

FootSteps...

TOWARDS PROGRESS

The Newsletter dedicated to finding a better way to live with erythromelalgia
Volume 4, Issue 1, March 2003, Published by The Erythromelalgia Association

AAPM: Lidocaine Patch Enhances Chronic Pain Therapy

By Bruce Sylvester, Special to Doctor's Guide News

NEW ORLEANS, LA -- February 25, 2003 -- A patch containing 5% lidocaine (Lidoderm) combined with gabapentin for the treatment of post-herpetic neuralgia, lower back pain and painful diabetic neuralgia appears to be safe, well-tolerated and treatment-enhancing, investigators report.

The research was presented here February 20th at the 19th Annual Meeting of the American Academy of Pain Medicine.

The investigators, from the Arizona Research Center in Phoenix, USA and Endo Pharmaceutical, Chadds Ford, PA, USA, enrolled 107 subjects who had reported a partial response to treatment with an analgesic regimen including gabapentin for this 2-week, open-label, multicentre pilot study. The subjects were 18 years of age or older, and females of child-bearing age were excluded. Eligible subjects had reported partial response to current therapy containing gabapentin but had an average daily pain intensity >4/10 on the Brief Pain Inventory (BPI), normal motor strength, normal responses to sensory testing and normal deep tendon reflexes.

Subjects underwent 24-hour, continuous application of up to 4 lidocaine patches to the area of maximum peripheral pain. They investigators maintained the subjects on their current gabapentin-containing drug regimen (dose stable for >= 14 days prior to this study).

The researchers used the BPI and the Neuropathic Pain Scale (NPS) to measure changes in response to treatment. All patients showed significant improvements in all measures of pain intensity and pain relief, including general activity, mood, walking ability, normal work, relations with other people, sleep and enjoyment of life.

"The results of this study suggest that the addition of the lidocaine patch 5% to a regimen consisting of gabapentin and other systemic analgesics significantly reduced pain intensity, improved pain relief and reduced pain interference with activities of daily living," noted lead author Joseph Gimbel, MD, of the Arizona Research Center.

"Most adverse events seen during the study period were unrelated to the study drug" the investigators said. The most frequently reported treatment-related adverse event was somnolence (2, 4%).

"The study provides evidence for the concept of rational polypharmacy," Dr. Gimbel reported, "combining an agent with peripheral nervous system mechanism with a central nervous system-acting agent."

The study was funded by Endo Pharmaceuticals.

[Study title: *Effect of lidocaine patch 5% on pain intensity and pain relief when used in combination with gabapentin in 3 chronic pain states. Poster 522*]

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TEA Now Accepts Credit Cards!

You can now use your credit card to join TEA, renew your membership, or make a donation to the Research Fund. No more mailing checks, or searching for a location to purchase International Money Orders! Just give us a call to use the system over the phone or try it out on our web site. To use over the phone, call:



*Member Services Representative
Ray Salza, at 860-529-5261
9 to 5 pm, EST*



President Bush Signs Rare Diseases Legislation

New Laws Address Unmet Needs of 25 Million Americans

N.O.R.D. News http://www.rarediseases.org/washington/bush_signs

Contact: Diane Dorman, Office: (202) 496-1296, Cell: (202) 258-6457

Danbury, Connecticut, November 7, 2002 — The White House announced today that President Bush signed into law the Rare Diseases Act (H.R. 4013) and the Rare Diseases Orphan Product Development Act (H.R. 4014). The legislation addresses a longstanding unmet need to develop new treatments and cures for rare disorders.

“Not since the passage of the Orphan Drug Act in 1983 which created financial incentives and research grants, has legislation been enacted that has such a profound and lasting impact on the millions suffering with rare diseases,” said Abbey Meyers, President of the National Organization for Rare Disorders (NORD). “The entire rare disease community has worked so hard for this momentous day”.

The Office of Rare Diseases at the NIH was initially established in 1993 to promote research and collaboration on orphan diseases. Today that office serves as a link between basic and translational research, and stimulates new research on rare diseases. H.R. 4013 provides a statutory authorization for this important office and will allow the ORD to play an increased role in formulating the research agenda at the NIH.

In the nearly twenty years since the passage of the Orphan Drug Act, the FDA’s orphan products research grant program has supported small clinical trials at academic institutions and small companies. The grants have enabled scientists to develop the preliminary scientific data necessary to prove that a new treatment warrants commercial development and FDA approval. With very limited funding, these grants helped 30 new drugs and medical devices to reach the American market. If not for this program, therapies for such rare diseases as sickle cell anemia and narcolepsy would not be on the market today. H.R. 4014 will enable the FDA to double the number of new research grants, thus propelling development of many new treatments for rare diseases in years to come.

Asked about the next steps, Diane Dorman, NORD’s Vice President for Public Policy said, “Our work is still cut out for us. The bills authorize increased funding for both the NIH and FDA research programs, but lawmakers must approve the funds to finance them. So we’ll be turning to our friends in Washington, DC asking for their help in the 108th Congress to ensure that the programs are fully funded in accordance with Congressional intent.”

NORD is a federation of approximately 125 voluntary health organizations and over 60,000 patients, families, healthcare providers, and individuals dedicated to helping people with rare “orphan” diseases. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

WINTER BOARD MEETINGS

Over this last Winter, the TEA Board discussed several exciting plans for a future fund raising campaign for the research fund. We have Welcomed Kathy Weaver on our board of directors and she is our new Fund Raising Chairperson. Kathy will pick up where Jan McKim had left off, due to Jan's health set-backs.

The fund raising efforts will include the creation of a committee that will be involved in raising funds for the research fund. If you are interested in joining in on this mammoth and important effort, please contact us and we can answer any questions you may have or help you get started.

Much of our time in discussion included ironing out many details in launching our new web site. The new Web Site includes new features like personalized passwords, credit card acceptability form, a searchable tool for the articles and newsletters, and the expansion of EM articles available, printable tools (a TEA brochure, or informational flyer), and lots more information about our organization. We are planning to be the best resource for information about erythromelalgia in the world... a place to come for patients, and their doctors to learn more about EM.

The board of directors is still looking for volunteers to fill some recently empty seats. Computer access and email is required as this is how we meet once a month. Please contact Ray Salza for more information at memberservices@erythromelalgia.org.

This is the time of year for elections of our board and you will notice the enclosed ballot for you to fill out and return to us for this bi-annual event.

In the planning stages are several items to help members who rely on the regular mail to keep current on EM related issues. In addition to this we are planning to create a catalog of available library items that can be mailed or Faxed to you for only the cost of the postage.

If you would like more information about any of TEA's activities and plans, please feel welcome to contact us. You may write to our Member Services Representative, Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109. We would love to hear from you!

New Members

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

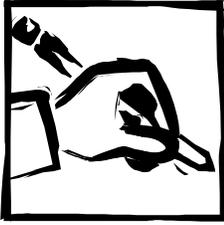
The following list is of the members that have newly joined us since December 2002.

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

Wendy Durand, Beth Huston, Camila SantaMaria, Patricia Ward, George B. McClary, MD, Carol Boulais, Georgia Stokowski, Sarah Sundstrom, Jennifer S. Jones, Robert/Jeny Narcisco, Denise Lefebvre, Jo Bennett, Hansel, Samantha, Laura Moravec, Germana (Joanna) Noest, Matthew Whitmore, Doris MacDiarmid, Carolyn Thomas, Kevin McDonough, Betty Thomas, Janet E. Dale, Françoise Kemp, Sandra Publow, Roger J. Leshner, Margie Novak, Shirley Peters, Suzanne Wildman-Chard, Lisa Guidroz, Carol Kaplan, Michelle Mattox, Jodie Stowe, Lewis Hanson, Kevin Wilcox, Joe Bassett, Lynn Hughes, Rita Furman, and Barbara Kent
...Welcome!... we're glad you've joined us!

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C 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.



Your Stories... and everyone has one!

TEA has been asking its members to write brief stories about their EM or daily lives. Several members have responded and we are printing a few of them here for you. We would love to hear your story too! Please send them to FootSteps Editor, 11591 North 5th East, Idaho Falls, ID 83401 or webmaster@erythromelalgia

My name is Ray Salza. I'm one of the founding directors of TEA and am currently the Secretary/Treasurer of the Association. Unlike most of you, I don't have EM, but my wife Carol does. She has been suffering with EM for 13 years and is disabled and housebound. Like many of you, she manages her EM by controlling her environment and maintaining a consistent temperature, minimizing stress, exercising, avoiding alcohol and certain foods & spices, and taking a large selection of medications. I was fortunate enough to be able to take early retirement from my career at Aetna 5 years ago so that I could better care for her.

This story is not about Carol and it's not for those of you who do have EM. Rather, please give this story to your closest male relative... spouse, adult child, father, etc., because it's intended to help them.

Most men feel that it's their role and obligation to fix things, to get things done; mechanical problems, business problems, finance problems, etc. However, when someone close to you has EM, you quickly find you are powerless to fix it. You might feel helpless, angry & frustrated... that's the way I felt.

What can you do when you feel this way? You might contemplate that; you can't ignore the problem because it's about the person you love, and because it also has a major impact on your own life. You now have all the work and responsibilities of a caregiver as well as the restrictions on the life you thought you were going to lead. You can't do what you normally do and just fix the problem. You can do nothing and try to ignore the problem, but you already know that won't work. You can try to be supportive (which you should), but that won't be enough, ...*so you come to the conclusion that you need to take some positive action to help.*

I joined NORD (National Organization of Rare Disorders), spent countless hours researching EM and related rare diseases and supported my wife through hundreds of different medications, doctors' visits, hospitalizations, surgeries, alternative and experimental treatments, and a week at the Mayo Clinic. Then about four years ago, through my NORD membership, Milt LeCouteur contacted me about taking a role in a new organization he was incorporating (TEA) to help people with EM.

For the first time in many years, I no longer felt powerless. Working for TEA gave me a chance to make a real difference in the future course of this disease and in the lives of the people who suffer from EM. What I brought to TEA was good health, energy and a strong desire to help. The Directors of TEA are a very hard-working bunch of people, but most suffer from EM and have to deal with the unpredictable health problems that periodically limit their lives and their ability to work on TEA goals.

TEA really needs the kind of help that can be provided by healthy men who are frustrated and in need of a way to "fix things" by helping their loved one overcome this terrible disease. Please seriously consider volunteering your time to serve on the Board of Directors, or get involved with fundraising, help write the newsletter, maintain our library, support the work of the Medical Advisory Committee, etc. TEA really needs you. Won't you please give this positive action some serious thought?

I welcome you to contact me if you are interested. I can answer your questions and understand your position in living with someone with EM. Please call at 860-529-5261, or write to Ray Salza, 24 Pickering Lane, Wethersfield, CT 06109, or memberservices@erythromelalgia.org

What's in a Name? By Jean Jeffery

I say sertraline ----- you say Zoloft. You say Cardizem ----- I say diltiazem. Confusing isn't it? Every drug is given two types of name: generic and brand. The generic name is the most important one to use because it is recognised worldwide. Generic names always begin with a small letter eg. sertraline, diltiazem. Each drug has many different brand names in different countries. Brand names always begin with a capital letter eg. Zoloft, Cardizem. In an organization like TEA which has worldwide membership, members from different countries will not be able to recognize all the different brand names. When the generic name is not given, use this handy chart to make the translation for many of the EM medications used by our members:.

Drug Type	Generic Name	Brand Name
Calcium antagonists	amlodipine	Norvasc
Calcium antagonists	diltiazem	Cardizem,Tiazac
Beta-blockers	propranolol	Inderal
Beta-blockers	atenolol	Tenormin
Opioid analgesics	fentanyl	Duragesic
Opioid analgesics	tramadol	Ultram
Anticonvulsants	gabapentin	Neurontin
Anticonvulsants	carbamazepine	Tegretol
Tricyclic antidepressants	amitriptyline	Elavil
Tricyclic antidepressants	imipramine	Tofranil
Tricyclic antidepressants	nortriptyline	Pamelor
Serotonin antidepressants (SSRI's):	venlafaxine	Effexor
Serotonin antidepressants (SSRI's):	sertraline	Zoloft
Serotonin antidepressants (SSRI's):	paroxetine	Paxil
Serotonin antidepressants (SSRI's):	fluoxetine	Prozac
Serotonin antidepressants (SSRI's):	citalopram	Celexa
Antihistamines	diphenhydramine	Benadryl
Antihistamines	cyproheptadine	Periactin

Further details of many of the drugs on this list are given in the Members Helpful Links page



Start Spreading the News...

Recently some of TEA's members have had some success in getting the word out about the terrible effects of living with erythromelalgia. TEA member, Sarah Sundstrom, contacted her local newspaper and the resulting article may reach thousands of readers in the Everett Washington area. A few months ago, TEA member, Nancy Mabry, had the same success in the Midland, Texas area. We encourage you to try the same approach and call up the features editor of your local newspaper. You can find the complete articles in the TEA Library on the web site, or let us know and we can send you a copy. The more exposure, the more prepared our doctors will become, and the easier our fund raising efforts may go towards the research fund. You can't lose! So, go on... Call them up!



Following is a message from TEA's Publicity Chairman, Sarah Sundstrom. Sarah would like you to consider helping TEA with our needs for spreading the news about EM. Feel free to use the letter below or to contact Sarah about the publicity project. Write to: Member Services, 24 Pickering Lane, Whethersfield, CT 06109, Attention Publicity Project



Sometimes, It's All In Who You Know... A Letter You Can Forward

Hi Everyone!

As most of you know, I have been struggling over the past 6 years with an extremely rare neurological disease, which causes my feet to get very red, swollen, and hot. This painful disease is called Erythromelalgia (EM).

Unfortunately, since this disease is so rare most doctors have never heard of it. This is unfortunate for those people whom are afflicted, because the majority of doctors don't know how to help these patients. Additionally, with such a rare disease most have never heard of, there isn't much research being done to find a cure. In fact, to date, there is no known cure or cause for EM. There are however many theories, but without research, these theories will never lead to a cure. This is what I would like to change.

Recently, I started assisting TEA (The Erythromelalgia Association) with fundraising. TEA has approximately 300 members worldwide, and is listed with the National Organization of Rare Disorders. If you have time, feel free to check out our website at www.erythromelalgia.org.

As a fundraiser, my goal is to get a story written in the personal interest section of our local newspaper, appear in a segment on a local television show, talk show or have an article written in a magazine. This is where your help comes in.

I would like to write to one of the above places, but before doing so, I'm wondering if you know anyone that works at a newspaper, magazine, TV station or TV show. I believe it will really help me to get my foot in the door if I have the name of a contact person.

I really appreciate your help, and please feel free to forward this letter to anyone. I figure the more people I ask the better my chance of getting some great contacts.

Sincerely,
Sarah Sundstrom

Hot



Flashes!

Of Mice and Men...

December 2002. Gene protein GIRK 2 plays major role in pain sensation.

Scientists in Texas and California have been surprised to find that males are better at tolerating pain than females because they have the gene protein called GIRK 2. GIRK 2 plays a major role in pain sensation and drug sensitivity. Many pain-killing drugs including morphine and clonidine activate GIRK 2 so that men are better able to withstand pain. This means that women are more vulnerable to pain than men. It is hoped that more research in this area could lead to new drugs specifically designed to ease pain in women. Submitted by Jean Jeffery

Tips for Toes...

Try Vick Vapor Rub for discolored toenails! It also helps to get rid of any athlete's foot type of fungal infection that may be lurking. Apply Vick daily to your nails for a few weeks and see the difference. Submitted by Jean Jeffery

TEA Trivia...

Did you know that TEA has 50 International members in 13 countries? We do, and they live in: England, Scotland, Ireland, Norway, Germany, Australia, New Zealand, Canada, South Africa, Denmark, The Netherlands, Belgium, and China. Which means that there are over 300 members of TEA in the United States.

Are your Membership Dues Due?

If you notice that you are not receiving the newsletter, or access to the web site, this may be the cause.

More Trivia...

Did you know that TEA is four years old? We incorporated in January of 1999, with only a handful of members and many of the same people on the board of directors. We've come a long way in 4 years! We now have a wonderful web site, over 350 members, and a research fund of over \$42,000.

An Invitation...

Invite your doctor to visit our library on EM. Send the editor your doctor's email address and we will send a guest password for their use to access our library.

Wish you were here...

Following are items that were discussed on the EMyahogroup List Service during January:

- ◆ Members shared their experiences, diagnoses, and medication suggested by their physicians, including those at Mayo Clinics. Diagnoses included autonomic dysfunction, anhidrosis, arthritis, hypothyroidism, Lyme Disease and RSD (reflex sympathetic dystrophy) as well as EM.
- ◆ Other topics covered incl. Raynaud's Disease, chilblains, itch-relieving creams, cooling units, social security disability, hypnotherapy, and weight/diet/personality type in relation to EM.
- ◆ Medical treatment is always prominent & discussion incl. the pros and cons of amitriptyline, Effexor, nitroglycerin, sodium nitroprusside, magnesium, Norvasc and Plaquenil.
- ◆ Several new members introduced themselves and received a welcome and help with any questions they raised.

So, if you haven't yet introduced yourself - come and join in! Contact Doris at: danndc@worldnet.att.net to learn more about it.

Submitted by Jean Jeffery

The Erythromelalgia Association
24 Pickering Lane
Wethersfield, CT 06109

It's Election Time... Find your ballot inside!

The Erythromelalgia Association Annual Report for 2002

ABOUT OUR ORGANIZATION

Founded in 1999, TEA currently has nearly 300 members of all ages, residing in many different countries. Originating from a handful of Erythromelalgia (EM) sufferers joining together to try and help others with this rare condition, TEA was created, and is still operated, by volunteers including our Officers and Board of Directors. TEA is advised and assisted by a Medical Advisory Committee of international doctors exceptionally experienced in EM research and working with EM patients.

Our Mission

The Erythromelalgia Association was formed to further education and research for the understanding and treatment of the rare disease, Erythromelalgia.

Our Programs

PATIENT AND FAMILY SERVICES- Provide emotional support to those diagnosed with EM and their families. Foster communication among members by sharing personal experiences with EM.

RESEARCH- Raise funds for research. Promote research into the causes, effects, diagnostic and treatment options of EM within the medical community. Work closely with medical organizations involved in finding new treatments for EM.

EDUCATION- Increase public awareness of EM and the need for special accommodations for those affected by the condition.

Our Board of Directors

Lennia J. Machen (president), Beth Coimbra (vice-president), Raymond Salza (secretary/treasurer), Milton B. LeCouteur, Helen Normandin, Judy Reese, Kathy Weaver, Gayla Kanaster

ACCOMPLISHMENTS DURING 2002

- ◆ In late 2001, TEA created a Medical Advisory Committee (MAC) composed of international doctors exceptionally experienced in EM. MAC members are Jay. S. Cohen, M.D. (University of California at San Diego, USA); Mark Davis, M.D., (Mayo Clinic, USA); Knut Kvernebo, M.D., Ph.D., (University of Oslo, Norway); Jan Jacques Michiels, M.D.(University Hospital, Antwerp, Belgium and Director of Goodheart Institute Rotterdam, The Netherlands); Cato Mork, M.D.(Rikshospitalet University Hospital, Oslo, Norway), and Ronald Schneeweiss, M.D.(University of Washington, USA)
- ◆ In 2002, Jill Belch M.D. (Ninewells Hospital and Medical School, Dundee, Scotland) joined the MAC.
- The first MAC “virtual” meeting was held over a week-long period in mid-2002.
- TEA membership exceeds 300 members
- The Research fund increased from \$30,741 to \$40,390.
- TEA was approved as a National member of NORD, the National Organization for Rare Disorders. Founded in 1983, NORD has since grown to be an important and influential advocacy organization in the U.S. and internationally. There are over 120 non-profit health organizations that make up the NORD federation. TEA is listed in all NORD publications; clearly recognizing TEA as the National and International resource for Erythromelalgia information and support.

2002 FINANCIAL REPORT

TEA's income is solely from donations made by Association members and friends. Donations designated for the Research Fund are deposited in segregated, interest-earning accounts being accumulated to fund a future research project.

During 2002, the Research fund increased by \$9649 to a total of \$40,390.

Income from membership dues is deposited in TEA's operating account and is used to pay TEA expenses such as printing, postage, insurance, website operations and other office expenses necessary to provide member services. All directors, officers and MAC members are volunteers and receive no compensation for their services. No funds were used in 2002 for fundraising.

During 2002, TEA operating income was \$3801.31. Operating expenses were \$3238.19. At the end of 2002, TEA's operating account had a balance of \$3403.18.

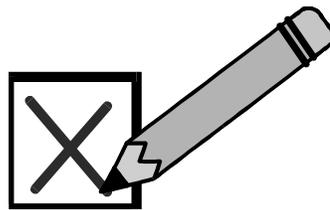
GOALS FOR 2003

- TEA will be launching an entirely new website in early 2003. The site is professionally designed and includes new information, improved color/graphics and easier navigation. An ever expanding Member's area will include current and past newsletters, medical articles and useful links.
- A credit card payment option will be added to the new website to support membership and Research Fund donations by credit card.
- TEA's Medical Advisory Committee will hold its second "virtual" meeting while planning is started for the first international conference on Erythromelalgia.
- A dedicated fundraising and publicity program will be developed to expose Erythromelalgia to a much wider audience and broaden our donor universe. TEA's goals for 2003 are to increase our membership to 350 active members and to raise an additional \$15,000 for our Research Fund.
- TEA will conduct a survey of its members to compile an up-to-date view of Erythromelalgia treatments and member information

TEA Ballot for the Board of Directors for 2003-2005

Please vote for eight (8)
names:

Beth Coimbra
Gayla Kanaster
Helen Normandin
Judy Reese
Kathy Weaver
Milton LeCouteur
Lennia Machen
Ray Salza



**Return the ballot no later than
April 30, 2003 to:**

**Ray Salza
24 Pickering Lane
Wethersfield, CT 06109**