PXE Awareness

National Association for Pseudoxanthoma Elasticum (NAPE, Inc.)

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Dr. Ken Neldner in Retirement

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

Vol. 17, No. 1, April 2011- This issue marks the seventeenth year of *PXE Awareness*, providing information and education for patients coping with PXE until treatments and the cure. Thanks to Diane Clancy, NAPE's first president, we have most of the early missing issues on our website. We continue to search for the last few missing issues and hope a member may send them along.

We also continue to receive calls asking about Dr. Ken Neldner. Long time colleague at the Texas Tech Dermatology Clinic, Carol Daugherty, joined Ken with her trusty camera for several photos and an update on his busy retirement.

It's time for NAPE members to get involved in more PXE research. Read "NDRI and NAPE: Research Cooperation" to learn how you can participate. This is extremely important to finding treatments and finally our cure.

Sarah Roberts, ACLU legal staff, has penned an update on Myriad Genetics' appeal in their gene patent case. NAPE's Board voted to join the case as a "friend of the court" against Myriad's patenting of human genes. The Obama administration joined the case to argue against Myriad's appeal. Roberts provides a link for those who wish to hear appeal arguments by both sides. Thanks to ACLU attorney Sandra Park and Sarah Roberts for keeping us informed.

Researchers now are focused on the role of magnesium in the mineralization of PXE affected tissue. Read the research abstract by Larusso, Li and Uitto, followed by NIH information about dietary magnesium, including food sources. Bear in mind that the research involved a PXE mouse model. Please do not begin to ingest huge amounts of magnesium unless you are under the care of a physician familiar with the research results. Those determined to increase magnesium intake should tap into the NIH website for a wealth of information about dietary magnesium - copy to share it with your primary care physician. This is exciting stuff- we want a treatment - and now -

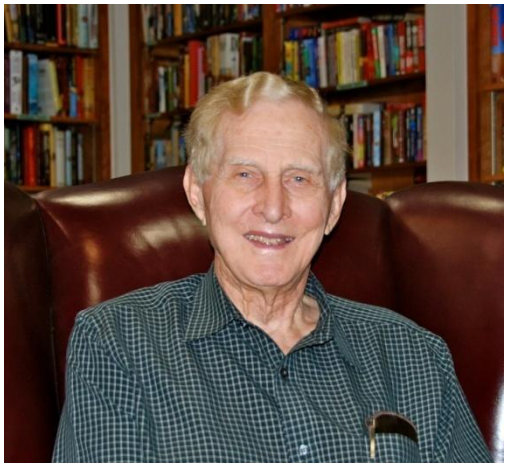
but please, we need to be careful so that we can enjoy it when our researches find it.

And speaking of research, John Newman has prepared an easy guide to search the internet for the most current (and oldest) PXE research. So you don't use a computer? That should not prove an insurmountable obstacle. We now have a generation of young adults who grew up using computers. Many of them will help if asked. And John's guide will teach them to receive an automatic update on PXE research at selected intervals - say once per month. Those who follow John's instructions can use their new skill to locate other medical information as they need it. Thanks, John , for guiding NAPE readers and for all your support in following and sharing PXE research.

Well, this issue is getting too long. All the articles are important, so please, read them and rejoice with me at our progress. And, if you are as grateful as I expect, look at the guy on our cover again. Years ago as a young professor of medicine, researcher and clinical practitioner, Ken Neldner chose to focus on PXE. His commitment resulted in the first detailed medical description of PXE. He worked tirelessly to establish our lab at Harvard that led to the identification of ABCC6. He traveled the world to educate the medical profession about PXE. We are where we are today in understanding and conquering PXE in large part thanks to his life's work. So thank you again Dr. PXE, Kenneth Neldner, for a job well done!

Fran Benham, PhD

Ken Neldner in Retirement



Dear PXE Friends and Families:

Fran has asked that I write a little note to update you, which I am happy to do. I have missed a couple of the last PXE meetings and some of you have been kind enough to notice my absence and inquire where I am. Well, if you have been wondering, continue.

You remember that in the early phase of our lives there were the so-called 3 R's--reading, writing, and arithmetic. Those 3 R's, the basics, served me well most of my life. During my early schooling I remember my English teachers telling me to read and review, write and re-write. You, as I, have generally supplemented those R's with more R's; we assumed a role in life; often that role included reproduction. We responded to the requirements of our lives and became responsible. We involved ourselves in recreation because we liked it and because we were told it was good for us and it is. We sometimes rested, relaxed, recuperated.

Well, you know how I can go on and I know there are many more R's I could site. What I want you to know about me is another R and that is the R of retirement—which is why you hear less from me these days.

After I retired from the position as Chairman of the Department of Dermatology at Texas Tech University Health Sciences Center, I continued to actively pursue my research interest (another R) in PXE. In the more recent past after the death of my wife I decided to sell my house and move to a retirement center. My new location at the Carillon Windsong retirement community is very nice. It provides me

with a two-bedroom/two-bath living space, three meals a day and housekeeping, the last two of which are very helpful since cooking and housekeeping are not among my stronger suits.

Moving has been an all-consuming process which has taken a good deal of my time and energy and which I often feel has not ended because I have not yet completed the reorganization of the disorganization of moving. You'd think I'd have all the time now to accomplish everything I always wanted to do but was unable to complete because of time restraints during my working life. I'm still working to that end. At retirement I thought that the first thing I would do is clean my drawers. Two years later I still plan to clean my drawers! The lesson learned is not to wait 50 to 60 years before sorting and throwing but to cull as you go, or at least periodically.

My life is simple. In line with Ben Franklin's old proverb I am early to bed and early to rise. You know the supposed result of that line; I'm still waiting. I go to my office every weekday for a few hours around lunchtime. I exercise three to four times weekly. I travel very little. I like to eat. I like to write. I got into the evolution/creation/science debate about four years ago and wrote a book entitled *God, Evolution and Natural Selection*. The book didn't sell well (my book on PXE was much more popular), so I'm trying a new and I hope more appealing approach. Also on my list, as documentation for my daughters and their families, is a family biography. I work more slowly. I am healthy.

I have not forgotten PXE. I still have a very strong interest in you and in PXE. You are after all my life's research. I look forward to the day when medications, maybe such as Avastin and Lucentis, will take care of the worst of PXE problems.

I no longer see patients but I enjoy talking and, if you are inclined, I am glad to receive emails or phone calls or mail.

Best regards and smiles to all of you,

KHN

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NDRI and NAPE: Research Cooperation

NAPE's Board voted to join NDRI (National Disease Research Interchange) over a year ago. NDRI, with 30 years of experience, is the major resource for supplying researchers with human biomaterials to conduct the studies which identify genes, develop treatments and find cures. Lee Ducat, founder and NDRI president is recognized by the scientific community for her organizational skills which have helped to move medical research forward in so many disorders. She brings to her work the same passion that created NAPE, support for a family member diagnosed as a diabetic child. NDRI's story was featured in the April 2010 issue of *PXE Awareness.*

The National Institutes of Health recently awarded NDRI almost eight million dollars to expand their programs to support rare disorder research. To make this happen, we who have PXE must register with NDRI so that we can be contacted when we need to donate blood, urine, an/or other biomaterials. Please watch NDRI's thirteen minute video, "Donate, Discover, Cure" to learn how they work. Next, and very important, call NDRI to register. As researchers contact NDRI for PXE biomaterials, we who are registered will be contacted.

NAPE members provided the blood samples that made Dr. Berthold Struk's search for our mutant gene possible. Since ABCC6 was identified, over 1400 PXE research articles have been published in the scientific literature. Let's do it again! Telephone NDRI and register your willingness to support our researchers. NDRI is a wonderful blessing for research efforts and for affected patients. Let's get NDRI's telephone ringing! Enjoy the video located on our website with the latest *PXE Awareness* issue, then call 1-800-222-6374 to register.

Gene Patent Appeal Hearing

By Sarah Roberts, Legal Assistant, ACLU

In May 2009, the ACLU and the Public Patent Foundation filed a lawsuit on behalf of twenty plaintiffs including pathologists, geneticists, patients, and health advocacy groups against the U.S. Patent and Trademark Office (USPTO), Myriad Genetics, and the University of Utah Research Foundation. They argued that Myriad's patents on two genes related to breast and ovarian cancer, BRCA1 and BRCA2, violate the First Amendment and patent law, as genes are "products of nature" which cannot be patented. Plaintiffs contend that the patents stifle scientific research and genetic testing. The USPTO has issued thousands of gene patents, resulting in the patenting of 20% of human genes. In March 2010, Judge Robert Sweet of the District Court for the Southern District of New York ruled that the BRCA1 and BRCA2 patents are invalid.

Myriad appealed to the U.S. Court of Appeals for the Federal Circuit in Washington D.C.. In a reversal of its previous position, the United States government submitted an *amicus* brief in October contending that isolated genes without modification, as in the case at hand, are a product of nature, and therefore cannot be patented. Briefing in the appeal was completed in December, and oral argument was heard on April 4th; an audio recording of the argument is available at http://www.cafc.uscourts.gov/oral-argument-recordings/search/audio.html, enter 2010-1406 in the appeal number box. The U.S., represented by Acting Solicitor General Neal Katyal, also argued against the Myriad claim. Many organizations, researchers, and individuals have submitted *amicus* briefs in support of the plaintiffs including: the March of Dimes and other patient groups, including NAPE (National Association for Pseudoxanthoma Elasticum); the American Medical Association and other medical organizations; AARP; Cancer Council Australia and Luigi Palombi; Andrew Chin and other scholars of biotechnology patent law; Professors Erika George and Kali Murray; Professor E. Richard Gold and other experts in gene patents; the International Center of Technology Assessment and other organizations that address the impact of technology on society; Professor Eileen M. Kane; the National Women's Health Network and other women's health and social justice organizations; the Southern Baptist Convention; and Universities Allied for Essential Medicines.

Editor's Note:

The ruling on the appeal is expected to take up to a year. NAPE will report it in *PXE Awareness.*

While we wait for the ruling, there are things each NAPE member can do. First, share with others the fact that human genes have been allowed to be patented - and thus controlled by individuals, groups, and businesses. If the response to you is typical, you will find much astonishment that this was ever allowed. Ask those who agree to spread the word and to advocate against this practice. Finally, let your elected officials know that you oppose patents on human genes. If a large number of citizens let our U.S. Congressional representatives know of our opposition, we may be able to have a law prohibiting human gene patents. Let's begin now as the development of such laws takes time - often a number of years. So let's go - we can make a difference!

PayPal Now Available at NAPE

Donations can be made using PayPal found on the NAPE website membership section. This is a protected site which can be used with many credit cards. The service has been requested by members. We hope it will prove useful to those who want to help NAPE. Thank you!

PXE Research Abstract

Pseudoxanthoma elasticum, the paradigm of heritable ectopic mineralization disorders - can diet help?

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Abstract

Pseudoxanthoma elasticum (PXE) is a heritable multi-system disorder manifesting with characteristic cutaneous lesions, associated with ocular findings and cardiovascular involvement. The skin lesions, yellowish papules which coalesce into plaques of inelastic and leathery skin, demonstrate by histopathologic and ultrastructural examinations ectopic mineralization of dermal connective tissues, primarily the elastic structures. PXE is inherited in an autosomal recessive fashion due to mutations in the ABCC6 gene. Significant insights into the pathogenesis of PXE have been recently obtained from observations on the Abcc6(-/-) knockout mouse which mimics the genetic, histopathologic and ultrastructural features of PXE. This mouse model has provided a platform to test various treatment modalities to counteract the mineralization phenotypes. **One of the intriguing findings emanating from these studies is that supplementation of the mouse diet with magnesium, at levels that are ~5-fold higher than those in control diet, completely inhibits the development of tissue mineralization. These and related observations suggest that changes in the diet might counteract the progression of PXE and improve the quality of life of patients with this, currently intractable, disease.**

Dietary Magnesium

Taken from the NIH website
http://ods.od.nih.gov/factsheets/magnesium/

Magnesium is the fourth most abundant mineral in the body and is essential to good health. Approximately 50% of total body magnesium is found in bone. The other half is found predominantly inside cells of body tissues and organs. Only 1% of magnesium is found in blood, but the body works very hard to keep blood levels of magnesium constant.

Magnesium is needed for more than 300 biochemical reactions in the body. It helps maintain normal muscle and nerve function, keeps heart rhythm steady, supports a healthy immune system, and keeps bones strong. Magnesium also helps regulate blood sugar levels, promotes normal blood pressure, and is known to be involved in energy metabolism and protein synthesis . There is an increased interest in the role of magnesium in preventing and managing disorders such as hypertension, cardiovascular disease, and diabetes. Dietary magnesium is absorbed in the small intestines. Magnesium is excreted through the kidneys.

Green vegetables such as spinach are good sources of magnesium because the center of the chlorophyll molecule (which gives green vegetables their color) contains magnesium. Some legumes (beans and peas), nuts and seeds, and whole, unrefined grains are also good sources of magnesium. Refined grains are generally low in magnesium. When white flour is refined and processed, the magnesium-rich germ and bran are removed. Bread made from whole grain wheat flour provides more magnesium than bread made from white refined flour. Tap water can be a source of magnesium, but the amount varies according to the water supply. Water that naturally contains more minerals is described as "hard". "Hard" water contains more magnesium than "soft" water.

Eating a wide variety of legumes, nuts, whole grains, and vegetables will help you meet your daily dietary need for magnesium. Selected food sources of magnesium are listed in Table 1.

Table 1: Selected food sources of magnesium

FOOD	Milligrams (mg)	%DV*
Halibut, cooked, 3 ounces	90	20
Almonds, dry roasted, 1 ounce	80	20
Cashews, dry roasted, 1 ounce	75	20
Soybeans, mature, cooked, ½ cup	75	20
Spinach, frozen, cooked, ½ cup	75	20
Nuts, mixed, dry roasted, 1 ounce	65	15
Cereal, shredded wheat, 2 rectangular biscuits	55	15
Oatmeal, instant, fortified, prepared w/ water, 1 cup	55	15
Potato, baked w/ skin, 1 medium	50	15
Peanuts, dry roasted, 1 ounce	50	15
Peanut butter, smooth, 2 Tablespoons	50	15
Wheat Bran, crude, 2 Tablespoons	45	10
Blackeyed Peas, cooked, ½ cup	45	10
Yogurt, plain, skim milk, 8 fluid ounces	45	10
Bran Flakes, ½ cup	40	10
Vegetarian Baked Beans, ½ cup	40	10
Rice, brown, long-grained, cooked, ½ cup	40	10
Lentils, mature seeds, cooked, ½ cup	35	8
Avocado, California, ½ cup pureed	35	8
Kidney Beans, canned, ½ cup	35	8
Pinto Beans, cooked, ½ cup	35	8
Wheat Germ, crude, 2 Tablespoons	35	8
Chocolate milk, 1 cup	33	8
Banana, raw, 1 medium	30	8
Milk Chocolate candy bar, 1.5 ounce bar	28	8
Milk, reduced fat (2%) or fat free, 1 cup	27	8
Bread, whole wheat, commercially prepared, 1 slice	25	6
Raisins, seedless, ½ cup packed	25	6
Whole Milk, 1 cup	24	6
Chocolate Pudding, 4 ounce ready-to-eat portion	24	6

*DV = Daily Value. DVs are reference numbers developed by the Food and Drug Administration (FDA) to help consumers determine if a food contains a lot or a little of a specific nutrient. The DV for magnesium is 400 milligrams (mg). Most food labels do not list a food's magnesium content. The percent DV (%DV) listed on the table above indicates the percentage of the DV provided in one serving. A food providing 5% of the DV or less per serving is a low source while a food that provides 10-19% of the DV is a good source. A food that provides 20% or more of the DV is high in that nutrient. It is important to remember that foods that provide lower percentages of the DV also contribute to a healthful diet. For foods not listed in this table, please refer to the U.S. Department of Agriculture's Nutrient Database Web site: http://www.nal.usda.gov/fnic/cgi-bin/nut_search.pl.

Recommendations for magnesium are provided in the Dietary Reference Intakes (DRIs) developed by the Institute of Medicine of the National Academy of Sciences. *Dietary Reference Intakes* is the general term for a set of reference values used for planning and assessing nutrient intake for healthy people. Two important types of reference values included in the DRIs are *Recommended Dietary Allowances* (RDA), and *Adequate Intakes* (AI). The RDA recommends the average daily intake that is sufficient to meet the nutrient requirements of nearly all (97%-98%) healthy people. An AI is set when there is insufficient scientific data available to establish a RDA for specific age/gender groups. AIs meet or exceed the amount needed to maintain a nutritional state of adequacy in nearly all members of a specific age and gender group.

Table 2: Recommended Dietary Allowances for magnesium for children and adults

Age (years)	Male (mg/day)	Female (mg/day)	Pregnancy (mg/day)	Lactation (mg/day)
1-3	80	80	N/A	N/A
4-8	130	130	N/A	N/A
9-13	240	240	N/A	N/A
14-18	410	360	400	360
19-30	400	310	350	310
31+	420	320	360	320

There is insufficient information on magnesium to establish a RDA for infants. For infants 0 to 12 months, the DRI is in the form of an Adequate Intake (AI), which is the mean intake of magnesium in healthy, breastfed infants. Table 3 lists the AIs for infants in milligrams (mg).

Table 3: Recommended Adequate Intake for magnesium for infants

Age (months)	Males and Females (mg/day)
0 to 6	30
7 to 12	75

Data from the 1999-2000 National Health and Nutrition Examination Survey suggest that substantial numbers of adults in the United States (US) fail to get recommended amounts of magnesium in their diets. Among adult men and women, the diets of Caucasians have significantly more magnesium than do those of African-Americans. Magnesium intake is lower among older adults in every racial and ethnic group. Among African-American men and Caucasian men and women who take dietary supplements, the intake of magnesium is significantly higher than in those who do not.

Even though dietary surveys suggest that many Americans do not get recommended amounts of magnesium, symptoms of magnesium deficiency are rarely seen in the US. However, there is

concern that many people may not have enough body stores of magnesium because dietary intake may not be high enough. Having enough body stores of magnesium may be protective against disorders such as cardiovascular disease and immune dysfunction.

The health status of the digestive system and the kidneys significantly influence magnesium status. Magnesium is absorbed in the intestines and then transported through the blood to cells and tissues. Approximately one-third to one-half of dietary magnesium is absorbed into the body. Gastrointestinal disorders that impair absorption such as Crohn's disease can limit the body's ability to absorb magnesium. These disorders can deplete the body's stores of magnesium and in extreme cases may result in magnesium deficiency. Chronic or excessive vomiting and diarrhea may also result in magnesium depletion.

Healthy kidneys are able to limit urinary excretion of magnesium to make up for low dietary intake. However, excessive loss of magnesium in urine can be a side effect of some medications and can also occur in cases of poorly-controlled diabetes and alcohol abuse.

Early signs of magnesium deficiency include loss of appetite, nausea, vomiting, fatigue, and weakness. As magnesium deficiency worsens, numbness, tingling, muscle contractions and cramps, seizures (sudden changes in behaviors caused by excessive electrical activity in the brain), personality changes, abnormal heart rhythms, and coronary spasms can occur. Severe magnesium deficiency can result in low levels of calcium in the blood (hypocalcemia). Magnesium deficiency is also associated with low levels of potassium in the blood (hypokalemia).

Many of these symptoms are general and can result from a variety of medical conditions other than magnesium deficiency. It is important to have a physician evaluate health complaints and problems so that appropriate care can be given.

Magnesium supplementation may be indicated when a specific health problem or condition causes an excessive loss of magnesium or limits magnesium absorption.

- Some medicines may result in magnesium deficiency, including certain diuretics, antibiotics, and medications used to treat cancer (anti-neoplastic medication). Examples of these medications are:
  - Diuretics: Lasix, Bumex, Edecrin, and hydrochlorothiazide
  - Antibiotics: Gentamicin, and Amphotericin
  - Anti-neoplastic medication: Cisplatin
- Individuals with poorly-controlled diabetes may benefit from magnesium supplements because of increased magnesium loss in urine associated with hyperglycemia.
- Magnesium supplementation may be indicated for persons with alcoholism. Low blood levels of magnesium occur in 30% to 60% of alcoholics, and in nearly 90% of patients experiencing alcohol withdrawal. Anyone who substitutes alcohol for food will usually have significantly lower magnesium intakes.
- Individuals with chronic malabsorptive problems such as Crohn's disease, gluten sensitive enteropathy, regional enteritis, and intestinal surgery may lose magnesium through diarrhea and fat malabsorption. Individuals with these conditions may need supplemental magnesium.
- Individuals with chronically low blood levels of potassium and calcium may have an underlying problem with magnesium deficiency. Magnesium supplements may help correct the potassium and calcium deficiencies.
- Older adults are at increased risk for magnesium deficiency. The 1999-2000 and 1998-94 National Health and Nutrition Examination Surveys suggest that older adults have lower dietary intakes of magnesium than younger adults. In addition, magnesium absorption decreases and renal excretion of magnesium increases in older adult. Seniors are also more likely to be taking drugs that interact with magnesium. This combination of factors places older adults at risk for magnesium deficiency. It is very important for older adults to get recommended amounts of dietary magnesium.

  Doctors can evaluate magnesium status when above-mentioned medical problems occur, and determine the need for magnesium supplementation.

Eating a variety of whole grains, legumes, and vegetables (especially dark-green, leafy vegetables) every day will help provide recommended intakes of magnesium and maintain normal storage levels of this mineral. Increasing dietary intake of magnesium can often restore mildly depleted magnesium levels.

Selecting a healthful diet

The 2000 *Dietary Guidelines for Americans* states, "Different foods contain different nutrients and other healthful substances. No single food can supply all the nutrients in the amounts you need". If you want more information about building a healthful diet, refer to the *Dietary Guidelines for Americans* (http://www.cnpp.usda.gov/Publications/DietaryGuidelines/2000/2000DGProfessionalBooklet.pdf) and the US Department of Agriculture's Food Guide Pyramid (http://www.nal.usda.gov/fnic/Fpyr/pyramid.html).

Control High Blood Pressure

We who live with PXE are at risk for high blood pressure. If not controlled, it causes the heart muscles to work hard to provide a good blood flow throughout the body. The muscle firms, thickens, and grows. While this is good for other muscles, it is bad news for the heart which loses its ability to function well. The result can be congestive heart failure and stroke. So take your meds exactly as guided by your doctor, shed any extra weight, exercise and eat a heart healthy diet. We have no control over our mutant gene, but we can make choices to enjoy a longer, healthier life.

Stay Current With PXE Research

By John Newman

Are you tired of waiting for the next NAPxE newsletter to learn about the latest PXE research? Wait no more! If you have access to the internet, you can easily search for the latest research news from several peer-reviewed journals yourself. You can even set up automatic e-mail notifications when there are new citations that meet your search criteria!

The U.S. National Library of Medicine (NLM), located at the National Institutes of Health (NIH) in Bethesda, MD, is the largest biomedical library in the world. The National Center for Biotechnology Information (NCBI) has the task of organizing this literature and other data pertaining to biotechnology. PubMed is their free online database of over 20 million citations for biomedical literature from MEDLINE, journals and books.

To access this wealth of information, type the following URL into your internet browser: http://www.ncbi.nlm.nih.gov/pubmed

An easier option is to type "pubmed" into a search engine such as Google. The first URL provided by that search will be the one listed above.

The PubMed website is simple. Near the top of the page is a search box -- a wide white strip on the screen. Directly above and to the left of this search box is the database that you will be searching. The default setting is PubMed which is what you want. Type your search terms -- e.g., "pseudoxanthoma" or "abcc6" -- into the search box. Now click on the button labeled "Search" directly to the right of the search box to get the results. Easy!

As of today, there are a total of 1437 citations for the search term "pseudoxanthoma" and this number steadily increases over time. Many of these citations are old, but thankfully they are listed by PubMed from newest to oldest unless you change the default display settings.

Several of the citations contain an abstract -- i.e., a summary of the full article written by the author(s). If an abstract is available, you can read it by clicking on the title of the article which is in bold letters and underlined.

Sometimes there is an option to read the article from the original online source. To do so, click on the "LinkOut -- more resources" link below the abstract.
You might decide to filter out undesired references from your searches. For example, you might only want citations that contain an abstract or full text, only written in English and only pertaining to human test subjects. You can do all this and more by clicking on the link labeled "Limits" directly above the search box.

The search box itself works much like other search boxes found on the internet. If you type more than one term into the search box, PubMed will return by default only citations that contain all of the terms. Boolean operators can be used to change this configuration. The words AND, OR and NOT can be placed between terms to modify your search results. These words must be written in capital letters, they are sequenced from left to right and they can be nested with particular terms in parentheses. Quotation marks can be placed around terms to search for a phrase rather than a single word. Asterisks can be used to find all references that contain the text string in front of the asterisk.

There are also ways to search for literature written by a particular author or from a particular journal. There are currently 58 and 12 citations for NAPxE's Kenneth Neldner and Berthold Struk, respectively. Keep in mind that, although it's the largest biomedical database in the world, PubMed is incomplete and misses some journals from Europe and other parts of the world.
More information about these more advanced searches can be found on the lower left hand corner of the main page under the heading "Using PubMed." Click on the links labeled "PubMed Quick Start Guide" or "PubMed Tutorials" for easy to follow instructions.

One of the most useful tools from the PubMed website is automatic e-mail updates for your searches. To do this, you will need to register and sign into "My NCBI" by clicking on the link of the same name on the upper right side of the PubMed screen. People who are severely visually impaired will surely need help because, as a security measure, part of the registration process involves typing some hard-to-read jumbled text. After providing some basic information and a valid e-mail address (which will need to be verified by an e-mail reply), you can sign into "My NCBI" and set up your automatic updates. This part is much easier. Type the search terms into the search box -- e.g., pseudoxanthoma OR abcc6 OR mrp6 -- and click on the "Search" button as usual. After you get the search results, there should be a link directly above the search box labeled "Save search." You will then be asked to provide a title to your search results, how often you want to be notified of updates, and so on.

With very little practice, you too can use PubMed to stay informed of the latest PXE research and other biomedical news!

PXE Pals

If you would like a PXE friend with whom you can correspond, NAPE members listed would like to hear from you. Please notify the NAPE office if you have trouble contacting a PXE Pal.

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

Donations - Membership

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:

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)** _____

_____

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**

National Association for Pseudoxanthoma Elasticum
8760 Manchester Road
St. Louis, MO 63144-2724

ADDRESS SERVICE REQUESTED

Nonprofit Organization
U.S. Postage PAID
St. Louis, MO
Permit No. 1337

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