Migraines and Other Severe Headaches: What You Need to Know

Transcript Highlights from Facebook chat on July 31, 2013

PainPathways: Welcome! Thank you for joining us today for “Migraine and Other Severe Headaches: What You Need to Know”. This Facebook chat will be co-hosted by Dawn Buse, PhD, and Matthew Robbins, MD.

Dr. Buse is an Associate Professor of Neurology at Albert Einstein College of Medicine and Director of Behavioral Medicine for the Montefiore Headache Center in New York, NY. She is a licensed clinical psychologist and fellow of the American Headache Society. Among other things, she conducts research on headache and pain and is a co-investigator on the American Migraine Prevalence and Prevention (AMPP) Study, a large, longitudinal US population-based study.

Dr. Buse’s website: http://dawnbuse.com/ and Twitter: @dawnbuse.

Dr. Robbins is an Assistant Professor of Neurology at Albert Einstein College of Medicine, the Chief of Service for Neurology at the Einstein Division of Montefiore Medical Center and the Director of Inpatient Services for the Montefiore Headache Center, where he also has a practice exclusively devoted to patients with headache.

Find more about Dr. Robbins on Twitter: @mrobbinsmd and http://www.einstein.yu.edu/faculty/11689/matthew-robbins/.

Dr. Robbins: We are so happy to join in and answer your questions about headache.

Dr. Buse: I am excited and honored to be partnering tonight with my colleague Dr. Matthew Robbins and Pain Pathways Magazine. I am a fan of Pain Pathways Magazine for all of the great information and support that they provide to people who live with chronic pain, migraine and other pain conditions. We look forward to answering your questions and also hope to provide additional helpful information, links and resources.

Dr. Buse: Migraine is a common and disabling neurological condition that affects about 12% of the population (18% of women!) or more than 36 million Americans. Migraine has been around since the beginning of recorded human history. In fact, it was mentioned in scrolls buried with Egyptian mummies in 1500 BC and in writings from ancient Babylon from 300 BC.
Dr. Buse: Migraine is made up of a constellation of symptoms. Headache is usually the main symptom and can last from 4-72 hours. It is often unilateral (one sided), with pulsating pain, and aggravated by movement or activity such as walking up stairs. Migraine attacks also often involve nausea, vomiting, photophobia (sensitivity to light), phonophobia (sensitivity to sound), and osmophobia (sensitivity to smell). All of these symptoms make it very difficult to function during an attack.

Dr. Buse: **Allodynia** (or heightened pain sensitivity such as a pain with a pony tail, wearing earrings, or even taking a shower) is a hallmark of migraine and especially chronic migraine. (see resource guide)

Dr. Buse: Barby asked if migraine is **inherited**. Yes. Migraine has a strong biological component. Like many conditions, it is probably caused by a combination of genetic and environmental factors. It runs in families, especially on the mother’s side, and more than half of people with migraine have at least one close relative who has the condition as well. Some people may remember a mother or grandmother referring to “sick headaches” and retreating to a dark, quite room for hours or days at a time. Twin studies have taught us that about half of the genetic risk for migraine comes from genes. So someone with one parent with migraine has a 50% chance of inheriting the disease while someone who BOTH parents with migraine has a 75% chance.

Dr. Buse: People with migraine have a very sensitive nervous system. This may have actually been a great survival mechanism at one point in human history when we needed to be very alert to changes (and danger) in our environment. There is a lot of cutting edge research right now in migraine and genetics. In fact, we took saliva samples from patients as part of the AMPP study to see what clues we could find in DNA. We will keep you posted.

Dr. Robbins: If someone has frequent or debilitating headache attacks, they should consult their primary care doctor first, and depending on how frequent or severe the attacks are, a shared decision should lead to referral to a neurologist or headache specialist.

Dr. Robbins: Botox can be a great treatment for people who have chronic migraine, where headache attacks occur on more days than not. A great resource for understanding Botox is here on the ACHE site. (see resource guide)

Dr. Buse: Rodriguez M. asked about the link between **migraine and stress**. Absolutely! Stress is a common migraine trigger. And the "let-down" or relaxation period following stress can also be a trigger. So it is important to manage stress by taking good care of oneself. Considering yoga, taking a walk, spending time with a pet, or listening to guided visual imagery. I have free audio relaxation audiocasts at dawnbuse.com that you might like. If stress overwhelming consider talking with a mental health professional.

Dr. Buse: Terrific. There are lots of great relaxation audio podcasts on iTunes, in Amazon, and also free on my website at dawnbuse.com. You can also listen to soothing music, meditate, try yoga or prayer if any of those are more attractive to you. Best wishes for your good health!

Setina A. So true. Many of my worse migraines come on day 1 or 2 of vacation when I finally start relaxing
Dr. Buse: The trick is to try to avoid the PEAKS in stress so that there is not as much of a drop when your vacation starts. I know this is easier said than done! (see resource guide for Biofeedback and Relaxation)

Dr. Robbins: There is ALWAYS hope. There are so many new and emerging treatments, both medication, non-medication, procedures, complementary and alternative therapies, biobehavioral therapies, and combination treatments in any of these categories. There are many headache specialists nationwide who are devoted to seeing patients who feel that there are no other options.

Dr. Robbins: NDPH (new daily persistent headache) is a condition that features daily nonstop headache from the beginning, rather than attacks of headache that eventually progress to a daily pattern, as can happen in some people with migraine. NDPH can be a tough condition to treat but it is great that someone wants to rigorously investigate your symptoms to make sure no diagnosis is missed.

Dr. Robbins: The treatment for new daily persistent headache (NDPH) is mainly borrowed from other chronic headache treatments (chronic migraine and chronic tension-type headache). It is not a very well-understood condition, though up to 1 in 1000 people may have it in any given year, and it is particularly common in teenagers. (see resource guide for additional information on NDPH)

Dr. Buse: Kristin H. asked if migraine can affect one side of the entire body. Yes, that is possible. Migraine headache pain is often (but not always one-sided) and there are other symptoms such as aura symptoms and prodromal symptoms which may be felt on one side of the body.

Dr. Robbins: Unfortunately only onabotulinum toxin A (Botox) is approved by the FDA for chronic migraine treatment. However, most headache specialists use many other medications, often "off label" (not approved), for chronic migraine treatment. Sadly, the government and pharmaceutical industry needs to take a bigger interest in chronic migraine so we can get more approved therapies out there!

Dr. Buse: "Is it still considered migraine when the pain never goes away?" Yes, unfortunately 1% of the population has chronic migraine. Migraine is divided into episodic migraine (EM) and chronic migraine (CM) based on the number of days per month that someone experiences headache. Episodic migraine is defined as meeting International Classification of Headache Disorders (ICHD-2) criteria for migraine with fewer than 15 headache days per month. Chronic migraine is generally defined as meeting criteria with 15 or more headache days per month. Some people with chronic migraine experience headache every day, and some people have continuous headache pain. If you have continuous headache and have not talked with a doctor or headache expert I would suggest that you do so.

Dr. Buse: Finding a headache expert can be challenging. If you can not find one listed on the AHS website, you may want to work with a neurologist near you to start. He or she may make recommendations about what to do next. There are a few inpatient programs in the country too that can be helpful for intractable conditions, but hopefully it will not get to that point. Best wishes.

Dr. Buse: Recent research by some of my colleagues found that as of 2012, there were 416 UCNS headache specialists practicing in the United States. Six states had NO headache specialists at all, while 8 had only 1 and 5 had only 2. The shortages are not evenly distributed across states. New York has the highest number of specialists (56), followed by California with 29, Ohio with 29, Texas with 25, Florida with 24, and Pennsylvania with 23. Six states—Alaska, Delaware, Montana, North Dakota, South Carolina, and Wyoming—have no headache specialists. States with the worst ratios of provider to migraine patients include Oregon, Mississippi, Arkansas, and Kansas. The District of Columbia has the
best ratio, followed by New Hampshire, New York, and Nebraska. We obviously need more headache specialists considering that more than 36 million people in the US have migraine alone!

**Butterfly Affect Coaching** Thank you, I have been under medical care for 14 years but just felt that the definition of CM didn't seem to fit. Thanks for the clarification.

**Dr. Robbins:** The best way to handle severe attacks of headache is to have an action plan with your provider before it happens. If a headache does not stop with medications at home and it is debilitating or is accompanied by new or unusual symptoms (one-sided weakness, visual changes, etc.) then it may require an emergency department visit. This is best to be avoided as emergency rooms are loud, noisy, bright, and unpleasant environments for headache sufferers!

**Dr. Robbins:** Headaches during pregnancy can be challenging, but many treatments (both medication and non-medication) are safe, and it is bad for both the mother and developing fetus's health for the mother to suffer from frequent pain, nausea, vomiting, and in such circumstances, the benefits of headache treatment often outweigh any risks. (Find link to Dr. Robbins' research on pregnancy and headache in the resource guide).

**Dr. Robbins:** A plan could and should include a first line medication, a second line medication, a medication for severe nausea or vomiting, and often a non-oral medication in case the nausea or vomiting interferes with intake of the initial medications. A "rescue" medication may also be needed, and part of the plan should be when is the appropriate time to call your provider when no improvement or worsening happens.

**Paul G.** How about other non pharmacological

**Dr. Buse:** Thanks so much for bringing up non-pharmacologic approaches to migraine management. They should be a component of treatment for every severe headache sufferer. Biofeedback, relaxation training, and cognitive behavioral therapy have strong evidence. They are relatively inexpensive (often free), benefits are long lasting (longer than medications) and they are safe for everyone even (especially) pregnant women.

**Dr. Buse:** Non-pharmacologic treatments for migraine management include strategies to manage stress and improve coping (including biofeedback, relaxation training, and cognitive-behavioral therapy), and trigger awareness and management. Someone who experiences migraine has a sensitive nervous system. A migraine attack can happen when the combination of biological and environmental factors (triggers) exceed a certain biological threshold. This threshold can change based on various factors. Triggers can include stress, relaxation after a stressful period (which surprises many people), too much or too little sleep or changing sleep patterns on the weekend or due to travel or other reasons, changing time-zones or jet lag, skipping meals or dehydration, bright lights, sustained loud noise or certain strong odors, weather changes and certain foods such as aged cheese and some alcoholic drinks among other factors. In many women, hormonal changes may trigger migraine. Maintaining a regular schedule with good sleep hygiene, healthy regular meals, staying hydrated, getting regular exercise and managing stress can help raise the threshold for attacks. Practicing relaxation techniques such as meditation, guided visual imagery, yoga, or other ways to quiet the mind can also have beneficial effects. Instructions and links to guided visual imagery are available at dawnbuse.com. If stress, depression, anger or anxiety seem unmanageable it is wise to speak to a mental health professional.
Dr. Buse: Setina A. asked about the relationship between weather and migraine. Yes Setina, weather changes are a common trigger for many people with migraine. In fact, people with migraine can often predict the weather because changes in barometric pressure, such as that preceding a storm, can trigger a migraine.

Setina A. Thanks Dr Buse. My husband always says I should be a meteorologist.

Dr. Robbins: There is a new patient-led organization under the umbrella of the American Headache Society which is called "AHMA" (American Headache and Migraine Association): https://ahma.memberclicks.net/

Dr. Robbins: Kate K.--sometimes it is hard to tell the difference between chronic migraine and new daily persistent headache, but if a nonstop daily headache had a beginning that was clearly recalled, and headaches weren't so frequent before then (4 days per month or less), the condition is likely new daily persistent headache.

Dr. Robbins: Many of you are asking great questions about particular conditions and their relationships to headache and migraine. It is hard to answer them individually...headache may be a symptom of such conditions, or migraine may happen more often in such conditions (we call this "comorbidity").

Dr. Robbins: Teri Morgan mentions cluster headache, which is such an excruciating condition and typically does not resemble migraine at all. Though some of the medication treatments overlap with migraine, many do not, and it is approached very differently.

Dr. Buse: Paula asked about several comorbidities. Paula, we do not have that specific info at hand right now, but you bring up an important point about comorbidities. Having migraine is associated with several medical and psychiatric comorbidities. Comorbidity is the occurrence of two conditions at rates higher than expected by chance. Common psychiatric comorbidities include depression, anxiety, panic disorder, post-traumatic stress disorder, adverse childhood experiences (e.g., physical, emotional and sexual abuse) and higher rates of suicide attempts. And rates of these conditions are even higher in people with chronic migraine. It is not clearly understood in many cases whether one condition causes the other, or they both develop out of shared underlying genetic or biological predispositions. In the case of migraine and depression, it has been shown that they are bidirectional, and each place those who experience one at a higher risk for the other. Medical comorbidities of migraine include epilepsy, stroke, cardiovascular disease, sleep disorders (e.g., insomnia, restless leg disorder, and sleep apnea), musculoskeletal disorders, chronic pain conditions (e.g., fibromyalgia, chronic back pain), obesity, respiratory disorder (e.g., asthma, allergic rhinitis), irritable bowel disease, cervical dystonia, celiac disease, chronic fatigue and other conditions. These conditions are also even more common among people with CM compared to those with EM. For more info about comorbidities you can see one of our research articles from the American Migraine Prevalence and Prevention (AMPP) Study. (see resource guide)

Dr. Robbins: Occipital neuralgia is a condition that may be discussed by providers, which means that the occipital nerve (which transmits sensory and pain information from the back of the head) is the source of the pain. In reality, migraine often features pain in the "occipital" (back of the head) area anyway, and it is much more common of a cause of pain in that region.

Kate K. Thank you, that helps to clarify that it could 'still' be a migraine.
**Dr. Robbins:** the term "cluster migraine" creates confusion, because "cluster headache" and "migraine" are very different conditions, though both feature severe headache. Some providers refer to "cluster migraine" when patients who have migraine only have attacks in clusters, with weeks or months of pain freedom in between bouts of attacks.

**Dr. Buse:** We have talked a lot about medications tonight, and they can be a vital component of a migraine treatment plan. Treatment of migraine includes both medication (pharmacological) and non-medication approaches. Medication approaches can be acute, meaning that they are intended to be used when pain occurs, and preventive, which are medications that are taken on a daily basis or given throughout the day.

**Dr. Robbins:** many people ask about "migraine surgery," which many surgeons advertise as a cure for migraine. There is no cure for migraine. (see resource guide on Surgical Intervention).

**Dr. Robbins:** Many women do experience significant improvement of their **migraines after menopause.** However, often in the middle of menopause, which can take years, migraine can worsen and become very unpredictable. Also, patients with chronic migraine may not experience the same rate of remission after menopause than those patients whose migraine attacks are not as frequent.

**Dr. Buse:** In the AMPP study of 24,000 people with severe headache the prevalence of migraine peaked between the ages of 20-50 and dropped dramatically after age 60 (generally after menopause is complete and hormones have stabilized).

**Dr. Buse:** "What is the number one advice you would give to someone suffering with headaches that can give them hope?" Headache has existed since earliest recorded history, and that’s just as far back as we know. However, the good news is that the science of headache treatment and management is constantly growing. Therapies can be divided into pharmaceutical, interventional and behavioral. There are recent developments in all of these areas, which can give hope to those who suffer from headache, especially migraine. In terms of pharmacologic treatments (medicines), researchers are looking into new classes of medications for migraine acute and preventive treatment. In terms of interventions, nerve stimulators and implantable devices are being tested in many forms. And in terms of behavioral treatments, mindfulness, stress management, and cognitive behavioral therapy for migraine management continue to develop both treatments and our understanding of how they work. MRIs have given us especially interesting insights into how the human brain responds.

**Sharron M., MS, RN** I would add, in terms of acupuncture and a number of mind-body techniques not mentioned, research is also ongoing and shows promising results in changing pathways in the brain, and balancing the body's response to stress:).

**Dr. Buse:** Here are some of the most important things that someone with migraine can do for him/herself: Getting an accurate diagnosis is an essential step towards getting the right treatment plan. If you have headaches that affect your work, school or personal life talk with your doctor about them. Depending on what type of headache you have, there are a range of effective treatments.

**Rodriguez E. M.** Thanks to everyone at *PainPathways Magazine* and Dr. use and Dr. Robbin! This was very informative!

**Kate K.** Thanks you so very much. I was afraid I really wouldn't learn anything being that I am unfortunately VERY EXPERIENCED with headaches - LOL. But I did learn a few things and
walked away with some resources I didn't have before. Most of all - I am very appreciative of the time that Dr. Robbins and Dr. Buse took with all of us.

Hi everyone! This is Amy North, editor of *PainPathways Magazine*. On behalf of Dr. Richard Rauck, we’d like to thank Dr. Buse and Dr. Robbins, and all those who participated in tonight’s chat. We are excited to be offering this forum for information and inspiration.

**Lucille H.** Thank you, Amy! It really was a wonderful chat! Full of some great questions, conversation, and valuable information! I’ve passed it on to our RSD ATLANTA support group! Good stuff! Thanks to all involved!

**Dr. Buse:** Thank you to everyone who participated in this important chat tonight. Sorry we could not get to everyone’s questions. Please use the links that we provided during the chat for more information: AHS, ACHE, NHF, AHMA and follow us on Twitter for new research and ongoing information. Special thanks to Pain Pathways for hosting this chat and to my colleague and friend, headache expert neurologist Matthew Robbins, MD, for offering his expertise.

**Dr. Robbins:** Thanks to all of you who have asked such great and informative questions. This was a great experience for us and Dr. Buse and I thank *PainPathways Magazine* for inviting us to co-host this chat!
Resource Links

**What Is a Headache Specialist? Do I need one? And how do I find one? | ACHE**

http://www.achenet.org/resources/what_is_a_headache_specialist_do_i_need_one_and_how_do_i_find_one/

**Allodynia When Touch Hurts But Shouldn’t** by Dr. Gretchen Tietjen.
http://www.achenet.org/resources/allodynia_when_touch_hurts_but_shouldnt/

**American Migraine Prevalence and Prevention (AMPP) Study**
http://jnnp.bmj.com/content/81/4/428.long

**What is a Headache Specialist? Do I Need One and How Do I Find One?**
http://www.achenet.org/resources/what_is_a_headache_specialist_do_i_need_one_and_how_do_i_find_one/

**Botox**

http://www.achenet.org/assets/2/7/May_2012_Newsletter.pdf

**Cluster Headache | ACHE -- www.achenet.org**
http://www.achenet.org/resources/cluster_headache/

**Biofeedback and Relaxation Training for Headaches | ACHE**
http://www.achenet.org/resources/biofeedback_and_relaxation_training_for_headaches/

**Relaxation for Headache Relief** by Dr. Buse -- www.painpathways.org
http://www.painpathways.org/2013/05/24/breathing/

**Find a headache expert by zip code**
http://www.achenet.org/resources/healthcare_professional_search/

**Infographics Explains Headaches**
http://www.painpathways.org/2013/01/18/headsaches-101/

**Study Holds Up ‘Let-down Headache’ Hypothesis**

**ABCT Association for Behavioral and Cognitive Therapies (Cognitive Behavioral Therapy)**
www.abct.org
http://www.abct.org/Home/

**36 Million Migraine Campaign | American Migraine Foundation**
http://www.americanmigrainefoundation.org/support-the-foundation/36-million-migraine-campaign/
Chronic Migraine Prevalence, Disability, and Sociodemographic Factors: Results From the American Headache Society.  

New Daily Persistent Headache - The Basics | ACHE  --  www.achenet.org  
http://www.achenet.org/resources/new_daily_persistent_headache__the_basics/

Neurology Reviews : Shortage of Migraine Specialists in the United States  
http://www.neurologyreviews.com/Article.aspx?ArticleId=iApjP2F0Q+8=

Secondary Headaches Flag Medical Conditions in Pregnancy: Skin & Allergy News  
http://www.skinandallergynews.com/sl.-view/secondary-headaches-flag-medical-conditions-in-pregnancy/63f0b3881def148bd617e87af347b2f.html

Stigma of Migraines  
Migraine Sufferers Face Significant Stigma, Study Finds – WebMD  --  www.webmd.com  
PLOS ONE: The Stigma of Migraine  --  www.plosone.org  
http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0054074  
http://www.huffingtonpost.com/tag/migraine-stigma

Surgical Intervention  
American Headache Society Urges Caution in Using Any Surgical Intervention in Migraine Treatment  

7 Surprising Things You Don't Know About Migraines  
http://news.health.com/2013/06/27/surprising-about-migraines/

Books  
A Brain Wider Than the Sky  --  www.goodreads.com  
Pain Chronicles by Melanie Thernstrom
Websites

Dr. Buse:  http://dawnbuse.com/
Dr. Robbins:  http://www.einstein.yu.edu/faculty/11689/matthew-robbins/
American Headache Society:  www.americanheadachesociety.org
American Migraine Foundation:  www.americanmigraineorganization.org
American Headache and Migraine Association (AHMA):  https://ahma.memberclicks.net/
Headache Journal:   http://www.headachejournal.org/view/0/toolboxes.html
National Headache Foundation:   http://www.headaches.org/

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