FootSteps...

TOWARDS PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia Volume 5, Issue 2, June 2004, Published by The Erythromelalgia Association

"A Hollywood Celebration" Raises \$16,000

By Sarah Sundstrom, TEA Fund Raising Chairperson and Auction Organizer

The first fundraising event ever held to benefit The Erythromelalgia Association was a resounding success. With 118 people in attendance, more than \$16,000 was raised, reports Sarah Sundstrom, TEA Fundraising Chairperson and the event's coordinator.

"We far exceeded my original goal of \$10,000," says Sundstrom, who worked tirelessly for months acquiring the donated items for auction, producing a video about erythromelalgia and TEA, and making arrangements for the event itself.

"A Hollywood Celebration," held June 13, 2004, at Club Hollywood in North Seattle, began with a silent auction that garnered nearly \$6,200 from the 100 items sold. Games, including Shooting for the Stars, Wine Toss, and a special raffle, brought in another \$1,200 early in the evening.

Attendees paid \$30 a plate for a dinner of Miso soup, salmon or chicken stir-fry, spring rolls, and sushi. Club Hollywood charged



Sarah Sundstom and Gayla Kanaster

TEA just \$10 per person for each meal allowing TEA to keep the difference and further increase the funds raised.

"Club Hollywood provided a great meal at a very low price to our organization," said Sundstrom, who introduced herself after dinner and thanked everyone for supporting TEA by attending. She also recognized the ten TEA members in the group and invited them to stand. Attendees then watched the newly created video, learning much about the rare disease and TEA.

Guest auctioneer Dave Mahler, a Seattle radio personality, took over and conducted the live auction, which raised another approximately \$6,150.00 for TEA. Using his engaging sense of humor and talent, he was successful in encouraging the crowd to bid generously for the 16 live auction items. The three most lucrative live auction items—a Pepsi Vending Machine, four tickets to the Mariners vs. Yankees baseball game with a \$100 gift certificate to a well know restaurant near the stadium, and a \$100 gift certificate to a wonderful seafood restaurant in Seattle combined with a limousine ride and a baby sitter for the evening-brought in almost \$2,000.

"I would like to extend a heartfelt 'thank you' to all who sent monetary donations, those



Beverly Taylor, Marie Materi, Lori Stout

who donated auction items (especially Willene Dominichelli who was able to donate three cases of wine for the auction, members of TEA's Board of Directors, and to all others who supported the auction. Those of us who suffer daily with EM truly appreciate your generosity and giving spirit to further our goal of supporting EM research. Because of you, we are a step closer to our goal of seeing relief from EM," Sundstrom says.



Milt LeCouteur, Judy Reese, Gayla Kanaster

EM Survey Results

By Lennia Machen with data provided by Beth Coimbra

The results are in, the numbers tallied, and TEA is proud to report the following summary of data collected from the EM Survey conducted earlier this year. Almost half of our members—222—took the time to fill out and return the questionnaire. Spreadsheets of the complete results may be obtained from the web site library or from Networking Program Administrator Judy Reese.

These results were shared with our Medical Advisory Committee at the recent conference in Norway. The physicians were most impressed with our active participation in creating this survey and by how many responded.

The data collected fit into 5 categories: Personal Statistics, Diagnosis, Symptoms, Treatments, and Emotional Support.

Personal Statistics

Of the 222 respondents, 53 were males, and 169 were females. Most (173) live in the US, while 27 are from the UK; 6 from Canada; 5 from Australia; and 2 from Germany. We received one reply from each of the following countries: Belgium, Denmark, Holland, Japan, Mexico, New Zealand, Norway, and South Africa. Most of the respondents were over 40 when first diagnosed with EM— 36 of the respondents were over 70 years old; 80 were over 60; and 91 between 40 and 60. Just 36 respondents were between 20 and 40 years old and just 7 were under 20 when diagnosed. Many (161) of those who responded would participate in EM research.

Diagnosis

In general, survey results show that EM is a rare disorder that many physicians have never seen. Consequently, patients often have difficulty getting a diagnosis and receiving appropriate treatment. The majority of respondents (124) report being diagnosed within the last 4 years, while 69 received their diagnosis in the 1990s. Only 14 were diagnosed

the 1980s; 5 before 1970; and 10 respondents have not yet been diagnosed

Dermatologists made the diagnosis of EM for 59 respondents. But 45 people reported that a rheumatology specialist diagnosed their EM; 35 said a neurologist; 17 a vascular specialist; 16 a general practitioner; 14 an internist; 12 a foot specialist (podiatrist); and 8 were self diagnosed. Pain specialists, hematologists, oncologists, cardiologists, and gynecologists, the team at Mayo Clinic, and even an allergist, endocrinologist, and a nutritionist recognized EM and diagnosed 5 or fewer of the respondents.

The majority of respondents experienced the same sort of quest for a diagnosis—seeing a number of doctors who did not diagnosis EM. Most (91) saw general practitioners; 60 saw neurologists; 50 dermatologists; and 47 rheumatologists, all without success. For the entire list, please consult the spreadsheets.

Of the 222 respondents, just 33 have no other diseases or conditions; 25 have hypertension; 21 Raynaud's syndrome; and 12 peripheral neuropathy. For the rest of the list, please consult the spreadsheets.

The majority of respondents, 156, have no other relatives with EM, while 5 have a father with EM and 16 have a mother with EM. Just 6 have a brother with EM; 8 a sister with EM; and 7 have a son or daughter with EM. 16 have relatives with EM who are not members of their immediate families.

Symptoms

By and large, survey respondents reported symptoms that are the hall-marks of EM. They also verified that EM has a negative effect on their lives because the symptoms limit their ability to engage in many activities of daily living, including walking, standing, and exercising. Most people with EM share the same challenges in living with this disease.

Not surprisingly, almost all (209) of respondents have EM affecting their feet. Another

27 have symptoms of EM on their lower legs; 21 their knees; 10 their thighs; and 9 have symptoms on their ankles. Almost half (119) also have EM on the hands; 8 their arms; 8 their backs; 8 their necks; and 7 on their trunks. Quite a few (88) have EM symptoms that affect their faces and other parts of their bodies, including 32 with symptoms on their ears; 9 their noses; and 5 their scalps. Just 4 people report having EM-like symptoms only on their faces.

Most of the respondents suffer symptoms that flare frequently; 63 members reported continuous flaring, while 21 suffer 6 or more attacks per day; 54 have 3-4 attacks per day; and 49 have 1-2 per day. Just 27 have fewer than one attack per day and 27 members suffer attacks on a once per week to once per month basis. The duration of flaring is greater than 6 hours for 68 members, while 28 have flares lasting 4-6 hours. Another 65 respondents have flares lasting 2-3 hours, and 41 have flares that last 1-2 hours.

Respondents were asked to report the severity of their pain on a scale from 1 to 5 with a score of 5 being excruciating pain and 1 being mild. 28 respondents rate their pain at 4.5 to 5; 69 score of 5 being excruciating pain and 1 being mild. 28 respondents rate their pain at 4.5 to 5; 69 score their pain between 3.5 and 4; 74 between 2.5 to 3; and 36 rate theirs at just 1.5 and 2 on the scale. Rating their pain between 0 and 1, just 10 people have mild pain or none at all. Almost all (201) experience "burning pain" that is aggravated by warmth (206) and relieved by cooling (204). 164 experience skin that is hot to the touch with burning pain. For (Continued on page 5)

First TEA-MAC Meeting A Big Success

By Lennia J. Machen

TEA's Medical Advisory Committee held it's first face-to-face meeting on June 7 through 10 in Oslo, Norway. Present at the meeting were three MAC members: Dr. Knut Kvernebo, Dr. Cato Mørk, and Dr. Mark Davis. I also attended representing TEA.

As this was the first live meeting, many items constituted the agenda including the MAC's purpose and relationship to TEA, a consensus document on EM, the classification of EM, medical treatments of EM, new suggestions for TEA, future projects and issues, as well as plans for future meetings.

The MAC examined its goals and purpose and decided to remain a small advisory committee for now, look into expansion and look into the possibility of holding live conferences in the future, open to all doctors., the MAC members, and possibly patients. The MAC will continue to address issues brought to their attention by TEA as well as continue looking further into questions surrounding EM.

One request is that we to continue to respect them and not contact these physicians outside of regular processes to become a patient. Our MAC doctors are <u>not</u> online or on-call doctors to TEA members. (Your continued respect for them is appreciated. If you are interested in becoming a patient, please go through normal channels and contact their office scheduling clerks.)

The main issue of this meeting was the creation of a consensus document to finitely describe EM. The nomenclature, etiology, definition, severity ratings, and basic hypothesis of what causes EM were all well discussed. It is planned that a conclusive document will be constructed over time that will reflect several different MAC views. It is the hope of the MAC to reach consensus on these important details in-

volved in understanding EM, as this would be the first time such a consensus has ever been reached. The MAC will edit and write this dynamic document and post it on the TEA web site as it develops.

The classification of EM is another task the MAC will take on. Presently, EM is classified as "other neurological condition" in the IDC coding system. The MAC plans to examine this classification and make any needed changes.



Dr. Cato Mørk, Lennia Machen, Dr. Mark Davis, and Dr. Knut Kvernebo

Effective EM treatment is of high concern for all of us, and it is for the MAC as well. While there are many ineffective treatments, some remain more widely used than ever. The application of ice or cooling to the affected extremity, which is one of the worst. Icing is very dangerous due to the high probability of self-inflicting cold damage to the skin tissues and capillaries. While the application of ice or cooling may provide a temporary feeling of relief, those using ice may be inadvertently causing their EM to go from the acute stage to a chronic one without noticing the vicious cycle of dilation of the blood vessels followed by vaso-constriction that is caused by extreme temperature changes. It was strongly recommended by the MAC that TEA spread the word to EM sufferers to stop the practice of applying ice or other cooling devices and seek help from their doctors to find other treatments.

One treatment discussed was the IV administered medicine of PGE1. This is one of the most effective treatments for those with severe cases. While it is not available in the US, it is available in many other countries. In the US, an oral type of prostaglandin is available, called Cytotec or misoprostol. Any treatment should be well discussed with your doctor and all risks and side effects know by the patient.

The MAC discussed the possibility of EM being present when the patient only has redness on the face and no other area. They believe it is highly unlikely. Red-face syndrome is a very difficult condition to accurately diagnose. A patient may have EM-like symptoms, but not actually have EM as the mechanisms of the face versus the extremities are so vastly different.

The MAC also asked TEA to create a Physicians' Area on the TEA web site to post article abstracts, and other documents helpful to physicians which the MAC will maintain.

In the future, it is planned to meet live again and continue with discussions on many topics and items. The more meetings, the faster we will come to decisions on classifications, treatments, and other important topics. The MAC is going forward with research and projects and will keep in contact with TEA regularly.

In conclusion, much was accomplished and meeting face-to-face was a vital step towards future work and discoveries concerning EM. Thanks to those who generously donated money to support the live meeting. This fund will be continued for future meetings.

For more information the MAC meetings, contact TEA Member Services.

Member's Corner... where your stuff gets printed!



New Articles in the Library

New documents are available in the TEA Library. The recent report by Cato Mork, MD, PhD, is now available under the title: "Erythromelalgia: Studies on Pathogenesis and Therapy," the complete data spread sheets (results) of the TEA 2004 Survey of EM patients, are also now in the article library.

If you would like copies of these documents mailed to you, please consult the order form at the back of this newsletter or contact our Networking Program Administrator Judy Reese for costs and charges.

These and many more documents are also available online in the Member's section at www.erythromelalgia.org.

Members Encouraged To Host Events

TEA encourages members to help raise funds for research by hosting and organizing events. If you are interested in learning more about how you can help TEA raise funds for research, contact Sarah Sundstrom, TEA Fund Raising Chairperson. Sarah recently organized the successful auction held in Seattle, Washington, raising over \$16,000 for the fund. Sarah has many good ideas and suggestion for all types of events including tag sales, bake sales, auctions, among many others.

TEA is not able to host each event, but will do its best to help with information and printed materials to help your event be a great success.

Editorial Notes from Oslo By Lennia Machen

During the trip to Oslo and meeting with the MAC, I had the rare opportunity to be in the presence of many doctors who not only could spell "erythromelalgia" but who actually knew what EM was and had participated in studies about EM. What a rare and exciting event.

Realizing the valuable opportunity the MAC meeting presented, I used this time to talk to these doctors about our organization and ask them about some of the more challenging problems our organization faces like effective EM treatments and the direction for TEA's future in research.

During these conversations I realized there are many hospitals and clinics who are already conducting valuable research into EM, like the hospital in Oslo.

While EM research is happening without the financial support of TEA, the outcomes of these projects may need more promotion in order to educate our physicians. This may be an area that TEA might realistically contribute to.

It has always been the goal of TEA to fund and promote EM research, and though we have been planning for the funding of

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Contact the TEA Library and learn how you can be a contributor to the growing library of articles about EM. Contact Member Services, or TEAwebmaster

@erythromelalgia.org

an actual TEA project, we have not really looked into just the promotional part of EM research.

I asked myself, why not fund the trips to conferences for doctors like Cato Mørk to present his findings to a conference of appropriate specialists? This is an area that the hospitals and clinics may not presently support but can possibly cause EM to become a more discussed and notable condition. Wouldn't this ultimately help TEA reach our goals of EM education, and awareness? Wouldn't this help assure that our doctors and medical schools learn more about EM such as what is a good treatment, and what is not? Perhaps this new attention to EM may generate interest from some of the larger pharmaceutical companies and spark interest into new medications for EM.

TEA might realistically promote existing findings along with our other research goals, and become an important part of the process of educating our doctors. After all, what good is the research if it never gets promoted and publicized? Perhaps this is an important niche that TEA can afford to fill.

As this is simply the start of an ambitious idea and only my own thoughts at this point, I welcome your ideas and suggestions as well. If you have some creative and new thoughts on how best to reach the goals and objectives set out by TEA, please contact me. Your opinions and views truly matter.

The views in the above editorial are not necessarily those of the TEA Board of Directors or members.

EM Survey (Continued., page 2)

more complete results, consult the spreadsheets.

When asked what activities were limited by EM, 172 reported their walking is limited, and another 172 said EM limits sleeping. EM also limits exercising for 164 members; standing for 156; sitting with their legs dependent for 141. Respondents reported that EM limits their socializing (139), working (117), cleaning (104), cooking (100), driving (87), and sexual activities (65). Others mentioned eating hot or spicy foods, gardening, travel, knitting, and "everything" as being limited by their EM.

Treatments

This category is difficult to summarize, and the spread sheet is shown below. Members were asked what treatments they used, which were effective,, and which did nothing or made the EM asked what treatments they used, which were effective,, and which did nothing or made the EM worse. Gabapentin remains the most used and effective medication. Effexor is also fairly effective, while aspirin is somewhat effective. A number of other treatments were disclosed by participants and are reflected on the complete spreadsheet.

Emotional Support

Most respondents (158) would recommend that others with EM join TEA, while only one said he or she

would not. Many of the respondents (74) said that joining TEA provided "good" emotional support, while 80 felt it was "somewhat good." 94 felt the medical support from TEA was "good," while 46 members felt it was "somewhat good." We also asked respondents to tell us about other support groups like *EMyahoogroup*, *EM Chat*, the *Red Hots*, and NORD, and fewer than 10 told us they would recommend these other groups or that they provided "good" or "somewhat good" support.

If you would like a complete copy of the results, please contact the Networking Program. (See contact information on page 7.)

Medication/Therapy	# Used	Complete Relief	Moder- ate Relief	Mini- mum Relief	No Relief	EM Wors- ened	Dosages Reported
Amitriptyline (Elavil)	82		17	16	43	5	10mg - 75mg /day
Antihistimines	43		9	8	26		
Aspirin	128	4	17	22	78	6	81mg - 650mg /day
Carbamazepine (Tegretol)	22		5		13	4	100mg 2/day, 75mg 1/day
Clonazepam (Klonopin;Rivotril)	16		3	3	9	1	.5mg - 50mg / day
Cyproheptadine (Periactin)	16		2	3	9	2	1.6mg - 8mg up to 3/day
Diltiazem (Tiazac, Cardizem)	43	2	4	3	17	17	10mg-2/day to 30mg 3/day
Venlsfaxine (Effexor)	50		16	8	21	5	75mg 2/day to 300mg 1/day
Fluoxetine (Prozac)	16		3	2	9	2	10mg 1/day to 60mg 1/day
Fluboxamine (Luvox)	4		1		3		1300mg 1/day to 250mg 1/day
Gabapentin (Neurontin)	129	7	48	22	39	11	100mg 3/day to 3600mg/day
Imipramine (Praminil, Trafanil, Janimine)	11	1	2	1	5	2	10mg 2/day to 100 mg 3/day
Magnesium	75	2	10	17	34	12	200mg 1/day up to 2000mg/day
Misoprostol (Cytotec)	9		1	1	5	2	
Nortriptyline (Aventil)	18	1		7	8	2	10mg 1/day to 125mg 1/day
Norvasc (Amlodipine)	23		4	4	6	9	.25mg 1/day to 50mg 2/day
Opiates - oral	32	2	16	4	8	2	varied depending on medication
Paroxetine (Paxil)	28	2	5	6	14	2	5mg 3/day to 40mg 1/day
Pentoxifylline (Trental)	24		1	5	14	1	300mg 3/day to 400mg 4/day
Phenoxybenamine (Dibenzyline)	3		1		1	1	10mg 2/day
Midodrin (Proamitine)	1			1			5mg 3/day
Propanolol (Inderal)	41	2	6	24	4		10mg 1/day to 120mg 2/day
Sertraline (Zoloft)	24	1	4	6	9	4	20mg 1/dat to 150mg 1/day
Tramadol (Ultram)	30		4	10	14	2	50mg 1/day to 100mg 3/day
OTC Capsaicin Cream	44		1	4	8	31	.75mg 2/day to 45mg 4/day
EMLA Cream	11			4	5	2	2 - 3 times per day
Doxepin Cream	5			3	2		2 - 3 times per day
Other Topicals	5	1	1	1	1	1	most popular - lidocaine patch
Morphine Pump	5	2	2		1		10mg 2/day to 10mg continuous
Spinal Cord Stimulator	10		1	3	6	1	
Acupuncture	60	2	5	6	39	8	2 treatments to 34 treatments
Biofeedback	25		2	7	51	1	3 months of therapy
Hypnosis	15			2	13		
Magnets	26			3	18	5	

Your Stories... and <u>everyone</u> has one!

TEA has asked its members to write brief stories about their EM or daily lives, and we would love to hear your story too! Many of you have already written, and we thank you for your effort and time in doing so. We all enjoy getting to know our fellow members and learning what they have done to live with their EM. This valuable information helps us all. If you feel you are not a writer—never fear—

we will be happy to help you write or edit your story.

Please send them to Gayla Kanaster, 2556 W. 234th St., Torrance, CA 90505, USA or gaylakanaster@aol.com

"A Hollywood Celebration" - My view, by Gayla Kanaster

When we first entered Club Hollywood for the TEA Fund-Raising Auction-Dinner we were in awe of everything going on around us. After checking in at the desk, manned by Michelle Sundstrom, Sarah's sister-in-law, and volunteer Heather Becker, we were each given a program, a table assignment and a number to use for the silent auction.

We then had to decide what to do first: "Shooting for Stars" gave everyone a chance for a prize. For \$5.00 we selected our favorite Hollywood celebrity photo and claimed the prize hiding behind their star. There were some very nice prizes there.

There was a wine toss, a raffle table (manned by TEA Board member from Salt Lake, Judy Reese), long tables laden with the wonderful silent auction items and hundreds of movie star photos on the walls. As we mingled around the waiters constantly checked to see if they could bring drinks—all the soft drinks, teas, fancy lemonades, sodas and a delightful dinner were included in the very reasonable \$30.00 admission.

Writing our numbers instead of names to bid on the silent auction items was a smart move on Sarah's part. After the bidding closed, my daughter Pam and I discovered we were bidding against each other on several items. Most of them were things that I had hoped to get for her and she unknowingly outbid me. We laughed about it and since it was a cause so close to our hearts, we didn't mind a bit.

The video featuring an introduction by TEA President Lennia Machen, a TV interview of Sarah Sundstrom and discussion of their Erythromelalgia problems by members Wendy Durand and Dr. Pamela Costa made quite an impression. The room was totally silent afterward and I believe it made people want to be even more generous in their bidding.

The auctioneer, a local sports radio announcer, was terrific at getting the bids up for the live auction items and desserts, which most people bought to share with their table. Most of the desserts were from donations collected from local bakeries. Also TEA Board Member, Debra Mosarski's Mother, Regina Bayer, made and donated many silent auction items.

It was such a pleasure to have the opportunity to meet other TEA members including one of the founding TEA Board members, Milt LeCouteur, and his lovely wife Jean, Lori Stout, Beverly Taylor, Marie Materi, Wendy Durand, her husband Jim and mother Nancy Rose.

It was amazing to see the wonderful auction items donated thanks to Sarah's hard work and persistence. Not one detail was overlooked to make this a truly successful event enjoyed by everyone who attended. Sarah Sundstrom deserves a huge "thank you" from all of us.

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

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TEA Research Fund Donors



Following is a list of the donors who have given to the Research Fund in the past three months. We thank each one of you for helping us all step that much closer to finding relief from EM.

Jane Allison, Kagehiro Amano, Davis Ballard, Linda Barr*, Helen Bean, Dolores Besch, William Blaha, Mary Burkwall, Mrs. Kate Carless, Elizabeth Chalmers, Benjamin Cohen, Pam Costa*, Doris Cunningham, Cheryl Curtis, Elizabeth Clinton, Janet Dale, Sue Davis, Willene Domenichelli*, Wendy Durand, Meg Edelson, Kimberly Eldred, Teresa English*, Roslyn Evans*, Rebecca Fisher, Tom Francuz*, Debra Frenzel, Jeanne Gossmann, Theresa Hoffman, Judie Huddleston, Kirk Hull, Beth Huston**, Jean Jeffery, Jill Johnston, Gayla Kanaster*, Lucine Kassabian, Barbara Kent, Erma Kipe, Milton LeCouteur, Nancy Mabry, Doris MacDiarmid, Susan Reinecke-Masak, Marie Materi, Furman Mayberry, Michelle McQuade, Mary Stuart-Menteth, William Meurs, Elizabeth Miller, Tillie Miller, Geraldine Montgomery, Irma Ohlenkamp, Hawthorne O'Rourke, Faith Payne, Katherine Pelly**, Phil Pennington*, Stephanie Pratola, William Rennie, Allison Roscoe, Marie Stricker, Joann Stokowski, Nathan Taylor, Shirley Thatcher, Constance Triniane, Polly Vogel, Marilyn Wade, Suzanne Wildman-Chard, Hermann Weber.

*Donors to TEA's "in memory of" and "in honor of" programs.

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

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Member Services: Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109. Or email to: 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

New Members 🧠 😘

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

The following are members that have joined TEA in the past three months.

Charles Allardice, Zev Ancel, Amy Bernardo, Jean Blades, Marten Bootsman, Janet Box, Nina Bunton, Mary Burkwall, Carmen Cantuniari, Jennifer Carlson, Rachel Cassell, Myra Catching, Jeff Clawson, Scott & Cathy Clawson, Benjamin Cohen, Katherine Conklin, Melba Crittenden, Paula Cunningham, Cheryl Curtis, Lillian Costa, Nancy Dardarian, Lucinda Dei Rossi, Cyndie DeRemer, Ciscle Devine, Judith Elsey, Anne Feigin, Lynne Ferguson, Cristin Filipuzzi, Elizabeth Anne Fox, Crystal Freitag, John Goddard, Mary April Groover, Sue Ellen Gruber, Sat Gulati, Beverley Hajri, Neal Henry, Katharine Hooper, Alessandra Iaderosa, Julia Jenkins, Lucine Kassabian, Irving Kennedy, Karen Kimble, Heather Lane, Anwar Lateef, Jannie Lawrence, Peggy Lilleby, Catherine Mack, Anne Marie McCusker, Michelle McQuade, Elizabeth Miller, Mrs. Burton Miner, Charlotte Minto, Muriel Mittwol, Sam Mortlock, Mary Moulton, Rita Moynihan, Kerry Anne Murray, Sheryl Neely, Deirdre Ochipinti, Danielle Pallo, Bina Rajamani M.D., Allison Roscoe, Chris Sanders, Monica Schmidt, Martha Sherin, Marilyn Radin Shindler, Scott Stacks, Marie Stricker, Kathleen Talley, Beverly Taylor, Anita Telford, Diane Tiltman, Constance Triniane, Kelly Vitousek, Harriet Ward, Jana Clawson Ward, Joseph Ward, Neata Williams, James Wise, Nancy Witt, Trisha Yannuzzi.

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

^{**}Donors supporting the MAC Conference

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 with 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.

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Country		(optional) Phone ()_	
(optional) E-mail address		<u>@</u>	
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Prices of copies: 1-5 pages is \$1 6-10 pages is \$.			Member Charge (If you are <u>not</u> a member of TEA, there is a service charge of \$5.00 for each order)	
11-15 is \$3 16-20 is \$4 21-25 is \$5	\$2 extr	ational shipping char a shipping charge t Canada)	rge: International Shipping Charge	
26-30 is \$6 31-35 is \$7 36-40 is \$8	(-11-4)		Total	

TEA Library Articles and Documents Page 1 (new items in bold)

Article #	Title, Author, Date	# Pages	Cost	Order?
M001	Erythromelalgia: New Theories and New Therapies, Jay Cohen, 2000	10	\$2	
M002	Erythromelalgia, Dr. Mark Davis, 2002	14	\$3	
M003	Erythromelalgia: A Clinical Study of 87 Cases, Kalgaard, Seem, Kvernebo, 1997	8	\$2	
M004	Reduced Skin Capillary Density During Attacks of Erythromelalgia Implies Arteriovenous Shunting as Pathogenetic Mechanism, Mork, Kvernebo, Asker, Salerud, 2002	1	\$1	
M005	High-Dose Oral Magnesium Treatment of Chronic Intractable EM, Jay Cohen, 2002	8	\$2	
M006	EM: a condition caused by microvascular arteriouvenous shunting, Kvernebo, 1998	36	\$8	
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