

# PXE Awareness

*National Association for Pseudoxanthoma Elasticum (NAPE, Inc.)*

Volume 11, Issue 2 . April 2005



## 2005 NAPE Annual Conference



Los Angeles



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# National Association for Pseudoxanthoma Elasticum (NAPE, Inc.)

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NAPE, a non-profit 501(c)(3) support group whose mission is to provide education and support for PXE-affected persons publishes PXE Awareness. Articles in this newsletter are provided for information only and are not a substitute for professional medical advice. You should not use information in this newsletter to diagnose or treat medical or health conditions. Please consult your healthcare provider before beginning or changing any course of treatment.

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## President's Letter

Dear Friends,

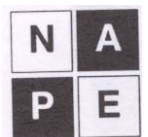
Welcome from the NAPE Office where early Spring is in the air with bulbs poking above the earth and birds chirping to greet longer sunny days.

NAPE Board members started the year with committee activities via conference calling. This brings our Board scattered across the USA and in Canada and England together as needed with great savings in time and costs. Special thanks to Board members Rosemary Atallian and Jane Tipton for managing this helpful innovation.



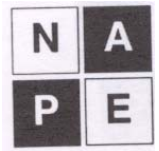
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The Board met in Kansas City after last November's conference and made plans for this year's conference. We hoped to bring Dr. Berthold Struk to talk about the heart and PXE. Dr. Struk practices cardiology in Berlin. Our members know him best as the researcher whose work led to the identification of the gene whose malfunction results in PXE. Dr. Struk performed his research at Harvard University.



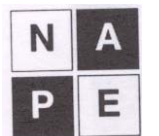
After several years of research, and in the long tradition of scientific discovery, Dr. Struk

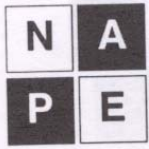
announced his break-through identification of the locus of the gene. At that point, three other labs joined the search building on Dr. Struk's findings. All four labs announced their finding of the gene within the same month. That all four labs identified the same gene confirmed Dr. Struk's work and the validity of his findings. We are thrilled that Dr. Struk will take time from an exceedingly busy schedule to meet with us. This is a wonderful opportunity for us to learn from one of the world's few great authorities on PXE. Though home in Berlin, he has continued to confer and advise by email and telephone.



Dr. Struk's research in PXE would not have occurred if Dr. Kenneth Neldner, after years of seeking, had not been successful in identifying Dr. Klaus Lindpaintner as the main source of funding for the expensive research project. Dr. Neldner, our very own world authority on PXE, participated in the project, including the identification of the PXE families needed for its success. Dr. Neldner has also been vital to the development and life of NAPE. He has been a key speaker at NAPE conferences, sharing with participants information needed for living more fully with PXE. The Board is delighted that Dr. Neldner will be a featured speaker at this year's meeting. He will have two full hours late Friday afternoon to give enough time to guide conference participants in their own health care.

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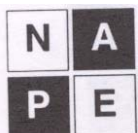
We will meet in Los Angeles, California, on July 15 (Friday) and 16 (Saturday). The first meeting will begin at 4:00 pm Friday, July 16, with Dr. Neldner's two-hour program. Following a short break, we will gather for a buffet supper and have time to share experiences prior to a full Saturday meeting schedule.

We are working with staff of the Jules Stein Eye Institute of UCLA to prepare other presentations. The Jules Stein Eye Institute, among the most highly respected eye centers in the nation for research and clinical services, is heavily involved in macular research and we expect to have a program on this topic – especially on newer therapies and research. We are working on another presentation on how PXE affects the body's elastic tissue, including information on where elastic tissue is found in the human body.

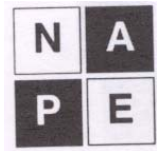
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You may know that the FDA is holding hearings on its proposed new food pyramid. The new pyramid is quite different from the current one. It is being hailed by many nutritionists and physicians as a great improvement. We are planning a program on it in relation to PXE nutrition needs.

And finally, we plan to demonstrate our website natural language program and to talk about NAPE automation and its role in providing



information to those with PXE. As well, there will be a short business meeting for members.



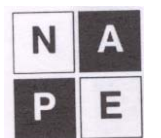
In short, we have planned an ambitious program for a Friday evening and Saturday. In addition to the buffet supper on Friday, we will provide lunch and snacks on Saturday. Participants will need to provide their own breakfast Saturday morning. The meeting will end no later than 5:00pm on Saturday. Our hope is that participants will leave on Saturday with knowledge to cope with PXE and with new friendships with others coping with similar issues.

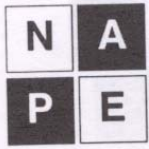
All conference activities will take place at the Holiday Inn, Brentwood, which is within walking distance of UCLA and the Jules Stein Eye Institute. We hope many participants will stay at the Holiday Inn, which is giving us a special rate, so that you can visit with and get to know your peers. Please find the registration form for the conference on page 23.

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The Board is working hard to provide a significant PXE conference in Los Angeles. We hope many members, especially those in the West, will join us for a lively and helpful conference.

See you all there!  
Frances Benham, PhD  
President





## Double Vision

*By Jennifer Trueland (HWU Magazine)*

A technique developed to allow armies to detect camouflaged vehicles could help doctors diagnose the most common diseases of the eye, potentially saving the sight of millions of people.

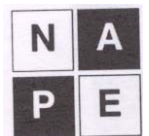
“The key is the chemical make-up of substances at specific wavelengths which translates into different colors in the image. These can then be analyzed.” Interview with Dr. Andrew Harvey.

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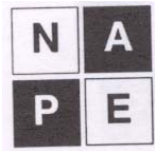
Researchers in Heriot-Watt’s School of Engineering & Physical Sciences are working on a new way of taking pictures of the retina to study blood vessels in the eye to look for signs of disease.

They believe the technique, using spectral imaging, can detect the presence of the most common eye diseases, glaucoma, diabetic retinopathy and age-related macular generation.



If diagnosed at an early stage, glaucoma and diabetic retinopathy can be treated successfully

so that the patient's sight can be saved. But current methods of detecting eye diseases are unreliable and, in some cases, even dangerous.



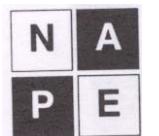
The Heriot-Watt technique involves using a standard ophthalmoscope, which has been modified with a liquid crystal tunable filter, which allows images to be taken of the retina at specific wavelengths. These images can then be analyzed to show the level of oxygen in the blood vessels in the eye, which gives important information about how healthy you are.

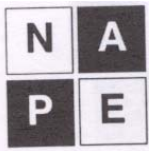
Healthy vessels take oxygen and other nutrients from the blood as it pumps through, while diseased vessels will be less efficient at doing so, leaving the blood more highly oxygenated. Where the metabolism is lower due to disease, less oxygen is used.

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“There's no other way of measuring the oxygenation other than through its spectrum,” says Dr. Andrew Harvey, a senior lecturer and supervisor of the project. “Other techniques look at the flow of blood so they can tell if there are blockages. But they can't show the biochemistry of the blood. What we're providing is chemical imaging of the retina and that's very exciting.”

Dr. Harvey and his colleagues developed the tool as a way of finding a medical application for technology being developed for the Ministry of





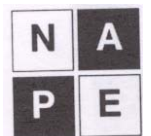
Defense. They have found that spectral imaging allows armies to differentiate between different types of vehicle or between a tank and foliage, for example. The key is the chemical make-up of substances at specific wavelengths, which translates into different colors in the image. These can then be analyzed.

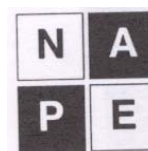
“The technique allows us to combine pictures at different wavelengths to give a true picture of what’s going on,” explains Dr. Harvey. “The retina is unique because we are able to look into living tissue, unlike other parts of the body where the skin gets in the way. That means there’s greatly reduced clutter, which is quite attractive.”

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The team has shown that the concept works and have carried out preliminary trials, both on healthy people and on patients with glaucoma and diabetic retinopathy. So far, it has proved successful in helping doctors to detect and monitor the conditions. The next stage will involve testing it more widely. The team has made sure some of the aspects of the technology are under patent and has already attracted interest from a company keen to develop it commercially.

Dr. Harvey believes it has the potential to be a cost-effective tool which would be a vast improvement on current methods. “Retinal eye examinations can be very unpleasant and some,






such as the Fluorescein Angiogram for diabetic patients, which involves injections of dye, can be dangerous. Some people have bad reactions to it and it can even be fatal. So it's no surprise that sometimes people don't go along for their treatments. But this technique is safe, simple and non-invasive, so we think people would be happier to attend for regular screening."

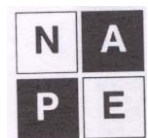
He is hopeful that, if all goes well, the technique will be widely available in the next three to four years.

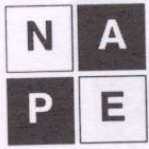
But it doesn't stop at eye disease. Because spectral imaging of the retina gives a clear picture of vascular function, it may also give clues to how the vascular system in the rest of the body is working. That means it might give early warning of other problems which could lead to strokes, for example, giving an opportunity to take preventative action.

"I suppose you could say that in this case the retina is the window to the vascular system," says Dr. Harvey. "I think this technique has enormous potential." 

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# C-Reactive Protein and Blood Lipids

*By Kenneth H. Neldner, MD*

Inquiries have been submitted to NAPE regarding C-reactive protein (CRP), what it is and why it is important. Explaining CRP is actually rather difficult but this article provides a brief explanation and a summary of what we need to know about it.

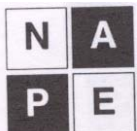
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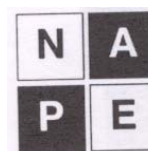
Briefly, CRP is a measure of inflammation anywhere in the body. If it involves blood vessel walls, chronic inflammation seems to have the ability to bind cholesterol to arteries and increase the risk for cardiovascular problems. Hence, an elevated CRP level could be a predictor of heart disease. This is why CRP testing has been added to the list of the so-called lipid profile group of tests.

A recent article in the *New England Journal of Medicine* reported on a large group of patients with coronary artery occlusion due to cholesterol deposits. They were treated with the statin drugs which reduced their cholesterol and CRP levels, both of which had been elevated.



Dr. Kenneth Neldner





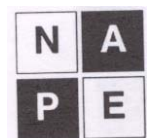
These observations lead to why CRP and its inclusion in the lipid profile series of blood tests is important. Cholesterol blood levels were the first to be included, followed by triglycerides. Then came the high-density lipoproteins (HDLs) and the low-density lipoproteins (LDLs). But it was soon learned that the HDLs prevent accumulation of cholesterol in blood vessels, so high blood levels are good, whereas the LDLs promote the deposits of cholesterol. Ideally, HDLs should be 50 or above and LDLs should be 100 or below. Since high CRP levels have been associated with high cholesterol levels, CRP has been added to the lipid profile group of tests. It was next learned that homocysteine—a normal substance in the blood was important in determining LDL levels, so a high homocysteine blood level could increase LDL levels further.

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In summary, a complete lipid profile must include all six items listed below. If any are abnormal, appropriate measures should be taken to get them back to a normal range.

1. Cholesterol
2. Triglycerides
3. High-density lipoproteins (HDL)
4. Low-density lipoproteins (LDL)
5. Homocysteine
6. C-reactive protein (CRP)


Note that CRP levels could be artificially inflated in the case of an existing injury or





infection. The American Heart Association set standards for CRP levels as follows:

- low risk of developing cardiovascular disease: less than 1.0 mg/L
- average risk: between 1.0 and 3.0 mg/L
- high risk: greater than 3.0 mg/L

The last item to consider is blood pressure. Clearly, high blood pressure is undesirable for everyone but perhaps more so for PXE patients more prone to retinal and gastric hemorrhages. Blood pressure of 140/90 was always considered the upper limit of normal, but recently cardiologists have reduced the upper limit to 120/80. Ask that your blood pressure be taken two or three times when in your doctor's office. You will be surprised at how it varies. Better still, purchase your own digital device and monitor yourself under different conditions; they can be purchased for as little as \$50. They are battery operated, so all you have to do is wrap the cuff around your arm and press a button. 

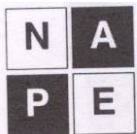
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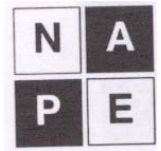
## Renagel for PXE?

*By Deborah M. Clark*

Dr. Mark Lebwohl, head of Dermatology at Mount Sinai School of Medicine in New York City, has received a \$490,000 grant from the Food and Drug Administration (FDA) to investigate the,




drug, Renegal, in the treatment of PXE.

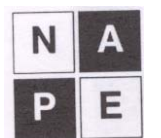


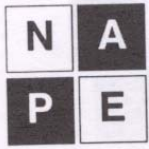
Renegel was developed primarily for the treatment of end-stage renal disease patients. Patients who suffer from kidney failure due to hyperphosphatemia, or too much phosphorous in the bloodstream, respond well to treatment with Renegel.

Renegel is a phosphorus binder that contains no aluminum or calcium and is made of sevelamer hydrochloride on anhydrous bases. The human body tries to stay in a state of homeostasis, or balance, in the ratio of phosphorous to calcium. So the potential benefit to those with PXE is that as phosphorous is lowered in the bloodstream, so too is calcium. Calcifications of certain of the body's elastin fibers are serious symptoms of PXE. Renegel then acts as a robotic agent that is *not* absorbed into the body and *may* reduce calcification. And here's some good news: there is **no** calcium bone loss of renal disease patients treated with Renegel and it has been shown to have the additional benefit of lowering LDL (bad) cholesterol.

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Dr. Lebowhl thinks that Renegel might reverse some of the effects of calcification in PXE patients' skin flexural areas, Bruch's membrane, and the vascular circulatory system. It would be terrific if he proves correct. 





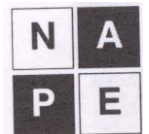
# A Promising New AMD Treatment

*By Frances Benham, PhD*

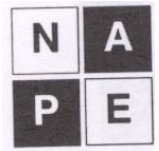
Pfizer, Inc., through its Eyetech Pharmaceuticals division, received FDA approval February 1, 2005, for its new drug Macugen. Macugen is Pfizer's tradename for an anti-VEGF treatment; it binds to and so inhibits vascular endothelial growth factor (VEGF) activity.

VEGF, a protein, has been identified as an essential signal for the processes that underlie the formation of wet age-related macular degeneration (AMD). VEGF is critical to the formation of undesirable new blood vessels, increased leakage from blood vessels and inflammation, all of which contribute to the progression of the neovascular (wet) form of AMD. VEGF has also been implicated in blood retinal barrier breakdown and pathological ocular neovascularization.

Macugen joins the select group of medications that inhibit conditions leading to AMD. Pfizer indicates Macugen will be an improved longer-lasting treatment. PXE patients may benefit from this new AMD treatment, although this has not yet been established. As always, our retinologists must evaluate its potential for individual cases. Additional information is on the Pfizer Macugen websites.



# PXE Care: How to Find a Doctor



*By Frances Benham, PhD  
and Mary Krieger, R.N., MIS*

The request most often received by NAPE is to identify a doctor experienced in PXE care. These requests come from across the United States as well as from other countries. NAPE would love to be able to provide that information, but we do not have it except for a few

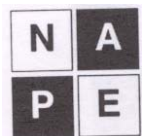


locations, typically in a few urban areas. Those of us who have PXE are widely scattered in the general population so that most doctors may never meet a patient with PXE. How then does one get appropriate medical care?

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The first step is to learn as much as possible about PXE. This may seem strange, but it is an important experience learned by those who live with PXE. The NAPE website ([www.napxe.org](http://www.napxe.org)) provides much information. Reading this material, if possible with a family member or trusted friend will help you to understand your situation better and to talk more usefully to a physician.

The next important step is to talk with others who have been diagnosed with PXE. NAPE's website and newsletters provide contact information for those happy to talk with you. Check the PXE Pals list. You may also contact the NAPE office to obtain PXE contacts.



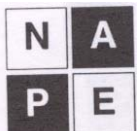


to talk with you. Check the PXE Pals list. You may also contact the NAPE office to obtain PXE contacts. For example, a young woman who has PXE and plans to become a mother will benefit through direct contact with a new friend who has recently had that experience. A business person struggling with vision loss can benefit through contact with others who have similarly struggled. All can benefit by learning how others have coped and live full lives. In the process, you can gather information about medical care and perhaps locate a physician. The NAPE office will try to provide contacts in your geographic region. The annual NAPE conferences are another way to meet others with PXE who can help you gather insights on how to live with PXE.

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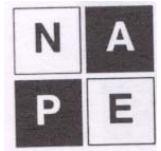
Another step which may prove vital in identifying local doctors is to determine if there is a nearby association which provides services to those with vision problems. Here you may be provided physician contact information. Check your local telephone directory.

What specialists should you see in addition to a general practitioner (these days, this may be a doctor of internal medicine)? You should develop relationships with a retinologist and a cardiologist. If you are having digestive problems, you will want to find a gastroenterologist. Dermatologists often provide the diagnosis of PXE when contacted because of the skin disfigurement caused by PXE. Once you are established with each specialist, you will determine frequency of check-ups and personal care protocols.

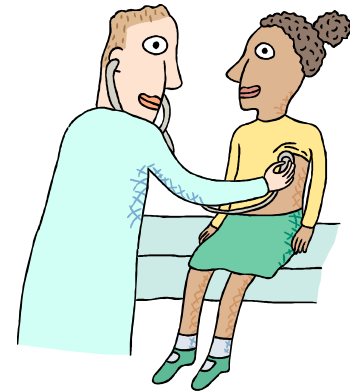


If you live near a medical school, you may find needed help more easily. Many medical schools are associated

with clinical practices dedicated to training new doctors through the care of patients under the guidance of experienced teaching physicians. It is here that you may find the most up-to-date knowledge of current medical research and practice.



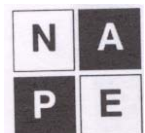
Medical associations - local, state, and national, especially those focused on the specialty needed - may be identified through the Internet, in a local telephone directory, or by requesting assistance from the reference department of a public or academic library.

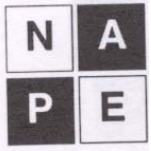


One Internet resource that may be particularly helpful is MedlinePlus (<http://www.nlm.nih.gov/medlineplus/>). This web site has extensive information from the National Institutes of Health and other reliable organizations on medical conditions and diseases. Under the “Directories” link, you can find board certified physicians in various medical specialties. Under the “Other Resources” link, there are lists of local libraries which provide services to consumers and a list of medical associations by health topic, for example retinal disorders. NAPE has a medical advisory committee whose members may be available to your local physician on specific PXE issues. Your local doctor can contact them directly to discuss your problem. If one can travel, these physicians may be contacted for an appointment, but it is important to build relationships with physicians close to home.

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Finally, it is of great importance to recognize our own responsibility for our wellness, both physical and emotional. NAPE’s mission is education and support of PXE patients. There is much we can do to make our lives better and in the process we will be better able to identify and work well with our physicians.





## NAPE Q & A



*By Kenneth. H. Neldner, MD*

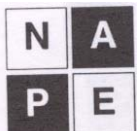
**Q** I read that bone marrow transplants were being used in sickle cell anemia and also that there was some overlap between sickle cell anemia and PXE. Therefore, might bone marrow transplants help PXE?

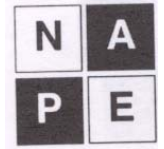
*- West Virginia*

**A** The quick answer is no. The only overlap lies in the fact that a rare patient with sickle cell anemia (SCA) will develop angioid streaks in their eyes that may resemble the angioid streaks seen in PXE. However, the streaks in SCA are due to iron accumulation in the retina and not calcium as it is in PXE.


In brief, SCA is a severe, hereditary form of anemia, most common in African Americans. It gets its name from the fact that their red blood cells are sickle shaped (like a last quarter moon) and not round, so they cannot carry oxygen as a normal red blood cell. This causes a great variety of problems in most all organs of the body as their hemoglobin falls due to the anemia. Pain is often a major symptom. There is no known cure, but blood transfusions are very helpful during crisis periods. SCA patients have no skin lesions as in PXE.

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Now, getting back to the original question, the thought is that if bone marrow cells (which make our red blood cells) could be transfused into the SCA patient and ‘take over’ their bone marrow where they would then make good normal red blood cells that it might help or even cure SCA.


We can only wish and hope that there might some day be something that could be injected into the PXE patient that would shut off the disease process and prevent the complications of PXE. In my opinion, this will have to come out of genetics studies. But even though we now know the genes that cause PXE, we still don’t know what these genes do to cause the elastic fibers to take on extra calcium. 

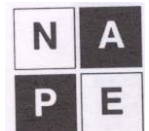
# 21

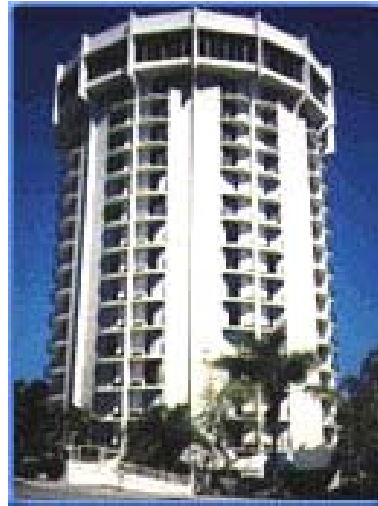
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If you have any questions you would like answered in upcoming issues of PXE Awareness, please write to us at NAPE  
8764 Manchester Rd., Suite 200, St. Louis, MO  
63144-2724

Or email us at [NAPEStLouis@sbcglobal.net](mailto:NAPEStLouis@sbcglobal.net)

Also, if you have had any unusual experiences with PXE – good or bad – we would love to hear from you. It is important for us to learn from each others’ experiences since most physicians know so little about PXE. Write to us or call us and we will write your story. 





Join us in Los Angeles for the

## 2005 NAPE Annual Conference

The conference will be held at the  
Holiday Inn, Brentwood/ Bel -Air.

[www.hibrentwood.com](http://www.hibrentwood.com)

More information will be mailed  
separately to NAPE members soon.

### Nearby Attractions É

Getty Center Museum (1 MI/1.61 KM)

UCLA (1.5 MI/2.41 KM)

Skirball Cultural Center (4 MI/6.44 KM)

Beverly Hills Shopping Rodeo Drive (4 MI/6.44 KM)

Santa Monica Beach and Pier (5 MI/8.05 KM)

Hollywood (6 MI/9.66 KM)

Universal Studios Hollywood (16 MI/25.75 KM)

Downtown Los Angeles (15 MI/24.14 KM)

Venice beach (12 MI/19.31 KM)

Disneyland (50 MI/80.46 KM)

\* The hotel offers free shuttle service within a 3-mile radius.

# NAPxE National Association for Pseudoxanthoma Elasticum

8764 Manchester Road, Suite 200, St. Louis, MO 63144-2724

Telephone: 314-962-0100 Website: [www.napxe.org](http://www.napxe.org) Email: [napestlouis@sbcglobal.net](mailto:napestlouis@sbcglobal.net)

## REGISTRATION FORM ANNUAL MEETING

Friday, July 15 Saturday, July 16, 2005

The registration fee is \$45 per person and includes Friday evening reception/supper and the Saturday annual meeting with guest speakers, Q & A sessions, lunch, and meeting refreshments.

NAME \_\_\_\_\_ PHONE \_\_\_\_\_

ADDRESS \_\_\_\_\_ FAX \_\_\_\_\_

CITY \_\_\_\_\_ EMAIL \_\_\_\_\_

STATE \_\_\_\_\_ ZIP \_\_\_\_\_ COUNTRY \_\_\_\_\_

ARRIVAL DATE \_\_\_\_\_ DEPARTURE DATE \_\_\_\_\_

NAME(S) OF GUEST(S) ATTENDING WITH YOU:

\_\_\_\_\_

NO. ATTENDING MEETING \_\_\_\_\_ x \$45.00 = AMOUNT ENCLOSED \$ \_\_\_\_\_

You are responsible for making your own hotel reservations. Please call the **Holiday Inn, Brentwood, in Los Angeles, California at 1-310-476-6411 or 1-800-465-4329**. Be sure to call **by June 27, 2005**, and say you are with NAPE to get the group rate of \$109 per night (single or double) plus tax. Parking is \$11 for one vehicle or you may park on the street. You may request a room away from the highway if you are sensitive to noise.

Check here if you do not plan to stay at the Holiday Inn and write in the telephone number where you can be reached while in Los Angeles in case we need to get in touch with you.  
Los Angeles telephone number \_\_\_\_\_.

Payment of the registration fee must accompany this form. Please make your check payable to NAPE, Inc., in U.S. currency. We cannot accept credit card payments. Mail your registration and check to NAPE at the address shown above. Upon receipt, we will send you a confirmation packet.

If you require special assistance to participate fully, please provide a written description of your needs on a separate sheet of paper. In addition, vegetarian meals can be arranged if you note your request.

SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

Please mail this form to NAPE with payment by July 6, 2005  
CANCELLATIONS ARE NOT REFUNDABLE AFTER JULY 6, 2005

# PXE Pals



If you would like a PXE friend with whom you can correspond and talk, these NAPE members would like to hear from you (please notify the NAPE office if you have trouble contacting a PXE Pal so we can stay current):

## **Joan Bittner**

111 Willis Drive, Tonganoxie, KS 66086  
Phone: 913-845-2554

## **Steve Boyle**

828 N. 2<sup>nd</sup> Street, Montrose, CO 81401  
Phone: 970-249-8731  
sboyle@bio-geo.com

## **Lydia Chang**

77-11 35<sup>th</sup> Avenue, Apt. 2P  
Jackson Heights, NY 11372  
Phone: 718-898-1762  
stockchang@msn.com

## **Ron Dore**

282 Ole Road, St. Augustine, FL 32080  
Phone: 904-471-4662

## **Kimberly Edwards**

744 Eayrestown Rd., Apt. 40  
Lumberton, NJ 08048  
Phone: 609-702-9189  
kedwards0514@juno.com

## **Anita Fekkers**

P.O. Box 40, Wauneta, NE 69045  
Phone: 308-394-5917  
aef@bwtelcom.net

## **Patricia Gadziala**

5359 Ashleigh Road, Fairfax, VA 27030  
Phone: 703-263-7949  
(had translocation surgery)

## **Susan Golasz**

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Coconut Creek, FL 33066  
Phone: 954-974-7630  
susang2604@bellsouth.net

## **Marilyn Grobeson**

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Culver City, CA 90230-4810  
Phone: 310-390-6087  
pxeladyng@webtv.net

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Phone: 952-239-9495  
jay\_lindy\_humphreys@hotmail.com

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Puyallup, WA 98371  
Phone: 253-845-2527

## **Jeff Parnell**

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Granite City, IL 62040  
Phone: 618-931-3831  
par3jcn@forteisp.net

## **Michele Strohl**

98 Covington Place  
Catasauqua, PA 18032  
phone 610-264-1356  
mvstrohl@fastnet.com



# N A P E, Inc.

## The Three Amigos Lo28w-Vision Aid Program — Request Form

NAME \_\_\_\_\_ APT. \_\_\_\_\_  
 ADDRESS \_\_\_\_\_ CITY \_\_\_\_\_  
 STATE \_\_\_\_\_ ZIP \_\_\_\_\_ COUNTRY \_\_\_\_\_  
 PHONE \_\_\_\_\_ EMAIL or FAX \_\_\_\_\_

*An invoice or receipt must accompany each request*

Description: Doctor Visit/Other — Name/Address/Phone#

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

(Invoice enclosed , Receipt enclosed ) Cost \$ \_\_\_\_\_

Item 1: Company/Address/Phone#

Description of Purchase

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

(Invoice enclosed , Receipt enclosed ) Price \$ \_\_\_\_\_

Item 2: Company/Address/Phone#

Description of Purchase

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

(Invoice enclosed , Receipt enclosed ) Price \$ \_\_\_\_\_

- I am a N A P E member who does not qualify for this assistance from another source.
- In order to continue leading an active life, I am in need of the above vision help.
- I am attaching a physician's statement of visual acuity and a diagnosis of PXE.

YOUR SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_

N A P E APPROVES:  payment to doctor and/or vendor(s) for above expense(s)  
 reimbursement to member for above expense(s)

N A P E AUTHORIZATION \_\_\_\_\_ DATE \_\_\_\_\_

(Complete other side if your purchases exceed \$200 or if you have any comments or suggestions.)

8764 Manchester Rd., Suite 200, St. Louis, MO 63144  
 Phone 314-822-6273 Fax 314-962-0100



# NAPE, Inc.

## The Three Amigos Lo28w-Vision Aid Program — Request Form

**NAPE now reimburses 50% for the cost of purchases to a lifetime total of \$1,000**

Please complete this portion of the form if the vision aids you need exceed \$200 and explain the circumstances that prevent you from making these purchases without financial assistance:

I have \_\_\_\_ dependents;      I share my home with \_\_\_\_ adults;      I live alone

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Please use this portion of the form for comments or suggestions on how we can improve services to our members:

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**THIS SECTION RESERVED FOR NAPE RECORD KEEPING**

1. Date \_\_\_\_\_ Ck# \_\_\_\_\_ To: \_\_\_\_\_  
Description \_\_\_\_\_  
Amount \$ \_\_\_\_\_ Reimbursement Balance \$ \_\_\_\_\_
2. Date \_\_\_\_\_ Ck# \_\_\_\_\_ To: \_\_\_\_\_  
Description \_\_\_\_\_  
Amount \$ \_\_\_\_\_ Reimbursement Balance \$ \_\_\_\_\_
3. Date \_\_\_\_\_ Ck# \_\_\_\_\_ To: \_\_\_\_\_  
Description \_\_\_\_\_  
Amount \$ \_\_\_\_\_ Reimbursement Balance \$ \_\_\_\_\_

Please cut out, complete, and send this form to the NAPE office. Upon approval NAPE will return this form to you with an authorized signature insuring reimbursement upon receiving proof of service or purchase; or, a check can be issued to the doctor/vendor if you have submitted an invoice.

# National Association for Pseudoxanthoma Elasticum

8764 Manchester Rd., Suite 200, St. Louis, MO 63144-2724

Donations, Subscriptions and Membership for 2005

***One part of your contribution is for helping yourself; the other part is for helping others, but no one will be turned down for membership if no donation is received.***

PLEASE PRINT LEGIBLY & MAKE DONATION IN U.S. CURRENCY

Friend of NAPE Membership     Professional Membership     New     Renewal  
 \$1,000 or more     \$100—\$500    Other: \_\_\_\_\_  
 \$ 500—\$1,000     \$ 25—\$100    \$ \_\_\_\_\_

Donations can be made in Honor or Memory of a loved one, and also for the Research Fund and/or the Low-Vision Fund. All donations are tax deductible in the USA.

Honor     Memory     General Fund     Low-Vision Fund

Name of Loved One: \_\_\_\_\_

Address for Acknowledgement: \_\_\_\_\_

✓ PLEASE COMPLETE THE SECTION BELOW IF YOU HAVE PXE, THINK YOU HAVE PXE, OR ✓  
ARE FILLING THIS OUT FOR SOMEONE ELSE

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Fax: \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_ Country: \_\_\_\_\_

Male  Female  Birthdate: \_\_\_\_\_ Age: \_\_\_\_\_

I am diagnosed with PXE  Yes  No Occupation: \_\_\_\_\_

Are you legally blind?  Yes  No Request Newsletter:  Printed  Taped

Do others in your family have PXE?  Yes  No If so, whom? (Mother, Father, Sibling, etc. & Name) \_\_\_\_\_

Please list the medical problems you are experiencing; e.g., eyes, skin lesions, gastric bleeding, etc., and comments/questions: \_\_\_\_\_

Please list any medical problem(s) you are experiencing: e.g., eye involvement, skin lesions, gastric bleeding, etc., and comments/questions (use another page if required): \_\_\_\_\_

Are you willing to be contacted, for example, by someone in your area who wishes to talk with someone else who has PXE?  Yes  No

*Thank you for your contribution. It is deeply appreciated.*

## Have You Changed Your Address?

Please help by letting us know. Please be sure to print your new zip code number, including the extra four digits, if possible. When we use the full zip code, our costs of mailing in the United States are lower. Please help.

### *New Address*

Name: \_\_\_\_\_

Street: \_\_\_\_\_

City, State, Zip \_\_\_\_\_

### *Old Address*

Name, if different: \_\_\_\_\_

Street: \_\_\_\_\_

City, State, Zip \_\_\_\_\_

***PLEASE PRINT NEATLY***

National Association for Pseudoxanthoma Elasticum  
**NAPE, Inc.**  
8764 Manchester Road, Suite 200  
St. Louis, MO 63144-2724

**ADDRESS SERVICE REQUESTED**