

FootSteps

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

Spring 2019, Vol. 20, No. 1

2019 is TEA's 20th anniversary!

In the mid-1990s, people with hot burning feet, hands, even ears, found one another on the Internet. Eager to share experiences and potential remedies, they formed a long email chain communicating with each other and building a sense of community. Some of these people worked through the process of forming The Erythromelalgia Association, which became a 501(c)(3) nonprofit organization on January 20, 1999. Another participant became the moderator of a Yahoo! Group—also begun in 1999—where people with the symptoms of EM could share their stories online and help one another.

During its first few years, TEA established a Research Fund, started distributing an online newsletter *FootSteps*, elected its first officers, created a website, and applied for membership in the National Organization for Rare Disorders. By 2002, TEA had created a Medical Advisory Committee and a Networking Program for people without access to the Internet. In the early years TEA's officers focused on collecting medical journal articles about EM to add to TEA's growing online library, which became valuable to patients and doctors alike. In 2004, the MAC met face to face in Oslo, Norway, with TEA President Lennia Machen attending. Sixteen years later, TEA's professionally designed, updated, easy-to-use website went live. Anyone searching "burning feet" now goes directly to TEA's site where a wealth of information awaits. People can find others who want to network in the online member directory or doctors with expertise in EM in the physician directory. Almost 100 medical journal articles are easily accessed on the website as are issues of *FootSteps* back to 2000.

In the early 2000s, people living with EM caught the attention of news media around the world. Dubbed the "Man on Fire" disease, erythromelalgia was featured in publications like *Scientific American*, *Medical News Today* and the *Wall Street Journal*. Yale announced findings from a study of the DNA of members of a large Alabama family with inherited EM in 2005, sparking media interest. Electronic and print media featured people with EM, especially Alabama family member Pam Costa, Ph.D., also a TEA member. In 2017, she was again featured, this time in a BBC documentary and an article in *Wired* magazine. Pam has lived with the searing pain of inherited EM since she was a child and became a frequent spokesperson for TEA and the

(continued on pg. 3)



TEA president Lennia Machen at the first MAC meeting in Oslo, Norway, in 2004.



Event Coordinator Sarah Sundstrom, (left) with Gayla Kanaster at the first TEA fundraiser in Seattle, WA, USA, in 2004.



Kate Conklin, Triathlete on Fire, pictured with the ESPN crew at the Ironman 2008 finish line.



Pam Costa, Ph.D., in the BBC documentary 'Incredible Medicine: Dr. Weston's Casebook'.

FootSteps

is published by



The Erythromelalgia Association

erythromelalgia.org
burningfeet.org

facebook.com/erythromelalgia



TEA Postal Address

200 Old Castle Lane
Wallingford, PA, USA 19086

Information/MemberServices

(610) 566-0797

memberservices@burningfeet.org

FootSteps Editor

Isabelle.Davis@gmail.com

Board of Directors

Beth Coimbra

President and Treasurer

Isabelle M. Davis

Vice President

Laura Beaton

Angela Demerle

Michael Givan

Jackie Lee

Deborah Mosarski

Any information contained in this publication is protected by copyright and may not be reproduced without express permission from the editor.

The intent and purpose of this publication is to inform those with EM or their friends and families—not, in any way, to provide medical advice.

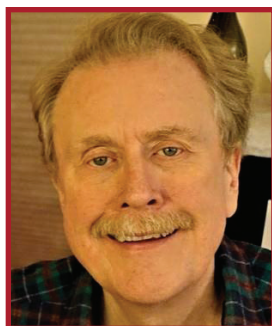
Gayla retires from board



*Gayla Kanaster
Former TEA Board Secretary*

During the past 15 years, thousands of people sought information from TEA. Board of Directors member Gayla Kanaster responded to many of those requests personally or coordinated small teams of volunteers to answer emails and phone messages left on TEA's memberservices email and phone line. This was just one of Gayla's contributions as a TEA Board of Directors member, serving from 2003 to late 2018, when she formally retired from the board. Gayla enlisted many volunteers for TEA during those years, acting as the TEA point person—finding people and then giving them roles to play. She also acted as TEA's contact person for members with stories to contribute, among other requests. In 2006 Gayla was elected Secretary of TEA, an office she held for more than five years. Gayla has to deal with her own EM symptoms. She is a member of a large extended family from Alabama, many of whom carry a genetic mutation causing EM. She and her daughter have both volunteered to be part of research studies into inherited EM.

TEA founding member dies

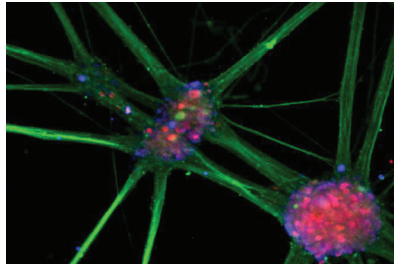


*Karl Granat
TEA Founding Member*

One of TEA's founding members Karl Granat, 66, died in Salem OR, USA, in February. Karl, an MBA, had worked for the State of Oregon's Adult and Family Services Division eight years when he was forced to leave for health reasons in the 1990s. He had several medical disorders, but it was the painful EM that left him bed-bound for four years. During those years, Karl thoroughly researched the medical literature about EM and found a group of people with EM on the Internet. He was among the people who helped found TEA in 1999. For many years Karl was the first point of contact for dozens of people from all over the world who sought help for their painful condition. With his knowledge of the disease and his strong faith in God, he was able to help prevent at least six people from committing suicide.

TEA's 20 (continued from pg. 1)

Yale research effort, in which she participates. ESPN, an international television network, and NBC followed TEA member and “inspiring athlete” Kate Conklin as she competed despite constant EM pain in a 2008 “Ironman World Championship”.



Pain-sensing nerve cells colored green to make them more visible. (Photo courtesy of Pfizer)

During its early years, TEA began cooperating with medical researchers interested in EM. Members with the inherited form of EM provided blood samples to the Dutch researcher Joost Drenth, M.D., Ph.D., who identified the EM gene SCN9A in 2002. Through a NORD grant in 2005, TEA donated \$30,000 to this same researcher, who by then was searching for a second gene that might be involved in inherited EM. Dr. Drenth’s research team received another gift of \$15,000 from TEA in 2010. Members with inherited EM also sent blood samples to pain researchers at Yale. Physician scientists there used DNA from the samples to prove that certain mutations to SCN9A—the EM gene—cause the pain, redness and burning of EM. This gene includes codes for sodium channel Nav 1.7, which is found along the length of nerve fibers and acts as a molecular battery generating and transmitting nerve signals like pain. Yale pain researchers had been studying the role of Nav 1.7, and EM gave them a genetic model for pain. More importantly, developing a drug that would specifically block this ion channel gave pharmaceutical companies a target for potentially breakthrough, non-addicting drugs for pain. EM became a model for pain research in general.



Research continues on EM pain blockers.

Since its inception, one of TEA’s goals has been fundraising for research into a cure for EM. The Research Fund grew through frequent gifts from members of the EM community. One very successful fundraising event was held in the Seattle, WA, USA, in 2004. Another fundraising event—a TEA-sponsored teleconference with Dr. Jay Cohen—in 2006 again raised money for the

Research Fund. In 2004, TEA made its first large donation to support research to cure EM—\$60,000 to support studies into inherited EM being done at Yale. Further donations to Yale from TEA’s Research Fund followed: \$45,000 in 2008, \$15,000 in 2010, \$40,000 in 2012, and \$75,000 in 2018. These donations were made directly to Yale’s Center for Neuroscience and Neurorehabilitation Research, a multidisciplinary laboratory—now 30 strong—where EM research is conducted under the direction of Stephen Waxman, M.D., Ph.D. Private dollars like TEA’s pay for salaries, supplies, and equipment and “give us stability, allow us to move rapidly and give us the flexibility to try new things,” according to Dr. Waxman.

In 2007, TEA began sending an “Annual Appeal” through the mail to its growing list of members, families and friends. The first appeal raised more than \$10,000, an amount that grew every year to a high of \$30,874 in 2013. These appeals help the organization operate and pursue other goals. One of these is raising awareness of the rare disorder among people with EM, health care practitioners, and the public in general. Providing accurate information to help educate these same groups is yet another objective, and the website and *FootSteps* had been the primary sources of information about EM. TEA added a Facebook page in 2013 to help achieve both goals. One of the world’s most popular social networking platforms, Facebook allows TEA to reach thousands of people with each “post.” And in 2016, TEA published *A Patient’s Guide to Erythromelalgia*, a well researched handbook with medical journal references footnoted. A comprehensive overview of EM, the guide includes common symptoms, symptom relief, lifestyle modifications, finding a doctor, and getting a diagnosis. This 28-page booklet is another TEA resource available to people living with the rare, under-diagnosed disorder EM.



TEA promotes EM awareness and education through Facebook, a website, and *FootSteps*. A patient guide is a recent addition.



The Erythromelalgia Association

200 Old Castle Lane,
Wallingford, PA, USA 19086

PRESORTED
FIRST CLASS MAIL
US POSTAGE
PAID
Milwaukee, WI
PERMIT NO. 966

20-YEAR ANNIVERSARY ISSUE

Share your story about how EM has affected your life. Send a head shot and your story (350 words or less) to memberservices@burningfeet.org or mail to 200 Old Castle Lane, Wallingford, PA, 19086.



Raising Awareness.

Raising Research Funds.

Raising Hope.

erythromelalgia.org
burningfeet.org



The Erythromelalgia Association

FootSteps

TEA by the numbers

MEMBERSHIP While remaining all volunteer, TEA has grown through the years to an organization with members in at least 17 countries. TEA eliminated yearly dues and keeps no official membership numbers. However, more than 5,000 people are website "users," which means they registered to become members in the past 10 years. In 2018 for example, TEA had 362 new members. TEA suggests new members make a donation of at least \$20.

FACEBOOK TEA now has 2,848 Facebook "likes." More importantly, almost 3,000 people "follow" TEA on FB, which means they get TEA posts in their "newsfeeds."

RESEARCH Since 2004, TEA has donated \$265,000 to EM research.



20
YEARS
ANNIVERSARY