

# FootSteps . . . TOWARDS PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia

## TEA ENCOURAGES PARTICIPATION TO FIND THE EM GENE



Dr. Joost Drenth is asking for our support for his research in locating the gene that causes erythromelalgia in our families. This research focuses on the primary or familial type of EM and relies on blood samples from those who believe they have this type of EM. If you and any of your family have this type of EM, you may want to consider taking part in this important step in EM medical history. Following is information about this project from Dr. Drenth. (note: "erythromelalgia" = erythromelalgia)

**Autosomal dominant primary (familial) erythromelalgia, A study aimed to identify the erythromelalgia gene. By Joost PH Drenth, Rockville, MD, 2 September 2003.**

Autosomal dominant primary (familial) erythromelalgia (EM) is a very rare and incurable familial disorder that presents, or exhibits, as painful attacks of red vasodilatation and congestion with elevated skin temperature. Attacks are provoked by heat and exercise and symptoms are relieved by cooling or elevating the affected extremities. Although the first cases have been described as early as 1878, little progress has since been made in terms of explanation of the mechanism of the disease.

In an article that appeared in 2001, we described how we located the gene for familial erythromelalgia. We traced 6 families from the United States, Canada, France and the Netherlands with familial erythromelalgia. During the genome wide search that followed we identified a region on the long arm of chromosome 2 associated with susceptibility to this form of erythromelalgia. This result was confirmed for all 6 families.

In order to understand the implications of this study it is important to know that all of us have 46 chromosomes in the cells which make up our bodies. The chromosomes are the packages of our hereditary material which come in units called "genes." We inherit one copy of our chromosomes from each of our parents. Thus, there are 23 pairs of chromosomes. As chromosomes come in pairs, so do our genes.

Familial erythromelalgia is described as an autosomal dominant genetic disorder. This means that it takes only one abnormal gene copy to result in the disorder. Persons who are affected with familial erythromelalgia therefore have one normal copy of the gene for erythromelalgia and one abnormal copy. Every time a person with familial erythromelalgia has a child, there is a 50% chance to pass on the abnormal copy of the gene and thus, the disorder. There is also a 50% chance for a child to inherit the healthy gene copy and be unaffected.

It is to be expected that patients with familial erythromelalgia carry mutations in one of the genes on the long arm of chromosome 2. Until now, it is not known which gene it is. The efforts described in our article in 2001 have managed to pinpoint a region on chromosome 2 that must contain the erythromelalgia gene. This interval still contains 81 genes, and we do not know which of these 81 genes is the precise gene involved in familial erythromelalgia.

Well, the question is, how to identify that gene? Here, it would be useful to illustrate the situation with an analogy.

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Continued from page 1. **EM Gene Research**

Imagining that our hereditary information is contained in a set of encyclopedias which represent chromosomes. A volume is a single chromosome and each page represents the information encoded for a gene. These are the instructions for the production of a necessary product (a protein). The page must be printed perfectly to communicate its critical information. One misspelling or typo may interrupt production of the product. On one page there are many different misspellings which possibly can occur; these represent different mutations in the gene. To go back to familial erythralgia, the specific volume has been identified but the page number (mutation) has not.

These “misspellings” in one erythralgia family is not likely to be the same as that in another family. Direct testing, which means looking specifically for the “misspelling” in the gene, may be offered once the gene has been discovered and has been well characterized. Such testing is already available for certain other genetic disorders. For familial erythralgia we have first to identify the gene in order to develop a genetic test. What we would like to do is to identify the gene for familial erythralgia. The way to do this is two-fold.

First, we find families with this disorder and to test markers in the chromosome 2q region. Markers are simply well-characterized pieces of DNA which exist in a great variety of forms (often illustrated as numbers), so one person's chromosome 2 may be easily distinguished from another's. The goal is to define specific markers that all people in a given family with familial erythralgia have inherited from their affected parent, and that all people without disease have not inherited. This will give us a stretch of DNA that is similar among affected family members. Comparison of this stretch of DNA between families can allow us to narrow down this interval as we will search for the smallest portion of the chromosome 2q stretch that is shared by all patients from the different families.

Next, we will identify the genes that are within this chromosome 2q stretch. The more families that are studied, the higher the chance is that we can downsize this interval. Then we will go on to test all genes in that identified region in order to see whether we will find “misspellings” (mutations) that occur in erythralgia patients, but not in their healthy family members.

## **Frequently Asked Questions:**

### **What will be done with my blood sample?**

Once your blood sample has arrived in our laboratory it will be given a unique identification number. Then we will extract DNA from the blood using current techniques. We will test your stretch of chromosome 2q by testing a panel of markers. This will give us a unique pattern. We will then compare your pattern with that of your affected and unaffected family members. After identification of the erythralgia gene, we will test your DNA for mutations (misspellings) within this gene. We will communicate this result to you, if you wish.

### **Will my family benefit from this study?**

We will perform indirect DNA testing with the blood from you and your family members. This will help us in order to narrow the chromosome 2q interval. It can help you and your family because we can also use it as a genetic diagnostic test. Although the diagnosis of familial erythralgia may be confidently established in most affected individuals based on clinical features and symptoms, at times it is not certain whether an individual is affected, for example in children who have not shown EM symptoms yet. Thus, people who may choose to obtain information from DNA testing are those whose diagnosis is ambiguous. To establish the diagnosis is obviously helpful in guiding the medical management plan. It will also provide reassuring information for those who are found not to be affected.

### **I do not have family members with the disease. Can I still participate?**

Although we can test your blood for the chromosome 2q markers, the results are less well interpretable as we cannot compare them to affected and non-affected family members. This means that we cannot establish whether you suffer from the familial form of the disease. We will store your blood until we have identified the gene for erythralgia. Then we will go back and check your blood as well. We will correspond with you with respect to the results. Of course the study that aims to identify the gene for familial erythralgia benefits most from the participation of many families.

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Continued from page 2. **EM Gene Research**

**What information will I get from this study?**

As indicated, linkage studies can serve as an indirect genetic test. We will communicate with you about the results from this part of the study. Once the gene for familial erythralgia has been established we will test your DNA for this gene.

**Once the results are known do I get a treatment for EM?**

Of course it is our first hope to identify the erythralgia gene. This will give us information on the protein that is defect in familial erythralgia. Knowledge about this protein can give us directions as to how the disease arises. Also it gives us valuable information about which type of drugs we should use.

**Can I withdraw from this study after I send my blood?**

At any time you can stop participating in our study. Your participation is completely on a voluntary basis.

**How can I participate?**

You can participate by donating a blood sample. Please contact me by e-mail before submitting a blood sample. The blood must be drawn in a 10 cc EDTA non-coagulated tube. It must be packaged properly in a box, so that the tube will not break during the shipment. Plan to use FEDEX for transportation.

**I want more information, where can I get this?**

I can be reached at: [jphdrenth@yahoo.com](mailto:jphdrenth@yahoo.com)

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

## ***New Members***

The following list is of the members that have newly joined us between June and August of 2003. And, on this occasion, we would like to extend a great big welcome to them all!

Jane Donald, Edwin Franklin, Lisa Grabarec, Elizabeth McGrath, Vivian Miller, Jenifer Rademaker, Patricia Silva, Margaret Boorman, John Clarke, Phyllis Dorminy, Sarah Greenwood, Mark Grossman, M.D., Jennifer Harris, Susan Hartley, Christi Howry, Sheila Kirchmann, Rhonda McElroy, Virginia Meldrum, Cathy Shuman, Philip Singleton, Sharon Strickland, Regina & Dieter Bayer, William Blaha, Mervat Boutros, Mrs. D. Brisley, Stephanie Curran-Frenzl, Mabel Djuvstad, Yvonne Donaldson, Betty Kennedy, Paul Lebrun, Jean Leff, Marion Levy, Cynthia McRae, Judith Palmitessa, Jean Ann Pyle, Mary Randa, Peter Rowland, Mary Ruf, and Marcy Weissman.

*Welcome!... we're glad you've joined us!*



# Your Donations are Adding Up!

By Lennia Machen

TEA's Research Fund now contains over \$50,000! Isn't that exciting? It truly is, and we thank all of those who have donated so generously to this important cause. However, as that is a nice round number, and one that is certainly commendable, much more is still needed.

In today's world of increasing costs in the medical research field, TEA needs to plan, and *plan big*, to reach that mark of being able to commission a research project. The fact of the matter is, we really don't have an exact number in mind that we know it will take to complete a research project. We are aiming for \$100,000. Another nice round number. But whatever the number, one thing is true... the faster we raise the funds, the faster we send out the proposals for a project... and the faster the process of finding relief from EM actually starts!

If you have read the article on page one about the exciting research being done to identify the EM gene, you probably noticed the sentence in the Frequently Asked Questions section about treatments... "Once the results are known do I get a treatment for EM?" But most importantly, did you notice the answer? "*Of course it is our first hope to identify the erythralgia gene. This will give us information on the protein that is defect in familial erythralgia. Knowledge about this protein can give us directions as to how the disease arises. Also it gives us valuable information about which type of drugs we should use.*" This could be the start of something really meaningful to us all... the start of truly valuable research that could help us to find some solutions to living with EM.

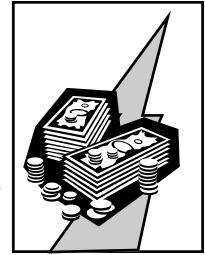
TEA wants to be a part of this process but we cannot do it without funding. We have a great start thanks to all of you who have given so generously, but more needs to be done. We need to reach outside of our membership and reach those who would also like to help and support this effort. Hold events, stir up public interest, draw attention to our need, ..all of these things would help. Some members have graciously suggested to host events like a silent auction, tag sales, and even letter writing campaigns. All are great ideas, and all are encouraged and appreciated.

TEA has commissioned a special committee to start some action in fund raising for our Research Campaign and you will be hearing more from them in the near future. For now, we can all start with the things in our reach... like asking friends and family to give to the fund instead of giving us material gifts. (Check out our new *Gifts* feature on the web site or contact Member Services to use your VISA or MasterCard for this easy process.) Perhaps we could give to the fund in someone's name for their Christmas gift... how wonderful to receive a note that a gift has been given in your name that will help bring relief to that loved one! What could bless us more than that? Certainly not another pair of slippers. And, to go further in this thought... how about giving to the Research Fund when a loved one passes on? Gifts can be given In Memoriam as well.

What else can be done? Raising public interest and connecting it to the Research Fund is always an important step. While it is not easy to offer your story up to your local media, it is a very effective way to draw interest. Recently Sarah Sundstrom contacted her local paper in Seattle and they published an article. This was great in itself, and caused some local interest, but the real icing on the cake was the local TV talk show inviting her to appear. Her interview on this show was a great success and Sarah received many contacts of others who were interested. Sarah then turned the whole event into a true benefit to the Research Fund when she donated the cost of the tape copies to TEA for each and every tape order. We thank Sarah for this selfless gift, and also thank those who ordered copies of Sarah's show.

There are many ways to help support EM research. You can contribute financially to the fund, you can donate your time to helping with the Fund Raising Campaign, you can solicit donations from your friends, family, or employers, or you can hold events like the tag sales and silent auctions. It all comes down to one thing... *just how fast we can start to find a solution to EM is directly related to how fast we can raise funds.* If you don't mind waiting, then take your time in joining the effort. If you would like to speed the process, then, please join us and *let's get started!* I, for one, am in a hurry and have already sent off my story to my local newspaper as well as to several magazines. In addition, I donate several hours every week to TEA and helping speed the process. Do these efforts sound generous? They aren't really. I consider my donation of time an investment into my own treatments and solutions to my case of EM, and that is *very* personal. Won't you join me and start working towards a cure to this awful disease we share? Lets really DO SOMETHING that will bring relief... *to us... and faster!*

**See the addresses on the next page for finding more information on how you can help.**



# TEA Research Fund Donors

Following is a list of the active members who have given to the Research Fund since the beginning in 1999. We thank each one of you for helping us all step that much closer to finding relief from EM.

John Allen, Jane Allison, Kagehiro Amano, Robert & Betty Backer, Carol Baker, Wendy Baker, Lawrence Batlan, M.D., Rhonda Batts, Jill Baxter, Regina & Dieter Bayer, Keith Bennett, Sheryl Black, Elaine Blanchette, Kate Carless, Marvin Carnish, Elizabeth Chalmers, Zack Collar, Rhea Cope, Sandra Correa, Dr. Pamela Costa, Vincent Cox, Doris Cunningham, Marilyn Darnell, Maureen Davies, Isabelle Davis, Willene Domenichelli, Yvonne Donaldson, Harold Dondis, Phyllis Dorminy, Teresa Eckert, Meg Edelson, Kimberly Eldred, Mary El-Khadem, Barbara Ellerbeck, Seymour Ellis, Catherine Erickson, Barbara Ernst, Nancy Farish, Russell Flynn, Jackie Fox, Debra Frenzel, Angela Gervasi, David & Charlene Gonsalves, Sarah Greenwood, Heidi Grein, Delores Griffith, Ann Haller, Jennifer Harris, RD Hawkins, Catherine Heckel, Kathryn Henriksen, John Hicks, M.D., Judie Huddleston, Ralph Huey, Lynn Hughes, Kirk Hull, Derek Humphry, Beth Huston, Paul Isacoff, John Izzy, Jean Jensen, Vivian Kammerer, Larry & Gayla Kananster, Emma Kipe, Joy Knoll, Edith Kylo, Milton LeCouteur, Patricia LeVasseur, Marion Levy, Roberta Libby, Brian Loeffler, Norm & Helen Longley, Mimosa Low, Sharon Lyons, Nancy Mabry, Doris MacDiarmid, Lennia Machen, Herbert Mansmann, M.D., Amy Marcotullio, Marie Materi, Michelle Mattox, Lois Mavsar, James May, Furman Mayberry, Jan McKim, Gail McNitt, Tillie Miller, Margaret Miller, Terri Miller, Geraldine Montgomery, Erin Morgan, Debbie Mosarski, Ellen Naylor, Helen Nelson, Wayne Nelson, Ann Nestor, Masa Okabe, H. Ruth O'Rourke, Demetrios Papadopoulos, Charles E. Parker, Jr., Katherine Pelly, Joyce Perkins, Andre Pilate, Andrew Prince, Melinda Pruitt, Sandra Publow, Geneva Ray, Jim Read, Judy Reese, William Rennie, Patricia Rusch, Ray Salza, Marianne Schwartz, Pricilla Sebeniecher, Robert Self, Thelma Shiller, Beverly Shoenberger, Kathleen Soto, Madeline Steingut, Tom Stocks, Joann Stokowski, Mary Stuart-Menteth, Robert Subias, Nathan Taylor, Shirley Thatcher, Lex Trelford, Valerie Tumiel, Mary Turner, Marsha Turney, Joan Veldhuizen, Polly Vogel, Marilyn Wade, Marion Walker, Freda & Herman Weber, Robert Weitzel, Suzanne Wildman-Chard, Deborah Winslow, Steven Withers, and Tibor Zemplenyi, M.D.

Kathy & Dave Janke, Anthony & Joan Marchio, L. Gottstein, Albert & Susan Colianni, have all recently contributed in Memoriam of Ida Marchio

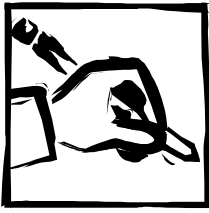
***....Our Many Thanks to Each One of You!***

## **Library Articles Available by Mail...see the last pages of this newsletter!**

You can now order any of TEA's Library Articles by mail! As part of the new Networking Program, you may request articles for a small charge. The fee is based on mail inside the US, plus the cost of copying. The fee formula is simple.... a minimum of 70¢ per order or 20¢ per page, whichever is greater. If you live outside the U.S., please write for the additional charge (International postage rates) for the amount in postage rates.



To order write to our Networking Program Administrator:  
**Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, Utah, 84117.**



## Your Stories... and everyone has one!

TEA has asked its members to write brief stories about their EM or daily lives. We would love to hear your story too! Please send them to Gayla Kanaster, 2556 W. 234th St., Torrance, CA 90505, USA or [gaylakanaster@aol.com](mailto:gaylakanaster@aol.com)

*(The following letter comes from TEA Member Debbie Mosarski and describes her recent visit with Dr. Joost Drenth, researcher and author of several informative articles about EM. See article on page one of this newsletter.)*

Dear Group,

I saw Dr. Drenth at the end of last week and wanted to tell you all about it. For those of you that don't know Dr. Drenth, he wrote the article on the EM gene (which you can access on the TEA website). He is from the Netherlands and here, in the US, actually for different reasons (not sure why) but he's still working on the EM gene project during his mornings and nights. Dr. Drenth is mild mannered younger doctor, very compassionate, and his English was perfect with only a slight accent.

I was in a mild Raynauld's state while seeing him unfortunately, but I believe the referring doctor at NIH (National Institute of Health) showed him my EM pictures that the TEA uses on the web site. Still I was hoping he would see either my severe EM or Raynaud's. I guess I shouldn't have used the cold wraps all morning. I was kind of expecting him to examine me and suggest treatments for EM but quickly found out he is very focused on the gene aspect of EM. He looked at the treatments I have tried and didn't have much else to suggest except maybe human growth hormone (HGH). I asked him about prostaglandin's, IVIG and Plasmapheresis. He didn't think any of it would help much but it would depend on the cause of the EM. He agreed with me that EM itself is a symptom of an underlining disorder rather than it's own disease entity, unless triggered by having the EM gene.

From what I understand, if you have the gene it can be dormant or active for other family members, and any circumstance can bring it into an active mode. In my case I would think that it was taking a calcium channel blocker (CCB) like Verapamil. For those without the tendency towards EM, stopping the CCB would stop the EM symptoms. But for those with the EM gene or with a disorder that can give EM symptoms something as simple as taking a CCB could trigger the EM. The challenge is to know if you have the EM gene or a secondary EM.

Dr. Drenth feels EM is a symptom of having another disorder...like having the gene that gets triggered, having hypertension, autoimmune disorders, neuropathies, myeloproliferative disorders such as thrombocytopenia, etc... We do not have the gene located yet, but he has the chromosome located. That's a long way off from finding the gene actually. Dr. Drenth explained to John and I that the chromosome has 87 genes and then 40 subtypes to each gene. He has to find that!

That is what Dr. Drenth is currently working on. He needs people with familial EM to donate their blood in order to help him find the gene. I told him we had members in our group with familial EM. I also told him I would try to get him some volunteers to donate blood. My dad, brothers and myself are all going to help.

Please know that giving your blood and knowing if you have the chromosome will not effect the way you're treated by your doctors. But, it helps with progress and hopefully it will lead to more answers for us all in the future. Personally I want to know because it helps me zero in on what process to follow more closely. It may also help me to be able to stop searching for an underlining disorder. As you all know I have been searching for 8+ years now. Knowing if I have the gene or not could allow me to put to rest the idea of the possibility of an autoimmune disorder or some other underlining disease process. For me personally, I think peripheral neuropathy is the cause of my EM.

I believe this man is committed to finding this gene and he seems to have the passion to do it. So let's help him to help us.

I wanted to ask him why he has chosen EM to research. I don't know if EM just intrigues him or if he has a family member with this disorder. If I ever get to see him again I will ask. Even though he couldn't suggest much in the form of answers it was still a comfort to finally see a doctor that knew more about EM than I did! Usually I am explaining EM to the doctor but this time EM was being explained to me. A nice switch. I wish I hadn't been so sleep deprived when I saw him. He explained things very thoroughly but I didn't absorb as much as I could have because I was so tired.

Best Regards, Deborah Mosarski, Ashburn, VA, USA



## A "Summit Meeting" of Two EM'ers



MAY, 2003, BOISE, ID. This last spring found two TEA members finally meeting face to face. Jim Read and Lennia Machen met up at the Simplot Sportsplex during Lennia's son's soccer game to go over some important EM news, and to put a face and voice to the personality behind the email messages, finally going past the "virtual meeting" of knowing each other for several years.

"Jim and I had a great time chatting about various issues surrounding the EM community, and of course, we solved many world problems while we were at it!" said Lennia.

Jim Read is the moderator of the EMyahogroups, and Lennia Machen is the President of TEA. Both enjoy helping others learn about, and solve issues relating to EM, and both highly recommend others making the effort to meet up with fellow EM'ers. The human and emotional connection is really important to our well being and helps us to validate and realize our need for help.

## TEA Director Fills Seat on NORD Board

Beth Coimbra, TEA Vice President, will soon take a seat at the National Organization of Rare Disorders, Board of Directors table. Beth will bring them her experience and knowledge in working with non-profit organizations in accounting. Just as TEA appreciates her contributions, we are sure NORD will also gain much from Beth's input.

Coimbra also holds the TEA position of Facilitator to the TEA Medical Advisory Committee.

## A Helpful Letter to Dr. Jay Cohen

Dr. Cohen,  
I am a neurologist and have written to you in the past for assistance in managing my wife's primary EM. I started her on Lidoderm 5% patches to the plantar aspect of her feet for 12 hours daily starting at night time about 3 months ago, in conjunction with Mg 500-750 mg/d. This regime has been very helpful, especially with the hotter weather. She is not symptom free but has clearly improved. The patches are cut down to the areas of maximal pain and covered with Tegaderm. I hope you can share this information with other patients with this terrible disabling disorder.

Regards, Jay Klazmer

## TEA to Distribute New EM Survey

You will soon receive an updated survey of EM Patients. The new questionnaire will gather valuable information about your individual case of EM. As in years past, our members have been asked to tell us about your EM.

This confidential information will be used to help doctors identify helpful treatments, unsuccessful treatments, life style limitations, types of EM, types of doctors who most often treat EM... and much, much, more. The information is valuable not only to us as patients, but to our Medical Advisory Committee and other concerned entities in the medical community. Results will be published in FootSteps.

When you receive your questionnaire, please take a few minutes to complete the form and return it to TEA promptly. This is one way you can help us all take one step closer to finding some helpful solutions to our EM.

## Members Corner For TEA Members

The Member's Corner is for TEA members to send in their information to be printed. Letter's to the editor, news clips, photos, jokes, or anything that you would like to share. We would love to hear from you! **So, come on! Send it in!** webmaster@erythromelalgia.org, or Member Services, 24 Pickering Lane, Wethersfield, CT 06109

# Hot Flashes!

... "hot tips" and news items  
just for us "EM'ers!"



## Ever wonder about those tests your doctor orders?

Now you can look up the suggested medical test at <http://www.labtestsonline.org/> and learn more about it. This site offers helpful information about 150 different tests, and a number of interesting items like autoimmune disease, magnesium, etc.

## Chill-out with a "Chillow"

As seen on Oprah... There's a cool pillow sized pad that needs no refrigeration, is not electric, and doesn't need any power device. You can order one, or get a big discount for buying two. Originally developed for pets, but perfect for people too! Available at Sooth-Soft for about \$30. The email for info is [Info@soothsoft.com](mailto:Info@soothsoft.com) or phone 1-888-chillow (244-5569).

<http://www.chillow.com/MeetChillow.htm>

Maverick Marketing Ventures,  
Inc.  
3341 N. Cascade Ave  
Colorado Springs, CO 80907



Found in The September Issue of Reader's Digest:

## Relief from Hot Flashes...

Yes, Hormone Therapy can relieve hot flashes. But it may increase your risk of stroke, breast cancer and heart disease. A study from the University of Rochester suggests an alternative: the prescription seizure drug gabapentin (Neurontin) reduced hot flashes by 54%. "Hot flashes can be distressing," says lead author Thomas Guttuso, Jr. "They interfere with sleep, night after night, and that severely affects quality of life." The drug's side effects (sleepiness, dizziness) aren't as scary as those of HT, but it may affect absorption of calcium pills; gabapentin should be taken an hour after calcium.

## A User Friendly Translation...

Jean Jeffery, TEA Member, has provided the following simplification to an article about: **Inflammation of blood vessels and clotting caused by platelets in thrombocythemia which is responsive to aspirin, except when bleeding occurs at very high platelet counts.** By J.J. Michiels, April 2003

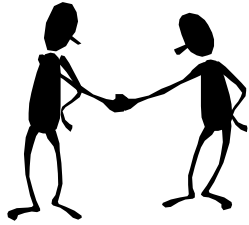
EM is usually present with thrombocythemia & polycythemia. Aspirin and indomethacin, which inhibit cyclo-oxygenase (cyclo-oxygenase is an enzyme which causes pain and inflammation) give complete relief from EM and painful cold and blue extremities.

In EM, excess platelets damage the walls of blood vessels, and increase clotting. This may be evident in skin biopsies. These abnormalities are corrected by aspirin. A temporary deficiency in blood supply (ischaemia) to the nerves, eyes, or heart coronary arteries frequently precedes or follows EM.

In thrombocythemia, ischaemia and clotting occur at platelet counts above 400 X10<sup>9</sup>/l. Low-dose aspirin will prevent these up to platelet levels of 1000 X10<sup>9</sup>/l. Above 1000 X10<sup>9</sup>/l spontaneous bleeding from the blood vessels usually occurs due to the presence of von Willebrand disease, an inherited bleeding disease similar to hemophilia

At high 1000-2000 platelet counts, low-dose aspirin can control the clotting, but may actually worsen the bleeding symptoms. Bleeding can be reduced by using other platelet-lowering drugs.





## Networking Program is Going Great!

There are already 13 TEA members in our Networking Program. They have received an address list of their fellow TEA members and expect to start writing and receiving letters soon.

Besides the letter writing, many members have ordered and received several different articles and informative information from our catalog of library articles. There have been a couple of new additions lately and we expect more soon as we have added new OCR software to assist us in scanning and working with the printed types of documents.

Don't miss out on the opportunity to get connected to others who have EM and share your successes and EM information for treatments, therapies, and even doctors. If you are a member who does not have a computer or email, you may enjoy communicating with other TEA members just like you. If you have a treatment or therapy that works, why not share the information and help others like yourself?

To sign up for the program, use the application form on the back of this page or contact:

Judy Reese  
1155 E. Wild Duck Lane  
Salt Lake City, UT 84117



## Be a Library Contributor



Do you have EM articles at home that you would like to share? Contact the TEA Library and learn how you can be a contributor to the growing library of articles about EM. Our goal is to become the definitive resource for EM information... for you, our fellow sufferers, and the medical community. Contact Member Services at the address below, or email [webmaster@erythromelalgia.org](mailto:webmaster@erythromelalgia.org).

## TEA Contact Information:

**Fund Raising Chairman:** Milt LeCouteur, 4343 Roosevelt Way NE #305, Seattle, WA 98105.  
Or email to: [miltjean@blarg.net](mailto:miltjean@blarg.net) 206-632-0894

**Member Services:** Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109.  
Or email to: [memberservices@erythromelalgia.org](mailto:memberservices@erythromelalgia.org) 860-529-5261

**Network Program:** Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, UT 84117  
or email to: [network@erythromelalgia.org](mailto:network@erythromelalgia.org)

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The intent and purpose of this publication is to bring information to those suffering from erythromelalgia or their friends and family, and not, in any way, to provide medical advice.

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# TEA Networking Program Application Form

Yes, I want to participate in the EM Networking program, I agree to the following rules, and I give TEA permission to distribute my contact information to other members of the program.

1. You must be a member of TEA, and annual dues paid up to date.
2. You must sign and submit the form giving TEA permission to disclose your name and address to other participants in the program.
3. You must agree to respond to all correspondence from other Network Program members who write to you.

Signature: \_\_\_\_\_

Name \_\_\_\_\_ Date \_\_\_\_\_

Street Address \_\_\_\_\_

City \_\_\_\_\_ State/Province \_\_\_\_\_ Zip/Postal Code \_\_\_\_\_

Country \_\_\_\_\_ (optional) Phone (\_\_\_\_\_) \_\_\_\_\_

(optional) E-mail address \_\_\_\_\_@\_\_\_\_\_

## Mail this form to:

**Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, UT 84117**

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## TEA Articles—Order Form

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State/Province: \_\_\_\_\_ Zip: \_\_\_\_\_ Country: \_\_\_\_\_

Are you a TEA Member?  Yes  No \*NOTE: If you are not a member of TEA, there is a service charge of \$5.00 for each order.

Are you a TEA Network Program Member?  Yes  No

Method of payment:  Check enclosed  Other : \_\_\_\_\_

VISA/MC Credit Card Number: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

## Order Form, Page 1

Quantity	Item Number	Title ♦ = Newly Added to Library	Number of Pages	Cost
	T005	♦ <b>TEA Bylaws.</b> The complete bylaws used to operate TEA. 2003	(10 pages)	\$2.00
	T006	♦ <b>TEA Policy &amp; Procedure.</b> The supplement document to the bylaws for the operation of TEA. 2003	(7 pages)	\$1.40
	M015	♦ <b>Unexpected healing of cutaneous ulcers in a short child (with EM)</b>	(2 pages)	\$ .70
	T001	TEA Introduction Letter, 2002	(4 pages)	\$ .80
	T002	2002 Financial Report	(2 pages)	\$ .70
	T004	TEA Brochure (full color)	(2 pages)	\$1.50
	M001	Erythromelalgia: New Theories and New Therapies	(13 pages)	\$2.60
	P001	Disease has Midlander Crusading for Awareness	(2 pages)	\$ .70
	T003	TEA Information Flyer	(1 page)	\$ .70
	P002	Current Treatment for Erythromelalgia	(2 pages)	\$ .70
	M002	Erythromelalgia	(16 pages)	\$3.20
	M003	Erythromelalgia: A Clinical Study of 87 Cases	(6 pages)	\$1.20
	M004	Reduced Skin Capillary Density During Attacks of Erythromelalgia Implies Arteriovenous Shunting as Pathogenetic Mechanism	(1 page)	\$ .70
	M005	High-Dose Oral Magnesium Treatment of Chronic Intractable Erythromelalgia	(15 pages)	\$3.00
	M006	Erythromelalgia: a condition caused by microvascular arteriovenous shunting.	(36 pages)	\$7.20
	P004	Causative Symptoms in Erythromelalgia Identified	(1 page)	\$ .70
	P005	Fighting Pain with Fire: Hot Chili Peppers Offer Relief— Capsaicin	(1 page)	\$ .70

## Order Form, Page 2

Quantity	Item Number	Title	Number of Pages	Cost
	M007	AAPM: Lidocaine Patch Enhances Chronic Pain Therapy	(1 page)	\$.70
	M008	Erythromelalgia: A Mysterious Condition?	(7 pages)	\$1.40
	M009	Treatment of Refractory Primary Erythromelalgia in a Child Using Continuous Epidural Infusion	(2 pages)	\$.70
	M010	The Primary Erythromelalgia-suseceptability Gene is Located on Chromosome 2q31-32 2	(6 pages)	\$1.20
	M011	Erythromelalgia Caused by Platelet-Mediated Arteriolar Inflammation and Thrombosis in Thrombocythemia.	(6 pages)	\$1.20
	M012	Histopathology of Erythromelalgia in Thrombocythemia	(10 pages)	\$2.00
	M013	Pathological C-fibres in patients with a chronic painful condition.	(1 page)	\$.70
	M014	Prevention and treatment of thrombotic complications in essential thrombocythaemia: efficacy and safety of aspirin	(6 pages)	\$1.20
	P003	Lynnwood Woman Hobbled by Chronic Burning Foot Pain,	(3 pages)	\$.70

Mailing Address if different from the address on the order form on page 10:

Name: \_\_\_\_\_

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City: \_\_\_\_\_

State/Province: \_\_\_\_\_

Zip/Postal Code: \_\_\_\_\_

Country: \_\_\_\_\_

Total Documents ordered	
Sub-Total	
Non-TEA Member Charge*	\$5.00
Total**	

\*NOTE: If you are not a member of TEA, there is a service charge of \$5.00 for each order.

\*\*Total may be adjusted if shipped outside the U.S.

**Make Checks payable to TEA.**