UNDERSTANDING BONE DISEASE AND LIPIDS

Family Focus

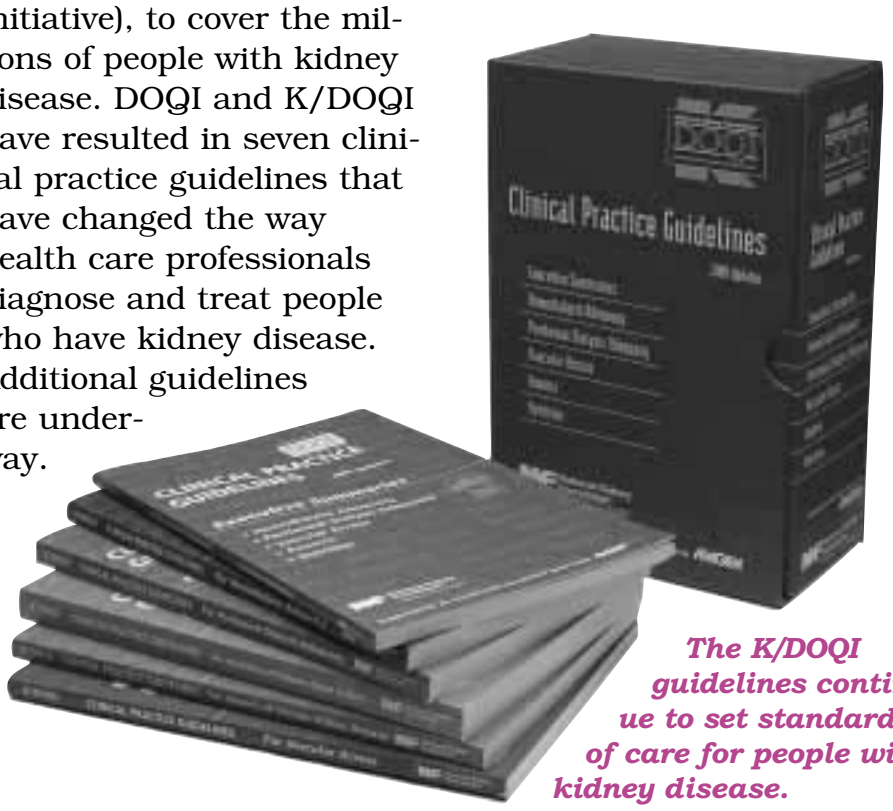
VOLUME 12 NUMBER 3 SUMMER 2003

Clinical Practice Guidelines for Kidney Disease

By John Davis, National Kidney Foundation Chief Executive Officer

Over 600,000 people will be on dialysis by the end of this decade—double the current figures—according to *Healthy People 2010*, the federal government's public health plan for this decade.

The National Kidney Foundation's (NKF) Dialysis Outcomes Quality Initiative (DOQI), founded in March 1995, was originally created to help improve the care of people who receive dialysis. In 2000, the NKF renamed DOQI "K/DOQI," (Kidney Disease Outcomes Quality Initiative), to cover the millions of people with kidney disease. DOQI and K/DOQI have resulted in seven clinical practice guidelines that have changed the way health care professionals diagnose and treat people who have kidney disease. Additional guidelines are underway.



The K/DOQI guidelines continue to set standards of care for people with kidney disease.

HOW ARE K/DOQI GUIDELINES DEVELOPED?

All K/DOQI guidelines are developed by work groups, made up of medical professionals, who put the guidelines together. First, the work group researches all of the related scientific studies and articles. They read these articles to make sure that the guidelines are based on evidence whenever possible. Before the guidelines are completed, other experts and organizations read them and make suggestions. After the work group reviews these suggestions, they might rewrite parts of the guidelines to make them clearer, and then, finally, the guidelines are published in the *American Journal of Kidney Diseases*.

ORIGINAL DOQI GUIDELINES

In 1995 the NKF formed four work groups to research and study all available, relevant, scientific literature and use it to develop evidence-based clinical practice guidelines for adequacy of dialysis, vascular access and treatment of anemia. These work groups reviewed the descriptions of more than 11,000 articles. Next, the work groups read more than 3,000 of these 11,000 articles to make sure they were the most important ones for their guideline topics. About half of these articles met the requirements, and the work groups critically analyzed the articles to develop the guidelines. Finally, in the fall of 1997, the NKF published its first four DOQI guidelines: the *NKF-DOQI Clinical Practice Guidelines for Hemodialysis Adequacy, Peritoneal Dialysis Adequacy, Vascular Access* and *Treatment of Anemia of Chronic Renal Failure*.

Because nutrition is an important issue in advanced kidney disease, the NKF put together another work group which developed a fifth set of guidelines published in June 2000: the *NKF-DOQI Clinical Practice Guidelines for Nutrition in Chronic Renal Failure*.

AN ONGOING PROCESS

Since there are always new studies and breakthroughs in medicine, the NKF updates its guidelines every few years. In 1999, the first four Work Groups got back together to study the newest information on dialysis practice. The updated guidelines were then published in 2000.

All K/DOQI guidelines will be updated as new research is published.

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Karren King

"I learned a great deal from reading the articles in this issue, and I hope you will, too."

from *the* editor

As you can tell from the title of this issue of *Family Focus*, the theme will be **bone disease and lipids**. I must admit that although I have worked in the field of dialysis and kidney transplantation since 1979, this is an area about which I had little knowledge. As a result, I learned a great deal from reading the articles in this issue, and I hope you will, too.

BONE DISEASE AND LIPIDS are two areas that seem as if they can be ignored, at least initially, with no obvious ill effects. Do you ever think, "What if I don't take my phosphate binders as prescribed? I've skipped them before and didn't see any difference." Or perhaps you have thought, "I love to eat all of those fatty foods that the dietitian tells me to avoid, and I haven't had any problems as a result." Well…those things may be true for now. However, it is important to remember that you can have a long, healthy life with chronic kidney disease. So, what about your future? The things you do (or do not do) right now will have a definite effect, either positive or negative, on your health and subsequent quality of life. That does not mean that following medical advice is always easy. That is one reason the dialysis and transplant teams of health care professionals are there to assist you. But, if you succeed in making these health care recommendations a part of your life, I believe that you will feel the benefits were well worth it!

I am very excited about our next issue, which happens to be the last issue of the year. It will focus on communication in the dialysis unit between those who are on dialysis and the dialysis staff. Your relationship with these health care providers is so very important and communication plays a major role in the type of relationship you have. Many have received and returned the communication survey we sent to randomly selected *Family Focus* readers. We appreciate your response and look forward to reading what you had to tell us. We will share the responses in that issue so that all of us in the dialysis community can learn what we need to do to enhance those communications. Thank you for being our teachers!

For the Editorial Board,
Karren King

Family Focus

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Opinions expressed in this newspaper do not necessarily represent the position of the National Kidney Foundation

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dear editor

I have a disease called "amyloidosis" with kidney involvement. It has been such a struggle to explain and understand such a rare disease. Amyloidosis is a blood problem that causes proteins to accumulate throughout the body. These proteins have damaged my kidneys, causing chronic kidney disease. At the time of diagnosis I was given a prognosis of 18 months survival. As a 40-year-old active mother with two young boys and a husband, this prognosis was not an option for me. I went through many years of tests, and a year ago I was hospitalized and given high-dose chemotherapy and a stem-cell transplant. I've been bald from the chemotherapy for about a year.

During my hospital stay, I would write an inspirational thought that I would focus on each day. It truly helped me heal, reading it over and over in my hospital bed each day. I even collected my thoughts into a book, called *Messages of Hope*, to share with staff, family and friends.

During my hospital stay, my husband stayed by my side and made sure my kids were well cared for. He is a brilliant and humbling inspiration to my kids and me. He works hard at his job and brings work home every day. He keeps everybody's lives in perspective. For a month or so, I had a visiting nurse in my home to help me heal, but my best nurses were my husband and children. Their fun, happy spirit helped me heal and now I am in remission.

A brief description of this disease can be found on the Internet at **www.amyloidosis.org**. Information is still limited because it is a rare disease. There is no cure and no research funding for amyloidosis. My goal is to work towards raising awareness. I will continue the journey to fight this rare disease.

EARLY DETECTION OF THIS DISEASE COULD SAVE MANY LIVES!

Sincerely,
Joy Heroux
Gaithersburg, MD

Dear Editor:

Family Focus *is very informative. I enjoy reading the information, and it is very helpful. I had a transplant on February 1st after almost four years on dialysis. I have to watch my blood sugar, but I am taking a pill which so far is controlling it, along with my diet. All in all, things are progressing. I appreciate the updates in your newspaper and found the issue on diabetes very helpful. Please continue your great coverage on kidney disease information.*

Thank you,

C. Long
Xenia, Ohio

Clinical Practice Guidelines...

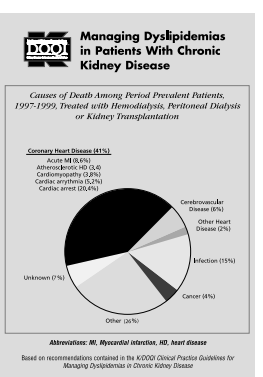
continued from page 1

CHRONIC KIDNEY DISEASE

In 2002, the NKF published its *Clinical Practice Guidelines on Chronic Kidney Disease* (CKD). This was a tremendous milestone, as these guidelines provided evidence that 20 million Americans have CKD and 20 million more are at increased risk, which had not been previously known. The CKD Guidelines formed a framework so that all future guidelines would refer to the five stages of kidney disease, from mild damage to kidney failure. These stages give health care professionals, payors and individuals with kidney disease a common language on which to base diagnosis and treatment discussions.

MANAGING DYSLIPIDEMIAS IN CHRONIC KIDNEY DISEASE

These guidelines were published in April 2003. Many people with CKD also have cardiovascular disease. These guidelines urge physicians to test individuals with CKD for elevated cholesterol levels and for changes in the balance of "good" and "bad" cholesterol to help prevent cardiovascular disease.



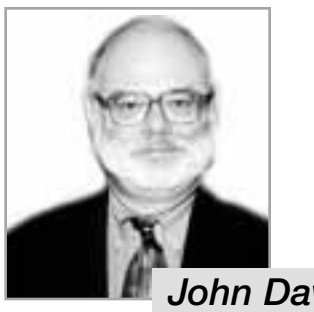
The NKF is producing publications for professionals (above) as well as for patients.

BONE METABOLISM AND DISEASE IN CHRONIC KIDNEY DISEASE

People with kidney disease often develop mineral imbalances and bone disease. The next set of K/DOQI guidelines will focus on this issue to help doctors treat people with bone disease and CKD. These guidelines will be published in Fall 2003.

BLOOD PRESSURE MANAGEMENT IN CHRONIC KIDNEY DISEASE

These guidelines will focus on managing blood pressure in people with CKD. They will recommend the best drugs for treating high blood pressure in individuals with kidney disease, blood pressure goals and how to prevent heart disease. They are in the review stage and will be published by the end of this year.



John Davis

CARDIOVASCULAR DISEASE IN DIALYSIS PATIENTS

These guidelines will focus on risk factors for cardiovascular disease and how to manage them in people who are on dialysis. They will be published in early 2004.
For additional information about K/DOQI Clinical Practice Guidelines and related materials, please visit **www.kdoqi.org**

About the Author
John Davis is the CEO of the National Kidney Foundation, Inc.

Diagnosing the Different Types of Bone Disease

By Kevin Martin, MB, BCh, FACP

When people have chronic kidney disease (CKD), their kidneys often have problems controlling the levels of the minerals calcium and phosphorus in the body. This may lead to bone disease. Often, people experience no symptoms from bone disease in the early stages, but if it is not treated, the bones can cause pain and break easily. The abnormal levels of calcium and phosphorous can even cause heart problems. Therefore, it is important to know how to identify bone disease in its early stages. This article describes the most common bone diseases for people with CKD, and how doctors identify these problems.

Bone disease can be described as a range of problems with the skeleton, from very high "turnover" of bone to the opposite extreme in which bone turnover is very low. Turnover refers to the activity of the bone. Many people think of bones as simple, hard objects, like wood or metal. In fact, bones are living and constantly changing. The old material in bones is broken down, and new material is built up. Bones that are too active are said to have a high turnover problem. Bones that are not active enough have a low turnover problem.

It is also possible for people with kidney failure to have normal bones, particularly if they follow their diet and other recommendations of their kidney doctor.

To make a definite diagnosis it is necessary to remove a small piece of bone and make careful measurements of what is present in the bone under a microscope. In most people, however, it is possible to make a diagnosis by looking at blood tests.

When minerals in the blood (calcium and phosphorous) are not balanced properly, the parathyroid glands may release parathyroid hormone (PTH). When people with CKD have high levels of PTH in the blood (greater than 500 pg/mL), it is because of a condition called secondary hyperparathyroidism, often seen with OF or MUO (described in the box below). PTH draws calcium out of the bones, causing them to become weaken. In people with very severe CKD, very high serum phosphorous levels (hyperphosphatemia) are often seen with hyperparathyroidism.

On the other hand, very low levels of PTH (less than 100 pg/mL) are often seen with AD or osteomalacia. Osteomalacia is seen most often with aluminum in the bone, and a test of aluminum levels in the blood may be helpful in making this diagnosis.

When PTH levels are normal (between 100 pg/mL and 500 pg/mL), other tests of bone cell activity may be helpful. For example, a blood test that shows high levels of serum alkaline phosphatase may indicate OF or MUO.

Hypercalcemia (high levels of serum calcium) may occur with both high and low levels of PTH. High calcium levels with a PTH less than 100 pg/mL may be a sign of AD. The bones may not be absorbing the extra calcium in the blood, which could cause a heart or blood vessel problem. High serum calcium levels combined with high PTH levels (over 500 pg/mL) may be a sign of tertiary hyperparathyroidism. High calcium levels usually "turn off" the parathyroid gland so it stops releasing PTH. With tertiary hyperparathyroidism, this no longer happens. Surgery may be needed to remove the parathyroid gland.

Whether you have kidney disease, are undergoing dialysis or have a kidney transplant, it is very important that you know what your numbers are for calcium, phosphorous and PTH levels. Learn what you and your health care team can do to keep them in the proper range so that you can avoid the different types of kidney bone disease.

	CKD STAGE 3	CKD STAGE 4	CKD STAGE 5
PHOSPHOROUS (MG/DL)	2.7-4.6	2.7-4.6	3.5-5.5
CALCIUM (MG/DL)	"NORMAL"	"NORMAL"	8.4-9.5; HYPERCALCEMIA = >10.2
INTACT PTH (PG/ML)	35-70	70-110	150-300

The recommended blood levels for different minerals. "CKD Stage 5" is kidney failure. Stages 3 and 4 include people who have reduced kidney function, but do not require dialysis or a transplant.

The types of bone disease can be grouped into four categories:

a) Osteitis fibrosa (OF), which is a high turnover bone disease that occurs when parathyroid hormone (PTH) is very high (hyperparathyroidism).

b) Mixed Uremic Osteodystrophy (MUO), which looks something like OF, but also has a mineralization defect (i.e., the bones are soft because they do not contain enough calcium).

c) Adynamic Bone Disease (AD), which has very low bone turnover and little cellular activity;

d) Osteomalacia, which is a severe mineralization defect usually due to aluminum buildup in bone.

About the Author
Kevin Martin, MB, BCh, FACP is professor of Internal Medicine and director of the Division of Nephrology at St. Louis University.

Managing Serum Lipids in Chronic Kidney Disease:

Answering Questions About the New Guidelines

An interview with Dr. Bertram Kasiske, MD, Work Group Chair and Editor in Chief of *American Journal of Kidney Diseases*

In April 2003, the National Kidney Foundation (NKF) published the Kidney Disease Outcomes Quality Initiative (K/DOQI) Clinical Practice Guidelines on Managing Dyslipidemias in Chronic Kidney Disease (CKD).

Q. WHY WERE THE GUIDELINES WRITTEN?

People with kidney disease have increased risk for cardiovascular disease (CVD) (heart disease) and atherosclerosis (hardening of the arteries) and tend to die earlier than they should from heart attacks and strokes. One of the major risk factors for heart disease is abnormal blood lipid (fat) levels. The new guidelines give advice to doctors about how to treat people with kidney disease who have high cholesterol and other abnormal fat levels.

Q. WHAT LIPID LEVELS DO THE GUIDELINES RECOMMEND?

Abnormal blood fat levels are very common in patients with CKD. There are several different kinds of fats in the blood in addition to cholesterol (Table 1). High levels of cholesterol, LDL and triglycerides are considered bad while high levels of HDL are good.

Q. FOR WHOM WERE THESE GUIDELINES WRITTEN?

The guidelines are for all people with CKD, on dialysis and with a kidney transplant, including children with kidney disease. All these individuals have a high chance of having abnormal blood lipid levels and a high risk of CVD.

Q. WHAT DO THE GUIDELINES SAY ABOUT ABNORMAL LIPIDS IN PEOPLE WITH CKD OR A KIDNEY TRANSPLANT?

- People with CKD should be considered to be in the highest risk category.
- Lipid levels should be measured when a person is found to have CKD, after any changes in treatment, if the person's medical condition changes and at least once a year.
- People with abnormal lipids need to make "therapeutic lifestyle changes" (TLC), that include maintaining a normal body weight, blood pressure, and blood sugar, regular exercise, eating a healthy diet, no cigarette smoking and drinking alcohol only occasionally.
- Medicine should be used for LDL levels of 100 to 129 mg/dL after three months of TLC with no decrease in the levels. The first drug therapy for high LDL should be with a type of medicine called a statin.
- Medicines called fibrates may be used for people on dialysis with triglycerides greater than or equal to 500 mg/dL. These medicines should also be used for individuals on dialysis with triglycerides greater than or equal to 200 mg/dL who also have non-HDL cholesterol greater than or equal to 130 mg/dL, who cannot take statins.

Q. SHOULD PEOPLE WITH CKD READ THE GUIDELINES?

These guidelines are for doctors, nurses, pharmacists, dietitians and others who care for people with CKD. The information in these guidelines can and should be given to individuals who have CKD and their families and the NKF will provide materials that will aid in educating them about this important topic. It is especially important to know where your lab values are and where they should be. Ask your health care team about your lipid levels and see where they fit into the chart below. If your levels are abnormal, talk with your team about how to improve your numbers.

FATS IN THE BLOOD

TYPE OF FAT	LEVEL (MG/DL)
Total cholesterol	
Desirable	<200
Borderline high	200-239
High	≥240
Low-density lipoprotein (LDL) cholesterol	
Best	<100
Better	100-129
Borderline	130-159
High	160-189
Very high	≥190
Triglycerides	
Normal	<150
Borderline high	150-199
High	200-499
Very high	≥500
High-density lipoprotein (HDL) cholesterol	
Low	<40

Knowing Your Numbers for Minerals

By Sharon Moe, MD, FACP

People with chronic kidney disease (CKD) have a variety of bone and mineral (calcium, phosphorous, parathyroid hormone [PTH]) abnormalities. Mineral disorders not only affect your bones, but they can also impact the rest of your body, including your heart. If your bones cannot properly store calcium and phosphorus then it may go to parts of your body where it does not belong such as in blood vessels (leading to "hardening" of the arteries), skin (leading to itching) and joints (leading to pain). We have learned a lot in the last few years, but in the past there has been no standard way of treating bone and mineral disorders in individuals who have kidney disease.

The National Kidney Foundation has been a leader in establishing new standards and goals for doctors who take care of people with chronic kidney disease (CKD), The Bone and Mineral Metabolism and Disease in CKD guidelines include target goals for phosphorous, calcium and PTH. These target lab values are listed in a chart at the top of page 4. Study the chart to see what your lab values should be, and ask about your levels at your next treatment or doctor's appointment.

The K/DOQI Guidelines tell doctors to pay more attention to helping you control your blood fats, decrease high phosphorous levels, have more normal levels of serum calcium and limit the amount of calcium you receive through diet, dialysis or medicines. Fortunately, new therapies may make it possible for these things to happen. However, it can only be done if you learn more about the levels of calcium, phosphorus, and parathyroid hormone (PTH) in your blood, and how you may need to adjust your diet, medications, and other things you can do to keep your bones healthy and become a partner in your care with your kidney doctor, nurse, dietitian, social worker and other kidney professionals.

About the Author

Sharon Moe, MD, FACP, is Associate Professor of Medicine and Associate Dean for Research Support at Indiana University School of Medicine and Roudebush VAMC in Indianapolis, Ind.

Take the Time to Prepare Yourself

By Pedro Recalde, MS, ACSM

Bone disease and lipid abnormalities are two of the challenges that people with kidney failure must face. Although regular exercise should be part of your plan to manage both bone and lipid problems, this article will focus on your bones.

As you know from other articles in this issue, keeping bones healthy requires a balance of the minerals calcium and phosphorus. When your kidneys are not working properly, an imbalance between these two minerals develops. One of the results of this imbalance is loss of bone mass and a greater chance of fracturing (breaking) bones.

There are no special exercise training guidelines to help combat bone disease, but physical therapists believe that a well-balanced exercise program focusing on both aerobic and strength training should be considered. Strength training (like lifting weights) can help keep bone mass while strengthening the muscles around your bones for extra protection and balance. Building strength in one area of the body does not help other areas, so it is important to develop a weight lifting program that involves all of your limbs and major muscles.

Before you begin exercising, you should consult your physician and, if possible, a trained exercise physiologist to discuss your program and limitations to your program. Some exercises need to be modified to avoid increasing the amount of pain you may already have due to bone disease. If you are experiencing pain, they may suggest you avoid weight training and try other activities like chair exercises, water aerobics, swimming or walking in the water. There are many options for those who find it painful to even carry their own weight.

One of the major concerns of those with bone disease is guarding against "slip and fall" situations. There are some things that you can be aware of to help protect you from these injuries. Women should consider wearing flat shoes versus high-heeled shoes. Flat shoes give a greater feel for the ground and lower your chance of turning an ankle on uneven sidewalks. Also, the fear of falling by itself may be contributing to your risk of falling. People tend to take smaller and quicker steps as they age. Unfortunately, this may train the feet to have a limited range, making them unable to take wide steps, regain balance and avoid a fall.

There are some exercises you can do at home to help you regain your sense of balance and increase your reaction time, which can aid you in avoiding painful injuries. Find a comfortable place in your house, but near your bed, couch or a table that can be used for balance. Stand with your feet together, then step forward with one leg and maintain your stance for 10 seconds. Take the time to feel your center of gravity, and then step back to your "feet together" position. After stepping forward 10 times, try stepping to your side just beyond shoulder width, feel your center of gravity, then back to the "feet together" position. After this exercise try stepping backwards, maintaining balance, then returning to beginning position. Try these exercises with your right leg first and then your left leg. You never know which leg you might need to stop you from falling. Doing these exercises may help make you stronger, but more importantly, you will become more aware of your body and reaction time. There is a world of uneven sidewalks, cracked walkways, sudden steps and slippery floors out there, and we should prepare ourselves the best we can.

As always, be careful and have fun exercising.

Eating Right for Your Heart

By Judy Beto, PhD, RD, FADA

If you listen to the news on television, read the local paper or scan the latest magazines, you will often find information on foods that may make you feel better and help you live longer. Many foods that you buy in the supermarket are now labeled "heart healthy." People with kidney disease have an even higher risk of developing heart disease, because problems such as high blood pressure and diabetes affect both the kidneys and the heart. This risk starts before you need dialysis and continues to be high after transplantation. The National Kidney Foundation K/DOQI Work Group on Lipids recently released guidelines on how to manage lipids (fats in your blood that may contribute to heart disease) in those with kidney disease.

The good news is that there are some logical food choices you can make that may be helpful in protecting your heart. The really good news is that these better food choices are also healthy for the family and loved ones who share the food in your home. Everyone can benefit from these diet ideas!

You already know that you should try not to eat large amounts of "saturated" fat. This fat cannot be digested by the body quickly and often remains in your blood for a long time. Then it begins to stick to the inside of your blood vessels, making them narrower and more difficult for blood to pass through. Saturated fat is found in organ meats (such as liver), egg yolks (but not egg whites) and fatty meats (sausage, bacon and luncheon meats). It is also hidden in baked goods such as cake and cookies.

There are many ways to keep your dietary protein level and your serum albumin (a protein in the blood) high without also eating a lot of fat.

There are many ways to keep your dietary protein level and your serum albumin (a protein in the blood) high without also eating a lot of fat. For example, you may talk to your dietitian about the number of eggs you can eat per week, or you can use egg substitutes for scrambled eggs and baking recipes.

You can lower fat by throwing out the butter and instead using special margarine now available that is made from plant sterol esters, a heart-healthy source of fat. Two common brands are Take Control™ and Benecol™. They look like the margarine that is packaged in tubs, but they contain no trans fatty acids, which are bad for your heart. Trans fatty acids are found in most stick margarines and hydrogenated fats (solid fats that come in a can that are often used for frying). It is recommended that you use two tablespoons of the newer margarine every day to help reduce the "bad" fat in your body.

You can also begin to use healthier oils in your cooking. Olive oil, canola oil and soybean oil are better for your heart. In Italy, olive oil is used to dip bread in at the table, instead of margarine or butter. Pour olive oil in a small dish and add some pepper, dried herbs, garlic powder or other low sodium ingredients for extra flavor. The good fat will add calories in a positive way.

The good news is that there are some logical food choices you can make that may be helpful in protecting your heart.

Another way to reduce the "bad" fat in your body is to increase the fiber in your diet. If you have a fluid restriction, dry fiber (found in seeds, nuts, wheat, bran and whole grains) is hard to add to your diet without making you thirsty and constipated. Soft fiber, or soluble fiber, is much better because it will add soft bulk to your stool and help remove "bad" fat. It will also help decrease constipation without adding more fluid. Consider having one to one and a half cups of oatmeal for breakfast. Other soft types of fiber are found in vegetables such as eggplant, okra, zucchini or yellow squash. Ask your dietitian how to include these and other soft fiber foods in your diet.

These are just a few simple ideas to help make your diet more heart healthy. Talk to your dietitian and health care team members about other ideas. New brochures on lipid information will be available from the National Kidney Foundation soon. We all want you and your family to live a longer, healthier life!

About the Author

Judy Beto, PhD, RD, FADA is a research associate at the Loyola University Medical Center Dialysis Unit in Maywood, IL. She has been involved with kidney patients for more than 25 years. Dr. Beto was a member of the National Kidney Foundation Task Force that developed the K/DOQI guidelines for lipid management.

Some Diet Suggestions

FOOD	CHOOSE	DECREASE
Fats and Oils	Mono- and polyunsaturated oils—safflower, sunflower, canola, olive, peanut Margarine made from any oil and liquid forms; cholesterol lowering margarines made from plant sterols and plant stanols Salad dressings made from any of the oils above	Hydrogenated and partially hydrogenated fats Coconut, palm kernel, palm oil, coconut and coconut milk products Butter, lard, hard shortening, bacon fat, stick margarine Dressing made with egg yolk, cheese, sour cream or milk Certain nuts like Brazil nuts and macadamia nuts

"Sticks and Stones May Break Your

By Bobbie Knotek, RN, BSN, CNN

A man who had just started dialysis asked me why the doctors and nurses kept bugging him to take his phosphorus binders when he had more important things to worry about–like trying to juggle work, dialysis and his family responsibilities. I answered his question by telling him Patti's story.

Patti was one of the first people on dialysis I took care of when I started working as a dialysis nurse in 1975. A pretty young woman in her late 20s, Patti had a husband, a full-time job and a positive attitude. What no one knew was that Patti also had bone disease! Patti's bone disease did not become obvious until her third year on dialysis, when her bones started "crumbling" before our eyes. She sneezed and broke ribs; she bumped against a door and broke her arm. Not a month went by without a bone breaking somewhere in her body. After struggling for two years with severe bone pain, broken bones that would not heal and a quality of life that kept getting worse and worse, Patti made one of the hardest decisions of her life—she chose to stop dialysis.

As Patti's story shows, bone disease caused by chronic kidney disease sneaks up on you. Not only does bone disease start damaging bones in the early stages of chronic kidney disease (CKD), long before dialysis or a kidney transplant is needed, but the symptoms of bone damage (joint pain or broken bones) do not show up for years. Even though you may think your bones are fine, bone disease may be slowly and quietly damaging your bones, making them weaker and weaker.

The good news is that in the years since I first met Patti, medical science has developed medicines to help prevent crippling bone disease. The bad news is that these medicines are not a CURE. You still need to do your part in taking care of your bones. The first step is to learn about bones—what they do, how they work, what they are made of, what controls them and how kidney disease affects them.

HOW DO BONES WORK?

Bones are a living, changing part of your body. To stay healthy and strong, bones must break down "old bone" layers and build "new bone." A team of special bone cells work together to balance this process.

- "Building crew" bone cells make new bone and repair damage to your bones.
  "Messenger" bone cells carry food and oxygen to the bones and remove waste products from the bones.
- "Wrecking crew" bone cells break down the hard layer of old bone. When bone is broken down, calcium is released into the blood where it can be used by your muscles and nerves.

WHAT ARE BONES MADE OF?

Bones are made of cells, fibers, blood vessels, nerves and large amounts of minerals (mostly calcium and phosphorus). Bones have two main layers—an outside layer and an inside layer. The outside layer of bone is hard and very strong. It has small holes so blood vessels and nerves can get to the inside of the bone. The inside layer of the bone is soft and spongy and is made of tiny pieces of bone that mesh together, like the wire of a window screen.

WHAT CONTROLS BONE BREAKDOWN AND BUILDING?

Signals sent and received by your bone cells, intestines, kidneys and parathyroid gland keep your bones healthy and strong. The signals talk to the bone cells telling the building crew cells to build bone and the wrecking crew cells to break down bone and release calcium. The drawing on the next page shows how these signals work when the kidneys are healthy.

HOW DOES CHRONIC KIDNEY DISEASE AFFECT YOUR BONES?

With chronic kidney disease, the signals that talk to your bones and the other parts of your body get messed up. When this happens, the vicious cycle of bone disease begins:

- Damaged kidneys cannot dump extra phosphorus into the urine. This causes high phosphorus in your blood.
- Damaged kidneys cannot make Vitamin D to help your intestines take in calcium from digesting food. This causes low calcium in your blood.
- Like a playground teeter-totter, when the phosphorus in your blood gets too high, the calcium in your blood drops even lower.
- When your parathyroid gland senses low calcium in the blood, it sends a signal to the wrecker crew bone cells, telling them to break down bone so calcium can be released into the blood to raise the calcium level.
- As long as you have high levels of phosphorus in your blood, your parathyroid gland will never turn off—it will keep sending signals to the wrecking crew bone cells telling

Bones...and so May Bone Disease!"

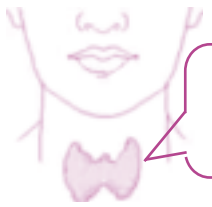
them to work overtime to break down bone and release calcium.

- This cycle of high phosphorous, low calcium and bone breakdown causes the bone disease that makes your bones weak and brittle. Unless something is done to break this cycle, bone disease will continue to cause more and more damage to your bones.

Read the articles in this newspaper to find out how you can work with your care team to break the cycle of bone disease.

Your bones need your help NOW!

Signals that control bones



Please make Vitamin D

Parathyroid glands in the neck send a message to kidneys, telling them to make vitamin D

The parathyroid glands stop sending messages to the kidneys when the blood has the right amount of calcium and vitamin D.

If calcium levels are still low, the parathyroid glands can also send signals directly to the bones, telling them to break down old bone so calcium stored in the bone can be sent to the blood.

The kidneys make vitamin D and send it to the intestine through the bloodstream.

The kidneys also help your body get rid of phosphorus by adding it to the urine.

Vitamin D

In the intestine, vitamin D helps the body "take" calcium from digesting food.

Calcium

Calcium is sent to the bones to help build new bone and repair old bone.

Break down bone and release calcium

Poetry Corner

For My Grandson

By Charles Bahus

Charles, by nature, you are my grandson by name
Charles, by God's grace, you are as my son to reign
Charles, by heaven's orders, Grandma and I enjoy your being
Charles, by God's laws, we guide you with his proper steering

Charles, by God's grace, you are as my son to reign
Charles, Grandma and I share our love to protect you from pain
Charles, please let us protect you against evil wills
Charles, we ask that you refrain from all ill

Charles, by heaven's orders, Grandma and I enjoy your being
Charles, we want everyone to know the good we are seeing
Charles, provide us the privilege to enjoy your good works
Charles, we wish you the joys to gain many special perks

Charles, by God's law, we guide with proper steering
Charles, provide us with joy we will be proud of hearing
Charles, Grandma and I and family love you with all our hearts
Charles, even through eternity we will never ever be apart

Written with love, Charles J. Bahus

Charles Bahus, who dialyzes in Indiana, Pa., wrote this poem when his grandson Charles began high school.

The Big Machine

By Thelma "Juanita" Paynter

As I come through the door
counting tiles on the floor
going to the big machine
for $3\frac{1}{2}$ hours (12 it seems)
it takes out our blood
and puts it back in
cleans it all with the help of saline
sometimes we think of early days
when we could work or even play
now we depend on the big machine
to get us through another day

The big machine, the big machine
where would we be without
the big machine

So let's pray to God every day
as on the machine we sit or lay
that he will be with us
and guide the nurses
because without them
we wouldn't be on
the big machine

Thelma Paynter dialyzes in Oceana, W.V.

Lipid Abnormalities After Kidney Transplantation

By Linda Harte, RN, BSN, MA, CNN, CCTC

Heart disease remains the most common cause of illness and death for people who have received a kidney transplant. Common causes for heart disease are high blood pressure, diabetes, cigarette smoking and dyslipidemia (having the wrong amount of fat in the blood). [1]

The rate of lipid (fat) abnormalities after transplant is very high.

- Over 60 percent of kidney transplant recipients have total cholesterol greater than 240 mb/dL (the normal level is less than 200mb/dL);
- 60 percent have a level of LDL (bad cholesterol) greater that 130 mg/dL (normal is less than 100 mg/dL);
- and 15 percent have an HDL (good cholesterol) less than 35 mg/dL (normal is greater than 40 mg/dL).[2]

These lipid abnormalities in transplant recipients have several causes. People with a family history of lipid problems tend to inherit this trait and there is not much we can do about that! Prednisone and other immunosuppressive medications such as cyclosporine, sirolimus or a combination of these can contribute to high lipids. Lifestyle can also add to the problem, especially through poor dietary habits, obesity and lack of exercise.

Why is dyslipidemia harmful? It leads to atherosclerosis, which is a build up of waste in the lining of blood vessels. This build up can cause heart attacks, strokes, poor circulation in the legs and feet and it can even affect the function of the kidney. Changes in the blood vessels of the kidney can lead to chronic kidney deterioration because these changes affect the kidney's ability to filter waste products.

Fortunately, recipients can control several of the causes of dyslipidemia. A diet low in calories (especially calories from fats), physical exercise and avoidance of large amounts of alcohol are helpful. No one can control your lifestyle except you, the transplant recipient.

But some causes of dyslipidemia are out of your control, particularly the medications that must be taken after receiving a kidney transplant. Cyclosporine usage started in the early 1980s and has been described as the wonder drug of transplantation. However, it has been associated with higher lipid levels. The same is true of steroids and sirolimus. Tacrolimus has been shown to cause less of a problem with high cholesterol than cyclosporine.[3] Some high blood pressure medications, such as water pills and a group of drugs called beta-blockers, are known to contribute to lipid problems. The reasons for all these things are too complicated to discuss here, but the benefits of these medications have certainly improved the lives of people with kidney transplants. The end result is we are faced with controlling the medications' side effects, including high cholesterol.

There is a fairly new group of drugs, called statins, which are being used to control cholesterol. Some examples of these are Lipitor, Mevacor and Zocor. They can, however, interact in a negative way with cyclosporine and tacrolimus, so the levels of these statins must be watched carefully. One side effect of statins is myopathy (muscle pain and weakness). If you get this symptom while taking statins, you should report it to your health care team. Liver function should also be monitored since the liver is important in the handling of statin medications.

The importance of close monitoring after kidney transplantation cannot be stressed enough. The short-term success is better than it has ever been. Close medical follow-up to manage long-term complications such as bone disease and dyslipidemia will help to improve outcomes. Whether follow-up is done in a transplant clinic or by a primary care physician (such as a family doctor), it is necessary to check more than just kidney function. A thorough physical exam is needed at least once a year. It will make a difference in living a long, productive life with such a precious gift.

A diet low in calories (especially calories from fats), physical exercise and avoidance of excessive amounts of alcohol are measures that can be taken.

References:

1. Kasiske BL, Vazquez MA, Harmon WE, et al. Recommendations for the Outpatient Surveillance of Renal Transplant Recipients. American Society of Transplantation. Journal of the American Society of Nephrology 2000; 11 (supp 15); 51-86.

2. Van don Dorpel MA, Ghanem H, Rischen vos J, et al. Conversion from Cyclosporin A to Azathioprine Treatment improves LDL Oxidation in Kidney Transplant Recipients. Kidney in 1997; 51(5): 1608-12.

3. Fellstrom B: Bio Drugs 15:261, 2001.

Do Children Need to Watch Lipids, Too?

By Barbara Fivush, MD

The National Kidney Foundation's newest chronic kidney disease (CKD) guidelines deal with management of lipid problems and bone disease. Most of these new guidelines only apply to adults, but some of them apply to children and adolescents.

Recent studies have suggested that diagnosis and treatment of high lipid levels is important in pediatric patients, particularly adolescents. It is thought that high lipid levels in adolescence may result in greater risk of cardiovascular (heart and blood vessel) disease. This may be true for younger children as well, but at this time this is not supported by clear evidence. Because we now know the dangers of high lipid levels in adolescence, this article will briefly summarize how the guidelines directly affect the care of adolescents with CKD and those on dialysis.

Adolescents who are on dialysis, those who have received transplants and others with CKD should all be evaluated for abnormal lipid levels. They should have blood drawn to check for cholesterol, high-density lipoprotein (HDL), low-density lipoprotein (LDL) and triglycerides (lipid profile). These levels should be checked when the adolescent is first diagnosed with CKD, and then on a yearly basis. If there is a change in the adolescent's medical condition or treatment, these lipid levels should be checked more often.

The lipid levels should be measured after an overnight fast, if possible, for the most accurate measurement. For adolescents on hemodialysis, lipid levels should be measured before dialysis or on nondialysis days.

If adolescents have high lipid levels, they should be screened for non-kidney causes of the high lipid levels, such as diabetes, liver disease or medications.

For adolescents with a fasting triglyceride level greater than or equal to 500 mg/dl that cannot be corrected by fixing a nonkidney cause, therapeutic lifestyle changes (TLC) should be considered. These changes include limiting fat in the diet and exercising more.

For adolescents with an LDL level greater than or equal to 130 mg/dl, treatment should be considered to lower the LDL level to below 130 mg/dl. TLC as described above should be tried, but if the LDL remains high, treatment with medications to lower lipid levels should be considered.

> "The lipid levels should be measured after an overnight fast, if possible, for the most accurate measurement."

For adolescents with a non-HDL cholesterol (total cholesterol minus HDL) greater than or equal to 160 mg/dl, in certain situations, treatment with TLC or medications may be needed to keep the non-HDL cholesterol below 160 mg/dl.

Hopefully, these new guidelines will help doctors take care of adolescents who have CKD, are on dialysis or have received a kidney transplant. Recent studies have revealed that young adults (20 to 40 years old) with advanced CKD have a much higher risk for cardiovascular disease than healthy individuals of the same age. Although there are little data in younger patients, it has been shown that cardiovascular disease accounts for approximately 25 percent of deaths in children with CKD who are less than 18 years of age, making it the second leading cause of death in this population. Therefore, it is extremely important that nephrologists begin to screen high lipid levels in adolescents with CKD, those on dialysis and those who have a kidney transplant.

Taking Care of Your Bones

By Linda McCann, RD, CSR, LD

It may seem like diet and nutrition advice changes frequently in popular magazines and news articles. One time we are told to eat more of a certain food and then we hear that the same food can be bad for us. It seems to go in circles and can be confusing at times. You may find that to be the case with dietary advice for those with kidney disease. The best food or medication choices change as we learn more. Also, very often, the advice is exactly the opposite of advice that is given to someone with normal kidney function. So what you hear on the radio or read in the paper may not be right for you.

Over the past few years, we have learned a lot more about the treatment of bone problems that can result from kidney disease. We have learned that:

- It is important to limit the amount of phosphorus in the diet in early kidney disease and after starting dialysis.
- Large amounts of calcium may not be appropriate, since foods high in calcium usually have a lot of phosphorus.
- Bone disease starts as kidney function decreases and should be monitored and treated earlier in the process of kidney disease.
- Vitamin D is needed for those with CKD, but the body needs a special, "active" form of it, that your doctor may give you.
- When the kidneys are not able to do their share of the work, balancing calcium and phosphorus takes the efforts of the health care team.

If you have kidney disease, the most important part of the team is YOU! The doctor, nurse or dietitian can give advice, but you are the one who has to do the work every day, such as:

- taking medications, like phosphate binders, as directed with meals or snacks
- making good food choices
- following your dialysis treatment prescription.

If you have decreasing kidney function, but are not on dialysis:

- Check with your doctor about your need for vitamin D and phosphate binders.
- Make sure that your blood levels of calcium, phosphorus and parathyroid hormone (PTH) are being monitored. If your PTH is high, you will need to limit dietary phosphorus and possibly take a phosphate binder even if calcium and phosphorus levels are normal. PTH causes the loss of calcium from the bones.
- Do not take any over the counter medications or herbal products without checking with your doctor, because their effects are not well understood, and they may be harmful.
- Do not change your diet to match what is recommended to the general public without talking to your doctor or a dietitian.
- Do not follow any fad diets, especially high protein diets.
- Talk to your doctor about how your bone health is being monitored and if you need any medications or supplements to keep your bones healthy.
- Do not take any medications or herbal products without discussing them with your doctor.

If you are on dialysis:

- Know your calcium, phosphorus and PTH levels and work with your health care team to keep them in appropriate target ranges.
- Eat enough protein and calories, but make choices that are lower in dietary phosphate. Limit those foods that are very high in phosphate.
- Take your phosphate binders as directed with every meal or snack. Binders should be taken immediately while eating to work best. Carry some with you even if you are dining out. Work with your health care team to find the best phosphate binder for you—one you can and will take!
- Do not take calcium or vitamin D products unless you are told to do so by your doctor, nurse or dietitian. Commonly, people are given a special vitamin D while on dialysis, but this medication will be held if your blood calcium and/or phosphorus are high, because it may increase them further.
- Make sure you get your prescribed dialysis treatment (come to treatment on time and stay for your full treatment; do not skip treatments).
- If you cannot keep your calcium, phosphorus and PTH within target ranges, talk with your health care team about what else you can do.
- Do not use calcium-fortified foods, over the counter medication, supplements or herbal products without talking to the doctor or dietitian. Some may have harmful effects.

If you have a transplanted kidney:

- Work with your health care team to make sure you are using the least amount of anti-rejection medication to protect your transplant, but minimize bone problems. Some anti-rejection medications may decrease calcium levels.
- Talk to your doctor about how your bone health is being monitored and if you need any medications or supplements to keep your bones healthy.
- Do not take any medications or herbal products without discussing them with your doctor.

Remember, you can make a difference in your own care by following the advice of your health care team and by participating in the decisions that affect you and your life!

About the Author

Linda McCann, RD, CSR, LD is Director of Nutrition Services for Satellite Healthcare in Redwood City, CA and was a member of the K/DOQI Bone and Mineral Metabolism Work Group.

Can You Connect the Dots?

By Mary Beth Callahan, ACSW/LMSW-ACP

People diagnosed with chronic kidney disease may feel overwhelmed by information: lab values, medications, diet and exercise are just a few of the things to keep track of.

As you read the articles in this issue, you may be thinking, "Great! Bone disease and cholesterol are two more health problems to worry about." Just remember: a lot of the recommendations for dealing with these health problems are closely related to things that you already know—watch your diet, increase your physical activity and work with your health care team.

But sometimes there is more to staying healthy than just a positive attitude. Both bone disease and cholesterol problems are often treated with medication.

Sometimes it becomes difficult to take these medications because of the cost. Medications to manage bone disease and cholesterol can be expensive, but there could be help available, especially for those in financial need. One of these resources is **www.helpingpatients.org** This is a directory of prescription assistance programs of various pharmaceutical companies. This Web site has links to other helpful sites for medications, including **www.RxHope.com** and the National Council of Aging's Benefits CheckUp Web site (**www.benefitscheckuprx.com**). Several other sites, such as **www.RxAssist.org** and **www.needymeds.com**, allow you to search for information by program or drug name. These Web sites have applications for assistance available. You might want to check out these resources and bring the information to your doctor or social worker and ask them to assist you in getting the medication.

Some states have state kidney programs that might pay for medications not covered by another source. The Missouri Kidney Program (800-733-7345) can help you determine if your state has a program or not. Some states' Medicaid programs pay for medications that might include phosphorus binders and cholesterol medications. These resources vary from state to state. You can find contact information for your state's Medicaid department on the Web at **cms.hhs.gov/medicaid/mcontact.asp** or by calling 877-267-2323. Local Agencies on Aging may be able to assist people age 65 or older who cannot afford their medications (**www.eldercare.gov** or 800-677-1116). The Health

Resources and Services Administration (888-ASK-HRSA) provides information about community health centers that may offer prescription assistance to low-income individuals.

Sometimes intravenous medications (medicine put directly into your blood) are used during dialysis to help keep your bones healthy. Medicare covers some of the cost of these medications, and the makers of the medicines sometimes have programs to help people pay for medications they need but cannot afford. Ask your social worker about any of these resources.

Being actively involved in your health is one of the best things you can do to live successfully with kidney disease. Strong bones are important when you think about doing the things you like to do. Managing calcium, phosphorus and fats in your food can also help you live long and live well.

Medicare Payments for Prescription Drugs

By Dolph Chianchiano, JD, MPA

With rare exceptions, Medicare covers only those drugs (for outpatients) that have to be given by injection in a doctor's office or clinic. Medicare does not pay for the tablets or liquids that people give themselves, even if a physician has prescribed them. This gap in coverage is why both national political parties have promised to change Medicare benefits to include prescription drugs and explains why people on dialysis must find other resources to pay for phosphate binders, including those that are not calcium based.

Among the few unique exceptions to the current Medicare policy are: drugs to prevent rejection of transplanted organs, drugs that facilitate clotting factors for treatment of hemophilia and oral cancer therapy (but coverage for cancer medications is limited to drugs that have a more expensive injectable version available.) The only reason that Medicare covers the drugs mentioned above is because Congress has directed that the program make these payments. Beneficiaries are responsible for 20 percent of the cost of these drugs.

With that in mind, advocates for payment for noncalcium based phosphate binders have gone to Washington to seek legislation that would make Medicare specifically cover these medications. Proposals were introduced in both the House of Representatives and the U.S. Senate in 2001, but these bills were not passed by either chamber in the 107th Congress. They have not yet been reintroduced for consideration in the 108th Congress that began its first session in 2003. Before Medicare will pay for noncalcium phosphate binders under the End Stage Renal Disease program, both the U.S. House of Representatives and the U.S. Senate must vote in favor of this requirement and the President must agree to provide this benefit. Noncalcium phosphate binders would also be covered under the new general Medicare prescription drug benefit, but Medicare may only pay 50 percent.

Even if a person must get a medication by injection in a physician's office or at a clinic, however, there is no guarantee that Medicare will pay for it. Knowing how Medicare policy determines if an injectable drug is covered may give us a clue about how Medicare policy for new oral medications will be determined.

Medicare has contracts with certain insurance companies to process payment requests at the state level. Each of these contractors can determine local medical review policies which say whether Medicare will cover an injectable drug and, if so, the conditions of that coverage, if a national coverage decision has not been published. There is no requirement that all local medical review policies be the same and there is nothing to prevent a Medicare contractor from reversing a local medical review policy. Because of this it is possible for someone to receive an injectable medication at Medicare expense in Chicago but not in Atlanta. Thus, the Medicare contractor in South Carolina, for example, will pay only for vitamin D in the form of calcitrol.

Another way Medicare develops policy for payment for injectable drugs is through national coverage decisions. A recent national coverage decision that affects people on dialysis who have Medicare concerns the drug levocarnitine, which is used to treat anemia and low blood pressure. Anyone can request a national coverage decision for a treatment. The requestor must submit the medical and scientific information that would show the need for payment. The requestor must explain whether the proposed coverage is for uses already approved by the Food and Drug Administration.

The rules stating how applications for national coverage decisions are handled give Medicare several ways to manage these requests. Medicare can make a decision against covering the medication or service—then local Medicare contractors cannot pay for the drug or service. Medicare can also decide that there should be no national coverage decision, which then allows each local contractor to decide whether it will pay for the drug or service in question. Finally, if Medicare issues a positive coverage decision, it can be limited to certain symptoms.

Medicare coverage for levocarnitine is an example of the first of the last two options. Payment will be given for individuals on dialysis with documented carnitine deficiency, but only if they have signs and symptoms of (1) erythropoietin-resistant anemia (erythropoietin is normally used to treat anemia) or (2) very low blood pressure during dialysis that gets in the way of dialysis treatment. Coverage is limited to these conditions because Medicare did not accept evidence that carnitor is effective for other uses.

For additional information concerning legislation or regulation that affects the ability of those with chronic kidney disease to obtain the medications they need, please phone the NKF Government Relations office at 800-889-9559.

About the Author

Dolph Chianchiano, JD, MPA, is the National Kidney Foundation's Vice President of Health Policy and Research.

Waiting for a Transplant? Watch Your Minerals Now!

By Linda Harte, RN, BSN, MA, CNN, CCTC

Bone disease is a common complication in people with chronic kidney disease. It often improves after a successful kidney transplant, but complications such as bone fractures due to loss of bone strength frequently can occur.

When a person has kidney failure, the kidney cannot eliminate phosphorus. The high level of phosphorus causes the parathyroid gland (in the neck) to secrete a hormone (PTH). High levels of this hormone "pull" calcium out of the bones. This can cause bone pain, muscle weakness and fractures. The kind of bone disease that people with kidney failure get is called renal osteodystrophy. Avoiding foods high in phosphorus and taking phosphate binders (calcium carbonate, calcium acetate) help keep the calcium and phosphorus levels in balance.

Failed kidneys also cannot convert vitamin D into an active form to absorb calcium in the intestines. Medications such as Rocaltrol help with this absorption to decrease the degree of bone disease.

Although bone disease can improve with kidney transplantation, close monitoring and treatment is still necessary. High levels of PTH continue to circulate in the body until the parathyroid gland is "turned off." Until then, the bones will lose calcium.

Another cause of bone disease after kidney transplantation is the use of steroids (prednisone) to prevent rejection. They decrease the calcium absorption in the intestines and increase calcium loss by the kidney. This progresses rapidly in the early months after kidney transplantation (when steroid doses are higher) and stabilizes one to two years after transplantation, as the dose is lowered.

Healthy postmenopausal women often have a problem with bone weakness (osteoporosis) because of a lack of hormones. This can be even more of a problem for women who already have bone disease because of kidney problems.

If your diet does not have enough protein and calcium, this may also contribute to bone weakness. There are other factors that cause bone disease after transplantation, but only the more common ones have been reviewed.

So what can be done to reduce the risks and treat bone disease after kidney transplantation? Control of calcium and phosphorus levels *before* transplantation with phosphate binders and diet (discussed elsewhere in the publication) is vital to prevent bone loss.

Calcium and phosphorus levels are as important as checking the creatinine (a waste product in the blood) after transplant surgery. The parathyroid gland still tells the kidney to get rid of phosphorus. Phosphate supplements may be needed for a while until this gland returns to normal and the kidney is getting rid of the right amount of phosphorus on its own. If this gland continues to over-function, it may be necessary to remove it with surgery (parathyroidectomy), although this is not done as often now that there are newer and more effective phosphate binders and vitamin D preparations.

To treat bone loss caused by steroids, lowering the dose as rapidly as possible can help. With the use of newer, more effective immunosuppressants, lower steroid doses can and usually are prescribed by doctors. This, along with calcium and vitamin D, can lead to healthier bones.

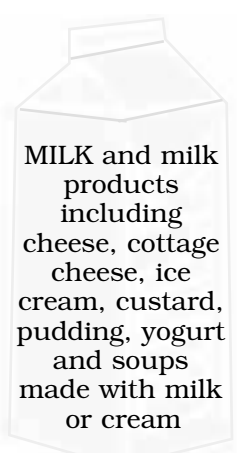
Weight-bearing exercise (like a good walking program), smoking cessation and a good diet help prevent bone disease, too. These lifestyle changes should be started before transplantation and continued afterwards.

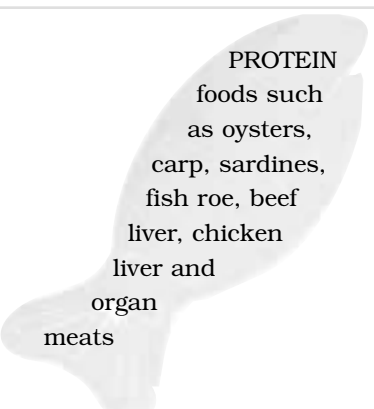
Sources:

2000 Annual Report of the U.S. Scientific Registry for Transplant Recipients and the Organ Procurement Network: Transplant Data: 1990-1999.

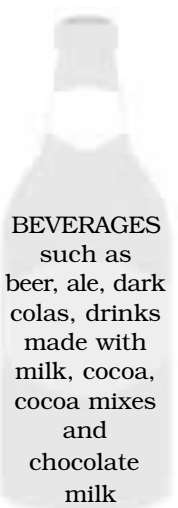
Heaf, JG: Bone Disease After Renal *Transplantation*. Transplantation, 75: 315-325, 2003.

The following foods are high in phosphorus. Talk to your dietitian about alternatives to these foods. As a certain amount of phosphorus is difficult to avoid, be sure to take phosphate binders with your meals if it has been prescribed to you.





Other foods such as nuts, seeds, wheat germ, whole grain products, caramels, brewer's yeast and bran cereals.



TOP 10 Reasons for NOT Taking Phosphate Binders

By Dale Ester

Taking medications as prescribed can be hard, especially when chronic kidney disease (CKD) makes so many demands on a person's schedule. You might even be tempted to skip a medication like a phosphate binder, that seems less important. However, knowing the impact phosphate binders can have on your life and longevity will make you realize this would not be a wise choice.

Excuses are common among those who are reluctant to take their phosphate binders as often as they should. I thought it might be interesting to share some statements made by people with CKD to explain their reasons for not taking their medicines, especially phosphate binders, as prescribed.

THE TOP 10 REASONS:

10. OOPS, I forgot! No big deal anyway!
9. Nothing ever happens if I forget to take my binders!
8. I'll take my binders — later — when I get back home.
7. The doctor can fix whatever goes wrong, right?
6. No one is ever going to know, so who really cares?
5. Nobody is watching whether I do or don't take my binders.
4. I feel okay right now, so why do I need to take phosphate binders?
3. It's a major inconvenience for me to take my binders when I eat.
2. My friends don't take binders, so why should I?
1. The binders are so expensive, I can't afford them.

Do any of these remarks seem familiar to you? Rather than making excuses or placing blame, let's use this as a good opportunity to get back on track with a strategy for taking your phosphate binders on time, when they have their greatest effect. The value of taking binders with every snack and meal is without a doubt one of the most important decisions a person with CKD can make. If you don't believe it for yourself, no one can make it seem important to you.

Kidney failure affects the functioning of many systems in the body. One of the functions of the kidneys is to filter and remove excess phosphorus from the blood. When the phosphorus level becomes too high, the blood needs more calcium to balance it out. Unfortunately, this much-needed calcium is often taken from your bones, which can be debilitating and painful. Osteoporosis, or bone loss and weakening, can also become a problem. All of this can result from the sole act of an individual not taking phosphorus binders as prescribed.

Thankfully, you can lower the risk of harm caused by high phosphorus. Taking a phosphate binder as directed by your doctor will guard the bones while controlling the levels of calcium and PTH. Take your phosphate binders when you eat, and remember that every missed dose adds to a growing problem later on. If you cannot afford phosphate binders, speak with your dialysis social worker and dietitian and advise them of your financial problems. Help is available only when someone is alerted to your need! Speak up so your bones will not suffer!