

From the Committee Chair

Maggie Carey,
Chair, Consumer Committee

What do Bone Disease, Binders, Phosphorous, and Salsa Dancing have in common? Well, if you don't pay attention to the first three, you won't be able to do the last one. Okay, I admit that not a lot of us are planning on doing any Salsa Dancing in the near future (although some of us are willing to give it a try).

The point is this, if you don't take care of your bones you won't be doing much of ANYTHING in the future.

Bone disease, a result of kidney disease, is one of those sneaky issues that doesn't show up right away. You might think you are getting away with something because the consequences of skipping your binders

don't show up for a few years. But, believe me, it WILL show up in your future. I don't know how many times I have heard someone say, myself included, "If I knew then what I know now, I would have done things a lot differently." Well, it is never too late to start protecting your future. Read and study this issue. We have brought you lots of information about bone disease and its prevention. Knowledge is power, but it only works if you use it.

We would also like to get your feedback on some resources that Network 11 has developed and distributed. We are always looking for ways to keep you informed of all the latest developments, options and resources available to you. Are we doing a good job? Are we missing the mark? Please let us know so that we can more fully serve you and your needs.

Renal Bone Disease

Many people with Chronic Kidney Disease (CKD) do not realize that the kidneys play an important role in maintaining healthy bones. Even before dialysis or transplant is required, processes are already in place that can damage your bones.

Normal Bone Health

Normal bone health depends on the presence of balanced amounts of certain minerals, namely calcium and phosphorus, in the body. Because of this, bone health is often referred to as mineral metabolism. If your phosphorus level goes too high, it causes the body to pull calcium out of your bones, resulting in weak and brittle bones. If your calcium level goes too high, calcium may deposit in your blood vessels or heart. This can lead to poor heart function and hardening of the arteries (arteriosclerosis).

Balance in mineral metabolism is a result of two processes.

1. Regulating substances
 - Vitamin D helps to absorb the calcium in your digestive tract.
 - Parathyroid hormone or PTH is a hormone produced by the parathyroid glands (4 small glands embedded in the thyroid gland in your neck) which helps to maintain the proper level of calcium in your blood.
2. Body Systems
 - Your digestive tract absorbs calcium and phosphorus from the food you eat.
 - Your kidneys activate Vitamin D so calcium is more easily absorbed from your digestive tract. Your kidneys also filter out excess phosphorus to maintain normal levels.
 - Your bones store calcium.

Renal Bone Disease

When someone develops CKD, several changes occur in mineral metabolism. First, the kidneys can no longer activate Vitamin D, and so less calcium is absorbed from the digestive tract and your blood level of calcium goes down.

In addition, because the kidneys do not filter as they should, phosphorus is not filtered out and the body retains higher than normal levels of phosphorus.

When these two things happen, the parathyroid glands start to secrete large amounts of the hormone PTH which pulls calcium out of the bones to help raise the blood calcium level back to normal.

When this process continues over several years, the result is weakened bones and too much phosphorus and calcium in your blood.

Too much calcium in your blood can result in calcium being deposited in your blood vessels and your heart. Weakened bones can cause fractures even without a fall.

Help for Renal Bone Disease

Prevention and treatment for renal bone disease is two-part. First is diet. Most patients on dialysis need to eat a low phosphorus diet. Your dietitian will help you with understanding what foods you can eat and what foods you should avoid. Some common foods high in phosphorus are beans, milk, and cheese. The second part is medication. There are 3 medications that may be used.

1. Phosphorus binders (Tums™, PhosLo™, Renvela™, or Fosrenol™ are examples).
2. Vitamin D (Calcijex™, Hectoral™, and Zemplar™ are examples)
3. Anti-PTH medication (Sensipar™)

It is important to take these medications as prescribed. An article regarding the importance of taking your phosphorus binders is included in this issue.

Protecting your bones is a team effort between you and your healthcare team. Working together will help you to maintain healthy bones!!

Taking Your Binders

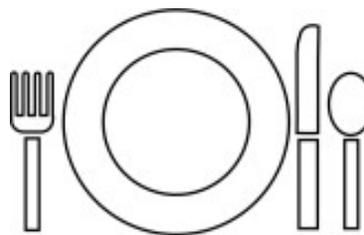
Sue Smith, MS, Registered Dietitian

Medications called phosphate binders are usually required for dialysis patients to achieve and maintain adequate phosphorus control.

Binders prevent excess phosphorus from being absorbed in the digestive tract. This makes it important to take the medications with meals and the occasional high phosphorus snack. Even with binders, a low phosphorus diet is important to prevent too much phosphorus from being absorbed from the food you eat.

Your health care team will recommend a phosphate binder after taking into account several factors. Calcium-based binders such as calcium carbonate or calcium acetate are possibilities as long as your serum calcium level does not become too high. Examples of these medications are Tums™, Os-Cal™, and PhosLo™.

If your doctor feels that your calcium intake needs to be limited, the choice might be a non-calcium binder such as Renvela™ or Fosrenol™. Your medical history also indicates which phosphate binder is the most suitable for you. Your preference for tablets, capsules, powders, or liquids might be another consideration.



Remember, it is important that phosphate binders be taken with meals and snacks to help keep phosphorus from getting too

high in your blood. This means having your binders with you for meals and snacks away from home. Storing the binders near or on the table where you eat your meals at home will help you remember to take them.

As is true for all of your medications, be sure to have your phosphate binders prescription refilled on time so that you never run out of them.

Keeping Bones Healthy: Two Patient's Perspectives

Christine

I am one of those patients who took my phosphorus binders almost all the time. I had heard all the stories about bone disease and how it impacts patients with renal disease. I also had Type I Diabetes, and so I had to consider what the 30+ years of that disease had done to my bones and body.

Don't get me wrong, I am sure there were occasions when I had a small snack and may have forgotten to take my binders. However, my mealtime routine was etched in stone; blood-sugar test, insulin and then any pills I needed, before eating any food.

As part of treatment following my kidney-pancreas transplant, I received large doses of Prednisone to protect both my kidney and pancreas from rejection. So not only was I dealing with renal disease and diabetes, but I also had massive amounts of cortisone, which also affects the bones.

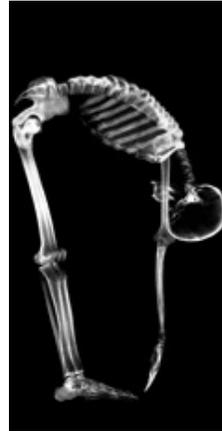
Fortunately because I was faithful with my medicines and exercised regularly, at the three-year anniversary of my transplant, a bone-density scan showed that my back was better than normal and my hips were normal for my age. The next year, we went on my dream trip to Paris for our 20th wedding anniversary and walked all over the city.

Although I have had additional problems with broken bones because of my compromised immune system and the steroids I continue to take to manage my transplanted organs, I was very blessed to heal remarkably quickly and completely.

Mitzi

Because I was diagnosed with Lupus 15 years ago, I have been on the medication Prednisone ever since. My

Rheumatologist suggested that I get a bone density test. The test revealed that I had severe bone loss. He showed me a model of a healthy bone, and then showed me a model of a bone with severe bone loss. I was told that my pelvic bone was the worst. The model of the bone with the severe bone loss looked like swiss cheese. My bones were very weak and susceptible to fractures.



I was prescribed a medication that I injected three times a week. After 3 months, another bone scan showed that my bone loss had stopped and was actually reversing. My bones were getting stronger and better. Although I eventually had to stop taking the medicine, there was no doubt it helped my bones to be stronger.

Now I use a nasal spray medication and vitamin D. These are working to keep my bones strong.

ImoGene's Corner

In my mind, Kidney Failure (or any failure for that matter) signifies a shortcoming in life or some other lack of achievement . . . you fail or failed at something. Well, to me that spelled BAD — run home and hide from shame — be embarrassed!

Even if you do not hide kidney disease from your family and friends — many people will know that you are undergoing life altering changes, because you are leaving the house at regular intervals or you must leave the room or home for unsaid reasons.

In this life, it is not what happens to us, it is how we work through or respond to what happens to us. Do your Treatments, Stand up, Walk Tall, Talk to Someone, and Hold your Head up HIGH — you are one of many.

You cannot fix what you do not first acknowledge. Confidentially tell someone how you feel — a family member, a friend, a peer mentor, a stranger, a church member, or God. Do not continue this journey alone. You do not need to travel as a party of one. Share the ride.

Five Diamond Patient Safety Program

To help promote patient safety, Renal Network 11 has implemented the 5-Diamond Patient Safety Program. The focus of this program is to help dialysis facilities implement patient safety principles for staff and patients.

The 5-Diamond Patient Safety Program consists of tools and resources necessary for improving patient safety. As the dialysis facility completes one module, Network 11 gives them a diamond. A maximum of 5 diamonds can be earned in one year. At that time, the facility is recognized as a 5-Diamond Patient Safety Facility.



The following facilities have achieved 5 diamonds as of September 30, 2011.

- Black Hills Dialysis – Eagle Butte
- Minneapolis Dialysis of DaVita
- Purity Dialysis – Brookfield
- Purity Dialysis – Germantown
- Purity Dialysis – Mukwonago
- Purity Dialysis – Oconomowoc
- Purity Dialysis – Waukesha
- Purity Dialysis – Waukesha South
- St. Catherine's Kidney Center
- Tri-State Dialysis – Platteville

This newsletter was developed under contract Number HHSM-500-2010-NW011C sponsored by Centers for Medicare & Medicaid Services, Department of Health and Human Services. The content of this publication does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government. The authors assume full responsibility for the accuracy and completeness of this newsletter.



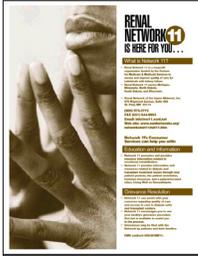
Renal Network 11
1360 Energy Park Drive
Suite 200
St. Paul, MN 55108

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Please help to evaluate Network 11 Resources

Your feedback is very important to Renal Network 11. Please indicate which of these resources you have seen, and if you have found them useful. See the back page for instructions on returning this form to Renal Network 11. Thank you!

Network 11 Poster



I have seen this resource in my dialysis unit or transplant center. Yes No

I found this resource helpful. Yes No

Dialysis Station Poster: Assessing Your Fistula



I have seen this resource in my dialysis unit. Yes No

I found this resource helpful. Yes No

Patient Rights and Responsibilities Poster



I have seen this resource in my dialysis unit or transplant center. Yes No

I found this resource helpful. Yes No

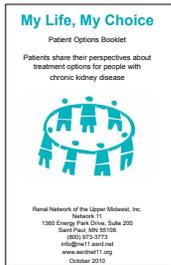
Fistula or Catheter Booklet



I have seen this resource in my dialysis unit. Yes No

I found this resource helpful. Yes No

Booklet on Different Treatment Options



I have seen this resource in my dialysis unit or transplant center. Yes No

I found this resource helpful. Yes No

Stop Sign Wallet Cards



I have seen this resource in my dialysis unit or transplant center. Yes No

I found this resource helpful. Yes No

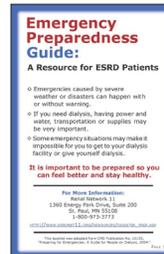
DVD on Exercise for Kidney Patients



I have seen this resource in my dialysis unit or transplant center. Yes No

I found this resource helpful. Yes No

Emergency Preparedness Booklet



I have seen this resource in my dialysis unit. Yes No

I found this resource helpful. Yes No

Is there another kind of resource that you would like to see?

What type of treatment do you receive? Hemodialysis Peritoneal Dialysis Transplant

Where do you receive the treatment? _____
(unit or center name)

Your feedback: Here are three ways that you can send us your completed form.

1. Fax to 651-644-9853.
2. Fold this page in half, seal the edges, and mail it to us.
3. Complete this form on our website at www.esrdnet11.org/consumer/feedback

Be Wise – Immunize!

Immunization is one of the most important things you can do to protect yourself from serious diseases such as pneumonia, hepatitis B, and influenza. The Centers for Disease Control and Prevention recommends that all chronic dialysis patients be immunized for these diseases. Talk to your dialysis staff about your immunization options.

**Renal Network 11
1360 Energy Park Drive
Suite 200
St. Paul, MN 55108**



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1360 Energy Park Drive
Suite 200
St. Paul, MN 55108**

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