“Understanding Depression”
Audio Conference Panelists

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What is Depression?

Research shows that, in any given year, almost 10 percent of the U.S. population is depressed. That's 19 million adults, with and without transplants. And in people with chronic illness, the incidence of depression is much higher. Some research suggests that up to 25 percent of people with illnesses become depressed at some point in their lives. So, if you are a transplant recipient and you feel depressed, you are definitely not alone.

But how do you tell when you’re depressed and not just discouraged because of declining health or other bad life events? Clearly, everybody feels “down” sometimes, especially when bad things happen. Everyone can feel discouraged after a particularly hard day. This is a totally normal and an expected way to feel.

But depression is different. It’s not just a bad mood, which is something everybody feels. Being depressed means that people feel at least five symptoms of depression for two weeks or longer. A bad mood should only last a couple of days. Depression is also more intense than a bad mood, and it interferes with regular life. It can affect sleep, appetite, and even how the body feels.
Why Does Depression Happen?

Depression is a medical condition, like high blood pressure and diabetes. It occurs because of a chemical imbalance in the brain. Our brains rely on two chemicals, serotonin and norepinephrine, to regulate our mood. When people develop a deficiency in these chemicals, depression can occur. This process can be triggered by difficult events, such as transplantation or other chronic illness.

It can be hard to admit to feeling depressed, and it’s not something everybody is comfortable talking about. But people generally don’t hesitate to talk to their doctors about high blood pressure and make sure that it is treated. Why can’t we think of depression in those terms?

Symptoms of Depression

Here are nine symptoms of depression:

- Feeling depressed for most of the day, almost every day.
- Lack of enjoyment of activities you once enjoyed, such as going to work or visiting friends.
- Weight changes (gaining or losing).
- Sleep problems (too much or too little).
- Feeling restless.
- Lacking energy, feeling easily fatigued.
- Feeling worthless or guilty.
- Trouble concentrating.
- Frequent thoughts of suicide.

Remember that people have to have at least five of these nine symptoms for at least two weeks before doctors will diagnose depression. This is to make sure that people who have bad days here and there are not misdiagnosed.

Depression After Transplant

Unfortunately, depression after transplant is extremely common. People who were prone to depression before their transplant are equally at risk afterwards, if not more so because of the added
stress from the transplant. Studies also show that up to one-quarter of people who are depressed after a physical illness had depression before they became ill. So in many cases, a transplant recipient’s depression may have nothing to do with his or her illness.

However, in some cases, transplant can actually trigger depression. As we mentioned earlier, people are often more likely to develop depression when life gets harder, like after a transplant. But on top of that, there are some transplant medicines that can cause depression as a side effect. For instance, steroids such as prednisone, which many recipients take to avoid rejection of their new organ, can cause depression.

Prednisone may cause a range of other side effects, such as violent mood swings. Some people may get a feeling of euphoria from prednisone. A small number of people also have psychotic episodes from the drug. So it’s a drug that can save a transplant recipient’s life, but it’s not always an easy process.

The stress of having a transplant can trigger depression. Having a transplant is a life-altering experience. The range of emotions people feel as a result of the procedure can definitely trigger depression in those who are susceptible to it.

It can be incredibly difficult for people to accept that one of the organs they were born with no longer works. For many, organ failure can feel like a profound loss. Some really grieve over it, which is totally understandable. Unfortunately, this grief can also lead to depression.

Having a transplant can create another loss, by changing recipients’ lives in an irreversible way. They may grieve that they can no longer lead the same life as before, now having to rely on doctors and medications to stay well. That can be hard to accept.

Some recipients may also find it hard to accept that they are more dependent on their families. They may feel like their illness disrupts their families’ lives, and they are dependent on them emotionally and sometimes financially. For recipients who are used to being the sole providers for their families, that can be really tough.

Financially, many transplant recipients also worry about their futures and how to afford the medicines they’ll need for the rest of their lives. People with kidney transplants often worry about their health insurance, knowing that they lose Medicare after three years.
Many transplant recipients worry about their futures in general. This may be the first time they have faced a serious health risk, and that can be very scary. And when they feel bad physically, that makes all the fear, frustration and uncertainty even harder to bear.

Some people say they feel pressure to be happy all the time after their transplant. There aren’t enough donor organs to go around, and people say they feel they need to be grateful all the time for theirs. But it’s not possible to feel happy all the time. Recipients are, indeed, blessed to receive a new organ. But that doesn’t mean they have no right to feel sad ever again, or to get discouraged about the burden this organ places on them.

Having a transplant does not mean a recipient is cured, which the average person may not understand. For that reason, friends, family and co-workers may think recipients are now good-as-new, and all their health problems are solved. It will take time for people to understand that recipients have a new set of challenges.

Some recipients also say that they feel guilty for taking an organ from another person. If it’s a kidney, maybe they got this wonderful gift from a loved one. They can never thank their donors enough, or repay them enough. Some recipients feel sad that someone had to die to give them their new organ. They don’t like the fact that they are benefiting from someone else’s tragedy.

All of these feelings—which are totally natural reactions to transplantation—also come on top of anything else recipients are dealing with at the time, another reason why depression is so common after transplant. Family, career, finances—these make life challenging for everyone, transplant recipient or not.

However, a recent study sheds light on what it means to be happy with a chronic illness. The researchers asked people on dialysis how happy they were, then asked the same question of people not on dialysis. Both groups of people gave the same ratings on a happiness scale.

This suggests that people both on and off dialysis are equally happy. However, the researchers also asked dialysis patients to say how happy they thought they would be if they had never developed kidney disease. On average, they all said they thought they would feel happier.
But from the previous results, the investigators knew that dialysis patients were already as happy, on average, as people who weren’t on dialysis. So why would they be happier if their kidney function improved?

To the investigators, this suggested that, even though chronic illness is very difficult, it doesn’t necessarily affect our happiness. Recipients are likely just as happy now and just as fulfilled as they were before their transplant. Because they are sick, they may think they are less happy, but this study suggests that may not be true at all.

The study was never meant to imply that people with chronic illness aren’t really depressed. It simply makes the point that being ill is very difficult, but we can adapt to it. We are capable of adjusting and still feeling happy, even when we’re sick.

**Physical Influences on Depression**

Our physical condition, like pregnancy and menopause, can influence depression. Many people may have heard of postpartum depression, the form of depression that can strike women after they’ve just given birth. It can be very intense. This is something to consider for transplant recipients who are pregnant or who recently were. If they are feeling depressed, it may be postpartum depression.

There are many factors in pregnancy that could increase women’s risk of depression. On top of dealing with their transplant, pregnant or post-natal women have intense changes in hormones and weight, and undergo stress from suddenly being totally responsible for another human. New babies also need constant feeding, which disrupts parents’ sleep. With all of this going on, it’s not surprising that new moms are particularly at risk for depression.

Menopause is also a time when recipients may be more vulnerable to depression, for similar reasons. Women’s hormones are totally “out of whack”; their bodies are changing radically; and all of this compounded with a transplant can make them vulnerable to depression.

Studies show that **teenagers are also very much at risk for depression**, perhaps because, like in pregnancy and menopause, their bodies are undergoing intense hormonal shifts. The teenage years are also a time of intense life changes, as people transition from children to adults.
People start to look at teenagers differently; they have more responsibilities; and they need to start making important decisions about school and careers.

Dealing with Depression

Treating depression is simply a matter of life or death. There are a lot of misconceptions out there about depression, and one of the biggest ones is that it’s possible to “snap out of it”—that a simple shift in attitude or circumstance will make depression go away.

That’s simply not true. Depression is a medical condition, like diabetes. No one can “snap out of” diabetes, and it’s the same with depression. People need professional help, in the form of therapy or medication, to treat depression. Without treatment, they may even get worse.

It’s also self-defeating to believe that depression is something people can overcome by willpower, because it implies that if they can’t snap out of it, they’re weak. It implies that if they were stronger, they wouldn’t be depressed. Being depressed is definitely not a sign of weakness. But admitting you have a problem and taking action to help yourself is definitely a sign of strength.

Treatment for depression can save a recipient’s physical health as well. Research shows that people who are depressed are less likely to take their medications and stick with rehabilitation programs. Plus, they are more likely to develop additional illnesses, like heart problems. For people with chronic illness—like transplant recipients—those who are depressed tend to fare worse over time. But when people are diagnosed and treated for depression, they recover better from physical illnesses.

The reason why depression appears to affect a person’s physical health remains unclear. Depression causes stress, which can raise levels of free radicals and fatty acids, the harmful molecules that can damage blood vessels. Mental stress can also cause changes that may block blood flow.

Depression can affect recipients’ families, as well. It hurts loved ones to see them feel this way, and research shows that if people are depressed, their spouses are more likely to become depressed, too.
The two principle types of treatment for depression are therapy and medication. Each one has pros and cons, and it’s up to recipients to decide which one they prefer, or if they want to try both in combination.

The most common type of therapy is called cognitive behavior therapy, or CBT. As part of the cognitive portion of the treatment, a therapist helps people correct any negative thought patterns that may be causing a depression. For instance, if people are constantly feeling hopeless, or that there’s no point in living, their therapist works with them to try to change those feelings.

The other part of cognitive behavior therapy is the behavioral part. This focuses on how people behave in certain situations, if those behaviors aggravate a depression. A therapist may help people avoid behaviors that are really self-defeating, such as sleeping all day, or avoiding things they used to enjoy.

There are also other types of therapy, such as interpersonal and behavior therapy. And if people don’t want to speak to a professional one-on-one, they can always sign up for group sessions.

Typically, one-on-one sessions last for 45 to 50 minutes, during which people talk about their feelings—whatever is on their mind. A therapist will also ask them questions, to make sure what they are talking about is helpful for their depression. If recipients attend a group session, they share their experience with others and listen to others talk about themselves. Sometimes hearing other people’s stories helps alleviate feelings of isolation or loneliness that can come from living with a chronic illness.

If you believe you are depressed, the first thing you should do is talk to your doctor. He or she should know reputable mental health professionals near you. It’s best to go with a therapist who has experience treating people with chronic illness.

Another great resource is a transplant social worker, or anyone on a transplant team who can help find a therapist with the right training for an individual transplant recipient’s situation.

However, insurance plans may not cover every therapist. People who want to make sure they’re covered should contact their insurer for a list.
of covered therapists in their area. Then they need to call or visit some of them and choose someone they are comfortable with.

In addition to therapy, medication can do a lot to ease depression in transplant recipients. We know the last thing many transplant recipients want to do is take another pill. But a lot of research shows that certain drugs can help people with illnesses, without unbearable side effects.

There are two main types of antidepressants: tricyclic antidepressants, or TCAs, and selective serotonin reuptake inhibitors, or SSRIs. These medicines work by correcting the chemical imbalance in the brain that causes depression.

Most often, doctors will start people on an SSRI. Each drug works a little differently in different people, so people may have to adjust their dose or switch drugs if it doesn’t feel right the first time. This is really common and it doesn’t mean that the drugs don’t work.

Older adults tend to react differently to antidepressants than younger people. For this reason, doctors may at first try different drugs with elderly patients than they would with younger people.

There are potential side effects that can come from antidepressants, but they can all be managed. Let your doctor know about any side effects.

A word of caution: A lot of people use herbal medicines to treat a variety of conditions. One very popular herbal medicine is St. John’s Wort, which people use to treat depression. One reason for its appeal is that people can buy it at a health food store, without a prescription. However, a crucial thing to remember about St. John’s Wort is that it interferes with other drugs transplant recipients are taking. One of the drugs it interferes with is cyclosporin, which people take to prevent transplant rejection. Transplant recipients have lost their organs after taking St. John’s Wort.

When it comes to depression, some of the best medicine is also the most accessible: communication. People who feel depressed should talk about their feelings, if they can. That’s why therapy is so successful.

So many feelings that can cause depression—feeling alone or scared about the future—can be alleviated by talking to others. It makes intuitive sense that keeping things bottled up inside can make people feel a lot worse.
Think of life’s trials and tribulations like a shaken soda bottle with a loose top. A transplant is worth at least 10 shakes, then add more shakes to represent whatever other challenges recipients are facing. If they don’t let out that accumulated air slowly, through talking about their feelings with others, that bottle’s going to explode.

For some recipients, a transplant support group provides the emotional support they need. Sharing with fellow recipients who know what they are experiencing can be a great comfort. Some groups are run by social workers and some are run by peers. Both allow recipients to help each other, and to get help from the community. People can form some really close friendships and build a network that will get them through tough times. Transplant social workers can help recipients find a group.

If people are at all hesitant to visit a therapist or support group, they should consider at least talking to anyone they feel comfortable with. This can be a family member, friend, health professional, or someone at their place of worship.

They can also consider some creative ways to express themselves. These can be very private, so they work for people who don’t feel comfortable talking to others. This can include writing about feelings in a journal, in poetry, or even in fiction. If people are writing a short story about fictional characters, they still write out what’s inside of them, and that keeps it from bottling up.

People who don’t like writing can try painting, pottery, drawing and other forms of art. Some say that art and creative activities allow people to express themselves, without considering what other people will think. If we write for ourselves, we don’t think about how other people will react to what we write. We don’t have to worry about seeming ungrateful for our transplant, or complaining too much, or thinking negative thoughts.

In fact, writing and art are both types of therapy, and there are professionals who are trained to use art and writing to help people deal with depression.

It may be best to just let creativity flow without second thoughts—perhaps by writing without using punctuation, or painting without lifting the brush off the page. This helps people really get into a flow, and let out things that are very deep.
No one needs to write or paint for hours a day to overcome depression. But a few minutes per day or an hour or two per week, at least, will help people express their feelings. And that will help them deal with depression. Depression is something people fight against every day, which takes a lot of energy. It may not be too much to ask to use a few minutes per week for these activities, if it results in lots of other minutes of feeling less depressed.

Artistic expression along with professional help can be a good combination.

Paying for Treatment

Many private insurance plans provide drug coverage, and pay for at least some of the bills. Transplant recipients should contact their insurance provider to find out whether some or all of their therapy or antidepressant medicines are covered.

People on Medicare are covered for a lifetime maximum of 190 days at an inpatient mental health facility. For outpatient care, Medicare pays for half of the number of sessions they think people need. Unfortunately, Medicare does not cover antidepressants.

Medicaid, the government program that helps people with low income, will pay for a limited amount of inpatient and outpatient care. The program will only pay for Medicaid-approved drugs.

Some people may also qualify for assistance from drug companies that sell antidepressants. In some instances, they will send the drugs for free. Recipients should talk to their transplant social worker to see if they are eligible.

People with concerns about medication and treatment costs can obtain the transcript from the NKF discussion on Medicare, which discusses state and federal programs that help transplant recipients pay for health care, and they can refer to the previous chapter in this booklet.
Spotlight: David’s Story

I am a transplant recipient and I have dealt with depression. It has been a real challenge, and it’s something I continue to deal with every day.

However, I’ve gotten through some really tough times, and I hope that sharing my story will help some of you get through your own. Life is full of crummy stuff, on top of everything else you deal with being a transplant recipient. Having a transplant can make it all that much harder to cope with other challenges in your life, putting you at risk for depression.

I’d like to say that having a transplant positions you precariously on a cliff, looking over the edge. If nothing else goes wrong in your life, you can turn around and walk back to safety. But if something does go wrong, it’s very easy to fall off. Whether or not you do depends on how you respond to what happens. I almost fell off my cliff a few years ago, when I got very close to taking my own life.

In the end, I didn’t. I landed on a ledge and am working hard to climb back up.

For me, depression was much harder than having my transplant. The transplant was a procedure and it ended. And, as long as I take my medication and try to stay healthy, it’s not an issue. But depression is something I fight every day. It’s a constant.

Here is my story.

I received a kidney transplant in 1987 and I’ve had very minor complications from it. However, in the 17-plus years since, I’ve taken 10 milligrams of Prednisone daily, which I now understand can affect your mood.

Another contributing factor was that, before my kidneys failed, I was the sole wage earner for my family. My father had raised me to believe that was what men did. But when I got sick, my wife had to go back to school and start working to pay our bills.
It was very difficult for me, because I had been raised to believe my family should depend on me, not the other way around. Then, a few years after my transplant, a tragic thing happened. My daughter was in a car accident and died.

Unfortunately, my wife and I responded very differently. She embraced God and was very expressive about how upset she was. I, on the other hand, kept my feelings more bottled inside. Sort of like Mary Beth’s soda bottle (page 32)—I was just being shaken over and over and not letting my feelings out by talking about them with other people.

And, of course, there was more. A few years ago, I learned that I had contracted hepatitis C during my transplant, either from the organ or donated blood.

So it was one thing after another. One night, I came unglued and tore up my house. I brought a rifle to the place on the road where my daughter had died with the intention of hurting myself. It was a beautiful spot, actually, and I sat there half the night.

I came very close to taking my own life. But I mustered up the strength to go home. Getting so close to suicide told me I needed professional help, so I made an appointment with a psychiatrist.

Now, I still see him, many years later. I also take antidepressant medication. It’s hard to swallow yet another pill, but I’m sticking with it.

Unfortunately, tragedy happens in everyone’s life, and having a transplant made it that much harder for me to deal with mine. The added burden of feeling different, the constant healthcare visits, and taking a handful of pills every day made it more difficult for me to handle my daughter’s death.

Now, to stay positive, I still see my psychiatrist. I don’t agree with everything he says, but I believe that he helps me. It’s hard to keep up with yet another doctor, but feeling positive is very important.
I also try to express my feelings more now, often through writing, which I really enjoy. Even if I don’t show anyone what I write, it keeps me from bottling up everything, which I now know isn’t good.

I’ve also looked into my past, at the circumstances that shaped how I look at things. It’s a very difficult thing to do, to face some of the unfortunate things that happened to you before, perhaps as a child. Maybe you were hurt or not well taken care of. That’s hard to face. But ultimately it’s very freeing.

It also helps me to distance myself from my transplant a little bit. I like feeling that I’m just like everyone else. I don’t want to be seen as “sick” or that I have special needs because of my transplant. I referee high school soccer; I hike; and I ride motorcycles. I still have to be careful, but it’s worth the risk. All of that stuff makes me feel like I’m alive.

Spotlight: Molly’s Story

I received my new heart in October 1995 under somewhat unique circumstances. I went into the hospital planning on getting open-heart surgery. Unfortunately, it didn’t go well and I was given two weeks to live. I received a transplant within days. So the last time I was conscious, I went into open-heart surgery, expecting to keep my heart. When I really came to, I had a new heart.

During the days of waiting, I had horrible hallucinations. I thought I had run over two children with my car and that my cousin was dead. I had started seeing a psychologist before my transplant, just to prepare for the open-heart surgery. I continued to see her after my transplant and she diagnosed me with post-traumatic stress disorder, or PTSD.

I think the PTSD came from the trauma of suddenly having a transplant and the emergency circumstances. I became overwhelmed by the hugeness of it all and I also felt very claustrophobic. My life would no longer be the way it was before because of the changes that come after a transplant. This made everything feel very final. My heart was gone and there was no going back.

All of a sudden, my future was uncertain. I worried about rejection, infections and how long my heart would last. It was really terrifying.
I also believe my antirejection medications might have also influenced my feelings, even my hallucinations. I started taking prednisone and I know that affected me, too.

I also felt some pressure, knowing that I was carrying someone else's organ inside of me. I knew the circumstances of my donor, who was a 15-year old boy, because my mother's cousin worked with his father.

When I received his heart, I felt pressure to try to live this boy's life for him. I wanted to do something really meaningful and impressive to make something great come out of his death and have his gift be worthwhile. But that was a very tall order, impossible to fill. The first year after my transplant, I spent a lot of time trying to figure out how I could win a Nobel Peace Prize. I also developed some classic signs of depression: I was over-sleeping. I no longer felt like being social, which was very unlike me. I also felt really hopeless.

To deal with these feelings, I kept seeing my psychologist and she really helped. She specializes in working with people who have chronic illnesses, and she made me realize I was having a totally normal reaction to my situation. That was a relief, of sorts.

Soon after my transplant, I also starting taking antidepressants and I still take them to this day.

I decided to treat my mental health like my physical health. My antidepressants are just as important as my antirejection medicines and I take them every day.

It was hard to start taking them, at first. Like other transplant recipients, I felt like I should be happy all the time, since I was lucky enough to receive a transplant.

I actually stopped my antidepressants once and I felt so sad and helpless afterwards that I had to start them again. That showed me how important they are.

As a young person (I'm only 31.), I'm in a strange position. I feel like it's hard to find a community that really understands where I'm coming from. I'm a lot younger than most transplant recipients. I love my friends, who are my age, but they are all buying houses, getting married and having kids. Having a
transplant affects how I think about these life choices because I worry I won’t be well enough to take on responsibilities. I want to get married and have children, but what if I die early? I don’t want to leave my family.

Then, a few years ago, I took a writing course called “Healing Through Writing, Writing Through Healing” at an independent writing center in my area. Many other students were my age and had their own health issues. One had received a lung transplant and another had Crohn’s disease.

The class was wonderful. Writing about my experiences was really cathartic and hearing other women share similar feelings and worries made me feel so understood and validated.

Now that the class is over, six of us still get together once a month and continue to write and support each other.

And—don’t get me wrong—I’ve gotten a lot of help from my friends and the transplant community, too. I attended a transplant recipient support group for two years after my operation, and that was great. I also have a great sense of adventure, which my friends share. When I turned 30, two of my friends and I went to South Africa. They understand that I want to live my life to its fullest now and not wait until I retire.

One thing I learned is that you may have to fight for your own mental health. Right after my transplant, my doctor couldn’t handle it if I cried. All I needed were some words of encouragement, someone who said they understood my grief and being suddenly uncertain about my future. He once joked that I should not go shoot myself.

So I switched programs, and I now go to a different hospital with a different doctor, who is much more respectful. I think we all need to advocate for our own health—mental and physical—and our own rights as transplant recipients. Lastly, for me it was vital to give myself permission to live my life differently than my peers and to give myself permission to grieve the losses that come with transplantation.
Summary

We at the NKF want to express our profound thanks to Molly and David, for being so open about their experiences. We know it’s not easy to talk about depression, but it really is incredibly common and when people can be open about it, it helps other people to be open about their own experiences, too.

To sum up, depression is not “just in your head.” It is a medical illness like diabetes or hypertension. And, like other illnesses, people can’t just “snap out of it.” If it’s not treated, depression can have serious consequences—it can affect people’s future and the outcome of their transplant.

Being diagnosed with depression doesn’t mean people are “crazy.” Not at all. It means they have a physical condition that makes them vulnerable to depression. This condition can be corrected with therapy or medicine. There are a lot of treatment options, and it make take time to find the one that’s right for each person, but it’s out there.

Being depressed is certainly not a sign of weakness. But admitting you have a problem and taking action to help yourself is certainly a sign of strength.

We at the NKF want to encourage everyone to take advantage of the resources available to them to help them deal with depression. Transplant recipients should contact their transplant social workers if they have any additional questions that we didn’t answer. They can provide very personalized help and advice. Use them.

There are also many resources available from the National Kidney Foundation, including the NKF transAction Council, for more information and support about depression. Visit us at www.transplantrecipients.org to stay up to date and to get answers to any questions we didn’t address. We will also use the Web site to keep people posted on any new information we get about depression.

If you have anything to share about depression, send us an e-mail at transactioncouncil@kidney.org. You can also call us at 800-622-9010.

If you would like some more written materials about depression, the National Kidney Foundation has a wonderful book called From Illness to Wellness: Life After Transplant, which was written by and for transplant
recipients. It addresses the emotions and changes recipients go through. Call us at 800-622-9010 to request a copy.

You can call that number to start receiving a copy of our free newsletter called *Transplant Chronicles*, or request a subscription on our Web site [www.kidney.org/recips/transaction/chronicles.cfm](http://www.kidney.org/recips/transaction/chronicles.cfm)

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**Learn more about Medicare Prescription Drug Coverage at** [www.kidneydrugcoverage.org](http://www.kidneydrugcoverage.org)

This Web site is an undertaking spearheaded by NKF in partnership with many kidney community organizations. Find fact sheets at [www.kidneydrugcoverage.org/patients.htm](http://www.kidneydrugcoverage.org/patients.htm) on topics such as:

- Choosing a Medicare Prescription Drug Plan
- Obtaining Help for People with Low Income
- What you Should Know about Medicare’s New Drug Coverage

Visit NKF’s teleconference archive to listen to a series of Web casts on the prescription drug coverage at: [http://www.kidneydrugcoverage.org/proTeleconferencePast.htm](http://www.kidneydrugcoverage.org/proTeleconferencePast.htm)

**Contact the NKF and request a copy of the newly published book**

“*Taking Control: Money Matters for People with Kidney Disease*”

to help answer questions about financing transplantation and kidney disease.

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**Visit NKF’s message boards:** [www.transplantrecipients.org](http://www.transplantrecipients.org)

to share with other recipients.