



**TRIGEMINAL NEURALGIA ASSOCIATION OF CANADA**  
Fall 2011 Newsletter

## Support Group



### Eastern Ontario Support Group

Our group consists of people from Kingston through to Cornwall and north to the hills of Gatineau! We are a group of people who enjoy coming together to encourage and support each other along the journey of TN. We swap stories, laugh, and even cry at times. Share news on where we are at in our TN journeys and what paths we have travelled.

Most of all we are always open and looking to welcome new members to our group.

For more information and the time place of our next meeting please contact Jane at [cmusicstudio@cogeco.ca](mailto:cmusicstudio@cogeco.ca) or by calling 613.936.6977

### Vancouver and Lower Mainland Support Group Update

Coordinator: Ann Hopkins

Vancouver & Lower Mainland Group  
**Meeting Time: 1.00 – 3.30 pm**

### G.F. Strong Rehab Centre.

Social Sciences Seminar Room 189,  
Main Floor,  
4255 Laurel St.  
(Laurel at W. 26th, one block east of Oak)

### Friends, family members and supporters are very welcome.

It's a longish walk to the meeting room so if you need a wheelchair give me a call and I'll organize one. Or if you want to have a chat or have questions please make sure you call or email me.

To get in touch: contact Ann Hopkins, email: [annhopkins@dccnet.com](mailto:annhopkins@dccnet.com), phone: 1 604 741 0662  
4945 Laurel Ave, Sechelt, BC VON 3A2

### Lethbridge Support Group

Coordinator Marion Guzik

The Lethbridge Support Group meets every second Saturday of the month at 2:00 p.m. in Rm A, Lethbridge Senior Centre, 500 - 11th Street, S., Lethbridge, AB.  
Coordinator: Marion Guzik, past president / founder TNAC email

[mguzik@telus.net](mailto:mguzik@telus.net) Phone: 403-327-7668



### Treasurer's Note

Message from the treasurer- Joya Dickson [joya@telus.net](mailto:joya@telus.net)

Again our executive would like to thank all those members who renewed annual memberships with TNAC for the July 1 2011- June 30/2012 fiscal. Your support and kind donations help our organization issue 4 newsletters annually to members across Canada, and our one overseas member Edith S. in Denmark, plus TNAC donates to TN research.

Remember donations are tax deductible.

To those members who prefer to join on your anniversary date please be aware Joya will be taking a break from mid December to mid February, Membership renewals arriving after Dec 15 will not be processed until late February. Mail box will be cleared daily

however receipts will be late arriving on your door step.

TNAC welcomed some new members within the past two months, Emily from Fanny Bay BC, Diane B. Harley Ont. Ralph S. Burlington Ont. Eric S. Burnaby BC and 3 new members who attended our Oct Support Group Meeting in Vancouver-Tracy H. Langley BC. Collette S. –Vancouver and Cindy Mc. Pitt Meadows, many thanks to you all for your support.

Seasons Greetings, remember turkey dressing can irritate the TN nerve and cause much pain, this comes from personal experience. Enjoy the season.



The following article, discussing hospital bed shortages, profiled TN and appeared in the Ottawa Citizen

### **Waiting for the pain to go away**

#### **Woman needs surgery to stop sudden bouts of agony, but lack of hospital facilities has caused delays**

By Hugh Adami, Ottawa Citizen

Imagine a nerve condition in which pain feels like a knife piercing your face, and then taking 30 seconds, a minute or longer to subside.

Now imagine that horrible sensation recurring over and over, perhaps 100 times a day.

Lianne Smith, 44, knows that “heart-wrenching” condition all too well. She has trigeminal neuralgia (TN), a nerve disorder that causes one of the most painful conditions known to medicine. In her case, the pain repeatedly strikes the area around her right eye. When she’s not going through one of those sudden attacks, she experiences numbness and soreness in that area.

TN is not fatal, but it’s known as “the Suicide Disease,” which tells you something. Sufferers live with the constant fear of an attack striking at any time. Lianne says there are days when the attacks aren’t frequent. Some days, she might not experience any. Drugs and a normal drop in blood pressure when she’s asleep help ward off the attacks, often for the night.

Lianne, who runs an information-technology and social-media business with her husband, Jeff Braybrook, has not worked since late spring, and only part-time for two or three years before that.

Lianne was scheduled to have brain surgery on June 2 for a similar procedure she underwent in 1997 after she was diagnosed with the condition.

The June 2 surgery was cancelled because there wasn’t a bed for her at the Civic campus of the Ottawa Hospital.

The operation was rescheduled for July 18, but that, too, was cancelled because her neurosurgeon was needed for emergency surgery. There were assurances that she was first on the elective surgery list, but she couldn’t get a new date for the operation. Frustrated, Lianne’s mother, Frances Smith, emailed The Public Citizen on Wednesday. She

also sent a copy of the email to the neurosurgeon.

“She’s at the end of her rope,” Frances said later that day. “I can hardly talk about it.” “They have been nothing but kind,” she said of the doctor and his staff. “But kindness can only do so much. I mean, it’s not fixing the problem.” Said Lianne: “It’s just hard to understand how I’m at the top of the list, yet everybody is getting surgery but me.”

The Trigeminal Neuralgia Association of Canada website says there are various causes for TN, but the most common is the result of a blood vessel compressing against the brain’s trigeminal nerve.

The nerve branches out to separate areas on each side of the face: The eye, forehead and nose, and the cheek and jaw.

Essentially, with every heart beat, the blood vessel rubs against the nerve, and eventually causes a lesion, which leads to the sudden acute pain. Lianne’s latest bout is the result of a second blood vessel pressing up against the same section of nerve.

The pain can be triggered by touch, sound, drinking and eating. Lianne says she spends much time “in the dark” when she’s awake and doesn’t go to movies or concerts. When she walks her dog, she covers the right side of her face with her hand or a scarf because even a sudden gust of wind can set things off. She says she’s learned to mask an attack quite well, especially when family and friends are around.

Lianne was first diagnosed with TN in 1997 following a trip to Florida. She and her mother were at a

highway rest-stop when she was suddenly overcome by “the sharpest pain” around her right eye. It brought her to her knees, she said. For the next 24 hours or so, as they continued back to Ottawa, the pain remained. It was one of those “sudden events,” she says, “that you remember for the rest of your life.”

TN is not common. Still, 1,500 Canadians are diagnosed with the disease every year.

Dr. Brian Benoit, a neurosurgeon, operated behind Lianne’s right ear in December 1997, inserting a Teflon pad between the offending blood vessel and nerve. The surgery was successful, and, for almost eight years, she didn’t suffer any attacks. But then, in 2005, the illness struck again - “with a vengeance,” says her mother.

Benoit would not operate a second time, feeling there were too many risks.

Lianne was resigned to spending the rest of her life taking painkillers, muscle-relaxants and anti-seizure drugs used to treat epileptics.

“Until I went into a coma,” she says sarcastically.

But last April, she received encouraging news. Dr. Amin Kassam, a renowned neurosurgeon who had recently moved to Ottawa, was eager to see if he could help her. He explained to her in May that he would wrap the nerve in Teflon tape so it would no longer come in direct contact with any blood vessel.

Everything was a go, says Lianne. She was sent for blood work and a CT scan prior to the June 2 surgery, before the operation was cancelled.

Paula Doering, the Ottawa Hospital’s senior vice-president of clinical programs, says cancelling a surgery is not taken lightly. But, says Doering, elective surgeries are usually cancelled because the bed has to be given to an emergency patient. And beds are tight.

She blames the situation on “the number of long-term care patients in our acute beds” and the lack of facilities to take them.

“That is our biggest challenge, because we have the staff, we have the physicians, we have the operating room capacity.”

“The other day, we had 163 longterm care patients,” she says. “If we didn’t have these 163 occupying our acute-care beds,” elective surgery cancellations would be minimal.

Lianne’s condition is not considered life-threatening. That’s why she’s not considered in urgent need. Says Doering: “What is considered urgent is typically life-threatening - life or limb, we say.”

But there is some good news for Lianne.

Kassam sent word Thursday morning that he will perform the surgery on Tuesday. She should be back home by next weekend, finally free of the pain that has made her life miserable for so many years.



A follow up to the story was posted a few weeks later ...

### **Surgery a relief for Ottawa woman**

**By Hugh Adami, Ottawa Citizen**

Lianne Smith would like you to know the pain in her face is gone, after six long years.

She also says she was touched by the concern of those who kept switchboard operators at the Civic campus of The Ottawa Hospital busy a couple of weeks ago after she had brain surgery for a nerve disorder called trigeminal neuralgia (TN). The hospital couldn’t provide callers with any information about Lianne, even whether she was even a patient there. But given the apparent interest in her story and fear that she would be disturbed by callers if she was placed in a regular ward, staff decided to have Lianne remain in the hospital’s neurological observation area until her release two days later.

“I have no pain in my face,” says Lianne, who underwent surgery on Oct. 4, two days after her story appeared in The Public Citizen. “It’s a miracle.”

Lianne’s TN involved sudden and intense pain in the area around her right eye.

But sufferers can get the pain elsewhere in their face, and in more than one area. Where the pain occurs depends on what part or parts of the trigeminal nerve is affected.

There are various causes for TN, but the most common is the result of a blood vessel compressing against the nerve.

The trigeminal nerve branches out to separate areas on each side of the

face: The eye, forehead, nose, cheek and jaw.

As the heart beats, the blood vessel rubs against the nerve and eventually causes a lesion, leading to sudden jolts of piercing or burning pain. The jolts might come minutes apart, though sometimes they might not occur for days.

Lianne, 44, was first diagnosed with TN in 1997 and underwent brain surgery months later. A Teflon pad was inserted between the offending blood vessel and nerve behind her right ear. The operation was successful and Lianne didn't suffer any attacks again until 2005. A second operation was deemed too risky, so Lianne began living on a concoction of painkillers, muscle-relaxants and anti-seizure drugs.

Last April, though, out of the blue, came the surprise that another neurosurgeon, Dr. Amin Kassam, could help her. His plan was to wrap the affected section of nerve in Teflon tape.

But there were delays in getting the surgery. Lianne's initial appointment in June was cancelled because there wasn't a bed for her at the Civic. A second appointment, on July 18, was cancelled, too, because Dr. Kassam was needed for emergency surgery. Her Oct. 4 surgery was scheduled the day after Lianne's mother, Frances Smith, emailed The Public Citizen on Sept. 28 to express her worry that her daughter still didn't have a new appointment. "(Dr. Kassam) is our only hope for a normal life for Lianne."

Lianne says the operation was "amazing. They do it, and all of a sudden, you're better.

"Dr. Kassam and his team came to see how I was (following surgery). I was groggy and he said: 'Can you feel anything?' And I said: 'Oh, my God. I can't feel a thing.' " She says she phoned her younger sister, Lauren, the day after the operation. "She started to cry because there was no pain in my voice."

Lianne says she thinks her face looks brighter and happier. The squint in her right eye and numbness are gone.

There is some surgical pain as well as some dizziness, nausea and vomiting, which Lianne says are related to the operation. She hopes she can get back to her information technology business next month, although her mother says she would prefer if Lianne rests a little longer.

Still, Frances says: "She sounds like herself (again). We were so used to her being so drugged."



### Ask Dr. Kaufmann

**The Ottawa Citizen recently profiled TN describing an MVD where the nerve was wrapped in Teflon. Is this different then a traditional MVD?**

Dr Kaufmann's response:

The operation of microvascular decompression was pioneered in 1967 by Dr Peter Jannetta, and since then has rescued thousands of people from the agony of trigeminal neuralgia. The surgery is performed

through a small opening made behind the ear. The trigeminal nerve is then visualized as it emerges from the brainstem surface and the surgeon mobilizes culprit vessels that are compressing the nerve. The aim of surgery is to then hold these vessels away from the nerve, as relief from the pulsating compression usually cures TN. Several modifications of Jannetta's original technique have been described, and results of surgery are generally excellent when performed by surgeons experienced with MVD. Usually implants of shredded Teflon felt are placed to maintain the vessel away from the nerve, and other variations are also used to minimize any pressure or contact on the trigeminal nerve root. Unfortunately, no technique can honestly assure "cure", as sometimes the surgery fails to provide relief and sometimes the pain returns in the future, regardless of the surgical technique. That said, MVD performed well still offers the best chances for permanent pain relief.

(Dr. Kaufmann is the medical advisor for TNAC and is a surgeon with the Health Science Center, University of Winnipeg)



### TNAC Social Media

Are you on Facebook? Do you tweet? Do you google? Have an ipad or tablet? Iphone or smartphone?

In the day of electronic media and social media TNAC has



discovered that more and more people are turning to the internet for support. TNAC established a facebook page over a year ago. This page is active daily with information and discussions on TN. If you are on facebook please find and 'like' our page.

We have yet to venture into twitter but if you 'tweet' please let us know. If there is enough interest we can expand our horizons!

Another area we have considered is the area of webinars. Webinars allow you to listen to speakers on topics related to TN without leaving home. You need a computer with speakers and high speed internet connection to participate. Depending on the webinar you may also need headset. To date we have not committed to the webinar hosting platform but we have noted that The Facial Pain Association (USA) is sponsoring webinars and are considering this as an option for TNAC. Again if you would be interested in attending a webinar please let us know!

As the world grows smaller through internet and social media the boundaries of TNAC expand. We exist to serve you, provide you with information,

and to support research into TN treatment and prevention in Canada. Our hopes is that, through social media, we can increase our support to people with TN across Canada.

If you have any thoughts on how TNAC can increase services please let us know by emailing

[president@tnac.org](mailto:president@tnac.org)



### **Contacting TNAC**

For information on membership or general information:

[president@tnac.org](mailto:president@tnac.org)  
613.936.6977

TNAC, 1602 Walton Street  
Cornwall, ON, K6H 1W2

For information on support groups:

[support@tnac.org](mailto:support@tnac.org)

For information on advocacy:

[advocacy@tnac.org](mailto:advocacy@tnac.org)

Do you have an article for the newsletter? Do you have a topic you'd like covered? Do you have a drug you'd like profiled? Please let us know. Deadlines for the next newsletter submissions is: Feb. 14th



### **Research**

One of the mandates of TNAC is to support research into the causes and treatment of Trigeminal Neuralgia. This unique mandate also sets us apart from the other TN organization in Canada (Canada TNA) which focuses only on support groups. To this end TNAC has provided financial support to Dr. Hodaie in Toronto, ON who is currently researching improved ways to image the trigeminal nerve.

Attached is an outline of her current research. TNAC relies on our membership dues and donations to help fund research such as Dr. Hodaie's. Though we are only a small part of the total funding it is wonderful to know that people living and coping with TN on a daily basis are also contributing to finding answers that will lead to a better future for all of us.



# **Utility of Tractography in Detailing Changes in the Trigeminal Nerve in Patients with Trigeminal Neuralgia – Dr. M. Hodaie**

## **Submitted to the Trigeminal Neuralgia Association of Canada**

Trigeminal neuralgia (TN) is characterized by highly intense, electric shock-like, paroxysmal pain in the distribution of one or more branches of the trigeminal nerve. The pain is usually unilateral and triggered by normally non-painful stimuli or movements such as draughts of wind, light touch or chewing motion. Although medications are commonly provided as the first line of treatment, they may be often ineffective in providing pain relief and surgical intervention becomes necessary.

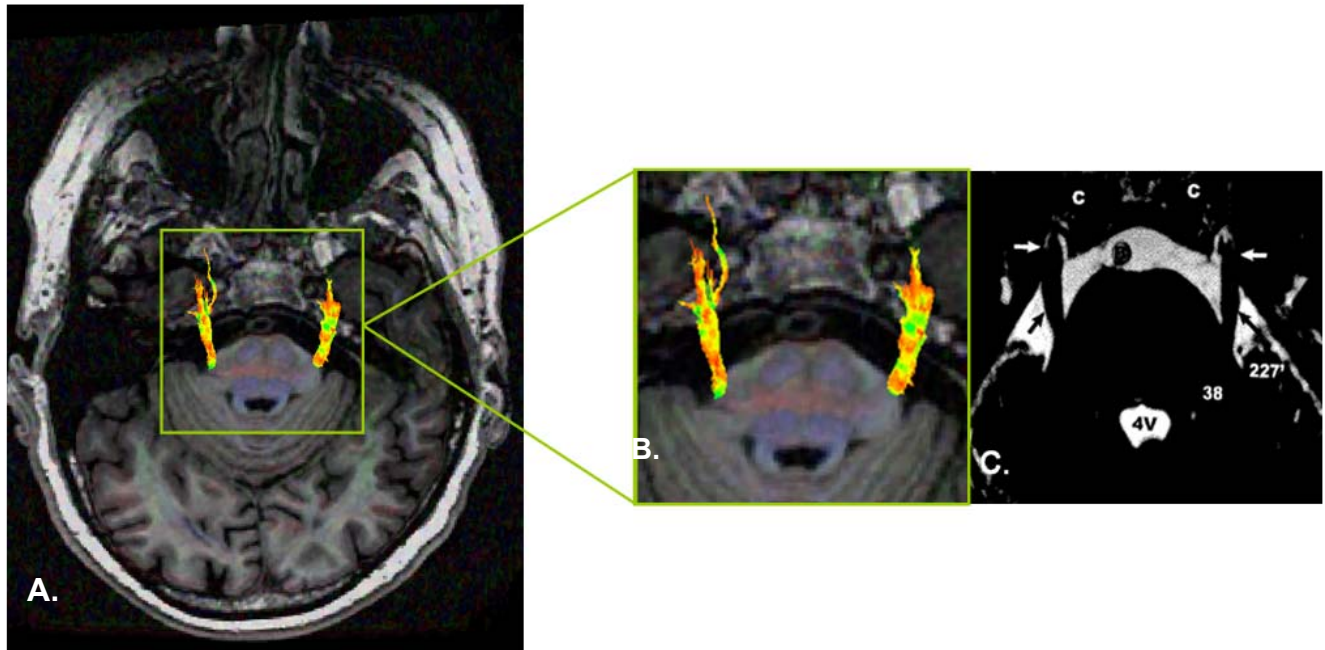
It is widely accepted that neurovascular compression of the trigeminal nerve by an arterial branch results in the paroxysms of trigeminal neuralgia, hence the role of the microvascular decompression procedure (MVD) as surgical treatment; however, the mechanism and exact events in the trigeminal nerve that result in trigeminal neuralgia remain unknown. One of the main issues is the current lack of adequate investigational tools to study this process.

We use new brain imaging techniques to gain insight into this process, by studying the fine microstructure of the trigeminal nerve using magnetic resonance (MR) techniques. Specifically, MR-diffusion tensor imaging (DTI) allows for the detailed analysis of the white matter fibres in the brain. Using this technique, white matter tracts in the brain can be visualized based on their diffusion properties, i.e., how water molecules move within these white matter tracts. Our lab has previously demonstrated that this technique can be used to visualize the trigeminal nerve in detail (Hodaie et al., 2010). This technique also permits us to obtain quantitative measures of the movement of water, which is represented in the measures of fractional anisotropy (FA) and radial diffusivity (RD), the latter closely correlating to the integrity of myelin (Song et al., 2005).

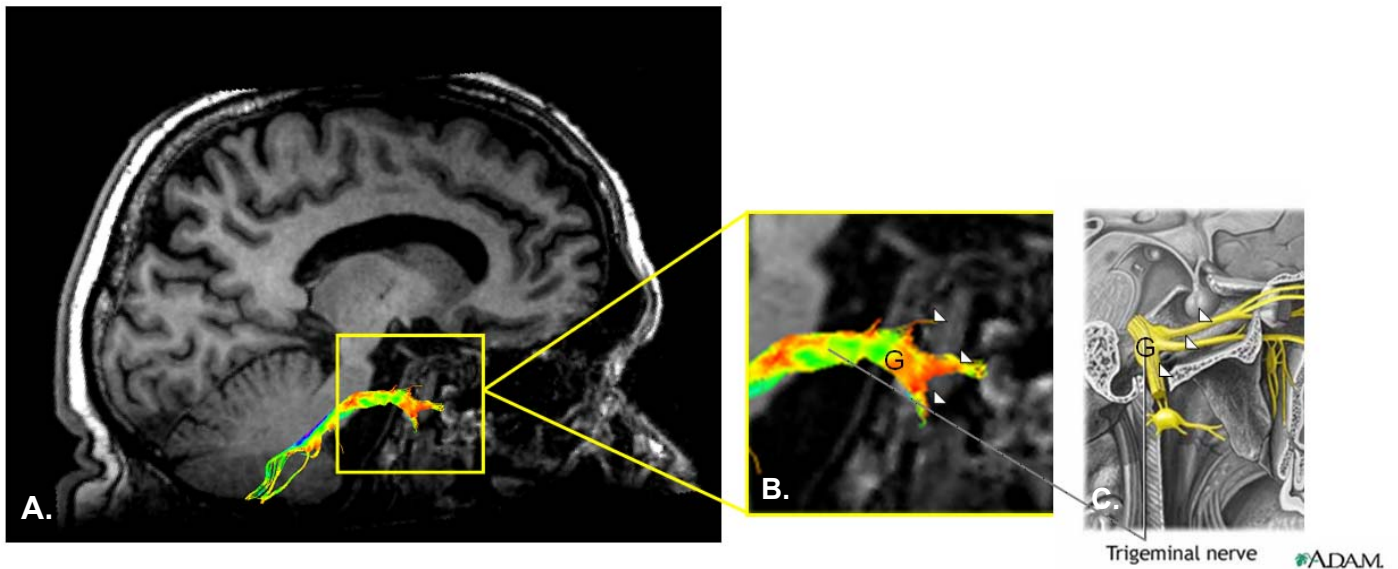
We are currently using this technique to elucidate the following:

1. How well can the trigeminal nerve be imaged?
2. What changes occur in the trigeminal nerves of patients with trigeminal neuralgia when we compare it with the trigeminal nerves of individuals without trigeminal neuralgia?
3. What is the effect of Gamma Knife radiosurgery, a form of treatment that involves delivery of radiation to the trigeminal nerve?
4. What are the microstructural changes in the trigeminal nerve following MVD?
5. Can the trigeminal nerve better visualized in cases of trigeminal neuralgia associated with tumors?

Our results show that DTI tractography can be used to image the trigeminal nerve distally to the level of the ganglion as well as its early postganglionic branches (Figures 1 & 2).

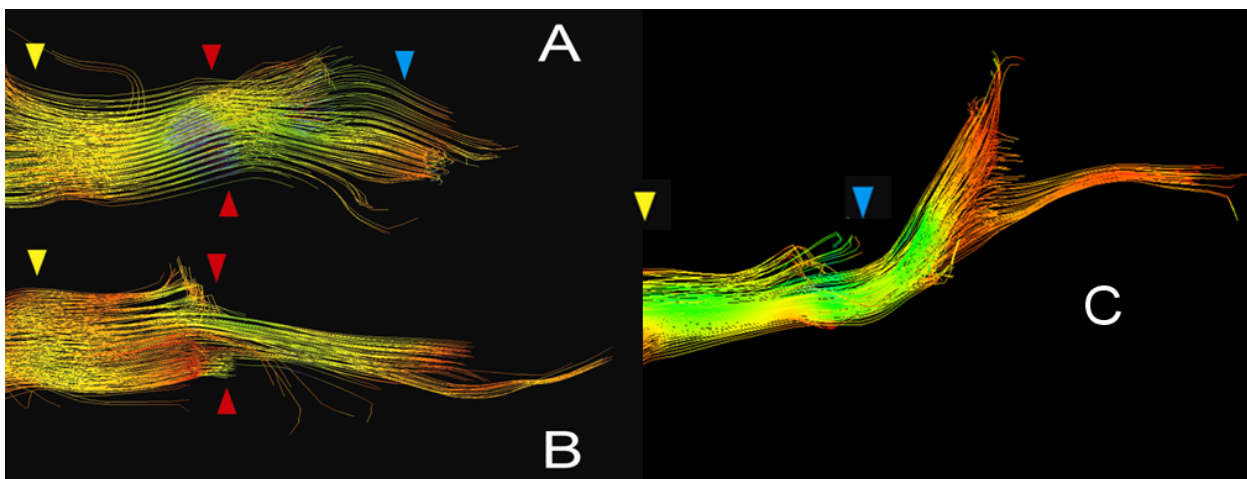


**Figure 1: Trigeminal nerve tractography (axial view):** Panel A. Axial section through entire brain at the level of the mid-pons. Green box highlights brainstem with the trigeminal nerve tracts superimposed. B. Closer view of the area demarcated by the green box. Black arrows highlight the cisternal segments of the trigeminal nerves. C. Axial view of same level from Duvernoy's Atlas (2009): 4V: fourth ventricle, 38: middle cerebellar peduncle, 227': simple lobule, c: internal carotid arteries, white arrows: lateral walls of Meckel's cave, black arrows: cisternal segments of trigeminal nerves.



**Figure 2: Trigeminal nerve tractography (sagittal view):** Panel A. Sagittal section through entire brain. Yellow box highlights brainstem and pontine cistern with the trigeminal nerve, ganglion and early postganglionic branches superimposed. B. Closer view of the area demarked by the yellow box. C. Medical drawing of trigeminal ganglion and postganglionic branches as it would appear in vivo (G: trigeminal ganglion, white arrow heads: postganglionic branches).

We also have evidence to indicate that Gamma Knife radiosurgery results in marked decrease in FA that can be clearly detected with tractography, even when these changes are not visualized on conventional 2D imaging (Figure 3A, B). These show as changes in FA that are not visualized in healthy controls subjects (Fig. 3C).

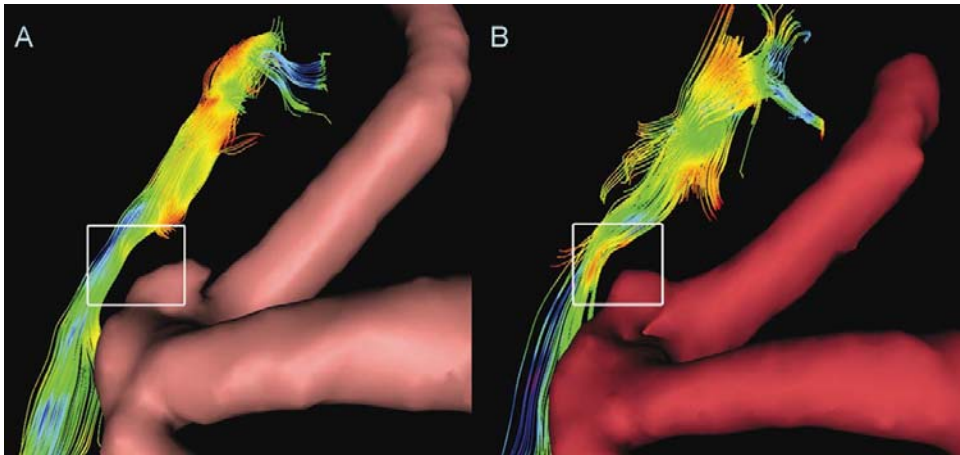


**Figure 3: Tractography outlines detailed FA changes in the trigeminal nerve after GKRS treatment:** Panels A and B depict the trigeminal nerve tracts of a TN patient pre- and post-GK treatment. The area between the yellow and blue arrows delineates the cisternal segment, with the yellow arrow being proximal to the brainstem and the blue arrow distal. The red arrow denotes the target area, which corresponds to the region where the greatest change in FA was observed. FA changes affect primarily the outlying fibers of the nerve. Panel C depicts the trigeminal nerve of a healthy pain-free individual (darkened area of FA not present between yellow and blue arrows as seen in patient, panel A).

For some individuals with neurovascular compression of the trigeminal nerve due to dolichoectatic or elongated and distended arteries, the trigeminal tracts and their relative position to

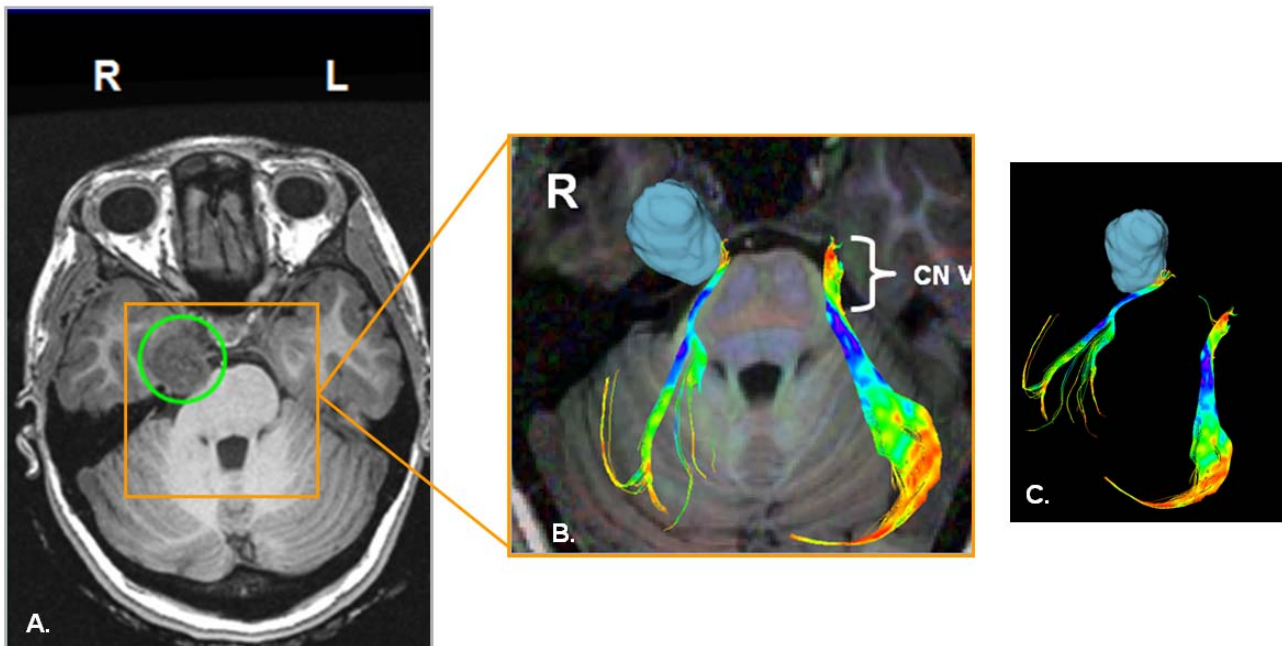


the offending blood vessel can be visualized in addition to FA (Fig. 4). Following MVD, specific changes in FA can be visualized in the nerve entry zone (Fig. 4B).



**Figure 4: 3D reconstruction of the trigeminal tracts and their relative position with respect to surrounding blood vessels in a case of a patient with a large dolichoectatic segment of the basilar artery:** The trigeminal tracts are represented next to the 3D reconstructed volume of the basilar artery. Panel A: 3D view prior to MVD and B: post-MVD. The white box represents the nerve entry zone of the trigeminal nerve, the region-of-interest where the scalar measures of FA and RD were obtained. Although there is no significant change in the overall 3D position and relationship of the structures, clear alterations in FA value in the ROI can be seen. This is represented by a change in FA closer to the orange spectrum, seen in panel B. Marked decrease in FA and increase in RD was seen in the nerve entry zone post-MVD.

In patients with TN secondary to tumour growth, we can visualize tumour-nerve relationships that are not visible in conventional neuroimaging (Fig. 5).



**Figure 5: Visualization of tumour-nerve relationship in secondary TN (axial view):** Panel A. Axial section through entire brain at level of pons. Green circle surrounds tumour (trigeminal schwannoma) and prevents visualization of trigeminal nerve. Orange box highlights brainstem, tumour and surrounding regions. B. Closer view of the area demarcated by the orange box with 3D visualization of tumour and trigeminal nerve tractography superimposed. C. Postero-lateral view of tumour-nerve relationship without anatomical scan.

In summary, we see great potential in the use of DTI tractography to visualize and study the trigeminal nerve in trigeminal neuralgia. We are now able to use this imaging tool to indentify changes in the nerve and distally to the level of the ganglion and even its early postganglionic branches. We have preliminary evidence which shows that the trigeminal nerves of individuals with TN are different microstructurally, as compared to the trigeminal nerves of healthy pain-free controls. These differences are viewed as changes in FA and RD in the location of the nerve entry zone. We have also shown that microstructural changes occur at the trigeminal entry zone following Gamma Knife radiosurgery and MVD procedures, again reflected as differing FA and RD values from pre- to post-treatment. Lastly, we are able to gain more information by using DTI tractography to visualize tumour-nerve relationships in patients with TN secondary to tumor growth.

Better visualization and characterization of the nerve in trigeminal neuralgia will in turn result in improved understanding of the disease, why the pain of trigeminal neuralgia recurs after treatment, and in turn, better treatment modalities for this disorder.

#### References:

Hodaie, M., Quan, J., Chen, D.Q. (2010). In Vivo Visualization of Cranial Nerve Pathways in Humans Using Diffusion-Based Tractography. *Neurosurgery*, 66: 788-796.

Naidich, T.P., Duvernoy, H.M., Delman, B.N., Sorensen, A.G., Kollias, S.S., Haacke, E.M. (2009). *Duvernoy's Atlas of the Human Brain Stem and Cerebellum*. SpringerWienNewYork: Austria.

Song, S-K, Yoshino, J., Le, T.Q., Lin, S-J, Sun, S-W, Cross, A.H., Armstrong, R.C. (2005). Demyelination increases radial diffusivity in corpus callosum of mouse brain. *Neuroimage*, 26: 132-140.