FootSteps *TOWARD PROGRESS*

The newsletter dedicated to finding a better way to live with erythromelalgia
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TEA Funds Dutch Researcher's Study

TEA is funding a research study in 2006 that aims to identify a second gene that causes inherited EM.

The National Organization for Rare Disorders (NORD) in October awarded a TEA-funded grant to Joost P. H. Drenth, M.D., Ph.D., Radboud University, Nijmegen, The Netherlands.

The $30,000, one-year grant will be administered by NORD's Clinical Research Grant Program.

Dr. Drenth was the first physician scientist to identify the genetic location implicated in inherited EM, describing his findings in an article published in 2001.

Then, he and his colleagues identified the gene linked to EM on chromosome 2. They then confirmed its role in EM by finding mutations to the gene in six families with inherited EM.

Based on research done since 2001, these researchers theorize that another gene exists that causes inherited EM.

In this research, they found several families with inherited EM that do not carry the first identified EM gene.

In the research to be funded by TEA, Dr. Drenth will study the DNA—each person's hereditary information—of members of as many families as possible with at least two members who have EM symptoms.

The goal is first to define specific genetic markers that everyone in a given family has inherited. These markers will lead the researchers to a part of a chromosome on which they can identify a mutated gene present in these EM patients.

For this study to be a success, Dr. Drenth needs to find as many families with inherited EM as possible who are willing to participate. Family members will be asked only to supply blood samples by mail.

If you wish to participate, please contact Dr. Drenth at j.drenth@mdl.umcn.nl

Discovery Health Channel To Feature TEA Member

A television documentary scheduled to air on the Discovery Health Channel in 2006 features TEA member Pamela Costa, Ph.D., who lives in Tacoma, Washington, U.S. She has suffered often excruciating pain from primary (inherited) EM since infancy.

Costa's story first was told in-depth in the *Tacoma News Tribune* on October 9, 2005. The crew filming the documentary spent most of two days in Tacoma in November filming Costa and those close to her.

Despite the challenges of living with EM, Costa, 40, earned a Ph.D. in clinical psychology and is currently Associate Chair of Social Sciences at Tacoma Community College (TCC).

The Discovery Health Channel program is part of its Medical Incredible's series that explores the lives of

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Costa Filmed

people around the world who live with very rare medical conditions.

Costa's segment, titled "The Burning Foot Syndrome," will be one of five or six stories in a one-hour program slated to air in 2006.

Australian documentary producers—Beyond Productions—are making the entire series.

The film crew talked with Costa on camera in her office at TCC—the only office with an air conditioner—and later at her home.

They filmed her giving a lecture to her developmental psychology class, then walking to her car and driving home, with special emphasis on the van Costa drives.

Equipped with a remote starting mechanism, Costa's van can be cooled down long before she ever reaches it. To minimize her having to use her hands on hot handles, the car doors also open automatically.

"I talked about how I know research has shown that the cold pillows I use to get immediate relief from the pain really have the effect of making my feet even worse, and how I'm trying not to depend on them," Costa said.

She also told filmmakers she needs to soon stop taking her pain medication as it has already permanently damaged her gastrointestinal tract.

At home, they filmed her cooking and watching her 5-year-old daughter play outside. The child was dressed warmly to protect her from the near-freezing November temperatures. In contrast, Costa kicked off the sandals she wears year-round.

Both Costa's morning and evening routines were captured on film, including her taking a handful of pain pills as she began her day. And getting into bed at night—a bed equipped with a "sheet lifter" device her husband Chris designed to keep the bedcovers from touching her elevated feet.

Others Filmed

Researchers at Yale University were filmed describing their latest findings.

Costa's mother Gayla Kanaster, a member of TEA's Board of Directors, told the filmmakers about taking Costa as a child to many doctors who did not recognize the rare disease. They prescribed some remedies that made the symptoms worse like high-top "Thomas heel" shoes.

Costa's husband was asked what it's like to live with a person with EM. And the film crew interviewed Costa's internist Tonia Jenson, M.D., about the challenge of treating someone with an incurable illness.

Costa said, "I spoke on camera about the research at Yale, how I hope a more effective treatment will be developed soon, and the crucial need for funding to continue the research. I ended on a very hopeful note."

TEA thanks Dr. Costa for "going public" about her life-long struggle with EM. Not only did she spend hours with the newspaper reporter last summer, but in November again gave freely of her time to the documentary film crew.

Dues Increase

Effective February 1, 2006, TEA's annual membership donation will be $20. (Tax deductible in the U.S. as a charitable donation)

This is the first increase since the founding of TEA in 1999. Exceptions are made for those unable to pay, and a larger yearly donation is encouraged from those with the ability to pay.

As you know, we are an all-volunteer organization; there are no paid staff.

Membership dues provide the operating funds for TEA, which means they pay for the printing and mailing of this newsletter, postage and supplies for membership services, and Web site services.

These funds also cover fees to NORD, bank charges, insurance and all the other expenses required to run TEA.

Nitroprusside Treatment Helps Children with EM

By Jean Jeffery

It is more difficult to treat EM in children than in adults. There are about ten reports in the medical journals that have described successful treatment with intravenous infusions of sodium nitroprusside for children and adolescents. This drug has not helped adults.

Two of these reports, which can be found in TEA's Article Archive, are summarised below. Some other reports are also briefly mentioned.

Two Young Boys Respond Well to NP (TR-41)[1]
This report from the United Kingdom describes the successful treatment of two boys, aged 5 and 11 years, with EM.

Both boys had raised blood pressure and kept their painful extremities constantly immersed in ice-cold water, which had caused ulceration. Many different treatments had been tried for both without success.

The 5-year-old boy, who had suffered for three years with EM in his feet, responded within hours to a nitroprusside dose of 4 mcg/kg/min (4 micrograms/ kg body weight/ minute). Infusion was continued for five days.

The boy's feet remained free of pain for five weeks after which EM symptoms returned. However, further nitroprusside infusion was successful and he remained free of EM at his six month follow-up.

The 11-year-old boy had EM in both feet and hands. He began on nitroprusside at 2 mcg/kg/min, which had to be stopped due to problems with low blood pressure.

Nevertheless, he responded well to a second dose that was raised to 3 mcg and continued for 10 days. He returned home on the beta blocker propranolol and has remained free of symptoms.

Dramatic Response Seen in Teenager (TR-22)[2]
This paper from the United States is a case report of a 15-year-old girl with EM. She had become bedridden after suffering with very painful EM in her hands and feet for seven weeks.

Previous treatment with many medications including sedatives were in vain so that she kept her extremities constantly cooled with ice packs.

The girl was admitted to a rehabilitation unit in Missoula where she refused all pain and anti-anxiety medication. She received nitroprusside at the rate of 1 mcg/kg/min. Her response was dramatic as after 17 hours infusion all her pain and redness from EM had ceased. Nitroprusside was withdrawn after 64 hours and the girl returned home with no need for medication or cooling packs. She remained free of EM when seen again at six months.

More Success Reported
Other reports describing success with nitroprusside infusion include two papers by Ozsoylu. EM symptoms of his three patients (one 9-year-old and two teenagers) ceased within a few days of receiving infusion rates between 1-5 mcg/kg/min.

Success for five children with EM and high blood pressure was reported by Drenth's team, while Zenz's team resolved EM symptoms in a five-year-old boy.

Kvernebo achieved remission of EM in an 8-year-old and 17-year-old after infusion rates of between 1-5 mcg. Rauck has treated a 17-year-old with epidural infusion of local anesthetics as well as nitroprusside. The patient remained free of EM for two years.

These reports indicate that the vasodilator nitroprusside is a valuable therapy and should be considered for use with children who have not responded to other treatments. The reason why nitroprusside can produce such dramatic results remains unclear while research continues to elucidate the different causes of EM.

1 Erythromelalgia: an endothelial disorder responsive to sodium nitroprusside. Chan MK, Tucker AT, Madden S, Golding CE, Atherton DJ, Dillon MJ. 2002. Archives of Diseases in Childhood 87: 229-30.

2 Nitroprusside treatment of erythromelalgia in an adolescent female. Stone JD, Rivey MP, Allington DR. 1997. Annals of Pharmacotherapy 31: 590-592.

Article Archive Expanded, Reorganized

An additional 10 scientific articles—most published in 2004 or 2005—now are included in the Article Archive on TEA's Web site. This growing library also has been reorganized so articles are easier to find.

Based on suggestions made by scientist and TEA member Jean Jeffery and TEA President Lennia Machen, articles now are sorted into six categories, each with its own prefix along with its number. (Most article numbers have not changed.)

Jeffery also wrote brief summary sentences describing each paper. These descriptions appear with the articles' titles on the Web site and should help members better understand the articles' contents.

Three of the recently added articles report the findings of Yale researchers Stephen Waxman, M.D., Ph.D., Sulayman Dib-Hajj, Ph.D., and colleagues. (This research—partially funded by TEA—has proved genetic mutations cause the problem resulting in the pain of inherited EM.)

And two more articles also deal with genetic mutations recently identified that cause the dysfunction underlying primary EM. Both are authored by European researcher Joost P. H. Drenth, M.D., Ph.D., and his colleagues.

The article that reports a clinical trial of misoprostol in treating EM (TR-58, formerly M058) by Drs. Cato Mork and Knut Kvernebo also is now available. This paper was the subject of a "plain English" explanation by Jeffery in the September 2005 issue of *FootSteps*.

New categories

G (General)—wide range of information on EM including descriptions, associated conditions, causes, and sometimes treatments.

R (Research)—technical articles published in medical journals. Most deal with research into vascular, neurological or genetic aspects of EM.

TR (Treatment)—survey of treatments. Most articles are from medical journals; some are written for the general public.

EM/R (EM and/or Raynaud's Phenomenon)—medical journal articles about Raynaud's—another temperature-associated disorder—and its relationship to EM. Some with treatment information.

TEA (TEA Document)—papers published by TEA.

PUB (Publicity/news media releases)—news media articles about people with EM and TEA and press releases.

Newly added articles

R-52 "Erythromelalgia: A hereditary pain syndrome enters the molecular era." Waxman, Dib-Hajj. 2005. Painful symptoms of EM caused by defective sodium ion nerve channel.

R-53 "Gain-of-function mutation in $Na_v1.7$ in familial erythromelalgia induces bursting of sensory neurons." Dib-Hajj, Rush, Cummins, Hisama, Novella, Tyrrell, Marshall, and Waxman. 2005. Study of the third mutation in the gene for sodium channel 1.7 in the Alabama family.

R-54 "Genetic heterogeneity and exclusion of a modifying locus at 2q in a family with autosomal dominant primary erythermalgia." Burns, Te Morsche, Jansen, Drenth. 2005. Discovery of the second known EM gene.

R-55 "SCN9A Mutations Define Primary Erythermalgia as a Neuropathic Disorder of Voltage Gated Sodium Channels." Drenth, Te Morsche, Guillet, Taieb, Kirby and Jansen. 2005. Sodium channel mutations cause neuropathic pain of EM.

R-56 "Erythromelalgia: Vasculopathy, Neuropathy, or Both? A prospective study of vascular and neurophysiologic studies in erythromelalgia." Davis, Sandroni, Rooke, Low. 2003. Detailed study of nerve abnormalities in EM patients. (Abstract only)

R-57 "Autosomal Dominant Erythromelalgia." Finley, Lindsay, Fine, Dixon, Burbank. 1992. Study of Alabama family with inherited EM.

TR-58 "The prostaglandin E1 analog misoprostol reduces symptoms and microvascular arteriovenous shunting in

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Research Update

Yale finds mutation in children with no family history

Yale School of Medicine researchers recently collaborated with a group of investigators from China in studying DNA samples from two children with EM whose parents have no symptoms of the disease.

They found that these children carry another mutation in the gene for sodium channel Nav1.7. This mutation is similar, although not identical, to the one they previously found in 17 members of the Alabama family with inherited EM. (See *FootSteps*, June 2005, "Study of Alabama Family with Primary EM Published.")

The children in this study are what the researchers call "founders" of inherited EM. Although their parents have no symptoms of EM, they are expected to pass their genetic mutations on to their descendents. This study points out that it can be useful to screen young patients with "burning feet syndrome" for mutations in Nav1.7 even if there is no family history of the disease.

Titled "Sporadic onset of erythermalgia: a gain-of-function mutation in Nav1.7," the study has been accepted for publication in the journal *Annals of Neurology* and is in the process of being published.

This will be the fourth article by these researchers about their findings in studies of EM to be published in 2005 in highly respected medical journals.

The researchers believe that because other pain syndromes, including acquired disorders, involve altered sodium channel function, EM may emerge as a model disease that holds more general lessons about the molecular neurobiology of chronic pain.

These neuroscientists discovered that the pain people with inherited EM experience is caused by a defective sodium ion channel in the nervous system. The defect is due to a mutation of a gene on chromosome 2.

Sodium ion channels are tiny pores in the walls of nerve cells. They regulate the flow of sodium ions into nerve cells to generate and transmit nerve messages that travel in waves along nerve fibers. (See *FootSteps*, June 2005, "Yale Research: Journal Article Translated.")

Funding for the Yale research was provided in part by TEA. Our organization gave Yale $60,000 in 2005.

Fundraising:

A Challenge for TEA Members

As an all-volunteer organization, TEA has to depend on the ingenuity of its members to raise money for the Research Fund.

Much of the approximately $115,000 raised in TEA's first six years has been put to good use by helping fund Yale University neuroscientists' breakthrough research into EM. And most recently by funding a grant to the Dutch researcher who is seeking to identify a second gene that causes EM.

Now we need to raise more.

Here's one method several members recently used to raise money: When holding parties to celebrate birthdays, ask invitees to make donations to TEA instead of buying gifts.

For example, when Scottish TEA member Nancy Farish celebrated her 80th birthday, family and friends invited to her birthday party were asked to donate to TEA rather than buy her gifts. The day of the party, buckets for donations were strategically placed throughout the house and garden. The result was $523 in gifts to TEA.

From the President

Priceless Gifts: My Reflection on Six Years

by Lennia Machen

As my term as President comes to a close, it's a time of reflection for me. I see the last six years as a kind of gift exchange. But it seems the exchange has been a bit one-sided—with gifts mostly from you to me.

You all have given me the gifts of experience and knowledge, with a little wisdom accumulated along the way. You've also given me the gift of acceptance and patience as TEA has grown. It's been a group effort to be sure, for which I am truly thankful.

Something you may not know is how very hard the TEA directors work to make TEA possible. A small group of eight individuals, most having EM themselves, others caring for someone with EM, work tirelessly to handle the many hours of administrative tasks as well as plan and implement new programs.

Without fanfare, without pay, this small group puts in many hours a week to make TEA possible. I'd like to thank each one of the TEA volunteers for all they do, all they sacrifice in pain, effort and time, all they give up for *all* of us. Just to be sure we receive the best information on EM available and the support we need. What value can be placed on giving of one's self? No price, because it's incalculable.

Another gift is that of financial support to see that TEA remains strong and research into EM continues. Many TEA members and others have given much. I thank all who have made donations to our Research Fund. My future holds hope because of your unselfish gifts—another offering of inestimable value.

Upon reflection, there is little that could compare to the bounty of gifts all of you have given me. I feel like the little drummer boy having only a song to give in return.

My gift, my drummer boy's song, is to suggest we all take heed of the advice to decrease and eliminate the archaic practice of treating our EM with cooling and icing. If my six years add up to only one statement, only one bit of advice, it would be that. I took the challenge years ago and after many months of burning pain, hot hands and feet I eventually found great relief.

Having the burning finally subside and the redness finally start to fade was a precious gift. All because of the advice given me by a young woman who pioneered this courageous path. Then, in 2004 the MAC doctors I met in Oslo reaffirmed the advice.

Giving you the gift of my experience is intended only to help people with EM. I pass along the challenge to each of you: Gradually stop using cooling and test the possibility of getting better. It's not easy and I can't guarantee the results. It remains the one gift nothing has matched. I got my life back and that's priceless.

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FootSteps is the official publication of The Erythromelalgia Association and is published quarterly for its members. The intent and purpose of this publication is to inform those with erythromelalgia or their friends and families—not, in any way, to provide medical advice.

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 have tales of the often long and difficult diagnosis process and the ways we've found to cope. TEA encourages you to share your experience by writing your story. If you think you're not a writer, never fear. We can help you write and edit your story. Please send your story to Gayla Kanaster, gaylakanaster@aol.com or 2532 N. Fremont St., Tacoma, WA 98406.

Barbara Oehl writes: I am 66 years old. Now that we are both retired, my husband and I live for six months in western Montana near Missoula and the other six months in Fountain Hills, Arizona.

My doctor first noticed my red feet during a routine exam in 1997. At the time, there was no pain that went along with the redness—but that changed rather quickly. She sent me to a dermatologist who correctly diagnosed this redness as EM while searching through his medical books. He told me there was nothing he knew of that he could do for me. He did order many tests, however, because his books told him EM was usually accompanied by an underlying more serious disorder or problem. At that time all of the tests came back negative, but, in 2002 I was diagnosed with peripheral neuropathy.

Several doctors dismissed me because they had no other patients with this problem and my case did not warrant their time to research. I then searched the Internet, found the Erythromelalgia Association Web site and eventually joined TEA. I happened upon a doctor here in Montana who was very caring and when I mentioned my problem with EM he recommended trying Neurontin. I told him many of the people in TEA use that drug with some success, and he prescribed it for me. This was in 2001 and the Neurontin did help me somewhat but I always wished for something better.

Then, I read with interest an article in the September 2004 issue of *Footsteps* by Dr. David J. DiCaudo at the Mayo Clinic in Scottsdale, AZ about venlafaxine (Effexor XR). I showed Dr. DiCaudo's article to my doctor here and he decided to give me samples of Cymbalta, which is an antidepressant like Effexor that is also used for people who have burning feet due to diabetic peripheral neuropathy. The first month I took this drug, I experienced about a 25 percent decrease in pain. My doctor said the drug can take about two months to get into one's system completely. Now, after having taken Cymbalta (30 mg once a day) for two months I can say I am 90 percent better. I am so encouraged that I wanted to tell my story. I am actually able to wear shoes and be in the garden in the sun for two to three hours without any problem.

My thanks to TEA, to *FootSteps*, and to Dr. DiCaudo in Scottsdale for the information that led to such a change in my life. Most days go by now without my even thinking about EM.

Lorraine Beard writes: I am 57 years old. I have both Raynaud's and erythromelalgia. In June 2003, I was treated for breast cancer and then started on long-term tamoxifen. Some months later, I began to have vicious cycles of chills, flushes and burning feet, particularly at night. I was losing a great deal of sleep. In February 2004, I was prescribed venlafaxine in the hope that it would control the flushes and associated symptoms. After one dose, I experienced dramatic and rather frightening side effects! I was advised to try a very small dose, which I did. Several hours later my fingers began to tingle and to feel tender when I typed on my keyboard. The tingling persisted intermittently for some weeks. Within a few days of taking venlafaxine, not only were my feet burning and becoming bright red, but my hands began to do the same. In the cooler weather I found that my long-standing Raynaud's disease had become much worse.

I did some research and came across information about EM and my symptoms began to make some sense. My local doctor and a specialist agreed with the diagnosis.

In June 2004, I started HRT, which broke the vicious cycle of chills, flushes and burning

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RESEARCH FUND DONORS

TEA thanks the people and organizations who made donations to TEA's Research Fund in the six months from June 1, 2005, through November 30, 2005.

Thank you all!

Aetna Foundation
John Allen
Michael Bame
Susan Barkauskas*
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Rolf & Nancee Wirthgren
Marion Wood*
Donna Young*

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Lorraine's Story

hands and feet. However, I continued to suffer from burning hands and feet whenever I got comfortably warm and my Raynaud's often caused discomfort at other times. The burning also affected my ears and nose at times.

I tried antihistamines, aspirin and ibuprofen with no benefit. I then tried a very small dose of amitriptyline at night. This seemed to reduce my erythromelalgia a little and to make my Raynaud's worse. Neither the addition of magnesium tablets, nor Prazosin for the Raynaud's helped.

In November 2004, I began gabapentin. Since then my symptoms of EM have decreased and I've had better nights.

I have a mentally challenging job and work in a Christian environment with understanding colleagues. I have continued to work full time through most of this. I am now very sensitive to cold (peripheral circulation shuts down in fingers and toes) and also very sensitive to warmth (EM symptoms). I am grateful, however, for improvement I have experienced since starting gabapentin. Last winter my Raynaud's caused more daily discomfort than my EM.

I would like to thank TEA for promoting better understanding of erythromelalgia and its management.

You're Not Alone

Networking Program Provides Support, Information

Would you like to contact others living near you who also have EM? TEA offers a service—the Networking Program—that helps you do just that. To participate in the Networking Program, just fill out the form below and send it to Judy Reese, Networking Chairperson, 1155 E. Wild Duck Lane, Salt Lake City, Utah 84117.

By signing the application form, you give TEA permission to provide your name and address to other TEA members who are a part of the program. And there are quite a few both in the U.S. and the U.K. TEA holds personal information about its members in strict confidence and will not disclose it unless you give TEA written permission.

You must be a member of TEA to participate in the Networking Program. And you must agree to respond to any letters or other communications you receive from other members.

Originally intended just for those without access to TEA's Web site, the program now is open to any member whether you are computer savvy or not. Initially members connected by writing letters, but now often communicate by phone or email.

Networking Program members without access to the Internet can also order copies of articles in TEA's Article Archive. At least once a year, the entire list of articles in the archive is printed in this newsletter. Those ordering copies of articles are charged a small fee to cover mailing costs and copying charges based on the length of the article.

Listed in this issue are only articles that have been recently added to the archive. (See "Article Archive Expanded, Reorganized," page 4.) Those wishing to order any of these articles should email Gayla Kanaster at gaylakanaster@aol.com or write to her at 2532 N. Fremont St., Tacoma, WA, USA, 98406.

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 correspondence from other Networking Program members who contact you.

Signature_____

Name_____ Date _____

Street Address _____

City _____ State/Province _____ Zip/Postal Code_____

Country_____ (optional) Phone (_____) _____

(optional) Email address _____@_____

Mail this form to:
Judy Reese, 1155 E. Wild Duck Lane, Salt Lake City, Utah 84117

(continued from page 4)

New Articles

erythromelalgia — a double-blind, crossover, placebo-compared study." Mork, Salerud, Asker, Kvernebo. 2004. Improvement of EM in 14 out of 21 patients.

EM/R-59 "Coexistence of erythromelalgia and Raynaud's phenomenon." Berlin, Pehr. 2004. A case report and comparison of the underlying causes of EM and Raynaud's.

G-60 "A refractory case of erythromelalgia involving the ears." Ramires, Kirsner. 2004. Detailed report of one EM patient who remained resistant to all treatment.

R-61 "Mutations in SCN9A, encoding a sodium channel alpha subunit, in patients with primary erythermalgia." Yang, Wang, Li, Xu, Li, Ma, Fan, Bu, Liu, Fan, Wu, Jin, Ding, Zhu, Shen. 2004. Discovery of two mutations in sodium channel 1.7 gene in a Chinese family.

Other Additions

In addition to medical journal articles, stories from the news media and press releases are now on the Web site as well.

In the Article Archive, you can find the media release about research into EM issued by Yale last July: PUB-60 "Insights into Understanding and Diagnosing Inherited Pain Syndrome."

TEA's press release issued the same day as the Yale release is now on the public side of the Web site in the "Events" section. Both articles about TEA member Pamela Costa, Ph.D., are also posted in "Events."

Published in the *Tacoma News Tribune* October 9, 2005, the stories about Costa are titled "Pain Haunts, But Cannot Break Her," and "The Pain Chronicles: Erythromelalgia."

The latter article focuses on the research going on at Yale University and what it could mean to people with EM as well as those who live with chronic pain because of other pain syndromes.

To order copies of any of the articles in the Article Archive, write to Gayla Kanaster, 2532 N. Fremont St., Tacoma WA, USA 98406 or email her at gaylakanaster@aol.com

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