

Hot News!... Some Members Find Success with Capsaicin

This is the hottest story since our... last newsletter! All kidding aside, some of our very own TEA members have realized some success in treatments using the capsaicin creams. If you've been tuned in to the EM Onelist or eGroup, you have probably already heard about the trials of capsaicin cream (7% to 10%), it's successes depending on the patient and when, in the study, it was applied.

Dr. Wendye Robbins, of UCSF, has been testing a new cream containing capsaicin (hot pepper ingredient) on various conditions that are similar to EM. The idea is that the capsaicin burns the nerve endings in the affected area, causing a depletion of P Substance in the nerves, thus dulling or eliminating the pain that is normally present. Because the capsaicin is so very hot, it's a challenge to be able to use it at all. It's so intense, the patient must use some type of pain medication in order to tolerate the treatment itself. Also, anyone in the room could experience irritation from the capsaicin vapors, thus suggesting protective clothing. It sounds like the capsaicin leaves a residue that can cause burning if spread to other areas by not using protective gloves, etc.

However, it seems to be worth the preparations, as the patient can experience relief almost immediately from the burning and pain due to the EM. Two members, who had recently undergone the treatment, wrote in to the Onelist with a detailed description of their experiences and it is most encouraging. However, since their initial reports, one member has not seen as much relief as she was hoping for.

In addition to the completion of their treatments, we may have TV stars in our midst..... Carol and Wendy were filmed by the Discovery Channel while receiving the capsaicin treatment from Dr. Robbins. They will inform us on the date and time it will be shown.

Carol's Story:

"I'm back at home after my second capsaicin treatment at the UCSF pain management center. I'm much more comfortable than after the first treatment, but time will tell what the lasting results will be. Here's some of the news from the visit.

1. "The Treatment"

Wendye is moving along in improving the means of treatment itself. The Treatment was much, much less painful for me than before. They did not have to use any pain medications at all during the application of the capsaicin - other than the topical anesthetic. The treatment was using 7.5% capsaicin rather than 10% as before. The new, improved numbing cream contains 4% benzocaine and 2% tetracaine from the label on the bottle we got. Wendye and her nurse emphasized this was a much more powerful anesthetic than the 4% bupivacaine that we used before. The application went smoothly. I applied the numbing cream at home, about 1 ½ hours before my appointment time. When I arrived, Wendye and resident tested the effectiveness of the numbing. I was still rather sensitive to heat. When she applied cold, I either couldn't feel it, or it felt warm.

She applied more of the numbing cream, and we waited another 45 minutes or so. Same test - I still had some sensitivity. So, even more numbing cream - and some more time waiting. Finally, my feet were essentially numb - I couldn't feel the heat they applied. (High drama with the camera crew filming the whole thing.) So, On went the capsaicin (more high drama with the camera crew). I felt nothing. It was left on for about an hour, with the start of some warmth at the end. Then, they washed it off. The sensation of heat continued to build up, so I am taking some of the oral pain medication. But they didn't have to use any of the IV pain killers or ankle blocks that made my first treatment such an agony.

2. Pre-treatment:

I received from Abbot's Compounding Pharmacy in Berkeley a package on Monday with some 100 gm. of the numbing cream and two tubes of a 1% capsaicin. Wendye has been working to improve the base of the creams to make them more absorbing. Fairly expensive stuff - about \$290.00. Wendye asked me to apply the numbing cream, wait 45 min or so, then apply the 1% capsaicin - and leave it on for as long as I could. Monday night I did this - with virtually no pain at all from the capsaicin. Tuesday night, after about 30 minutes, the capsaicin started burning a fair amount. I left it on for about an hour, then washed it off. Wendye said today that the capsaicin triggers production of chemicals in the "C" nerve fibers - that triggers the pain sensation. On Monday, the treatment probably "woke up" the fibers, so there was the increased sensation on Tuesday.

3. The Roman Circus

Well, there they all were when I arrived at the clinic this morning - Wendye, the resident, a UCSF PR person, and the crew from CBS news - a reporter, producer, cameraman and sound man. First setup shot had me going out to the front door of the clinic, being welcomed in by the clinic director and ushered into the treatment room. Then, after getting myself setup (now in a hospital gown rather than my pretty dress) in the treatment chair, the crew came in to film my feet, the unwrapping of the saran wrap off my feet (which I put on at home to protect the numbing cream), and the hot/cold test with water and large swabs. Then, next application of the numbing cream. While I was waiting for the numbing cream to work, the reporter interviewed me for quite some time about my background, the nature of the disease, and treatment. I put in plugs for: the TEA, the great support of the internet EM group, the fact that the treatment was experimental, and not approved by the HMO, The fact that there were quite a lot of other EM sufferers who could benefit from this kind of treatment. Wendye mentioned she had heard from several others, but could treat relatively few. Wendye mentioned that she had a grant covering capsaicin treatments for peripheral neuropathy associated with AIDS, but that I didn't qualify for that. She was donating her time, and the clinic was not charging for the facility, and that Carol was asked to pay for the medications. The crew had an in depth interview with Wendye in her office. Don't know when it will air, but the producer of the segment will let me know. It may air only on the west coast, or nationwide on a Saturday or Sunday over the next few weeks. I'll let you know.

4. Other thoughts. We asked Wendye where she was in development of the treatment. She has been working on a ton and a half of FDA paperwork to start trials soon on a delivery mechanism she is working on with a drug company. She said that she will include EM as one of the diseases this will treat, and petition the FDA for faster track approval based on designation of EM as an "orphan disease". We can only hope and pray for the success of the treatment, and the ability of this to help others. This is still experimental - no one knows if there are side effects that may lay down the road."

Carol

Pennies From Heaven - Research Fund

We're getting closer to our goals with the help of many generous angels who have been donating to the TEA Research Fund. But progress is slow and we need help to make our dreams of

reaching that goal. Presently we have a total of \$16,100 earmarked for research, between the two funds (N.O.R.D Fund, and our TEA dedicated account). The goal is to reach \$35,000 by the end of this year, but the truth is.... we actually need more than that to really get started. N.O.R.D requests proposals from the Medical Community at the \$35,000 amount, but there is no guarantee that the research could be done for that amount. While many ideas have been thought of as ways to reach our goal, we haven't implemented but one.... the Challenge of last fall. It was very successful and has made all the difference in our accounts, yet we need to continue to search out those donations. If any of our membership has experience in, or would like to try, grant writing as a way to apply for some of the funds available,..... please let us know. Research grant writing is a field of expertise and a draw of time that our board doesn't have available and would welcome those who would like to take on this task.

New Members

"Make new friends, but keep the old, One is Silver and the other Gold"

The following list is of the members that have newly joined since January 1st, 2000. And, on this occasion, we would like to extend a great big hug of a welcome to them all!

Susan Gates, Louise Glegg, John Hicks MD, Kiersten Kress, Roberta Libby, Della Noonkester, C.E. Parker, Dale Brower, Bridget Tietz, and Valerie Tumiel.

Histry Challenge

For those of you that have been involved with our Internet group for awhile, we have a challenge for you! Karl, Milt and I have been trying to remember just exactly how and who got our wonderful little group started? So far we have only come up with some rough pieces...

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Around the Spring of 1996, I have unearthed a note from Milt, on the Neurology Forum. We also found the names of Kevin Sives, Kelly Meister, Dan, B. Case, Al and Carol Baker, Bev Fontaine, Bonnie and Claude Sellars, and Kelly Garret. A few months later, in the Fall of 96, I see some from Karl Granat, and it was about that time that I joined in. Shortly after that we increased in number, until officially forming into an organization in January 1999, making us officially a year old. We know there were more in the original group of Internet communicators, but without copies of the messages, it's hard to remember names. Please don't feel offended if we have left you out, it's just a case of not keeping records that would help us piece this together. <LB

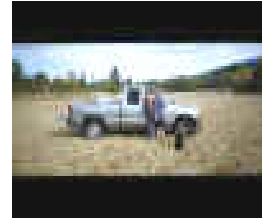
We would like to recall our "roots" and record them before none of us can remember any of the first beginnings. So, if you have more to add to our short story, please write me and we'll keep filling in those blanks until we have it all figured out. Thinks of it as a challenge!

T.E.A. for Two - Meet Karl and Milt

This feature is going to act as the "get to know you" corner. We will feature a couple of TEA Members each issue. Since we already know they have EM, we'll try to avoid that topic and focus on meeting the special person instead. This first article of "TEA for Two features two of our

founding members and current board officers and members.... Milton LeCouteur and Karl Granat.

Meet Karl Granat



FootSteps: Tell us something about yourself that is special to your life.

What is your favorite way to spend time?

Karl: "My favorite activity is spending time with my kids. I always knew I wanted kids, but from the time my two boys were conceived. To say that I spend most of my time thinking about them is an understatement. I have never had such an overwhelming feeling of love in my life as I have for them. I used to love going to church, walking, hiking, hunting and fishing with them- though that stopped with the EM, it has been transformed into computer use, funny stories about our family, and reading. Apart from trying to focus on getting over EM, I am a history and philosophy addict. I love reading civil war history, biographies of the great presidents, the history of science and technology, warfare, disease, and the spread of eastern culture to the West and western culture to the East. The development of Hong Kong and the role Jardine Matheson & Co. (the "Nobel House" of Clavell's novels) played in the development of modern China and Japan is probably my most esoteric interest in history."

FootSteps: Introduce us to your family, their names, ages, hobbies, sports, activities, etc.

Karl: "I am 46 years old, 6' 3" and 195# with reddish blond hair and green eyes. I live in Oregon, with my wife of almost 17 years; Lee, and our boys John (13) and Michael (10). John has more homework for a 6th grader than I can believe, and is in orchestra, some advanced jazz ensemble, advanced math and no sports. Michael is a 4th grader who gets good grades too, but seems quite worried about his future due to the homework his older brother has to do. (I don't blame him!) Getting my boys to do their homework seems to be my big problem nowadays- I frequently remind them that the founding fathers had to do schoolwork too, and they were encouraged to do it in an accurate and timely fashion by the daily, liberal application of a switch to their hind ends. It worked incredibly well. I tell them that I am increasingly interested in that method of encouraging study in children- though they are united in thinking that this is a very bad idea!"

FootSteps: Tell us a little about your past, special skills, sports, hobbies, trips you've taken, or anything that you are glad that you did earlier in your life.

Karl: "Many years ago, I got a Bachelors of Science Degree in history, with minors in philosophy, science and history. I then got an Masters in Business Administration. When in college, I spent my time with a number of friends and was very active in Mensa. I also tried to travel by car a lot, which I loved. I loved driving long distances very fast on desert roads- I thank God I wasn't killed, as once I lost control of my car and left the road at high speed. After an exciting ride through the desert, I managed to get back on the road without even damaging my car! I learned a lesson with that experience. After graduation I worked as a lumber broker, and then a fiscal analyst for the state of Oregon. There, I forecasted revenues and expenditures for the state."

FootSteps: Share a dream for the future.

Karl: "I believe that almost all of us can be greatly helped with EM, it is just a matter of getting the right treatment. I have had a 95% improvement, and am now walking for a minute at a time without the use of a walker or a cane. I have overcome obstacles that were supposed to be insurmountable in the past, so I am not going to quit trying! I have an autoimmune illness (a neuropathy, which was diagnosed only because of my trial of IVIG). My present dream is to obtain a complete remission from EM- I believe I have an excellent (75%+) chance of obtaining a remission of at least few weeks using plasmaphoresis. The problem is that there are risks, and my family disapproves of me taking substantial risks when I am doing so well. So, lately, this is what I have been dreaming of."

Meet Milt LeCouteur

FootSteps: Introduce us to your family.

Milt: "My wife, Jean, is terrific and helps me more than you will ever know with TEA's business. Our marriage is the second one for both of us, and together we have 14 children, and three grandchildren."



FootSteps: Tell us a little about your past, special skills, sports, hobbies, trips you've taken, or anything that you are glad that you did earlier in your life.

Milt: "I was born in San Diego, California, in 1929. I spent my young years mostly on the beach, and was somewhat athletic as a kid. I've lived up and down California for most of my life, and the past ten years, Jean and I have lived in Washington. Jean and I are retired teachers and spent between 15 and 30 years working with disabled children. My last position was in Ventura County, California, as the director of a county-wide special education program. Since retiring we have spent a good bit of time traveling. We've been to New Zealand, Australia, Mexico, and Britain, twice. My family, LeCouteur, was originally from the Channel Islands, the Island of Jersey, to be specific. I'm somewhat a genealogy buff."

FootSteps: Share a dream for the future with us.

Milt: "Since 1993, I have had a series of medical problems that have slowed life down, quite a bit. I had a heart attack and carotid artery problems starting in 1993, and EM beginning in 1995. TEA and all of our EM friends have helped me while away my time, and if I can help us win the fight against this god-awful disease, I will be more than happy!"