

# KIDNEY CONNECTION

Winter 2007

## Bone Disorders and Chronic Kidney Disease



People with chronic kidney disease (CKD) often develop problems with their bones. These problems begin in the early stages of CKD and come from vitamin D deficiency and mineral imbalances. Simple blood tests can be done to check for these problems. Your doctor should begin doing these tests in the early stages of CKD. To keep your bones healthy, take steps now to treat bone disease. Without treatment, bones can become painful and break easily. The heart and blood vessels may also be affected.

### What is Chronic Kidney Disease?

CKD means your kidneys have been damaged by diabetes, high blood pressure or other conditions. Your kidneys are less able to do some important jobs that help you stay healthy. These are:

- Remove wastes and extra fluid from your blood
- Release hormones that help to control blood pressure, make strong bones and prevent anemia (a low blood count that makes you feel tired)
- Keep the balance of important chemicals in your blood, such as **sodium, potassium, calcium** and **phosphorus**

### Why do people with chronic kidney disease get bone problems?

Calcium and phosphorus are two important minerals for healthy bones.

- In CKD, calcium and phosphorus get out of balance
- Phosphorus can build up from the foods you eat. Your kidneys can't get rid of enough phosphorus to keep the balance. Over time, phosphorus levels in your blood get high.

(cont. on pg. 2)

## Diabetes and CKD: African-Americans are at Greater Risk

More than 20 million people have Chronic Kidney Disease (CKD) and another 20 million are at risk and don't even know it. Diabetes, high blood pressure, and family history (father, mother, brother, or sister) puts an individual at risk for developing CKD.

Diabetes is the leading cause of Chronic Kidney Disease (CKD). One-third of those with diabetes may eventually develop CKD. Diabetes is a serious problem for African-Americans, with 13 percent diagnosed with the disease. High blood pressure, the second leading cause of kidney disease, strikes one out of three African-Americans.

African-Americans are more likely to develop complications such as heart and blood vessel disease and CKD than whites. The problems associated with diabetes and high blood pressure are serious. Solutions are not easy, but are possible. We must begin by educating ourselves and our families about these diseases and how they affect our lives (*cont. on pg. 4*).

### Inside this Issue....

- Feature: Talk to Your Family About Kidney Disease pg. 5
- Gift of Life Gala 2008 pg. 5
- The NKFK Wants to Crash Your Holiday Party pg. 7

## Mark your Calendar! 2008 Events

### Program Events

#### **Support Group**

2nd Thursday every month  
Call for information

#### **KEEP Screening**

**January**  
Lexington  
Location TBA



### Special Events

#### **Volunteer Appreciation Ceremony**

February 13, 2007  
Location TBA

#### **Gift of Life Gala**

Louisville  
March 8, 2008

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Johanna Clapp at 502-585-5433 or  
jclapp@nkfk.org!

## Bone Disorders and CKD (cont. from pg. 1)

Normally, the kidneys change vitamin D into an “active” form that tells the kidneys, bones and intestines to balance calcium and phosphorus in your blood.

- In CKD, your kidneys can't change vitamin D to the active form your body needs
- Calcium and phosphorus get out of balance

Normally, four tiny glands in your neck (the parathyroid glands) make enough of a hormone (parathyroid hormone or PTH) to keep the balance:

- Over time in CKD, too little calcium, too much phosphorus and too little active vitamin D cause the parathyroid glands to work harder
- When the parathyroid glands work harder, they become bigger. This is a condition called secondary hyperparathyroidism or high PTH.

### How does high PTH affect my bones?

- High PTH causes calcium to be pulled out of your bones.
- Bones become weak and painful

## NKFK Chapter News

### Lexington

The next Chapter meeting will be January 25, 2008 at 11:30am at the Kentucky Clinic Room J005. Lunch is provided. Anyone interested in learning more about the NKFK programs and services is welcome to attend. For more information, please contact Lisa Allgood at 800-737-5433.

High PTH levels can cause:

- Itching
- Bone pain
- Weak bones that break easily
- Heart Problems
- Blocked blood vessels
- Anemia
- Nerve problems
- Difficulty fighting off germs

(cont. on pg. 3)

## Bone Disorders and CKD (cont. from pg. 2)

### How does high PTH affect my heart?

- When PTH causes calcium to be pulled out of your bones, it goes into your blood. Some of this calcium ends up in the heart and blood vessels, where it doesn't belong. Over time, blood vessels can become stiffer and narrower.
- High PTH increases your chance of having heart disease.

### How do I know if my calcium, phosphorus and PTH levels are in the right range?

To check your level of calcium, phosphorus and PTH, your doctor will do blood tests. If you have Stage 5 CKD, your calcium and phosphorus levels should be checked once a month and your PTH level should be checked every three months. Know your numbers for calcium, phosphorus, and PTH. Learn what should be done to keep them in the right range. The chart below tells you what your phosphorus, calcium and PTH levels should be for healthy bones.

### How can I keep my bones healthy if I have CKD?

Phosphorus is found in almost all foods-

	<b>CKD STAGE 5</b>
<b>PHOSPHORUS</b>	<b>2.5-5.5</b>
<b>CALCIUM</b>	<b>8.4-9.5</b>
<b>INTACT PTH</b>	<b>150-300</b>

some more than others. Phosphorus from the foods you eat can build up to high levels in your blood because your kidneys no longer remove enough phosphorus from your body. Following a low-phosphorus diet helps to keep your blood phosphorus in the right range. The dietician will help you plan your meals and snacks to include the right amount of phosphorus and other important nutrients. Following a diet low in phosphorus may not be easy. Ask your doctor and dietician for help.

You will also need to take medicines called phosphate binders to help keep phosphorus under control. These pills help to keep phosphorus from building up. They "bind" to phosphorus in the foods you eat so it doesn't get into your blood. Many phosphate binders contain calcium, aluminum or magnesium. Others do not. You should speak to your doctor about which type of binder is best for you. Your doctor may give you a prescription, or tell you to take a phosphate binder that's "over-the-counter."

To work best, your phosphate binders should be taken with food or within 10 to 15 minutes of eating. However, be sure to take them even if you are a little late. Remember, using phosphate binders does not take the place of your low-phosphorus diet.

Article from the National Kidney Foundation, [www.kidney.org](http://www.kidney.org).

### Words you need to Know

Sodium: A mineral found in large amounts in table salt, in many canned foods, processed meats like ham, bacon, sausage and cold cuts, and in salted snacks like chips and crackers.

Potassium: A mineral in your blood that helps your muscles and heart work properly. Too much or too little potassium can be bad for your heart. Potassium is found in large amounts in some fruits and vegetables.

Phosphorus: A mineral that is needed by the bones, nerves, and brain. Phosphorus can build to high levels in your blood when you have kidney disease.

Calcium: A mineral that is involved with nerve and muscle activity and that forms and strengthens bones. Calcium can be lost from your bones when you have kidney disease, causing bones to become weak and painful.

Active vitamin D: A hormone that is made by the kidneys to keep your body healthy. Low levels of active vitamin D contribute to bone disease in people with kidney disease. Active vitamin D can be given as a medicine.

Parathyroid hormone: A hormone that regulates calcium and phosphorus levels in your blood

Secondary hyperparathyroidism: A condition that happens when you have too much PTH in your blood as a result of kidney disease. This condition affects many organs and tissues, including your bones, heart and blood vessels. (also called "high PTH.")

## Diabetes and CKD (cont. from pg. 1)

We must also identify the steps to take to prevent these diseases and to treat them effectively when they do occur.

### What is Diabetes?

Diabetes occurs when your body is unable to make enough insulin or use normal amounts of insulin properly. Insulin is a hormone that controls the amount of sugar in your blood. Diabetes can cause damage to many parts of the body including the heart, kidneys, eyes, and brain. People with diabetes often develop serious complications including high blood pressure, heart disease, CKD, and blindness.

The two most common types of diabetes is Type 1 and Type 2. Type 1 usually begins in childhood. If you have this type of diabetes, your pancreas does not make enough insulin and you have to take insulin injections. The most common type of diabetes in African-Americans is Type 2 diabetes. This type occurs mainly in adults over 45, but is becoming more common in younger people. It is usually associated with being overweight and tends to run in families. In most of these cases, the pancreas makes enough insulin, but the body cannot use it properly.

If you are unsure if you have diabetes, watch out for the following symptoms:

- Being thirstier at night
- Needing to pass urine much more often
- Being hungrier than normal
- Feeling more tired
- Losing weight even if you are eating more than usual.

It is also possible to have diabetes and have few or no symptoms. Yet, even this mild form of diabetes can cause damage to many organs in the body. For this reason, it is important to visit your doctor or clinic regularly and have your blood sugar checked. You should also check your own blood sugar as often as your doctor recommends.

If you have diabetes, there are things you should do to manage the disease and prevent further complications. They are:

- See your doctor regularly
- Check your blood sugar often
- Follow a healthy diet
- Have your blood pressure checked often (if you have diabetes, your target blood pressure is less than 130/80).
- Take all medication exactly as prescribed
- Quit smoking

### Three Simple Tests that can Save Your Life

If you have diabetes, make sure to ask your doctor to check

your kidney health. These three simple tests listed below may just save your life:

- 1. Test for protein in the urine:** The first sign of kidney damage is the presence of albumin (a type of protein) in the urine. A sensitive urine test for a tiny amount of albumin (microalbuminuria) helps to detect kidney damage at an early stage for people with diabetes.
- 2. Calculate your GFR:** Your kidney function is checked by estimating your glomerular filtration rate (GFR) from the results of your blood creatinine test. When your kidneys are damaged, they cannot clean your blood properly, and waste products build up in your blood. Your body will retain more water and salt than it should, which can result in weight gain and ankle swelling.
- 3. Blood pressure measurement:** High blood pressure may damage blood vessels in the kidneys, heart, eyes, and brain so that these organs cannot function properly. High blood pressure can be treated effectively with medicine, diet and a healthy lifestyle.

The table below lists the early and late symptoms of kidney disease in people with diabetes. If you are experiencing any of these symptoms, see your doctor immediately.

You don't have to manage your diabetes alone. Contact your local health department and speak with the diabetes educator about how to manage and treat your diabetes. For more information about diabetes management classes and support groups, please contact your local health department or call the NKF at 1-800-737-5433.

Information from National Kidney Foundation, [www.kidney.org](http://www.kidney.org).

#### Early and Late Symptoms of Kidney Disease

##### Early Signs:

- Albumin in the urine (also indicates an increased risk for heart disease)
- Going to the bathroom more often at night
- High blood pressure

##### Late Signs:

- Ankle and leg swelling, leg cramps
- High levels of blood urea nitrogen (BUN) and a decrease in your glomerular filtration rate (GFR).
- Less need for insulin or anti-diabetic pills
- Weakness, paleness, and anemia
- Itching
- Morning sickness, nausea, and vomiting.

## Gift of Life Gala 2008

The 2008 Gift of Life Gala will be held on March 8, 2008 at the Hyatt Regency in Louisville. At the Gala we will be celebrating the 40<sup>th</sup> anniversary of the founding of the National Kidney Foundation of Kentucky. Our honorees will be pioneers in the field of kidney disease treatment including Dr. Suzanne Ildstad, for her research at the University of Louisville in organ transplantation. Our Distinguished Volunteer Award will be presented to sisters Terra Jackson and Jenny Wrightington for their many hours of help and fundraising efforts throughout the years

Please join us for this special anniversary celebration and enjoy an evening of dining, silent/live auction, and special entertainment by “Eight Days a Week”, a Beatles tribute band.

A big thanks to Nephrology Associates of Kentuckiana for being our presenting sponsor.

Sponsorship and ticket information is available on the web site or by contacting [jclapp@nkfk.org](mailto:jclapp@nkfk.org).



*Mr. & Mrs. Lee Singleton at the 2007 Gift of Life Gala*

## Talk to Your Family about Kidney Disease



Family gatherings and reunions are a perfect way to enjoy family and celebrate the lives of your loved ones. It can also be a time to talk about diabetes and high blood pressure and the importance of getting tested for kidney disease. Talking to your loved ones about kidney disease may be difficult but it may also encourage your family to seize control of their health and lead a healthier life.

At your next family reunion, spend about 15 minutes sharing information you have learned about kidney disease and the importance of getting tested. The steps below can help you guide your conversation with your family.

- Introduce why we should be more aware of kidney disease and its causes. Kidney disease affects 20 million Americans and African-Americans are at greater risk of developing the disease. Developing kidney failure means that a person will have to have treatment which requires either dialysis or a kidney transplant.
- Talk about the risk factors associated with kidney disease. Diabetes and high blood pressure are the leading causes of kidney damage. Let your family know that not having these diseases doesn't mean they won't develop kidney disease. A family history (mother, father, brother, or sister) of diabetes, high blood pressure, and kidney disease increases chances of having kidney disease.

Most importantly, encourage your family to get tested. Unfortunately, many people don't know they have kidney disease until they are near kidney failure. Stress the importance of early detection for delaying or prevent kidney disease. Encourage your family to get blood and urine tests that will detect diabetes and kidney damage. The good news is that diabetes and kidney disease can be controlled by medications, healthy eating, regular exercise, and losing weight. Let your family know that seeing a doctor is the first step to preventing kidney disease.

If you would like to receive more information on how to talk with your family about kidney disease and its causes, please visit the National Kidney Disease Education Program (NKDEP) website at [www.nkdep.nih.gov](http://www.nkdep.nih.gov) or call 1-866-4-KIDNEY.



## Volunteer Spotlight: Janet Connell

Janet Connell has served as the President of the NKFK Board of Directors for six years. Her leadership and dedication has had a tremendous impact on the organizations outreach and growth. We appreciate Janet's unwavering leadership and commitment.

**Occupation:** Administrator, Nephrology Associates of Kentuckiana

### What is the importance of the NKFK to you and the patients you serve?

"The most important role of the NKFK is the dissemination of information about kidney disease. Most people have no information about kidney disease, its root causes and the life long consequences. The NKFK has an important role as a conduit for information. Through the KEEP screenings, the NKFK provides an invaluable service to the public in the areas where we are invited to offer the screenings. I would not be honest if I did not also mention the Patient Services Fund that we have available to assist patients with ESRD. I am acutely aware of the financial burdens carried by many patients suffering from a chronic illness like kidney disease. While we are not able to provide unlimited monies for this fund, we do fund it to the maximum we are able and we make sure that the funds are distributed to as many patients as possible by limiting the maximum amount any one patient can be granted in a year. "

### What pleases you most about the NKFK?

"I was a member of the Board when the organization was at its lowest and to see where we are now is truly remarkable. I am pleased that we are now truly a statewide organization with chapters in different areas of the state and with outreach to many other areas through the offering of the KEEP screenings. I am pleased and very proud of the number of KEEP screenings we offered in 2007 and the number we already have scheduled for 2008. I am pleased and very proud that we have the most skilled and talented Executive Director who has a passion for the NKFK and its mission and who serves with extraordinary dedication and seemingly boundless energy."

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## Going for the Gold:

### Team Kentucky Athlete Zachary Young

Written by: Debbie Ciresi, Zachary's mom



*Zachary proudly displaying his silver medal won in the sprinting competition.*

Zachary Young was born on August 27, 2000 and was diagnosed at eight weeks of age with an unknown disease of the liver. After numerous hospital tests and failed attempts to improve Zachary's liver functions with medications, we were referred to the closest pediatric transplant center (in Cincinnati, Ohio) for an evaluation. Unfortunately, in Zachary's case, the disease progressed very rapidly, and by five months of age, he was experiencing symptoms of end-stage liver failure.

Knowing we had to act quickly, we aggressively pursued an option we learned about from a recent transplant mother – living related donation – and I (Zachary's mom) was evaluated and found to be a suitable liver donor. Thankfully, we were informed by the same transplant mother about the excellent care and treatment provided to her family by the Center for Liver Disease and Transplantation at Columbia Presbyterian Medical Center in New York City.

We immediately called the hospital and were told to get Zachary there as soon as possible.

This initial telephone call was on April 12, 2001, and we arrived in their emergency room on April 14<sup>th</sup> – thanks to a wrong phone number and the overwhelming kindness of total strangers. You see, somehow, in our search for an airline that would provide discounted fares for medical emergencies, we ended up on the phone with a liver transplant recipient of 17 years (an "angel" who wishes to remain anonymous). She and her husband purchased the last-minute airline tickets we could not afford, and also paid for a hotel room so that a few of our family members could be in NY during Zach's transplant surgery.

Zachary's transplant was performed only a few short days later, on April 19, 2001, with me as his donor. Zach immediately took to the new organ and was hospitalized for only 12 days following the surgery! When he woke up for the first time on the morning of April 20<sup>th</sup>, Zachary's eyes were white for the first time, with a new awareness and a sparkle that had never been there before. This is one of the reasons we refer to April 19<sup>th</sup> as Zachary's "Life Day." He is now an incredibly energetic second grader who loves school and thinks he knows everything already! (*cont. on next page*)



## The NKFK wants to Crash Your Holiday Party



The **National Kidney Foundation of Kentucky** wants to *crash* your holiday party.

During the holiday season family and friends gather to celebrate and focus on blessings and holiday family traditions, while thousands of people right here in our community are battling kidney disease and waiting for life saving organs for transplantation.

There is a very good chance that you know someone who has or will develop kidney disease. It could even be you. That's because 20 million Americans-one in nine adults-have chronic kidney disease. Another 20 million more are at risk and don't even know it. There are over 97,000 Americans waiting for organ transplants.

We are crashing Chuck and Sue Fischesser's party. Chuck is a member of the National Kidney Foundation of Kentucky (NKFK) Board of Directors and he and Sue are the 2008 Gift of Life Gala co-chairs. Chuck and Sue have been personally affected by kidney disease and are very aware of how family traditions are so important in the face of illness. They are generous supporters of the NKFK and want to share with family and friends the importance of giving. Chuck says "I know the importance of gift giving as I have a family member who received a kidney transplant –**the gift of life.**"

Chuck and Sue have invited us to provide them with a holiday gift bag to collect gifts from their guests and we have one with your name on it.

**Your generous gift can help improve the quality of life for those living with chronic kidney disease and waiting for life saving organs. Your gift will help continue our statewide programs and services. Please help those with chronic kidney disease and their families enjoy their family traditions.**

The work that we do is reason to celebrate and what better way than for you to help us share our good work and ask for your family and friends to give a gift to help us. At your holiday party, please ask those dearest to you to consider a gift to the National Kidney Foundation of Kentucky. What better way to share the spirit of giving and help the many people in your community who are battling kidney disease.

Even if a holiday party is not in your plans this season, please consider a holiday gift today. Together we make lives better.

With gratitude,

*Lisa Allgood*  
Executive Director

P.S. Please enjoy your holiday season. We hope you will make a holiday donation to the National Kidney Foundation of Kentucky a family tradition. Honor someone with a gift made in their name-the perfect gift for someone who has everything.

### Zachary Young (cont. from pg. 6)

Zachary participated in his first US Transplant Games in 2006 when he was just five years old. He competed against other children his age in the bowling, long jump, 25 yard sprint, and softball throw sports. Zachary proudly won a silver medal in the sprinting competition and two bronze medals in the bowling and long jump competition. As Zachary says, "It's a lot of fun and hard work. You should be proud of yourself if you win a medal, but it's more important just being alive and healthy enough to compete." He is geared up to compete again in Pittsburgh, June 2008!

To learn more about the US Transplant Games and joining Team Kentucky, please contact Lisa Allgood, Team Manager, at 1-800-737-5433 or [lallgood@nkfk.org](mailto:lallgood@nkfk.org).

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