

# PXE Awareness

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

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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 Message

This is our shortest issue in years - focusing on only one topic. We are calling on the NAPE family to help document our story. The result will be recognition and appreciation for all who stepped up each time help was needed. It will also respond to questions we receive about NAPE. Most importantly, it will demonstrate the power of patient advocacy in cooperation with a few caring physician/scientists.



Our plan is to develop a NAPE 25th anniversary commemorative issue of *PXE Awareness* which will be posted on the website. We need, want, encourage and welcome your support in this effort. Dr. Ken Neldner has agreed to help and will host a history round table at our next annual meeting. We hope many of you will join him with your stories and photos. Vice President Lenore Seeuwen will manage the collection of your memories. Please read her article and contact her with your willingness to help. This will be work, but it can also be fun and rewarding. Please help.

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A final good news item. Linda Austin is back in the office. She has found help for her mother. They will continue to struggle with the tragedy and loss Alzheimer's disease brings. Linda enjoys our work, is very good at all aspects of it, and we hope it may give her a change of pace each week as she continues to care for her mother.

Warm good wishes,

Fran Benham





# NAPE at 21 - Coping With Energy and Confidence

by Lenore Seeuwen

NAPE, incorporated in 1988 in New York State as an IRS registered 501(c)3 nonprofit organization, is now 21 years old. Earlier it was an informal patient group seeking to cope with a rare, little understood genetic disorder which devastated too many lives. The commitment and achievements of the founders created the base of knowledge that may lead in the not far future to a treatment for PXE. We know little about our pioneers. Indeed we have been so determined to overcome PXE that we have neglected to document our history or to properly recognize those who have moved us to this point. And so it is, at age 21, soon to be 22, that we have decided to systematically gather, record and share our story.

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During the fall 2004 Kansas City annual meeting, Dr. Ken Neldner recalled major events of NAPE's story. His talk informs the following designed to help members recall their own roles or the roles of those they know. We hope to hear from all with memories to share. Our purpose is to develop NAPE's story in words and photos for our website which is read by people around the globe and which has become the source of almost all new members. Contact information is provided at the end of this article with our invitation to all who can help tell NAPE's story.

NAPE was incorporated in 1988 in New York. The Clancy family was one of its informal group founders. We would like very much to hear from those involved, family members or friends who can tell us about the informal New York group, how it worked and what it did to create NAPE. During the same period Dr. Neldner was conducting his study of some 100 PXE patients for his seminal publication describing PXE in the January-March issue of *Clinics In Dermatology* series. Many, perhaps most, of his study patients became NAPE members. We hear stories about how they, too, were meeting informally from time to time, sharing experiences and coping strategies with Dr. Neldner. We need more information about this. Were you part of the study? What do you remember about your participation? And what about those meetings? Where were they? Who attended and did it help you?



NAPE moved from New York to Denver in 1992. Persons active in early Denver developments were Carolyn Freedman, Al Ferrari and Jane Tipton. Al Ferrari worked to incorporate our nonprofit 501(c)3 status, which required bylaws, officers and a board of directors. NAPE's first office was established in his home in 1992. The office moved to 1420 Ogden Street, Denver, about 1994, and part-time office help were hired, including Carolyn Freedman, Sherri Milligan and Karolyn Kells (1994-96). In 1996 Joyce Kohn was hired as part-time office manager and newsletter editor. The office moved to 3500 E. 12th Street, Denver, in 1998. The board of directors met irregularly and was poorly utilized. Most concerns and questions were sent to Dr. Ken Neldner. He received almost all medical questions sent to the NAPE office, in addition to many sent directly to him. Those of wide interest were reported in the newsletter.



The quarterly newsletter was started in 1992. Publication required external help and proved expensive (about \$1,000 per issue). Our gratitude goes to Claudia and Blaine McCallister and the Three Amigos (Blaine McCallister, Fred Couples and Jim Nantz) annual golf charity event, from 1994-2003. It is difficult to imagine where NAPE would be without their support.

NAPE members participated in genetic research by volunteering to give blood samples (DNA) for a gene mapping project, resulting in the discovery of the PXE chromosome (16p13.1) in 1997 and the gene (ABCC6) in 2000. The project resulted from the collaboration of Drs. Ken Neldner, Klaus Lindpaintner and Berthold Struk. We would love to include memories of those who participated. How did you learn about the study and how were you involved?

Budgetary categories were established to include general operating expenses, including the newsletter, low vision fund and research fund. The first research award was presented in 1999 to Dr. Berthold Struk for genetic studies. The board agreed to work with Dr. Struk as he planned future studies.

Advocacy connections were begun with various groups and legislative bodies. Matthew Lange led this effort as a board member for a number of years. He initiated our lobbying of government representatives and agencies. Other connections such as NAPE-Australia started in 1996 under the leadership of Del Gaddes. Dr. Neldner spoke at their Sydney annual meeting in June 1997. The British group, PiXiE, initiated by

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Elsbeth and Bernard Lax before NAPE, is still in operation and can be accessed at [www.pxe.org.uk](http://www.pxe.org.uk).

NAPE relocated to St. Louis, Missouri, in 2002 with a new board. Fran Benham was elected chair and accepted responsibility for the newsletter and website. She established a formal accounting system and instituted standard business procedures. The website, started by Dr. Struk in Denver in 2001, was greatly expanded. The printed newsletter continued, new issues were posted on the website and recorded for computer users to hear online. Audio copies were sent to members on request who do not use computers. Today, almost all new members result from website searches shortly after PXE diagnosis. The website has made NAPE accessible to a global audience. We hear regularly from patients in many countries and respond to their concerns.

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These are a few of NAPE's memories, provided to jog the minds of members who make NAPE such a successful advocacy group. We welcome corrections and want your memories, too. We hope you will bring them to our attention. Lenore Seeuwen, NAPE Vice President, has accepted responsibility for collecting your memories and related photos. You may contact her by email, snail mail or telephone as listed below. Our goal is to have a well documented story online before our 25th anniversary, along with complete copies of all newsletters in a more easily navigable website. We need your help as we continue "to cope until the cure."

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## Donations - Membership

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***No membership fee is required, although donations are 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    Research

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

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

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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      Newsletter:  Print  CD

Are you legally blind?  Yes  No       Email notification

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

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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):

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

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**ADDRESS SERVICE REQUESTED**

## **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 (as required by the Postal Service for bulk mailing). Please help.

### ***New Address***

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

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

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

### ***Old Address***

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

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

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

***PLEASE PRINT NEATLY***