

## The Time is NOW!

There's never been a more important time to consider a donation to the research of erythromelalgia. Our T.E.A. Secretary/Treasurer, Milt LeCouteur, reports that we now have \$22,612 put aside for research (combined amounts from our NORD account as well as our dedicated T.E.A. account). While this effort has been very impressive so far, we need to continue to build onto that amount in order to reach our goal of \$35,000 by the end of 2001. (Which marks a three year effort to raise the needed funds.) While the strides towards a clearer understanding about effective treatments for EM have been great this past year, we are still a long way from understanding causes and cures for this condition. Lets face it, we really need to know more... and we surely cannot expect to meet this challenge sitting down and waiting. It's time to take action! We need to reach out and ask those around us to help out with their contributions. Neighbors, family, employers, friends... all can be assured that our organization is a non-profit organization, making their donation fully tax deductible. We just can't do it alone, we need everyone's help!

Donations can be made directly to the research fund for erythromelalgia at the National Organization for Rare Disorders (N.O.R.D.) at: N.O.R.D. P.O. Box 8923 New Fairfield, CT 06812-8923. N.O.R.D. can also be reached at:<http://www.rarediseases.org> Donations to the dedicated T.E.A. research account can be made at: The Erythromelalgia Association 4343 Roosevelt Way NE #305 Seattle, WA 98105 (Be sure to clearly state that it's towards the erythromelalgia research fund).

## T.E.A. Board Member Publishes Article about EM

Dr. Jay Cohen has had an article published in the Journal of the American Academy of Dermatology. The wheels of progress turn slowly sometimes, ...and with much elbow grease. Such is the case in getting an article published in a medical journal, especially one of such high notoriety as this one. The full article can be found by looking in the TEA library for: Erythromelalgia: New theories and new therapies. Following is an abstract for the article:

***Erythromelalgia: New theories and new therapies, by Jay S. Cohen, MD LaJolla, California.*** *Erythromelalgia is a rare condition that has remained an enigma diagnostically and therapeutically for decades. It has been assumed that erythromelalgia, which is characterized by hot, red, intensely painful feet or hands, may be the opposite of Raynaud's phenomenon. However, new research suggests that these two disorders are more similar than dissimilar. Erythromelalgia usually follows a chronic, sometimes progressive and disabling course. New evidence suggests that this may not be a disease entity at all, but a*

*syndrome of dysfunctional vascular dynamics; recent studies demonstrate that this dysfunction is reversible in some patients. This review article presents the latest theories and successful treatments for erythromelalgia, and data from a survey of members of The Erythromelalgia Association, which was formed to provide information about erythromelalgia to doctors and patients. (J Am Acad Dermatol 2000;43:841-7.)*

## Happy Anniverssay T.E.A.

We're two years old on January 20, 2001! My, how time flies when you're among good friends and caring people who share such a special understanding. To those of us on the Board of Directors, we all have enjoyed being involved in this young, and growing, organization. But with time passing, so things must change. "Two years old" means a time to celebrate, and a time to elect new board members. While some of our current members have chosen to step back and allow for new directors to take their seat, others have chosen to remain. All T.E.A. members will receive a ballot asking for them to vote for the new board members, during the month of December. This is the very first time we have held an election and the process is very new to us all on the board. But rest assured, we will not be holding any recounts looking for dimpled chads! We'll gladly leave such tedious tasks to the politicians. However, we will be counting each ballot as we receive it, and your help is needed to make sure that they are returned promptly. So, congratulations, T.E.A. members! You are the first members taking part in our first election... and we surely wouldn't be having one without your continued and appreciated support.

## 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 September 1st, 2000. This brings our membership to 73 members. And, on this occasion, we would like to extend a great big hug of a welcome to them all!

Beth Coimbra, Wilene Domenichelli, Barbara Salinas, Patricia McEown, Malisa Matheny, Dylan Gonslaves, Terry & Suzanne Porter, Geneva Ray, Margerie Wells, Ben Goble, Marsha Turney, Lisa Ramey, Herbert Mansmann, M.D., Laura Mooney, Mimosa Low, Elaine Blanchette, Marilyn Wade, Patricia Rusch, John Allen, Barbara Loeffler, Betty Bowen, Jane Faraca, Lex Trelford, Lisa Hellesis

## Taking a Step Up

TEA is taking a step up and applying for National Organizational Membership with the National Organization of Rare Disorders (NORD). For those who are not familiar with this organization, they are "the only organization of it's kind-a unique federation of more than 140 not-for-profit voluntary health organizations serving people with rare disorders and disabilities. Thousands of affected individuals and their families-as well as support groups, health care and human service professionals, and advocates for people with rare disorders and disabilities-rely on NORD's

assistance and leadership. NORD is a charity and continues its mission through the kindness and generosity of its donors" ([NORD, www.rarediseases.org](http://www.rarediseases.org)). Please visit their web site and learn more about this very helpful and supportive organization. As a National Organizational Member of NORD, TEA will be clearly identified within NORD publications, website links, etc., as the nationally recognized support organization for erythromelalgia. Other benefits of NORD membership include having voting rights within NORD and receiving technical assistance and consultation from NORD on TEA growth and development. If you have more questions about the membership application process please contact us (T.E.A.) and we can "fill in the blanks" about the project.