

Journal of The Facial Pain Association

Spring 2016

# Quarterly

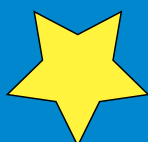


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## Cover

Regional Conference in Pittsburgh, PA

## FEATURES



5

**A TN Warrior Faces Medicare Part D.** Anne Ciemnecki reports on how she navigated the Medicare Prescription Drug Plan as a TN patient.



8

**Pasternak Named To Interagency Pain Research Coordinating Committee**  
Michael Pasternak, trustee of The Facial Pain Research Foundation, is appointed to a key NIH committee.



11

**Memorial Tribute to Albert L. Rhoton, Jr., MD**, one of the outstanding neurosurgeons and humanitarians of his time.



12

**MAB Corner with Jeffrey Brown, MD**



13

**Prescription for Harm: Dangerous drug mix leaves woman fighting for life**  
A preventable occurrence causes life-threatening symptoms.



24

**Pittsburgh Regional Conference Registration**

## IN EVERY Q

3

From the Chairman of the Board

21

Memorial and Honorary Tribute Fund

23

New Members

25

Tips from the YPC and Patient Profile

## From the Chairman of the Board

TNA's operations began with telephone calls, mailings and building regional support groups that met every few months. 25 years later, internet-based social media makes finding information and social interaction easier than ever but it is no substitute for getting together. In this letter, I'll summarize how TNA is using technology to be useful and how TNA is running programs that give people a chance to meet with healthcare professionals and each other.

TNA's website at [facepain.org](http://facepain.org) delivers information about facial nerve pain disease, treatment options, contact information for healthcare professionals, informative articles for download, assistance in finding a regional support group and a link to the Facial Pain Network. The Network at [facepainhelp.com/](http://facepainhelp.com/) is an online forum for talking with others and for posting photos and other information. That Network is busy every day, all day. Both our web site and the Network have links to the Video Project at [facepain.org/video-gallery/](http://facepain.org/video-gallery/) that brims with peoples' stories in their own words. You'll see a community of people with what can be a lonely disease; it doesn't have to be lonely and my story is there too. There are over 100,000 visits to our web site every month, TNA is the global online "go-to" resource for people with facial pain disease.

In addition to the Facial Pain Network, TNA is active on Facebook and Twitter. That makes it easier for people to find TNA, for TNA to announce its resources, and for people with facial nerve pain to find each other. TNA has over 5,000 Friends on Facebook and over 2,000 Followers on Twitter. TNA is pleased to support the Young Patients' Committee for people under about 40, and the YPC has its own Facebook page at [facebook.com/tnaypc](http://facebook.com/tnaypc). We use email too. Twice per month, the *FPA Newswire* with general and scientific news concerning nerve pain is sent to over 25,000 recipients. Every quarter, TNA

emails a digital version of this TNA Quarterly containing news, notices and articles by experts in diagnosis, pain management, medication and surgical treatment of facial nerve pain. Technology is also important in TNA's office. In addition to modern accounting and management software, TNA uses specialized software to keep track of members and what they find useful.

All of the technology described above evolves and TNA works to stay ahead. We have a staff that keeps it running smoothly, periodic updates are essential and another major update is under consideration. Although that technology helps TNA to be more useful to more people, the software and emails and internet are still no substitute for getting together.

TNA's conference programs give people a chance to talk with each other and to hear from and talk to dentists, psychologists, neurologists, neurosurgeons and others who are world-experts in treating facial nerve pain. Over 250 attended our national conference last October in New York City and we have regional conferences scheduled in Pittsburg, PA on April 23 and Minneapolis, MN on September 10, 2016. TNA also assists over 20 regional Support Groups. Close to home, Support Groups give people a chance to hear from healthcare speakers and to talk with each other about managing their lives outside of a doctor's office.

Through technology and opportunities to meet face to face we keep you educated, empowered and networked.

A handwritten signature in blue ink that reads "Jeff Bodington".

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

# Letter to the Editor



Dear Mr. Koff:

I have read with interest the paper by Kim Burchiel, MD, et al (TNA Quarterly, Fall 2015, Vol. 1, Issue 18, pp 12-13, "Trigeminal Internal Neurolysis (TIN) Procedure." This submission follows two recently published papers by Burchiel et al. The paper contains misinformation about which some of us are concerned and must be clarified in the interest of proper patient decision making.

Burchiel states that one third of newly diagnosed TN patients have no demonstrable neurovascular compression (NVC), that younger patients are less likely to have NVC and that younger females are even less likely to have NVC. All of these statements are in error. The truth is that almost 100 percent of patients have neurovascular compression, be they male or female, young or old. Patients and potential patients must be aware of this. If the surgeon does not see the offending blood vessel or vessels in virtually 100 percent of his patients, he should not attempt to perform microvascular decompression operation, as has been stated in a number of published papers and presentations.

Early recurrence of trigeminal pain after MVD is due to recollateralization of surface veins, or to missed blood vessels; late recurrence, to new vascular compression due to increasing elongation of arteries and brain "sag" due to aging.

I do agree that reoperation is difficult. Selective section of the portia-major (one of the three roots of the nerve) can relieve pain by causing loss of pain perception with relative retention of light touch perception. This was noted by Dandy in the 1920s.

Burchiel is a good man and chair. Unfortunately, he never learned to identify vascular compression or to treat it properly. Learning the procedure from an expert, is a necessary prerequisite for the surgeon. "Combing" the nerve as Burchiel proposes causes mixed numbness and results in high recurrence rates.

The integrity of the TNA Quarterly and the patients seeking pain relief above all must be protected.

Sincerely,  
Peter Jannetta, MD  
Vice Chairman Emeritus  
Department of Neurosurgery  
Allegheny General Hospital

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# A TN WARRIOR FACES MEDICARE PART D



By Ann Ciemnecki

On June 18, 2016, I will turn 65. Am I troubled by aging? Not at all! Though retired, I still feel and, I hope, look young. Graying hair, I hide it. Pravana hair color and Coppola Keratin treatments keep my brunette hair shiny and smooth. Wrinkles, I conceal them too. My medicine chest is stocked with Bare Mineral foundation with SPF 18; I use the best moisturizers; and swear by Active Cell Renewal Night Serum. I am not too unhappy that my grandson dubbed me “Didi” instead of grandma, even though, I love being his grandmother. I drive a car that my children envy, a sporty little Mazda Miata MX5 convertible. I own an iPhone 6s and use social media daily. Friend me on Face Book! I am intelligent, tenacious, and fearless. Like most Quarterly readers, I am a TN Warrior! A third generation person with facial pain (my mother and grandmother were warriors too), I survived two MVDs, a Gamma Knife and have taken more drugs than I can name: Trileptal, Baclofen, Cymbalta, Lyrica, Neurontin, Clonazepam, Methadone, Elavil. My pain is under control. What is the big deal about

turning 65? It is just another trip around the sun!

Except when you “Pass Go” on this particular trip, you “collect” Medicare, not \$200. Medicare terrifies me. Not **Medicare Part A** (the hospital insurance) or **Medicare Part B** (the medical insurance)—I am afraid of **Medicare Part D**, the prescription drug coverage. A Medicare Prescription Drug Plan (called a PDP by the alphabet soup-loving bureaucrats) has the potential to come between me and the drugs that control my pain. I worry that Part D will not be as generous as the private prescription drug plan that paid for every drug I needed in every amount prescribed. So, like many TN Warriors, I was determined to understand Medicare Part D and get the drugs I need now and in the future.

The first step was a vocabulary lesson. The PDP that I get for free as part of a retirement benefit is “Express Scripts Medicare.” I can use Express Scripts Medicare or select another PDP. If I select another plan, I will need to

pay for it and I will be automatically disenrolled from Express Scripts. You can only have one PDP at a time.

- All Medicare PDPs have a **network of pharmacies**. In most cases, prescriptions are covered only if they are filled at one of the network pharmacies. And, the network changes periodically. PDPs publish their directory of network pharmacies on their websites or you can request a printed directory. You might want to be sure that your pharmacy is part of the network. You can always switch to a network pharmacy or order prescriptions by mail if a mail order program is available. My pharmacy is in the network. *So far, so good!*
- Next, a **formulary**. A formulary is a list of covered drugs. Before I sign up for Express Scripts, I need to check the formulary. I will check for the drugs I take now and drugs that I may need in the future. The formulary can change too.
- If the *formulary* changes, and payment is denied for a drug, you

“Medicare” ...continued on page 6

can work with your doctor or prescriber and ask for an **exception**. Usually you can get a short term supply of the denied drug while you are asking for an exception.

- Express Scripts (and all Part D plans) have **drug payment stages**. At any time in your trip around the sun you will find yourself in a drug payment stage. The payment stage that you are in may affect how much you pay for a drug. Pay attention, this gets complicated.

- **Yearly deductible stage.** In the yearly deductible stage, you must pay for your covered prescription drugs before your PDP begins to pay its share. Medicare PDPs may not have a deductible of more than \$360 in 2016. My plan has no deductible. This could be a good omen!

- **Initial coverage stage.** In the initial coverage stage, the PDP will pay its share of the drug costs and you will pay your share. How much you pay for a drug depends upon which tier the drug is in. There are three tiers. These are the costs for the drugs in each tier and a definition of each tier in Express Scripts.

Cost Per Prescription			
Tier	Drugs in Tier	One Month at Retail Network Pharmacy	Three Months if Mail Ordered
Tier 1	Generic Drugs	\$10	\$5
Tier 2	Preferred Brand Drugs	\$22	\$33
Tier 3	Non-Preferred Brand Drugs	\$44	\$55

Page seven of my Express Scripts Medicare manual says that I will stay in this stage until the total cost of my drugs reaches \$3,310 per year. The total cost of the drug is the cost I pay plus the cost that Express Scripts pays. Under the 2016 Part D Standard Plan Cost-Sharing rules, Medicare beneficiaries pay 25 percent of the costs of covered drugs and their PDP pays 75 percent. While the cost sharing percentages are standard, each PDP negotiates a separate contract with the drug manufacturer, so the actual costs that you, the beneficiary pays, may vary from plan to plan. Three of my drugs are generic. I call Express Scripts to ask which tier my forth drug is in. It is in tier two.

In a retail pharmacy, I would pay \$624 annually:

3 generic drugs	12 months	\$10 a month	= \$360
+			
1 Tier 2 drug	12 months	\$22 a month	= \$264
I could save \$432 annually if I mail order the drugs:			
3 generic drugs	4 quarters	\$5 a quarter	= \$60
+			
1 Tier 2 drug	4 quarters	\$33 a quarter	= \$132

Remember, I am paying 25 percent of the total cost. The total cost of my drugs in a retail pharmacy is \$624 X 4 = \$2,496. This is comfortably below the \$3,310 maximum. But I may need other drugs, so I continue to investigate the other stages.

Note: Some PDPs have **out-of-pocket maximum costs**. If you reach your **out-of-pocket maximum**, you do not pay anything for your covered drugs for the rest of the year. My annual out-of-pocket maximum is \$1,351.

- **The Coverage Gap Stage.** After my total drug costs reach \$3,310, I enter the coverage gap stage, commonly known as the **donut hole**. There is nothing sugary sweet about the coverage gap stage. My Express Scripts Medicare plan is generous. While I am in the coverage gap stage, Express Scripts continues to cover my drug costs at the same cost sharing amount as in the Initial Coverage Stage, (*This is truly good news!*) In many plans, the PDP pays nothing when the insured reaches the coverage gap stage and the full cost of the drug is borne by the beneficiary. I stay in the coverage gap stage until I pay \$4,850 **true out-of-pocket** costs (better known as **TrOOP** by my alphabet soup-loving friends) for Part D drugs. Now I am really confused because my out-of-pocket maximum is \$1,351. So, I call the Express Scripts help line again and learn that out-of-pocket costs and *true* out-of-pocket costs are not the same. Out-of-pocket costs are actually member out-of-pocket costs or what I pay out of my own money for a drug: deductibles, co-payments and anything I might have to pay while wallowing in the donut hole. True out-of-pocket costs also include payments for covered drugs that are made from or by: a Medical or Health Savings Account, a Flexible Spending Account, family members or friends, Qualified State Pharmacy Assistance Programs,



Medicare's Extra Help (low-income subsidy), most charities, drug manufacturers, the Indian Health Service (IHS), or AIDS Drug Assistance Programs.

These additions to the TrOOP help you climb out of the donut hole faster and into the Catastrophic Stage. You move out of the coverage gap stage when you reach either the out-of-pocket maximum or the TrOOP, whichever comes first.

- The **Catastrophic Stage** is the final drug payment stage. If you reach this stage, you stay in it until the beginning of the next calendar year when you begin the stages all over again. In my Express Scripts Plan, if I reach my member out of pocket maximum, I do not pay anything for my covered prescription drugs for the remainder of the year. Otherwise,

Medicare Advantage plans are sometimes referred to as Medicare Part C. They are Medicare-approved private health insurance plans. When you join a Medicare Advantage plan, you are still in the Medicare program and must continue paying your Part B premium. Medicare Advantage plans provide all of your hospital and medical insurance. They generally offer additional benefits, such as vision, dental, and hearing, and many include prescription drug coverage. These plans often have networks, which mean you may have to see certain doctors and go to certain hospitals in the plan's network to get care. Pricing, benefits, and rules (like whether you need a referral to see a specialist or can only use doctors or facilities in the network) vary, so it's worthwhile to compare all plans in your area.



I pay \$2.95 for a generic drug and \$7.40 for all other drugs or five percent of the total cost, whichever is greater. The TrOOP of Lyrica, for example is \$1402.04 for a mail-ordered 90-day supply. If I had to pay for Lyrica, it would cost \$70.05 for a ninety-day supply because that is greater than \$7.40.

In summary, I am happy about Express Scripts Medicare. I have no premium or deductible and it seems that my annual drug costs will be \$624 annually if I continue to use the local pharmacy which is part of the network. I could reduce those costs to \$192 annually if I use the mail order service which is potentially more convenient. The plan is actually more generous than the plan I have now. If I move into the coverage gap stage for any reason, my drug costs will be the same as they were in the initial coverage stage.

My advice to my fellow-TN warriors is to shop around. While some costs are fixed by the Medicare program (such as the \$360 maximum deductible), plans offer variations within the fixed costs. Compare two or three plans. Visit websites, get manuals and formularies (either download them or request them), check whether your drugs are covered, in what amounts, and in which tier. Ask what coverage the plan offers while you are in the

Coverage Gap and Catastrophic Stage, and calculate your out-of-pocket costs. Visit [www.medicare.gov](http://www.medicare.gov) and click on "Find Health and Drug Plans" for more information. You can also call 1-800-MEDICARE (1-800-633-4227) 24 hours a day, 7 days a week. More free help is available through the **State Health Insurance Program** or **SHIP**. SHIP counselors can help you understand available plans and choices. Also know that if your income is limited, you might be eligible for **Medicare Extra Help**, a program that helps pay for drugs. The Medicare number listed above or the Social Security Office (1-800-772-1213) will help you see if you are qualified for Extra Help. Use the resources available to become an informed consumer. Doing the work or asking for help can assure that you have the drugs you need to eliminate or reduce facial pain.

Just one more piece of advice: even if you don't take many prescriptions now, you should consider joining a Medicare drug plan. If you decide not to join a Medicare drug plan when you're first eligible, and you don't have other drug coverage, and you don't get Extra Help, you'll likely pay a late enrollment penalty if you join a plan later. Generally, you'll pay this penalty for as long as you have Medicare prescription drug coverage from any PDP. 🌱

# PASTERNAK NAMED TO INTERAGENCY PAIN RESEARCH COORDINATING COMMITTEE



Michael Pasternak, Ph.D., a Founding Trustee of The Facial Pain Research Foundation (FPRF) has received an invitation from the Secretary of Health and Human Services, Sylvia M. Burwell to serve on the Interagency Pain Research Coordinating Committee (IPRCC) of the National Institutes of Health for a term beginning immediately and ending July 31, 2018.

The Committee coordinates with the Department of Health and Human Services and federal agencies all activities that relate to pain research. The committee reports to the Secretary of Health and Human Services. Management and support Services within the National Institutes of Health is provided by the Office of the Director, National Institute of Neurological Disorders and Stroke (NINDS).

The duties of the IPRCC include: develop a summary of advances in pain research supported or conducted by the Federal agencies relevant to the diagnosis, prevention, and treatment of diseases and disorders associated with pain; identify critical gaps in basic and clinical research on the symptoms and causes of pain; make recommendations to ensure that the activities of the NIH and other Federal agencies are free of unnecessary duplication of effort; make recommendations on how best to disseminate information on pain care; and make recommendations on how to expand partnerships between public entities and private entities to expand collaborative, cross-cutting research.

Michael is very excited about being involved in the development of the Federal Pain Research Strategy. He states "My appointment is really a compliment of the highest order to the research being done by the FPRF and the thousands of Volunteers who make this research possible. I am only one of the Foundation leaders. Our Trustees have believed in its mission and supported moving forward from the very beginning. Doug Anderson has overseen a unique and outstanding research program. Our Foundation's International Consortium of Scientists are involved because of the importance and challenge of the work. Frank Skoviera, Megan Hamilton, Thomasena Saunders, Pam Unverzart, Kathleen Sweeney and many hundreds of others have told their stories and communicated internationally the importance of our goals to find a cure. Thousands have participated in fund-raising activities. Wonderful anonymous donors, along with The Messing Foundation, Elizabeth Cilker-Smith, Gwen Asplundh, Tom and Susie Wasdin, Pat and Amy Tomasulo and their families have provided the necessary financial base to assure the Foundation's research funding. The Foundation's organization is a successful synergistic team, truly unique in the eyes of "Washington". Pasternak adds: "An important part of this outstanding synergistic team has been the help we have received from John Koff, Nancy Oscarson and Cindy Ezell at the Facial Pain Association.

Michael believes the IPRCC appointment puts the Facial Pain Research Foundation in an important relationship with those involved in pain research in Washington DC. "I am looking forward to working with the IPRCC and the opportunity to continue the quest to find a cure for trigeminal neuralgia and neuropathic pain. We are making great strides with our research and hopefully 2016 will bring us closer to our goals." 🌱



## Face Pain Patients:

**Help us learn the real cost of this disease.**

If you are a face pain patient, please go to [www.fpa-support.org](http://www.fpa-support.org) and click on the Patient Registry link at the top on the page to complete the Patient Registry Questionnaire.

This simple action will take only minutes of your time, but will help us gather definitive data to measure the effectiveness and cost of various treatment modalities.

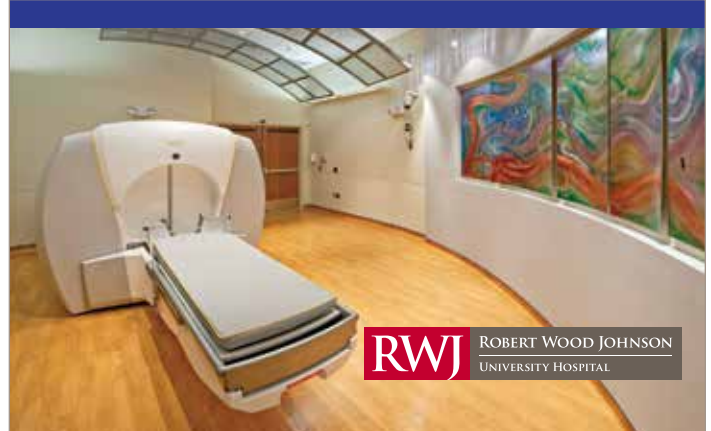
**By providing your answers, you can help us to empower patients and educate policymakers.**

It is crucial to gather data so that we can play an important role as an advocate for facial pain issues, and win the battle against neuropathic face pain.

Your information will be stored securely, and you can save a questionnaire in progress. Return as many times as you need to, to finish and update answers.

**Complete the TNA Patient Registry Questionnaire today and take an active role in the battle against trigeminal neuralgia and related face pain conditions.**

**[www.fpa-support.org/patient-registry](http://www.fpa-support.org/patient-registry)**



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# TRIBUTE TO A TRUE HERO, ALBERT L. RHOTON, JR., MD

By Cindy Ezell

In this day and time it is difficult to find a true hero, someone who is admired and idealized for courage, outstanding achievements and noble qualities. On Sunday, February 21, 2016 a true hero passed on, but will always be revered for his contributions to TNA and the treatment of trigeminal neuralgia.

During his 25 years with TNA, Dr. Rhoton became one of its greatest advocates. Not only was he a husband, father, grandfather, brother and friend, but found time to serve on TNA's Medical Advisory Board. He hosted several national conferences, and went on to be a founding member of The Facial Pain Research Foundation.

Dr. Rhoton practiced neurosurgery for over 50 years. During that time he served as President of the American Association of Neurological Surgeons, the Congress of Neurological Surgeons, the Society of Neurological Surgeons, the North American Skull Base Society, the International Interdisciplinary Congress on Craniofacial and Skull Base Surgery, the Florida Neurosurgical Society, and the International Society for Neurosurgical Technology and Instrument Invention. He was awarded the Cushing Medal of the American Association of Neurological Surgeons and the Medal of Honor of the World Federation of Neurosurgical Societies.

Albert Rhoton was one of the most influential humanitarians of our time and yet he had a way of making you feel that, single handedly, you were making the world a better place. His perspective on life was unparalleled. Over the years Dr. Rhoton shared his philosophy with us, and it was simply this.

- "In my early years, never in my wildest flights of imagination did I consider that my life would yield such rewarding and challenging work as that of a physician "
- "I am grateful for the opportunity to be a participant in the miracle we call neurosurgery. Our lives have yielded an opportunity to help mankind in a unique and exciting



way. Our work is done in response to the idea that human life is sacred, that the brain and nervous system are the crown jewels of creation and evolution, and that it makes good sense to spend years of our lives in study in order to be able to help others. The skills we use are among the most delicate, most fateful, and to the layman, the most awesome of any profession."

- "There is no substitute for an honest, concerned and sympathetic attitude."
- "Success may not mean that every patient is cured, because some problems are insolvable and some illnesses are incurable. Instead, success should mean giving every patient the feeling that he or she is cared about, no matter how desperate the situation, that their pain is felt, that their anger is understood, and that we care and will do our best."
- "It is a great challenge to guide patients competently and compassionately through neurosurgery. Death and darkness crowd near to our patients as we help them search for the correct path."
- "Neurosurgical illness threatens not only the patients physical but also their financial security, because it is so expensive and the potential for disability is so great."
- "The best ally in the treatment of trigeminal neuralgia is a well-informed patient."
- "The greatest satisfaction in life comes from offering what you have to give."
- "One of our greatest gifts is that we were created to help each other."

*Thank you, Albert Rhoton, for your contributions to trigeminal neuralgia and its treatment. TNA will continue forward knowing you spent much time teaching young neurosurgeons about microsurgical techniques and microsurgical anatomy so that they might carry on along your path. 🌿*



Jeffrey A. Brown, MD  
Chairman,  
Medical Advisory Board  
Facial Pain Association

I am pleased to take on the mantle so long and well held by Doctors Peter Jannetta and Ken Casey as chair of the medical advisory board for TNA-The Facial Pain Association.

We have come a long way since the time of my first presentation to the small collection of support group

leaders at the University of Cincinnati two decades ago. We are truly a global organization now, no longer limited to an "orphan disease" as TN is called by the National Institutes of Health, but one entity swimming in electronic "hits" from around the world.

Because our catchment is global our reach should be equal to its geography. Beginning this spring we will be producing a series of "webinars" designed to bring the members of the MAB closer to all of you. A series of live presentations with the option of questions each of you can send in to us as they occur to you is planned. Our hope is that the webinar will be in the format of an interview of a distinguished medical advisory board member regarding his thoughts on a given topic vital to the

understanding of the diagnosis and treatment of neuropathic facial pain. These internet-based presentations will be recorded and available for replay at your convenience. Our hope is that the information we transmit will be relevant and trustworthy to each of you whom we are here to help.

Be patient as we hone our digital degrees in the early stages and give us your feedback on how they work. We hope to engage those of you throughout the world of the web wherever you are, whatever language you favor. Please tell us of any ideas you may have towards this end as we move forward into the new digital world of healthcare information. 🌱



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## Prescription for harm: Dangerous drug mix leaves woman fighting for life

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By: Karisa King and Sam Roe  
Contact Reporters *Chicago Tribune*

In 2009, a life-threatening rash attacked Becki Conway after she took two drugs a doctor prescribed to her. She came down with a potentially deadly condition called Stevens-Johnson syndrome, in which the immune system attacks the eyes and skin.

Dangerous doses: First Becki had a sore throat and cough. Then a rash. Soon, her skin peeled off in sheets.

The first symptoms mimicked the flu. Becki Conway had a sore throat, a dry cough and irritated sinuses.

But the next signs were more puzzling.

A sharp pain radiated through her chest. Her eyes turned red and itchy. It seemed like she was fighting off some strange bug, or maybe it was just the normal exhaustion of keeping up with twin toddlers.

Then the scalding rash began.

Red spots popped up on Conway's face and neck. The next day, painful sores appeared in her mouth and then her throat.

Within hours Conway was in a hospital bed, watching with alarm as the rash spread across her torso, arms and face. The red dots turned into blisters that welted so quickly it looked like her skin was burning from the inside out.

No treatment could stop it. Within a day or two she wasn't recognizable. Eventually, the rash covered her eyelids with blisters and attacked the lining of her lungs. Her skin peeled off in sheets.

Only after it was too late to stop the rash did anyone figure out that Conway had taken a potentially dangerous mix of medications that can trigger the immune system to attack the body's own cells.

Drug interactions in which one drug alters the effect of another are a hidden epidemic in America, a decades long threat to public health that has been barely acknowledged, let alone addressed.

Many interactions involve relatively safe drugs that become dangerous only when taken at the same time. Hundreds of risky combinations involve common antibiotics, blood thinners, antidepressants, cholesterol drugs and medicine to treat migraines, heart problems and high blood pressure.

The tragedy is that much of the harm is preventable. The particular drug interaction that hospitalized Conway was identified years ago. But experts estimate that thousands of patients still become sick every year from drug interactions because of errors and neglect by front-line providers of medical care.

The result in such cases: Victims and their families are left with few answers,

***"Dangerous Mix" ...continued on page 14***

## Eight ways patients can avoid risky drug interactions

Experts say there are important steps patients can take to help protect themselves from a harmful mix of medications.

- With every new prescription, ask your doctor and pharmacist about what other medications you should avoid, including over-the-counter drugs, foods and dietary supplements.
- Carry a list of all current medications and bring it to any medical appointments. The list should include drugs taken only occasionally, over-the-counter medications, patches, tablets, inhalers, drops, liquids, ointments and injections, as well as herbal, vitamin and dietary supplements.
- Read the complete package insert for all medications you're taking.
- Use one pharmacy for all your prescriptions.
- Educate yourself about potential drug interactions for any medications you are taking.
- If a doctor provides you with a new drug sample, ask if it interacts with the medications you're currently taking. Routine computer safety checks may have been skipped.
- Take as few medications as possible.
- Do not take medications prescribed to someone else.

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### *"Dangerous Mix" . . .continued from page 13*

and the underlying safety failures go uncorrected.

The doctor who prescribed Conway's medications did not heed a black box warning about a fatal rash that could result from the drug pairing, according to medical and legal records and interviews. The pharmacy that dispensed the medicine did not call her attention to the danger. And as her symptoms rapidly worsened, a string of doctors and nurses missed the connection to the drug combination.

Most patients rely on their doctors to protect them, but studies show that prescribers often are unaware of harmful drug combinations or trust that pharmacists have more expertise. Pharmacists, in turn, tend to respect the discretion of doctors.

For pharmacists, warning patients about the risky mixing of drugs is one of the major responsibilities of the profession, according to the National Association of Boards of Pharmacy. Yet, when injured patients sue, pharmacies often take the legal position that they have no duty to do so.

Pharmacies and hospitals use computer programs to screen for unsafe drug pairs. But those systems trigger so many alerts about potential drug interactions — including many that pose little risk to patients — that doctors and pharmacists frequently ignore them. Research has found that some pharmacists are more likely to approve dangerous mixes of prescriptions while working busy shifts.

When drug interactions hurt patients, the Food and Drug Administration along with most state medical and pharmacy boards do not require

doctors and pharmacists to report cases. Pharmacists and doctors rarely face sanctions unless patients take the initiative to complain, according to the national pharmacy group.

"When you look at it from every conceivable aspect, the system is badly broken," said Philip Hansten, a professor of pharmacy at the University of Washington who has studied drug interactions for nearly 50 years. "It's really disheartening to see people are still dying from interactions we've known about for decades."

Dozens of legal complaints reviewed by the *Tribune* described how patients became sick or died from a toxic mix of drugs that was mishandled in nearly every health care setting, from family practice offices and corner pharmacies to specialty clinics, hospitals, emergency rooms and nursing homes.

One physician prescribed the cholesterol drug Simvastatin to a patient in north suburban Niles who was already taking Ketoconazole and Cyclosporine because of a kidney transplant years earlier. The potentially lethal mix led to a toxic buildup of the heart medication and left the man too sick to walk and requiring hospital care, according to a lawsuit that was later settled.

In North Carolina, the state pharmacy board found that a CVS pharmacist had ignored computer safety warnings about combining Allopurinol for gout and the kidney transplant drug Azathioprine. The 49-year-old woman who took the medications together for weeks grew increasingly ill as her bone marrow failed to produce enough blood cells, leaving her hospitalized, according to pharmacy board and medical records.





The interactions don't always set off a toxic reaction. In many cases, one drug makes the other drug ineffective, leaving patients vulnerable to the effects of HIV, cancer and other serious ailments.

When Becki Conway sought help, trusted health care providers failed her at nearly every turn, leaving her in a fight for her life.

#### ***A case of anxiety***

At 37, Conway was a high-energy mother of five children ranging in age from 2-year-old twin boys to a 17-year-old son.

The summer of 2009 was one of the most hectic periods in her life. She and her husband were working full time, installing a new roof on their two-story brick home in central Michigan and preparing to open a pizzeria in a month. Their twins were not yet potty-trained.

Making matters worse, Conway was battling an ex-boyfriend in a child custody dispute and had been feeling extremely anxious. She found herself lashing out at her husband and shouting at the kids.

Conway worked at Sparrow Urgent Care in the town of Mason, registering patients as they arrived at the clinic. She decided to seek help from a doctor she was friendly with, Thomas Bellinger. The two met for 15 minutes in a break room where employees often chatted, drank coffee and ate lunch, according to interviews and documents in a later court case.

Conway mostly talked about her family history, childhood abuse and previous medications. She told Bellinger she had taken medicine for depression years earlier but hadn't taken anything since. He told her he empathized with her and promised to bring her a book on bipolar disorder.

Bellinger had practiced family and

emergency medicine since receiving his medical degree in 1985 from Michigan State University. He worked at several hospitals and urgent care clinics in Michigan before taking a job at the Sparrow clinic.

Minutes after their consultation, Bellinger approached Conway at her desk and handed her two prescriptions: one for Lamictal, the other for Depakote, according to medical records and her legal deposition. Both drugs are used to treat epilepsy and bipolar disorder. Lamictal carries the FDA's strongest label, a "black box" warning, which highlights the potential danger of combining Lamictal and Depakote.

Research on the ability of doctors to identify harmful drug pairs shows that although many physicians consider the issue when they write prescriptions, their specific knowledge about drug interactions is generally poor.

In one 2008 study, researchers asked 950 prescribers to classify various drug combinations by severity of risk. More than a third of the prescribers answered "not sure" for half of those pairs. For three of the four highest-risk combinations, less than 25 percent of the prescribers correctly recognized that the drugs should not be taken together.

Training on specific drug interactions in medical schools is lacking because of time constraints and the vast number of hazardous combinations, said Dr. Alfred George, chair of the pharmacology department at Northwestern University's Feinberg School of Medicine. Doctors also are not required to demonstrate knowledge of drug interactions to

***"Dangerous Mix" . . . continued on page 16***

state licensing boards or when seeking hospital credentials, he said.

"New drugs are hitting the market every day, and clinicians rarely have time to read all the literature on the drugs they prescribe," George said.

Adding to the problem, no list of medications automatically follows patients from one medical provider to another. One physician may not know what another doctor has prescribed.

The label for Lamictal warns that the drug's concentration level in the body more than doubles when taken with Depakote. To lower the risk of a deadly reaction, the label advises doctors to decrease the normal starting dose of Lamictal by half when it is combined with Depakote.

Physicians may read such warnings but make prescribing decisions at their own discretion. Bellinger gave Conway a prescription for the full initial dose of Lamictal.

In depositions, Bellinger said his diagnosis of bipolar disorder was based on multiple conversations with Conway over a period of months and that his prescriptions were in line with successful treatment plans for other patients. He said he was familiar with the black box warning but assessing the combined risk of the two drugs was difficult because Lamictal also can cause a dangerous skin rash when taken alone.

Citing language on the drug label, Bellinger said the extent to which Depakote potentially increases the risk is unclear. He believed the possible risk posed by giving Conway the full dose of Lamictal was outweighed by the danger of giving her a dose that was too low to relieve her symptoms.



In her deposition, Conway said Bellinger made a prediction as he handed over the prescriptions: She would feel better by the next day.

### ***No warnings***

Conway faxed the prescriptions to her usual pharmacy at Sparrow Hospital in nearby Lansing, part of the same health system as the urgent care clinic. Her husband, Tim Conway, worked there transporting patients and picked up her prescriptions the next day.

No one at the pharmacy called his attention to the potentially lethal drug pair, he said in an interview. No one mentioned that the dose of Lamictal exceeded the guidelines for taking it with Depakote. And no one talked to him about a rash.

"There were no special warnings — nothing," he said.

Pharmacists serve as the last line of defense against bad drug combinations. Those who see a potentially unsafe pairing can ask questions of the patient, consult with the physician and ultimately withhold the medications.

"If a patient has a significant drug interaction that the pharmacist should've been aware of and didn't catch, then their license could be affected," said Carmen Catizone, executive director of the pharmacy group.

Yet pharmacists who are busy, distracted or inundated with alerts may fail to intercept potential drug interactions.

Sophisticated software systems automatically screen prescriptions for risky drug combinations and alert pharmacists about the danger. But more than a decade of research shows those systems fail to fully protect patients.

The safety checks produce a flood of alerts about a range of potential dangers, including drug interactions that cause only minor side effects. Pharmacists must contend with so many alerts that they can become desensitized to even the most serious warnings and dismiss them. One study found that pharmacists overrode more than 90 percent of alerts, including warnings about some risky drug interactions.

Heavy workloads for pharmacists also pose a threat. A 2007 study by University of Arizona researchers found that the risk of dispensing two drugs that could interact rose about 3 percent for each additional prescription filled by a pharmacist in an average hour.

The pharmacist who filled Conway's prescriptions, Ryan Hamelin, later testified in a deposition that he handled as many as 80 orders on a busy shift. He signed off on her medications at 6:51 a.m., nine minutes before his overnight shift ended.

When a technician entered the two prescriptions into a pharmacy computer, a red screen appeared with a warning that required a pharmacist's review, Hamelin said. The alert noted a potential overlap between the medications, which are both used to treat the same illnesses, but it did not call attention to the drug interaction, he said.

Hamelin, who had received his doctor of pharmacy degree a year earlier, said he had seen such drugs paired together previously. He also said he was aware of the drug interaction and the black box warning on Lamictal.

But it seemed to him that the doctor had used some discretion when writing the prescriptions, as Bellinger had prescribed initial doses that

increased over time. Hamelin trusted the prescriber's judgment, he said.

Hamelin said he did not see a need to warn Conway personally about the drug pair. Package inserts that advise patients about drug risks typically satisfy a pharmacist's obligation to warn about such dangers, he said.

Hamelin approved the scripts and left work.



### ***'This is not right'***

That day, Conway began taking the two drugs. She felt better almost immediately.

But two weeks later, she felt a tickle in her throat and pain inside her ears. She had a cough and bloodshot eyes. Then she woke up with her eyes matted shut with thick gunk. Conway went to work early to get medication for what she assumed was pinkeye.

At the urgent care clinic, Conway told the medical staff about taking Lamictal and Depakote, according to her deposition. She described her symptoms, including chest pains she suffered for a day or so before the episodes stopped.

No one realized that the seemingly unconnected symptoms foretold an agonizing condition called Stevens-Johnson syndrome in which the

immune system attacks the patient's skin and mucous membranes.

The cells in the lining of Conway's eyes, mouth and lungs were self-destructing. It was as if some switch in her body had been flipped and nothing could shut it off.

Exactly how the disease develops is not fully understood, but it is most often triggered by medications.

Numerous drugs including Lamictal have been linked to the condition when taken on their own. There is no cure; the best treatment is to stop taking the drugs that caused it.

Had Conway's condition been diagnosed, she would ideally have been sent to a hospital burn unit, which is best suited to treat the massive loss of skin as the disease progresses, said Jean McCawley, director of the Stevens Johnson Syndrome Foundation, a patient advocacy group.

Instead, Conway's chest pains became the main concern. A doctor at the clinic ordered X-rays and an electrocardiogram to test for possible heart problems. Both showed normal results. To be cautious, Conway was sent by ambulance to nearby Sparrow Hospital for more comprehensive heart tests, medical records show.

***"Dangerous Mix" ...continued on page 18***





Conway told the hospital intake nurse that she was taking Lamictal and Depakote. Because Conway's eyes were too inflamed for her to see, the nurse pulled the pill bottles from Conway's purse and noted the medications in a hospital record.

The second round of heart tests showed no abnormalities, and Conway was released from the hospital with a suspected strained chest muscle, records show. Her husband came to the emergency room to take her home.

After receiving her discharge papers, Conway went to a bathroom to change out of her hospital gown. She glanced at herself in the mirror before getting dressed. On her way out, she caught another glimpse and stopped to stare. Bright red spots had popped up on her face and neck. It looked like someone had thrown red pepper on her.

Conway flagged down a nurse and pointed to her face. "This is not right," Conway said, according to her deposition.

"Wow," the nurse said.

The nurse retrieved a doctor, who examined Conway. But no one connected the outbreak to the two new medications she had reported to nurses and doctors twice that day.

The nurse gave Conway a shot of Benadryl and sent her home.

### ***Deadly diagnosis***

Spotting the signs of a dangerous mix of medications can be critical to saving a patient's life. But because the interactions often cause common symptoms, such as low blood pressure or confusion, health care providers can easily miss the clues.

"Drug interactions hurt and kill like nobody has any idea," said David Juurlink, head of clinical

pharmacology and toxicology at Sunnybrook Health Sciences Centre in Toronto.

Juurlink has treated patients who arrived at the emergency room after taking an antibiotic with certain types of blood pressure medication, which can cause a deadly spike in the level of potassium in the blood. Such a death likely would be attributed to heart disease and old age instead of a drug interaction, he said.

After Conway got the Benadryl shot she went home and went to sleep. She woke up at 4 a.m. with painful blisters in her mouth. Her skin rash was turning into red welts. Conway drove herself to the clinic where she worked and was examined by Dr. Kellie Donahue.

The doctor asked Conway about her symptoms and any medication she had been taking. When Conway told her about the Lamictal and Depakote, Donahue stopped taking notes and looked up at her.

"I think you have Stevens-Johnson syndrome," she said, according to Conway's deposition.

Donahue, the first medical professional to notice the dangerous drug mix, explained to Conway that she was suffering from a serious skin rash caused by medications.

Even Donahue didn't realize how severe the rash would become.

After telling Conway to stop taking the drugs, which Conway had done when the chest pains began, Donahue gave her a steroid shot and sent her home.

Conway took a short nap and woke up with blisters spreading into her throat. She called Donahue, who



instructed her to go to the hospital immediately.

Her first night in the hospital, Conway sat up in bed until dawn researching Stevens-Johnson syndrome on her laptop computer. She'd never heard of the disease. The more she learned, the more alarmed she became. She discovered that, in its most extreme form, many victims die. The biggest risks stem from infections.

Becki Conway was transferred to an intensive care unit for burn victims at the University of Michigan Medical Center after several days of fighting Stevens-Johnson syndrome. Her husband, Tim, took photos to share with family members, who were not allowed to visit her because of the high risk of infection she faced.

In the next days, Conway's blisters spread and erupted. Swallowing food was too painful. She couldn't stop coughing and complained that she was struggling to breathe.

Her skin began to peel off in sheets, leaving angry patches of exposed flesh that turned black and bloody.

Worried about infection, her husband laid down a trail of towels so she didn't have to walk to the bathroom on the hospital floor. He spent the nights at her bedside in a chair. He didn't know what to tell the kids, especially the three youngest. He didn't want them to visit their mother — her wounds looked too gruesome. He did not disclose his biggest fear, that she might not come home.

Conway sporadically roused herself from a stupor of morphine, but mostly she was in too much pain to speak or open her eyes.

On Conway's 10th day at the hospital, nurse Kathy Sandoval was assigned to

treat her. The nurse had treated one other Stevens-Johnson victim years earlier, but when she walked into the room, she had never seen anything that compared to how Conway looked that day, Sandoval recalled in an interview.

From head to toe, only patches of skin could be seen. "It was red, open, exposed," Sandoval said. "She wasn't gushing blood, but there was blood everywhere."

Sandoval was afraid to touch Conway.

"She looked like she'd been in a fire," Sandoval said.

She knew how lethal the condition could be and worried that the sloughing tissue in Conway's lungs and throat might block her airway. Sandoval hovered over Conway's bed watching for signs of distress.

That night, at Sandoval's insistence, Conway was transferred in unstable condition from Sparrow to an intensive care burn unit at the University of Michigan Medical Center, records show.

At that point, about 70 percent of Conway's skin had blistered or peeled off. She could barely communicate.

The next day, an ophthalmologist tried to examine the damage in her eyes, but Conway was in too much pain to cooperate. In the doctor's notes from that day, he wrote that Conway told him she didn't expect to survive.

### ***Fighting to live***

Medical records document the flurry of activity that surrounded Conway at the Ann Arbor hospital. Nurses checked her vital signs at regular intervals. Doctors inserted a feeding tube. The wound care was constant.

Every hour, nurses pried open her eyelids to apply drops of medicine.

"They're just trying to keep the patient alive at that point," said McCawley of the Stevens-Johnson advocacy group. "Patients are usually monitored 24/7 with the most intensive care they can give them. ... The reaction has to run its course."

On Conway's third day at the hospital, her condition improved slightly. She was able to sit up on her own and was taken off contact isolation, which meant that staff no longer had to wear gowns and gloves to enter her room.

Over the next few days, the rash stopped spreading and parts of her skin began to grow back.

In an attempt to save her eyesight, doctors grafted amniotic membrane onto her eyes to help them heal. She continued to gain strength and looked better.

Medication was more effective in easing her extreme pain. The lesions on her face were clearing. Doctors removed her feeding tube and she was able to swallow soft food.

After nearly three weeks, Conway returned home with her eyes stitched shut so they could heal from surgery. Wounds were still red and visible on her face and neck. Her twins were too scared of her appearance to sit on her lap, so her husband turned off the lights in the living room and they sat with her on the couch.

She held their hands in the dark, tracing the outlines of their small fingers. Unable to see, she learned to distinguish the boys by the shape of their fingernails.

***"Dangerous Mix" . . .continued from page 19***

Conway spent the next two months unable to open her eyes and later received training on how to walk with the help of a long white cane. In the years since, she has slowly regained her strength, taking long walks and working on home repair projects with her husband.

But the trauma left Conway legally blind. In her left eye she can see only shadows and light. By holding a computer tablet close to her right eye and magnifying the text, she can read in limited amounts.

She can't drive a car or watch the kids at sports events or read a paperback book.

She also suffers stabbing pains in her eyes from nerve damage, leaving her unable to get out of bed on her worst days. She must frequently apply medicated eyedrops because her tear ducts were destroyed. She fights a constant cough caused by her lung injuries. The family now lives in Florida where the high humidity provides some relief for her eyes.

Conway said her approach to taking medication has changed.

"The general public trusts that what their doctors give them is OK," she said. "They don't question it, but they should question it — every time."

In 2012, Conway filed a lawsuit against Bellinger and Sparrow Health System that was settled in 2014 under confidential terms. She and her husband talked about her ordeal in several interviews but declined to disclose the names of the defendants, whom the *Tribune* identified through court records.

Her attorney, Andrea Dalton, said she has handled more than a dozen lawsuits for other patients, many of them children, who suffered from Stevens-Johnson syndrome after taking the same drug combination as Conway. The cases fit a pattern of errors, Dalton said.

"It starts with a hospital or physician error, then there's a pharmacy error and diagnostic errors, and that

becomes the perfect storm," she said. "At the end of this is someone who has to live with it for the rest of their life."

***Full coverage: Dangerous Doses***

Citing a confidentiality agreement, Bellinger's attorney declined to comment on the case. An attorney for Sparrow Health System said Hamelin, the pharmacist, turned down requests for interviews. The health system released a brief statement saying: "Sparrow cannot discuss specifics of this case due to the nature of the settlement agreement. But the safety and security of patients is always our top priority."

Bellinger stopped prescribing the two drugs together after Conway became ill, he said in a deposition. It wasn't worth the risk, he decided.

The case did not appear to change anything for Hamelin, the pharmacist who handled the prescriptions. He testified he would not have a problem filling the same order again. 🌱

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The following individuals joined or renewed their TNA membership between November 30, 2015 and February 29, 2016.

## December:

Robert Etheridge  
Denise Huf  
Patricia Mares-Mischke  
Elizabeth Morris  
Stacey Murphy  
Jeanette Praetorius  
Renate Sackhoff  
Kevin Schroeder  
Sherry Schroeder  
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## January:

Roberta Blumenshine  
David Bundy  
Marlene Clevenger  
Tom Evert  
Morris Hickman  
Stephen Iacovino  
Marleen Karns  
Kathleen Kempken  
Norm Klapper  
Aria Magi  
Michael Moller  
Linda Poland  
Megan Sommer  
Patricia Thompson

## February:

Elise Billock-Tropea  
Frances Chapman  
William Freeman  
Delfina Gary  
Kay Grim  
Donald Hansen  
Kathleen Hays  
Cheryl Hull  
Stan Kamin  
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Western Regional Director  
Medical Advisory Board  
TNA-The Facial Pain Association  
714-456-7002

# REGISTER NOW

**April 23, 2016**

University of Pittsburgh  
University Club, 123 University Place.

[www.FacePain.org](http://www.FacePain.org)  
phone 800-923-3608



Facial Pain Association  
**REGIONAL**  
Conference Program  
Pittsburgh

## Sampling of Conference Topics

**What is trigeminal neuralgia? Do I have It?**

**Everyone that has facial pain does not have the same diagnosis**

**Drug Therapies for Facial Pain, Understanding Microvascular Decompression**

**What can Ablative Procedures do for my type of facial pain**

**Understanding Facial Pain of a Dental Origin**

**Renowned neurosurgeon, Peter Jannetta, MD, Q & A**

**Living with Facial Pain**

**I was diagnosed with TN; What do I do next?**

**A live demonstration with an upper cervical chiropractor**

## Registration Form

PAYMENT: \_\_\_\_\_ Credit Card \_\_\_\_\_ Check Enclosed

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	Fee	# of People	Total
Member Registration	\$39	_____	_____
Non-member Registration	\$49	_____	_____
TOTAL DUE:			\$ _____

So that we will be able to prepare materials for each attendee please list the name of each person you have just registered.

\_\_\_\_\_ (relation to patient) \_\_\_\_\_

\_\_\_\_\_ (relation to patient) \_\_\_\_\_

RETURN COMPLETED FORM WITH FEE TO:

The Facial Pain Association, 408 West University Ave., Suite 402, Gainesville, FL 32601-3248 Phone: 800-923-3608



# 7 TIPS FOR PARENTING IN PAIN

By Jenny LeCompte

Jenny is a board member of the Young Patients Committee and mother to Connor, age 12.

*As a parent there's little you won't do for your child. Being a parent who also lives in chronic pain just makes doing anything and everything for your kids that much more difficult. I know as a single mama, I can't hide my pain from my child. I wish I could. But I spend every ounce of energy I have just trying to seem fine in every other situation in life. Home is where I get to be me. Our life might just look a little different. We're not out traveling and seeing the sights every weekend, we can't pack our evenings full of running from event to event.*

Here are some of the ways I have been able to navigate through life as a parent with facial pain:

**1** Pace yourself. Think about the *spoon theory* (reference below). If your kiddo has a dance recital, soccer game or piano lesson you need to attend, I don't suggest scheduling everyday things such as grocery shopping on the same day.

**2** Plan your meals. This is huge in my house! I love to cook, but often find it either exhausting or painful, as both heat or cold are triggers for me. I try to set aside two days each week for my meal prep times. On Friday afternoons while I'm waiting

for my son to get off the bus, I'm busy making dinner as well as preparing meals to get us through the weekend. Then I do this again either Monday or Tuesday during the daytime to get us through the week. I have snack bags ready for him in the fridge which he knows he can grab at any time. I also freeze meals so we have easy-to-heat options on days when I've run out of *spoons*.

**3** Create social stories. Social stories about the health of a loved one can really help our little ones understand not only the person they love but that there are all sorts of people with all sorts of abilities (and disabilities) out there. You can teach your child through these stories, you can do the same things other families do (excluding a thing or two potentially) you just do them in a different way. These stories can even be fun to make, if you'd like them individualized. You can write the story and let your kiddos draw or color the story as they see it. You might learn from them at the same time. It's interesting to learn how kids interrupt pain.

Springtime is upon us - a time to celebrate new beginnings, rebirth and, come early May, motherhood! We on the YPC are grateful for all mothers - our own, of course, but also those mamas who live with facial pain and the moms of our youngest TN patients. In this edition of the TN Quarterly, we feature parenting tips from one of our own members and words of advice on parenting a child with TN from the mother of one of our board members. We also showcase young patient Faun Danson, a mother of two who we met at the national conference last fall. Happy Mother's Day to all of you!

**4** Practice self-care. This is critical for you as the person in chronic pain, but it's also something you can make routine for the whole family. Let's face it - if you have a spouse or partner who's consistently doing whatever they can to help and support you, make sure to treat them to some self-care from time to time. Not only will they come back refreshed and feeling better than ever, it can really help you feel better as well. Even kids love self-care! Send them out for a special day at the park, the movies, out to a picnic or a weekend with friends. When you feel up to it do what you can to hold a sleepover at your house (or a nice afternoon/evening- baby steps).

**5** Practice the things you love and bring you joy. Neuroplasticity helps me quite a bit. Training your neuropathways to feel good can, in time and with practice, lead to lower levels of pain or even pain-free days. Some of the greatest things as a parent are often some of the things you love doing. Baking cookies with your kids or kicking around the soccer ball, for instance. Or maybe you enjoy things you can do solo. Gardening may be more of your thing;

**Spoon Theory:** The spoon theory is a disability metaphor used to explain the reduced amount of energy available for activities of daily living and productive tasks that may result from disability or chronic illness. Spoons are an intangible unit of measurement used to track how much energy a person

scrapbooking; knitting; or just sitting out on the porch enjoying a cup of tea and watching the sun rise (or set). And here's an added bonus: doing these things for yourself helps teach your kids the importance of discovering things they love.

**6** Take it easy. Let's face it - sometimes you just don't feel well. You know the days you just want to be snuggled up in bed with ice packs or heating pads or whatever you need. Add some fun pillows in your room, and a shelf of your kids' favorite books or movies. It's hard not to be able to get out. Why not bring the fun to you? Your kids will cherish the time you spend reading together, or watching Frozen for the seemingly billionth time.

**7** Live in the moment. If you're not in pain or have a low pain moment, take advantage of it! I'm not saying overdo it, but make sure to use this time as quality family time when you can. Not every day will be a good day, but find the good in every day.

has throughout a given day. Each activity requires a given number of spoons, which will only be replaced as the person "recharges" through rest. A person who runs out of spoons has no choice but to rest until their spoons are replenished.

# TNA VIDEO PROJECT

## 100 FACES • 100 STORIES

Watch • Listen • Share







Kenzie Winslow

# 7 TIPS FOR PARENTING A CHILD WITH TRIGEMINAL NEURALGIA

by Stacie Winslow

Stacie is the mother of 18-year-old high school senior Kenzie Winslow, a board member of the YPC

I'd love to say I am good at following my own advice all the time, but sadly I'm not. I have walked the Trigeminal Neuralgia road for seven years now as the parent of a patient, so it's only fitting that I share the seven tips that have pulled us through.

**1** Breathe; don't panic. My husband is fond of saying, "If you panic, you drown." When dealing with TN, that's very true. At first the pain is SO intense, SO debilitating and the words are SO big and SO foreign. But if you panic, your patient panics. And the pain and unknown are scary enough for them. You have to be calm and deliberate so you can....

**2** Listen. Listen first to your patient. There will be times that they can't speak and can't accurately convey what they are feeling. You will need to be their voice. But you MUST listen to be accurate. TN is a clinical diagnosis and so many of the treatment options depend on the words used to describe the pain: shocking, burning, lightning, electrical, pressure, etc. Listening to your patient will allow you to....

**3** Learn. And, WOW, is there a lot to learn. Read the book *Striking Back*. Read articles from the Facial Pain Association website. Read scholarly articles by experienced TN surgeons. Do not learn from social media groups. There is a lot of hurt, anger and frustration that comes with having TN and a lot of times that surfaces on social media sites. Be careful about taking posts on group sites as gospel and instead use those sites for....

**4** Support. Your TN patient needs your unconditional love and support. There will be days that you are tired, exhausted even. But so are they, AND they are in pain. Remember numbers one and two above.... your patient needs you to be strong when they can't. But support also means ask for it when you need it. Feeling supported yourself will allow you to be a powerful....

**5** Advocate. This is the absolute most important role for a caregiver. It will fall to you to call and beg for appointments. It will fall to you to speak by proxy for your patient— especially at school and activities. It will fall to you to ask for what you know your patient needs and when one door closes, re-open it and walk back through until you get the answer you want. You will be far more educated than many doctors who see very few, if any, cases of TN in their career. You will have taken the time to learn about the options available and you will know what your patient needs next, as long as you are careful to....

**6** Be Deliberate. You will be so desperate to get your patient out of pain that you will try anything and everything to help them and you will want it all done right now. But if you are not deliberate in your approach, you will never know what's really working. If you try upper cervical chiropractic care when you up the dose of her medication and also add

Chinese herbs, you'll never know which one works. This comes from experience. I tried the kitchen sink approach: MAGO (mouthguard), chiropractic, acupuncture, massage, herbs, four different TN medications, steroids, nerve blocks, biofeedback, the Sherwood diet, etc. We wasted time and money because we never knew what, if anything, was helping. Be deliberate. Take it one day at a time, one procedure or pill at a time and, most importantly....

never, ever, ever giving up is never, ever, ever letting your patient, your loved one, give up. There are days you have to force them up and out. No one beat TN lying down and no one made themselves feel better by laying alone in a room. If it hurts while you are laying down alone, it can hurt while you are at a movie with a friend. TN is a disease of isolation. It's so rare that few understand it and fewer know how to respond to it. So be there to love your patient through it. Because tough love is still love. 🌿

For more information about the YPC, visit [ypc.tna-support.org](http://ypc.tna-support.org)  
f /tnaypc

**7** Never Ever, Ever Give Up!! I believe we will find a cure. But in the meantime, as long as you as a caregiver are being calm, deliberate, and supportive advocates who are listening and learning, we will beat TN. Part of

## Young Patient Profile

**Name:** Faun Danson

**Current age:** 33

**Where do you live?**

Ottawa, Ontario,  
Canada



**Q: How old were you when you first experienced facial pain?**

**A:** 31 - I first experienced it while running and it progressed quickly from then on

**How old were you when you were diagnosed?**

**A:** 32 - it took quite a while for a final diagnosis. It felt as if no one wanted to make the final diagnosis.

**Q: What was your diagnosis?**

**A:** Glossopharyngeal Neuralgia and Trigeminal Neuralgia

**Q: What do you do for fun?**

**A:** Netflix binging, playing with my kids, dates with the hubby, texting friends, colouring (good stress reliever!) - I used to be much more active, but my pain or fatigue often stops my activity.

**Q: What has TN taught you?**

**A:** If you open up and ask for people to help, you would be surprised how many people are there for you!

**Q: What treatments (non-surgical) have you tried?**

**A:** A cocktail of medications, a TENS unit, cold and hot compress, psychological treatment.

**Q: Have you had any procedures?**

**A:** I had a microvascular decompression on October 29, 2015

**Q: How has your facial pain changed you?**

**A:** My pain has lessened my physical activity substantially. It has changed my interactions with people; I have become more empathetic. I have found a new group of people who understand me to a different level, and I feel blessed for those people.

**Q: What tips do you have for other young patients?**

**A:** ASK FOR HELP! As a society we tend to close up and feel we have to deal with things alone. This is something you don't have to deal with alone; there is a huge group of people ready with open arms. ADVOCATE for yourself. No one knows you better than you, so step up, speak your mind, and ask questions until you are completely satisfied with the answer. DON'T SPREAD YOURSELF TOO THIN. Plan your days in advance and ensure you are taking time for yourself. You need time to recharge. And you are worth that time! 🌿

# RELIEF AFTER A DECADE OF FACE PAIN

*“The whole procedure took less than an hour—and it worked!”*

*—Mary Hamilton, Warwick, NY*

At first, Mary thought she just needed to see a dentist for her chronic face pain. But after being diagnosed with trigeminal neuralgia and over a decade of different high-dose medications, she had had enough. On December 15, 2015, Mary was treated with the Gamma Knife procedure. In less than an hour at The Valley Hospital Gamma Knife Center in Paramus, NJ, she went from managing her condition, to being free of it.

Start writing a new chapter to your story. Learn more about the procedure and our nurse navigator, who guides patients every step of the way. She will coordinate appointments, field questions and manage your follow-up care.

**Schedule a consultation at The Valley Hospital Gamma Knife Center today by calling 201-634-5677 or visiting [www.ValleyGammaKnife.com](http://www.ValleyGammaKnife.com).**





# World Class Trigeminal Neuralgia Facial Pain Program

## The New York Area's Experts



Michael H. Brisman, M.D.

Dr. Michael Brisman, Dr. Jeffrey Brown and Dr. Alan Mechanic perform all of the different procedures for trigeminal neuralgia, and are leaders in the field of face pain surgery.

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.



Jeffrey A. Brown, M.D.

Dr. Brown is the 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.



Alan Mechanic, M.D.

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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