FootSteps *TOWARD PROGRESS*

The newsletter dedicated to finding a better way to live with erythromelalgia
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Yale Scientists Host TEA Board Members

Scientists at Yale University welcomed TEA Vice President Beth Coimbra and Board of Directors member Isabelle Davis March 7, 2005, for lunch and a tour of the Center for Neuroscience and Regeneration Research in West Haven, Conn.

TEA's Board of Directors in November approved donating $60,000 from the TEA Research Fund to support research into primary EM being done at the center. (See "TEA to Help Fund Yale Research in Primary EM," *Footsteps*, December 2004.)

The center's researchers include neuroscientists, molecular biologists, cell biologists, physiologists and pharmacologists all working together toward common goals—one of which is finding new and effective treatment strategies for chronic neuropathic pain (like the pain of EM). With a yearly budget of $2 million and a staff of 40, the center, led by Stephen Waxman, M.D., Ph.D., chair of neurology at the Yale School of Medicine, chief of neurology at Yale New Haven Hospital, and director of the Veterans Affairs Rehabilitation Research Center in West Haven, is a collaborative effort of the Paralyzed Veterans of America, the United Spinal Association, the Department of Veterans Affairs, and Yale University. For more information about the center, go to http://info.med.yale.edu/neurol/pva-epvacenter/facil/facilities1.html

Researchers invited TEA Board of Directors members to visit the center, meet the scientists involved in the EM studies, and see firsthand the extensive, advanced facilities where they work. Dr. Waxman told Coimbra and Davis that partnering with a "grassroots" patient organization has been a "dream" of his.

Gifts like TEA's allow the scientists to be "spontaneous and truly creative," quickly following leads that develop in research without the time-consuming requirements of the grant process. Also, meeting people like Coimbra and Davis, who live with the limitations of EM, helps the scientists see the human side of the diseases their work involves.

In part because of TEA's gift, the scientists have completed a second, larger EM study using DNA from blood collected from more than 25 members of a family in Alabama, Coimbra and Davis learned. (See Powell's Burning Foot Disease, p. 9.) Their findings, which confirm and extend their initial observations, will be made public when they are published in the journal *Brain.*

Their first EM study, published in the *Journal of Neuroscience* in September 2004, provided the first explanation of what happens at the cellular level in the bodies of people with primary EM that causes their pain.

In the future, the researchers told Coimbra and Davis, they want to study other families with primary EM and will request the help of TEA in identifying people willing to donate their blood. (For an in-depth, first-person report of the Yale visit, see "Visiting Yale" by Davis, *Footsteps* editor, p.4. To learn more specifics about the Yale research, see the research story on p.5.)

ALSO IN THIS ISSUE

"Dress Down Day" Brings in $529 for TEA

Hats off to Jane Hrynio of Latham, New York! She's responsible for getting the charitable committee of the New York State United Teachers union (NYSUT) to hold a benefit event, called Dress Down Day, Jan. 7, 2005, with proceeds going to TEA.

Employees pay $3 for the privilege of "dressing down" on specified days, usually once or twice a month. The committee collects the money, which is then donated to a charity.

Ms. Hrynio explains, "I prevailed on a managerial employee of the NYSUT to get [the committee] to look at the EM web site and see if they'd consider a Dress Down Day on behalf of TEA since a person (me) in their building has EM."

Despite an ice/sleet/snow storm on Jan. 7, employees opting for casual dress gave $529 for the privilege. TEA received the check from the NYSUT in late January. Thank you, NYSUT employees, and thank you Jane!

Editor's Note:

If the company you work for sponsors fund-raising activities similar to NYSUT's Dress Down Day, why not follow Jane's example and suggest TEA as the charity to receive funds raised? Or, if no such activity exists, go one step further and suggest to your employer that it create a charitable committee. Maybe a "Dress Down Day" fundraiser wound work for your company.

Board Seeks New Director to Fill Opening

TEA's Board of Directors is seeking a volunteer to fill an open position. Although serving on the board is open to any TEA member, access to e-mail is a requirement as monthly board meetings are held via e-mail.

Deborah Mozarski, board member since 2003, describes what serving on the board means for her: "I joined the TEA board because I wanted to help make a difference for all of us diagnosed with this relentless illness. I find an identity and satisfaction knowing I'm a part of a cause that will ultimately help all of us who suffer. I was seen by Dr. Drenth a few years ago and he mentioned his study of the EM gene. I offered to help him get blood donors. He was happily surprised with how many EM sufferers' names I was able to give him (after checking with the individuals). This gave me a sense of somehow assisting with the progress of much needed research into EM and that felt good."

She continues, "I have been diagnosed with EM for ten years. I had been a flight attendant, an avid runner and ballroom dancer. When I could no longer work or do the things I love, I felt a great loss of identity. For years I continued to tell people I met that I was a flight attendant because . . . I couldn't accept the fact that I could not go back to work. As time went on and my involvement with TEA grew, I have accepted the knowledge that returning to work is not an option for me."

Phone Survey Coming in Late April

Don't hang up! You may receive a call from a TEA representative during the last week of April or the first week of May asking for a few moments of your time to answer some questions. The 2005 TEA Satisfaction Survey will be conducted during that time frame.

A random sample of TEA members will be called to answer questions about *Footsteps*, the web site, and other TEA programs. A number of the questions are open-ended allowing members to explain why they have the opinions they do.

Please say "yes," if someone from TEA calls you, asking if you have "a few minutes for a short survey?"

EM NORD Grant Deadline Nears

Medical researchers with an interest in EM have until April 13, 2005, to let the National Organization for Rare Disorders (NORD) know how they would use a $35,000 grant being funded by TEA.

NORD in January issued a Request for Proposal (RFP) for an EM research study giving researchers until the April deadline to submit a letter of intent and an abstract or summary of their proposed study. The RFP was posted on NORD's web site, advertised in medical journals, mailed to every university-affiliated hospital and medical school in the U.S., and mailed to 5,500 scientists who ask to be notified of all NORD funding opportunities. NORD also sent the RFP to any researcher worldwide who has published studies into EM in the past two to five years and notified research institutes in Europe and Canada.

NORD's Medical Advisory Committee of academic scientific experts will assess the responses to the RFP and select several finalists—using the same peer review system used by the National Institutes of Health. Finalists must then submit full grant applications that will be evaluated before a winner is selected sometime this fall.

Once research is under way, NORD will send TEA the researcher's interim reports so we can keep our members up-to-date. Also, the grant recipient is required to acknowledge both TEA and NORD in any publications resulting from the study.

The researchers who receive the grant have one year to complete their study, which will most likely be a preliminary project testing a new drug or medical device through small clinical trials, which are studies involving people. NORD's Clinical Research Grant Program focuses on small, preliminary studies because most organizations like TEA that represent people with very rare disorders get the most benefit by funding what are known as "seed" money grants. If the data gathered show promise, the researchers can apply for much larger grants from the government or drug companies.

Workshop: NIH Recommends Seed Money Grants, Gifts

Funding seed money grants like the one TEA is offering this year is a proven technique for getting younger scientists interested and involved in research into a rare disease. That's one of the strategies representatives from the National Institutes of Health (NIH) suggested patient support organizations like TEA use to ultimately get funding for research from the NIH at "Gaining Access to Research Resources," a workshop attended by TEA Vice President Beth Coimbra.

Held in Philadelphia in late January, the workshop was sponsored by the NIH's Office of Rare Diseases and featured speakers from the Food and Drug Administraton and the National Organization of Rare Disorders as well as the NIH.

The NIH representative also endorsed groups such as TEA's giving money "with no strings attached" to established research programs like the one TEA is supporting at Yale University. Since patient support groups are generally able to provide just a small amount of the money medical researchers receive, "gifting" money without time-consuming, restrictive reporting demands makes the dollars most valuable.

"During our meeting with Dr. Waxman at Yale, we learned that our gift of $60,000 is much appreciated because it allows the researchers to be spontaneous and creative, following leads without restrictions imposed by the normal grant process," Coimbra said.

Organizations need to get to know the director of the NIH institute under which their diseases fit—a relationship that helps when seeking funding. The National Institute of Neurological Disorders and Stroke (NINDS) is the one in TEA's case. These institutes are funded by the federal government and making direct contact with the director is an appropriate move for organizations like ours.

Because our mission includes raising public awareness of EM, we also need to educate our congressional representatives. TEA members should be encouraged to write letters and visit their congressmen to inform them about the rare disease EM, TEA and its mission, and the progress of research.

Visiting Yale: A Personal Account

By Isabelle M. Davis

The researchers at Yale invited TEA board members to visit. Although Beth Coimbra and I knew each other only through e-mail, we accepted. We picked a date and planned our trip well in advance. Beth, TEA's vice president, lives in southeastern Penn. My husband and I live outside Detroit, Mich., but often visit our daughter in Stamford, Conn., not even 45 minutes from Yale University in New Haven.

Beth and I decided to meet well before our noon appointment at the center where the potentially breakthrough research in EM is being done. We wanted time to work on our agenda for the meeting so we could be sure to get our questions answered. (While the invitation had appeared sincere in their e-mail, I was wary. Although $60,000 is a huge donation to TEA, I knew it was "small potatoes" to scientists who routinely get grants in the millions.)

But from the moment I saw Beth in the lobby of her hotel, I made an instant connection with her—the sort one only makes with another person who has experienced the same kind of painful, puzzling, rare symptoms associated with EM. Agendas were forgotten. We talked only about our experiences of living with EM. Now mostly a stay-at-home Mom, Beth, a CPA, had driven to Conn. the day before with her husband and two sons, 9 and 12. I met her wonderful family as they left the hotel to explore a museum in New Haven. And all too soon it was time for us to head to the center.

Any doubts I had about the researchers' desire to meet us evaporated as soon as we got there. We were expected! Walking into the one-story building, we were immediately warmly welcomed by several people who had been anxiously awaiting our arrival. Their pleasure in meeting us was obvious. And that included Stephen Waxman, M.D., Ph.D., chair of neurology at Yale's School of Medicine, chief of neurology at Yale New Haven Hospital, and director of the center. He ushered us into his office for a private conversation, first thing.

He told us that partnering with a patient "grassroots" organization like TEA was a dream of his. The center's building was constructed with millions of dollars donated by, among other organizations, the Paralyzed Veterans of America and the United Spinal Association. And millions of dollars of grants keep the center operating. (Called the Center for Neuroscience and Regeneration Research, it's a collaboration among Yale University, the Veterans Administration, the Paralyzed Veterans of America, and the United Spinal Association.)

Gifts like ours—TEA is donating $60,000 in 2005 to EM research at the center—allow the researchers to quickly follow leads they discover.

Meeting people like us who suffer from diseases they're investigating is extraordinarily valuable, he said. Meeting us makes their work real. Then he told us a story about a group of paralyzed veterans who asked

Continued on p.5

Gathering at the conclusion of the Yale visit are (from left) Rachael Blackman, B.S., research assistant; Sulayman D. Dib-Hajj, Ph.D., Research Scientist in Neurology; Stephen G. Waxman, M.D., Ph.D., professor and chairman, Department of Neurology; Isabelle Davis, TEA board member; Beth Coimbra, vice president, TEA; Lynda Tyrrell, M.S., research associate; and Anthony M. Rush, Ph.D., associate research scientist in neurology.

Yale Visit, continued

to visit soon after the building was first completed. These researchers work in highly specialized research laboratories with the aid of technologically advanced equipment that allows them to magnify single cells to the point where they can visualize the molecules within them and decode the messages held in genes within a cell's nucleus. Why would these busy scientists want to see people? The veterans' visit, however, turned out to be one of the most motivating and valuable experiences the scientists ever had, he told us. Later when we showed them our feet and they asked about out symptoms, we understood their genuine interest.

Dr. Waxman gave Beth and me a tour of the entire facility where some 40 people work. All doors to labs and offices were open—by design Dr. Waxman told us. Scientists are encouraged to be collaborative and share everything they are doing with each other.

I remember meeting someone working on cellular transplantation for MS. And others who were creating tissue cultures in one lab and examining electrical activity of nerve cells in another. The labs have computerized microscopes and much specialized equipment I couldn't identify (and can't remember). Amazing.

Next we had lunch in the conference room with many of the people who have been directly involved with analyzing the DNA samples taken from the blood of the "Alabama family." It's the family to whom TEA introduced the researchers. (See "Powell's Burning Foot Disease," p. 9)

Dr. Waxman talked us through a PowerPoint presentation explaining their work with EM. Even though Research Scientist Sulayman Dib-Hajj, Ph.D.—who manned the computer—had patiently explained much of this information to me before I wrote the article in the last newsletter, I found my eyes glazing over somewhat at the highly technical nature of the presentation. All of Beth's and my questions were answered patiently.

And then they asked us questions like, "What medications relieve your pain?" I had a Lidocaine patch on the bottom of my foot, which interested them greatly. Lidocaine and its oral medication form—mexiletine—are sodium channel blockers, the very kind of substance they are theorizing will help people with inherited EM.

Our two-hour visit ended with a picture-taking session. Beth and I left feeling very special because of the extraordinary welcome we'd received. And hopeful because these Yale scientists really are the best of the best and they're working on curing primary EM!

What Research into Primary EM at Yale Is All About

Investigating how neurons (nerve cells) conduct messages and what happens when trauma like war injuries or diseases like multiple sclerosis damage nerves and disrupt their signals is the focus of research at Yales's Center for Neuroscience and Regeneration Research. One of their three main projects involves neuropathic pain (nerve pain from disease)—the project where the EM studies fit.

They've been investigating a certain protein called a sodium channel since it was discovered ten years ago because it's linked to pain. The protein is a voltage-gated sodium channel of the subtype Nav1.7—one of 10 sodium channels. These proteins (channels) are strings of amino acids (like strings of beads) that are "expressed" by neurons and serve as "molecular batteries" because they power the nerve messages that travel along neurons. An example would be the messages pain-signaling neurons send from the skin, via the spinal cord, to the brain.

The Yale team became interested in EM when studies outside the U.S. linked inherited EM to mutations in the gene SCN9A, the gene that "codes for" the Nav1.7 channel. That's why they contacted TEA and got blood samples from the Alabama family. The first paper they published in September 2004 reported that a newly found mutation in gene SCN9A appeared to cause a mutant Nav1.7 channel. The flaw—a change so small one can think of it like one unmatched bead in a string of 62,000—caused neurons to become hypersensitive, firing at higher than normal rates, causing pain. Scientists now are finished analyzing the DNA from all the blood samples. These studies yielded more information, which they submitted as an article to the journal *Brain.*

2004 TEA Annual Report

TEA's Annual Report for 2004—including the 2004 Financial Report—now is posted on TEA's web site. (www.erythromelalgia.org) It was a productive year for TEA, which now has nearly 500 members in 17 countries. Here are some highlights from the report.

Accomplishments

- TEA's Research Fund grew to more than $90,000, and the Board of Directors decided to put the money to use by funding two research projects in 2005. TEA will donate $60,000 to Yale University's Center for Neuroscience and Regeneration Research specifically to help fund continued research into what goes wrong in the nerve cells of people with EM that causes pain. TEA also will fund a $35,000 "seed money" grant through the National Organization for Rare Disorders (NORD) Clinical Research Grant Program. The "winning" study will be chosen by early fall.
- TEA sponsored its first major fund-raising event—a dinner and auction held in Seattle in June. More than $17,000 was raised for the Research Fund from this one event.
- Also in June, three members of TEA's Medical Advisory Committee met face to face for the first time in Oslo, Norway. TEA President Lennia Machen was a participant in the meeting.

Goals for 2005

- Conduct a $25,000 fund-raising campaign to help fund additional research projects.
- Apply for a grant to help support TEA program expenses and fund some of the work done by board members and other volunteers.
- Increase EM awareness among the general public and increase symptom recognition among health care practitioners using tactics like media placements.
- Conduct surveys of TEA members to determine satisfaction with communication efforts and other programs and to seek suggestions for improvement and new services.

TEA Library Offers Wealth of Information

by Gayla Kanaster

The TEA library contains articles offering a wealth of information for members. Since I'm moving from Southern California to the Pacific Northwest this summer, I was concerned that my present medication for Raynaud's may not be as effective in the colder climate. My internist referred me to a rheumatologist.

To prepare for the appointment I checked out the list of TEA library articles and found two pertaining to my situation. One (MO33) is on the "Treatment of Raynaud's Phenomenon with the Selective Serotonin Reuptake Inhibitor Fluoxetine." The second, (MO34) "Serotonin Reuptake Inhibitors, Raynaud's Phenomenon and Erythromelalgia," questions some of the first article's theories and was of particular interest to me since I also have EM. Although they both have complicated titles, I found the articles to be clear and very helpful. Not only will I take them to my doctor to discuss a new approach, but he will see that I've done my homework.

A complete list of articles in the library appears on p. 11 and 12. Articles are available to members on the TEA web site. And members may obtain any of the articles from Networking Chairperson Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, UT 84117. E-mail:Judy@datafest.com. Phone: (801) 631-3833.

Primary Erythromelalgia in a Child Responding to Intravenous Lidocaine and Oral Mexiletine Treatment

Erythromelalgia is a rare, chronic, debilitating condition characterized by redness, warmth, and severe burning pain of the distal extremities. The feet are more commonly affected than the hands. Pain is precipitated by increases in temperature and by exercise. Patients often obtain relief by immersing the affected extremity in cold water. The pain is often refractory to treatment. For many patients, multiple pain medications have been useless in achieving complete relief of pain symptoms. Previous reports of **erythromelalgia** among adolescents indicated prolonged relief of pain with sodium nitroprusside infusions, epidural infusions of local anesthetics, or gabapentin treatment. We present a case of an 11-year-old, white, male child with primary **erythromelalgia**, whose initial symptoms started in his preschool years and whose childhood was marked by escalating episodes of pain with warmth and redness of his feet, precipitated especially by increases in temperature and by activity. All conventional pain management techniques had failed to relieve our patient of his symptoms, and he obtained some relief only by soaking his affected extremities in ice water. He had experienced minimal benefit from seeing a pain psychologist, who helped him develop techniques to cope with the pain. At the time of presentation, the patient's episodes of pain had increased to 15 to 20 per day, and there was evidence of chronic immersion injury to the skin of his feet. Before his most recent hospitalization, the pain had spread to involve his hands as well. The patient was overwhelmed with anxiety and could not participate in school or social activities at the time of admission. During his current hospitalization, he did show some therapeutic response to sodium nitroprusside infusion, which unfortunately had to be discontinued because of side effects and because his family desired to leave the ICU environment, which was stressful to the patient. He also had some response to lumbar epidural infusion of local anesthetics, which could not be continued because he found the motor blockade that accompanied his analgesia intolerable. However, intravenous lidocaine infusion, with subsequent transition to oral mexiletine therapy, proved very effective in reducing the frequency and severity of the pain episodes. The patient was discharged from the hospital with oral mexiletine therapy and has been monitored at the pain management clinic. He returned to and completed school, attended summer camp, and enjoys an active happy life. He walks without precipitating pain in his feet and sleeps 9 to 10 hours every night. He has needed to soak his feet on only 4 occasions in the 6 months since his discharge from the hospital. His quality of life has improved significantly. He has shown no evidence of liver toxicity, and his mexiletine levels have been stable.

Aruna Nathan, M.D., John B. Rose, M.D., Jessica W. Guite, Ph.D., David Hehir, M.D. and Karen Milovcich, C.R.N.P., Department of Anesthesiology and Critical Care Medicine, Children's Hospital of Philadelphia, and Department of Anesthesiology, University of Pennsylvania, School of Medicine, Philadelphia, Pennsylvania.

PEDIATRICS (doi:10.1542/peds.2004-1395)

N O T I C E

This issue of *FootSteps*, which is dated March 2005, did not arrive in your mailbox or appear on the TEA web site in March. Rather, you had your first opportunity to read it sometime in late April 2005. We intend to produce a newsletter four times each calendar year to keep members as up-to-date as possible on research findings and other news. However, we are quite short on staff—not surprising since we're volunteers. Let me know if you'd like to help!

The Editor

Your Stories— *everyone has one!*

We can all empathize with fellow members who face the daily challenges of living with EM. Because EM is so rare, most of us also have long and difficult tales to tell about the diagnosis process. TEA invites you to share your experience with EM by writing your story. If you think you're not a writer—never fear. We can help you write and edit you story. Please send stories to Gayla Kanaster, gaylakanaster@aol.com or 2556 W. 234th Street, Torrance, CA 90505.

My name is Carolyn Quinn. I'm 54 years old and live in Tucson, Arizona. I have had EM for about two years. It started three months after I broke the fifth metatarsal bone in my left foot. I believe that I have had Raynaud's syndrome all my life too. My hands and feet are usually cold in even temperate conditions, but change to hot around dinner time and thereafter. Most recently, these symptoms have spread to my hands.

I tried taking 1,200 mg of Neurontin daily, but found the side effects nasty. Now take 1,000 mg of nortriptyline at night, and that amount makes me able to sleep through the night without waking up in pain. I read that antidepressants like nortriptyline somehow can make the blood flow better, so that's why I think I was able to go off Neurontin. I also tried diltiazem and magnesium, but they both made my symptoms worse. I went off them right away!

It has been difficult to accept that I have this disorder, and it seems to take over my life at times. My husband has been very understanding and realizes that my symptoms are real and not in my head, although I think I drive him crazy with my constant monitoring of the temperature in our house. I find that being on my feet for about 30 minutes or more gets them to the "flare" stage, no matter the time of the day or the outside or inside temperature. I need it 70 degrees or cooler.

My form of exercise is water aerobics three or more times a week. I tried going to the gym and riding a stationery bike, but I flared doing that too!

Life is one day at a time, and I do appreciate every day.

In Memoriam

Condolences to the friends and family of **Milton LeCouteur**, one of TEA's founding members, who died April 6, 2005, following heart bypass surgery. Milt, a resident of Seattle, is the reason TEA was incorporated as a 501(c)(3) non-profit organization in the state of Washington. His determination to found a group to help other people with EM and find a cure through research translated into countless hours of work, both in completing all the paperwork required to incorporate and then serving as TEA's secretary-treasurer for four years. He will be sorely missed.

TEA Contact Information

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Networking Program: **Judy Reese,** 1155 E. Wild Duck Lane, Salt Lake City, UT 84117 Or e-mail to: judy@dataquest.com (801) 631-3833

FootSteps: **Isabelle Davis**, 24 Pickering Lane, Wethersfield, CT 06109 Or e-mail to: imdcomm@aol.com

Powell's Burning Foot Disease

by Gayla (Powell) Kanaster

Imagine living in an area where you know nearly 40 people with EM. And they're all related—an ideal support group. It is frustrating often when they can't help each other, but by simply having the same pain, it can be very gratifying that they can just be there for each other.

I'm describing the family of TEA member Shirley Powell Longmire. (It's my family, too. Shirley's my cousin.) She was born and raised in Birmingham, Alabama, and most of her extended family members still reside there. Shirley and three of her five sisters were born with EM, which they called "Powell's Burning Foot Disease" when they were young. Now, many of their children and grandchildren have EM, too. Because of her granddaughter's illness, 70-year-old Shirley and her husband are raising their great-grandson Caleb, 3, who also has EM.

It's Shirley's Alabama family who recently was studied by the researchers at Yale University. Shirley hosted the scientists from Yale in 2004, gathering together more than 25 relatives at her house for blood tests, photos and lunch. (See "Yale Scientists Host TEA Board Members" and "Visiting Yale: A Personal Account," also in this issue.)

Participating in EM research is nothing new for this Alabama family. Shirley remembers when in 1966 a doctor was intrigued by her sister Juanita's family. Four of Juanita's five children, including one son, had the burning symptoms. The doctor arranged for them to go to the Mayo Clinic on a government grant. That's when they learned Powell's Burning Foot Disease already had a name—erythromelalgia. Mayo Clinic doctors M. K. Burbank and J. H. Spittle also came to Birmingham to examine other family members. Shirley remembers the doctors feeling behind their ankles as part of the EM testing.

It's Shirley's Alabama family who recently was studied by the researchers at Yale.

Doctors at the University of Alabama, Birmingham, (U.A.B.) also got interested in the family disease after Shirley took daughter Debbie—then young and having a particularly painful flare—to a clinic. There a Dr. James Lindsay, still in training, was so fascinated by Debbie's burning, red feet that he wrote his thesis on EM. He took his findings to a friend at U.A.B., Dr. W. H. Finley, who started intensive research into the Powell family's EM. Studies by U.A.B. and Mayo traced the disease to a great grandfather in Wales, a grandmother, uncles and many cousins. An article entitled "Autosomal Dominate Erythromelalgia," published in 1992 in the Journal of Medical Genetics, chronicles the family's history with EM.

In 2005, Shirley leads a very busy life and is always upbeat. She smiles when she talks about how glad she is that they have air conditioning and cool ceramic tile to walk on during sleepless nights when her feet flare.

Growing up in the days when most homes were not air- conditioned, Shirley recalls how she was able to get a coveted job working in an air-conditioned office of a high school advisor. Her mother struggled to raise six daughters after her father died as a young man. Shirley sometimes could not afford the textbooks.

When the advisor offered her some free books, Shirley thought about her office and said her mother would only allow her to accept them if she worked, and offered to help with office work. She chose the last class period, since that was the hottest time and her most painful. The job in that cool office helped her get through those high school years.

Even though keeping up with little Caleb isn't always easy, she keeps a youthful outlook and stays very active, despite her EM. She even manages to visit friends and relatives. And to enjoy her favorite pastime—reading mystery novels.

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.

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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Mail to: Judy Reese, NW Program
1155 E. Wild Duck Lane
Salt Lake City, UT 84117

TEA Library Articles and Documents Page 1

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	
M007	AAPM: Lidocaine Patch Enhances Chronic Pain Therapy, Bruce Sylvester 2003	2	$1	
M008	Erythromelalgia: A Mysterious Condition? Mørk, Kvernebo, Archives of Dermatology, 2000	7	$2	
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