

# The PPD/TMS Peer Network

## Strategic Plan for 2014 - 2016

### Goal Statement

To relieve suffering from Tension Myositis Syndrome (TMS) by raising awareness about the syndrome and its equivalents, providing information based on scientific evidence, facilitating expression of a wide variety of perspectives on TMS-related concepts and issues, and providing individual support to people with TMS.

### Programs

- **The TMS Wiki** is a free, 600+ page online resource on all things TMS. Originally created in 2008 by recovered TMSers, this website precedes the creation of the PTPN, the nonprofit organization that now hosts the website. Many of the Wiki's original contributors are also on the board of the PTPN.
- **The TMS Discussion Forum** has been running nearly as long as the Wiki. It provides a safe and welcoming place for people to discuss their symptoms and experiences. The forum has active participation from peers who are recovering and have recovered from TMS, as well as from TMS practitioners.
- **The Drop-In Chat** is a weekly online peer support chatroom, running without interruption since October 15th, 2011. It is moderated exclusively by peer volunteers.
- **The Call-In Discussion Group** is a peer discussion group held every Tuesday evening that talks about common TMS concepts and themes. The group often uses TMS books to structure the discussion. This weekly event started in January 2013.
- **The Structured Educational Program** is a free 37-day recovery program, written by members of the PTPN who have recovered from TMS.
- **Thank You, Dr. Sarno** refers to a physical book and an online website containing over 70 thank-you letters written to Dr. John Sarno. The PTPN presented a physical book to him in honor of his retirement. The PTPN also maintains the website [www.thankyoudrsarno.org](http://www.thankyoudrsarno.org), which displays the letters found in the book and all letters submitted after the book's publication.
- **Practitioner Directory**: the TMS Wiki is home to the most comprehensive and up-to-date directory of TMS practitioners. Each entry in this directory includes general contact information, as well as a link to a completed survey asking practitioners to comment on their experience with TMS, both personally and professionally.
- **Professional Survey Project**: to help our website's visitors make an informed decision when contacting a practitioner, we ask that practitioners complete a more in-depth professional

survey before adding them to our directory.

- **Newsletter:** since 2011, we have produced a monthly e-newsletter specifically for practitioners, with general information on past and upcoming events as well as exclusive interviews with and features on notable TMS professionals.
- **Conferences:** The PTPN and its members have both participated in and helped organize two different conferences for mental health professionals interested in learning about TMS.
- **Webinars:** since the summer of 2012, the PTPN has hosted several special online events, branded as "webinars," featuring various guest speakers, including TMS therapists, physicians, and authors.
- **Local Chapters:** community members within the PTPN have started in-person, local support groups that meet regularly through. Current active chapters exist in Boston, Kansas City, and the UK.

## Mission Statement

The PTPN will be a respected, high traffic, multi-voice internet resource providing comprehensive and unique information, along with developing a community of people who are recovering or have recovered from TMS and to help them to turn their negative experiences with TMS into positive experiences by empowering them to help others learn about and recover from TMS.

## Value Statement

As a peer association, and as individuals, we value the ideas, opinions, and thoughts of all people, along with confidentiality, democracy, high quality treatment, trust, reason and well supported arguments. We strive to support people with TMS because the mind body approach worked in curing our chronic symptoms. As an organization we strive to be transparent and avoid conflicts of interest. We provide the reader with high quality information, and they decide for themselves what techniques to use. We recognize that recovery is different for everyone; therefore different people will need different treatment approaches. If a given approach or technique, worked for one person than we want to create a platform for that person/approach so other people will be able to decide if it will work for them as well. We value self determination, and believe that everyone has the right to choose an approach to healing their TMS that works for them. We are committed to develop more resources on TMS and strive to raise awareness about this treatment approach, of which we are eternally grateful to all of the TMS practitioners especially Dr. John E. Sarno.

We believe TMS peers are a great source of information on how best to treat TMS. We strive to empower peers to share their wisdom with others. Peer signifies many of the ideas we value. We use "peer" because we believe that peers have a lot to offer each other and that an organization run by peers can have a distinctive voice that can strengthen the overall movement.

We aim to support and partner with other organizations with similar values and goals. Partnerships with practitioner driven organizations provide us with scientific guidance, allowing us to promote evidence based approaches and approaches that represent a consensus of opinion by practitioners. If a reputable organization of practitioners comes up with core principles for treatment and diagnosis or other subjects we will promote these as part of our goal as being providers of high quality scientific information.

As people who went through the experience of having chronic pain and recovering from it, we strive to share our experiences with others and help them, not as practitioners, but as a community of friends and peers.

## **Objectives, Goals, Strategies**

### **Provide Services to Peers**

#### **Increase Web Traffic**

In order to reach more people, we need to increase our presence on the web. We aim to increase web traffic by 20% each year for our entire network. To do this, we will utilize Facebook and Google advertising services, and re-start our link building initiative (where we reach out to various website administrators and ask for links).

#### **Mailing Lists**

Hosting specialized mailing lists creates community and fosters discussion and support. Current mailing lists for peers are the TMS and Parts Therapy mailing list and the TW-Design mailing list, for active volunteers.

#### **Drop-In Chat (Headed by Matthew)**

The drop-in chat continues to be one of the Peer Network's most successful programs as it provides a safe place for peers to support each other. Under Matthew's leadership, it has run without interruption since October 2011 and is moderated exclusively by volunteers from the Peer Network community. The chat also provides peers with the opportunity to become more involved with the Peer Network by becoming part of the drop-in chat's moderation team.

#### **Podcasts (Headed by Herbie)**

Our weekly call-in discussion group, or podcast, is a more structured discussion around a TMS book or other material, and the themes those readings bring up. In providing the technology to host these discussions and producing recordings of each discussion, the Peer Network facilitates stimulating and useful discussions that allows callers to support each other through sharing their own experiences and struggles. Like the drop-in chat, podcasts also present participants with the opportunity to take on leadership roles as discussion facilitators.

## **Develop Volunteer Infrastructure**

*Develop a strong volunteer infrastructure to allow for future growth based on realistic fundraising.*

Utilizing mailing lists such as TW-Design is both low-budget and engages existing volunteers. Creating more specialized mailing lists using specific interests of community members is another way to familiarize members with other aspects of the Peer Network.

## **Unify Practitioners**

Practitioners are a vital channel for bringing people in. In supporting practitioners, we can unify them to help spread the word about TMS. We provide following services for practitioners:

### **TMS Therapists Mailing List**

In providing a mailing list specifically for TMS practitioners (which, despite its name, is not limited to therapists), we provide practitioners a space to discuss patients, cases, and advances in TMS with other professionals from around the world. The list also helps foster professional relationships, helping to build community within the TMS movement.

### **Find a TMS Doctor or Therapist (Practitioner Directory)**

The practitioner directory on the TMS Wiki is the most comprehensive, up-to-date directory of TMS practitioners. Listings typically contain contact information, short biographies, and links to surveys (part of the Professional Survey Response Project) that visitors read to make informed decisions when contacting potential providers. The directory also serves as an archive of professionals who at one point in their career were affiliated with the TMS movement, as it lists the names of retired, deceased, or otherwise unavailable practitioners.

### **Peer Supervision Teleconferences**

These bi-monthly teleconferences are an important service, as they allow TMS practitioners (primarily therapists) to discuss specific cases and get valuable feedback from their colleagues in a confidential and professional setting. Continuation of this service is vital, as it brings together all TMS practitioners, regardless of location (whereas other peer supervision groups can be limited to a certain area).

## **Present a Professional and Informed Image**

*Present a professional and informed image to best represent what people with TMS can accomplish/better represent people with TMS to the world.*

As a TMS nonprofit and popular website, our appearance will affect how people evaluate the TMS movement. We need to make sure that we put our best foot forward through a professional and dignified appearance.

# Strengths, Weaknesses, Opportunities, Threats

## Strengths

- The members of the Peer Network have personal experience with chronic pain and/or other symptoms. We know firsthand what our visitors are suffering from.
- Support groups and other patient driven content are inexpensive.
- Due to low expenses we have no need for advertisements and limited needs for other sources of revenue, which enhances our credibility with our visitors.
- Anyone can create or edit a page, which gives us a potentially endless supply of editors.
- We have the largest amount of TMS-related information on the internet.
- We can have volunteers write newsletters and manage mailing lists for practitioners and peers.
- Because of our strict and clearly expressed Conflict of Interest Policy and a board controlled by people with no conflict of interest, we can post information by and about practitioners, without creating the appearance that we promote professional interests.
- With members from around the globe, we have the potential to reach anyone suffering from TMS.
- As an organization we have many members with substantial technical expertise, allowing regular enhancement of the features on our site.

## Weaknesses

- Since we are not practitioners we lack the professional credentials to recruit and teach practitioners about TMS.
- We lack the resources and professional credentials to reach out to the media and gain coverage/publicity for TMS.
- We are limited in reaching people who have chronic symptoms but are not accepting of a TMS diagnosis, since we are not practitioners.
- The vast majority of successful wikis are extremely large sites, consisting of tens of thousands of pages. Large websites like this can be overwhelming, hard to use, and confusing.
- The public perception of wikis is that other sources of evidence-based health care information may be more reliable.
- Our revenue and fundraising resources are minimal.

## Opportunities

- More and more people are learning how to use internet resources, including wikis.
- Social networking has become highly popular with the rise of Facebook and Twitter. Consequently, people are now more willing to become active in an online community.
- The success of Wikipedia has increased familiarity with wikis. Since we also use the same software as Wikipedia, people will already be familiar with how our site works.
- Disappointment with the lack of formal training about TMS in most practitioners of western medicine is leading increasing numbers of people to explore new options, including a mind-body approach to persistent, unexplained symptoms.

- Accurate information about TMS is limited in availability from poorly trained health care professionals. This has created a large need for a free online resource.
- We have an excellent reputation among medical and mental health practitioners.

### **Threats**

- The move to fully incorporate the term PPD in the organization's name may lead to confusion and a significant loss of search engine traffic. Even though we won't change any content on the site, doing so may be confusing to people.
- It is easy for individuals to use services without contributing. Activating, training, and motivating volunteers consumes resources.
- Few people are knowledgeable about TMS, which limits our potential membership and support.
- For our complex organization to function, new volunteers need considerable training; however many people only volunteer for around 4-6 months.
- People with TMS frequently have traits of perfectionism and goodism, causing them to take on too much and then burn out. Therefore they need to be reminded that their participation should be a source of joy and meaning, not one of frustration and obligation.
- People willing to accept a diagnosis of TMS without a physician's confirmation are typically confident about questioning authority. Getting such opinionated volunteers on the same page without diminishing enthusiasm can be time consuming and exhausting.