

FootSteps...TOWARDS PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia
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Extra! Extra! TEA Holds First Elections!

January brought the first official election of Directors for TEA. For the first time since TEA's inception, all it's members were sent ballots and asked for their vote to establish the 2001-2003 Board of Directors. Many members returned their votes, and even included some kind words about their thoughts of our organization. It was great to hear from those folks, and receive suggestions and compliments.

The new Board of Directors and Officers are as follows:

President - Lennia Machen
Vice President - Wendy Baker
Secretary/Treasurer - Milt LeCouteur
Medical Consultant - Dr. Jay Cohen
Board Members: Karl Granat, Nancy Mabry,
Dr. James Read, Ray Salza, and Amy The

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In addition to the officer positions being filled, several new committees have been formed, with chairpersons ready to begin. There are many openings for helpers to these new committees and we welcome you to contact us if you see a spot that you would like to fill. We are always looking for folks with experience that would like to share ideas and tips with us, even if you would not be interested in serving on a committee. If you are interested in serving, our job requirements include: having a positive and enthusiastic attitude to want to be a team player and being committed to helping others. You may contact me, FootSteps Editor, if you are interested, and I will put you in touch with the appropriate committee chairperson.

Member Relations - Wendy Baker
Publicity - Nancy Mabry
Fund Raising - Ray Salza
New Contacts - Karl Granat
List Server Liaisons - Dr. Jim Read and Amy The

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 December 2000. This brings our membership to nearly 100 members.

And, on this occasion, we would like to extend a great big hug of a welcome to them all!

Arlene Gronet, Lawrence Batlan, Jane Allison, Mae Coover, Isabelle Davis, Tom Roe, Jim and Joseph Lubitz, Margaret Edelson, Francine Monseu, Rachel Burkhart, Ann Haller, Marilyn Darnell, Pat LeVasseur, Joy Ward, Charles Bradley, Phyllis Wilson, Anita Woods, Herman Weber, Keith Bennett, Furman Mayberry

Welcome! We're glad you've joined us!!



Hope of Remission?.. It's worth it!

by Karl Granat & Wendy Baker

...At least it was for one of our members, Marilyn Collins. After fighting erythromelalgia for years, of which the last three or four had left her bedridden with her feet and legs on a cooling blanket and fans cooling non-stop, Marilyn is now in a total remission!

Last July Marilyn traveled to the Mayo Clinic to find a reason for her EM. They found that she had Hemochromatosis, a disorder in which the body absorbs too much iron from food. (Normally excess iron is expelled. With Hemochromatosis, the excess iron is stored throughout the body, including pancreas, liver, joints, muscles, skin, heart, etc. The accumulative iron deposits can cause damage to these organs and tissues over time.) As the treatments began for the Hemochromatosis, which includes having her blood drawn, her EM improved. This was an interesting development, yet, she still had enough EM to leave her in great pain. Her doctor prescribed an infusion pump to be implanted into her spine for administering Ziconitron, a drug derived from a poisonous snail. This treatment greatly helped with the pain. ...but there's more ...

Battling other symptoms, like low blood pressure, along with the EM and Hemochromatosis, Marilyn's doctor was reluctant to allow her to take other medications, but allowed her to take Magnesium, at 800 mg a day, ...and the results were incredible! She shortly found the EM to have retreated into a complete remission. Something we all dream of...

Marilyn is back on her feet again and experiencing great relief from many extreme symptoms since her treatment of the Hemochromatosis, and EM began. What a true blessing it is to hear about an EM case of such severity retreating into remission. Our congratulations and cheers of encouragement go to Marilyn and her family as she continues to heal and mend, and regain her life style without the burdens of such pain. We can all surely empathize with the devastating effects that being debilitated causes for our families and our own lives, and we know having the courage to pursue further treatments is not easy either. It's unfortunate that one type of treatment does not work for all of us, yet incredible that something as simple as Magnesium can work for even a few! It renews our commitment to seeking a treatment that may work for each of us.

Contributing Just Got Easier!

by Nancy Mabry

We now have available to us, thanks to the hard work of Ray Salza, another option for paying our TEA Membership Dues or Research Fund Donations. We think you will agree that this method will make "doing your part" much easier! TEA has registered with Helping.org to be able to receive funds electronically, and without fees or charges for the service. This unique concept is a great way to help non-profit organizations like ours, become more easily accessible to our members.

The benefits and features of using this option are:

1. You may use your VISA or Mastercard.
2. Your donation (100% of it) goes directly to TEA.
3. Helping.org will send you a receipt via e-mail that can be used with your tax records.
4. Helping.org is safe, secure and private.
5. Helping.org offers several donation options: You may specify the purpose of your donation (research fund, dues, etc.), you may donate anonymously, or you may specify that the donation is "on behalf" of on "in memory of" someone.

Beginning April 1, 2001, you may make your payments/donations by simply following the instructions below.

1. Go to "<http://www.helping.org>"
2. Enter the word: "erythromelalgia" into the search box.
3. The Erythromelalgia/Erythralgia Association name will be displayed. Click on the name.
4. Information about TEA will be displayed. Click on the nearby "Donate Now" button.
5. Fill out the donation form with your personal and credit card information. Click "Submit."

All done!!.... It's that easy! We hope this helps make the process easier.

A Letter from the President...

"It's official! We have begun our third year as the leading source for information about erythromelalgia. It's time to celebrate!.. ah, but not so fast... along with all the pats on the back and the excitement of being a part of this important organization comes some very serious thoughts.

First, we must remember and recognize why TEA was founded those short two years ago. One reason was to ensure that the existing educational information about EM would always have a way to be available to those searching for it. Another reason was to promote, and further, more current and accurate information to be created and made available by use of our collective experiences. Yet another reason was to promote and facilitate communication between the ones afflicted with, or associated with, the condition of erythromelalgia.

Therefore, it's at a turning point such as this that we need to ask ourselves if we are doing what we set out to do. As we each ponder our parts in these goals and objectives, we also need to examine what more can be done. And isn't this the really hard part of any association such as this?... Asking ourselves "what more can I do?" It's a particularly poignant question when the answers are not so cut and dried.

Along with the examination of our original mission, it's goals and objectives, comes our look towards the future. And for us, it's here that we need to focus our attention for this coming year.

Currently, TEA is operating in the black when it comes to it's daily operations and expenses. (And, for those of us who have been in this from the start, that in itself is a blessing. Thank you Milt!) But TEA is not in the black when it comes to the last, and most important frontier, yet to be seriously challenged... that of raising funds for research. In that department, I reluctantly can say we are in the "red." With a minimum of \$50,000 needed just to begin a dedicated research project with NORD* (National Organization of Rare Disorders), we are just to the half way mark. And the really tricky part about this "watermark level" is... it's a moving target! As time passes the mark rises along with the costs of research. Therefore, it's easy to see that even if we were to continue as we have been, gratefully accepting the occasional donation, we would never quite reach the mark. And that's a truly tragic thought.

That is why it is here where we have to look to ourselves and truly ask "what more can I do?" It's at this juncture that we must seriously examine our resources of time and energy to know how we each can best answer this call for help. Can you take a few more hours per month to help on a fund-raising committee? Do you have experience in fund raising that we could be helped by? ...Or, could you take time to hold bake sales, garage sales, or other fund raising activities? Do you have friends or employers that are interested in offering help to this condition you have and would be interested in making a donation? I'd be willing to bet that for most of us the answer is "yes," we do have extra hours or ideas to help find these types of donations, but that you just haven't stepped forward yet. And for those of us that don't have the time, or aren't able, but do have other resources, ...perhaps you would like to make a donation and really hadn't given it much thought until now, or known much about the research funds that are already in place and their intended purposes. Either way, if you can help, in whatever way you are able, we'd love to hear from you (see the pencil at the end of this letter).

This may be where our collective resources and experiences may truly be put to work. It's time to think of our research needs as a task that needs to be undertaken, not just a wish for someone with extra money to come along and bail us all out. Instead, We need to find that help and start getting the work done. This won't be easy, and it will take all of our efforts, but the pay-off will be spectacular. Just imagine it... no more erythromelalgia? If our research project were to produce either an effective therapy, a known cause for the condition, or a cure, can you imagine how your own life would change? And what about all those other sufferers out there? This could be an important contribution that we can be a part of, all for only giving a small share of our time or resources.

So, is this the hardest part of the journey? The first step? If so, let me be one of the first to put my foot forward and pledge those few hours each month towards our research fund drive. Won't you all consider joining me on this journey? There are many openings... But let's make 2001 our year to meet our research goal.
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As TEA grows and evolves it's wonderful to watch the progress and hurdles we have passed so far. Like Dr. Jay's great article seeing publication, the discovery of magnesium being so helpful to some, and the upcoming chance of membership into NORD, to name a few. There's no doubt that the talents and dedication of the membership of TEA has been effective in making progress towards an improvement in life for those with erythromelalgia. So let us take up the challenge to continue making life affecting improvements to those with erythromelalgia and start out our third year with the enthusiasm and commitment to embrace our mission wholeheartedly, and to strive to meet or even exceed those goals we set. Let's make it happen!

Thank you for taking the time to read my annual "State of TEA" address. As the first full term of TEA's officers passes, it's an interesting time to be pondering what this next term will bring. I'm looking forward to being a part of the new board of directors and beginning work towards our goals. Unfortunately, because of the great spaces between us all, we cannot physically meet to discuss your ideas and visions, but I invite you to take the opportunity to bring them forward for us to discuss at this time. Along with handling the normal business items at hand, these next few weeks are a good time to initiate communication on these new thoughts and topics... so let's hear them... I've had the opportunity to voice my thoughts, now it's your turn! So come on, Send 'em in! I'd really love to hear from you!"

Sincerely,
Lennia J. Machen
President of The Erythromelalgia Association



Address:
Lennia J. Machen
C/o The Erythromelalgia Association
4343 Roosevelt Way, NE #305
Seattle, WA 98105

We've Lost Some Dear Friends

On February 19, 2001, Ben Goble passed away. Ben was an avid supporter of TEA and we will truly miss his input and helpfulness. We were informed by his son that Ben died due to pneumonia and was surrounded by his loving family at the time of death.

On December 12, 2000, Audrey Schwartz died from a possible stroke. Audrey was a very generous member of TEA through her daughter, Marianne, and will be truly missed.

Our prayers and best wishes go out to those families of our two past members for healing and fond memories to replace this time of sadness and loss.



Hot Flashes!..."hot tips" and news items just for us

FLU VACCINES: Consult your doctor BEFORE getting any flu shots! Sorry this news item comes too late for this year's flu season, but we have just heard about the possible dangers in getting flu shots. There is a low possibility that some flu vaccines are contributors to neuropathy problems... and erythromelalgia can be connected to these diseases, particularly Peripheral Neuropathy, or CIDP. So, just to be safe, check with your EM doctor before getting any vaccines, make a note of it for winter!

DR. JAY DOES IT AGAIN! Congratulations to Dr. Jay Cohen for his recent publishing of 2 articles on Viagra.

MEMBERSHIP DUES ARE DUE: A lot of our TEA members renew their yearly membership dues at this time of the year, so if you are one of those Spring-Time Friends... It's Spring! so,...send 'em in! The fee is still \$15 per year and can be paid by check, money order, or by using our new credit card service through "helping.org."

RESEARCH FUND IS GROWING! The past few months have been very good for our research fund. A lot of our dear TEA friends have donated generous gifts to the fund. Although we are still a long way from being ready to start a project, we are certainly inching our way up to meeting the goal. Let's continue to keep those dollars compounding, every bit helps.

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More Hot Flashes!...

USING THE EM-yahogroups ARCHIVES: Have you even wondered how to use the archives for the EM group? If you are a member of the yahogroups list, here's some simple directions to help you in your search for information:

1. Go to: <http://www.yahogroups.com> and "sign in" using your user ID and password.
 2. After signing in, you should see "EM" listed on the left side of the screen under the "MY GROUPS" title.
 3. Click on the "EM" and the next screen will be the EM page.
 4. On the left side there's a list of the possible features for you to use. Click on the "SEARCH ARCHIVES" title. After the screen changes, enter the topic you would like to search for. Cool, huh?
- See the online version of FootSteps for some other helpful tips on using the yahogroups list server.

LIGHTEN UPI Since it's common that increased amounts of stress makes the EM flare up, we thought you might enjoy some humor in this month's FootSteps... hope you enjoy! (submitted by Wendy Baker)

"Eye Halve a Spelling Chequer"

Eye halve a spelling chequer
 It came with my pea sea
 It plainly marques four my revue
 Miss steaks eye kin knot sea.

Eye strike a key and type a word
 And weight four it two say
 Weather eye am wrong oar write
 It shows me strait a weigh.

As soon as a mist ache is maid
 It nose bee fore two long
 And eye can put the error rite
 Its rarely ever wrong.

Eye have run this poem threw it
 I am shore your pleased two no
 Its letter perfect in it's weigh
 My chequer tolled me sew.

- Sauce unknown



..so, until next time,
 Take one "FootStep" at a time, and you're sure to make progress!



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