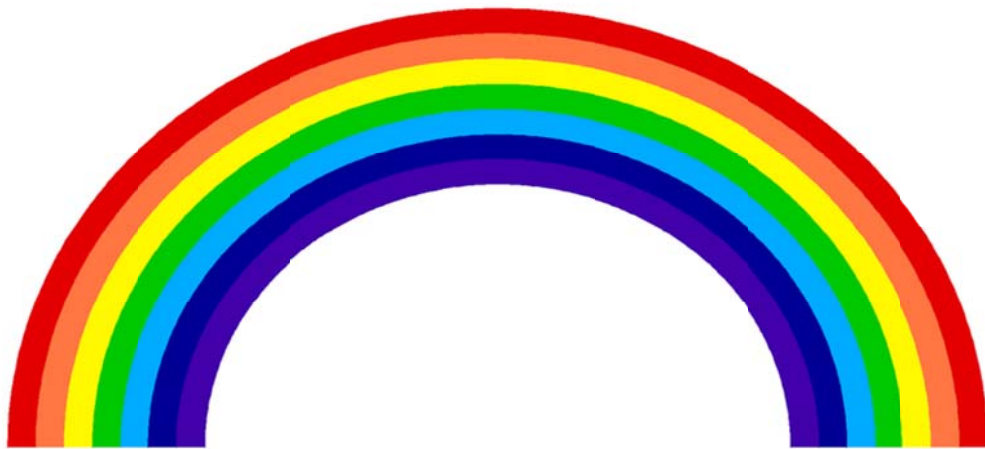


PXE Awareness

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

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Good Nutrition: A Rainbow Feast

By
Eyes Only

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Contents

| | |
|--|----|
| President's Message. | 4 |
| MyPlate. | 6 |
| 10 Tips to a Great Plate. | 8 |
| Good Nutrition: A Rainbow Feast. | 9 |
| 10 Tips to Fast Cooking. | 15 |





President's Message

Research on ABCC6 indicates that PXE is, at least in part if not wholly, a metabolic disorder. We may eventually have a treatment based on nutrition. Even without this significant step, we know much about the value of dietary behavior. This issue focuses on using what we know to our advantage. The information gathered here from major health organizations can prove helpful not only to those of us with PXE but anyone concerned about good health.



MyPlate is the latest Food and Drug Administration effort to guide Americans to healthy, less obese lives. Our article is an edited selection of the FDA introduction to MyPlate as a replacement for the Food Pyramid. 10 Tips To A Great Plate demonstrates use of the plate.

4

Good Nutrition: A Rainbow Feast is reprinted with permission by the Association for Macular Diseases, the research group which, according to Dr. Lawrence Yannuzzi, includes PXE. Their newsletter, *Eyes Only*, is a great source of information for patients. We are grateful for the opportunity to share their excellent nutrition guidance.

10 Tips For Fast Cooking is reprinted with permission by WebMD to help us prepare nutritious tasty meals quickly. Let us know if any of these practical tips help you and share your own tips with us.

Members should have received our recent letter urging PXE patients of all ages to register with NDRI for research opportunities. NDRI and NAPE are cooperating to increase PXE human research. Please review our article in the last issue and telephone 1-800-222-6374. Lets join with NDRI to help researchers help us.

Please also take advantage of PayPal on our website to provide a donation on your credit card. We need your help to support Dr. Kattesh Katti's research which, in animal models, keeps Avastin in the eye for six months. If this can be achieved in humans and gain FDA approval, it can cut dramatically the frequency of Avastin injections into the eye. NAPE is also eager to support human magnesium trials to determine if success with PXE mice can be replicated in humans to reduce or eliminate tissue calcification. Please help us



support these two efforts which offer potential relief for PXE patients and their families.



And speaking of Avastin, the National Eye Institute, a division of the National Institutes of Health, announced in late April, first year results of their two year comparison of Avastin and Lucentis effectiveness and safety in the treatment of AMD. Results: the two medications are equally effective and safe. Lucentis injections cost \$2,000 per shot while Avastin shots cost as little as \$50 per injection.

Check www.nei.nih.gov/news/pressreleases/042811.asp for the full report. You may want to share it with your physician if you are receiving injections of either drug. PXE patients around the world are reporting success with these treatments. I am happy to report that a recent bleed after six years without one was treated successfully with one Avastin injection. No new scarring or vision loss resulted.

So for now, eat lots of veggies and fruits. And don't forget the importance of moderate exercise! Enjoy a great summer!

Fran Benham, PhD

5





MyPlate

There's a new U.S. symbol for healthful eating: The Agriculture Department unveiled "[MyPlate](#)," abandoning the food pyramid that had guided many Americans but merely confused others.

The new guide is divided into four slightly different-sized quadrants, with fruits and vegetables taking up half the space and grains and protein making up the other half. The vegetables and grains portions are the largest of the four.



6

Gone are the old pyramid's references to sugars, fats or oils. What was once a category called "meat and beans" is now simply "proteins," making way for seafood and vegetarian options like tofu. Next to the plate is a blue circle for dairy, which could be a glass of milk or a food such as cheese or yogurt.

The new plate is simply guidance for those looking to improve their diet. It's supposed to be a suggestion, not a direction, said Agriculture Secretary Tom Vilsack. "We are not telling people what to eat, we are giving them a guide," he said. "We're not suggesting they should not have a cookie or dessert, that's not what it's about."

Vilsack said the new round chart shows that nutrition doesn't have to be complicated. After almost 20 years of leaders preaching good eating through a food pyramid the department now says was overly complex, obesity rates have skyrocketed. He showed off the new plate with first lady Michelle Obama, who has made healthful diets for children a priority through her "Let's Move" campaign.

"Parents don't have the time to measure out exactly three ounces of protein," Mrs. Obama said as she introduced the new graphic. "We do have time to look at our kids' plates."



The department is planning to use social media — posting advice every day on Twitter, for example. The address of the website, choosemyplate.gov, will eventually feature interactive tools that help people manage their weight and track their exercise.

Even though the plate is divided into four different-sized sections, the servings don't have to be proportional, since every person has different nutritional needs, based on age, health and other factors.

The graphic is based on new department dietary guidelines released in January. Those guidelines, which are revised every five years, tell people to drastically reduce salt and continue limiting saturated fats. They say diners can enjoy food but should balance calories by eating less. The guidelines also suggest making half of your plate fruits and vegetables — a message easily translated on the dinner plate.

“We know Americans want to be healthy, but making those healthy choices is not easy, it's hard,” said Surgeon General Regina Benjamin, who joined Mrs. Obama and Vilsack to unveil the plate. “We're trying to make it easier.”

The first food pyramid was introduced in 1992, with detailed descriptions of recommended foods and their portion sizes. The tip of the pyramid represented fats, oils and sweets, cautioning diners to “use sparingly.”

After research showed the pyramid wasn't working, the department worked with a public relations firm and came up with an all-new pyramid in 2005 that was characterized by vertical lines of color and a stick figure walking up a staircase to symbolize exercise. At the time, officials said they wanted something motivational and recognizable. But the Obama administration eventually ditched that model, opting for something fresher.

7



choose MyPlate

10 tips to a great plate



Making food choices for a healthy lifestyle can be as simple as using these 10 Tips.

Use the ideas in this list to *balance your calories*, to choose foods to *eat more often*, and to cut back on foods to *eat less often*.

1 balance calories

Find out how many calories YOU need for a day as a first step in managing your weight. Go to www.ChooseMyPlate.gov to find your calorie level. Being physically active also helps you balance calories.

2 enjoy your food, but eat less

Take the time to fully enjoy your food as you eat it. Eating too fast or when your attention is elsewhere may lead to eating too many calories. Pay attention to hunger and fullness cues before, during, and after meals. Use them to recognize when to eat and when you've had enough.



3 avoid oversized portions

Use a smaller plate, bowl, and glass. Portion out foods before you eat. When eating out, choose a smaller size option, share a dish, or take home part of your meal.

4 foods to eat more often

Eat more vegetables, fruits, whole grains, and fat-free or 1% milk and dairy products. These foods have the nutrients you need for health—including potassium, calcium, vitamin D, and fiber. Make them the basis for meals and snacks.



5 make half your plate fruits and vegetables

Choose red, orange, and dark-green vegetables like tomatoes, sweet potatoes, and broccoli, along with other vegetables for your meals. Add fruit to meals as part of main or side dishes or as dessert.

6 switch to fat-free or low-fat (1%) milk

They have the same amount of calcium and other essential nutrients as whole milk, but fewer calories and less saturated fat.



7 make half your grains whole grains

To eat more whole grains, substitute a whole-grain product for a refined product—such as eating whole-wheat bread instead of white bread or brown rice instead of white rice.

8 foods to eat less often

Cut back on foods high in solid fats, added sugars, and salt. They include cakes, cookies, ice cream, candies, sweetened drinks, pizza, and fatty meats like ribs, sausages, bacon, and hot dogs. Use these foods as occasional treats, not everyday foods.

9 compare sodium in foods

Use the Nutrition Facts label to choose lower sodium versions of foods like soup, bread, and frozen meals. Select canned foods labeled "low sodium," "reduced sodium," or "no salt added."



10 drink water instead of sugary drinks

Cut calories by drinking water or unsweetened beverages. Soda, energy drinks, and sports drinks are a major source of added sugar, and calories, in American diets.



Center for Nutrition Policy and Promotion

Go to www.ChooseMyPlate.gov for more information.

Good Nutrition: A Rainbow Feast

This is the first in an occasional series of single-subject issues of *Eyes Only*. There are a handful of subjects that are vital in the coverage of Age-Related Macular Degeneration (AMD). [NAPE readers should know that much of what serves AMD patients is also good for PXE patients. Readers with no disorders can benefit from this content as well since, as the authors say, it is of universal usefulness.] By devoting entire issues of this newsletter to these significant topics from time to time, we hope to give them the attention they deserve.

These pages have, in the past, contained a generous amount of information about nutrition and AMD. There has been a lot of new information and healthy doses of repetition. The worth of good advice improves the more times you hear it.

And the value of this advice begins to soar even higher as its universality becomes more apparent. AMD studies indicate that adherence to a proper diet will slow down the onset and progression of the disease. Also, according to a mountain of other studies by many respected major health organizations over the years, good dietary practices will improve virtually all of the ways your body functions.

Eyes Only is indebted to Michelle Cimino for her massive contribution to this first special issue. She has been a member of the LuEsther T. Mertz Research Center and Association for Macular Diseases teams for five years.

Ms. Cimino earned a degree in nutrition from Cornell, and is now completing her work toward a Master's of Science and Registered Dietician in nutrition and public health at Columbia. She knows her subject and how to communicate it.

THE GREAT DEBATE: PILL v. FOOD

These days, the mere mention of nutrition conjures up an image of platoons of pill bottles on shelves identified by signs indicating the symptom of your choice. From bone and brain health to sleep and stress support, and for every health concern in between. In our quick-fix culture, where there's an ill, there's a pill. And eye health is no exception.



The Age-Related Eye Disease Study (AREDS) indicates antioxidants significantly reduced the risk of AMD and its associated risk of vision loss. New eye-health supplements joined the pill-bottle army. It certainly was a welcome addition.

Eye-health supplements like ICaps, OcuVite, and PreserVision contain more than 500% of the daily value of antioxidant vitamins A, C, and E, as well as zinc. These supplements have been found to reduce the risk of vision loss from AMD by 25%. That's a huge level of protection from just a small handful of these pills.

This is partly because the nutrients in supplements are usually better absorbed and utilized by the body than those found in food. The rigid cell structure in foods like fruits and vegetables actually encapsulates its nutrients. The nutrients remain out of reach until the food is lightly cooked or thoroughly chewed. Conversely, the nutrients in pills are almost immediately available to the body. A simple swallow makes supplements effortless and wildly popular.

10

We seem to have come a long, long way from "An apple a day..." Or have we?

It is important to remember that, while supplements can be an excellent source of added nutrition to support overall health, they should only be used as the name they bear, as supplements to a healthy diet rather than the prime source of nutrition.

Fruits and vegetables, for example, contain much more than just the vitamins and minerals listed on their packaging. They contain a bounty of other plant chemicals with protective antioxidants and other disease-fighting properties.

Eating a variety of fruits and vegetables, whole grains and legumes, and lean meats and fish on a daily basis is the best prescription for a lifetime of protection against disease. But it wouldn't hurt to include that eye-vitamin supplement in your daily regimen for optimum defense. So let's embark on that lifetime disease protection by looking at a menu of nutrient rich foods.





SOURCES OF VITAMIN A

The most usable and active form of vitamin A is best absorbed in the body by consuming animal products such as whole milk and cheese, butter, whole eggs (shell color irrelevant), liver, and A-fortified food products.

Also, dark green, yellow, and orange fruits and vegetables like pumpkin, butternut and acorn squashes, spinach, and broccoli contain vitamin A, but in a less active form known as carotenoids. These must be changed by the body into a useable form of vitamin A.

SOURCES OF VITAMIN C

Vitamin C is found in all fruits and vegetables. Again, some sources are richer than others. The best food sources of vitamin C, listed in order, include green peppers, citrus fruits and their juices, strawberries, tomatoes, broccoli, dark leafy greens, all types of potatoes, and cantaloupes.

Still other sources of this vitamin (talk about surfeits of riches) are tropical fruits such as papaya and mango, Brussels sprouts, cauliflower, cabbage, winter squash, red peppers, raspberries, blueberries, cranberries, and pineapple.

11

SOURCES OF VITMAIN E

Vitamin E exists naturally in a number of forms. The most active and most readily absorbed form comes from wheat germ, nuts and nut butters, seeds (e.g., pumpkin, sesame, sunflower) and vegetable oils. Significant amounts of this vitamin are also available in green leafy vegetables and fortified cereals.

SOURCES OF ZINC

Many foods contain this valuable mineral. The best sources are shellfish and animals. These include oysters, red meats, poultry, shrimp, crab, and lobster.

Other good sources of zinc are plants and grains like nuts, beans, and whole-grain food products. Peanuts and peanut butter are some of the best sources of zinc from plants.





Addressing the problems of AMD vision loss is not an easy task. But doing so in terms of your diet does not require slavish adherence to a regimen of complicated, footnoted rules and regs. On the contrary, it's a snap. An easy way to get to the dietary pot of gold at the end of the rainbow? Simple. Just eat the rainbow.

Look, for example, at the colorful array of fruits and vegetables listed in the source sections above. The vibrant colors of these fruits and vegetables are actually produced by a variety of pigments like lutein. These pigments act as powerful antioxidants as well as anti-inflammatory and other disease-preventing agents.

12

Each color is produced by a different pigment that imparts distinct forms of protection inside our bodies. These pigments include carotenes, xanthenes, cyanines, and flavenoids, as well as lycopene and the aforementioned lutein. Each of these pigments has been found to offer protection to the eyes. So, for your next meal, challenge yourself to eat the rainbow. Plate a variety of colorful fruits and vegetables. Think red, orange, yellow, green, blue, purple, and yes, even brown and white.

To start you off with a couple of kaleidoscopic dishes, let's go...

Cranberry Apple Sauce

This red and green dish requires just 20 minutes and will leave you with several days' worth of a delicious accompaniment to turkey, chicken, or pork. (A sauce for ice cream? Yes!)

In a medium saucepan, dissolve over heat 1/4 cup of sugar in 1/3 cup of apple juice or apple cider. Stir in one 12-ounce bag of fresh or frozen cranberries and 2 green apples that have been cored and chopped into 1-inch cubes.



Bring to a boil, then reduce heat and simmer until the berries pop and the sauce thickens. Stir occasionally. Let cool. For a delightful and nutritious crunch, put in some toasted, chopped walnuts for added eye-healthy omega-3 fatty acids.

Roasted Eggplant Spread

This red, yellow, and purple recipe can be spread on sandwiches, accompany meats, or used as a dip for snacking, especially with bell pepper, carrot, or celery sticks.

Pre-heat oven to 400 degrees.

Cut a medium purple eggplant, 2 yellow bell peppers and a red onion in 1-inch chunks into a large bowl with 2 cloves of minced garlic, 3 tablespoons of olive oil, and salt and pepper to taste. Spread the mixture on a baking sheet and roast for 45 minutes. Start testing at about 20 minutes. Toss once during cooking. The vegetables are done when lightly browned and soft. Cool and then transfer to a food processor. Add 1 tablespoon of tomato paste. Process until smooth.

Cauliflower/Potato Mash

Remember that the nutrition in brown and white vegetables counts too. Bring a 3-quart pot of water to the boil while you roughly chop a small head of cored cauliflower and 2 large potatoes - Yukon gold are nice. Drop the vegetables into the boiling water and cook until fork tender. Start testing at about 10 minutes.

Drain, then add an 8-ounce cup of Greek yogurt and salt and pepper to taste. Mash to desired consistency. White and brown vegetables are nutritious, but chromatically challenged. Add a healthy dusting of the minced dark green leaves of Italian parsley, which is also a good source of vitamin E.



From Greek yogurt to the last letter of the Greek alphabet. Omega-3 fatty acids are another nutritive factor of great significance to your eye health. And virtually everything else health.





Several important studies suggest that omega-3 fatty acids protect adult eyes from AMD and its associated vision loss, dry eye syndrome and glaucoma, as well as reducing the risk of cardiovascular disease by controlling blood pressure and heart rate.

Simply eating two servings of cold-water fish each week will reduce your health risks. Fresh or canned, fish like sardines, herring, salmon and tuna will do the trick. Other good sources of omega-3 fatty acids include flaxseeds, flaxseed oil, walnuts, and dark leafy greens.



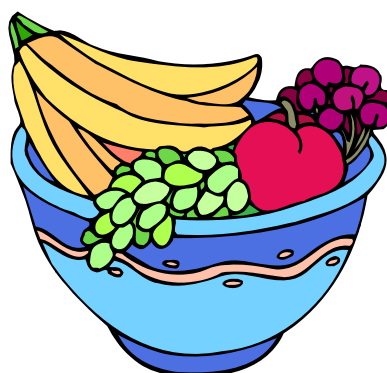
"An apple before bed robs the doctor of his daily bread" is one of the quaint English origins of this issue's theme. The information in this issue should help you better identify and select the kind of foods that will help you in your quest, but not a really arduous one. Just pretend you live in the south of France.

14

You are what you eat.

Editor's Note

Those who wish to receive the *Eyes Only* newsletter may contact Association for Macular Diseases, 210 East 64th Street, New York, NY 10065. Your financial contribution will support their research programs.



10 Tips for Fast Cooking



Quick, easy, and healthy meals that help keep you out of the kitchen.

WebMD Expert Column

By Elaine Magee, MPH, RD

When you think about cutting down the time you spend in the kitchen, you might think that means buying more takeout and processed foods (with plenty of calories, fat, and sodium). But it doesn't have to be that way. You can prepare meals in your kitchen with an eye toward health while still keeping the time spent in a hot kitchen to a minimum. Here are a few fast-cooking tips and tricks to help you save on prep time while making healthy meals for yourself and your family.

Fast-Cooking Tip No. 1: Use Pre-cooked Meats

- In your grocery deli, you can often buy roast beef or roasted turkey, both of which are lean meat choices. You can even ask for extra thick slices so you can dice it and use in recipes.
- Fresh off the rotisserie or grill, skinless chicken breasts, whole chickens, and half turkey breasts are available in many supermarkets. Remove the skin, then shred or cut the meat as needed for your recipe.
- A couple of companies are now offering seasoned grilled chicken strips. Find the packages near the lunch meat section in your grocery store.
- You can buy cooked shrimp at the fish counter or in the frozen fish section.

15

Fast-Cooking Tip No. 2: Have a Main Dish Salad

Main dish salads are the perfect summer supper -- cool, light, and quick to fix. Salad greens are the base ingredient and that's easy: just open a bag of salad greens or spinach leaves and pour into a bowl. Then throw in the rest of the ingredients and toss. Convenient add-ins include reduced-fat cheese or crumbled blue cheese, grilled chicken, cherry tomatoes, baby carrots, dried cranberries, walnuts, etc.





Fast-Cooking Tip No 3. Make It Vegetarian

One way to save time cooking the meat portion of your meal is to skip the meat. Some easy vegetarian entrees include bean and cheese burritos, vegetarian burgers (they take about four minutes to brown in a nonstick frying pan), egg-based entrees like omelets, and vegetarian sandwiches featuring cheese and/or roasted vegetables.

Fast-Cooking Tip No 4: Heat up an Upscale Frozen Entree

You can find flavorful frozen entrees in many supermarkets. There are even great-tasting and lower-fat choices for people looking for vegetarian, fish, ethnic cuisine, or lean meat options. You'll find a plethora of vegetarian and ethnic cuisine selections in places like Trader Joes and Whole Foods Markets.

Fast-Cooking Tip No. 5: Add Some Store-Prepared Gourmet Items

16

Save time in the kitchen -- while cranking up the fancy factor -- by buying a few key gourmet items often prepared at Whole Foods Market and similar upscale markets. Look for items like:

- Freshly assembled avocado-mango salsa (great for gourmet style quesadillas, tacos, meat entrees, and more).
- Roasted vegetables (great for sandwiches, vegetarian quesadillas and tacos, and more).
- Grilled salmon and chicken breast (great for pasta dishes, main dish salads, Mexican-style entrees, and more).

Fast-Cooking Tip No. 6: Whip Up a Stove-Top Meal

Even on a hot evening, some of us are willing to spend five minutes over the stove if it means a freshly made meal. Armed with a nonstick frying pan, you can quickly whip up:

- Grilled sandwiches (you could also use a panini press)
- Quesadillas
- Omelets
- Fried rice (if the rice is already cooked)
- BLT sandwich (while the turkey bacon is cooking, toast the bread and slice the tomato)
- Fajitas take 5 minutes to make if you buy your meat already cut into small pieces and use bottled fajita sauce.
- Sloppy Joes





Fast-Cooking Tip No. 7: Make a Microwave Meals in Minutes

Three of my favorite microwave meals:

- Make mealtime nachos by layering multigrain tortilla chips, canned vegetarian refried beans or black beans, shredded reduced-fat cheese, chopped green onions and tomatoes, and grilled or roasted chicken breast (if desired) on a microwave-safe plate and cooking on HIGH for a minute or two.
- Make a burrito to order by filling a whole-grain flour tortilla with your fillings of choice, wrapping up into a burrito shape, and microwaving for a minute or two.
- A baked potato bar is easy to assemble. Pierce each potato a couple of times with a fork and microwave on HIGH until cooked throughout. Meanwhile, get your toppings ready (shredded reduced-fat cheese, fat-free sour cream, chopped chives or green onions, and/or turkey bacon bits.) Your favorite canned chili makes a good topping, too; just nuke it in a microwave-safe bowl.

17

Fast-Cooking Tip No. 8: Use Low-Fuss Veggies and Beans

These veggies are easy to use in recipes because they require minimal preparation:

- Bags of baby carrots
- Asparagus spears (just trim off the ends and they're ready to cook whole)
- Bags of washed spinach leaves
- Potatoes and sweet potatoes (just pierce each a couple of times and microwave)
- Cherry and grape tomatoes
- Canned tomatoes (for some recipes, you'll want the ones with seasonings added)
- Canned beans (just rinse them and add to recipes)
- Bags of precut broccoli and cauliflower florets





Fast-Cooking Tip No. 9: Serve a Low-Fuss Fruit Salad

With the following fruits, whipping up a side serving of fruit or a fruit salad is as easy as rinsing and tossing:

- Raspberries, blackberries, and blueberries
- Grapes (red and green)
- Apple slices in bags
- Bananas (just pull away part of the peel and then cut into slices in the peel).
- Canned pineapple chunks (in juice)
- Strawberries are easy to serve as a garnish. Just rinse, and serve them with their leafy tops.

Fast-Cooking Tip No. 10: Use Bottled Sauces, Dressings, and Marinades

These are some of the most convenient products available:

- Bottled light salad dressing (for green salads and pasta salads, or use as a marinade)
- Bottled marinara and pizza sauce
- Bottled salsa, taco sauce, salsa verde, and enchilada sauce
- Teriyaki sauce
- Fajita sauce
- Asian cooking and dipping sauces (hoisin, sweet and sour sauce, and more)
- Pesto sauce

18

Elaine Magee, MPH, RD, is the "Recipe Doctor" for WebMD and the author of numerous books on nutrition and health. Her opinions and conclusions are her own.

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<http://www.webmd.com/diet/healthy-kitchen-11/10-tips-for-fast-cooking>



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Name: _____ Phone: _____

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Address: _____

City: _____ State: _____ Zip: _____ Country: _____

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I am diagnosed with PXE Yes No Newsletter: Print CD

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

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

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

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