice Parameter: Evidence-based Guidelines for Migraine Headache (an Evidence-based Review).” AAN report for the Quality Substands Subcommittee of the American Academy of Neurology. 2000.

2. Loder et al. “The 2012 AHS/AAN Guidelines for Prevention of Episodic Migraine: A Summary and Comparison with Other Recent Clinical Practice Guidelines.” *Headache*. 2012;52:930-945.

3. Warner. “FDA Approves Topamax for Preventing Migraines.” WebMD. Aug. 12, 2004.



But before beginning any kind of treatment plan, migraineurs and headache specialists should weigh the drug's benefits and risks.

THE UPSIDES

Topiramate was introduced to the United States in 1996 as an anti-seizure medication (also known as an anti-convulsant or anti-epileptic).⁴ Similarities between epilepsy and migraine suggested the drug could work for headache. For instance, both migraine and epilepsy affect how neurons fire and both are associated with hyperexcitability in neurons.⁵

In cortical spreading depression, which may be related to migraine pain, neurons in the brain's outer layer (the cortex) become hyperexcited. The hyperexcitability then moves in a wave across the brain. People who have migraine with visual aura can actually see this effect, as blinking lights or geometric patterns move through their field of vision with the same timing as the cortical waves, about two to five millimeters per minute.⁶

A study published this year in the journal *Cephalalgia* examined topiramate's effect on cortical waves. Researchers induced cortical spreading

depression in groups of anesthetized rats (some had been treated with topiramate daily for six weeks, while others had never received the drug). Among the untreated rats, waves of hyperexcitability traveled across their brains unimpeded. But in rats treated with topiramate, cortical spreading depression faded significantly and the time between wave episodes increased.⁷

Headache specialists recommend a certain dosage and regimen to receive the full benefit of the drug.

"When topiramate is selected, the average dose for the average person looking to prevent their headaches is

2012 MIGRAINE PREVENTION GUIDELINES

In the 2012 "Guidelines for Prevention of Episodic Migraine," preventive medications were organized into five categories:

- Level A drugs have been established as effective for the treatment of episodic migraine, based on clinical trials.
- Level B drugs are labeled "probably effective" and should be considered for migraine prophylaxis.
- Level C drugs "may" be considered for preventive treatment.
- Level U includes drugs that have insufficient data.
- A separate category was created for drugs considered ineffective.

In the updated guidelines, Level A drugs now include three beta-blockers (metoprolol, propranolol and timolol), anti-epileptic drugs (e.g., topiramate and sodium valproate) and the herbal treatment butterbur. Amitriptyline, which was in Level A in 2000, has been downgraded to Level B. It is accompanied by the herbal treatment feverfew, vitamin B2, venlafaxine (an antidepressant), and several NSAIDs (e.g., ibuprofen). Level C drugs included coenzyme Q10 (coQ10) and several NSAIDs as well (e.g., flurbiprofen). Among the drugs considered ineffective for migraine prevention were the anti-epileptic drug lamotrigine as well as oxcarbazepine and telmisartan.

Other guidelines—such as those for chronic migraine, pregnant women or pediatric migraineurs—were outside the scope of the study. Researchers working on the updated guidelines also excluded onabotulinumtoxin A (Botox®) because the AAN has previously identified it as ineffective for treatment of episodic migraine.¹

Despite researchers' conclusions about the efficacy of various preventive medications, the authors of the updated prevention guidelines have noted, "A majority of migraine sufferers who would benefit from prevention therapies do not receive them." According to one study sponsored by the National Headache Foundation in 2005, some 43 percent of migraineurs have never used preventive therapies, despite having migraine frequencies that would benefit from treatment.¹⁵ A lack of physician awareness and confidence in the quality of medication guidelines could be to blame, the guideline authors suggest.

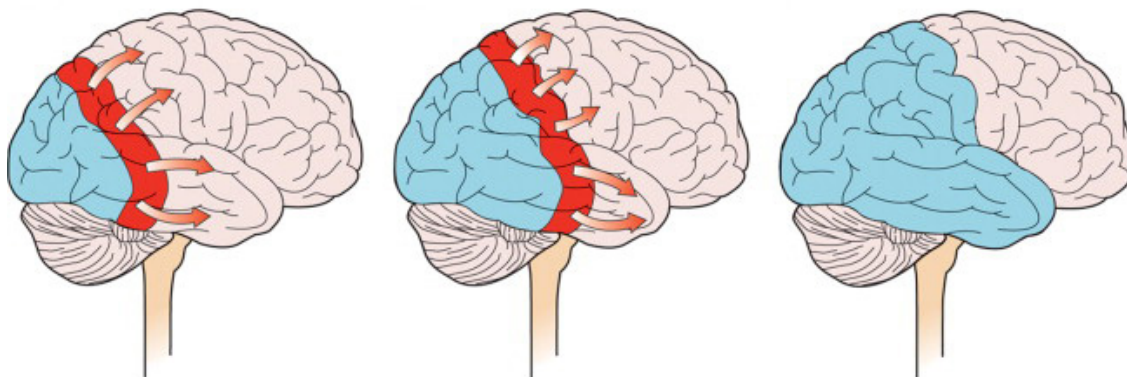
4. National Institutes of Health. "Topamax." Dailymed.nlm.nih.gov. January 2012.

5. Haut et al. "Chronic Disorders with Episodic Manifestations: Focus on Epilepsy and Migraine." *Lancet Neurology*. 2006;5(2):148-157.

6. Mulleners et al. "Visual Cortex Excitability in Migraine with and Without Aura." *Headache*. 2001;41(6):565-572.

7. Unekawa et al. "Suppressive Effect of Chronic Peroral Topiramate on Potassium-induced Cortical Spreading Depression in Rats." *Cephalalgia*. 2012;32(7):518-527.

CORTICAL SPREADING DEPRESSION



100 mg, divided into two doses daily,” says Mark W. Green, MD, FAAP, director of Headache and Pain Medicine at the Mount Sinai School of Medicine in New York City. “It is best to start with 15 or 25 mg and increase that dose weekly over four to six weeks, to 90 to 100 mg.”

But the regimen generally doesn’t end at six weeks.

“The longer we keep you on it, the higher the chances are that you’ll do well without it,” Dr. Green says. “We don’t assume that we are going to treat you forever. I might treat someone for a year and slowly reduce the drug and see if they still need it, and often, they do fine.”

In a 2006 study of 970 migraineurs, patients who received topiramate (regardless of dose) during a clinical trial saw their migraines decrease from three to 12 attacks per month, to an average of 3.4 attacks per month after the first six months of treatment. After eight months, patients saw their

migraines decrease to an average of 2.2 attacks per month.⁸ It is not known how long this trajectory continues, but it seems to be maintained even after the drug is discontinued.¹

Patti Havens, 52, is among those who saw the benefit increase over time.

“[At first] I was like, ‘Oh my gosh, that stuff is brutal! I don’t want to take it!’” says Havens, who lives in Claremont, Calif. and works in her husband’s law office.

But Havens says she was missing out on life and needed to manage her migraines. Shortly after she started taking Topamax® (topiramate), the number of migraines decreased from 12 to 15 a month to just three migraines during her first 18 months on the drug. Then suddenly, her migraines disappeared altogether.

SLIMMING EFFECT

In addition to curbing migraines, some migraineurs have also noticed

that topiramate triggers weight loss.

In a 2012 study, which compared topiramate to the antidepressant medication amitriptyline, patients treated with topiramate lost an average of five pounds during the 26-week trial, while patients treated with amitriptyline gained about five pounds.⁹

“It’s one of the few migraine drugs that can cause weight loss and doesn’t cause weight gain,” Dr. Green says. “Obesity is a risk factor for the progression of headaches, so if you can help reduce weight, this can have a therapeutic effect on migraine.”

Still, while the drug may commonly cause weight loss, it is not approved by the FDA for that effect. Therefore, though migraineurs may find themselves losing weight on the drug, headache specialists prescribe it for migraine prevention alone—not for the promotion of weight loss. (On a separate note, the drug Qsymia™, which combines topiramate and phen-

8. Rapoport et al. “Long-term Migraine Prevention with Topiramate: Open-label Extension of Pivotal Trials.” *Headache*. 2006;46(7):1151-1060.

9. Dodick et al. “Topiramate Versus Amitriptyline in Migraine Prevention: A 26-week Multicenter, Randomized, Double-blind, Double-dummy, Parallel-group Noninferiority Trial in Adult Migraineurs.” *Clinical Therapeutics*. 2009;31:542-559.



The drug's most worrying side effect is the **slight but serious risk for glaucoma**, Dr. Green says, as topiramate has been associated with increased pressure inside the eye, which can lead to blindness if left untreated.

termine, was approved by the FDA for weight loss in July 2012.¹⁰)

THE DOWNSIDES

Though weight loss may be a welcome side effect for some, other side effects of topiramate are more concerning. Topiramate is linked to a long list of potentially negative side effects, from fatigue and anxiety to kidney stones and word-retrieval problems.¹¹

"I jokingly call it Dopamax," Havens

says. "I was foggy for months when I started using it."

While on the drug, Havens says she will occasionally have trouble thinking of the right words to say, but the effect has largely faded over time. Word retrieval is a particularly frightening cognitive side effect of the drug, Dr. Green says.

"It makes you a little loopy—I don't think I'm as sharp a thinker when I take it," says Anne Brinkley, a retired

North Carolina high school chemistry teacher who had to retire early due to incapacitating migraines. "It's a trade-off. I'd rather not think as well than have more migraines."

The drug's most worrying side effect is the slight but serious risk for glaucoma, Dr. Green says, as topiramate has been associated with increased pressure inside the eye, which can lead to blindness if left untreated.

But overall, the most common side effects are less alarming. About one-third of patients in one trial complained of paresthesia, the most common side effect, which involves a pins-and-needles feeling in the hands and feet.⁸ The tingling does not damage nerves and resolves in most patients, Dr. Green says. In that same trial, some 17 percent of patients complained of fatigue, 11 percent said their sense of touch was blunted and about 10 percent experienced nausea. Perhaps most frustrating, many of these side effects appear before the drug's benefits start, Dr. Green says.

These side effects make it even more important for physicians to use a "start low/go slow" approach to treatment, easing patients up to their effective dose, Dr. Green says, adding that most side effects disappear over time.

BIRTH DEFECT DILEMMA

Topiramate could also have worrying side effects for the unborn. In May 2011, the FDA announced an association between topiramate exposure during pregnancy and increases in certain types of birth defects. The agency found

10. FDA. "FDA Approves Weight-Management Drug Qsymia." Press release. July 17, 2012.

11. Drugs.com. "Topiramate Side Effects." 2012.

Topiramate for Chronic Migraine Too?

Although the FDA approval and prevention guidelines only cover episodic migraine, some studies suggest topiramate could also work in chronic migraine (or migraine that occurs 15 or more times per month).

Currently, onabotulinumtoxin A (Botox®) is the only FDA-approved treatment for chronic migraine (although it is considered ineffective in the prevention of episodic migraine).¹⁶ In one 2011 study, 59 chronic migraineurs were divided into two groups: one that received topiramate and one that received onabotulinumtoxin A. After four weeks of treatment, both groups took a Physician Global Assessment that measured improvement in chronic migraine. Of the topiramate group, 74 percent had improved; of the onabotulinumtoxin A group, 60.7 percent had improved. By week 12, 70.8 percent of the topiramate group had improved and 79.2 percent of the onabotulinumtoxin A group had improved. Ultimately, the treatments showed near-equal efficacy.¹⁷

that women taking topiramate during the first trimester were more likely to give birth to infants with oral clefts. Specifically, the prevalence of oral clefts was 1.4 percent in topiramate-exposed patients, compared to 0.38-0.55 percent in infants exposed to other anti-epileptic drugs and 0.07 percent in infants who weren't exposed to any anti-epileptic drug.¹²

Due to these findings, the FDA recommends pregnant women *not* be prescribed the drug, except under dire circumstances. The FDA has also dropped the drug's pregnancy category rating from Category C (which means the risk of the drug to a baby is unknown) to Category D (which means there is evidence of fetal risk).¹³

Other studies do not support the FDA's conclusion. For example, a 2012 study, which was published in the journal *Headache* (Mark W. Green, MD, FAAP, was the lead author), found little

or no increase in risk from topiramate compared to other anti-epileptic drugs. The study followed insurance claims related to 4,485 infants born from mothers exposed to topiramate (870 infants) and other anti-epileptic drugs (3,615 infants) during the first trimester of pregnancy. The study found little or no increase in risk from topiramate compared to other anti-epileptic drugs. Comparatively, in the topiramate group, oral clefts occurred in 0.23 percent of births. Among those exposed to other anti-seizure medications, the birth defect occurred in 0.17 percent of births.¹⁴

"Ultimately physicians need to weigh the risks and benefits accurately in cases in which migraine control is necessary," Dr. Green says.

CASE BY CASE

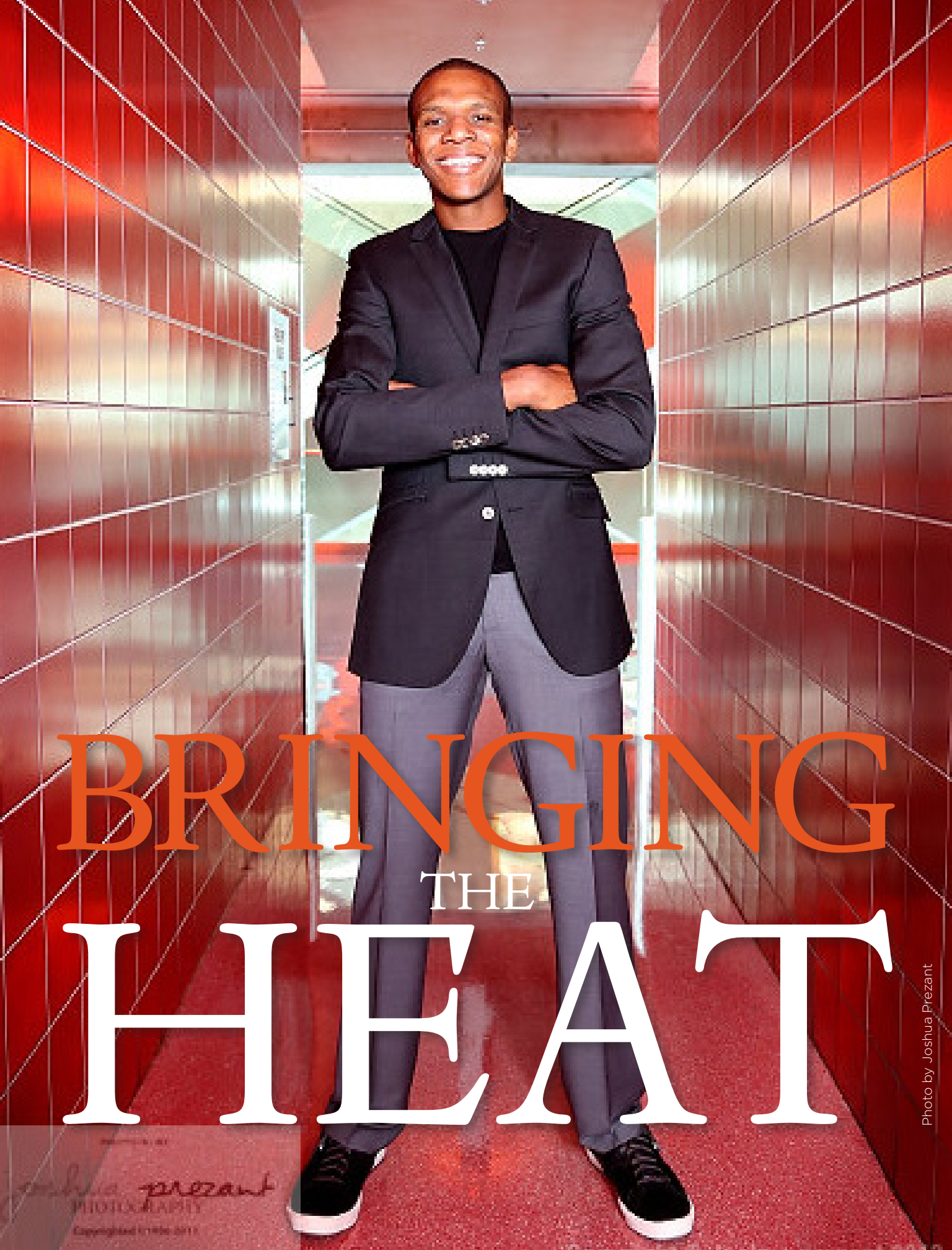
While no drug is a cure-all and no one medication will work for every migraineur, a better understanding

of the benefits and risks of preventive medications could help headache specialists and migraineurs to determine the best possible treatment plan.

"The 2012 prevention guidelines are an important starting point to understand the need and scope of migraine therapies for prevention," Dr. Cady says. "Beyond this starting point is the need for clinicians and patients to form an ongoing collaborative partnership that is outcome-based and directed to the individual needs of the patient."

This partnership, coupled with research into a drug's efficacy and a review of the patient's medical history, is a necessary step in understanding and treating migraine and other headache conditions. If you are searching for a headache specialist, visit the National Headache Foundation's website at www.headaches.org or call 888-NHF-5552 for help. **HW**

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12. FDA. "Topamax (topiramate): Label Change - Risk for Development of Cleft Lip and/or Cleft Palate in Newborns." www.fda.gov/Safety/MedWatch/SafetyInformation/SafetyAlertsforHumanMedicalProducts/ucm245777.htm
13. FDA. "FDA Drug Safety Communication: Risk of Oral Clefts in Children Born to Mothers Taking Topamax (topiramate)." www.fda.gov/Drugs/DrugSafety/ucm245085.htm
14. Green et al. "Utilization of Topiramate During Pregnancy and Risk of Birth Defects." *Headache*. 2012;52(7):1070-1084.
15. National Headache Foundation. "Largest Study of Migraine Sufferers Reveals Preventive Therapies Are Underused." *Head Lines*. Sept./Oct. 2005.
16. Mathew et al. "A Double-blind Comparison of Onabotulinumtoxin A (BOTOX) and Topiramate (TOPAMAX) for the Prophylactic Treatment of Chronic Migraine: A Pilot Study." *Headache*. 2009;49(10):1466-1478.
17. Cady et al. "A Multi-center Double-blind Pilot Comparison of Onabotulinumtoxin A and Topiramate for the Prophylactic Treatment of Chronic Migraine." *Headache*. 2011;51(1):21-32.



BRINGING THE HEAT

Photo by Joshua Prezant

Joshua Prezant
PHOTOGRAPHY
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WHEN A MIGRAINE FORCED MIAMI HEAT FORWARD JAMES JONES TO MISS THE MOST IMPORTANT GAME OF THE YEAR, SPORTS FANS TOOK NOTICE OF THE CONDITION.

BY JACKIE WALKER GIBSON

e had worked his whole life for this opportunity.

He grew up playing basketball in Miami and was drafted out of the University of Miami in 2003 to play for the Indiana Pacers in the National Basketball Association (NBA). He was traded two more times before returning to his hometown. Nine years later as his team, the Miami Heat, entered the 2012 NBA Finals, 6'8 forward James Jones began to feel the onset of a migraine just hours before Game 1. He returned to his hotel room, took some medication and tried to sleep it off—but it wasn't enough. The 32-year-old Heat star had to miss the biggest game of the year.

Jones returned to play in the following four games, and the Heat won the championship in a five-game series against the Oklahoma City Thunder. Yet it is the migraine that sidelined him that will remain in many fans' memories.

Jones is not alone with his condition. Miami Heat teammate Dwyane Wade, who led the NBA in scoring during the 2008-09 season, also experiences migraines and sometimes wears rose-colored sunglasses during games to avoid light triggers. Their coach, Erik Spoelstra, has said that Wade and Jones have made the team more aware of the complexities of migraine. *Head Wise* recently spoke with Jones to discuss his experiences with migraine and why it is important for male migraineur-athletes to speak out about the condition.

Head Wise (HW): Why do you love the game of basketball?

JONES: In most sports (football, baseball, soccer) you need a partner, somebody to pitch to you or a receiver to catch. In basketball, your partner is the basketball itself and that allows you to grow and develop even if you don't have a coach, friend, parent or someone else around.

HW: When did your migraines start?

JONES: [They got worse] four years ago in the NBA, when I came back home to Miami. Prior to that, I had migraines sporadically but I never really paid close attention to them. In the last five years, I started to talk to physicians and trainers and they would ask me about my headaches.

I had a conversation with my mom and said, "They're doing all these tests and everything looks good. I just don't know where these headaches

are coming from.” She said, “You’ve been having headaches your entire life.” I said, “I had migraines as a kid?” And she said, “Sure, you had migraines all the time.” I guess I never paid attention because as an athlete, you automatically figure that any type of pain or ailment results from dehydration or overexertion.

HW: Did you have a family history of migraine?

JONES: [My mom] has suffered [from migraine] for a good part of her adult life.

HW: What are your triggers?

JONES: Dehydration, bright lights and camera flashes. A lot of the arenas are switching to the brighter LED lights and those trigger it for me. Eating chocolate—if I’m on a brownie binge—I’m more prone to having them. If I [eat] really salty foods like salty popcorn, it usually compromises me and leaves me in a bad spot.

HW: It sounds like your triggers are all things in an arena.

JONES: The irony is that everything around me triggers migraine.

HW: How do you handle pre-game in the locker room with all the cameras and the noise?

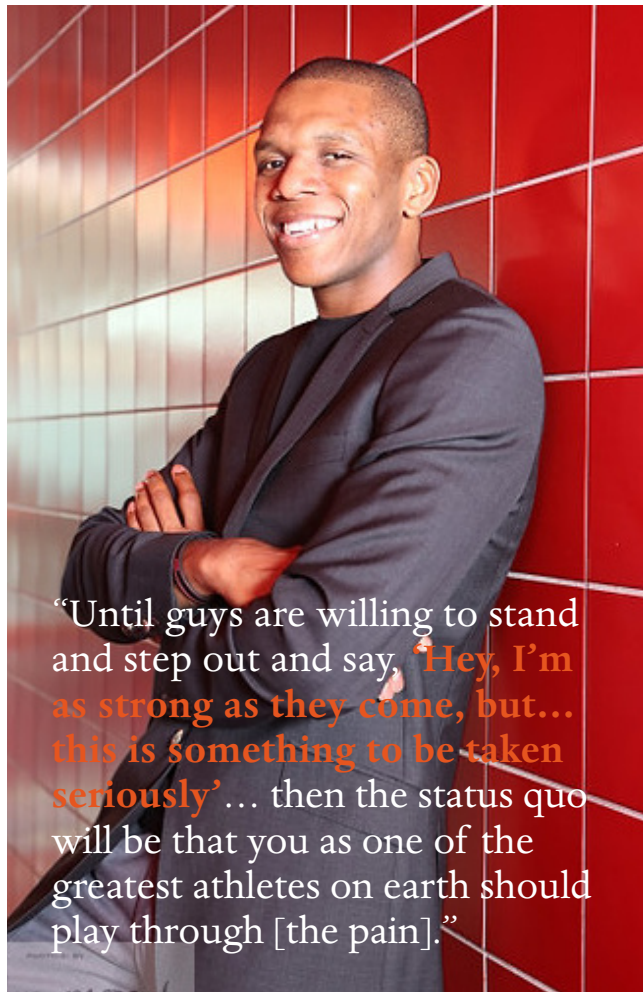
JONES: Pre-game I find myself in mid-lighting in the weight room or off in our lounge. I also avoid taking electrolytes or sodium packets close to the game. But really it’s about staying out of the light because light is my worst trigger.

HW: How do you manage your migraines?

JONES: If I start to feel symptoms, I try to hydrate quickly, sit down and get out of the light. I try to avoid taking pills as much as possible, but I’ll start taking Advil or some prescription-strength headache medicine. If it doesn’t work, I’ll try an [aspirin] injection [to get the medicine in my system faster].

It’s tough because rarely am I able to stop it. Once it’s triggered, it usually runs its course for 12-24 hours. I’ll get sick, start to have visual aura, and then from there I’ll become nauseated and vomit. And then I can finally relax and maybe sleep an hour or two and start to feel better.

HW: Did the impact of missing Game 1 of the NBA Finals change the way you’ll treat migraines in the future?



“Until guys are willing to stand and step out and say, ‘Hey, I’m as strong as they come, but... this is something to be taken seriously’ ... then the status quo will be that you as one of the greatest athletes on earth should play through [the pain].”

JONES: No, it just reaffirmed for me that there’s no quick fix. At the end of the day it’s a condition that I have to live with. Medication works for some people, but it doesn’t work for everyone. My focus is to try to find a system that works for me—if it’s a particular medication or drink, a massage, sunglasses, sleeping—I’m always tinkering, trying to find the right mix that will allow me to combat my individual symptoms.

HW: Your migraine during Game 1 was not your first headache, but the media took notice of that one. What was your reaction to the coverage?

JONES: I think it raised awareness and showed the severity of a migraine. If a migraine is severe enough to stop me from playing in Game 1 of the NBA Finals, which is the most important game of the year that every athlete would literally die [to play in], then it shows that [migraine] must be debilitating, and it must be a crippling pain. So I think it brought

recognition to the fact that migraine is more than just a simple headache from staying up too late or not getting proper rest. Migraines will shut down your entire body.

HW: Do you think you and Dwyane Wade are bringing awareness to the team as well?

JONES: I think so. We're two guys who are extremely competitive; our team comes first. So it shows the impact [migraine has]. But I think there needs to be more accommodations and more awareness [of migraine in sports]. If you're not functioning, there's no way to be the best.

HW: It seems like a lot of athletes don't like to talk about their health. Do you see that?

JONES: I see it because it's a very competitive sport. A lot of guys view that as a sign of weakness. Until guys are willing to step out and say, "Hey, I'm as strong as they come, but this is something that weakens me, this is something I deal with, this is something to be taken seriously," until guys do that, then the status quo will be that you as one of the greatest athletes on earth should play through it and if you don't play through it that means you don't have the desire or that you're not exerting yourself. As more high-profile guys, with proven track records of persevering and putting their teams first, step to the forefront, I think organizations will respect it and understand and I think fans will too.

HW: Do you and Dwyane Wade ever talk about your migraines?

JONES: Yes, normally we talk about them after we dodge a bullet [a migraine] or after we both come off of a migraine. Only if you experience them do you recognize the severe aching pain that you [suffer].

HW: The *South Florida Sun-Sentinel* reported this summer that retirement was on the table for you. How have migraines impacted that decision?

JONES: Just for the record, there was no way I was retiring. But as you get older and playing sports starts to take a toll

on your body, it becomes more difficult to fight through and combat your migraines. So much of what we do is physical. At the end of the day you do want to play this game as long as possible, but you also want to be conscious that you don't leave the game and be in a bad state of health.

HW: What would you have to say to others who have missed out on important days due to headache?

JONES: It's tough, there's no doubt about it. [Missing an important day to deal with your health] is a tremendous sacrifice, but I think you have to do it because at the end of the day you're talking about your health. We want life experiences and when you're in the moment, they're the most important thing you can think of. But really there's nothing more important than your health. The more you can get under control, the more you can avoid migraines, the better you are. Outside of the birth of my children, everything else is an experience that could be possibly replicated in the future.

HW: You're an NBA champ, a father, winner of the 2011 Foot Locker Three-Point Shootout—you even run your own Legacy Foundation to give back to youth. What do you consider your greatest accomplishment?

JONES: It's a perfect storyline: I was born in Miami. I went to high school here. I went to college here. I was the first male in my family to graduate, the first Academic All-American in the family, the first professional basketball player in the family, three-point champion and NBA champion. Individually it's tough to say because it seems like my accomplishments have been a bundle and it's all happened here in Miami.

Winning the championship in Miami is by far one of the greatest accomplishments. But I think graduating from the University of Miami with my bachelor's degree in finance as an Academic All-American, for my family and for the people who helped me achieve, I think that was a very big moment. **HW**

Do you experience migraine or other headache types? Remember that treatment is available. To avoid increased severity of your condition, seek treatment early with the help of a headache specialist. A list of headache specialists is available at www.headaches.org or call 888-NHF-5552 for more information.

wise words



NAME: Paula Dill

RESIDENCE: Moraga, Calif.

CONDITION(S): Tension-type headaches

FIRST DIAGNOSED: Early 1970s

Photography by Anthony Lindsey

How do you manage your condition?

It depends on the degree of headache. I know my body enough now to know what I need. Twenty-five milligrams of Imitrex® (sumatriptan) is usually enough to knock out my headache. I take it with a third of a Phenergan® (promethazine) suppository, [which is used to treat allergies and motion sickness]. It helps to get the queasiness out of my stomach. If the headache is really bad, I just take another Imitrex. Then I lie down with a cup of tea and try to get some sleep. I usually only sleep about five hours per night, but that's the way I am. If my headache is still really bad, I'll crawl back into bed with a cold compress.

In the early years, I felt that doctors thought headaches were just a female problem. They wouldn't pay attention and would tell you to just suffer through it. But I think doctors are a lot more tuned into headache sufferers now. If you can get someone to listen to you patiently and really help you, I think that's the answer.

What is the most frustrating thing about your life?

I'm retired now, but when I wasn't retired, I had to drag myself around to do things whether I had a headache or not.

What are you most thankful for?

Life. I'm thankful that I'm able to get up in the morning and enjoy my family and spend time with my husband. We can do things now we weren't able to do before when we were both working. Now we're able to take walks together, which are very helpful for my headaches. We have our first grandchild

now and I'm delighted to spend time with her and watch her grow. I'm thankful that I'm able to see the sunshine every day.

What's your favorite book?

I just read a biography of Peggy Guggenheim. Usually I like short stories because I can read them before bed and pretty much get to the end. I read before I fall asleep; it helps relax me.

Where do you get the greatest support?

I have had a great husband through the years and he's given me a lot of support. He can just look at me and say, "You have a headache. Why don't you go lie down?" He's very patient. He's been a wonderful companion.

What is your idea of happiness?

Happiness is waking up in the morning and not being sick, and being able to live through the day and enjoy the beautiful California weather. I'm very fortunate—I'll go knock on some wood right now.

Paula Dill is a retired public health nurse and a proud grandmother of a one-year-old girl. She was also the lucky winner of the annual raffle at the 2012 National Headache Foundation fundraising benefit.

Your Contributions to the National Headache Foundation Help Fund Projects

What's being done to help your headache problem? There is an unprecedented amount of research being done regarding migraine and other headache pain. The National Headache Foundation is involved in this effort with the help of funding from you. Contributions are a key part of the financial support of important headache research. Your gift provides funds for (a) NHF-financed research projects, (b) education for health care providers, and (c) patient-education initiatives. You can help! The National Headache Foundation, the #1 source for headache help, provides these services and many others through the generosity of people like you.

Please select one of the following giving categories:

\$250 \$125 \$100 \$75 Other _____

Name: _____

Address: _____

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State/Zip: _____

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Method of Payment:

Check or Money Order payable to National Headache Foundation

Visa MasterCard Amex Discover

Card #: _____ Expiration Date: _____

Leave a Legacy to the National Headache Foundation

With a planned gift to the National Headache Foundation, you can combine your desire to give to charity with your overall financial, tax and estate planning goals. Your planned gift gives you a special connection with NHF: **you will help those suffering from recurring headaches and migraines now and for years to come.**

The following general forms are suggested:

Specific Bequest in your will or trust - "I give to the National Headache Foundation, whose national office is presently located at 820 N. Orleans, Suite 411, Chicago, IL 60610-3132, [the sum of _____ (\$_____) or describe property] to be used for _____ [describe purpose] or for general purposes."

Residual Bequest in your will or trust: "I give to the National Headache Foundation, whose national office is presently located at 820 N. Orleans, Suite 411, Chicago, IL 60610-3132, [all or _____ percent (____%) of the rest, residue and remainder of [my or the trust] estate to be used for _____ [describe purpose] or for general purposes."

This information is not intended as legal advice, but is merely suggestions as to content. The specific language should be written or adapted by your legal counsel.