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MemberGram

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Dear Friends,

We have very exciting news. PXE International moved from Massachusetts to Washington, DC over the summer! The foundation has grown by leaps and bounds over the past seven years - we now partner with the National Institutes of Health, collaborate with Transgenomic, Inc., in the mutation detection phase of our research, and walk hand in hand with the Genetic Alliance (the world's largest coalition of genetic lay advocacy groups) – all in the DC area. In January, I was elected president of the Genetic Alliance and work with many lay advocacy groups like PXE International. Piggybacking on their work and sharing our advances with them helps all of us, whether we are working on PXE, or other rare conditions such as Hutchison-Gilford Progeria, or common conditions such as breast cancer!

We moved the PXE International office to the Genetic Alliance office - we will participate in the technical assistance to lay groups that the Genetic Alliance does so well. Our new office is in a prime location in DC right above a subway stop. We have already hired some of the part-time help we need - a bookkeeper and a genetic counselor/family studies coordinator. This move provides the physical and geographic resources we need for expansion. We are not a tiny organization trying to make its way anymore!

We consider this a major move for PXE International – it is a monumental next step in the growth of our foundation and will greatly accelerate our work. However, it is also a move that is not without risk for us. Our board of directors voted to make this move trusting that you will continue to support us. We now are positioned to catapult PXE research into meaningful advances for affected individuals – and we have more interested scientists than we can fund at this point. It is now up to all of you to support us as we go forward. Together we can make a difference.

Even with this move, we still have very low overhead. We still spend most of every dollar on research – as of our last audit our overhead accounted for 7% of our expenses! Please use the enclosed envelope and help us help you today! Also take a look at our suggestions for ways you can help (page 26)!

Our new address and phone numbers are:

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Best wishes,



Sharon F. Terry

PXE 2002

PXE 2002 was an exciting meeting. Over 200 people attended from 21 states and 10 countries. This was our third international meeting, following the *International Centennial Meeting on Pseudoxanthoma Elasticum*, Bethesda, MD, in 1997, and *PXE 2000* in Boston, MA. We anticipate that *PXE 2004* will take place Summer 2004 in Washington, DC. We missed all of you who could not attend – so please join us next time. There is no way we can capture the information, enthusiasm and camaraderie at one of these meetings, but we try over the next few pages to present a snap shot of images, session and reports.



General Overview of PXE

Dr. Lionel Bercovitch, Medical Director for PXE International, presented several sessions at the Oakland meeting: a general overview of PXE, a talk focusing on gastrointestinal and heart complications called "Beyond Skin and Eyes", and another talk called "Women's Health Issues in PXE". The following paragraphs are a short summary of some of the information he presented. Most of the critical information he presented will soon be part of PXE International bulletins.

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After presenting the various signs and symptoms of PXE (which are detailed in the PXE International General Bulletin), Dr. Bercovitch shared recommendations for good health for individuals with PXE. He stressed that exercise, avoiding or stopping smoking and a heart-healthy diet may reduce the risk and severity of cardiac and vascular complications. Individuals with PXE should develop good relationships with physicians who can provide periodic exams, especially in the event of cardiovascular and visual complications.

Cardiac testing is recommended for individuals who plan to enter a vigorous exercise program, such as training for competitive sports. Cardiovascular checkups should occur every five years until around age 40, then about every two years between 40 and 50 years old, and annually after age 50.

Retinal exams should be done more frequently throughout life, and individuals with PXE should see a retinal specialist. This physician should respond rapidly when visual changes are noted, for example, with regular

use of the Amsler grid. Affected individuals should use protective eyewear when participating in sports, and wear sunglasses to protect the eyes from ultraviolet rays. Individuals with PXE should also avoid contact sports or activities that involve straining ("the Valsalva maneuver"), such as weightlifting. Impact and straining can cause hemorrhaging in the eye, which can lead to loss of vision.

Since vision loss is common in PXE, it is especially important for individuals to protect their eyes – from a PXE point of view, you never know which eye will be better, so it is wise to take extra care to protect your eyes from an injury that could cause vision loss not related to PXE, too.

The Vascular System

Heart-related complications of PXE include coronary artery disease, mitral valve prolapse, peripheral vascular disease, and stroke. Although these are not the most common manifestations of PXE, they are important ones. All of these complications, like other PXE symptoms, result from mineralization of elastin fibers. Individuals with PXE should keep a careful eye on risk factors for cardiac disease, such as high blood pressure and cholesterol levels, and should work with their physicians to manage them. They should also do regular, moderate exercise (such as walking) and refrain from smoking, which is a contributor to heart disease.

Treatments for PXE-related cardiovascular conditions are the same as for those conditions generally, with some exceptions. For example, when a bypass operation is performed, a surgeon may choose to harvest an artery from the chest rather than a vein from the leg to provide tissue for the bypass. But in PXE, arteries are more likely to be mineralized and less elastic and may eventually narrow like the coronary artery it is attempting to bypass.

Individuals with PXE can have vision loss as a result of retinal bleeding, so treatment with blood-thinners, or anticoagulants (even aspirin),

should be considered carefully. Daily aspirin therapy, which can cause erosion in the stomach and also reduces the blood's ability to clot, should be used with caution. In those instances when aspirin or platelet inhibitors like Plavix are being used for stroke prevention, the patient and physician will have to jointly weigh the risk of bleeding complications against the risk of stroke to decide whether to use these medications and for how long.

The Gastrointestinal System

Case reports in the medical literature have suggested that individuals with PXE are at an increased risk for severe gastrointestinal complications, such as uncontrolled bleeding. While there is some evidence that once bleeding begins, it can be hard to stop, as our population of people diagnosed with PXE grows, it is becoming clear that this serious complication is less frequent than was previously believed.

When gastrointestinal bleeding does occur, it is most likely to happen in the stomach, but the specific source can be hard to find. Small blood vessels in the GI tract may be stiffened by calcification and less able to contract to close themselves off when bleeding starts.

While gastrointestinal bleeding is a rare complication, individuals with PXE can reduce their risk of it further by avoiding medications that cause gastric erosion (damage to tissues in the stomach) and thinning of blood, such as aspirin. When bleeding does occur, surgery and a hospital stay may be required to manage it.

Nutrition

Individuals who do not take in enough calcium and Vitamin D can suffer from conditions produced by low calcium over time, such as osteoporosis. Because minerals, including calcium, are found in the tissues of individuals affected by PXE, it has sometimes been recommended that affected individuals take in less calcium. However, restricting calcium has not shown a definite benefit in

individuals with PXE. In the absence of data to suggest otherwise, individuals affected by PXE should take at least the US Recommended Daily Allowance (RDA) of calcium. There is no reason to risk a known and serious problem in pursuit of an unproven benefit.

Although studies for other conditions have yielded confusing results about antioxidant vitamins, a diet rich in these vitamins may be beneficial for individuals affected by PXE. PXE International recently published a booklet on nutrition. See the back cover to order one.

Issues for Women with PXE

Dr. Bercovitch addressed issues of women's health and PXE. He addressed the incidence of PXE in relation to gender distribution, oral contraceptives, pregnancy, hormone-replacement therapy, calcium and mammography.

PXE is reported more often in women. This could be for several reasons. Since the gene is not on a sex chromosome, there is no reason to suspect that women are more likely to be affected, but it is possible that having two copies of the mutated gene associated with PXE might make males less likely to survive gestation. It may also be that women are more likely to seek care, for example for skin symptoms, than men are. Since the overall incidence of individuals with PXE is not known, it may also be that the pool of individuals diagnosed with PXE is too small to draw a conclusion.

As is common in rare diseases, information in the medical literature about PXE has historically focused on very dramatic, complicated cases. This is particularly true for reports of PXE and pregnancy. Even a series of 20 and 50 patients emphasized life-threatening complications. Dr. Bercovitch has studied a much larger group than has been reported on in the past, with a very large number of pregnancies, and this group has an extremely low incidence of severe complications (such as uncontrolled bleeding). Dr. Bercovitch said that in some cases, C-section, which reduces the amount of pushing

a woman does in labor, could be a useful approach for avoiding the Valsalva maneuver – straining that can accelerate eye damage in people who have neovascularization (blood vessels growing through cracks in Bruch's membrane (angioid streaks)). At the same time, there is no evidence that women who had vaginal deliveries have worse vision.

In recent months we have seen significant news on hormone-replacement therapy (HRT). One major study (the one where estrogen was combined with progestin) stopped because interim data analysis showed an unacceptable rate of adverse effects (the estrogen-only arm of the study is continuing). In PXE, there is an increased risk for some of the same cardiovascular complications, and Dr. Bercovitch described a new direction for hormone-replacement therapy: women will more likely be offered hormone-replacement therapy to treat menopausal symptoms, and then tapered off the hormone therapy over time. In contrast to this menopausal experience, women using hormones at younger ages, such as women under 35 using birth-control pills, need not be concerned.

Mammography presents another area with considerations for the individual with PXE. Calcification can occur in arteries within the breast, breast skin, elastic tissue within the breast, and underarm skin, so small calcifications are frequently seen in mammograms of women with PXE. Because of the frequency of small calcifications in mammograms in PXE, many women with PXE have undergone breast biopsy with benign findings. However, the pattern of calcifications in breast cancer is quite different, and a study that Dr. Bercovitch has just concluded will help radiologists become familiar with the spectrum of findings in PXE.

**If you have not donated blood to the
PXE International Blood & Tissue
Bank, please contact us at
202-362-9599 or dna@pxe.org.**

Questions and Answers from: PXE and the Eye (Wayne Fuchs, MD) and Treatment of the Eye (Richard Alan Lewis, MD, MS)

The meeting offered two eye sessions, presented multiple times. Dr. Wayne Fuchs of the Mount Sinai Hospital gave a presentation entitled, "PXE and the Eye". His presentation opened with the anatomy of the eye, discussed eye signs and symptoms of PXE, and offered recommendations to prevent or manage vision loss. Dr. Richard Alan Lewis of Baylor College of Medicine gave a presentation entitled, "Treatment of the Eye", which went into more detail about recent nutritional studies and specifics of laser therapy. Here are some of the questions Dr. Fuchs and Dr. Lewis answered during their sessions.

Q. Does peau d'orange lead to angioid streaks?

A. Both signs are often seen in PXE, but peau d'orange does not cause angioid streaks. Peau d'orange is seen in most people with PXE, and angioid streaks probably develop in many, but not all, people with PXE. However, it is extremely rare to see angioid streaks in PXE without the co-existence of peau d'orange.

Q. Does vision loss only come with angioid streaks?

A. Angioid streaks are one of the signs often seen in the eyes of individuals with PXE. While they do not cause vision loss, they are an effect of the process that can lead to vision loss. Bruch's membrane, one of the layers behind the retina, can develop cracks, called angioid streaks, which can be seen on examination. New blood vessels can then grow into these cracks, and these new vessels may crack and bleed. This bleeding can lead to loss of vision. However, it is not the angioid streaks that lead to the bleeding, but rather the defective and fragile Bruch's membrane. Well-documented subretinal bleeding in PXE patients has occurred with peau d'orange and without any angioid streaks.

Q. Can eye strain damage Bruch's membrane?

A. "Eye strain" is simply fatigue to the eye, and suggests that rest is needed, but this kind of fatigue does not injure the eye. In fact, you should keep your eyes in shape by using them!

Q. What happens when your eye is red? Is that the same kind of hemorrhage as in PXE?

A. When the "white" of your eye is red, as when you are exhausted or your eye is irritated, this is on the surface of your eye, and is not related to the kind of hemorrhaging seen in PXE.

Q. Can a direct hit to the eye cause angioid streaks?

A. Angioid streaks appear when there are cracks in Bruch's membrane, caused by the mineralization of elastic tissue. This is not caused by injury such as a blow to the head. However, a direct hit can cause or speed up leaking from blood vessels that are growing into those cracks. A direct hit may also cause other damage to the eye that could lead to visual loss, not directly related to PXE.

Q. How often should a person with PXE get an angiogram?

A. An angiogram of the eye is useful in detailed diagnosis of the eye, but it is not a routine examination. If a retinal specialist sees signs in the eye, or if a person notices a new distortion while using the Amsler grid, then an angiogram may be recommended to aid in planning surgical treatment. However, the angiogram procedure involves injecting a dye (which shows up brightly on the imaging), and it is best to save procedures like dye injection for when more investigation is needed, rather than using them routinely. The use of color photographs alone is usually sufficient to document peau d'orange and angioid streaks; the angiogram is necessary only if there is a threat of or strong suspicion of

new blood vessel membranes under the retina threatening the fovea.

Q. What is the difference between "hot" laser and "cold" laser?

A. "Hot" (conventional) and "cold" (photodynamic) lasers differ in wavelength. What that means is that the light used for the surgical treatment is different, although they have a similar effect. Also, photodynamic therapy includes the injection of a drug that makes the tissues that take the dye up more sensitive to the laser. The cold laser does not damage the healthy tissues of the eye. These treatments may both offer benefit in limiting vision loss resulting from PXE-related hemorrhages and new blood vessel membranes in the eye, and one may be recommended over the other based on the location of the vessels to be targeted. Neither have been studied as treatments for PXE.

Q. Are nutritional supplements helpful for PXE eye health?

A. Several combinations of supplements have been used in randomized clinical trials to see if they improve outcomes in people with age-related macular degeneration. Results of these studies have shown some benefit in individuals at high risk for vision loss, and they are safe to use. There is, however, no evidence that they are selectively beneficial in PXE.

Q. My child with PXE stays with his grandparents, who smoke. Is that safe?

A. Second-hand smoke is unsafe, but in terms of creating a significant risk for people with PXE, brief exposures are probably not a major concern. People with PXE should avoid smoking, of course, for all the reasons it is wise to avoid smoking, particularly in individuals at risk for accelerated arteriosclerosis. In every population study ever to look at primary smoking, smoking is a statistical risk factor for age-related macular degeneration, and its incidence is linearly correlated with number of pack-years (a pack-year is smoking one pack of

cigarettes per day for a year; two packs per day for a year is two pack-years). Secondhand smoke has not been diligently investigated.

Q. Do people with PXE need to be careful about altitude?

A. There is no reason that individuals with PXE and symptoms of the eye should approach altitudes differently.

Q. Is it OK for people with PXE to SCUBA dive?

A. There is some controversy about which forms of exercise and activity are safe for individuals with PXE. Although SCUBA diving places pressure on the eye, Dr. Fuchs notes that the pressure is evenly applied, and so does not increase the risk of hemorrhaging inside the eye. Other activities - such as weightlifting, some positions in yoga, and even sit-ups - can cause the "Valsalva maneuver", in which pressure is increased and can cause rupture of fragile vessels if present within the eye. In general, use eye protection with all sports and avoid straining (activities that "make your face red"). Dr. Lewis recommends SCUBA no deeper than the equivalent of one additional atmosphere (32 feet of water). He said that this is purely a guess based on very shabby data, however.

Q. Is LASIK OK for people with PXE?

A. LASIK is a laser treatment to improve vision for people with myopia. There is no reason why a person with PXE can not have LASIK safely. Considerations for the person with PXE are the same as for others: balance the risk of side effects from LASIK against the improvement in vision you can expect. It should be noted, however, that the suction rings that stabilize the eye during the LASIK procedure may increase the intraocular pressure to several hundred millimeters mercury. Theoretically, fracture of blood vessels can occur with such high pressures. Each person contemplating LASIK should discuss individual risks with his ophthalmologist so that there will be no surprises afterward.

Q. Can people with PXE benefit from the artificial retina now under development?

A. The artificial retina showed promise for light and shadow and now seems to be allowing some people to distinguish the big E on the eye chart. While this is good news for people with some kinds of blindness, it may be less important for people with PXE, because the macular damage in PXE only causes loss of central vision.

Q. Will stem-cell research help people with PXE?

A. Stem-cell research is an area of science that can help us understand how cells in the body develop, and that may help us to find ways to reliably grow tissues that can be used for transplants. Stem cells may also help us develop other treatments for disorders and conditions, and experiments are already under way to test treatments for vision loss using tissues developed with the help of stem cells. While every retina seems to have about 10,000 stem cells, we do not know how to stimulate

those cells to differentiate into retinal cells and their derivatives. Adult stem cells are not inducible into all other cell types. Fetal stem cell research holds much more promise conceptually.

Q. What should I tell my 7 year-old son about contact sports?

A. Contact sports place people at a higher risk of eye injury, and at the very least, good eye protection should be used. Good eye protection consists of shatterproof lenses (for example, made from polycarbonate) and a frame that is secure on the head and that transmits force to the orbit of the eye. Goggles that make solid contact with the eye orbit are a good example. While protection from impact is especially important to people who are already showing eye symptoms of PXE, it is a good idea for all individuals with PXE to protect their eyes from injuries that can cause vision loss by themselves, PXE or not. Similarly, those contact sports that offer headgear should be played only with the appropriate helmet and facemask or small mesh cage (football, lacrosse, etc.).



Photo by Michael D O'Neill

Ivonne Pasquali Ronchetti, PhD



Photo by Michael D O'Neill

Sisters enjoying the meeting

Artist Affected by PXE Shares Her Quest for Peace

Carolyna Marks has vision loss due to PXE. She attended PXE 2002, and shared with us about the Peace Wall. Many of us who attended the conference visited the wall and were awed by its beauty and moved by the collaboration it signified. Here is her description of the Peace Wall from her web site: <http://www.wwfp.org>.

In response to the Cold War, someone in my neighborhood had painted a sign on their fence in huge letters: DO SOMETHING TODAY FOR PEACE. Every time I drove past that fence, I asked myself, "What could I do? How could I contribute to peace in the world?" Slowly, my answer began to emerge. If peace meant bringing together or unifying opposing forces, then every creative act, no matter how large or how small, would be a peacemaking process. Every time the artist puts wet paint to dry paper, brings color to barren and empty places, introduces feeling and thought into a void, opposites are united. I knew for certain that if the artist in everyone were restored, the world could be saved.

Challenged by that sign on the fence, I set out to create the first Peace Wall. I invited people to bring forth the artist in themselves by painting their own vision of peace on ceramic tiles. With these tiles we would build a wall - not a wall that separates - but a wall of love and communication. Because tiles last for centuries, they would be the perfect medium for a message of peace. If we were all to die in a nuclear holocaust, we would leave behind this lasting monument to our affirmation of life and to our creativity.

I formed a core of dedicated volunteers. It would take five years of effort before our first wall, made of three thousand tiles, would emerge in downtown Berkeley. Since then the first World Wall for Peace has evolved into the vision of a healing Medicine Wheel of love encircling the Earth, with sections in different countries and cultures around the world.

The Peace Empowerment Process has been taught in widely disparate places around the world, including thirty schools in Moscow, and in Artek, Vladivostok, Troitsk and Padorsk in the (then) Soviet Union; and in El Khader (near Bethlehem) and Jerusalem, Israel.

The World Wall for Peace now stands in over 40,000 individually handpainted tiles across the world. Around the world, you can see WWFP walls in Hiroshima, Kobe and Nagano, Japan; Moscow, Russia, El Khader, Israel (occupied West Bank); and in The Netherlands and China. Proposed projects (as of November, 2001) include Capetown and Johannesburg, South Africa.

In the United States, completed or in progress Peace Walls can be found in Berkeley and Oakland, California; Atlanta, Georgia; Nashville, Tennessee; Detroit, Michigan; Loudenville, New York; Myrtle Beach, South Carolina. In the San Francisco Bay Area, you can see sections of the Wall at Martin Luther King Park and Willard Middle School in Berkeley; and the Fruitvale BART station and Jack London Square in Oakland.

As more walls were built, it became clear that more was happening than just painting tiles and building walls. The process of painting tiles helped unveil the "Artist in Everyone" and the importance of creativity in preventing violence became clear. I created and developed the Peace Empowerment Process, in which students develop their emotional wisdom through creative processes. The building of a wall became a framework in which participants learn skills and develop their creativity.

A more detailed history of the World Wall for Peace, and more information on the Peace Empowerment Process can be found in the book [Creativity in the Lions' Den](#), by Carolyna Marks.

One of many letters from participants:

Dear PXE International,

I feel refreshed, renewed and strong. Attending the conference was very uplifting. Making new friends, experiencing new low vision technology, feeling nurtured, cared for and informed... such a great feeling! Thank you! Thank you!!!

I came back from the Boston conference excited and did get to help out at the Dermatology conference, but I really want to help more. I know that there are things that I could do to help out. Monday a dermatologist came into the store where I work to pick up an order and also on Monday we got a letter telling us that my son's scoutmaster for the world jamboree is an eye specialist. So I guess being presented with all these contacts so quickly after being at the conference... I need to get a clue... I want to help out getting more people on the registry but am not sure how to do that. I just need a little direction.

The other thing I wanted to say was that when I get to see people that have come to a point of their daily life where work is a celebration of existence... To see people working from a point of compassion, determination and collaboration and how powerful it is - wow! It is VERY INSPIRING! The PXE International staff and volunteers are all amazing! You all have given new meaning to the word "Pro-active!" With heartfelt gratitude, many thanks!

EL

P.S. I was so glad my family came, because they both seemed to become more accepting and feel and act more "included". Somehow their being there bridged a gap that existed between us because of PXE. It seems the gift of information for them was empowering and connected us more as a family. Thank you! Thank you!



Photo by Michael D O'Neill

*Jouni Uitto, MD, PhD
Presented: PXE & Genetic Testing*

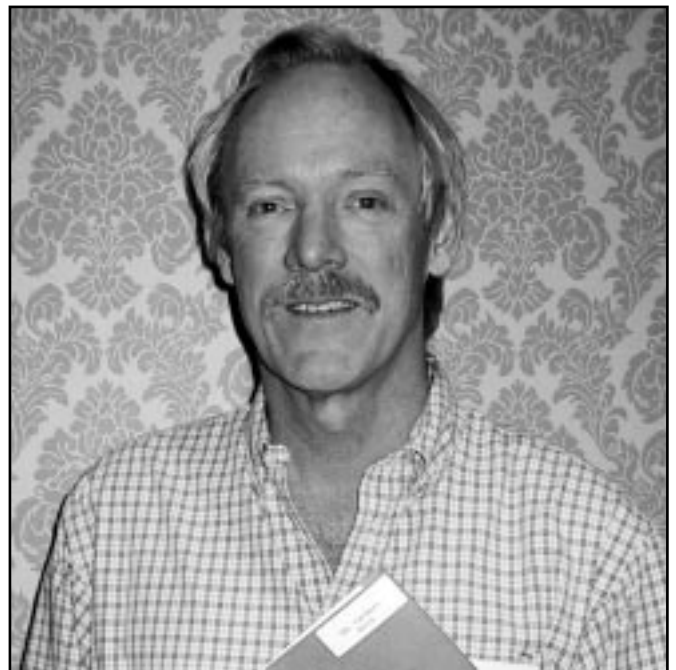


Photo by Michael D O'Neill

*Charles Boyd, PhD
Presented: Genetics of PXE*

Gordon Fundraising

It is Sunday, July 14, 10:15 PM. I'm writing this immediately following a 6-hour drive home from Oakland, which followed a three hour meeting of the PXE International Board of Directors, which followed an amazing two days at the PXE International 2002 Conference. I promised the Board that I would write this article, but I thought about getting some sleep and putting this off at least until tomorrow. Then I thought to myself, "WW PAST DO?" – meaning What Would Pat And Sharon Terry Do? And since these people apparently never sleep, I'm writing to you.

In the closing minutes of the PXE Conference, an audience member posed the question "Why can't we get everyone who is affected by PXE to give money to the organization so the research projects can continue?" Pat Terry's answer was that we could only ask people for what they can give comfortably, even if that means a hope or a prayer.

The purpose of this article is to take that a step further and to ask you for money – plain and simple. And it's not like I'm going to ask for anything I haven't done myself. As some of you may remember, our daughter, Amy, was diagnosed with PXE at age 19, four years ago. Sheila and I contacted PXE International within hours of receiving the biopsy results and a few hours after that we were determined to help. A few months later we sent out a letter to all of our friends, describing PXE and asking them to make donations. We attached a one dollar bill to each letter, and we asked our friends to use that as "seed" money – returning our dollar along with a few of their own. That letter raised \$20,000 for PXE International, and that was just about twice the amount raised the whole year before. We were on our way.

This year, PXE International has raised over \$300,000 in donations. But it is not enough. Now that the gene causing PXE has been located, we are closer and closer to being able to help those

who have PXE, and to help those who haven't even been diagnosed yet. My question to you is this: are you ready and willing to help us help you? Imagine what we can do if everyone reading this newsletter decided, today, to donate \$20 and asked one friend to do the same? That's \$200,000. If each reader could raise \$100, we'd have half a million dollars! And that would help us fund the ten on-going research projects, plus another five that we've had to turn down.

On page 26, you will find a fact sheet that Ron Adler and Christine Vocke have put together on how to raise money for PXE research. Take a look at some of these ideas and see if there's something you can do.

And maybe it is as simple as just walking over to your desk and writing a check to PXE International. Remember, out of every dollar you give, only seven cents goes to administrative overhead. The rest goes to making you and/or your loved ones healthy.

*Sincerely yours,
Gordon Morrell*



Photo by Michael D O'Neill

Elizabeth Terry calls numbers out at the auction at PXE 2002 - afghans, jewelry and gorgeous scarves (made by board member Maria Hof) netted PXE research several thousand dollars!

South African Meeting

Anna-Susan Marais, our genetics nurse working in South Africa recently organized a meeting of the Kwa Zulu Natal support group. The event was a great success. The following notes from attendees convey a flavor of the meeting.

Aan Anna-Susan Marais en Judy Williams ek wil net my dank betuig vir Saterdag 24 September toe ek die voorreg gehad het om saam met ander PXE-lyers te kon wees. In die 24 jaar sedert ek agtergekom het ek het PXE, diagnose met die hulp van Prof Hennie Meyer en Prof Francois Van der Rijks van Gent in Belgie, was dit die eerste keer dat ek saam met ander PXE-lyers kon bymekaarkom. Ek het dit baie leersaam gevind, ons kon eerstens aan Anna-Susan vrae stel oor PXE, tweedens kon ons inligting oor PXE met mekaar deel en derdens kon ons as PXE-lyers leer dat die meeste mense met PXE, dieselfde probleme het. Hoop daar sal nog sulke byeenkomste wees. Ons dank aan Judy en haar man Allan vir die reelings.

Eugene de Klerk

"As a mother of two PXE affected daughters it was so uplifting to join with the Kwa Zulu Natal support group for our get together; to see all the PXEers with vision problems getting on happily with their lives and not complaining at all made my husband and I feel so much easier in our minds about our own two daughters future. Thank you Anna-Susan for taking the time to come to Durban to join us all and give us your care and support."

Anonymous

As I have both the honour and pleasure of running the KZN support group in South Africa and as I have come to know all my group well over the years I decided that the time had come to bring everyone together for a day of caring and sharing both of the PXE problems BUT also

the coping skills we have all learned. I asked everyone to bring along their husbands, wives or partners since I feel very strongly that PXE is not an individual's problem but rather a family problem and the partners also deserve some recognition for their wonderful support.

I am so blessed to have these special people in my group that I don't see this as 'work' but rather a very great honour. I am thrilled to tell you that our day together was a total success, in fact members of my group are still congratulating and thanking Allan (my husband) and me for arranging this and finally making us into the "family" that I always dreamed my group would become. I would like to take this opportunity to thank Anna-Susan Marais for taking the time to spend a weekend in Durban with us all; without her care, love and support I could never have arranged this special day.

While I am thanking everyone I would also like to thank the entire group for their food contributions towards our lunch and also for their friendly, relaxed attitudes. I knew you could all be that way, and you are all very special to me. I remember that without all of you I wouldn't have a support group to run. I hope that my group of PXEers had as good and informative a day as Allan and I did.

All you people out there that run PXE International support groups around the world, take it from me, this wasn't hard, or difficult work, it was wonderful; don't let the thought of all the preparations and arrangements frighten you off, it is a really worthwhile and pleasurable thing to do, I recommend it to you all. Believe me when I say that I gained far more than I gave on that day.

Judy Williams

A PXEer's husband's perspective:
When Judy first broached the subject of this PXE International get together in our home I was excited at the prospect of meeting the members I hadn't yet met that Judy constantly talked about, as well as getting together with the

ones I already knew. The day went off really well with everyone having a positive and practical approach to his or her condition. In fact, we all decided that PXEers don't only have this rare condition, they also have another genetic condition that many other people don't have - it manifests itself with "extra friendliness, compassion, boundless strength of character and a very well developed sense of fun".

Allan Williams

"It was great to meet fellow PXEers and to be able to chat about our mutual health problems and concerns. I am enormously grateful to the Terrys for all that they are doing for us, and for their total dedication and enthusiasm. Where would we all be without them? To Anna-Susan, I say "thank you" from the bottom of my heart, for embracing PXE as your own; for showing such an interest in us and our fears and concerns; and for being the special caring person that you are."

Thanks again Anna-Susan.... you were a breath of fresh air and really do have the right temperament for what you are doing. We all really do appreciate your love and concern.

*Lots of love,
Lynn Rich*

Dear Anna-Susan,

Thank you very much for organizing the gathering at Judy's house. It was an experience meeting other people with the same disorder. It was a great experience to share the ways of handling difficulties with other people and to know that I am not alone in this. Thanks for all

the info that you share with us and answering all our questions.

Thanks and good luck with your job.
Corrie Cronjè

The idea of a get together for all the Durban PXE "patients" at Judy and Allan's house to share in the latest news from Anna-Susan who was visiting from Cape Town sounded like a good idea. The problem was meeting all these new people. Apart from Judy, Allan and Anna-Susan I hadn't met any of the others before.

Well, what a surprise! I learned more about

PXE in one afternoon than I had learned since my first encounter with it in '98. What a great bunch of people they all turned out to be. The closest words I heard that came anywhere near a complaint was a comment about the disappointment of not being able to

read anymore. I realize just how fortunate I am in that my eye problem occurred in '98 when modern laser treatment and gifted specialists were able to prevent the inevitable blindness. God is good to me, I don't know why. Maybe it is because Jesus loves the sinners!

Thank you Anna-Susan for sharing with us.
Thank you Judy and Allan for your local support
God bless you all
Peter B.



Spotlight on the Eye:

Questions and answers with Richard Alan Lewis, MD, MS

Transpupillary Thermal Therapy (TTT)

Q. Has anyone tried TTT laser for active hemorrhaging in his or her eye? My retinal specialist suggested that it might be a treatment possibility. It is a laser similar to what they use in PDT, I think, but they don't use the Visudine (drug) with it.

A. Transpupillary Thermal Therapy is a recent attempt to destroy vessels in the macula by heat without an enhancing dye. Most people who have tried this when there is no other alternative seem to feel that TTT is less effective than PDT. I would not recommend it in the absence of proof of efficacy, but, of course, that is just my opinion.

Conventional Laser

Q. I have just recently begun the laser treatment routine in one eye after having been first diagnosed with PXE (by retina specialist) about three years ago. The vision in my left eye has deteriorated from 20/20 to 20/80 in the span of 6 weeks. For years before my first laser treatment (hot), I experienced distortions in my near peripheral vision. The distortions changed somewhat with time, but always occupied the same general area. The hot laser treatment was not begun until the distortion caused a gray smudge instead of merely wavy lines, and was beginning to encroach on my central vision. My question is as follows: Why wait until the bleed is encroaching upon my central vision and then treat it in a manner which is guaranteed to permanently destroy a portion of my retina?

A. That depends on where the new blood vessel membrane began (erupted), where the network of blood vessels was located on the day that the retina specialist first saw you, and how large it was.

Q. Would it have not made more sense to have utilized the Visudyne therapy earlier, therefore, stopping the progression of the bleed before my central vision was affected and eliminating the requirement for the destructive hot laser procedure? Why is the hot laser procedure ever used if similar results can be achieved without destroying retinal tissue?

A. Absolutely not. No evidence suggests that Verteporfin has any effect on PXE neovascular membranes or that it is as good or better a choice than conventional argon or alternative visible light lasers for the treatment of new blood vessel membranes when the blood vessels are outside the critical central vision area.

The concern is the advertising by the manufacturer of the Verteporfin drug to convince the public that it is superior to conventional laser therapy for any network of classical abnormal vessels under the retina outside the center vision area. No data whatever supports that idea.

Q. After having the hot laser treatment, a new bleed in the same general area occurred within about four weeks. The bleed progressed daily and was already into my central vision. My vision deteriorated to about 20/40 as a result. I immediately scheduled a visit to my retina guy. After a visual and dye exam, the decision was made to do nothing. One week later, after continued steady deterioration of my vision to 20/80, the decision was made to start Visudyne therapy. Since the vision loss associated with the bleed is largely irreversible, again I have to ask, why the delay to start treatment?

A. That question can only be answered by your retina specialist in reviewing both the visibility of the abnormal new blood vessels under the retina, the size of the net of abnormal vessels,

and the extent of the blood. Lasers do not penetrate blood well, and the Verteporfin is not accessible to its stimulating laser if the abnormal blood vessels are covered by blood or if the blood vessels are under the retinal pigment epithelium and therefore “occult”. Verteporfin is not approved for the treatment of “occult” new vessel membranes in Age-Related Macular Degeneration, and there is no good evidence of its efficacy in PXE in similar situations.

Q. Is there some reason that these treatments cannot be initiated until permanent vision loss has occurred?

A. You should discuss that matter with the retina specialist who evaluated the new vessel membranes. The blood that you mentioned may have played a major role in the decision process. Further, there is no pre-emptive therapy for this condition.

Q. The treatments appear to be totally reactionary. I'm trying to figure out the decision making process involved. The procedure seems to be not to start any kind of treatment until real vision loss has already occurred and then try to contain the damage. The medical profession has been accused of being overly focused upon treating symptoms and fixing things that are broken instead of concentrating on prevention. That certainly seems to be the case here.

A. Not at all.

Q. I am asking myself... if the available treatments are incapable of restoring vision, can't be initiated until vision is lost and only marginally effective at preventing future problems, what good are they?

A. I agree. No clinical trial has been directed at the new vessel events in PXE. There is exactly zero information that shows that any therapy has any benefit in this condition. All the evidence is extrapolated from entirely different medical conditions, mostly in age-related macular degeneration. The widely altered retinal pigment

epithelium visible everywhere in PXE and called “peau d’orange” suggests that the mechanisms of initiation of neovascular membranes and the response to therapy are unlikely to be the same as in those clinical trials of other entities, no matter how similar they might be in concept.

Q. I am somewhat discouraged and feel that the only thing my doctor has to offer is a more expensive way to go blind.

A. These are the only approved therapies available. These are the only options in our armamentarium, and we adapt them by analogy to similar situations in PXE as they arise.

Peripheral Vision

Q. Having had laser on both eyes, and currently having loss of central vision in both eyes, I am torn between seeing eye docs in the future who may want to do more laser, or just letting nature take its course, and come what may.

My question is: what is the likelihood of losing peripheral vision due to new bleeds if left untreated?

A. Unlikely, but not impossible. PXE is one of the few diseases in which disciform degeneration does occur outside the macular areas and so there is some possibility that some involvement of peripheral vision may occur. Standard recommendations would still be that a complete ophthalmologic [NOT optometric] examination should be done each year.

Angioid Streaks

Q. My son, N, was diagnosed with PXE at 10 years old. Recently, at age 18, angioid streaks were detected. Does this mean a bleed is a certainty at some time in the near or more distant future, or whether the streaks may

Continued on page 18

Rockbrokers Do It Again: Largest Fundraiser for PXE International for the third year in a row!!!

In the early part of 2000, four stockbrokers from the New York Stock Exchange (who were all playing in different bands) started jamming together once a month. Joe Bocklet, Brian Egan, Tom Caterina and Kevin McColgan enjoyed these informal jam sessions so much, they decided to play a gig somewhere in Manhattan. Mike Berger, Gary DeSouza and Mike Ryan were added to the group and the "Rockbrokers" were born.

The band realized there was a huge pool of musical talent in the Wall Street community, and they needed to find the best way to showcase this talent. Recognizing the historical generosity of the NYSE and its members, a charity event was the answer. PXE International and De La Salle Academy became the children's charities that would benefit from the Rockbrokers' efforts.

Earlier this year, the Rockbrokers proudly became Rockbrokers Foundation, Incorporated, guided by President Joe Bocklet and Board members CJ Bocklet, Brian Egan, Barry Bocklet and Charlene Bocklet. Creating the foundation provided several freedoms that are essential in planning and financing a large-scale event such as the Rockbrokers Revue (the annual event's official name). This year, the Revue showcased



5 hours of live Rockbroker music including nearly 50 guest musicians from the NYSE. Held at Irving Plaza, one

of the premier venues in New York City, the event provided food and spirits to a crowd of 1,000 people who contributed over \$200,000!

The event kicked off with Ben Willis performing a powerful rendition of the Star Spangled Banner. Ben is a regular performer at NJ Nets and Devils games. Highlights featured Mike LaBranche and Todd Christie teaming up as Jake and Elwood Blues to perform Soul Man. CJ Bocklet sang a Devil in a Blue Dress/Good Golly Miss Molly medley that brought the house down. Jamie Friedman performed Losing My Religion, featuring Mike Berger on mandolin.

This completes a third successful year of fundraising, yet Rockbrokers Foundation, Inc. will not rest. The Rockbrokers hope to broaden their presence further into the Wall Street community, secure larger venues and play to larger audiences. And, of course, to continue raising money to help find a cure for PXE.

Joe Bocklet's nephew, Robert Hersey, has PXE. His sister Kathy is on PXE International's board of directors.



Brian Egan Leads One of the Headlining Bands



Mike LaBranche



Joe Bocklet, President of the Rockbrokers



Mike Berger



NYSE Rocks & Rolls

remain for a lifetime without bleeding and causing vision loss?

A. Not all people with PXE develop macular degeneration. I have cared for siblings with PXE, one of whom lost vision in his late 30's, the other of whom had normal vision in each eye (but with angioid streaks and peau d'orange) in his late 60's. No one knows what factors predispose to new blood vessel ingrowth and bleeding.

Furthermore, the ingrowth of new blood vessels does not necessarily occur at the edge of the streaks. As you well know, peau d'orange, diffuse changes in the retinal pigment epithelium (RPE), always precede the development of the angioid streaks. Bleeding can occur anywhere in the RPE without new blood vessel membranes.

Q. He is taking an over the counter eye vitamin daily (lutein) in the hopes of preventing problems, and is very nutrition and exercise oriented.

A. No information is available from any randomized clinical trial that demonstrates that supplemental dietary lutein has any beneficial (or detrimental) effect on any retinal disease, despite many theories as to why it might.

Q. Our greatest concern is whether he's likely to lose central vision and/or if there are steps we aren't aware of to attempt to prevent progression. He sees several specialists, including an ophthalmologist, about once a year. Any advice you or the specialist you mention might have will be gratefully received.

A. Apart from seeing a retina specialist who is familiar with the variations in these disorders, eventually a cardiologist who understands the spectrum of the disorders would be beneficial. Also, depending on the family situation, a geneticist who is familiar with the disorder may provide guidance to others in the family.

Artificial Retinas

Q. I was 43 when I lost central vision in my right eye and was diagnosed with PXE. At age 50, I started losing central vision in my left eye and was treated with hot laser. I lost central vision in my left eye but the cloud isn't as dark as the right eye. My retina specialist told me at this time that I would never be any better and maybe even worse.

After 25 years of research have there been any new developments in retina transplants or other means to restore sight or central vision in cases such as mine? Is there any hope?

A. Not yet. The "artificial retinas" or retinal implants are exceedingly primitive at this time. Consider looking at a TV image made up of a checkerboard of five squares by five squares. Not much information... However, the development is coming!

Photodynamic Laser Therapy

Q. In your opinion, what about FDA approval for PDT as treatment for those with PXE?

A. The initial approval for age-related macular degeneration was quite restrictive; subsequent approval for non-classic (so called "occult") new vessels was withdrawn and cancelled. Approval for some indications such as high myopia (near sightedness) is also highly restrictive. I suspect that some lobbying may be necessary for the add-on approval for PXE-related events. All this is predicated on the belief that PDT is an effective treatment, and several manuscripts are in process that suggest that, even in age-related macular degeneration, the drug benefits vision in only 2 to 4% of all folks treated. Those types of long-term outcome data are unlikely to persuade the FDA to approve PDT for another indication unless a separate clinical trial shows substantial efficacy.

Q. Since I was diagnosed in November 2001, I got insurance in January 2002. At this point, none of my exams are covered because of the pre-existing clause, and because PDT does not have FDA approval, the PDT treatments are not covered either.

A. True.

Q. I had a treatment in November, and had to (and still must) pay out of pocket. Fortunately, one treatment has stopped the bleed for now, but if there are more in the future, my insurance won't cover them.

A. True.

Fluorescein

Q. There have been some postings lately about repeat Fluorescein angiograms and their potential side effects on the body.

A. Fluorescein has been available as a chemical since about 1878. As a diagnostic tool for angiography of the retina, it has been used since the late 1950's. The current preparations by the several national suppliers is chemically more pure than ever, and the risk rate for a serious adverse reaction is quoted at about 1 chance in 20,000, although the rate of any reaction, major or minor, is about 1 in 5,000. Except for extremely rare allergy and the risk of death quoted as about 1 in 225,000 (roughly a quarter-million), there is no "cumulative" effect of Fluorescein. It is water-soluble and about 99% is excreted by the kidney in the urine in less than 36 hours in all people with normal kidney function (and it is dialyzable for those who are on kidney dialysis since it is water soluble). The other 1% is compounded in the liver and excreted in bile. Thus there is no 'long-term effect', since the drug isn't around long enough to do anything (unless you decide to sunbathe right after an angiogram; not a good idea since it will substantially increase the absorption of some wavelengths of visible light and several anecdotal reports document severe sunburn among those who go to the beach or sunbathe in the 24 hours after a Fluorescein angiogram—

not the most brilliant of ideas!).

Miscellaneous

Q. Can men affected by PXE use Viagra?

A. Viagra is well tolerated and safe for the majority of users. There is no data regarding its safety in PXE and we cannot give specific assurances regarding individuals wanting to use the medication, especially since I have no knowledge of their medical histories and have not examined them.

However, some general comments: The safety of Viagra in patients with pre-existing coronary disease, angina, cardiovascular disease in general, and high blood pressure is not known. Serious cardiovascular side effects including heart attacks, strokes, and cardiac arrhythmias have occurred after sexual activity (and before sexual activity) in individuals taking Viagra. Viagra dilates the blood vessels and can cause drops in blood pressure. Flushing and headaches are fairly common side effects. Certain drugs such as the organic nitrates (for example isosorbide dinitrate, a drug used in angina treatment, nitroglycerin, etc.) should not be used with Viagra. Antibiotics such as erythromycin can inhibit the metabolism of the drug, so this should be discussed with the pharmacist or physician prescribing either of the drugs. My advice therefore is for each individual to discuss the risks with his primary care physician or cardiologist. It is interesting that there is thought to be some risk of Viagra in retinitis pigmentosa because the enzyme inhibited by Viagra is deficient in the retina in that disease. As far as I know, no such abnormality has been described in PXE.

Testicular Ultrasound Study

If you are a male willing to have a testicular ultrasound in Providence, RI, please contact Dr. Bercovitch ASAP: lbercovitch@pxe.org or 202-362-9599.



Carmen Drake, age 14

To fund or not to fund - there's no room for question

*By Carmen Drake, from the LaRue County
Herald News, Hodgenville, KY,
January 30, 2002.*

Can you imagine having a disease that only one out of 100,000 people will get? Sounds like something out of a Sci-Fi movie right? Well, its not!

I am speaking about a disease that I have to face every day. It is called pseudoxanthoma elasticum, or PXE for short. My grandmother has this genetic disease, and it has caused her to go blind, along with developing heart problems. Every night I go to sleep wondering if I'll wake up blind in the morning. Children go to bed at night wondering if their mommy or daddy will be able to see them when they wake up. This type of fear is one that only one in 100,000 people will know.

But perhaps this fear would be abolished if a cure could be found. There is only one problem. PXE, like other "orphan diseases" in so rare that big pharmaceutical companies won't take

them on to be researched. This, in my opinion, is wrong, because they do not even try to find a cure for the "orphan diseases". They choose which diseases to research based on how many people have or could have the disease.

Pharmaceutical companies do not want to waste money researching a cure because the medicine would cost so much to develop and sell to the few people with the disease. The profit margin would be too small.

Due to this, small independent research companies do most of the work, but they often fail to get government grants and other advanced technology because the number of people they represent is so low.

PXE international is such a grassroots organization that was established by a couple when they learned their children had PXE.

**While not publicized
like cancer or AIDS,
the efforts of
this organization
are paying off.
PXE International
has shown a
light through the darkness
that is PXE.**

They have put together a registry of patients, a blood and tissue bank for researchers, and helped to privately funded the research which led to identifying the gene which causes PXE. While not publicized like cancer or AIDS, the efforts of this organization are paying off. PXE International has shown a light through the darkness that is PXE.

But there is so much more that could be done if only they had money.

An article in the Fall 2001 PXE International newsletter is called Research Roundup.

It details many different projects that they are trying to fund. And the price tag for each.

The costs are outrageous!

Preliminary studies on possible drugs that might slow the progression of PXE are \$25,000. Developing and refining a genetic test for PXE and subsidizing its cost to make it affordable is estimated at \$40,000 per year.

There are simple steps, not yet targeted toward a cure. The list goes on with projects, and the costs become greater.

What can you do to help? An obvious answer is personal donations. Secondly, write your congressional delegation. Senate Bill 1379 (this was supplanted by H.R. 4013 and 4014)* is now awaiting action. Its purpose is to establish a Rare Illness Department within the National Institute of Health.

This is the question I ask you. Should all diseases be equally funded, or should future profits drive research?

Now pretend a loved one has a rare disease and ask yourself the same question. The answer is not so easy.

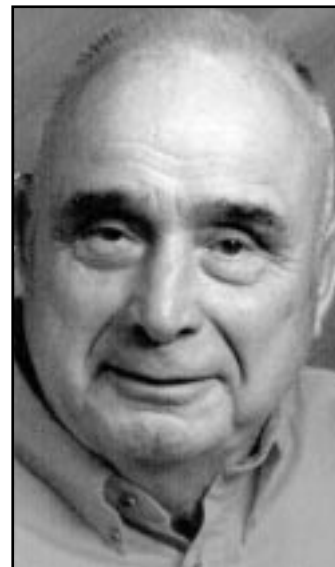
**Editor's note: On October 17, 2002, both H.R. 4013 (the Rare Diseases Act) and H.R. 4014 (the Rare Diseases Orphan Product Development Act) were approved by the Senate, after having earlier been approved by the House of Representatives. The bills now go to President Bush for his signature. Thanks to many of you who wrote and called and to the Senate and House sponsors of the bills: Senators Edward Kennedy (D-MA) and Orrin Hatch (R-UT) and Representatives John Shimkus (R-IL), Mark Foley (R-FL), and Henry Waxman (D-CA).*

President Bush signed both H.R. 4013 (the Rare Diseases Act) and H.R. 4014 (the Rare Diseases Orphan Product Development Act) into law on November 5, 2002.

Carmen's grandfather, Carl Flanders, passed away recently. Our condolences to the Flanders/Drake family. We are very grateful for the numerous memorial donations made in his name.

In Memory of Seth Arthur (Woody) Wood

Seth Wood passed away October 8, 2001. He was very special to PXE International, having supported its establishment, along with his wife, Frances Wood who survives him. He is also survived by his children, Valerie, Wendy, Bob, Leslie and Gary. His son Andy passed away two years ago.



As the father of three children with PXE (Wendy, PXE International's Vice President, Andy and Bob) he was dedicated to supporting the Wood family's many activities for PXE - from our first fundraisers to large ones like the many wine and beer tastings organized by Wendy.

Woody was much loved by the PXE International board and staff and is greatly missed. Our deepest condolences to his family. Our world is richer because of him, and we have much to carry on in his memory.

We cannot adequately express our appreciation for the many donations made in memory of Woody.

Transgenomic Signs Collaboration Agreement with Lay Advocacy Group PXE International

Thursday, October 17, 2002

COMPANY PRESS RELEASE

Goal is assay for mutations in gene linked to the disease Pseudoxanthoma Elasticum (PXE)

OMAHA, Neb., and WASHINGTON, D.C., October 17 / – Transgenomic Inc. (Nasdaq: TBIO) and the non-profit organization PXE International today announced that they have entered into a collaboration to develop a diagnostic test for the genetic condition, pseudoxanthoma elasticum, commonly known as PXE. The intent is to develop a test based on Transgenomic's WAVE System and make it available to laboratories around the world.

PXE, which affects an estimated one in twenty-five thousand to fifty thousand people, can affect the skin, eyes, cardiovascular system and/or gastrointestinal system, with significant symptomatic variability among affected individuals. Research conducted at the University of Hawaii in collaboration with PXE International has identified a gene — the ABCC6/MRP6 gene — that is linked to the disease. This gene is a member of the ATP-binding cassette (ABC) transporter gene family, one of the largest gene families known. ABC transporters have been shown to be involved in various inherited diseases, immune system function and resistance of cancer cells to chemotherapy.

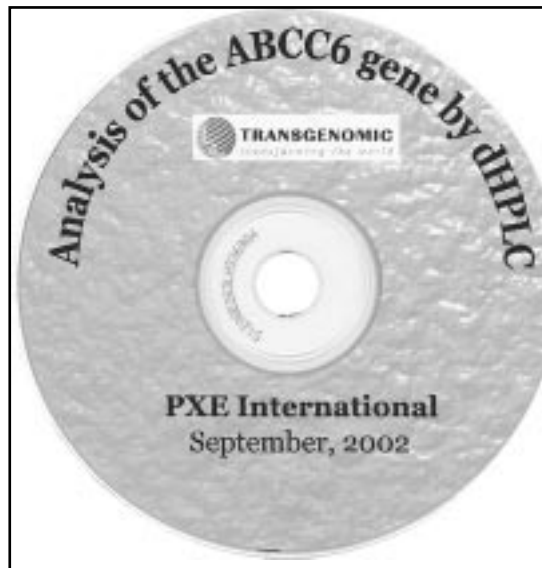
For Patrick and Sharon Terry, husband and wife co-founders of PXE International, the collaboration with Transgenomic represents the next stage of a long and ongoing journey that

started in 1994 when their daughter and son were both diagnosed with PXE. The Terrys, neither of whom have a medical background, channeled their emotional energy away from worry and despair by educating themselves and then taking action to positively impact the lives of those affected with the disease. They collected and consolidated extensive data on the subject, set up a tissue bank and registry of patients, and engaged in fundraising to support new research. These activities have enabled

them to engage the research community to stimulate new research and to help ensure that laboratory findings ultimately translate to better diagnosis and treatment of PXE and related conditions.

In pursuing their goal, PXE International has stayed attuned to the need to strike a balance between profit motives and reasonably priced accessibility to diagnostics and treatment, the essential element that aligns patient advocacy groups with industry in

pursuit of win-win situations. Their approach caught the eye of Francis Collins, director of the National Human Genome Research Institute at the National Institutes of Health, who commented, "By establishing this unique collaboration, Sharon and Pat Terry are once again showing how creative and dedicated consumer groups can empower research on rare diseases and speed the process of identifying causes and cures of genetic disorders." Today, in addition to their involvement with PXE International, the Terrys are involved in multiple organizations including the Genetic Alliance that help to empower the consumer as a full partner in the use of genetic research to improve diagnosis and treatment of disease.



A CD of an analysis of the ABCC6 gene - PXE hits the big time!

In explaining why PXE decided to partner with Transgenomic, Patrick Terry said, "Transgenomic's technology is a key component in the linkage of value that we are assembling in our global enterprise. The WAVE assay platform is simply unrivaled in specificity, accuracy and high throughput scanning capacity for genomic analysis of disease. In addition, Transgenomic's bioinformatics portal, MutationDiscovery.com™, is the collaborative management system we were looking for. It allows us to expand scientific knowledge transfer, capacity building and services to a world community. Transgenomic is integrally involved in the beginning of our success to deliver a win-win result." To that, Sharon Terry added, "We are excited with the prospect that progress in diagnosing PXE provides hope in the battle against other rare diseases; hope that today's affected individuals will enjoy a quality of life better than those that went before them."

Nancy Taylor, vice president of Global Marketing and Alliance Development with Transgenomic, sees this collaboration as just the start. According to Taylor, "The direct simplicity of our WAVE technology is ideal for the design of new tests for inherited diseases, particularly those characterized by a variety of potential mutation sites dispersed across large or complex genes. Since the WAVE System detects any mutation within a particular DNA fragment, there is no need to design and optimize a specific probe-or primer-based assay for each individual mutation." She concluded, "This also simplifies the ongoing incorporation of newly-discovered mutations into a genetic test and provides the ability to optimize the disease detection rate at a fraction of the cost of other approaches."

About PXE International

Founded in 1995 and based in Washington, D.C., PXE International is a lay advocacy group for the genetic condition pseudoxanthoma elasticum (PXE). This dynamic non-profit organization fosters ethical research and policy as well as supports members and the public. It initiates, coordinates and funds research and provides worldwide patient support. In seven

years, PXE International has established and directs a 19-research lab consortium, more than 52 offices worldwide, a blood and tissue bank, a database of thousands of affected individuals, and provides many important services for affected individuals.

For more information about PXE International, go to their web site at www.pxe.org.

About Transgenomic

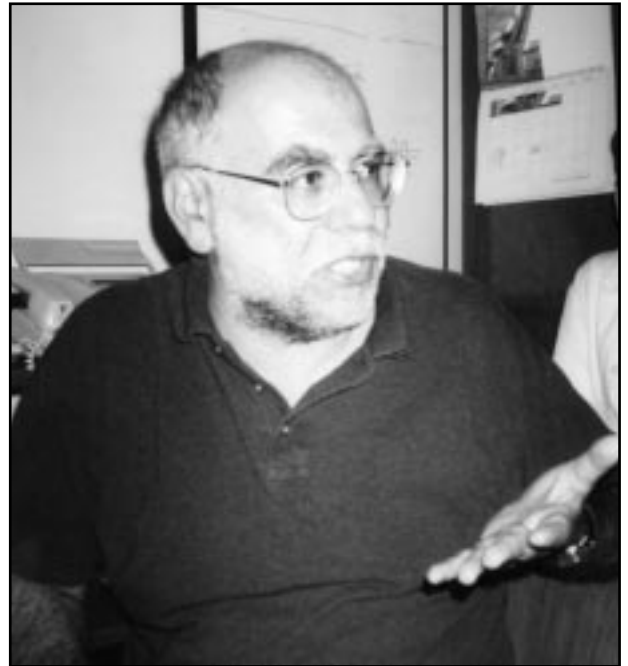
Transgenomic is headquartered in Omaha, Neb., and has offices in the United States, Europe and Japan. Major manufacturing facilities are located in San Jose, Calif., Omaha, Neb., Cramlington, Newcastle, U.K., and Glasgow, Scotland, U.K. The company provides innovative research tools to the genomics segment of the life sciences industry. These tools enable researchers to discover and understand variation in the human genetic code, or genome, in order to accelerate and improve drug development and diagnostics.

For more information about Transgenomic, go to their web site at www.transgenomic.com.

Forward Looking Statement

This press release may contain forward-looking statements that reflect management's current views and estimates of future economic circumstances, industry conditions, company performance and financial results, including the ability to develop a diagnostic assay for the disease PXE. Such statements are subject to certain factors, risks and uncertainties described from time to time in Transgenomic, Inc.'s reports to the Securities and Exchange Commission. Any change in such factors, risks and uncertainties may cause the actual results, events and performance to differ materially from those referred to in such statements. Accordingly, the company claims the protection of the safe harbor for forward-looking statements contained in the Private Securities Litigation Reform Act of 1995 with respect to all statements contained in this press release.

PXE International Awards Grant to Hungarian Scientists to Study the Consequences of Mutations in the Gene Associated with PXE



András Váradi, PhD

PXE International awarded \$115,000 to two prestigious Hungarian scientists. András Váradi, PhD, is a scientist at the Institute of Enzymology, Biological Research Center, Hungarian Academy of Science in Budapest. Balázs Sarkadi, MD, PhD is at the National Institute of Hematology and Immunology, also of the Hungary Academy of Sciences.

Their initial work on the protein produced by the ABCC6 gene is very enlightening. Details will be published in the MemberGram as soon as the scientists have published their findings in scientific journals.

Last year, Pat and Sharon Terry visited their labs and presented an overview of all of the research that PXE International is funding. This collaboration is an exciting one, allowing us to take a step closer to a treatment for PXE.



Balázs Sarkadi, MD, PhD



Fellows in András Váradi's lab

Victor A. McKusick, PXE International Medical Advisory Board member, wins presidential medal.

President Bush Names 15 to Receive National Medal of Science

5/10/2002

Fourteen scientists and one engineer today were named by President Bush to receive the National Medal of Science, the nation's highest award for lifetime achievement in fields of scientific research. The honorees will receive the medals at a White House ceremony in the near future. Thirteen of these premier researchers received funding support from the National Science Foundation (NSF) during their careers. The president also announced the recipients of the National Medal of Technology. "Each one of these individuals has helped advance our country's place as a leader in discovery, creativity and technology," the president said. "Their contributions have touched all of our lives and will continue to do so." Six of those named to receive the science medal have made lasting and continuing contributions to a burgeoning list of discoveries and technology breakthroughs in the biological sciences. Four have pioneered in studies of genetics, a rapidly expanding area of research that has been bolstered by their discoveries. Francisco J. Ayala of the University of California, Irvine revolutionized molecular biology in the study of the origins of species. Mario R. Capecchi of the University of Utah School of Medicine developed new tools that revolutionized the study of mammalian genetics and provided important new models for human genetic diseases. Victor A. McKusick of the Johns Hopkins University School of Medicine was largely responsible for bringing genetics into the mainstream of clinical medicine, and one of the first to push for the Human Genome Project.

Mount Sinai School of Medicine is currently conducting a study of a new treatment for PXE.

If you have been diagnosed with PXE (confirmed by biopsy) and are interested in participating in a 2-year long study involving a medication taken by mouth, you may qualify for the study. If you are interested in participating, and are able to visit the clinic in New York City approximately every three months during the two year study please contact Giselle Singer at (212) 241-3288.

Mt. Sinai Resident Wins Prize for Work on PXE!

Congratulations to Dan Sherer, MD. Dr. Sherer won first prize in the 2002 resident competition of the New York Academy of Medicine. His subject was a potential treatment for PXE. Dr. Sherer is working with Dr. Lebwohl and PXE International in the development of a clinical trial for a drug that might diminish the skin lesions caused by PXE.

How Can You Help Find Funding for PXE Research?

*By Ron Adler and Chris Vocke,
Board Members*

PXE International is dedicated to initiating, directing and funding research and supporting affected individuals. We have many exciting and critical research projects waiting to be funded, and not enough money to give them a green light.

PXE International spends only about 7% of its annual budget on administrative costs – the remainder is spent on research, and patient and clinician education! Our records show that only 10% of those with PXE actually donate to this cause. We need your help now.

The purpose of this article is to give you some concrete ideas on how you can support PXE International. Read these ideas, think about them, then decide what you can do to make a difference today!

Wendy Wood Hubbard, one of the very early supporters of PXE International writes: “When we started PXE International, we did not have a dime. We had many good thoughts on how to spread the word, so people diagnosed with PXE would not feel alone as my family did. Sharon and I took a small class on fundraising. It was very encouraging. They suggested we start small and with something that we knew. Put a committee together and delegate. I kept trying to think, what do I know best. I always kept coming back to social events, parties, etc. I took on the challenge. But, first I had to come out of the closet about my blindness with PXE. That was not easy.”

Wendy took the challenge, evaluated her skills and her comfort level, and as a result organized a local wine tasting. A friend who owned a wine shop, local businesses, friends and relatives, the Lions Club, all got involved. It was the first

fundraising event that Wendy and her friends had ever done and it raised \$10,000 for PXE International!

Our greatest need at this turning point is funding for research. We stand at the brink of a number of important projects. How can you help raise money for PXE International? Over 5,000 individuals receive this newsletter - if we each participate in even a small way in raising funds, we could double or triple (or more) the funds PXE could dedicate to research. What can you do?

Personal Donation Strategies

- Good old cash, check, and credit card donations. Send your check or credit card information using the donation envelope in this MemberGram, or make on-line donations through PXE International's website at www.pxe.org. Credit card payments are processed using a simple and secure on-line form.
- Set up an automatic monthly donation charged to your credit card or an automatic withdrawal from your checking account. If each of the 4,000 individuals currently registered with PXE International donated only \$10 per month, the yearly income generated would be \$480,000! Contact PXE International by phone, fax or email for details or help with setting up an automatic donation.
- For birthday, holiday, and other gifts: Ask friends and family for PXE International donations in lieu of items you really don't want or need.
- Donate gifts of appreciated (or depreciated!) stock and other securities. Here's a chance for you to take a tax deduction and help a worthy cause.

- Through a charitable gift annuity to PXE International, donors can receive income for the life of one or two people and a current income tax deduction, and designate PXE International to receive a future gift. Contact your broker or accountant for help.

- Sell items you make or services you provide, and donate proceeds to PXE. PXE'ers have crocheted afghans, sewed teddy bears, silk-screened scarves, created scrapbook pages. Items can be donated for raffles at PXE meetings, or sold online, at eBay (see web based giving below).

- Memorial and Tribute gifts provide special recognition for friends and family while helping PXE International.

- Talk to your financial advisor about a bequest, living trust or life income gift.

Ask your friends to give to PXE International

Gordon Morrell, father of a child affected with PXE, has found some innovative ways to ask his friends for donations to PXE International.

- Write a letter to your friends and family. Tell them about PXE, how it affects you, and about PXE International, and what we do. Enclose a crisp, new, \$1 bill, and a stamped envelope addressed to PXE International. Ask them to match your \$1 gift to PXE, and send a donation. Contact Gordon at GORDON@YARDI.com for a copy of his letter, and read his article in this MemberGram.

- Host a "Tea for PXE". You simply write a letter to your friends and family. Enclose a tea bag. Ask them to host a tea party at a certain day and time. The idea is that all of us are focusing our thoughts and energies on one thing on that day - in this case PXE. We ask each participant to chip in \$5.00, \$10.00 or whatever, which will go to the organization. Most people don't have a real party, but they have the tea bag to encourage them to participate, even if they do it alone. And, hopefully, they send in a check for

more than five or ten bucks. (You can read more about this idea at <http://www.hopemag.com/issues/2002/marApr/signsAPotent.htm>, or contact Gordon at GORDON@YARDI.com.)

Neighborhood Events

- Donate proceeds of garage sales. Clear out that unwanted stuff and help PXE at the same time. If you don't think you have enough stuff to have a decent yard sale, solicit your friends, co-workers, and neighbors to spring clean and donate their stuff as well. Several yard sales have been held for PXE International, and have netted up to \$1,700!

- Host a bake sale and solicit friends' contributions, and donate the proceeds to PXE International.

- Kids can help too: lemonade stands, car washes, etc., will make them feel like they've made a real contribution.

Employer Based Giving

- Employer Matched Contributions are often available from many employers to match charitable gifts made by employees. If you are considering a donation, why not double your contribution by asking your employer if they offer a matching gifts program?

- Some companies will donate the amount they would have spent on a retirement party to a charity of your choosing at your request. PXE International recently received a \$3,000 donation in this way! If you are nearing retirement, consider asking about this.

- Ask your employer about cashing in your PTO (paid time off). PTO is usually calculated at your hourly rate. If for example, you are paid \$20 an hour, and you choose to donate five hours PTO, your employer will make a \$100 donation to PXE International on your behalf, and deduct five hours from your vacation time.

PTO donations are easy and relatively painless, especially for someone with lots of time saved up.

- Designate PXE International in your local United Way or other company-wide giving plans – although all of these are franchised, and therefore PXE International cannot sign up to be a part of every one, you can write us in! Contact us to get the relevant information to write us in.

- Employer charitable foundations are part of some large companies. PXE International recently received a donation from the UPS Foundation, initiated by a UPS employee who recommended us to the foundation. Find out if your employer donates directly to charitable foundations, and recommend PXE International. We can provide information you will need to submit an application.

Web-Based Giving

- iGive.com allows you to support any charity or worthy cause with a percentage of your online shopping. Do you ever shop online at stores like Land's End, Amazon.com, Barnes and Noble, eBay or CDNow? If you register with iGive.com at <http://www.iGive.com/PXEInternational>, you can shop at these and over 330 other stores, and up to 26% of each purchase will be donated to PXE International. It's totally free for you, your privacy is protected, there is no spam, no tricky obligations or hidden costs. There is also a \$5 sign-up donation made to PXE International when you order anything within the first 45 days of signing up!

- At ShopsThatGive.com, every time you shop, you give...without paying extra. ShopsThatGive donates 50% of commissions paid by merchants to the cause that you designate. It's a risk-free non-profit fundraising idea. PXE International is a registered charity with ShopsThatGive.com, so choose us as your favorite charity!

- Auction something online at eBay, and donate the proceeds to PXE International. Do you have a piece of celebrity memorabilia, a handmade item, or a collectible you'd be willing to donate? Mary LeBlanc (Mcowleblanc@aol.com) auctioned a pair of Jimmy Buffett tickets for PXE International on eBay, and raised \$300 for PXE. She is willing to coordinate an effort to create a PXE eBay auction site. Contact Mary if you have items to donate or want to help.

Charity Fundraising Events

- Sponsor a gala social event: (wine tasting, dinner dance), etc. Invite local sponsors (hotels, restaurants, etc.) to underwrite, so all the proceeds go to PXE. Wendy Wood Hubbard (PXENewEng@aol.com) is willing to help you with the organization of such an event.

- Organize an athletic event: a race, walk-a-thon, swim-a-thon, etc. Raise awareness of PXE and money at the same time. Audrey Gordon, of The Progeria Research Foundation, Inc., has just conducted her first road race/fun run for this foundation that raised \$5,000. She is willing to share her experience with anyone interested in pursuing this fundraising idea. Contact her at progeria@netzero.net.

Some of these ideas are very simple, and others require detailed planning. Whatever you do, please consider how you can help us financially right now! As Wendy Hubbard writes: "I cannot encourage people enough to get involved. We have come such a long way and need to continue growing so others will not feel alone. Together, we have all made a difference for the research of PXE."

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**Don't see an office
in your area???**
Become one!!

If you are interested in helping other individuals learn about PXE, connect with someone else with PXE, and furthering the mission of PXE International, please contact the office coordinator, Diane Rohrman (see her contact information first in the listings).

If you live outside the USA

You will not receive our solicitation letter (begging for support) - it is mailed to USA subscribers only.

But don't feel left out!

Please go to <http://www.pxe.org/donate.html> and contribute to PXE research using your credit card.

Where in the World are PXE'ers?

The PXE International Registry includes over 2,500 affected individuals. This is a list of the numbers of individuals in all the countries, states and provinces registered with us. If PXE affects 1 in 50,000 to 100,000 people (a very rough estimate) and there are 6 billion people in the world, then there are 60,000 to 120,000 people in the world with PXE - help us find them!

Australia-104	Iran-1	Republic of	Canada	HI-8	NJ-41
Aruba-1	Ireland-2	Azerbaijan-1	AB-7	IA-9	NM-3
Austria-1	Israel-3	Romania-2	BC-16	ID-6	NV-4
Belgium-6	Italy-61	Saudi Arabia-1	MB-5	IL-45	NY-151
Brazil-5	Japan-1	Singapore-1	NB-1	IN-39	OH-54
Chile-2	Jordan-1	South Africa-88	NS-6	KS-24	OK-26
China-1	Lebanon-1	South Korea-1	ON-72	KY-22	OR-25
Croatia-1	Malaysia-3	Spain-9	QC-10	LA-26	PA-46
Cyprus-1	Malta-1	Sweden-1		MA-59	RI-26
Denmark-2	Mexico-2	Switzerland-7	United States	MD-26	SC-24
Deutschland-1	Morocco-6	Netherlands-58	AK-1	ME-6	SD-2
Egypt-1	Netherlands-2	Turkey-9	AL-24	MI-55	TN-27
Finland-2	New Zealand-8	United Kingdom-154	AR-17	MN-27	TX-78
France-41	Northern Ireland-1	Vietnam-4	AZ-18	MO-25	UT-17
Gabon-1	Pakistan-1	Venezuela-2	CA-164	MS-10	VA-56
Germany-108	Peru-1		CO-36	MT-9	VT-2
Greece-5	Poland-2		CT-24	NC-54	WA-49
Grenada -1	Portugal-3		DE-3	ND-5	WI-17
India-2			FL-69	NE-7	WV-19
			GA-62	NH-11	WY-2

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Please let us know if you'd prefer a taped copy.**

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I'd like to support PXE International, Inc. I understand my contribution is tax deductible in the USA.

- \$1,000 - \$500 - \$200 - \$100 - \$50 - \$25

Monthly Pledge - \$ _____

Credit card # _____ Expiration Date _____

Signature _____

Video Tape - Dr. Wayne Fuchs: PXE and the Eye - \$12/tape

I'd like to order the following free publications:

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| <input type="checkbox"/> General Bulletin | <input type="checkbox"/> General Bulletin/Spanish | <input type="checkbox"/> General Bulletin/Dutch |
| <input type="checkbox"/> PXE and the Dermatologist | <input type="checkbox"/> PXE and the Skin | <input type="checkbox"/> PXE for Dentists |
| <input type="checkbox"/> Angioid Streaks | <input type="checkbox"/> PXE and the Eye | <input type="checkbox"/> The ABCs of PXE |
| <input type="checkbox"/> Your Child and PXE | <input type="checkbox"/> PXE and Pregnancy | <input type="checkbox"/> PXE and the Primary Care Practitioner |

Nutrition Booklet by Kelly Dorfman - \$7



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