FootSteps

The newsletter for members of The Erythromelalgia Association
FootSteps online: www.erythromelalgia.org or www.burningfeet.org

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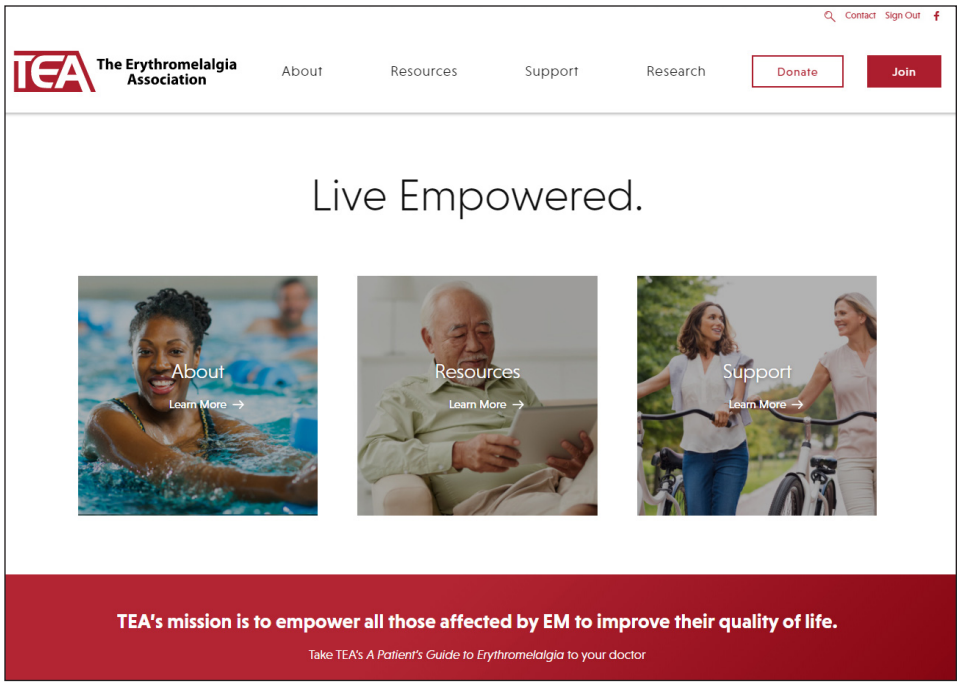
Redesigned, updated website goes live



After months of work with a website design firm, TEA's new website went live in January. Professional, engaging, easy-to-use—all these describe the new site. As the place where most people with EM symptoms first find TEA, the website is now updated and offers a wealth of information about EM. Although visitors are asked to donate to TEA, they are not required to join TEA or make a donation.

"The overall design of the site is polished, clean, simple and very easy to navigate by the user," said Beth Coimbra, president and treasurer of TEA. "TEA provided the wording and the design firm did the rest." To draw visitors into the information, there are large photos introducing the main sections. The type is large and easy to read, the colors and font are consistent throughout, giving the whole site a feeling of cohesion.

Under "Resources," visitors find Frequently Asked Questions and the entire text of *"A Patient's Guide to Erythromelalgia,"* a booklet published by TEA in 2016. TEA's library of almost 100 medical journal articles now is arranged with the most recently published studies first. Visitors can sort articles into four broad categories, for example, treatment or research. Checking one of the category

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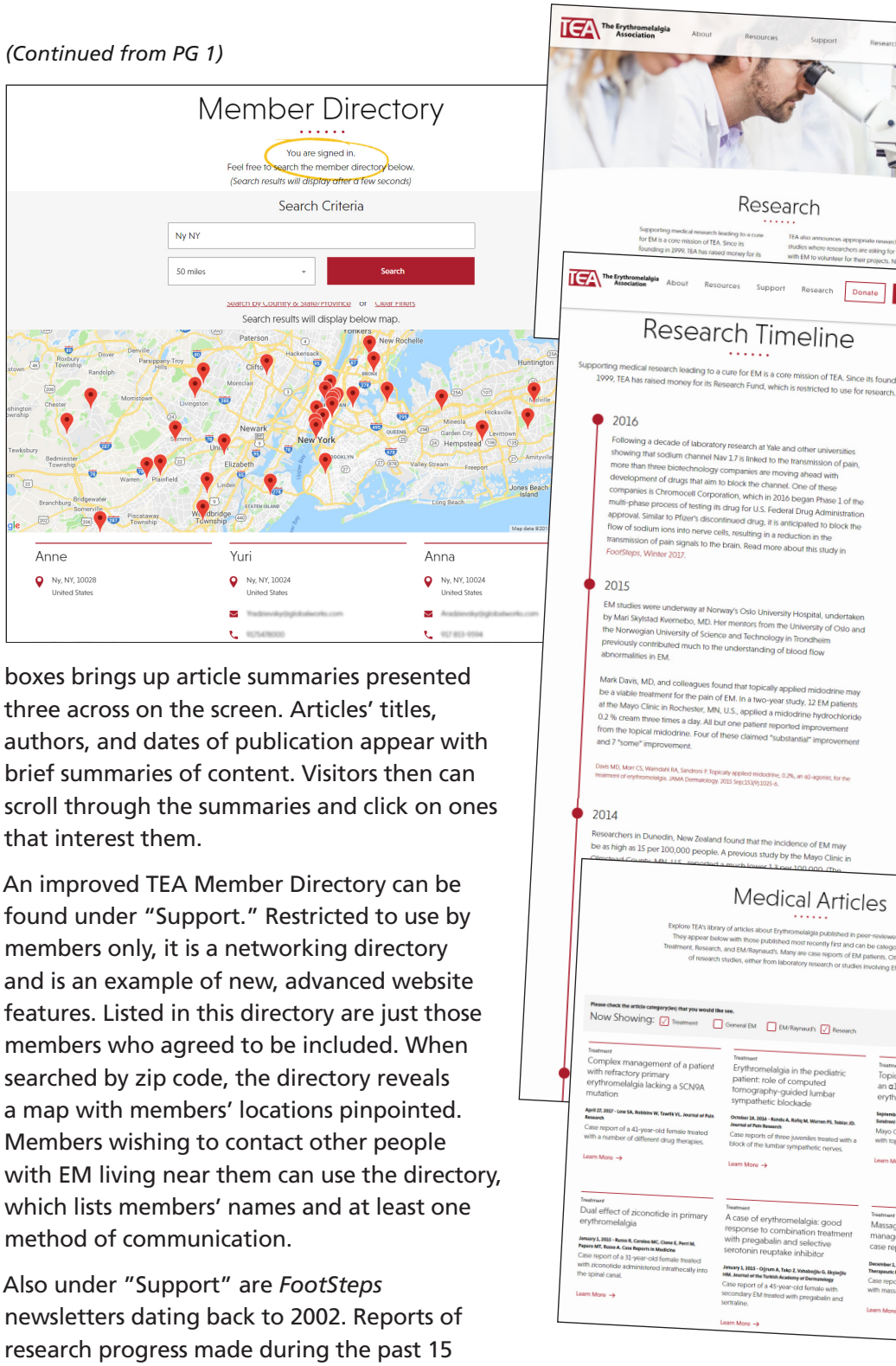

boxes brings up article summaries presented three across on the screen. Articles' titles, authors, and dates of publication appear with brief summaries of content. Visitors then can scroll through the summaries and click on ones that interest them.

An improved TEA Member Directory can be found under "Support." Restricted to use by members only, it is a networking directory and is an example of new, advanced website features. Listed in this directory are just those members who agreed to be included. When searched by zip code, the directory reveals a map with members' locations pinpointed. Members wishing to contact other people with EM living near them can use the directory, which lists members' names and at least one method of communication.

Also under "Support" are *FootSteps* newsletters dating back to 2002. Reports of research progress made during the past 15 years appeared first in *FootSteps.* Every new TEA program was also featured and many member stories were printed.

Under "Research" is a Research Timeline with the most recent findings first. Enhanced entries describe—in layman's language—major research as reported in medical journal articles, including new links to further information. In most cases, the article's scientific citation (the name, date, authors, publication, etc. in the format used by researchers) follows the entry. These citations also link to the articles.

There's much more to learn on the website, so visit www.erythromelalgia.org or www.burningfeet.org.

The Future of Pain Treatment Gets Personal

By Elisabeth Antoine

A recent study found that 1 in 16 patients will become a chronic opioid user following surgery, reinforcing the need for pharmaceutical companies to develop new, effective, non-addictive drugs for the treatment of chronic pain. One such target for drug development is the selective blockade of voltage-gated sodium channels, one of which, Nav1.7, was proven by researchers at Yale to be involved in causing inherited EM. Voltage-gated sodium channels are large proteins embedded in the cell membrane and have thus far been difficult for scientists to study.

As reported in the June 2016 *JAMA Neurology*, new microscopic technology is now making it possible to analyze the structure of these proteins. Using genomic analysis, molecular modeling, and functional profiling techniques, Stephen Waxman, MD, PhD, and his research team at the Yale now have successfully tailored a personalized treatment approach for patients with one particular inherited EM mutation.

While the direct results of their study apply only to the small number of patients carrying this mutation and do not point to a specific treatment that will help people with EM today, it is an important stepping stone for research. This new technology demonstrates that it is possible to use genomics and molecular modeling to guide pain treatment.

Most patients with inherited EM do not respond well to drug therapy, but one family with a mutation called V400M had previously been reported to be responsive to the sodium channel blocker carbamazepine. Yale's study, conducted from September 2014 to April 2015, began by creating a computer-based representation of V400M's molecular structure. This molecular model revealed that another EM mutation, S241T, interacted with V400M. Because of the close proximity of the two molecules, researchers predicted that carbamazepine would have a similarly beneficial effect on patients with the S241T mutation.

For the double-blind, placebo-controlled study, researchers recruited two patients from the same family with the S241T mutation. They then assessed the effects of a placebo and the drug carbamazepine on the patients' perception of pain. Results showed that carbamazepine did in fact reduce their pain.

The patients were instructed to report the duration and intensity of their EM pain and the number of pain-induced awakenings from sleep on a daily basis. One patient reported a reduction in total time in pain of about 50%, while the second patient reported an 85% reduction. Duration of each pain episode was also reduced, by 55% and 50% respectively. The first patient, who had a history of night awakenings due to EM, reported a 70% reduction in number of awakenings.

> New technology uses genomics and molecular modeling to guide pain treatment.

In addition, researchers employed functional magnetic resonance imaging (fMRI), a procedure that uses MRI technology to measure brain activity through changes associated with blood flow. In this portion of the study, pain was triggered using a heating boot, during which time patients continuously indicated their pain levels. fMRI was then used to assess patterns of brain activity during treatment with a placebo versus carbamazepine. In those patients treated with carbamazepine, their reduction in pain was paralleled by a shift in brain activity from areas involved in emotional processing to regions that encode accurate sensation, a pattern consistent with decreased pain intensity. Researchers concluded that reducing pain with carbamazepine may potentially have a positive effect on attention, decision making, and executive function.

A later Yale study published in 2017 used a similar structural modeling approach to learn that the Nav1.7 mutation I234T was also located in close proximity to S241T. Researchers assessed the effects of carbamazepine on I234T and found that the drug reduced the firing of sensory neurons.

The results of both studies support this new "pharmacogenomic" approach to pain treatment and provide needed hope for the future. Says Waxman, "I am hopeful that, some years from now, pain treatment will be transformed from trial-and-error to a precision medicine, first-time-around approach guided by the DNA of each individual patient."

*For full **JAMA Neurology** article with supporting data and charts, visit jamanetwork.com/journals/jamaneurology/fullarticle/2514552.*

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TEA encourages you to share your story about how EM has affected your life. Please consider sending a "head shot" and your story (350 words or less) to **GaylaKanaster@gmail.com** or mail to **2532 N. Fremont St., Tacoma WA, USA 98406**.

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Thank you for appeal support

TEA thanks all who answered the 2017 Annual Appeal. Donors gave a total of $26,794, the largest amount ever donated to a year-end appeal. TEA collected $17,622 in general donations, and $9,172 for the Research Fund. TEA is an all volunteer agency that depends on donations for its income. Appeal donations received through March 11, 2018, are included in the totals, and contributions should continue to trickle in through the spring months. TEA sends an appeal to our EM community for support for our ongoing operations and Research Fund at the end of each year.

"We thank everyone who donated to support the work TEA does to empower those affected by EM to improve the quality of their lives," said Beth Coimbra, TEA president and treasurer.