

PXE Awareness

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

Volume 13, Issue 2 July 2007

2007 NAPE CONFERENCE

Atlanta

September 28 - 29

CNN Tour

World of Coca Cola



Carter Presidential
Library

Martin Luther King Center

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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 Message

Dear NAPE Friends,

This issue provides the response to a patient question which requires the physician and patient to consider many specific issues before agreeing to a treatment option. The initial question seems quite simple. Its answer reveals its underlying complexity. We encourage readers to focus on this issue (can a PXE patient take an aspirin each day to protect against heart attack?) as it represents the types of problems we PXE patients face. This is so important that Dr. Berthold Struk will focus on the difficult treatment decisions in PXE in his conference presentation at our meeting in Atlanta this September. *PXE Awareness* will carry the results of his discussion in the fall issue.



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Nanotechnology, called by some “the science of the small,” relates a nano as a child’s marble compared in size to our planet. Nanomedicine offers the potential of much smaller amounts of medicine directed to treat specific diseased sites to obtain results with fewer side effects. Dr. Kattesh Katti will share with us in Atlanta his use of nanomedicine in cancer research and AMD. Dr. Chris Bergstrom is slated to update retina treatments and current research using stem cells in vision treatments.





We hope many of our Southern and Southeastern members will be present in Atlanta to learn and to question our speakers.

A recurring question for NAPE results from our stand on dietary intake of calcium. Our Board has voted to revisit this issue, to be the focus of NAPE's winter issue of *PXE Awareness*. Contacts have been made with physicians and researchers around the country to obtain a wider understanding of calcium needs over all stages of life. We are seeking answers to questions about calcium absorption and its possible role in tissue calcification in PXE. New research will be presented as we try to give our readers information they with their physicians can use to determine their own calcium needs over time. If readers want to send us their questions and concerns about calcium, please do so right away so that we can seek expert response for the winter issue. We will begin to put that issue together on October 15 and thus need your input by September 30.

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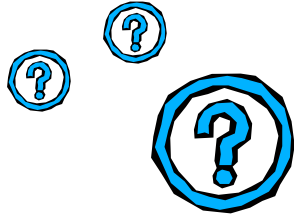
Finally, we remember Gerald F. Dwyer who passed away on June 5. Gerald's family was instrumental in the very early development of NAPE. We are grateful for the many letters about Gerald and for the memorial donations made in his honor. Please remember Gerald and his family as they cope with his loss.

Fran Benham





NAPE Q & A



Q Can a person with PXE take a baby aspirin every day? I am 67 years old.

A There is no easy answer to this like yes or no. As always in medicine...it depends...

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In order to come to the right conclusion for a single patient one needs to know the reason why someone wants to take a baby aspirin.

1. Does the person suffer from proven cardiovascular disease and does the person want to use aspirin as second line prevention against further cardiovascular injury events?
2. Does the person expect cardiovascular disease events due to age and wants to use regular aspirin intake to prevent cardiovascular disease events?
3. What is the current visual status?
 - 3a. Has the person had retinal bleeds?
 - 3b. Has the person angioid streaks running through the macular?
 - 3c. Is there any evidence that these streaks tend to leak?





4. What is the gastrointestinal status?
 - 4a. Has the person had stomach or duodenal ulcers?
 - 4b. Has the person ever had a gastrointestinal bleed?

5. What is the major health concern?
 - 5a. Is it to suffer a first stroke or heart attack?
 - 5b. Is it to prevent a second stroke or heart attack?
 - 5c. Is the worst thing to imagine the loss of your central vision?

Depending on the individual answers to these questions the individual recommendation for aspirin may vary.

In general the recommendation is that one should take a baby aspirin a day if there is proven cardiovascular disease, unless there are severe contra indications against aspirin intake. In order for you to come to the right individual conclusion (whether to take aspirin or not) answer these questions with your doctors. Your primary care physician, your cardiologist and your retinologist will need to work out the right answer for your individual case.

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- Berthold Struk, MD, Cardiologist





Q I am 68 years old and have been itching where my skin has PXE lesions, especially on the neck and inner elbows. There is no redness or other changes to the skin. I have tried several ointments that have not helped.

A Skin lesions of PXE do not usually itch. The fact that the lesions itch strongly suggests there are other external factors involved. There is a good chance that you have developed an allergy to one of the products you've been using. And just scratching the areas of skin will gradually irritate the site and cause itching which can be severe. Patients with eczema often have similar problems. It's called neurodermatitis.

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Therefore, without knowing more about the history, the first advice is to stop everything being used. Topical cortisone is one of the best topical anti-itch medications available. You can buy hydrocortisone ointment 1% without prescription. Just be sure it is 1% and in an ointment base (not cream or lotion). Apply sparingly three or four times daily. It should give relief in a few days. If it does not help, there are other stronger cortisone preparations, but these require a prescription. Consult a dermatologist if the itching continues.

- Kenneth Neldner, MD, Dermatologist





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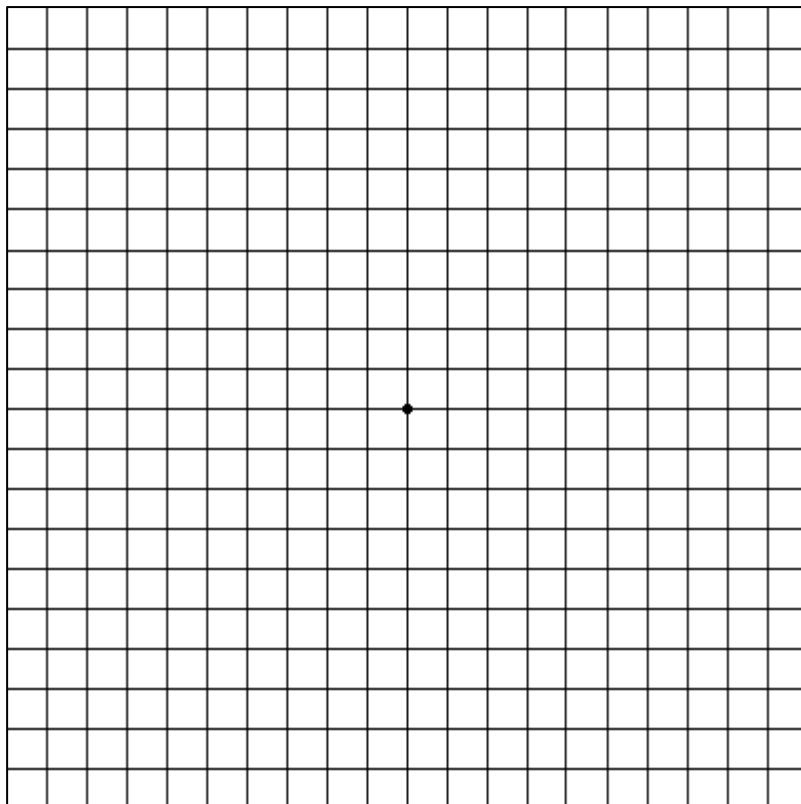


Amsler Grid

Use the Amsler Grid to test your vision each day.

1. Wear your reading glasses while doing this test.
2. Cover one eye.
3. Look at the center dot and keep your vision on the center at all times.
4. While looking directly at the center, all the lines should be straight and all the small squares should be the same size.
5. If you should notice any area on the Grid that becomes distorted, blurred, discolored or otherwise abnormal, call your doctor.
6. Test the other eye in the same manner.

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Mark your calendar!



**2007 NAPE Annual Conference
September 28 and 29**

The conference will be held in Atlanta, Georgia, at the Holiday Inn Select near the Atlanta International Airport south of the city center. Free airport shuttle, free on-site parking available.



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More information will be mailed separately to NAPE members who register for the conference by September 7. The conference registration form is at the end of this issue.





2007 Conference Information

When: Friday afternoon, September 28 through Saturday afternoon, September 29.
Schedule included in this issue and posted on the NAPE website. It will also be mailed to those who register by September 7.

Where: Holiday Inn Select – Atlanta Airport South
4669 Airport Blvd, College Park, Georgia
Room rate (single and double) \$85 if reserved by September 7, otherwise you will be charged the going rate. Call 1-404-763-8800 or 1-800-448-2296 and state that you are a NAPE conference registrant.

Meals: Conference registration fee of \$45 per person includes Friday evening dinner, Saturday early lunch, plus Saturday mid-afternoon break. You are responsible for your own breakfast on Saturday.

Air-travel: The Holiday Inn Select is near the Atlanta International Airport (ATL) south of the city center. A free shuttle is available to the hotel from the airport. (free shuttle from MARTA Atlanta Airport station also.)

Driving directions: From Interstate 85, take exit 71 and go east on Riverdale, then turn south on Airport Blvd to the hotel



2007 NAPE CONFERENCE SCHEDULE



**Holiday Inn Select – Atlanta Airport South
Atlanta, Georgia**

Friday, September 28, 2007 First Session

- 2:00-4:30pm NAPE Board Meeting (observers welcome)
- 4:45-5:00pm Conference Convenes
Welcome by Dr. Fran Benham, NAPE
President
- 5:00-7:00pm PXE 101 - Dr. Kenneth Neldner
- 7:00-7:15pm Break
- 7:15-10:00pm Buffet Dinner (included in your registration)
Enjoy a leisurely meal and visit with
conference peers

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Saturday, September 29, 2007 Second Session

- 8:00-8:10am Opening remarks by Dr. Fran Benham
(breakfast on your own before this session)
- 8:10-10:45am PXE Cardiology Issues, Inheritance and
Difficult Choices - Dr. Berthold Struk
- 10:45-11:00am Break
- 11:00am-12:30pm Lunch (included in your registration)





Third Session

- | | |
|--------------|--|
| 12:30-2:30pm | Nanomedicine and PXE
– Dr. Kattesh Katti |
| 2:30-2:45pm | Break (refreshments available) |
| 2:45-4:15pm | Ophthalmologist (to be announced
– see website) |

Fourth Session

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- | | |
|-------------|---|
| 4:15-5:00pm | NAPE Business Meeting
(this is an opportunity for NAPE
members to ask questions and to
provide information/suggestions
to NAPE Board members) |
| 5:00pm | Adjournment |



Atlanta Conference Presenters



Dr. Kenneth Neldner, Dermatologist, is a long term NAPE leader. His 1988 monograph described the first extensive PXE research.

Clinics for Dermatology: Pseudoxanthoma Elasticum remains a basic text for researchers interested in PXE. Dr. Neldner will set the stage on Friday, preparing for more fruitful discoveries and understanding of Saturday's program.



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Dr. Berthold Struk, Cardiologist, Max-Delbruck Center for Molecular Medicine and Franz-Volhard Clinic for Cardiovascular Disease in Berlin, Germany, will present information about the impact of PXE on the cardiovascular system, basic care procedures to be followed by patients and their physicians, the inheritance of PXE and difficult treatment choices PXE patients may face.





Dr. Kattesh Katti, PhD, Department of Radiology, University of Missouri-Columbia, enjoys a



worldwide reputation among scientists for his discoveries which have helped to usher in nanomedicine, as part of the nanotechnology revolution in science and industry. Dr. Katti, holder of such prestigious awards as the 2006 Gottingen Professorship and the St. Louis Academy of Science 2007 Scientist of the Year, will

explain basic nanomedicine and how he has used it to diagnose and treat cancer and AMD.

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Dr. Chris Bergstrom, Senior Retina Fellow, Emory Eye Center, Emory University, Atlanta, Georgia, will provide a research update on retinal treatments including vascular endothelial growth factor (VEGF) inhibitors such as Avastin, Lucentis and VEGF-Trap. He will also provide an update on stem cell research efforts related to the retina – both adult and embryonic.



Interesting Atlanta Sights



World of Coca Cola

Learn the story of Coca Cola, see the world's largest collection of Coke memorabilia, watch a fully functioning bottling line, taste a few of the over 70 Coke products.

Website <http://www.woccatlanta.com>

Martin Luther King, Jr. National Historical Site

Learn about Dr. King's life and influence, see the Peace Plaza nearby with the beautiful International World Peace Rose Garden

Website <http://www.nps.gov/malu>

Zoo Atlanta

Website <http://www.zooatlanta.org>

Georgia Aquarium

World's largest aquarium with more than 8 million gallons of water with more than 60 exhibits.

Website <http://www.georgiaaquarium.org>

Jimmy Carter Presidential Center and Library

35 beautifully landscaped acres just east of downtown

Website <http://www.jimmycarterlibrary.org>

Underground Atlanta

Unique shopping, dining, history and entertainment

Website www.underground-atlanta.com

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NAPxE – National Association for Pseudoxanthoma Elasticum

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St. Louis, MO 63144-2724
Telephone: 314-962-0100

Website: www.napxe.org Email: napestlouis@sbcglobal.net

REGISTRATION FORM – 2007 ANNUAL MEETING

Friday, September 28 – Saturday, September 29, 2007

The registration fee is \$45 per person and includes Friday evening's 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 _____

NUMBER ATTENDING MEETING _____ x \$45.00 = AMOUNT ENCLOSED \$ _____

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

You are responsible for making your own hotel reservations. Please call the **Holiday Inn Select, Atlanta Airport South in Atlanta, Georgia, at 1-404-763-8800 or 1-877-843-3621**. Be sure to call by **September 7, 2007**, and say you are with NAPE to get the group rate of \$85 per night (single or double) plus tax. Parking onsite is free and hotel-airport shuttle is available free.

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. We will send you a confirmation packet if registration is received by September 7.

If you require special assistance to participate fully, please provide a written description of your needs on the back of this form. Vegetarian meals can be accommodated.

SIGNATURE _____

DATE _____

Please mail this form to NAPE with payment by September 7, 2007
CANCELLATIONS ARE NOT REFUNDABLE AFTER SEPTEMBER 7, 2007

National Association for Pseudoxanthoma Elasticum

8760 Manchester Rd., St. Louis, MO 63144-2724

Donations and Membership

No membership fee is required, though donations are appreciated and needed to pay operational expenses, including telephone, fax, email, website and newsletter services.

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

Operations Honor Memory Low-Vision Fund Research 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: _____

Email: _____ Fax: _____

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 CD

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

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

Are you willing to be contacted by another who wishes to talk with someone else who has PXE? Yes No

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.
8760 Manchester Road
St. Louis, MO 63144-2724

ADDRESS SERVICE REQUESTED