the People's Doctor

A MEDICAL NEWSLETTER FOR CONSUMERS
by Robert S. Mendelsohn, MD

VOL. 9, NO. 1

P.O. Box 982
Evanston, Illinois 60204

IN THIS ISSUE:

Osteoporosis ... Paget's Disease ... PKU

Dr. Robert Mendelsohn

The ignorance of doctors about diseases of the aged--osteoporosis, Paget's disease--as well as about diseases of the newborn--PKU--might be tolerable were it not for their refusal to confess how little they know and the danger of the unproven remedies they prescribe. The purpose of this Newsletter is to provide information that can help you--and your children and your parents--avoid being damaged by doctors at both ends of the age spectrum.

Q I am 67 years old and have osteoporosis. My doctor has treated me with pain relievers in the past, and now he has prescribed Premarin. When he got through explaining the medication's side effects, I was afraid to take it. I trust my doctor; he's so gentle and kind to his patients. I just can't tell him I'm not taking the pills.

Please give me some information about this drug when used to treat my problem. And rush your reply.--Mrs. L.M.

A

Osteoporosis

Osteoporosis (a disease that weakens the bones) is not included among the conditions for which Premarin is known to be effective. The drug is listed as "probably effective" in treating this condition, and then only in conjunction with a diet, calcium supplements, exercise, and other health-promoting measures.

I'm not surprised at your hesitation to take Premarin after your doctor pointed out its possible side effects, which include blood-clotting disorders and salt and water retention.

I can also appreciate your reluctance to confess to your fine physician that you are not taking your pills. Your "non-compliance" is not unique; many surveys show that a high percentage of patients do not take the medicine their doctor prescribes.

One might argue that such game-playing certainly benefits neither doctor nor patient. (Or perhaps non-compliance by patients explains why the damage from powerful drugs is not more widespread.) But, if you and your doctor are to be equal participants in the management of your condition, you have no alternative but to tell him the truth and carefully investigate with him all the alternatives or adjuncts to hormone therapy for osteoporosis.

He sounds like the kind of doctor who would appreciate such frankness on your part.

The National Dairy Council reports that elderly women who suffer from soft, brittle bones (osteoporosis) can have their bone densities increased when they supplement their low calcium diets with calcium and calcium-rich foods. Twenty women received supplementary calcium and cheese during a six-week period, and their bone densities, as measured by hand x-rays, increased.

Q A dear friend of mine is suffering from osteoporosis. Can you tell me the cause and whether there is a cure? She is taking all kinds of vitamins to build up the bone in the tip of her spine, but she's still not improving.--J.C.

A Doctors are likely to tell you that osteoporosis has something to do with old age and the loss of female sex hormones at menopause. But they are not likely to tell you that, while osteoporosis affects only 25 percent of women after a natural menopause, it occurs in 80 percent of women after a surgical menopause (the doctor's term for removal of the ovaries, also known as oophorectomy and surgical castration). Nor will the doctor tell you that a high protein diet, particularly one characterized by overindulgence in red meat, has been linked to the development of osteoporosis.

Your doctor may tell you that the treatment of osteoporosis is female sex hormones, primarily estrogens. But he is far less likely to tell you the considerable risks, including cancer, of estrogens. Nor is he likely to tell you of nutritional approaches coupled with exercise in treating osteoporosis. So, your dear friend must find the correct answers on her own. Rudolph Ballentine, M.D., in "Diet and Nutrition," states: "Properly timed intake of calcium-rich foods (e.g., milk before bed), regular exercise, and overall good nutrition stressing fresh, tender vegetables are probably better ways of dealing with osteoporosis than taking huge amounts of calcium supplements." Although she is taking vitamins, your friend should investigate a number of methods recommended by authorities in the field of nutrition. A good place to begin is "Every Woman's Book," by Paavo Airola (Health Plus, $17.95).

Q Although I am a vegetarian, I have recently begun eating a pint of low fat yogurt every morning in an effort to beef up my calcium intake. I'm 49, and my mother suffers from osteoporosis, a disease currently featured in just about every women's magazine.

Common sense tells me that humans don't need to drink another animal's milk in order to achieve optimal nutrition. I question the recommended daily allowance (RDA) for calcium, a figure I think the dairy lobby came up with. But my problem is that nothing I read tells me how much calcium a woman really needs. I don't think it's anywhere near the recommended 800 milligrams daily, but I don't want to play around with my health. So I compromise with my ethics and eat the yogurt. I then supplement it with such things as sesame seeds, or perhaps I eat a big salad of greens.

When people find out I don't eat dairy products, they look at me like I'm crazy. When I tell them dairy products aren't essential to human nutrition, they really think I'm out in left field. We've all been taught to consider dairy products as one of the essential food groups.

I recently discussed this matter with the only clinical nutritionist who practices in this area (a former nutritionist for the National Cancer Institute). He not only told me how foolish and suicidal it was for me to continue my ban on dairy products (given my mother's history), but he recommended I immediately begin taking a hormone as a preventative. If there are any real nutritionists practicing in this area, I'd sure like to find out about them.--M.M., Washington

A

Within the field of nutrition, people can find practically any answers they want to whatever they ask. Plenty of best-selling books and famous contemporary and historical figures (such as George Bernard Shaw) laud vegetarianism. Other nutritional authorities, including many modern doctors, condemn those who avoid animal products, threatening them with Vitamin B12 deficiency and other dire effects.

Books written by many registered dieticians praise the benefits of cows' milk, while other published authorities, including pediatrician Frank Oski, M.D., advise against drinking milk. Some experts claim that milk intake is vital to the proper metabolism of calcium, while others point out that plenty of other foods--including collard greens and other dark green leafy vegetables--can satisfy calcium needs completely and more safely than milk and milk products.

All these divergent views are supported by a minimum of scientific evidence and a maximum of rhetoric, since there are practically no controlled studies in which half of a population is given one diet, while the other half, equally matched, is given another.

So in the absence of controlled scientific studies, what's a person to do? Obviously, the answer is to do what you already have done by using--as you express in your letter--common sense, a questioning attitude, suspicion about vested interests, ethics, compromise, and ongoing discussions with a broad spectrum of experts.

As for a nutritionist who practices in your area, I suggest that you communicate with any nutritionist who has written a book which agrees with your practice of vegetarianism. Ask him to refer you to local experts who can counter the arguments of that NCI nutritionist who recommended cows' milk and sex hormones in the prevention of osteoporosis.

Finally, with all due respect, I recommend a change in your social life. Why are you associating so closely with people who abhor your eating habits? Isn't it time that you changed friends so that you keep people around you who closely agree with and support your lifestyle?

Q

I have Paget's disease, and I have not been able to get satisfactory information about what I can expect from this illness. I'd appreciate your writing on Paget's--I read your advice faithfully.--E.S.

A

Paget's disease

Information on Paget's disease, a common bone condition of unknown cause which occurs in older folks, is not all that hard to come by. A good description of the symptoms, diagnosis, prognosis, and treatment of this condition named after Sir James Paget, an English surgeon who lived from 1814 to 1888 (for you history buffs), appears in "A Layman's Guide to Modern Medicine," by Daniel W. Foster, M.D. (Simon & Schuster, $14.95). Another reference appears in "Dr. Fishbein's Popular Illustrated Medical Encyclopedia," by the late Morris Fishbein, M.D. (Doubleday, $14.95).

Q

I recently have been diagnosed as having Paget's disease, with some bone damage evident in the right hip. I have quite a bit of pain if I do any sort of exercising or walking. I have reason to believe there also is some skull involvement, with mental deterioration.

I have been to two libraries to find out what can be done about this condition, but I could find very little. I understand from my local physician that there is nothing that can be done to prevent further progression of this disease. The only medication I am on at present is pain medication (Motrin).

I would certainly appreciate your writing about this strange disease, perhaps explaining why so little is known about the cause or cure. I am 53, and I wonder what the future holds for me.--P.D.

A

You raise a good question in asking why so little is known about the cause or cure of this slowly progressive bone disorder which x-ray studies show affects three per cent of people over 40 and 10 per cent of people over 80. To further complicate matters, you must be sure to refer to Paget's disease by its medical name, osteitis deformans, since Dr. Paget also described another, and unrelated, disease which occurs in elderly women and which involves the nipple and surrounding breast tissue.

If you plan to investigate the cause of your disease, there are a few clues which may point you in the right direction: It occurs more commonly in men. While it may affect more than one person in the same family, no-one has discovered any specific genetic (hereditary) pattern. The disease apparently is more common in Europe, England, Australia, and New Zealand, but it is rare in Scandinavia, Japan, India, and South America. Its onset is so gradual that the disease usually is discovered when x-rays or blood tests are obtained for another reason. While the diagnosis usually is based on x-ray findings, a number of other diseases (hyperparathyroidism, multiple myeloma, fibrous dysplasia, etc.) may be confused with Paget's disease.

Your belief that the skull may be involved is correct, since that bone as well as many other bony parts of the body (pelvis, femur, tibia, vertebrae, clavicle, and humerus) can be affected. Involvement of the skull can lead to change in the hat size or even deafness (be sure you are not confusing hearing loss with mental deterioration), and spinal cord compression may lead to paraplegia.

Doctors have not had too much success in relieving pain and other symptoms from this disease, as evidenced by the remarkable number of methods (estrogens, androgens, fluoride, x-ray therapy, analgesics, and a variety of experimental agents) that have been tried. Since your physician has placed you on Motrin, you should know that Paget's disease is not listed among the accepted indications for this powerful anti-arthritic. However, "mild to moderate pain" from any cause presently does constitute an indication for prescribing Motrin. Be sure that you read up on the many possible adverse reactions from Motrin.

While no-one can predict your future course with any accuracy, I suggest that you ask your doctor to introduce you to other patients who have this relatively common disorder so that several of you can jointly pursue the kind of investigation that will eventually shed light on what you correctly characterize as a "strange disease." Let me know what you come up with.

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Explaining and treating PKU

The three letters PKU are well-known to practically every mother in this country, not because of this extremely rare cause of mental retardation (phenylketonuria) for which it stands, but rather because of the mandatory screening for this condition in newborn babies. The conventional treatment for this rare disease is dietary, including a special infant formula.

While this management has gained wide acceptance, there have been dissenting voices. One such voice is that of Samuel Bessman, M.D., chairman of the department of pharmacology and professor of pediatrics at the University of Southern California School of Medicine.

As far back as 1970, Dr. Bessman stated that the current treatment of PKU is not only ineffective but undesirable. As recently as September 1978, Dr. Bessman reiterated his position that the mental retardation of PKU is not caused by high levels of this amino acid and is not significantly helped by diets aimed at providing low levels of the amino acid.

The reason I have collected the criticisms of the PKU diet voiced by Dr. Bessman and others stems from my own skepticism over the years of this dietary method of management which proscribes breast feeding. Until recently, my opposition was based only on theoretical grounds, namely a deep seated philosophic feeling that even for PKU babies, breast feeding had to be the best feeding. Thanks to the La Leche League, more solid evidence has accumulated to support my position.

In a March 1979 LLL publication, A Case for Breastfeeding the PKU Infant, several mothers reported their personal experience in at least partially nursing their babies who are afflicted with PKU. While these anecdotal reports are obviously not in the category of scientific papers, they represent the findings of mothers who believe that the conventional PKU diet may be at odds with their own feelings.

It is not easy for mothers to discuss this issue with their doctors. One mother stated, "I was totally emotionally drained from the ordeal of disagreeing with the professionals about Andrew...I felt sad and defeated in many ways because all my instincts and all the reading I had done on PKU together with my knowledge of breastfeeding combined to tell me I was right to nurse Andrew. The fight was a tremendously lonely one."

The fight for this mother may have been a lonely one, but as ever-increasing numbers of mothers elect to educate themselves, share their experiences, and question the experts, the fight may be just beginning.

PKU and diet

Few procedures are more revered by the medical profession than the PKU test. Required for practically every newborn infant in the United States, this laboratory blood test is designed to detect a rare enzyme deficiency that can lead to mental retardation.

The prescribed treatment consists of a special diet which is low in the amino acid phenylalanine.

Practically every parent has been told that the PKU test is accurate and that the PKU diet constitutes effective management. However, as in most of modern medicine, there is a gap between image and reality.

The Milupa Corporation of Darien, Connecticut, manufacturers of medical food for PKU children, has distributed a booklet entitled "A Concise Review of Phenylketonuria." One of the controversies highlighted in this brochure concerns the accuracy of blood tests conducted earlier than the second day of life and whether or not these should be repeated. Many PKU investigators urge that all newborns with negative (normal) reactions be re-tested one to two weeks after birth in order to find those infants who were incorrectly diagnosed as normal. Yet how many parents of newborn babies have ever been given this information?

Seven years ago, treatment centers in the United States, Australia, England, and Germany revealed that some children with PKU showed progressive neurologic deterioration "even though their disorders had been diagnosed early and dietary treatment had been promptly instituted." All of these children labeled as having "variant forms of PKU" died. Since the wrong treatment can have devastating results, how many parents of newborn PKU babies have been told about the necessity to determine whether their child has the classic or variant PKU?

Controversy also exists regarding the duration of treatment. While standard textbooks recommend discontinuing the special PKU diet at ages six to eight, recent papers suggest continuing the diet for the child's entire lifetime. At present, the practice of stopping the diet varies from one medical center to another; in the United States, 27 of 71 reporting institutions would give no guidelines at all on when the diet should be terminated. Fourteen stated the diet should never be terminated, and 30 recommended a normal diet at ages ranging from three to 10 years.

How good are the substitute foods which doctors prescribe for PKU children? In a recent survey in England, when parents were asked to describe the worst feature of PKU, "The parents without exception strongly declared that giving the protein substitute was the most exhausting, time-consuming, and disturbing feature of the disorder."

Milupa's publication criticizes two protein substitutes used in PKU treatment, Mead Johnson's Lofenalac and Phenyl-Free, because of offensive taste, tendency to cause obesity, poor consistency, monotony, and problems in mixing. All these problems can lead to non-compliance, but such problems presumably can be lessened or eliminated by using Milupa's new PKU products. (As one might expect, the many PKU babies who have been breastfed with good results are not mentioned in the Milupa booklet.)

Now that you know some of the confusion that surrounds PKU testing and treatment, it makes sense to ask your doctor a few questions:

1) Is it sufficient to test my baby once? Or must the test be repeated before I can be reassured that my child does not have PKU?

2) Since I have already decided to breastfeed my child in any case and since there is always a danger of infection from breaking the skin while taking a PKU blood test, may I safely postpone the PKU test perhaps indefinitely?

False-positive PKU tests

Another danger of the PKU test surfaced at the 1984 Spring Session of the American Academy of Pediatrics (American Academy Bulletin, page 6) when UCLA pediatrician, Dr. Delbert A. Fisher, reported that the false positive results on PKU testing are 100:1! In other words, 100 babies are falsely identified as suffering from PKU for every one baby who, on further investigation, proves to really have the condition. In the California Newborn Screening Program Follow-up at Harbor-UCLA Medical Center, although 357 babies had "presumptive positive" PKU's, only two babies were confirmed by further testing as actually having the disease.

One might argue that these odds are justified for identifying a treatable crippling condition--even if the treatment is controversial. But what about the tens of thousands of parents who every year are told by pediatricians that their child might have this catastrophic genetic defect? Despite all the attempts of pediatricians to reassure those parents ("The original tests must be repeated;" "Further tests must be done"), no-one ever has studied the extent of damage to the mother-child-family relationship that can result from this kind of devastating diagnosis issued by modern society's powerful medical priesthood.

When the doctor later tries to reassure the family ("The tests were negative"; "Don't worry, forget about it") are parents able to turn their emotions off as easily as the doctor turns his off? Or do they remember and observe their child for "signs" even though their intellect tells them that nothing is wrong? After all, studies of parents who have been "reassured" by doctors that their child's functional heart murmur indicates no disease show that inordinate numbers of those parents still tend to overfeed such a child and restrict his activity, with resultant obesity. No such studies have been carried out on false-PKU positive families.

The distraught parent may ask the doctor, "Why didn't you give me an opportunity to exercise informed consent before you pierced my baby's heel for a blood specimen? Why didn't you share with me in advance the information about all those false positives, as well as the controversies surrounding the test and the treatment?" The doctor can be depended upon to respond, "What difference would it make? Your infant must have the test. It's the law."

But, I'll bet he won't tell you that it was the doctors, not the people, who went to the state legislatures to mandate this procedure--and other similar controversial tests--into law. And you can be sure that the doctor didn't write anything in the legislation about "informed consent."

You might begin the long road back to common sense by asking your pediatrician at your next visit, "Oh, by the way, doctor, what is the incidence of false positive PKU tests?"

Potpourri

Chorionic sampling vs. amniocentesis

When I grew up in Chicago, the initials CVS stood for Chicago Vocational School. But no more. Today, those same initials stand for a new fetal testing technique--chorionic villus sampling. The chorion is the outer tissue of the sac which surrounds the embryo inside the uterus. The villi (plural of villus) are tiny fingerlike projections of the chorion, but they are not actual parts of the fetus. While some of the villi disappear by the twelfth week of pregnancy, those which remain become the placenta.

Within the past 20 years, Scandinavian and Chinese researchers began to biopsy these villi in order to make fetal diagnoses. When the procedure first was used by American researchers, it was called chorionic biopsy, but since the word "biopsy" conjures up visions of cancer in the minds of many people, the researchers turned to the allegedly more accurate (and certainly more reassuring) word, "sampling."

But what is the truth about this new procedure, which is being widely promoted as a replacement for amniocentesis in detecting fetal abnormalities?

CVS can be performed earlier in pregnancy then amniocentesis and can be more quickly analysed. Ultrasound scanning--with all its known and unknown risks--is used to guide the CVS catheter just as it guides the amniocentesis needle. (The amniocentesis needle is inserted through the mother's abdomen into the amniotic fluid which surrounds the fetus, while the CVS catheter is inserted through the cervix into the chorionic villi.)

Concerns about CVS are presented honestly in "Family Planning Perspectives," November/December 1983. First, no-one knows for sure that the tissue collected by CVS is genetically identical with that of the fetus. In other words, maybe the biopsy truly represents the fetal condition, or maybe it does not. Second, the effect of the biopsy procedure itself on the fetus is unknown. Researchers simply "assume" that the removal of apparently "useless" villi has no effect on fetal development. But since they don't know whether or not this is true, CVS may increase the likelihood of spontaneous miscarriages. Third, CVS cannot detect all the problems which amniocentesis can detect. For example, neural tube defects cannot be detected in the first trimester, nor can a number of other malformations. Thus, for some women, both CVS and amniocentesis may be necessary. Fourth, CVS may detect apparent genetic defects that never appear in the infant. Through CVS, Eugene Pergament, M.D., a Chicago researcher, has diagnosed a fetus with a chromosomal abnormality (known as trisomy 16), but other researchers say it is quite possible that trisomy 16 is a defect of the chorionic membrane, rather than of the fetus itself.

If your obstetrician claims that CVS is a better technique than amniocentesis, you now have some questions to ask him.

Dr. Mendelsohn's latest book, "How to Raise a Healthy Child in Spite of Your Doctor," has just been published by Contemporary Books ($13.95).

"Confessions of a Medical Heretic" is available from WarnerBooks ($3.25).

Another View

by Marian Tompson
Executive Director,
Alternative Birth Crisis Coalition

While it's true that women are eight times more likely than men to develop osteoporosis, I'm impressed that there are so many ways we can decrease bone loss as we grow older. While heredity does play a role in determining who is at risk, if simple prevention strategies are undertaken early, one can stave off the classic "dowager's hump," back pain and frequent fractures associated with this syndrome. Exercise, for example, actually enhances bone formation. A group of postmenopausal women who exercised for one hour a day, three times a week, were found to have a significantly improved calcium balance and no signs of bone loss. Vitamin D, obtained from the sun or diet, also is critical for the creation of new bone.

After age 35, one begins losing bone mass at the rate of about one-half of one percent per year. In the five years after menopause, this rate doubles. Yet vegetarians have stronger, denser bones and lose less bone with age. One study has revealed that the bone density of vegetarians in their seventies was greater than that of meat eaters in their fifties. When older white women who ate meat were compared to women who were lacto-ovo-vegetarians, it was found that, although the meat eaters and vegetarians had similar amounts of calcium in their diets, the meat eaters lost 35 percent of their bone mass between the ages of 50 and 89, and the vegetarians lost only 18 percent. Red meat is rich in phosphorous, and a diet that has more phosphorous than calcium can create a negative calcium balance. Phosphorous is a major component of processed foods. Bread, cereal, potatoes, meat and cola drinks contain much more phosphorous than calcium.

The more salt in our diets, the more sodium we excrete. The more sodium we excrete, the more calcium we excrete. An intake of 200 mg a day does not seem to affect the amount of calcium excreted, but at 2,000 mg a day there is a significant increase of calcium in the urine. Did you know that there are 2,325 mg of sodium in one teaspoon of table salt? That six ounces of tomato juice contains 659 mg of sodium? And that one cup of spaghetti with tomato sauce and cheese contains almost 1,000 mg?

Pregnancy is a plus. The chance of developing osteoporosis is higher in a woman who has never had children. About 25 percent of women who have experienced a natural menopause will develop osteoporosis, but the risk increases to 50 percent in women who have had their ovaries removed before menopause.

Some medicines stimulate bone loss. These include anticonvulsants, steroids, heparin and antacids such as Maalox, Rolaids, Di-Gel and Mylanta which contain aluminum. (Antacids without aluminum include Alka-Seltzer, Tums and Bisodol.) Heavy coffee drinkers also lose more calcium from their bodies.

For more detailed information on the prevention of osteoporosis, how to deal with the condition if one has it, and the latest research on this subject, I recommend "Stand Tall! The Informed Woman's Guide to Preventing Osteoporosis," by Morris Notelovitz, M.D., and Marsha Ware (Triad Publishing Co., 1982). Dr. Notelovitz is the founder and director of The Center for Climacteric Studies at the University of Florida College of Medicine, and he deals with changes which take place during a person's middle years. "Stand Tall!" contains tables giving the sodium content of foods, the calcium-phosphorous ratio, and suggested calcium equivalents for those who are cutting down on dairy products. When preparing soup stock from bones, I've always added a small amount of vinegar to the water to dissolve the calcium out of the bones. I was happy to learn that this simple procedure can make a single pint of homemade soup equal to a quart or more of milk in calcium content.

Osteoporosis may be a women's issue, but the measures suggested to prevent it make good health sense for us all.

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P.O. Box 982
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Published monthly. Subscription rate: **$24.00** annually.
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