Wolfgang Liedtke MD, PhD
Chair of Neurology, Psychiatry, Pain Medicine and Sensory Systems
Regeneron Pharmaceuticals, Tarrytown NY
Adjunct Professor, Duke Neurology
Adjunct Professor, NYU Dentistry - Dental Pain Research
Member, NYU Pain Research Center

- these are my private opinions and insights, not those of Regeneron, Duke or NYU.

This post is exclusively informational-educational-scholarly. My answers are of general-informational nature, this is NOT medical advice.

Samantha Bankey
Apr 29, 1:20 PM
I have to do the chewable tegretol to keep my pain low every 4 hours. it does taste horrible but effective for me

GREAT, Samantha.

sharon r s
Apr 29, 1:21 PM
ANy evidence for Baclofen? Low Dose Naltrexone?

Baclofen is a suitable medical treatment for trigeminal neuralgia, trigeminal neuropathic pain. It can be 2nd line add-on, used in-lieu of other effective medicines when taking a needed drug holiday, and in situations when carbamazepine and related sodium channel blockers have little effects or cannot be taken. Also for consideration when doing intrathecal pumps. Also with an excellent profile in case there is muscular spasm (chewing muscles; occipital-neck) that goes along with the trigeminal pain
LdNtx was covered extensively separately. I believe the FPA should try to set up a clinical study that goes on record of its beneficial effect in trigeminal pain, I have found it vastly effective during my 17y of practice at Duke.

Maria Peterson
Apr 29, 1:21 PM

I landed in the ER last week for supraorbital neuralgia crisis, had Phenytoin IV drip, broke the pain cycle. Then prescribed it in pill form along with Tegretol.

Great to hear. Re pheny iv: needs to be safely iv, no wiggle room for infusion NOT into the vein - can lead to abscess formation in that case.

Robyn Soerries-Funk
Apr 29, 1:22 PM
I get high blood pressure with attacks. ER rushed me back thought i had a stroke.

That represents unfortunate diagnostic confusion because the pain should be centerfold of all therapeutic actions. - Cannot fault the ER for going after a stroke - overlooking a stroke open legal liabilities.

Amy Reyer
Apr 29, 1:22 PM
What do you recommend for constant atypical pain?

For constant "atypical" pain, treatments can include low-dose naltrexone plus lacosamide, then as needed add-on (gradually, one by one), of Lyrica/Gabapentin, Cymbalta/Venlafaxine, anti-inflammatory in case there is indication of an inflammatory pain driver, anti-CGRP antibodies for self-injection, botox.

Sekula Raymond
Apr 29, 1:22 PM
What are the new drugs and are they coming soon to the pharmacies? Basimglurant by Noema Pharma, this is a FDA Phase 2/3 study...there are 5 sites in the U.S., and I will discuss later in the day.

Specifically, re inhibition of neurogenic inflammation, which contributes to most trigeminal pain syndromes, using -gepant compounds: zavegepant just got approved by the FDA last month.
New sodium channel blockers need to be fed into the FDA pipeline (not trialed for trigeminal pain, therefore would be re-purposing; some positive evidence in phase-II trials for acute pain), there is also an interesting new AAK1-kinase inhibitor coming up in the pain landscape with encouraging data in diabetic and postherpetic pain (Lexicon Pharma), a bit behind the Nav1.8 inhibitor.
Overall, fortunately, the field has not lost its dynamics, might be picking up.

Osvaldo Brusco
Apr 29, 1:23 PM
I have used Gabapentin for 10 y for atypical pain (after having originally typical pain) with good success by having background tolerable discomfort....would adding oxocarbamezapine on top of gabapentin be safe and help to take away the atypical pain? Thanks

can try (overall not a big risk - discuss with your doctor); my experience with lacosamide in that setting has been more encouraging - how about low-dose naltrexone, when there is no time pressure to see increased effectiveness

Sekula Raymond
Apr 29, 1:24 PM
Can the fast-acting oxcarbazepine / carbemazepine be used on top of a daily maintenance dose? Yes, your doctor can prescribe 100 mg tablets.

fast-acting meds on top of maintenance meds: YES. Generally, carbamazepine toxicity is assessed clinically (blood monitoring not so informative), cerebellar symptoms stand out (balance, coordination, slurred speech, double vision), also "brain fog" and low-sodium with longer term high-dose.

Robyn Soerries-Funk
Apr 29, 1:24 PM
my BP has been as high as 180/120

And that might be quite common, more common than we assume. You are paying attention to this important issue, Robyn, of note you apparently can keep a clear head and measure your bp during an attack (not always feasible for many patients - family can jump in).

Sekula Raymond
Apr 29, 1:25 PM
Which of these medications for facial pain do you recommend for TN type 2 constant burning pain? Thought leaders are abandoning the classification scheme of Type 1 and Type 2 TN. It's a statistical construct, but really doesn't help the field.

Re constant burning pain, see my response above.

Stephanie Sorensen
Apr 29, 1:26 PM
What if I can not take the carbamazepine drugs at all?

In case of carbamazepine/oxcarbazepine non-feasibility, lacosamide is a highly suitable alternative, however the caveat of approval-

coverage and the drug being expensive remains. More "textbook" views favor gabapentin/lyrica or baclofen.

Robyn Soerries-Funk
Apr 29, 1:26 PM
3 doctors have told me to eat more salt cause it's so low. The pills don't work anymore

Low sodium caused by an SIADH at milder level can be compensated for, also the nervous system appears to adapt. But once sodium goes below a certain threshold (very roughly, 130; 128 if the process is very protracted), which might be different from individual to individual, only lowering the dose of the offending drug helps.
There are also medicines like tolvaptan, but one needs a nephrologist's Dr's office to support that script - I was never able to accomplish that.
Practically, lower carba/oxcarba and try to fill the gap with another drug.

Ronke Luke
Apr 29, 1:26 PM
Carbamazepine gave me gastritis. Anyone have same experience? Was so disappointed as it helped me

that sounds like possibly related to formulation. Try a different maker, try brand name, try oxcarbazepine liquid.
These drugs can lead to cerebellar malfunction which can impress similar to an alcohol intoxication, which sometimes has dominant symptom of nausea - vomiting.

Sekula Raymond
Apr 29, 1:27 PM
Is there any eye drop for burning eye pain with AD? You can discuss with an opthamologist or neuroopthamologist. He or she may prescribe an anesthetic (e.g., bupivicaine) eye drop, but you would need to use somewhat infrequently.

AD here anesthesia dolorosa (in other worlds: Alzheimer's Disease; Atopic Dermatitis, two biggies ...).
There is need for improvement here.

I have once been able to get lacosamide liquid (for intravenous), to be reformulated into an eye drop - need a competent compounding pharmacy that can pick this up.
More specific medications for Dry Eye are coming, for example adiponectin analogues, TRPM8 modulators. Bot not approved yet. They can then be re-purposed.
Converting a patient's serum into artificial tears is perhaps the best bet. Need a compounding pharmacy - eye clinics - optometrics facility that does this. I had encouraging experience with "autologous tears" (autologous serum converted into artificial tear fluid) for chronic eye irritation.

For pain medicine institutions, there is a strong mandate to "de-silo", and get pain medicine specialists, neuro-docs, and ophthalmologists to the table. - They should not be allowed to eat until they have come up with a workable solution to this problem. Also not allowed - a shoulder-shrug at the end of it all.

Sekula Raymond
Apr 29, 1:27 PM
I use chewable Phenytoin for breakthrough pain. It works pretty well for me. Never knew I could try oxcarbazepine as a chewable. I use long-acting oxcarb. I will have to ask my neuro for chewable. This is a very good observation.

Great, excellent.
A patient of mine was not able to get orally-dissolving clonazepam, he could get regular tablets at 0.5 mg which he cut into 1/2 and then diligently chewed, did it for him.

Samantha Bankey
Apr 29, 1:27 PM
I have TN2 and take the chewable tegretol every 4 hours. that helps keep my pain tolerable

Excellent, that has been a very safe practice with my patients.

Sekula Raymond
Apr 29, 1:28 PM
How do you know if it is second branch or third-branch attack and whether to take lidocain nasal spray or oral jelly? Generally, the second branch innervates tissue to the level of the upper lip.

After some explanation and/or googling around, every patient knows. - There are multi-branch trigeminal pain syndromes, also

there is branch spreading, initially it's for example a V2L, which then becomes a V2-V3L, (which can even become bilateral in case of insufficient pain control).
Orally-applied fast acting meds reach nerve endings of V3 (some V2 - maxilla and roof of the oral cavity/palate); nasal spray fast acting meds reach V2. Both also accomplish rapid systemic concentrations, depending on drug nasal sprays more rapid and more effective. That also depends on the medicine in the topical: Oxytocin is a peptide, oral application or swallowing oxytocin do not lead to any absorption. Ketamine nasal does reach systemic concentrations (+V2), ketamine oral appears weaker, much less systemic concentration.

Luat Dao
Apr 29, 1:28 PM
@Ronke You might ask for Carbamazepine manufacture by different companies, The one work for me made by Torrent

Endorsed.

Sharon Whitener
Apr 29, 1:28 PM
I have never tried chewable Tegretol.

Benign safety experience in my patients; alternative liquid trileptal (here a feasible alternative: swish-and-spit for exclusively topical exposure and minimal systemic exposure; vs swish-and-swallow for topical AND pretty rapid systemic exposure - however, systemic exposure adds to the total daily amount taken: a bit extra can be beneficial, but there can also be patients who have to "household" carefully).

Samantha Bankey
Apr 29, 1:28 PM
for me it was a game changer...Sharon Whitener

highly beneficial to many patients of mine (often combined with orally-dissolving clonopin 0.25 or 0.125 mg per od-tablet). - Patients also feel much safer having these meds at home and when outside the home/at work/traveling.

Robyn Soerries-Funk

Apr 29, 1:28 PM
What did he say? If you have...i remember

Presentation posted, plus these answers.

Sekula Raymond
Apr 29, 1:29 PM
I have used Gabapentin for 10 y for atypical pain (after having originally typical pain) with good success by having background tolerable discomfort....would adding oxocarbamezapine on top of gabapentin be safe and help to take away the atypical pain? the term "classical" is now the accepted term for most of what was called "typical" in the past. If it was classical in the beginning, you are probably still a good candidate for MVD.

In addition to Dr Sekula's comment, oxcarbazepine can be added with benefit to a long-term gabapentin regimen - try-out with oxcarbazepine liquid or simple tablet. Two alternatives, gabapentin + cymbalta or gabapentin + venlafaxine have helped many patients of mine; or add-on of low-dose naltrexone given its excellent safety profile.

Kerry Bradley
Apr 29, 1:30 PM
The side effects of the top three medications aren't for me. Toxed on all plus a few others. I'm very interested in the ketamine nasal spray for beak through pain. Fortunately I'm not severely depressed.

Many patients of mine have had excellent experience with ketamine nasal (compounding pharmacy), for breakthrough pain and also for individualized longer-term management.
Consider anti-CGRP antibodies for self injection (completely different principle from all traditional approaches), or botox given that botox certainly does not work systemically.
https://journals.sagepub.com/doi/full/10.1177/03331024221141683

Sekula Raymond
Apr 29, 1:30 PM
my BP has been as high as 180/120. Yes, severe pain will certainly elevate one's BP.

And fast-acting anti-hypertensives will help manage pain exacerbations, at a minimum by enhancing safety by lowering dangerously high bp, with certain likelihood helping directly analgesic approaches work more effectively.

Maria Peterson
Apr 29, 1:30 PM
I have supraorbital neuralgia, what is the best abortive when in crisis for SON strictly? I've used topical lidocaine, does not do much. Dilantin has helped. I also have HFS which aggravates everything.

Chewable carba - liquid oxcarba; orally-dissolving clonazepam; ketamine nasal spray.
Then with this exclusive location, a Cefaly neurostimulator is worth considering, don't need a script any more. As soon as the pain anounces itself, start stimulation (with low intensity). - I believe the manufacturer takes it back within 60 days if it does not work (which means no effect, or can enhance the pain when overstimulating; but more likely to be effective).

Sekula Raymond
Apr 29, 1:31 PM
What if I can not take the carbamazepine drugs at all? Consider Noema's trial if you have classical TN. If not, dr. Liedtke has provided lots of suggestions.

Lacosamide is a suitable alternative; baclofen, gabapentin/lyrica.

Natalie Merrithew
Apr 29, 1:32 PM
indomethacine and meloxicam

indo for short term use - it's a very powerful anti-inflammatory.
Meloxicam for anti-inflammatory use longer-term.
These anti-inflammatories should have an effect within a few days, 3-5 days max. If not effective can drop them right then.
Need stomach protection with indo (e.g famotidine, prilosec), copious hydration, monitoring together with Dr's office. Better to take these measures with meloxicam as well.
When in need of a drug holiday with NSAID anti-inflammatories: can use a combination of tylenole plus 2-3gram/d of turmeric OTC nutraceutical herbal anti-inflammatory.
Anti-inflammatories still very effective with migraine, and migraine is often co-morbid with trigeminal pain. A simple, but powerful treatment for migraine attacks is a combination of anti-inflammatory + triptan (in case either does not suffice). Suppressing migraine

(and other headaches) very diligently (not to say aggressively) can help keep trigeminal pain much more effectively contained.

Sekula Raymond
Apr 29, 1:33 PM
I have supraorbital neuralgia, what is the best abortive when in crisis for SON strictly? I've used topical lidocaine, does not do much. Dilantin has helped. I also have HFS which aggravates everything. Supraorbital neuralgia may respond to a nerve block for a prolonged period, and in some cases, it may be best to injure the nerve but that is very nuanced.

SON longer-term management.
1 - try botox first, in my opinion preferable over long-term blocks/steroids (repeated blocks/steroid can be risky for evoking necrosis of the injection site - terrible outcome). Combine botox w Cefaly neurostim - good safety profile.
2 - my former Duke University colleague Ilya Leyngold performed a peripheral nerve operation where he re-engineers forehead innervation by connecting supraorbital V1 branches with one another. Patients who were selectively referred to him did well.
Dr Ilya Leyngold is now in private practice
https://www.leyngoldplasticsurgery.com/about/ilya-leyngold-bio/

Arun Rao
Apr 29, 1:35 PM
My wife gets relief only after taking extra strength Tylenol when there is a severe pain. She is on gabapentin and also dulaxotine and Bupropion. We often wonder whether is it because what she has is not trigeminal. is this common?

add-on tylenole makes me think of actions of this drug on TRPA1 ion channels. - Arun's wife has 3 anti-pain meds that act on the pain-brain. Then extra tylenole appears effective - patients have been continuing on such regimens, keeping it safe by doing it together with treating doctors (liver remains OK ?).
This account does not distract from a trigeminal pain diagnosis.
https://pubmed.ncbi.nlm.nih.gov/29738273/
https://pubmed.ncbi.nlm.nih.gov/22109525/

Sharon Whitener
Apr 29, 1:36 PM
Tylenol might not help this pain of TN.

Typically and by itself not, but in combination with anti-neuralgics it can.

Sharon Whitener
Apr 29, 1:39 PM
What is LDN?

low dose naltrexone
https://pubmed.ncbi.nlm.nih.gov/36169808/
https://pubmed.ncbi.nlm.nih.gov/36974308/
https://pubmed.ncbi.nlm.nih.gov/35354341/

Jorge Funes
Apr 29, 1:39 PM
will it be possible to post or email the slides?

Will be posted, plus these answers.

Anna Williams
Apr 29, 1:39 PM
So glad to see the CGRP injections listed too - I did Aimovig for 3.5 years, first thing that helped my TN (didn't help my migraine though)

An impression shared by many of my patients.

Art McHaffie
Apr 29, 1:39 PM
How about Nurtec which is a migrain medication?

I have made that observation, in limited numbers of patients who used rimegepant for as-needed add-on medication.

https://www.pharmaceutical-technology.com/data-insights/rimegepant-sulfate-odt-pfizer-trigeminal-neuralgia-tic-douloureux-likelihood-of-approval/#:~:text=Rimegepant%20sulfate%20ODT%20is%20under,for%20progressing%20into%20Phase%20III.

Anna Williams
Apr 29, 1:39 PM
He talked about Nurtec on an earlier slide it's currently in clinical trials for TN :)

Yep

Cheryl Rosen
Apr 29, 1:40 PM
Started using it for my Chronic Variable Immune Deficiency. But I think it may have also helped as one of my drug protocol for TN.

Here is something on CVID and pain
https://n.neurology.org/content/94/15_Supplement/794
A -gepant medicine for CVID: I have not heard of that.

Jess McCleary
Apr 29, 1:40 PM
Methadone worked so well for my TN2! Pretty hard to come off though.

Weaning-off methadone hack that worked for several of my patients. Go on liquid methadone, then very, very gentle and slow reduction.

Kim Fields
Apr 29, 1:42 PM
I have been taking 4.5 mg LDN daily since summer 2019. It has been so helpful, along with low doses of trileptal and gabapentin.

Great to hear, Kim !

Margaret Hennessey
Apr 29, 1:42 PM
Does anyone have a neurologist in Houston that is helpful with emergency Trigeminal episodes?

Colleagues with these credentials and skills are critically needed. For patients who lived in areas where there was no such help, I tried to write up action principles what to generally do in the ER/urgent care, plus a disclaimer that the patient who presents ER/Urgent Care with trigeminal pain is in supra-maximal pain, thus under supramaximal stress, with difficulty speaking, cannot be "interrogated", in severe need of urgent attention, not to be "parked" at the end of the line.
- It has been helpful, as I heard.

Doris Shapiro
Apr 29, 1:45 PM
What can you do about the weight gain associated with so many of these medications?

In my practice, I made good experience with topiramate plus phentermine.
https://medlineplus.gov/druginfo/meds/a612037.html

Also not to continue on obesogenic treatments, such as marinol (and anything cannabis related), Lyrica (there seems to be a obesity susceptible % of those treated - gabapentin can still work without the effect on regulation of body weight)
I believe that very recent anti-obesity treatments are reason for renewed hope, I mean medicines that act on the GLP-1 receptor system (e.g -glutides).

Robyn Soerries-Funk
Apr 29, 1:46 PM
What did you say about low sodium? My last test at GP called and said it was critically low. Eat more salt. What med is best for Sunct and Paroxysmal hemicrania?

See my answer above.
Might have to dose-reduce the offending medicine, carbamazepine/oxcarbazepine are more suspect than others here.

Kim Fields
Apr 29, 1:46 PM
Thank you, Dr. Liedtke! I always learn so much from your presentations. You are so generous to share your time and expertise. We are so lucky to have you on FPA's MAB :)

Osvaldo Brusco
Apr 29, 1:46 PM
Any Neurologist with particular experience in TN and or emergencies in or around San Antonio, Tx ?

UT Southwestern Dallas has an ensemble of headache-headpain physicians under their wing.
I know that Dr Ken Hargreaves at the UTSAHC is a global authority on dental-trigeminal pain, deservingly. It might be worth inquiring with the dental school, they must have clinics dedicated to chronic orofacial pain.

Pam Adams
Apr 29, 1:46 PM
Is there anything on the horizon for stem cell therapy as a possible cure?

SC have an issue that I continue to grapple with.
Once cells are seeded/ implanted into a patient with chronic pain, there is the inherent risk what these cells might do many years down the road, whether they have helped the pain or not. The question

here is whether they might become cancer/leukemia/lymphoma cells, or influence neighboring cells to become a cancer or sarcoma. Even a small percentage of patients experiencing this would end such programs, plus ultimately represent a path of medical development that turns out to be very problematic, or perhaps even outright disaster.
Use of what SC secrete to try to help with pain: sounds more geared toward safety, but then these approaches are besieged by variation.

There are examples of patient's own plasma used, which is sort-of a low-tech SC related method, thrombocyte enriched plasma.
Or topical use in the form of autologous serum eye drops.

If we see the day when we will have SC based therapies that really help with trigeminal pain, safe and effective, I'll be the first to cheer. Right now, I would not put my money on it, rather on different approaches. - But that's my subjective take on this crystal ball ...

Cheryl Rosen
Apr 29, 1:47 PM
I've had migraines since 1983 (after my first car accident) and symptoms of TN since the late 1990's. It took years before my MRI actually showed the artery pressed against the nerves bilaterally, and now there is an indentation on one of the sides.

Sounds like a case to discuss w specialized neurosurgeons.
I had patients with related situation/situs as you describe, they got improved with MVD. Also considering MVD to prevent worsening of the anatomical "mark" that they artery has already left.

Pam Adams
Apr 29, 1:49 PM
what about ketamine troches instead of nasal spray?

Seems to work much better as nasal spray because there is topical effect on V2, and also (perhaps to increased degree) systemic absorption via the nasal route (one can do nasal insulin, but oral insulin has never worked).

Myers Amy

Apr 29, 1:50 PM
What do you do when you max out on a cocktail of meds. How do you transition?

Try to exchange some of them against other meds that work completely different.
Add measures that act on the nerve topically: Cefaly neurostim, other neurostim as discussed during out meeting; botox, other topical injections.
Add-on CGRP neutralizing antibodies.
- low dose naltrexone part of the mix ?

Myers Amy
Apr 29, 1:51 PM
Do you do that transition in the hospital?

That can be very helpful, e.g the patient can be given iv meds that sedate, plus under medical supervision (literally).
BUT - US culture is strongly against this. This was very typical in Germany where I trained eons ago (still goes like that, my German neurology friends reassure me).
Perhaps our FPA neurosurgeon opion leaders can start changing this culture ? Patients would be inpatient for only a few nights. Once nursing personnel knows how to handle them they are not difficult to manage.

Diane Harrison
Apr 29, 1:51 PM
Exercise=blood pumping=PAIN. How do you exercise for help with Anethsia Dolorosa?

I tried to express that exercise is not a universal adjunct approach for trigeminal pain, including anesthesia dolorosa.
This was workable for one particular patient of mine.
In general, once one approach starts working (a bit), try to leverage add-on measures that by themselves might not be decisively effective. Add-on, add-on and get the upper hand in small steps.

Ally Kubik
Apr 29, 1:54 PM
@Diane I totally hear you! There are times when exercise is super helpful for me as part of my treatment but then there are times that I realize I can't.

Yep - customize and try to optimize individually. - During part of the year it might be workable, during other part of the year - no - then what else can you do.

Nancy Roach
Apr 29, 1:55 PM
I have bi-lateral TN along with Anesthesia Dolorosa from a Rhizotomy on my right side. This also has caused blindness in my right eye due to total nerve damage to the Cornea.

All my best to you, Nancy.

Kenneth Handel
Apr 29, 1:55 PM
I have to take 2400 mgs of neuroton and 3300-3750 mgs of trileptol in ordrt to keep my pain controlled. I am 75 years old and my symptons started at age 50. I started out having MVD and then had a deep brain stimulation and then motor cortex which helps my anastesia de.la rosa. What do you suggest to lower me lower trileotol?

Patients who came to see me, reminiscent of your situation, benefited from low-dose naltrexone, try to replace part of the trileptol with lacosamide, perhaps add-on cymbalta, try botox.

Jess McCleary
Apr 29, 1:56 PM
Thank you Dr. Liedtke or your time! Always find your talks so interesting and helpful!

William Freeman
Apr 29, 1:56 PM
what to do with the onset of humid conditions/barometric pressure changes that can exacerbate facial pain? also, in preparation for travel on airplanes, with

REALLY important points re what can have major impact on disease course of trigeminal pain.
Barometric pressure might be ultimately unfixable except residing geographically where it is more tolerable.
Change of barometric pressure: maximum unswelling of sinuses and upper airways: flonase + afrin + allergy medication. Try out air travel if tolerable. Before take-off, can take extra orally-dissolving clonazepam 0.25mg which has additionally sedative-anxiolytic effect, which is good in this situation.

Skelton Linda
Apr 29, 1:56 PM

Thank you so much. I would be so grateful if you could answer my question in your transcript. You are so inspiring to listen too.

William Freeman
Apr 29, 1:57 PM
air pressure, what preventative/preparation measures can one take in advance of air travel

see my above answer

Vanessa Jeffrey
Apr 29, 1:57 PM
I have been diagnosed with CRPS as well as ATM (although after the last two days I am confident that I have Anasesia Delarosa) as well. What do you advise patients for treatment of these?

CRPS - can be a questionable diagnosis in the trigeminal territory.
Autonomous nerve fibres part of the pathologic pain - that could be it.
Anesthesia dolorosa: in my patients with this issue, here are measures that have helped, needs to be a customized approach.
baseline therapy with lacosamide and low-dose naltrexone (cannot live without opioid ==> then no low-dose naltrexone).
Ketamine nasal spray; botox; steroid infusions; perhaps Cefaly more helpful than anti-CGRP antibodies.
Vigorous fighting of co-morbidities.

Maria Peterson
Apr 29, 1:58 PM
Much appreciated Dr. Liedtke, Dr. Sekula and Mr. Bodington

Vanessa Jeffrey
Apr 29, 1:58 PM
Thank you for such a fabulous session.

Myers Amy
Apr 29, 1:58 PM
THANK YOU DR LIEDTKE

Francine Chang
Apr 29, 1:58 PM
Thank YOU!

Angie Schreiber
Apr 29, 1:58 PM
Thank you so much

Tahiri Amine
Apr 29, 1:58 PM
thank you, very clear

Jan Boydstun
Apr 29, 1:58 PM
Great session!

Monica Williams
Apr 29, 1:58 PM
Thank you very much

Sandra Rygh
Apr 29, 1:58 PM
Thank you!

Katherine Ihde
Apr 29, 1:59 PM
Thank you!

Sarah Clark
Apr 29, 1:59 PM
Thank you! Such great information!

Jane Procise

Apr 29, 2:01 PM
That was amazing!

Amy Reyer
Apr 29, 2:01 PM
Thank you, would be great if drs were listening.

I hope they will ...

Nancy Roach
Apr 29, 2:02 PM
To finish my question...I have also had an MVD for the left side which didn't take the TN pain away. I am wondering what your thoughts are on the Caudalis Drez procedure and the risks involved?

Nucleus caudalis DREZ procedure (it's in my presentation) had a surprisingly good safety profile, as conducted at Duke University, when working together with my neurosurgical colleague Dr Nandan Lad. Initially we thought of it more as an "ultima ratio", but then saw our own data of it being quite safe.
So DREZ caudalis can be an option for you.
You need to sit down with a doctor's office where this method is being applied with some proficiency.

I also suggest for you to undergo more exams why you have bilateral trigeminal nerve pain. - You must have had multiple neuroimaging so that multiple sclerosis cannot have been overlooked.
My #1 suggested disease to look for in your case is fibromyalgia with small fiber neuropathy. The latter can be decisively diagnosed by conducting a harmless skin biopsy and send the skin samples (1 buttock area, 1 from below the knee - no sampling in the head-face area) to a specialized neuropath lab for nerve fiber counting in skin/epidermis and also sweatglands, in case sweatglands are in the biopsy. Too low count: positive diagnosis of small fiber neuropathy, a general-systemic peripheral nerve condition that predisposes to chronic pathologic pain, pain that does not resolve after minor injury. In case you had that disorder, at least one would know an underlying condition that predisposes you for nerve pain.

Jane Procise

Apr 29, 2:03 PM
I'm definitely suggesting this conference to my neurologist! Hopefully he won't be offended
Sharon Whitener
Apr 29, 2:28 PM
He should not be. I think all neurologists need more information on TN.

Marlaine Hysell
Apr 29, 9:57 AM
I have mild relief from a steady-state of clonazepam. Does that give any clues as to what other med might be helpful for non-lancinating pain?

Patients of mine have reported benefit of lamotrigen in this situation; also consider combining with SNRI/NDRI meds (duloxetine; bupropion); low-dose naltrexone was found beneficial as well.

Marlaine Hysell
Apr 29, 9:55 AM
I have seen you recommend 5 days on and 2 days off of Clonazepam. Do patients go w/o any meds on the 2 days off?

no, then patients were bridging over with sedating anti-histamines/anti-emetics such as prochlorperazine, chlorpromazine, (droperidol), or simple OTC phenergan liquid, and it resolved the situation.

Marlaine Hysell
Apr 29, 9:54 AM
Are there sprays or topicals available for nostril/breathing pain?

Patients of mine have reported beneficial use of ketamine nasal spray for trigeminal pain in the second branch, including nostril. Breathing-associated pain: probably a patient will need to co-consult with neuro-pain and also with pulmonology/allergology. Fight respiratory allergies/chronic inflammation to the max, in general.
As I mentioned, a well-done report from China points to the beneficial use of lidocaine nasal spray which will numb the nostril area - that can give 1/2h-plus cover time to do sth else that does not kick in on-the-spot, such as most effective oral anti-pain med.

Marlaine Hysell
Apr 29, 9:54 AM

What’s working for non-lancinating pain? Ie: burning eye pain, breathing pain

see my answer above to you, also answer above re "burning pain".

Marlaine Hysell
Apr 29, 9:53 AM
Since opioids don’t usually provide TN pain relief what are the benefits of Rx’ing them?

Of course, opioids ONLY go in case of benefit for the trigeminal pain, and suitability of long-term opioid use IN A SPECIFIC PATIENT'S case for her/his disease.
That can be done to everybody's benefit, and I did this in my two practices at Duke.
Unless the patient also has an opioid use disorder AND trigeminal pain, and that opioid use disorder is calling for a substitution, e.g with methadone (I personally like it better), butorphanole (officially endorsed much stronger - I still like methadone better), or levorphanole (I like the best, but as I was winding down my practice it became prohibitively expensive; hopefully that has changed now).

Marlaine Hysell
Apr 29, 9:52 AM
Marinal - please give general comments re: forms of Marinol ie: pill, topical, inhaled. And examples of how prescribing information.

Marinol is a capsule of 2.5, 5 or 10 mg. No topical, certainly not inhaled.
E.g prescribed for pain-associated nausea, start at 2.5 mg take 2 tablets twice per day, 1 month, 5 refills, is a typical Rx. Some patients of mine did best with 2.5 mg 1-2/d, others needed 10 mg up to 3-4x/d. Whether it helps becomes clear within a week or two. If not, drop it.
https://www.accessdata.fda.gov/drugsatfda_docs/label/2005/018651s021lbl.pdf

Marlaine Hysell
Apr 29, 9:49 AM
Re:Ketamine nasal spray - You have suggested up to 24 puffs per day. Does that mean spread out at suggested length of time intervals? Several puffs at one time? What is the general length of time of relief per puff?

I have suggested to former patients of mine a daily upper limit of 240 mg (soft limit), whereby 1 puff was 10 mg (100 mg/mL).
This is applied on an as-needed basis, not for regular use, i.e puff in case the pain anounces itself or comes on stronger. One puff helps, but incomplete, repeat, up to 4 puffs per application (=40 mg). That was for many patients a suitable dose. With that, I gave 6 such doses as upper limit, which served as good guidance.
Many patients needed less, some few (a bit) more.

Skelton Linda
Apr 29, 5:26 AM
In your experience, which medicines work best for patients with TN (with no nerve deviation) and also unspecified autoimmune conditions (not MS)? If an inflammatory condition causes irritation on the nerve could a different drug regime work better to reduce inflammation? Especially in young patients. Thanks

With "unspecific autoimmunity" - my patients have benefitted from a thorough, not to say aggressive approach to try to diagnose the disease more precisely. Typically this takes a more open-minded autoimmune specialist who is open to listening to patients' pain, and to leaving a thorough diagnosis open, yet confirming that it is autoimmunity, but not yet ready to fit a known diagnostic code. Such colleagues are unfortunately not too common.
So unless there is a need for opioid medication, definitively low-dose naltrexone, also bring in an anti-inflammatory, indo or meloxicam, to test pain's responsiveness - driven by NSAID-responsive inflammation - is that so ? This can even be tried with 400-600 mg liquid ibuprofen OTC.
Re anti-inflammatory, and a method that went a bit under-appreciated in my presentation and also here in Q&A, INTRAVENOUS CORTICOSTEROIDS as "steroid pulse"
500-750 mg methylprednisolone iv per day for 3 days in a row, or Monday-Wednesday-Friday, can make that up to 5 days in a row, and go up to 1000mg methylprednisolone. This goes in a Dr's office or an infusion center. Such centers are everywhere, even

remote, because that's where outpatient chemo is applied for cancer patients.
So high-dose steroids iv should be tried.
Second round of infusions, in case first was somewhat helpful, can be done 4-6 weeks later, can be done for at least a year if helpful.
Once steroid responsiveness is clear, talk to autoimmunity Dr or rheumatologist which options there are for saving steroid. (Don't go on daily oral steroids.)
Alternatives - add-on:
Anti-CGRP neutralizing antibodies for self injection, as for migraine.
Botox.