Journal of The Facial Pain Association

Quarterly

Winter 2016

"This conference had a broad range of expert presenters, who limited content to high-level, significant information."

"The passion of the leaders and participants provides hope for coping with this disease, and pain management in general."

"The most meaningful part of the conference for me was listening to the experts and realizing that there is considerable hope."

"When I walked into the conference, I felt normal for the first time in 30 months."

"The FPA Conference changed my life."

"I loved the variety of speakers and information."

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TNA FACIALPAIN ASSOCIATION

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Quarterly

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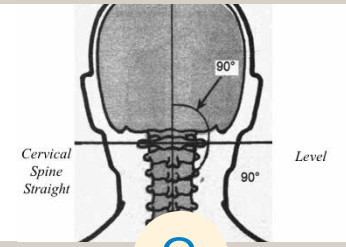

IN EVERY Q

Corrections to the Fall 2015 Issue of *Quarterly*

The article on Dr. Jannetta incorrectly stated the number of residents he trained while Chairman of the Department of Neurosurgery at the University of Pittsburgh. Dr. Jannetta trained over 150 Residents, 22 of whom went on to be Department Chairs.

Our apologies to James Zisson who was inadvertently left off the list of past TNA Board Members. Mr. Zisson was a valued board member, serving from 2005 – 2007.

TNA FACIALPAIN ASSOCIATION

From the Chairman of the Board

TNA's 25th Anniversary National Conference took place in New York City on October 10 and 11, 2015. The conference was a huge success! Nearly 300 attendees listened to a day and half of informative presentations by neurosurgeons, dentists and a psychologist with expertise in treating facial nerve pain. Attendees also had time to meet in small groups with those experts and with each other. Traveling from as far away as Alaska, they tell TNA that the conference helped them to better understand their disease, see that they have treatment options, decide what options may be best for them and to find, although TN is rare, that they are not alone. We thank Dr. David Sirois for arranging the venue, Dr. Jeffrey Brown for arranging the speaker program and speaking himself, over ten other speakers, and TNA's CEO John Koff and Staff for all their work.

No recap of the Anniversary Conference is complete without another thank you to Ms. Claire Patterson and Dr. Peter Jannetta who started TNA. TNA's essence is providing proactive and personal assistance to people, and to those who support people, who have facial nerve pain. It all began with Claire and Peter 25 years ago.

Now, let's look forward.

TNA's regional conferences give people a chance to meet close to home. Thanks to generous support from Mr. Brett Frankel, we are planning years ahead for a series of one-day conferences. During 2016, there will be a conference on April 23 at the University of Pittsburg Medical Center and then another on September 10 at the University of Minnesota School of Dentistry. Like speakers at the Anniversary Conference in New York, the speakers at regional conferences have treated thousands of cases of facial nerve pain. They are the hard-to-find experts. Attendees also learn a lot from each other including managing drug side effects, relationships, work and other aspects of life outside of the doctor's office. Watch TNA's web site and emails, or check with your local Support Group, for details.

Although the evidence is anecdotal, doctors tell TNA that fewer people now arrive in their offices after long trails of misdiagnoses and ineffective treatments. But that still happens too often and TNA will continue its Healthcare Professional Education Program in an effort to accelerate correct diagnosis. Keep an eye on the TNA Quarterly; we have a series of articles by topic experts on pain psychology, medications and surgeries on the way. Many of TNA's programs involve the Internet; those include our web site, TNA News Wire, TNA Quarterly, Face Pain Network, Video Project and our Facebook page. Internet-based communication and media are changing rapidly and TNA's new staff member, Ms. Carly Kosmacki, is working to put TNA at the leading edge of using the Internet to be useful to you and to manage our organization.

While most of TNA's programs help people now, TNA's Facial Pain Research Foundation is our program that funds early-stage research to improve diagnosis and treatment in the future. Exciting research includes a search for genes that are associated with facial nerve pain and an effort to repair the myelin insulation around nerves that may be compressed or damaged.

As always, call TNA's office anytime for information or assistance.

Jeff Bodington, Chairman of the Board
TNA – The Facial Pain Association

UPPER-CERVICAL CHIROPRACTIC CARE FOR FACIAL PAIN

Larry S. Arbeitman, D.C. (Logan College of Chiropractic in St. Louis, Missouri) is licensed in the state of New Jersey and has met the requirements of the National Board of Chiropractic Examiners. He is an active member of the National Upper Cervical Chiropractic Association (NUCCA), Quantum Spinal Mechanics3 (QSM3, and the Association of New Jersey Chiropractors (ANJC). He presents at regional TNA-The Facial Pain Association Conferences and Support Groups. He is well known for his treatment of patients with facial pain.

Since its inception in 1895, chiropractic has been a philosophy, art, and science deeply rooted in restoring health through empowering the nervous system. The nervous system, which is protected by the skull and spine, is the command and control network for our bodies. When it is stressed physically, chemically, or emotionally, we lose the ability to function and heal optimally. Chiropractic has hundreds of techniques that support this vital truth, realizing that health is reached by empowering the whole body rather than by suppressing parts of it.

Upper-cervical care is one chiropractic technique that focuses on balancing the entire spine and reducing interference in the nervous system by precisely adjusting the misaligned or subluxated spine through the upper neck, at the level of the brainstem where the brain meets the spinal cord. An upper-cervical correction is delivered in a calculated and controlled fashion with no twisting, pulling, jerking, or cracking of the neck. One common misconception of upper-cervical care is that it focuses solely on neck and back pain. Although

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QUARTERLY
is published four times per year by
The Facial Pain Association,
408 W. University Avenue, Suite 402
Gainesville FL 32601-3248

800-923-3608

www.facepain.org

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upper-cervical care has helped thousands with neck and back pain, patients also have found relief from a variety of other health conditions, including facial pain.

Due to the public's misconception that chiropractic care is only for the treatment of neck and back pain, patients with facial pain are rarely advised nor often take it upon themselves to contact a chiropractor. Add to that the fact that only an estimated 2,000 chiropractors in the world practice upper-cervical treatment, and many patients with facial pain never consult with an upper-cervical practitioner. However, through facial-pain support groups and conferences, word of mouth, social media, and increasing awareness, upper-cervical doctors do have significant experience working with facial pain.

The track record has been promising with upper-cervical care. Although more published studies need to be performed, case studies have been published and a large body of anecdotal patient reports have demonstrated significant and sometimes complete pain relief.

The spine and facial pain connection

Upper-cervical chiropractors detect and correct misalignments or subluxations in the upper spine that can cause facial pain in two ways. One is by an injury or macro-trauma, such as a fall or a car accident that traumatizes the upper spine. The other is a more gradual misalignment or micro-trauma that develops throughout life from common spinal traumas such as the birth process, hundreds of falls as a child, sports injuries, poor posture, or neck-stressing repetitive actions.

Researchers have determined that TN pain originates from damage not only to the trigeminal nerve in the face but also from damage to the central trigeminal system in the upper spinal cord and the pontomedullary levels (pertaining to the pons and medulla oblongata) in the brainstem.

Therefore, concussive trauma to the head, neck, or upper back that results in injury to nerve pathways in the spinal cord and brainstem has been shown in medical literature to be a possible cause of TN. Following the trauma, facial pain can be triggered immediately or can take months or years to develop.

These traumas can affect the position and alignment of the top three vertebrae and particularly the uppermost bone, the atlas or C1 vertebra. The atlas is a doughnut-shaped bone that surrounds the spinal cord directly below the brainstem. In ideal position (i.e., orthogonal), the atlas is exactly horizontal without any twist or rotation, the spine is gently curved backwards, and the head doesn't tilt abnormally. But most of us have had a variety of spinal stressors or have less-than-ideal posture.

The C1 spinal level is unique. It is the only level of the spine that does not have an intervertebral disc above or below; nor does it have interlocking joints like the rest of the spine. The C1 is attached to the skull above and spine below only with soft tissues (muscles, ligaments, and cartilage), thus allowing for maximum movement so we can turn our heads 80 degrees in each direction. This freedom of motion and soft-tissue attachment lend themselves to a high probability of upper-cervical misalignment following a head or neck trauma. In fact, it does not take much for misalignments to occur when a 10- to 18-pound ball (the head) is held atop a narrow bone that houses the all-important spinal cord. But spinal misalignment or subluxation may not cause any noticeable symptoms for years. It is postulated that, for

some patients with facial pain, upper cervical misalignment can tug on the top of the spinal cord, affecting nerve transmission, cerebral spinal fluid, and blood flow to the base of the brain.

Raymond Damadian, MD, at the Cranio-Cervical Syndrome symposium, demonstrated with Fonar MRI that upper-cervical misalignment can cause a blockage or congestion of cerebral-spinal-fluid flow to the mid-brain. An accumulation of fluid in the brain can lead to neuro-degenerative diseases. Further, he highlights that as much as 11 years can pass between the initial trauma and the onset of neurological symptoms.

Since the trigeminal nerve originates in the trigeminal nucleus (bundle of nerves), which extends down through the entire brainstem and into the upper cervical spinal cord, trauma of the nucleus at the level of the cord may produce symptoms at the end of the nerve in the face. This mechanism is known as referred pain and can be equated to a patient experiencing sciatic-nerve leg pain that originates from a trauma to the nerve in the lower back.

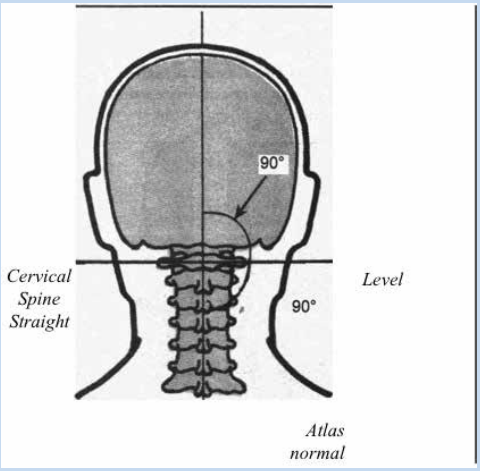
Just as a compressing blood vessel at the nerve's root can make the whole trigeminal system hyper excited, damage to the trigeminal nucleus may have the same effect. Or it may take both of these offenses to cause TN in some people. This might explain cadaver studies that have shown some people who did not have TN but who have nerve/vessel contacts near their brains. And it may also explain why most people with misaligned upper spines do ***not*** have TN: they're lacking a compressing blood vessel in the skull as the additional triggering factor.

Searching for problems

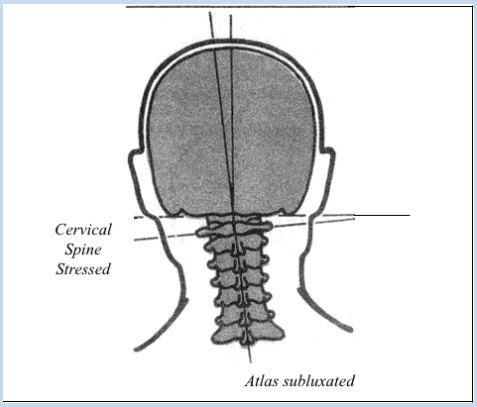
An upper-cervical chiropractor will perform a health history to understand a patient's condition and spinal history. Potential traumatic causes will be discussed. The doctor will perform an orthopedic, neurologic, and chiropractic examination, including a postural evaluation that focuses on head tilt, uneven shoulders, a tilted pelvis, a twisting of the torso or pelvis, and leg-length inequality. Postural imbalance and leg-length inequality is secondary to spinal compression, subluxation, proprioceptive (awareness of posture and sensations of body movement) and vestibular (relating to the ear) rebalancing, and neurological tension.

Some practitioners also use instruments, such as infrared thermography that measures minute temperature differences of the skin at various points. Temperature differentials usually indicate an imbalance in blood flow and autonomic function at a particular spinal level. Surface Electromyography (sEMG) is another form of objective measurement of the misalignment, which allows the practitioner to measure motor nerve function or areas of muscle imbalance secondary to aberrant nerve signals.

Almost all upper-cervical techniques utilize precise upper-cervical x-rays to evaluate and measure the upper-cervical subluxation. Modern technology enables these studies to be digital and misalignments can be measured to 1/100th of a degree. It is the precision of the x-rays and measurements coupled with the gentle mechanics of the adjustment that allow upper-cervical care to be calculated and noninvasive.



Cervical Spine Straight



Cervical Spine Stressed

The sketch at the top shows how the atlas (the top bone of the spine) should be orthogonal (aligned perpendicular) to the head and the axis of a straight cervical spine. The sketch below shows how the atlas may be tilted, causing pressure on the nerves that run through it.

Reprinted with permission of Vogel Enterprises, Inc.

Aging is considered a contributing factor to TN because, as we age, our spinal discs thin, the joint spaces get tighter, cartilage erodes, and our necks shorten. The result is extra pressure on the spinal ligaments. Further, as demonstrated by Dr. Damadian, cerebral-spinal-fluid flow to and from the mid-brain may be

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blocked by advanced degenerative changes. That may help explain why TN is much more common in older people.

Fixing the misalignments

If pressure on the upper spinal cord is contributory, then the way to address it is to adjust the upper spine in order to correct mechanics, position, and physiology. The goal is to take pressure or traction off the spinal nerves or, in effect, to decompress the spine and nerves. In that regard, the aim is similar to that of neurosurgeons in moving a compressing blood vessel off the trigeminal nerve root in an MVD.

By some estimates, there are as many as 150 different chiropractic techniques. Upper-cervical is a specialized subfield of chiropractic that's practiced by roughly only 2,000 chiropractors out of the estimated 60,000 chiropractors now practicing in the United States.

Even within this specialty, about 10 different subspecialties go by names such as Quantum Spinal Mechanics3, Orthospinology, Atlas Orthogonal, Advanced Orthogonal, NUCCA (those who are members of the National Upper Cervical Chiropractic Association), Knee-chest, Blair Upper Cervical, Kale Brainstem, and the Laney Technique.

Some doctors use only the hands to adjust the spine. Some use different types of instruments or equipment. Some use supplemental therapies such as ultrasound, electrical stimulation, and ice or heat treatments. Methods of assessment and adjustment vary among the techniques. And the angle and degree of adjustment may differ among upper-cervical chiropractors all of which justifies that chiropractic is an art as well as a science.

Upper-cervical chiropractors say this field has become so specialized in part because of the precise adjustments that are needed when working in the upper spine. "Due to the unique anatomy and the overall importance of the neurology of the upper cervical spine on human health, most upper-cervical practitioners practice upper-cervical care exclusively," commented one practitioner.

Unlike the traditional high-velocity and high-force adjustments that are administered by many chiropractors, upper cervical adjustments are generally less forceful. In some of the techniques, the adjustment amounts to little more than a slight tap or some mild vibrations. Many upper cervical adjustments use no more pressure than if you were going to check a tomato to see if it were ripe.

Retired Alabama chiropractor Dr. Cecil Laney, himself a patient with TN, says it doesn't take much force to adjust the atlas. However, he says it does require a very precise movement by a skilled practitioner using accurate before-and-after X-rays.

The cervical spine is a very complex mechanical structure; more nerves go through it than any other part of the body. An upper-cervical adjustment feels similar to the pressure a nurse uses when checking your pulse; it's usually a little tap.

However the adjustment is done, the idea is to achieve alignment of the entire body. This means the head is balanced on top of a horizontal atlas, the spine and pelvis directly balanced underneath without any twist in the head, torso, or pelvis. The number of adjustments required and length of care varies based on each individual case. Some patients utilize the care for a short while for relief while others incorporate maintenance upper-cervical care as part of their overall healthcare management strategy.

Success rates

To date, no clinical trials have been published on TN and chiropractic. Published case studies and patient's anecdotal experiences remain as the evidence supporting the utilization of upper-cervical care for facial pain.

In a pilot study in 2000, an upper-cervical chiropractor treated eight patients between the ages of 47 and 79 who had had TN pain for an average of just over seven years. Each patient got between three and 12 spinal adjustments over an eight-week period. Of the eight patients, two got complete relief after the first session and had no recurrence during the eight-week study. The remaining six all got significant relief over the first four weeks, averaging 69 to 78 percent pain reduction based on two different before-and-after pain questionnaires.

All eight patients had significant decreases in pain scores during the eight-week study period. None continued to have lancinating pain at the end of the study, though several continued to have significant numbness and abnormal sensations from previous surgeries.

The chiropractor added that results did not differ between the five patients who had undergone previous TN surgery and the three with no history of surgery, suggesting that prior surgery might not affect chiropractic success rates.

In a personal survey of upper-cervical colleagues who together had treated a total of 68 patients with TN, chiropractors reported that 73.5 percent of their patients got complete pain relief, 21 percent got at least some relief, and about 6 percent were not helped at all.

The goal is to realign the spine so it no longer interferes with nerve physiology. Says one upper-cervical chiropractor, "The time frame varies from person to person. As a rule of thumb, I tell people to give it 30 days to notice a change."

Also, it may take some extra time for injuries to heal even if the spine is successfully realigned. People who have had especially severe pain for a long time also take more time to see improvement.

In rare instances, some patients feel some temporary discomfort for a few days after a chiropractic adjustment, particularly muscle stiffness related to the change in spinal position. That's the body readjusting to its new posture. However, there should be no sharp pain, bad headaches, or other adverse effects. When this treatment is done by an experienced chiropractor, the patient should have no complications.

Be sure to stay in close touch with your primary care doctor before reducing or stopping any TN medications. Decreasing too quickly can cause significant, even dangerous, side effects.

Keeping the pain away

Often the stability and longevity of the correction requires successive visits. One chiropractor explains that when the tissues around the spine are stretched or weakened, it takes some "retraining" to get them to tighten enough so they can hold the spine in its new, corrected position. Furthermore, posture and movement patterns are entrained neurologically. Successive adjustments are required to create a new neurological and motor pattern. That's why a series of adjustments may be needed at the beginning and why practitioners recommend tapering off care to maintain alignments. Once patients are stabilized, they usually need to go back every so often for a checkup if they utilize maintenance care. Checking for misalignment or subluxation regularly allows the doctor to correct the spine prior to the pain relapsing.

In addition to adjustments, chiropractors also usually attempt to figure out what might have caused the misalignment in the first place. If it's a posture problem, for example, the chiropractor may recommend different walking, sitting, or sleeping habits. If it's a repetitive action like cradling the phone on the job, a headset may help. Often, postural and supportive exercises are recommended.

Upper cervical chiropractic's role in facial pain

Upper-cervical chiropractic's main appeal to patients with facial pain is that it offers a possible way to get pain relief without the sedating side effects of medicine and the potential complications of surgery. These people hope that if all goes well, they won't face a lifetime of pills and won't have to make a decision that might leave them with a numb face or worse.

Others turn to upper-cervical chiropractic only after they weren't helped by those more mainstream therapies. And still others use upper-cervical care as one part of a multi-pronged approach that includes mainstream therapies and other CAM therapies.

The bright side is that some people report getting remarkably good results from just a few adjustments. Some are able to get off medication and at least get a temporary reprieve from pain.

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Upper-cervical chiropractors say they're having equal success with those who have anesthesia dolorosa or pain of obscure etiology two conditions that don't respond as well to mainstream therapies. And they point to the low risks and the fairly quick results.

The down side is that, at best, it's unknown how helpful spinal adjustments will be over the long haul. As with other therapies, the pain may find its way back despite repeated series of adjustments.

Repeat or regular adjustments can be done so long as they are helping. There is an obvious cost for care, although some insurance policies and Medicare may cover a portion of the required care. Those who find relief find the investment worthwhile.

Then there's the confusing issue of finding someone who offers the particular technique that's most likely to help you.

Given the relatively few upper-cervical specialists, you may have trouble finding one, especially in rural areas. And if there are only one or two, you may not be able to choose whether you prefer, say, a hands-only practitioner versus an instrument practitioner. The techniques vary tremendously. That means the only way you're going to know whether a particular chiropractor is going to help is to try it.

Be sure to ask about the chiropractor's training and experience and to ask what kind of success she or he has had in treating cases similar to yours. If possible, get recommendations from other people with facial pain.

If you don't have success with one upper-cervical chiropractor, try another. A different technique may work where the initial one failed.

HOW TO FIND AN UPPER-CERVICAL CHIROPRACTOR

Besides getting recommendations from others with facial pain and searching online, you can locate different types of upper-cervical chiropractors through their organizations. Some of these and other upper-cervical resources are:

- Academy of Upper Cervical Chiropractic Organization
  1637 Westbridge Drive, Unit H4, Fort Collins, CO 80526
  www.aucco.org
- American Chiropractic Association
  1701 Clarendon Blvd., Arlington, VA 22209
  1-800-986-4636
  www.amerchiro.org
- International Chiropractors Association
  1110 N. Glebe Road, Suite 1000, Arlington, VA 22201
  1-800-423-4690 or 703-528-5000
  www.chiropractic.org

- National Awareness Campaign for Upper Cervical Care
  5215 Colbert Road, Lakeland, FL 33813
  1-888-622-8221
  www.uppercervical.org

- National Upper Cervical Chiropractic Association
  2608 West Kenosha, Suite 224, Broken Arrow, OK 74012
  918-748-1900
  www.nucca.org

- Quantum Spinal Mechanics3
  12850 Hwy 9 Ste 600-161
  Alpharetta, GA 30004
  770-641-9797
  www.QSM3.com

- Society of Chiropractic Orthospinology
  770-517-9921
  www.orthospinology.org

- Up C Spine
  An informational website on all the techniques, founded by patient Greg Buchanan; includes lists of practitioners worldwide
  www.uppercervicalspine.com

TNA Membership

The following individuals joined or renewed their TNA membership between May 31, 2015 and November 30, 2015.

June
Michael Brannock
Nancy Firsichbaum
Judith Gardner
Marvin Gorley
David Goss
Wendy Lyka
Denise Meyers
Faye Olivier
Sandra Rosenblatt
Joseph Scheuchenzuber
Russell Sjaarda
Gloria Thomas
Dillard Thompson
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July
Diane Adams
Theresa Bruno
Laurie Donlon
Paul Interval
Catherine McCarthy
Nathan Pieper
Lila Rissman
Donna Sullivan
Johana Vargas

August
Lonnie Capon
Howard Kilby
Douglas Law
Theresa Loughnet
Laurisa Sellers
William Stern
Jessica Vlack

September
Lollie Abramson
Robert Chernow
Jennifer Donahue
Sarah Donly
Jeffrey Fogel
Stuart Gause
Hayim Herring
Joy Seaton
Rose Tuozzola
Susan Zeman

October
Ellen Malessa
Jeffrey Norwood
Esther Psarakis

November
Mariellen Esler
Elaine Kicklighter

Facial Pain Association REGIONAL ConferenceProgram

sponsored through the generous donation of Brett Frankel

2016

April 23

University of Pittsburgh Medical Center,
Faculty Director, Raymond Sekula, M.D.

Sept. 10

University of Minneapolis Dental School,
Faculty Director, Donald Nixdorf, D.D.S.

Register at www.facepain.org or call 800-923-3608

TNA FACIALPAIN ASSOCIATION

10th National Conference

The Facial Pain Association's 10th National Conference, held in New York City October 10th & 11th, brought together over 300 patients, caregivers, doctors and supporters from across the world. Among the conference highlights were the Lunch with the Experts on Saturday, and Brunch with the Experts on Sunday. These two events gave patients and caregivers a chance to connect one-on-one with the leading experts in facial pain in a relaxed, informal setting.

This year's conference also had over 40 young patients in attendance, with special sessions led by the Young Patients Committee (YPC) during the conference.

Many patients said their favorite part of the conference was having the chance to meet others who have facial pain. For some patients, this was the first time they had met someone else with the same disease. For others, it was an opportunity to transform an online friendship that began on social media.


















Thank you again to everyone who was able to attend the conference. If you were unable to join us in New York City, we will begin our Regional Conference Program this spring in Pittsburgh, PA. More information, including conference dates, will be made available on our website facepain.org in the coming weeks.



















By Eleanor Nelsen

TEACHING THE NERVOUS SYSTEM TO FORGET CHRONIC PAIN

"It was an emergency situation," she says. The horse Sally was riding was barreling straight towards another, younger horse, and the only way to stop him was to pull back on one rein, hard. She felt a pop in her wrist. Heat shot up her arm, excruciating pain fast on its heels.

That was four years ago. No one knows quite what happened to her wrist that day, but whatever it was has left her with constant pain that stretches from her fingertips to her neck, and sometimes creeps into her ribs. On the really bad days, even a hug is unbearably painful.

Sally is my youngest sister, and she is one of an unlucky fraction of people for whom an injury catapults their nervous system into a state of chronic pain. The injury itself heals, but like an insidious memory, the pain lingers. We don't know why. ***"The whole issue of the transition from acute pain to chronic pain—why some individuals develop that chronic pain and many don't—is a major, major question,"*** says Allan Basbaum, a professor at the University of California, San Francisco. Genetics may play a role. So can the severity of the original injury.

But what we do know is that once that pain has gotten a foothold, doctors and patients don't have very many choices. "The irony is that morphine, the 2,000-year-old drug, still remains the number-one weapon against pain," says Yves De Koninck, a professor of neuroscience at Université Laval in Canada.

And it's not a weapon that anyone enjoys using. Opioids like morphine and oxycodone are famously addictive, and the numbers of people who abuse them are climbing. Painkiller overdoses now kill more people than cocaine and heroin combined. And while opioids are invaluable for acute pain, they're less effective for persistent, chronic pain. In fact—in a particularly cruel irony—long-term opioid treatment can actually make pain worse. Non-opioid pain medications exist, but they don't work for the majority of patients, and even then they are only partly effective.

Opioids work so well for acute pain because they bind to the receptors the body has designed for its own painkillers—molecules like endorphins and dynorphins that blunt the pain response. Finding good alternatives to opioids for treating chronic pain will mean finding different neurological mechanisms to target—mechanisms that explain not just why people hurt, but why some people hurt for so long.

De Koninck has found such a mechanism. One of the keys to understanding chronic pain, he believes, is to pay attention to the similarities between long-lasting pain and another, very familiar, neurological process that makes some connections stick around longer than others: memory.

Chronic pain is like "a maladaptive memory," Basbaum explains. Both constitute patterns etched in your brain and nervous system that quicken

the connections between "snake" and "poison" or between "bump" and "ouch." Evidence has been piling up that chronic pain and memory share some of the same cellular mechanisms—and now, De Koninck's work has shown that a neurochemical trick used to erase memory may be able to turn off chronic pain, too.

An Unmet Need

The number of people struggling with chronic pain has been hotly debated, and the fact that chronic pain is broadly defined and difficult to quantify doesn't help. But even conservative estimates suggest that about 20% of the population have had at least one episode of serious, chronic pain. In the United States alone, that's more than 60 million people. "It's a major unmet need," De Koninck says.

Pain is physically and psychologically debilitating in a way that few other conditions are. "In fact, it's often the most debilitating component of many diseases," De Koninck notes. And it sharply circumscribes the lives of people who suffer from it. People can find a way to live with the other challenges of painful conditions like arthritis, cancer, even paralysis, he says, but "if you actually ask the patient, their number-one concern, and the one thing that they want us to cure, is the pain."

When chronic pain gets severe, many patients withdraw, sometimes even from their families. Sally says that she's constantly nervous, afraid to accept invitations or do things that she loves—like riding horses—in case it makes her arm even worse. The ride that day, Sally says, "changed my life." For some patients, chronic pain can lead to serious mental health problems—it's strongly correlated with depression and suicide risk.

When pain pathways are functioning properly, they play a protective role. They are a relay of chemical and electrical signals that move from nerve endings to our brains. Pain teaches us to avoid things that are sharp, prickly, or hot. It's the way our nervous system has adapted to living in a hazardous world. People who can't feel any pain typically don't live very long.

Our skin is packed with millions of specialized nerve endings, programmed to detect dangerous conditions like heat or pressure. When one of these pathways is activated, the neuron sends an electrical current shooting up its long, thin axon towards the spinal cord. When it reaches the end of the neuron, that electrical signal prompts the release of chemicals called neurotransmitters into the synapse, or the gap between the first neuron and the next. The neurotransmitters dock in receptors on the next neuron, triggering pores to open in the cell's membrane. Charged particles rush in through these open pores, creating a new electrical current that carries the signal farther up the nervous system.

The first handoff occurs in a region of the spinal cord known as the dorsal horn, a column of grey matter that looks, in cross-section, like a butterfly. From this first relay point, the signal travels to the thalamus, one of the brain's switchboards, and eventually to the cerebral cortex, where the signal is processed and decoded.

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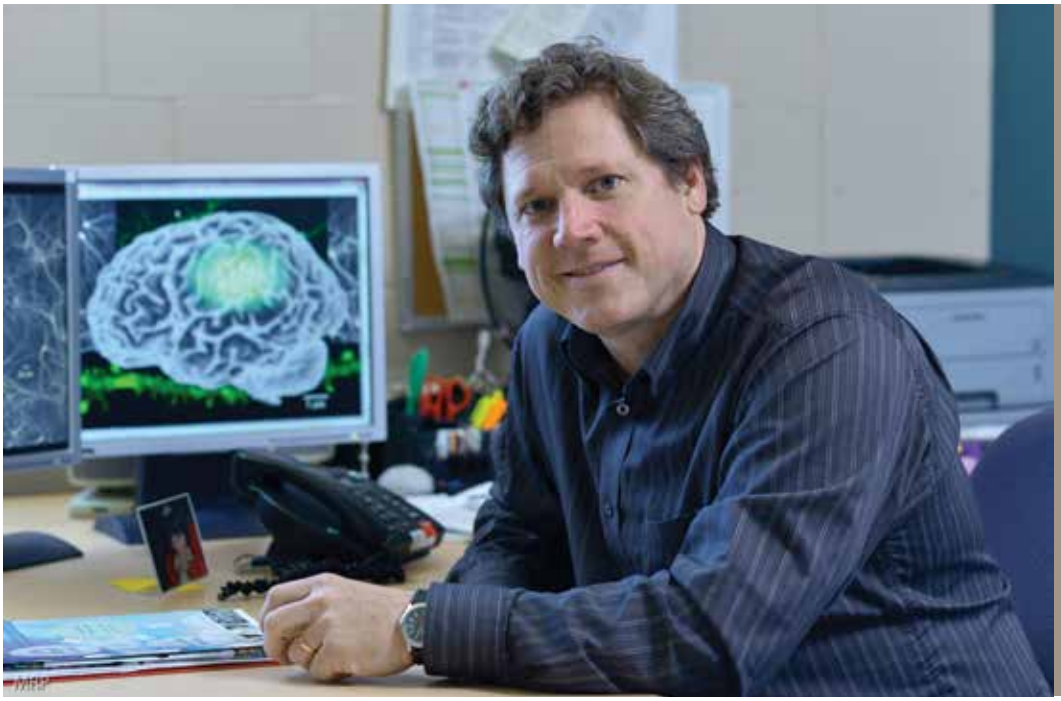

Yves De Koninck, PhD, professor of neuroscience at Université Laval in Canada

After an injury, it's normal for the damage sensors near the trauma site to be touchy for a little while. During that time, your nervous system is encouraging you to protect the damaged tissue while it's healing. But sometimes that extra sensitivity, called "hyperalgesia," sticks around long after it's useful. Hyperalgesia is often a major component of chronic pain, and it means that people with chronic pain have to be unceasingly alert. For example, Sally says, before she hurt her arm, hot coffee sloshing onto her hand might have hurt for a few seconds. Now, a careless moment like that means days of burning pain.

Symptoms like this suggest that changes in the nervous system have migrated to the spinal cord. De Koninck believes that a major factor is the number of receptors on the signal-receiving neurons in the dorsal horn. If those neurons synthesize too many receptors, they'll pick up too many neurotransmitter molecules. Then the neurons' pores will flutter open to let charged particles in more often than they should, sending electrical signals shooting up to the brain at too high a frequency. The result is a pain signal that's much stronger than it should be. De Koninck's work gives us a new window into how it happens, and how to stop it.

Recall, Then Erase

The key lies in a study about memory that was published nearly 15 years ago. Long-term memories seem to depend on the synthesis of extra receptors, too, and scientists knew that blocking the synthesis of those receptors during a memorable event could keep memories from forming.

But what a group of researchers at New York University discovered was that there is a brief period when interrupting receptor synthesis can actually erase old memories. Memories are reinforced when they're retrieved, but, paradoxically, during that process, even well-established memories have a brief window of vulnerability—like jewelry in a safe deposit box, memories are useless when they're stored but accessible to thieves when they're being used. A chemical called anisomycin blocks the production of receptors that neurons need to form memories. When the researchers injected anisomycin into rats' brains right after triggering a particular memory, that memory didn't just fail to get reinforced—it was erased altogether.

Accumulating evidence that pain and memory use similar mechanisms led De Koninck to wonder if this same neurochemical trick could erase chronic hyperalgesia. De Koninck

and his colleagues made mice hypersensitive to pain by injecting their paws with capsaicin, the chemical responsible for chili peppers' fiery bite. Capsaicin activates the same pain sensors that respond to extreme heat and can turn on hyperalgesia without the tissue damage that an actual burn would cause. After their capsaicin injection, the mice's paws were more sensitive to pressure for hours afterward.

Before that sensitivity had had a chance to wear off, the team gave the mice a second capsaicin injection—and this time, they added an injection of anisomycin. What happened after this second injection is "like magic," De Koninck says. When the second injection initiated the same flurry of neurotransmitters and electrical signals that encoded the hyperalgesia the first time—the pain analogue of recalling a memory—anisomycin shut down the pain-amplifying mechanism by keeping the spinal cord neurons from making extra receptors. "It's in the process of reorganizing itself," De Koninck explains, "and then there's that window of opportunity to actually shut it back down." The mice lost seventy percent of their hypersensitivity to pain.

The theory that overdeveloped connections other than memories could be attenuated by retriggering them "is not a new idea," Basbaum says, "but the fact is, there really has been very little evidence that it's doable." De Koninck's results suggest that the right chemical injected at just the right place at just the right time, can erase the physiological "memory" of pain. Ted Price, a professor at the University of Texas-Dallas, says that this " paves the road to disease modification instead of just palliatively treating people with these terrible drugs like opioids, which everybody, everybody in the field wants to get away from."

New Options

For now, there are a few other types of treatment doctors can turn to besides opioids. Antidepressants help some people, as do certain antiseizure medications. A controversial technique called "transcutaneous electrical nerve stimulation" may work by making sure that there are plenty of receptors in the dorsal horn for the body's natural opioid chemicals; a wearable device using this technology was just approved for over-the-counter sale by the FDA.

Treatments based on De Konick's capsaicin-anisomycin model would constitute an entirely new category of drugs. "When you find a new mechanism," De Koninck says, "boy, it opens a whole new array of things." But finding the right combination of chemicals won't be easy. Capsaicin patches are already sold over the counter at drugstores, but anisomycin is far too indiscriminate for clinical use. Brian Wainger, a physician and researcher at Massachusetts General Hospital, says, "It's obviously going to be a long time for a discovery like this to work towards a clinical approach, but I think it sort of sets a framework for some options."

"Options" is a word that seems to come up a lot among pain specialists. One of the reasons chronic pain is so difficult to treat is because "there's a lot of different forms of chronic pain," De Koninck says. "But the arsenal that we have so far to treat it is still quite meager." And the weapons we do have are woefully inadequate.

Still, discovering that this retrigger-and-erase phenomenon works for hyperalgesia, as well as for memory, suggests that it may be useful in other parts of the nervous system. If that's true, these kinds of treatments could help with pain syndromes more complicated than hyperalgesia—conditions that are so severe that even light touches become painful, or in cases where patients experience pain with no stimulus at all.

One big advantage of De Koninck's strategy is that it isn't just an incremental improvement, a way to make a slightly more effective or slightly less addictive analgesic. It's a totally different angle on the problem. It targets the "chronic" part of chronic pain. "What the field I think really needs is options," Price says. "And more importantly, patients need options." For millions of people, and their doctors, a totally different angle is exactly what they've been looking for.

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There are special people in our lives we treasure. Increasingly, TNA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support TNA's growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received as of November 2015:

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YPC TNA – The Facial Pain Association
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TN AND THE WINTERTIME BLUES

Living with trigeminal neuralgia, or any facial neuralgia/chronic pain condition, requires a tremendous amount of energy - mental, physical, and emotional - to get through any given day. The constant struggle to adjust our schedules, attend school or work, juggle social activities, engage in romantic relationships, or simply exert the effort to get out of bed in the morning can be exhausting and lead to feelings of depression, sadness, or hopelessness. It is important to acknowledge that these feelings are completely normal; frustration with our condition and its impact on our lives is a common response to the ups and downs of living with TN.

As we head into the darkest part of winter, it is also important to acknowledge the periodic mood changes that come with shorter days, colder weather, and a decrease in social engagements for weather-related reasons. Depression related to the changing seasons, specifically from fall through winter, is common in up to 20% of the U.S. population. The severity of the depressive symptoms varies from person to person but the characteristics are similar to clinical depression and can include change in appetite, alteration in sleep pattern, feelings of lethargy, and a sense of hopelessness. For those of us with TN, these symptoms often mimic medication side effects and normal coping mechanisms developed to deal with our pain.

For many of us, our pain is worse in cold weather, so feelings of sadness and frustration may increase during the winter months. Exacerbation of depression in the wintertime, known as Seasonal Affective Disorder, is thought to be caused by an absence of exposure to sunlight. There are lifestyle changes that can be made to help combat S. A. D., including walking outside when the weather allows, sitting next to a window during the sunniest part of the day, and - in some cases - light therapy under the guidance of a trained physician.

Coping mechanisms utilized to deal with stressors/depression related to chronic pain may differ from those used to deal with environmental stressors such as school, work or relationships. As a result, it is important to know how to distinguish between environmental stress and TN-related stress. Different coping mechanisms can include intervention with social

"YPC". . .continued on page 20

In pediatric patients, the presentation of depression may be markedly different than in young adults, and can include school impairment, decreased participation in recreational activities, behavioral changes, and social difficulties.

For more information about the YPC, check out our website ypc.tna-support.org

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"YPC"...continued from page 19

workers, psychologists or psychiatrists trained in individual therapy, or medication management. Some people may also choose to explore alternative treatments including acupuncture, biofeedback, and meditation. Support from other patients can be found in the ever-growing network of online support groups, web pages, and networks dedicated to both TN awareness and ongoing patient-to-patient support.

The relationship between depression and chronic pain/TN can be cyclical. Many patients have experienced feelings of depression, hopelessness and discouragement on their journey with this disease, and those feelings can fluctuate from season to season. Young patients and caregivers are tasked with teasing out the causes of mood symptoms and their relationship to medication side effects from the normal life stress of school/work/relationships. It is important to acknowledge that our moods can change with the seasons, and also to be prepared to possibly add additional treatment modalities to our already long and detailed list of resources - at least until sunnier days return.

Young Patient Profile

Name: Mackenzie Winslow

Current age: 18

Where do you live? Highlands Ranch, Colorado.

How old were you when you first experienced facial pain? I was 11 years old and playing softball when I first experienced TN.

How old were you when you were diagnosed? I was diagnosed pretty quickly, just weeks after I first experienced pain. I was still 11 years old. It was an emergency dentist who first uttered the words "trigeminal neuralgia" to me and my parents. The diagnosis was confirmed at an emergency room later.

What was your diagnosis? My diagnosis is TN1.

What do you do for fun? For fun, I read, hang out with my friends, color, and model in California!! I'm also applying to colleges currently. College was something I never thought I'd be able to do, especially not out-of-state. But now, after my MVD, I have the chance to really chase my dreams. It's been so rewarding to receive admission into some of my top choice schools (I'm still waiting for most!) and to see how much they believe in my ability to succeed. Middle and high school was difficult with TN, yet the hard work has paid off and I have been awarded scholarships I never thought possible. Looking to the future like this has really been a great experience that I'm lucky to have!

What has TN taught you? TN has taught me that I AM capable of adapting to new situations. I had to change much of my daily routine, that was hard at first, but it became my new normal. It also taught me the power of family and friends. I lost a lot of friends along the way, but the friends who stayed by my side proved to me they were true friends. TN helped me see the true side of people sooner than I would have if I didn't have TN.

What treatments (non-surgical) have you tried? MAGO (Maxio Anterior Guided Orthotic), acupuncture, upper-cervical chiropractic treatments, massages, trileptal, gabapentin, steroids, chinese herbs, marcaine injection, biofeedback, valtrex, a TENS unit, tegretol, oxtellar, and gralise.

Have you had any procedures? I had a microvascular decompression on March 4, 2014.

How has your facial pain changed you? I had to grow up a lot quicker. I don't wish my diagnosis never happened because I think it shaped me into the person I am today. Because of what I've been through, I've realized that I want to use my life to help people. Having TN helped me see people's true colors, which has given me the chance to form stronger bonds and friendships with people who are worth it.

What tips do you have for other young patients? I think that having an open mind is vital. If I didn't have the optimism I did when I was going through pain it would have been much more difficult. I've experienced healing pain since my surgery that I think a lot of people have post surgery and it's been extra tough to stay optimistic through that, but it's also been incredibly important. I know that with four years of pain comes four years of healing and I'm ready to face that. But you have to stay optimistic and happy throughout the healing process or you'll only cause more challenges for yourself. Also, I realized that tough love from significant others is still love. I struggled with the tough love my parents gave me, but in the end I realized that they only wanted the best for me and were trying to help me. Take one-on-one time with those you love because it can be overwhelming for them too and it's important for them to know that even amidst your pain you can still love them.

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Dr. Brisman is Chief of Neurosurgery at Winthrop-University Hospital and Co-Medical Director of the Long Island Gamma Knife® at South Nassau Communities Hospital.

Dr. Brown is Northeast Regional Director and immediate past Co-Chairman of the Medical Advisory Board of TNA-The Facial Pain Association. He is the Neurosurgery Director of the Winthrop-University Hospital CyberKnife® Program and Chief of Neurosurgery at Mercy Medical Center, Rockville Centre, New York.

Dr Mechanic served as Chief of Neurosurgery at Huntington Hospital, in Huntington, NY, from 1996 to 2014. He is Chairman of the Nassau Surgical Society Section of Neurosurgery.

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