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Newsletter #12

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## First volunteer Section Editor

Hot off the press! We are delighted to announce that WIKISTIM has its first volunteer Section Editor, who will be developing the section on PNS. We will publicize the name of this editor as soon as we have permission.

## Editorial: Once there were no abstracts

In 1978, when my first child was born, I found work that I could do from home--writing abstracts for POPLINE, a Johns Hopkins University Population Information Program that distributed abstracts of articles of interest to people working in the field throughout the developing world. Hopkins had to create these abstracts because most journals did not require that authors submit abstracts with their manuscripts. As abstracts became more widespread, they took two forms: unstructured (i.e., with no headings) and structured (divided into sections such as Introduction, Methods, and Results). The hyper-structured abstracts that can be produced using the WIKISTIM data categories will push this trend forward. WIKISTIM completed entries present data in a format that facilitates comparison, is extremely accessible, and eliminates the "noise" of unnecessary narrative (how many times do we need to read the details of the first SCS procedure?). One day, journals might require authors to submit datasheets like those we are developing for WIKISTIM. This would not only improve the chance that authors include important information, it will also be of service to peer reviewers. JS

## Status update

- Search for new citations yielded 11 SCS; 14 DRG; 3 DBS for OCD; 20 DBS for PD
- 119 subscribers (thank you for continuing to spread the word about WIKISTIM!)
- WIKISTIM now has a discrete searchable section for DRG as well as for SCS and DBS
- Completed correspondence about a potential grant
- Submitted 2 abstracts to NANS 2014
- NEW! WIKISTIM has permission from *Neuromodulation's* Editor-in-Chief, Dr. Robert Levy, to include links directly to the *Neuromodulation* publisher's site so that WIKISTIM users can access (through library subscriptions or direct purchase) full-text articles.

## September behind-the-scenes

During September, we worked with our website engineer on the capacity to download multiple WIKISTIM entries into a single document so that our users can easily create a table. We learned the hard way that quotation marks signal the “comma-separated value” format to push data into the next (incorrect) cell. This required us to revise all of our completed datasheets to replace quotation marks with QUOTE and ENDQUOTE. We use quotes whenever it is impossible for us to paraphrase, and we are careful to signal properly when we quote text. Our website engineer has developed the capacity to create a table from the list of searchable papers, and he is working on creating this capacity from the results of our customized Google search.

## October plans

- Apply for additional grants
- Upload DBS data category list
- Submit a manuscript describing WIKISTIM to *Neuromodulation*
- Link all *Neuromodulation* citations to the publisher’s website

## Ongoing goals

- Update SCS, DRG, and DBS (for OCD and for PD) citations
- Our website developer is creating the ability to sort the list of papers by “date citation added” and “date data extraction completed,” so that users can easily check “what’s new”
- Complete additional datasheets and continue to seek feedback from authors
- Continue quality control (e.g., updating our internal links in light of the structural changes we made in August, rechecking the search engine functionality, updating search synonyms for accented names, updating epubS, checking the rendering of recently added citations, etc.)
- Continue to add new sections (PNS, TENS, GES, etc.)
- Create links from WIKISTIM data fields (e.g., “migration”) back to the appropriate pages in the “Practice Parameters for the Use of Spinal Cord Stimulation for Neuropathic Pain” (see [neuromodfound.org](http://neuromodfound.org)) and update those entries
- Improve and safe-guard the specificity and sensitivity of the search results as we expand in scope
- Increase the number of registered users by increasing awareness of WIKISTIM
- Identify authors and researchers who will submit datasheets for WIKISTIM or become WIKISTIM Section Editors

## Frequently-asked questions

**As it is currently configured, is WIKISTIM conducive to collaboration or sharing of information among clinicians, scientists, and engineers?**

Collaboration and sharing of information among clinicians, scientists, engineers, and others is WIKISTIM’s *raison d’être*. Thus, WIKISTIM is configured to allow everyone to submit data, download datasheets, submit suggestions, and communicate via the forum. We welcome suggestions and collaboration to enhance the user experience.

**Will patients find WIKISTIM helpful?**

It would be easy, but presumptuous, to surmise that WIKISTIM is of interest only to professionals; we all know that patients use the Internet as a source of health information. WIKISTIM provides scientific information pertinent to patients in a format that many will find helpful. We expect that patients will tell their doctors, “I found this on WIKISTIM.” Furthermore, our companion website ([neuromodfound.org](http://neuromodfound.org)), which contains a series of questions and answers about the use of SCS for chronic neuropathic pain, is patient-friendly.

**Registration for WIKISTIM asks for degrees and institution names. Is this required?**

An entry of some kind is required by the degree field, but registrants can and have entered free text. Some actual examples are: “Professor Emeritus, Medicine and Surgery,” “Psychology Physiotherapy,” “Research,” “Student,” “Engineer,” and “Biomedical Engineering.” These are, obviously, not “degrees.” We ran a test registration and found that “High School” was accepted in the degree field. Institution is not required. Visitors to WIKISTIM do not have to register to look at the NEWS.

**Why do you collect degree/institution data from your registrants?**

We believe it is important that we understand the range of backgrounds of our registrants so that we can confirm that we are supporting broad collaboration. Our first 110 registrants include those with the following degrees: AAS (1), BS/BA (9), BSME/MBA (3), JD (1), MA (4), MBA (12), MS (17), MS/MBA (2), PhD (21) MD/PhD (8), MD (18). MD/MPH (2), PharmD (1), other (11). Because we collect this information, we can report that we have subscribers from Brazil, Canada, Denmark, England, France, Germany, Ireland, Italy, New Zealand, Spain, Switzerland, USA, and Vietnam.

### **WIKISTIM includes some engineering articles, do you plan to include all that are of relevance to neuromodulation?**

We plan to include all articles in all fields that are relevant to neuromodulation. We began with the field that we know best, SCS, and we have included all of the engineering articles of which we are aware; however, whereas we believe we have been exhaustive on the clinical side, we can't be as certain on the engineering side, and we'd be delighted to work with an engineer to identify entries for SCS and other sections. Because it is web-based, WIKISTIM has no limits on its growth.

### **What constitutes a WIKISTIM section, and what is needed to create a new section of WIKISTIM?**

Our sections reflect the various stimulation targets (SCS, DBS, DRG, PNS, TENS, etc.). To create a new section before we can attend to it ourselves, we simply need a volunteer to work with us to identify a list of potential entries and to devise a list of data categories.

### **How does the range of search parameters on WIKISTIM compare with that available on PUBMED?**

WIKISTIM uses a customized Google search. One can search ANYTHING with this search engine. Our "range of search parameters" is not limited, as is PUBMED's. WIKISTIM does have "data categories," but searches are not limited to these categories. Unlike PUBMED where, for example, a search for "SCS" and "infection" will only yield those articles that have "infection" in the title or in the abstract, an identical search on WIKISTIM will yield articles with "infection" in the title and all articles in which the data category "infection" has an active (i.e., filled in) field.

In addition, unlike PUBMED, where a search yields a great deal of "noise," the searchable papers on WIKISTIM have been curated so that the list includes only those pertinent to the subject at hand. This will save researchers a great deal of time and makes WIKISTIM valuable even as we are increasing the breadth and depth of the information available.

### **Does WIKISTIM include articles from journals that are not included in PUBMED?**

WIKISTIM already includes 28 SCS articles (including book chapters and abstracts) from sources (including journals) that are not included in PUBMED. Inclusion in PUBMED is not a criterion for inclusion in WIKISTIM.

### **The logistical needs of WIKISTIM are substantial and rely heavily on the services of volunteers, much like Wikipedia. How will you attract volunteers?**

We are pursuing a number of ways to attract volunteers. For example, the WIKISTIM datasheets are useful as a starting point for authors as they plan studies, prepare study reports, and review the literature. We anticipate that authors who prepare tables and do meta-analyses will use our datasheets and share the results with us. We further expect that these authors will abstract their own work into WIKISTIM data sheets and submit the results to us, so as to facilitate access and citation by others. This has already happened for a number of papers. Peer reviewers will also find these datasheets useful as a checklist. We hope that eventually journals will use WIKISTIM data fields as part of the submission and review process.

### **How will the WIKISTIM data entries be reviewed and edited?**

One of the strengths of WIKISTIM is that this review can be done by anyone at any time, and corrections can be incorporated easily. Ms. Shipley comes to this task having written approximately 6,000 abstracts in the 1990s for the Population Information Program of the Center for Communication Programs at the Johns Hopkins University School of Public Health and with decades of experience in medical/scientific editing. To date, she has reviewed and edited all of the submissions and expects that others will review her work. WIKISTIM entries must be succinct and accurate, and the dictates of copyright law must be observed.

### **What is the added value for users of WIKISTIM vis-à-vis PUBMED and other databases?**

What WIKISTIM offers, even in its infancy, is a curated list of papers, all of which are relevant to neuromodulation, which means that a WIKISTIM search is highly specific, whereas a PUBMED search is not. Author searches that return thousands of PUBMED references will return only relevant references when done on WIKISTIM. Thus, our users can easily find specific papers that might have otherwise taken a great deal of time to locate or might even be missed. The WIKISTIM entries for which data abstraction has been completed provide the only access to these data in a format that facilitates rapid analysis and comparison, and the WIKISTIM data abstraction scheme yields much more information than will be found in a PUBMED abstract. WIKISTIM content will not be limited, as are meta-analyses and literature reviews, by date of publication, by the search terms the authors chose, or by the research question they asked. WIKISTIM will allow its users to ask their own questions and conduct up-to-the minute literature searches.

For papers that are listed in PUBMED, WIKISTIM users can link to PUBMED abstracts, which in many cases link to the sites of publishers, where people can purchase full-text articles. At the moment, PUBMED does not offer a portal to full-text articles in *Neuromodulation*. We are in the process of creating these links on WIKISTIM so that interested WIKISTIM users can easily purchase full-text version of articles that appear in our journal.

## How you can help

- Support WIKISTIM with a tax-deductible donation to The Neuromodulation Foundation, Inc., a nonprofit 501(c)(3) organization. Our address appears below; please contact [janeshipley@gmail.com](mailto:janeshipley@gmail.com) with questions about donations.
- Spread the word (see below)
- Submit extracted data
- Notify us about any reports we might have missed for SCS and DBS/OCD or reports you would like to see added for DBS/PD
- Suggest improvements to the SCS data categories
- Review and suggest improvement to the draft DBS data categories appended below

## Points you can make about WIKISTIM

Who will use WIKISTIM? Everyone in our field!

- Authors who write a series of papers can use WIKISTIM to confirm that data reported in a new paper are congruent with data reported in a prior paper. Over the years we have seen several cases of data discrepancy. WIKISTIM should help reduce this
- Busy clinicians who need answers to clinical questions or literature support for reimbursement
- Representatives of industry who are seeking regulatory approval or need comparative data for approved devices
- Researchers who want to determine research needs, review background information, prepare evidence tables, etc.
- Authors working on scientific publications who could profitably search WIKISTIM and, if they are writing a protocol or research report, could use the WIKISTIM data category template as an outline for their work (and could then submit the completed datasheet to us as soon as their report is accepted for publication, expediting entry and facilitating readership and citation)
- Authors and readers who wish to query and correct inconsistencies in published scientific papers
- Critical thinkers who want to discuss published reports without the typical space and time limitations of Letters to the Editor
- Investors and other interested lay people who are exploring neuromodulation therapy
- Regulatory agencies and third-party payers who need a basis for decision-making

## Features of WIKISTIM

- Subscription remains free
- Published neuromodulation data abstracted and categorized
- Custom Google search engine
- Users download datasheets and can perform their own meta-analyses
- Users submit data from published papers
- Discussion of papers unlimited by time and space
- Links to PUBMED abstracts and to SCS Practice Parameters ([neuromodfound.org](http://neuromodfound.org))
- Includes citations that are not listed on PUBMED

## Goals of WIKISTIM

- Improved patient care
- Support for reimbursement
- Facilitated regulatory submissions
- Improved quality of published reports
- Inspiration for research and innovation
- Increased communication that will extend the useful life of published reports

## Disclosure

WIKISTIM includes citations of studies of the use of neuromodulation therapies for indications that are or might be considered off-label or experimental in the United States.

## Thank you for your continued interest in WIKISTIM!

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