Be Part of a Bigger Voice

Join the FPA community
Join the world's largest organization providing education, support and advocacy for all those with trigeminal neuralgia and neuropathic facial pain.

The bigger our membership, the bigger our voice. The bigger our voice, the more patients will receive the support they need and more medical professionals will be capable of early diagnosis and correct treatment.

Join the thousands of patients and medical professionals who are active FPA members. Go to facepain.org and click on **become a member**. Membership provides exclusive access to: FPA Quarterly Magazine and archives; live and recorded webinars; discounts on FPA conferences and books.
IN THIS EDITION OF THE Q

3
Long time Support Group Leader Deborah Kurilchyk on how to start a local FPA support group.

9
Published research by FPA Medical Advisory Board member Nicholas Barbaro, MD, et. al., on long term relief rates following MVD and Radiosurgery.

19
Patient Profile with artist Karl Kroeppler.

Q FEATURES

2
From the Chairman of the Board

7
Ask the Doctor with Dr. Ramesh Babu and Cindy Ezell

22
YPC & Patient Profile

27
New Members, Memorial and Honorary Tributes

Cover:
A call to action.
Join the FPA and let your voice be heard.
Two exciting initiatives are underway at the FPA. We are pleased to have elevated the importance of our young members, built a set of articles and FPA website resources for your information, energized our Medical Advisory Board and rationalized our continuing support of research. Now, the initiatives underway involve improving our support for and engagement with members and, second, ensuring that our Board of Directors continues to be a vital guide for the FPA.

In several previous issues of the Quarterly, I have written about how the FPA is working to evolve along with technology-driven changes in how those with neuropathic trigeminal pain find information and community. Our organization and web site are the global “go-to” source of information. We are active on Facebook, Facebook Network and Twitter. Our MAB holds webinars, we distribute the Newswire every month to keep you up to date, and you are reading the Quarterly. But when I ask our members what we do that is most useful, over and over, they say something like “You provide community, I am not alone with TN.” So our support and engagement initiative is working to optimize the balance of how we use technology and how we reach out to touch those with facial nerve pain. We spoke with many of our Support Group leaders, we spoke with leaders of TN-related organizations in other countries, and we examined how other rare-and-dispersed-patient disease support organizations are dealing with similar challenges. Under the leadership of our CEO John Koff, our organization is evaluating what we do and what we ought to do, day in day out, to reach out. Stay tuned here for updates on our progress and you will see it on the web, in your email and in person.

The second initiative underway involves our Board of Directors. Although the BODs of many small non-profits actually do much of the organization’s work, the FPA is fortunate to have a professional, effective and enthusiastic staff that does the work from offices in Gainesville, FL. Hand-in-hand with CEO John Koff, the BOD determines our strategic direction, it monitors the quality of what we do, and it ensures that John and his staff have the resources to get the job done. We have 10 Directors, a Director’s term is three years, and most of our Directors have served at least two terms. For me, being a Director is a joy. We care about those in TN pain, and the FPA organization enables us to help thousands of those people. That’s leverage. We’d like to add a few Directors and we need to plan for a few who will move on after serving for many years. So this Letter is an appeal.

Here is a bit more information about our BOD. We meet four times each year, usually three in person and one or two by telephone/video. Meetings are often scheduled next to FPA conferences so that Directors can attend for their own benefit and also so they can stay in touch with the needs of those we serve. Each meeting involves reports and then decisions concerning FPA operations and key initiatives. We value transparency, open discussion and dissenting views. We invite the spouses and significant others of Directors to attend meetings and participate too.

All of our Directors’ lives have been touched by TN. We had it, we have it, or it burdens a family member or friend. Each of us has resolved to do something about it. We understand that TN can take over one’s life and make doing well at work and caring for one’s relationships a consuming challenge. After that, if you have the interest and bandwidth, then the FPA would like to hear from you about joining our BOD. Do call our CEO John Koff.

Jeff Bodington, Chairman of the Board
The Facial Pain Association
Having been support group leader for the Orange County Trigeminal Neuralgia Association (OCTNA) for 10 years, I hope to encourage you to grow a support group in your community. OCTNA’s motto is, “If you don’t feel well, you need us. If you feel better, we need you!”

Here are some tips to help get you started:

**It’s not hard.** We recommend keeping it simple so you can enjoy the meetings. Keep your expectations realistic. With time the group will grow.

**Find a place to meet.** Medical Centers, public libraries, religious institutions are a few places that may provide free meeting space. Check for hospitals in your region that treat TN; often they will offer additional support such as refreshments, access to audio visual equipment, printed materials. Try to establish a set location. We recommend holding it in a public place instead of a personal residence.

**Start with a leader.** Have one designated leader who will be accountable. He/she will schedule meetings, reserve the site and delegate tasks.

**Form a trusted team.** It’s good to have a core group of people who will share responsibilities. We refer to our team as the Board. It’s helpful to find people with different talents. Besides my management and teaching skills, we have a retired ER nurse, a development company VP and a professional fundraiser. Over the years, people have come and gone from the board with our greatest appreciation for their service. Continually invite new members to join you.
Do everything electronically. It’s fast and free.

Create an email address for the support group. Our email address is OCTNA@aol.com. Collect email addresses from members for your email distribution list.

Have one designated phone number. Share it with the FPA National Office, support group members, and publicize it in local healthcare publications. This is usually how we receive new members.

Plan your meetings. Invite speakers. FPA Medical Advisory Board (MAB) members are willing speakers, along with physicians or CAM practitioners who treat members in your group. Skype with guest speakers from out of town or other support groups. Besides neurosurgeons and neurologists, there are a wide range of medical professionals with information for TN and NFP patients; such as dentists, psychologists, chiropractors, massage therapists. Watch a webinar on the FPA website. Share updates and literature from the FPA National Office.

A few pointers to ensure your success:

Hold quarterly meetings: that’s our recommendation. We meet in January, April, July & October. Our board meets independently and we speak with members by phone in the interim. More frequent support group meetings can result in a low turnout. You want to make the most of your efforts. The OCTNA holds its meetings on the 4th Saturday of the month from 1-3pm. I send out an electronic meeting notice on the 10th and a reminder a few days prior to the meeting.

OCTNA meetings are divided into three parts:

1. The first half hour is devoted to welcoming and orienting new members and guests. New attendees are introduced, handouts are distributed and resources discussed.

2. The guest speaker is introduced. We reserve an hour for their presentation including Q&A.

3. The last half hour we conduct a “round robin” where we invite members to share about their condition. The entire group has an opportunity to offer support and suggestions for each member. The leader guides the discussion to ensure everyone has an opportunity to speak and stay on time.

I hope this gives you some insight into the mechanics of organizing a Support Group. It sounds like a lot of work at first, but it really isn’t. Take it step by step, you will be rewarded for your efforts. The OCTNA Board and I have had the privilege of helping many facial pain sufferers over the years.

Trigeminal Neuralgia was a decade-long nightmare for me, before I was successfully treated by Dr. Mark Linskey. Serving in this capacity has helped me heal emotionally and make sense of the experience. It has blessed my life in so many ways; it can do the same for you. If our OCTNA support group can be of assistance in your decision, it would be our pleasure. Just let us know.

For more information about starting a Support Group please contact the Facial Pain Association at info@tna-support.org or call us at 800-923-3608
FPA NATIONAL SUPPORT GROUPS

FPA National Support Groups

ARIZONA
Tucson
Thom Kruse
Phone: (520)544-5191
Email: facialpain.tucson@gmail.com

Angela Sorensen
Phone: (520)877-2236
Email: facialpain.tucson@gmail.com

CALIFORNIA
Northridge
Eloise Wickham
Phone: (818)246-6120
Email: eloise444@yahoo.com

Orange County
Deborah Kurilchyk
Phone: (714)730-1600
Email: octna@aol.com

Palo Alto - Stanford University
Steven Chang, MD
Phone: (650)736-0262
Email: veevo@stanfordmed.org

Sacramento
Allan Enis
Phone: (916)774-4792
Email: aenis@alum.rpi.edu

San Diego
Cherie Sato
Phone: (760)889-2047
Email: trigeminalNeuralgiasandiego@yahoo.com

San Francisco - East Bay
Joan Cannelli
Phone: (510)531-3490
Email: joancannelli@comcast.net

John Porter
Phone: (510)388-5118
Email: John.C.Porter@icloud.com

COLORADO
Denver
Sharon Jones
Phone: (719)632-3457
Email: jonessharon2005@gmail.com

Don Martinez
Email: TNDonmartinez@yahoo.com

FLORIDA
Orlando
Tina Johnson
Email: TNWarrior818@gmail.com

Palm Beach Gardens
Barbara Turczyn
Phone: (561)676-3775
Email: jobar04@aol.com

Tampa Bay Area
Rohn Harmer
Phone: (813)949-2879
Email: bubbman@aol.com

INDIANA
Central
Kathy Hays
Phone: (765)534-5053
Email: teacherhays50@aol.com

KENTUCKY
Louisville
Kenny Wilmont
Phone: (502)338-4338
Email: kwilmont@twc.com

MARYLAND
Central
Teresa Cordonnier
Phone: (410)654-3734
Email: LLCordonnier@comcast.net
Advanced Treatment for Facial Pain

Expert, integrated care for patients with trigeminal neuralgia, addressing both your physical and emotional needs

Offering a full roster of advanced options for treatment, including:

- Microvascular Decompression
- Radiofrequency Lesioning
- Stereotactic Radiosurgery
- Neurostimulation
- Alcohol Rhizolysis

The Facial Pain Program at the Weill Cornell Brain and Spine Center is an innovative program that focuses on the diagnosis and treatment of trigeminal neuralgia, one of the most disabling causes of facial pain. Our team includes top specialists in vascular neurosurgery and pain disorders—internationally recognized experts in the field who have advanced training in the very latest minimally invasive procedures used to treat facial pain. Find out more at weillcornellbrainandspine.org or call 212-746-4684 to make an appointment.
Q: Botulinum toxin is one of the most poisonous biological substances known, what makes botulinum toxin type A (Botox) safe for use?
A: Even though botulinum toxin is known for its toxicity, administered by well-trained people in its weak and diluted version makes it relatively safe. Also, the injection into the muscle directly and underneath the skin makes it stay at one place without migration and hence reducing potential side effects.

Q: If it weakens or paralyzes muscles, how does it work to stop TN pain?
A: Most of the patients with trigeminal neuralgia have trigger points originating in muscles in the face. Botox paralyzes the trigger point muscle and potentially blocks the impulses coming from the brain and thus lessens the perception of pain.

Q: Where on the face are the injections given, multiple areas?
A: Injections can be given to all the trigger points at various parts of the face in the distribution of the trigeminal nerve.

Q: How many injections are given in each area?
A: The number of injections is not important but it is the total dose that is important, which should not exceed more than 200 units.

Q: What is a typical dose? How long until the botulinum toxin type A injections take effect?
A: Typically, the dose should start at a total of 100 units (1 vial) and not to exceed 200 units (2 vials). The use of Botox in trigeminal neuralgia is not proved like magic. Results vary, some patients may see some relief and some do not. Successful use may provide relief within days.

Q: What are adverse side effects?
A: Local side effects include bruising at the injection site and local allergic reactions like skin rash, hives and itching. Muscles of injection can feel weak temporarily and if injection is given around the eye, patient may experience drooping of eyelids.
Q: Can I take existing medications while undergoing botulinum toxin type A injections?
A: Even though Botox is well tolerated with most of the medications, aminoglycoside antibiotics are known to increase the duration of the effect. We strongly recommend to discuss the medication interactions with pharmacist and health care providers prior to receiving Botox.

Q: How long do the effects last?
A: Usually three to six months.

Q: Should botulinum toxin type A injections be avoided if the pain is in the eye area?
A: It is not necessary as long as the injections are not given into the ocular muscles which could cause temporary visual changes.

Q: I understand botulinum toxin type A injections are not recommended for everyone, should I avoid this treatment if I am pregnant, have multiple sclerosis or neuropathic facial pain that is not classic, trigeminal neuralgia?
A: We advise avoiding injections during pregnancy and there are no contraindications for patients with multiple sclerosis or neuropathic facial pain to receive Botox.
Trigeminal neuralgia (TN), also known as tic douloureux, is a syndrome characterized by paroxysmal facial pain in the somatosensory distribution of the trigeminal nerve. Common surgical treatments for TN include ablative procedures, such as stereotactic radiosurgery (SRS) and percutaneous rhizotomy, and non-ablative surgical microvascular decompression (MVD). Ablative therapies are based on desensitizing or injuring the nerve to resolve the pain, whereas nondestructive surgical procedures aim to relieve the causative physical compression of the trigeminal nerve from adjacent vasculature.

There is a growing body of literature describing the efficacy for each of these procedures. For MVD, several large series with long-term follow-up have reported pain-free rates of 70%–80% in patients at 5–10 years. The published rate of pain relief in patients who have undergone SRS is more variable, ranging from 35% to 65% at 5 years to 20% to 45% at 10 years. Despite the large body of literature describing surgical outcomes for single procedures, there have been relatively few studies that directly compare efficacies between the procedures while controlling for potential confounding patient variables. Most have included patients with recurrent or atypical trigeminal pain. In addition, SRS for TN treatment was popularized in the late 1990s, and there are few reports with large patient cohorts with long-term follow-up to capture pain-recurrence rates. Given the variable reported outcomes, a direct comparison of outcomes for these common surgical procedures would be valuable in guiding management and counseling patients.

We report our institution’s longitudinal experience in the surgical treatment of idiopathic TN from a prospectively collected database. With standardized data collection and long-term follow-up, we performed a direct comparison of pain control rates following MVD and SRS in a relatively homogeneous population of patients with idiopathic...
TN undergoing first-time surgical treatment. By finding the relative efficacies for these first-time procedures and identifying predictors of pain-free outcome, we aim to provide valuable information in guiding treatment selection in this patient population.

**METHODS**

**Patient Selection**

Clinical data for all consecutive patients who underwent evaluation for surgical treatment for TN at University of California, San Francisco (UCSF), were prospectively collected since 1997. Because of the relatively low number of patients who underwent radio frequency ablation (RFA), this study is an analysis of all patients who underwent MVD or SRS treatment between 1997 and 2014 by 2 surgeons (N.M.B. and E.F.C.). During the study period, 680 surgical procedures, including 364 SRSs and 316 MVDs, were performed. Inclusion criteria were as follows: idiopathic TN without mass lesions or multiple sclerosis; classic Type 1 trigeminal pain;7,8,12 first-time surgical treatment for TN; > 1 year of follow-up; and sufficient preoperative and follow-up data. We identified 332 patients who met inclusion criteria for analysis: 164 who underwent MVD and 168 who had SRS (Fig. 1). All research protocols were approved by the UCSF IRB for human research (Committee for Human Research).

**Data Collection and Outcome Measures**

Clinical information was prospectively collected when patients underwent evaluation for TN surgery at UCSF. Variables that were prospectively recorded during the initial clinical visit included patient demographic data; symptom duration, location, and features; TN medications; relevant family and medical history; baseline physical examination findings; and imaging findings. Subsequent postsurgical follow-up visits were usually scheduled at 4–8 weeks, 4–6 months, and 12 months. Additional visits were scheduled on an as-needed basis. Variables collected at follow-up visits included treatments received, medications, TN pain description, and sensory disturbances, as well as examination findings. If patients did not undergo regular follow-up, telephone calls were placed and the same variables (except for physical examination findings) were recorded. Of note, the reporting period began before the availability of high-resolution, fine-cut MRI with gradient echo sequences.

Outcome measurements included Barrow Neurological Institute (BNI) Pain Intensity scores34 at last follow-up (primary), surgical complications, and sensory changes. Patients were designated as free of pain if they did not have trigeminal pain when not taking medication (BNI score of I). Patients were designated as having favorable outcomes if they had BNI scores of I or II (occasional pain off medication). Patients who were not free of pain included all of those with residual pain (BNI score of IIIa: pain free on medication; IIIb: pain adequately controlled with medication; IV: pain not adequately controlled with medication; or V: no relief).

**FIG. 1.**
Flow chart showing number of patients included in the study.

**Treatment Protocols**

Patients were not randomly assigned and were counseled on all 3 treatment modalities (MVD, SRS, and RFA). Selection of the procedure was guided by the following general considerations. For younger (in general < 75 years old) and
healthy patients, MVD was recommended. For those in this group who refused MVD, SRS or RFA was performed based on patient preference in treatment modality. For older patients with medical comorbidities, SRS or RFA was performed. RFA was not recommended for any patient with V1 distribution pain. Ultimately, treatment selection followed the patient’s decision, which was influenced by the perceived risks and benefits of each procedure.

Following any procedure, patients were typically instructed to taper their TN medication once they became free of pain. For patients who received MVD, if they were free of pain postoperatively at time of discharge, medications were tapered one at a time for 2–6 weeks, with the goal of being off medication at their first postoperative visit. For patients who underwent SRS, medications were tapered after 6 weeks of complete pain control. If breakthrough pain occurred during the tapering-off period, all patients were instructed to hold off on the medication tapering and restart it when able. However, in many cases, primary care physicians or outside neurologists helped with patients’ medical management and therefore not all managements were standardized.

**Operative Technique**

**Microvascular Decompression**

The general operative technique followed that of previously described standard procedures. A small retrosigmoid craniectomy was made, and the trigeminal nerve was examined under the microscope for vascular compression along the root entry zone or its cisternal course. Any compressive arteries or veins were identified, dissected from the nerve, padded with Teflon felt, and secured with biological adhesive. Some compressive veins were coagulated and divided. For selected patients without obvious vascular compression intraoperatively, a partial sensory rhizotomy was performed by dividing the nerve. Intraoperative auditory brainstem evoked potential monitoring was used in all cases.

**Stereotactic Radiosurgery**

SRS was performed using a Gamma Knife apparatus. The Leksell stereotactic frame (Eleka Instruments, AB) was applied under local anesthesia. All patients underwent stereotactic MRI for target definition. High-resolution T2-weighted images or T2-type fast imaging employing steady-state acquisition (FIESTA) sequences (when available) and contrast-enhanced T1-weighted images were used for target planning. A single isocenter using a 4-mm collimator was used to target the trigeminal nerve root in the cisternal portion of the trigeminal nerve. The majority (79%) of patients received 80 Gy (range 70–85 Gy).

**Statistical Analysis**

All statistical analyses were performed using SPSS version 23 (IBM). All analyses compared the MVD and SRS cohorts only. Continuous predictor and outcome variables were compared between the cohorts using either the parametric Student t-test or the nonparametric Mann-Whitney U-test after assessing for normality with the Shapiro-Wilk test. Categorical variables were compared with Pearson’s chi-square or Fisher’s exact test, as appropriate. The duration of pain relief for the various surgical procedures was plotted using Kaplan-Meier survival analyses, and statistical significance was measured using the log-rank test. Univariate analysis was performed to find predictors of outcome for each procedure type. Multivariate analysis was performed using the Cox proportional hazards model to assess the contribution of other predictor variables in TN pain relief. Only variables with a p value < 0.2 from the univariate analysis were included in the multivariate regression model to avoid over fitting. The threshold for statistical significance was set at a p value of 0.05.

**RESULTS**

Between 1997 and 2014, a total of 316 MVD, 364 Gamma Knife SRS, and 84 RFA procedures were performed at UCSF. After excluding patients who had received procedures for their TN, had mass lesions or multiple sclerosis causing their trigeminal pain, had atypical trigeminal pain, and had <1 year of follow-up, a total of 164 MVD, 168 SRS, and 8 RFA patients were included in this study (Fig. 1). Given the small number of patients who underwent RFA, we performed all analyses on the MVD and SRS groups. Demographic data (Table 1) demonstrated that patients who received MVD were younger than those who received SRS (median age 63 years for MVD vs 72 years for SRS; p < 0.001), had shorter preoperative symptom duration (median 48 months for MVD vs 84 months for SRS; p < 0.001), and had fewer preoperative sensory disturbances such as hyperesthesia or numbness (2% for MVD vs 11% for SRS; p = 0.003). There were no differences in sex, laterality or distribution of pain, family history of TN, or length of follow-up.

Eighty-two patients with idiopathic TN who had MVD and...
who underwent SRS were lost to follow-up (p < 0.001). Results of univariate analysis comparing preoperative characteristics of patients lost to follow-up with those included in the analysis for each procedure are shown in Supplementary Table 1. All of the factors were similar between the groups, except we found that patients who were lost to follow-up in the SRS group were significantly older compared with those in SRS with > 1 year of follow-up (p = 0.019, Supplementary Table 1).

**TABLE 1. Demographic data and clinical characteristics of patients in the MVD and SRS cohorts**

<table>
<thead>
<tr>
<th>Variable</th>
<th>MVD</th>
<th>SRS</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of patients</td>
<td>164</td>
<td>168</td>
<td>—</td>
</tr>
<tr>
<td>Median age in yrs (range)</td>
<td>63 (18–87)</td>
<td>72 (35–99)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Male sex</td>
<td>66 (40)</td>
<td>65 (39)</td>
<td>0.823</td>
</tr>
<tr>
<td>Median preop symptom dura-</td>
<td>48 (24–84)</td>
<td>84 (44–168)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>tion in mos (IQR)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TN laterality</td>
<td>0.823</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rt</td>
<td>96 (59)</td>
<td>101 (60)</td>
<td></td>
</tr>
<tr>
<td>Lt</td>
<td>68 (41)</td>
<td>67 (40)</td>
<td></td>
</tr>
<tr>
<td>TN distribution</td>
<td>0.234</td>
<td></td>
<td></td>
</tr>
<tr>
<td>V1</td>
<td>12 (7)</td>
<td>15 (9)</td>
<td></td>
</tr>
<tr>
<td>V2</td>
<td>38 (23)</td>
<td>27 (16)</td>
<td></td>
</tr>
<tr>
<td>V3</td>
<td>39 (24)</td>
<td>35 (21)</td>
<td></td>
</tr>
<tr>
<td>V1 + V2</td>
<td>25 (15)</td>
<td>20 (12)</td>
<td></td>
</tr>
<tr>
<td>V2 + V3</td>
<td>36 (22)</td>
<td>48 (28)</td>
<td></td>
</tr>
<tr>
<td>V1–V3</td>
<td>14 (9)</td>
<td>23 (14)</td>
<td></td>
</tr>
<tr>
<td>Positive family history</td>
<td>3 (2)</td>
<td>9 (5)</td>
<td>0.139</td>
</tr>
<tr>
<td>Preop sensory disturbance</td>
<td>4 (2)</td>
<td>18 (11)</td>
<td>0.003</td>
</tr>
<tr>
<td>Follow-up in mos, mean ± SD</td>
<td>58.8 ± 34.7</td>
<td>58.7 ± 45.4</td>
<td>0.969</td>
</tr>
</tbody>
</table>

Values are expressed as number (%) of patients unless otherwise indicated.

**Survival Analysis of Pain Outcome**

Patients who underwent MVD had longer pain-free intervals than those who received SRS. Almost all of the patients who underwent MVD (n = 157, 96%) reported being free of pain (BNI Pain Intensity score of I) postoperatively, whereas only 75% of patients who received SRS had a BNI I outcome following their procedure (n =126; p < 0.001). At the last follow-up visit, 57% of patients who had undergone MVD had a BNI I score and 44% had a favorable outcome (p = 0.038). Fourteen patients who had undergone MVD (8%) and 12 who had undergone SRS (8%) had symptoms that were controlled with medication (BNI scores of Illa and IIlb). Fifty-five patients who had undergone MVD (33%) and 78 who had undergone SRS (46%) had little to no relief after their procedure (BNI scores of IV and V). These outcomes are reported in Table 2.

To further assess the difference in outcomes between the MVD and SRS groups, a Kaplan-Meier survival analysis was performed. Survival functions depicting time until pain recurrence for patients in the cohorts showed divergent outcomes that were significantly different (p = 0.006, log-rank test). The median estimated pain-free duration was 94 months for the MVD group (interquartile range [IQR] 57–131 months) and 53 months for the SRS group (IQR 37–69 months; p = 0.006). The estimated percentages of patients with a BNI score of I at 1, 5, and 10 years after MVD were 83%, 61%, and 44%, respectively. The corresponding estimated percentages for patients in the SRS group were 71%, 47%, and 27%, respectively (Fig. 2).

**TABLE 2. Pain-free outcomes among patients in the MVD and SRS cohorts**

<table>
<thead>
<tr>
<th>Variable</th>
<th>MVD, n = 164</th>
<th>SRS, n = 168</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever pain free, BNI I</td>
<td>157 (96)</td>
<td>126 (75)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>BNI Pain Intensity score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>93 (57)</td>
<td>74 (44)</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>2 (1)</td>
<td>4 (2)</td>
<td></td>
</tr>
<tr>
<td>Illa</td>
<td>4 (2)</td>
<td>1 (1)</td>
<td></td>
</tr>
<tr>
<td>IIlb</td>
<td>10 (6)</td>
<td>11 (7)</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>7 (4)</td>
<td>9 (5)</td>
<td></td>
</tr>
<tr>
<td>V</td>
<td>48 (29)</td>
<td>69 (41)</td>
<td></td>
</tr>
<tr>
<td>Favorable outcome, BNI I</td>
<td>95 (58)</td>
<td>78 (46)</td>
<td>0.038</td>
</tr>
<tr>
<td>I or II</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median pain-free dura-</td>
<td>94 (57–131)</td>
<td>53 (37–69)</td>
<td>0.006</td>
</tr>
<tr>
<td>tion in mos (IQR)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complications</td>
<td>18 (11)</td>
<td>0 (0)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Values are expressed as number (%) of patients unless otherwise indicated.

**Characteristics and Outcomes for the MVD Group**

Compression characteristics for all patients who underwent MVD are depicted in Table 3. In 26% of the MVD cases, at the discretion of the attending surgeon, a partial sensory rhizotomy (Rhiz) was performed in addition to the vascular decompression. Those who received MVD with Rhiz (MVD+Rhiz) had lower pain-free rates compared with those who received MVD alone. The cumulative 1-, 5-, and 10- year rates of BNI score of I for MVD alone were 84%, 64%, and 53%, respectively, and those for MVD+Rhiz were 80%, 50%, and 20%, respectively. Survival analysis confirmed this
trend and showed a median pain-free interval of 45 months for the MVD+Rhiz group (IQR 14–113 months) compared with the MVD group, in which no median pain-free time was reached (p = 0.022, log-rank test; Fig. 3).

The presence of vascular compression of the trigeminal nerve on MRI and the presence of vascular compression confirmed intraoperatively were not associated with favorable outcome in patients who received MVD (Table 3). In addition, even when a compressing vessel was found intraoperatively, the specific blood vessel involved was not associated with the primary outcome. The culprit vessel involved in trigeminal nerve compression was found to be the superior cerebellar artery in 82 (50.0%) patients, the anterior inferior cerebellar artery in 6 (3.6%) patients, multiple arteries in 17 (10.4%) patients, a single vein in 23 (14%) patients, and an artery in combination with a vein in 26 (15.9%) patients.

Post-MVD sensory changes were not associated with outcome. Multivariate analysis using Cox regression showed that longer preoperative symptom duration (HR1.005, 95% CI 1.001–1.008; p = 0.006) and MVD with Rhiz (HR 1.954, 95% CI 1.154–3.308; p = 0.013) were associated with unfavorable outcome (BNI Pain Intensity score of III–V) (Table 4).

Characteristics and Outcomes for the SRS Group

For 168 patients who received SRS, the median time to freedom from pain was 27 weeks (Table 6). Sex, preoperative symptom duration, treatment side, and pain distribution were not predictors of favorable outcome (BNI score of I or II). Treatment dose seemed to have an effect on outcome (p=0.041), but this difference was not significant on multivariate analysis. However, a posttreatment sensory deficit was significantly associated with achieving favorable outcome on multivariate analyses (HR 0.392, 95% CI 0.213–0.723; p = 0.003; Table 7).

DISCUSSION

The reported efficacy of ablative and nonablative procedures for surgical treatment of medically refractory TN is highly variable due to differences in technique, study methods, and patient selection across different institutions.
Here, we present the long-term experience of a single institution’s surgical outcomes following treatment of TN and MVD and SRS and we compare their relative efficacies. We found higher long-term pain-free rates in MVD-treated patients.

**Pain-Free Rates Among Patients Who Underwent MVD or SRS**

The pain control outcome for MVD in this study is similar to those of other studies reported in the literature. \(^2,17,30,31,70,41\) We achieved a pain-free (BNI score of I) rate of 96% postoperatively, with a median estimated time to pain recurrence of 94 months. For SRS, up to 75% of our patients were free of pain postoperatively and the median estimated time to pain recurrence was 53 months which is within the range reported in other large SRS series.\(^17,25,30,31,33\) Importantly, the long length of time to pain recurrence for MVD and SRS demonstrates the need for long-term follow-up when comparing treatment efficacies. With the relatively recent advent of SRS technology as a standard of treatment for TN, to our knowledge our series represents one of the largest cohorts wherein a substantial number of patients (38%) had > 5 years of follow-up. Our results are consistent with other reports and support the conclusion that MVD has the most durable success in pain control.\(^41\)

**Predictors of Freedom From Pain**

Previous reports on outcome following MVD indicate that prognostic factors for success include immediate postoperative relief, male sex, arterial compression, arterial compression, and sensory changes post-MVD. Relevant factors and results are listed in Table 3.

**TABLE 3. Univariate analysis of MVD outcomes**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total</th>
<th>Favorable, BNI Score of I or II</th>
<th>Unfavorable, BNI Score of III–V</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of patients</td>
<td>164</td>
<td>95 (58)</td>
<td>69 (42)</td>
<td>—</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td>&gt;0.99</td>
</tr>
<tr>
<td>M</td>
<td>66 (40)</td>
<td>38 (58)</td>
<td>28 (42)</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>98 (60)</td>
<td>57 (58)</td>
<td>41 (42)</td>
<td></td>
</tr>
<tr>
<td>TN laterality</td>
<td></td>
<td></td>
<td></td>
<td>0.748</td>
</tr>
<tr>
<td>Rt</td>
<td>96 (59)</td>
<td>57 (59)</td>
<td>39 (41)</td>
<td></td>
</tr>
<tr>
<td>Lt</td>
<td>68 (41)</td>
<td>38 (56)</td>
<td>30 (44)</td>
<td></td>
</tr>
<tr>
<td>TN location</td>
<td></td>
<td></td>
<td></td>
<td>0.087</td>
</tr>
<tr>
<td>V1</td>
<td>12 (7)</td>
<td>6 (50)</td>
<td>6 (50)</td>
<td></td>
</tr>
<tr>
<td>V2</td>
<td>38 (23)</td>
<td>18 (47)</td>
<td>20 (53)</td>
<td></td>
</tr>
<tr>
<td>V3</td>
<td>39 (24)</td>
<td>21 (54)</td>
<td>18 (46)</td>
<td></td>
</tr>
<tr>
<td>V1 + V2</td>
<td>25 (15)</td>
<td>21 (84)</td>
<td>4 (16)</td>
<td></td>
</tr>
<tr>
<td>V2 + V3</td>
<td>36 (22)</td>
<td>20 (56)</td>
<td>16 (44)</td>
<td></td>
</tr>
<tr>
<td>V1–V3</td>
<td>14 (9)</td>
<td>9 (64)</td>
<td>5 (36)</td>
<td></td>
</tr>
<tr>
<td>Median preop symptom duration in mos (IQR)</td>
<td>48 (24–84)</td>
<td>48 (24–72)</td>
<td>60 (23–99)</td>
<td>0.085</td>
</tr>
<tr>
<td>Median time until pain free, wks (IQR)</td>
<td>0 (0–0)</td>
<td>0 (0–0)</td>
<td>0 (0–0)</td>
<td>0.965</td>
</tr>
<tr>
<td>Median age in yrs (range)</td>
<td>63 (18–87)</td>
<td>63 (26–87)</td>
<td>63 (18–84)</td>
<td>0.502</td>
</tr>
<tr>
<td>Rhizotomy performed</td>
<td></td>
<td></td>
<td></td>
<td>0.047</td>
</tr>
<tr>
<td>Yes</td>
<td>43 (26)</td>
<td>19 (44)</td>
<td>24 (56)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>121 (74)</td>
<td>76 (63)</td>
<td>45 (37)</td>
<td></td>
</tr>
<tr>
<td>MRI compression*</td>
<td></td>
<td></td>
<td></td>
<td>0.389</td>
</tr>
<tr>
<td>Yes</td>
<td>74 (53)</td>
<td>46 (62)</td>
<td>28 (38)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>65 (47)</td>
<td>35 (54)</td>
<td>30 (46)</td>
<td></td>
</tr>
<tr>
<td>Intraop compression</td>
<td></td>
<td></td>
<td></td>
<td>0.324</td>
</tr>
<tr>
<td>Yes</td>
<td>154 (94)</td>
<td>91 (59)</td>
<td>63 (41)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>10 (6)</td>
<td>4 (40)</td>
<td>6 (60)</td>
<td></td>
</tr>
<tr>
<td>Compressing vessel</td>
<td></td>
<td></td>
<td></td>
<td>0.562</td>
</tr>
<tr>
<td>Artery only</td>
<td>105 (64)</td>
<td>62 (59)</td>
<td>43 (41)</td>
<td></td>
</tr>
<tr>
<td>Vein only</td>
<td>23 (14)</td>
<td>15 (65)</td>
<td>8 (35)</td>
<td></td>
</tr>
<tr>
<td>Artery + vein</td>
<td>26 (16)</td>
<td>14 (54)</td>
<td>12 (46)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>10 (6)</td>
<td>4 (40)</td>
<td>6 (60)</td>
<td></td>
</tr>
<tr>
<td>Sensory changes post-MVD</td>
<td></td>
<td></td>
<td></td>
<td>0.577</td>
</tr>
<tr>
<td>Yes</td>
<td>37 (23)</td>
<td>23 (62)</td>
<td>14 (38)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>127 (77)</td>
<td>72 (57)</td>
<td>55 (43)</td>
<td></td>
</tr>
</tbody>
</table>

Values are expressed as number (%) of patients unless otherwise specified.

* Percentage reflects the number of patients for whom data were collected regarding vascular compression of the trigeminal nerve observed on MRI.

“Comparison” . . .continued on page 15
shorter duration of symptoms, and typical trigeminal pain. As for SRS, most studies show that postoperative facial numbness is a positive predictor of pain control, which was confirmed by our results. The presence of postoperative facial sensory disturbance in our MVD cohort did not seem to be associated with outcome, which is in agreement with 2 previous studies. In our MVD cohort, shorter symptom duration was a prognosticator for favorable outcome. For patients who received MVD, we found that neither the presence of vascular compression on MRI nor finding vascular compression during the operation was a prognostic of outcome. This could be due to the fact that the reporting period began before the availability of high-resolution, fine-cut MRI with gradient echo sequences, which would be more likely to demonstrate neurovascular contact within the CSF space.

In addition, vascular compression may not be the only cause of trigeminal pain. A recent study using blinded evaluation of 3.0-T MR sequences of patients with unilateral classical TN found that neurovascular contact was prevalent on both the symptomatic and asymptomatic sides, and only displacement or atrophy of the trigeminal nerve was highly associated with the symptomatic side. TN involves numerous pathways from peripheral receptor activation; transmission and projection of nociceptive information; and convergence of afferents into the thalamus, limbic system, and somatosensory cortex.

Besides physical compression, inflammation and demyelination have been implicated in the pathophysiology of TN. Based on newer time-of-flight and diffusion tensor imaging techniques, microstructural abnormalities in the trigeminal nerve in the form of demyelination without significant axonal injury is an essential pathological basis for the disease. Therefore, it is not surprising that in some cases, decompressing or transposing the offending vessel alone is not sufficient to alleviate trigeminal pain.

In cases where there is no obvious vascular compression, a rhizotomy is performed in addition to MVD. Surprisingly, patients who received MVD+Rhiz had significantly higher rates of pain recurrence. One study compared pain-free rates in 142 cases of MVD with 68 cases of MVD+Rhiz and

### TABLE 4. Multivariate analysis of MVD outcomes

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>HR (95% CI)*</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>TN location</td>
<td>—</td>
<td>0.263</td>
</tr>
<tr>
<td>V₁ vs V₁–V₃</td>
<td>0.539 (0.162–1.791)</td>
<td>0.313</td>
</tr>
<tr>
<td>V₂ vs V₁–V₃</td>
<td>1.029 (0.405–2.612)</td>
<td>0.952</td>
</tr>
<tr>
<td>V₃ vs V₁–V₃</td>
<td>0.814 (0.313–2.113)</td>
<td>0.672</td>
</tr>
<tr>
<td>V₁–V₂ vs V₁–V₃</td>
<td>0.326 (0.091–1.167)</td>
<td>0.085</td>
</tr>
<tr>
<td>V₁–V₃ vs V₁–V₃</td>
<td>1.109 (0.43–2.861)</td>
<td>0.831</td>
</tr>
<tr>
<td>Preop symptom duration</td>
<td>1.005 (1.001–1.008)</td>
<td>0.006</td>
</tr>
<tr>
<td>Presence of rhizotomy</td>
<td>1.954 (1.154–3.308)</td>
<td>0.013</td>
</tr>
</tbody>
</table>

Multivariate Cox regression analysis using only variables with p < 0.2 from univariate analysis (Table 3).
found significantly higher pain control rates in the group that received additional rhizotomy during a follow-up of 2 years. 45 Our response rates were similar between MVD and MVD+Rhiz initially, but after 6 months, the groups became divergent and the MVD+Rhiz group had higher pain-recurrence rates. This may suggest that patients without obvious vascular compression have a different pathophysiology than those with compression. Rhizotomy may work by temporarily interrupting the pathological pain pathway, but the underlying pathophysiology is still present.

**Benefits of Ablative Versus Nonablative Procedures**

Both ablative and nonablative treatment modalities have merits and limitations. Ablative procedures work by injuring the sensory fibers, whereas nonablative procedures work by physically decompressing the nerve, presumably without causing damage. Besides the relative efficacies of treatment, additional considerations must be made in patient selection. Although MVD has the best overall long-term efficacy, it is also the most invasive procedure and requires a longer hospital stay. Complications include CSF leak, chemical meningitis, wound infections, facial paresis, hearing loss, hematoma, and rarely, death. 2

SRS is the least invasive procedure and does not require general anesthesia. It is well tolerated with low risk of complications. However, maximum efficacy takes months to achieve, and it is associated with a higher rate of trigeminal nerve dysfunction. RFA is generally safe and straightforward to perform, but requires patient cooperation with dermatome mapping. It has the benefit of providing immediate pain relief, but it also has higher rates of facial dysesthesia and pain recurrence. 6,9,15 Studies show that the risk of complications from MVD increases with patient age (primarily from cardiopulmonary and not neurological risks) 35 and is higher compared with RFA and SRS. 18,20 Although some studies have reported no difference in the rate of complications for MVD in the elderly, 38,39 MVD is generally recommended for younger and healthier patients.

<table>
<thead>
<tr>
<th>TABLE 6. Univariate analysis of SRS outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Variable</td>
</tr>
<tr>
<td>No. of patients</td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>M</td>
</tr>
<tr>
<td>F</td>
</tr>
<tr>
<td>TN laterality</td>
</tr>
<tr>
<td>Rl</td>
</tr>
<tr>
<td>Lt</td>
</tr>
<tr>
<td>TN distribution</td>
</tr>
<tr>
<td>V1</td>
</tr>
<tr>
<td>V2</td>
</tr>
<tr>
<td>V3</td>
</tr>
<tr>
<td>V1 + V2</td>
</tr>
<tr>
<td>V1 + V3</td>
</tr>
<tr>
<td>V1–V3</td>
</tr>
<tr>
<td>Median preop symptom duration in mos (IQR)</td>
</tr>
<tr>
<td>Median time until pain free in wks (IQR)</td>
</tr>
<tr>
<td>Median age in yrs (IQR)</td>
</tr>
<tr>
<td>Dose, Gy</td>
</tr>
<tr>
<td>70</td>
</tr>
<tr>
<td>75</td>
</tr>
<tr>
<td>80</td>
</tr>
<tr>
<td>85</td>
</tr>
<tr>
<td>Sensory changes post-SRS</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

Values are expressed as number (%) of patients unless otherwise specified.
This analysis does not take into account recurrent pain following failure of 1 procedure to control pain. No single procedure works 100% of the time, and it is necessary to have alternative treatment options when pain recurs. One prior study from our institution found that within a 7-year period, a small subgroup of patients (32 of 209 patients) required retreatment for recurrent TN; following any 2 procedures for recurrent TN, 94% had pain control.10

Limitations of the Study

Patients in our study were not randomly assigned to treatment; therefore, treatment selection was subject to bias. Because of differences in baseline characteristics between the MVD and SRS cohorts (age, symptom duration, and incidence of preoperative sensory disturbance), we cannot exclude the possibility that these differences may have contributed to the observed differences in outcome. Because medical management post procedure is sometimes done by outside neurologists or primary care physicians, post procedure management was not standardized in our study. We only reported results for surgically naive patients with idiopathic TN. Therefore, our results are not applicable for patients with recurrent trigeminal pain,16 atypical trigeminal pain,17 or TN secondary to multiple sclerosis.10

CONCLUSIONS

Surgical decision making for treatment of TN depends on several factors. Several surgical options are quite effective. Our institutional experience shows that MVD is more effective than SRS in providing long-term pain-free benefits in patients with idiopathic TN. Limitations of MVD include the need for a hospital stay and an increased incidence of complications, although overall quite low. Ablative procedures such as SRS can still provide benefit to patients who are not good surgical candidates or who simply prefer not to undergo open surgery. Our data hopefully provide valuable information for counseling patients on treatment selection.

REFERENCES

30 Pollock BE: Comparison of posterior fossa exploration and stereotactic radiosurgery in patients with previously nonsurgically treated idiopathic trigeminal neuralgia. Neurosurg Focus 18(5):E6, 2005

Disclosures
The authors report no conflict of interest concerning the materials or methods used in this study or the findings specified in this paper.

Author Contributions

Supplemental Information
Online-Only Content
Supplemental material is available with the online version of the article.

Supplementary Table 1. https://thejns.org/doi/suppl/10.3171/2016.9.JNS16149.
MAKING THE INVISIBLE VISIBLE: AN ARTIST’S APPROACH TO TRIGEMINAL NEURALGIA

One frustration we hear from many facial pain patients is that others can’t truly imagine the horror they feel, especially since their condition is an invisible one. How can you accurately convey to someone the excruciating pain you’re feeling if they can’t see what is going on inside of your head? One trigeminal neuralgia patient we met, Karl Kroeppler, has a one-word answer: art.

The French artist Edgar Degas once said “Art is not what you see but what you make others see.” Karl has been an artist for almost his entire life and now uses his talent as a way not only to make a living but also to educate others about trigeminal neuralgia and raise awareness. We recently sat down with Karl to discuss.

FPA: Thanks for talking with us, Karl. Before we talk about your work as an artist, could you first tell us your TN story?

Karl: It started about 10 years ago. I was toweling off after a shower one night and I felt a small spark in my forehead.
I didn't think anything of it at the time but was concerned. Over the next 2-3 weeks, it turned into full blown electric shocks on the right side of my face. I screamed and swore uncontrollably when the episodes occurred.

I feel very lucky that the first doctor I saw knew about TN so she sent me for an MRI, which came back clear. My neurologist put me on various meds that, frankly, didn't help much. All hell broke loose over the holidays in 2015 and I was in a state of constant terror. Before, the pain would come and go, but this time it wouldn't stop. I was in and out of the hospital a few times and on the third visit, I told the doctors I wasn't leaving until they found a solution. We decided then I definitely needed microvascular decompression. The MVD kept me out of pain for 3 months, after which the pain began to return. I later tried a Cyberknife procedure, which didn't eliminate my pain but did allow me to establish a good relationship with my oncologist – he helped me find the right cocktail of medication that enables me to live a fairly normal life.

**FPA:** Where does art come into your TN story? Have you always been an artist?

**Karl:** Yes, I've always considered myself an artist. I was the kid who was always drawing and painting. After high school, I studied at Arizona State University and received my Bachelor of Arts Degree in Studio Art. Thirteen years later I returned for my Master of Fine Arts Degree in Drawing and Painting.

My wife and I were tired of the Arizona heat so we moved to Georgia to be closer to family. Shortly afterward is when my TN started. It could have been the change of climate, or it could have been a hard fall on my head. (I'm a skateboarder as well.) But when everything got worse at the end of 2015, I told my wife from here on out I would only create work about TN to educate people. When you go into an emergency room – or anywhere, really – people have no idea what you're talking about. The ER had no understanding of how to treat me and told me to take Tylenol for my headaches. I made the decision then that this has to stop. Not only is it terrifying to have episodes of facial pain, it's more terrifying to have an entire hospital staff not know how to treat you. It's awful.

**FPA:** What role does art play in your life now?

After the last horrible hospital experience, I quit my job in the sign business – pulled the plug on that career so I could pursue my art full-time. Part of that transition has included a teaching position – I now teach foundation art courses
to both majors and non-majors at Georgia State University, including 2-dimensional Design, Water-Based Media, Life Drawing and Drawing One. I share my TN story with my students – they know all about my pain and why I have this cool gash in the side of my head from my MVD.

I am also active in the art community in the Atlanta area. I invite people to my studio, and they all get an earful about trigeminal neuralgia. They leave my studio with a packet of information about facial pain provided by the FPA.

All of the art I create deals with trigeminal neuralgia in one way or another. I’m putting myself out there to educate the general public, in all of the forms of art I produce.

**FPA:** Tell us about your art. Do you prefer certain media over others?

**Karl:** Most everything I do is mixed media – a lot of drawing and painting, and some experimental forms as well. For instance in one series, I printed out images of my face, removed parts of the image and redrew it again. I’ve used MRI images as inspiration and incorporated them into a series. Nothing is off limits. When I get an idea, I explore it. I’m not bound by what has come before me or held down by tradition. Portraiture, figurative work, abstract work – it all interests me. One of the latest series I’ve worked on is still life drawings and paintings of the pills I’ve been on for my TN over the years. There’s no aspect of my TN that can’t be represented by my art.

**FPA:** What is your goal?

**Karl:** My goal in life is to educate people. I want to show them there’s a formally trained artist, working in the fine arts, trying to reach out to the general public and educate them about trigeminal neuralgia. This is my life from here on out, and I can’t imagine doing anything else other than this kind of imagery. I realize the power of art. Art truly can heal and provide comfort. I know there are people out there who are expressing their experience with this affliction through various media and I encourage them to continue in order to help them find some peace or comfort during their darkest days.

I want to show people that there’s someone out there making lemonade from lemons.

Thanks, Karl.

To learn more about Karl’s art and see more examples of his work, visit https://kroeppler.weebly.com
Pets can be the best medicine. Really! Did you know that you can get a prescription from your doctor for a pet, just as you would a medication? It has been proven that simply petting and playing with an animal can reduce pain and anxiety. Some facial pain patients have even benefitted from the assistance of a service dog. With so many different titles for “working animals,” it can be difficult to find the right fit. We hope these tips can point you in the right direction!

What’s in a Name

There are three main types of assistance animals, each with different purposes and legal rights.

Service animals must perform at least one task for a person with a disability defined by the Americans with Disabilities Act (ADA). If facial pain substantially limits one or more of your major life activities, it is covered under these rights. Service animals require obedience, public access, and task training. They typically take around two years to fully train. While you are legally allowed to train your animal without assistance, it is highly recommended to work with a professional trainer. Service animals are typically dogs, though miniature ponies have proven to be successful! Service animals are considered medical equipment and are allowed access almost everywhere, though there are some exceptions for the safety of the animal and others.
Emotional support animals (ESAs) do not require formal training. The only purpose of an ESA is to provide love and comfort to a person with a disability. Unlike service dogs, they do not have public access rights, except for where any animals are allowed. The only time a doctor’s note would be required for an ESA is when the owner is attempting to acquire a housing residence where animals are not allowed, or on an airplane, as ESAs are able to fly for free. Be sure to check with your airline to see their rules and regulations before flying with your pet. And if you do choose to fly with your ESA, please be sure he or she is non-aggressive. It will never be necessary for an ESA to wear a vest, so save your money!

Therapy animals are pets that are trained to be comfortable in a variety of environments to provide comfort to people in need. They visit environments where animals may not be present, though missed, such as hospitals, assisted living facilities, schools, and other places where people may be anxious, hurting physically or emotionally, depressed, or where the comfort of petting an animal may make a situation less stressful. Therapy animals must be comfortable having paws, ears, and tails touched, must be clean and healthy, and must be non-responsive to loud noises or things that might frighten the average animal.

Beware! There are many websites that claim to provide certifications online for a price. These are scams! There are no service dog or emotional support dog registries. A doctor’s note is all that is required. Visit ada.gov for more information regarding what is required of working animal owners.

HOW TO GET STARTED

If you think you may benefit from the assistance of a service animal or emotional support animal, speak with your doctor. As a service animal requires significantly more time, training, and money than an ESA, it is important to thoroughly discuss the pros and cons with your doctor.

First, ask yourself what problems you are dealing with that substantially limit life activities. What difficulties do you face in a day that you wish could be changed?

Once you explore the problems you would like to address, it is time to decide what tasks you would like the animal to perform. Examples of tasks might include:

- **Deep Pressure Therapy**: Animal lays on you during especially painful times to alleviate anxiety.

- **Medical Alert**: Some animals can naturally sense when

“Service Pets”…continued on page 24
so drowsy, your blasting alarm clock might as well be a lullaby? A service animal may wake you up by licking your face until you wake, nudging you, or even pulling off your blanket!

- **Medication Reminder:** You’ve set alarms on your phone to remind you to take your meds. It rings, and you turn it off as you go to take your medication. And then you get distracted and forget. We’ve all been there. A service dog can carry medications in his vest and bother you until you take your meds.

- **Contact Emergency Services:** If you are alone and are not able to call 9-1-1 in an emergency, your dog may be able to do it for you using a special device.

After speaking with your doctor and determining if a service dog or emotional support animal would be beneficial, it is time to begin the training process!

*Therapy animals are typically certified under an organization that provides insurance and testing for a minimal yearly price. Since the animal would be working for the benefit of others, and not yourself, speaking with a doctor would not be necessary in this situation. If you think your animal has what it takes, search for organizations in your area to get started. It is a great way to give back!*

**TIME TO TRAIN!**

Different types of working animals require various levels of training.
Therapy animal organizations all have different requirements, so it is important to research what training will be required. A basic obedience class is a great place to start! Practice playing with the paws, ears, and tail, and work on perfecting commands like “sit,” “stay,” and “leave it.”

Emotional support animals do not require any formal training. However, if you have a pet in a housing development that does not allow animals, or plan to fly with your pet, training your dog to control barking and to be comfortable in a small pet carrier will be helpful.

Service dog training is extensive. Some people find a rescue dog that shows potential. Others go to a reputable breeder so they can mold the puppy into the dog they want him to be. There are training books available with day-to-day steps to train the dog. Some go through organizations that train the animal for them. While there are some organizations that provide animals for free or little cost funded by donors, others cost thousands and thousands of dollars. All of these options are completely legal.

If you decide to train the animal on your own, he should go through temperament testing. A dog that is easily frightened, or shows early signs of aggression, will likely be unsuccessful as a service dog. Starting training as early as possible is vital! Even a simple obedience course or puppy class at a local pet store can help. Not only will this help with teaching basic commands, but it is a great way to socialize your dog, which is another vital aspect of training.

There are countless resources available, but picking up a book at the library or talking with service dog handlers on social media is a great place to start.

KNOW YOUR RIGHTS

Legally, there are two questions you may be asked concerning your service dog:

1. Is the dog a service dog because of a disability?
2. What task(s) does your animal perform?

A handler is not required to answer anything beyond these questions. A service dog is not required to wear a vest, though many prefer their animals wear something to signify they are working and cannot be pet. Service dogs must be leashed, and may be asked to leave only if causing destruction, barking excessively, or showing aggression.

The only proof required for an emotional support animal is a doctor’s note. Remember, there is no formal registry for service animals or emotional support animals. For more information, visit ada.gov.

Whether you are just beginning your working animal journey, or know firsthand how amazing your pet can be at easing the pain, there is no denying the helping and healing power of animals!
Noelle (Ellie) Eichenlaub

• Age 24

• Where do you live? Long Island, NY

How old were you when you first experienced facial pain? 8 years old

How old were you when diagnosed? 13 years old

What was your diagnosis? Initially trigeminal neuralgia. Over time I also developed geniculate neuralgia and glossopharyngeal neuralgia. All three conditions are bilateral.

What do you do for fun? I love to perform, do different types of crafts, read and spend time with my dogs, Molly Mae and Coco.

How has your facial pain changed you? Since I’ve had facial pain for so long, I don’t think it has changed me as much as it has shaped me. It has helped me to become more sensitive to others' needs. I can often tell when people are hurting without them saying something, and that has been a gift that has allowed me to help others. Facial pain has also made me resilient. If you can get an “A” on a final while going through a terrible flare, you can do anything!

What treatments (non surgical) have you tried? Various medications, chiropractor, CBD oil, essential oils, medical massage, vitamin B supplements, service dog-in-training.

Have you had any procedures? MVD on both sides

What tips do you have for other young patients? Do your homework! One of my first neurologists told me not to have surgery because I would “outgrow TN.” Apparently he didn’t realize it is a progressive condition, and the earlier you address the problem, the better. I listened to him and later regret waiting, as my pain has only worsened and the meds have needed to be taken at much higher doses. I’ve learned that nobody regrets knowing too much about their condition, so buy “Striking Back,” become active in the facial pain community, and learn. Just be sure to pay it forward to the next new facial pain patient.
FPA’s Memorial Tribute Fund

There are special people in our lives we treasure. Increasingly, FPA supporters are making gifts in honor or in memory of such people. These thoughtful gifts are acknowledged with a special letter of thanks, are tax-deductible, and support FPA’s growing initiatives on behalf of TN patients and families. We are delighted to share recent Memorial Tribute gifts received from March 2018–May 2018

In Honor:
The AD/TD Group
Sarah Donly, RN, LMT

All Facial Pain Sufferers
Kay E. Grim

Dr. Nicholas Barbaro
Jane D. Andersen, RN

Dr. Douglas Barrett
Patricia Mares-Mischke

Frances Booth
Patrick N. Hogan

Kayla Brewster
Zachery Nielson

Jill Brough
Helen Brough

Dr. Jeffrey Brown
Lonnie Capon

Dr. Ken Casey
Donald J. Hansen

Carolyn Chisolm
William Self

Dhun Gandhi
Freddy Gandhi

Dr. Harvey Greenberg
Ivy Lutzker

Kathy Hayes
Helen J. Nicholson

My daughter, Julie
Sandra Brendel

Lars Okeson
Cynthia L. Okeson

Dr. Rob Parrish
Joe L Christian, Jr

Claire Patterson
Ida R. Ashby

Laura Smith Romney
Shannon Reich

Sarah Sabold
Joseph P. Scheuchenzuber

Dr. K. Singh Sahni
Josephine Knight

Self
Joyce Chunias
Audrey Martinuzzi
Barbara Paolozzi

Maryann Sgarlata
Susan Sgarlata

Dr. William Smith
Alberta Abbott

Dr. Michael Stechison
Mildred Smith

TN Warriors, like me
Anonymous

Susan Wolf
Leo Sprecher

Amity Zepeida
Tracy Angold

Memorial Tributes:
William A. Bauman
Jean F. Bauman

Frank and Muriel Borello
Patricia Foggin

Mary Cuervo
Mary Lynne Cuervo

John DeMunter
Catherine M. De Munter

Jane A. Goodin
Robert L. Goodin

Dr. Steven Graff-Radford
Bahareh Safaie, DDS

Lucille Guith
Tim Guith

Mary and Ernest Healey
Ann H. Toole

Marilyn Hoxie

Maureen E. Muck

Emma Hutyra
Kenneth Hutyra

Dr. Peter Jannetta
Mary Ann Grace

Connor Joos
Elena Joos

Richard Kohley
Donna Kohley

Herbert Levin
Rochelle Levin

William Lodico
Joan F. Lodico

Nancy Mitchell
Bob Mitchell

My Folks who were there for me
Judith A. Libbey

Jerline Peters
Connie Thomas

David Reibman
Alison Rosenberg

Effie S. Roth
Helen I. Roth

Lawrence Ruether
Jonna Bowen
Debbie Matthys

Gina Simon
Linda Bennethum

Grace Timblin
Charles E. Timblin, Jr.

Dorothy Willis
Dorothy Rainwater, RN
**FPA Membership**

The following individuals joined or renewed their FPA membership between March 2018–May 2018.

<table>
<thead>
<tr>
<th>MARCH</th>
<th>APRIL</th>
<th>MAY</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Richard Bowen</td>
<td>Arthur Abbey</td>
<td>Shannon Bailey</td>
<td>Melissa Prescott</td>
</tr>
<tr>
<td>Paula Brown</td>
<td>Gloria Aplin</td>
<td>Martha Bertrand</td>
<td>Jeannette Rusbosin</td>
</tr>
<tr>
<td>Eugene Bryan</td>
<td>Mariso Arvizo</td>
<td>Susan Bruner</td>
<td>Milton Seward</td>
</tr>
<tr>
<td>Sharon Carrigan</td>
<td>Janis Asrat</td>
<td>Margie Chodorow</td>
<td>Dick Tedford</td>
</tr>
<tr>
<td>Marlene Clevenger</td>
<td>Vicente Ayarza</td>
<td>Angela Collins</td>
<td>Joanne Thompson</td>
</tr>
<tr>
<td>Richard Cretter</td>
<td>Beverley Christensen</td>
<td>Kay Cousineau</td>
<td>Nancy Trent</td>
</tr>
<tr>
<td>Ernest Cuni</td>
<td>Charles Curtis</td>
<td>Vickie Dance</td>
<td>Jane Will</td>
</tr>
<tr>
<td>Juan de Bedout</td>
<td>Thomas Desjardins</td>
<td>Faun Danson</td>
<td>Karin Woeste</td>
</tr>
<tr>
<td>Ellen Heckler</td>
<td>Christine Garvale</td>
<td>Anita Davis</td>
<td></td>
</tr>
<tr>
<td>Gloria Kennard</td>
<td>Driftnery Gonzalez</td>
<td>Lynn Deal</td>
<td></td>
</tr>
<tr>
<td>Jennifer Legerstedt</td>
<td>Leslee (Lezley) Harding</td>
<td>Bill Dione</td>
<td></td>
</tr>
<tr>
<td>Diana Manzo</td>
<td>Douglas Holden</td>
<td>Sarah Donly</td>
<td></td>
</tr>
<tr>
<td>Sal Milito</td>
<td>Floyd Holliiday</td>
<td>George Downs</td>
<td></td>
</tr>
<tr>
<td>Richard Motta</td>
<td>Wolfgang Juekoff</td>
<td>Shera Farnham</td>
<td></td>
</tr>
<tr>
<td>Dain Paxton</td>
<td>Mary Keller</td>
<td>Diana Ferris</td>
<td></td>
</tr>
<tr>
<td>Larry Rosser</td>
<td>Jihyun Kim</td>
<td>Vickie Guite</td>
<td></td>
</tr>
<tr>
<td>Bahareh Safaie</td>
<td>Jason Luedtke</td>
<td>Donald Hansen</td>
<td></td>
</tr>
<tr>
<td>Romelia Schiro</td>
<td>Phil Malik</td>
<td>Rohn Harmer</td>
<td></td>
</tr>
<tr>
<td>Valerie Schmiedier</td>
<td>Maureen Muck</td>
<td>Mary Ann Harrison</td>
<td></td>
</tr>
<tr>
<td>Joseph Sepic</td>
<td>Shirley Persinger</td>
<td>Vijay Kumar</td>
<td></td>
</tr>
<tr>
<td>Heather Stanton</td>
<td>Jennifer Seile</td>
<td>Barry Lasner</td>
<td></td>
</tr>
<tr>
<td>Teresa Thomae</td>
<td>Alan Siporin</td>
<td>Deborah Lockwood</td>
<td></td>
</tr>
<tr>
<td>George Turk</td>
<td>Bronwen Stimpert</td>
<td>Tracy McGehee</td>
<td></td>
</tr>
<tr>
<td>Marla Turner</td>
<td>Dillard Thompson</td>
<td>Michael Moller</td>
<td></td>
</tr>
<tr>
<td>Sondee Wolff</td>
<td>Elizabeth Welsh</td>
<td>Kari Nations</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lynne Wendell</td>
<td>Cynthia Okeson</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dee Wood</td>
<td>Barbara Omoth</td>
<td></td>
</tr>
</tbody>
</table>
Find freedom from trigeminal neuralgia.

Gamma Knife “radiosurgery” is a single-session, non-invasive treatment offering significant to complete relief of trigeminal neuralgia (TN) symptoms. Gamma Knife also treats other disorders of the brain, from tremors to tumors.

If you think you may have TN, ask your doctor about seeing a neurologist. For a referral to someone with expertise in TN and Gamma Knife treatment, please contact us at 1 (866) 254-3353. To learn more visit endtrigempain.com.
World Class
Trigeminal Neuralgia Facial Pain Program
The New York Area’s Experts

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 facial pain surgery.

Dr. Brisman has served as Chief of Neurosurgery at NYU Winthrop Hospital, Mineola, NY, and is Co-Medical Director of the Long Island Gamma Knife® Center at South Nassau Communities Hospital in Oceanside, NY.

Dr. Brown is the chairman of the Medical Advisory Board of TNA-The Facial Pain Association. He serves as the Neurosurgery Director of the NYU Winthrop Hospital CyberKnife® Program in Mineola, NY.

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.