



A PROGRAM OF  
**RSN**  
Renal Support Network



The bi-annual update helping educate and motivate people living with chronic kidney disease.

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### Legislative Update



## Having a Voice in Healthcare

by Kathe LeBeau

Today, whenever you read a newspaper, watch the news, or listen to talk radio you are sure to see or hear a story on healthcare reform. With close to 50 million people living in America without health insurance, healthcare reform was a platform of President Obama's campaign and it is evident that change is in the air.

It can be difficult to understand

all the complexities involved in these discussions in the houses of Congress, and how changes will impact people who have kidney disease. WeKAN (a patient advocacy program of RSN) works hard to stay on top of the issues that will affect kidney patients. Currently these are our top legislative advocacy issues:

- Medigap coverage access should

be universally available; currently 21 states do not require access to this important and necessary supplemental Medicare coverage.

- Lifetime coverage for immunosuppressive medications for kidney transplant recipients; currently this is capped by Medicare at 36 months following transplant.
- Affordable healthcare options

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### Product Review



## Blood Pressure Monitors

by Julie Glennon

Nine hundred million people world wide have high blood pressure (HBP). If not managed well, HBP is the second leading cause of kidney failure and HBP ironically is one of the most common symptoms of kidney failure.

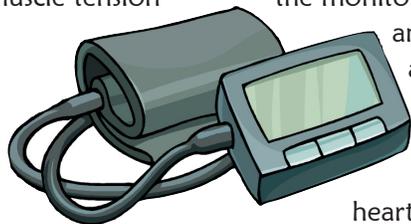
To get an accurate reading it is best to take your blood pressure at the same time everyday using the same arm, because results can vary between arms. Blood pressure can be affected by many things such as diet, emotion, and muscle tension to name a few.

Owning a blood pressure monitor is a great way to regulate your blood pressure.

There are a few factors such as usability and accuracy that go into choosing the right monitor. The British Hypertension Society (BHS) provides highly regarded guidelines to manage HBP and also has lists of blood pressure monitors that scored a "B" or better using BHS protocols.

Electrical/digital blood pressure monitors are either automatic inflation or semiautomatic manual inflation. The more expensive the monitor the more bells

and whistles such as automatic inflation, larger displays, error indicators, reading printouts, built in heart-rate measurement, a



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# Turning Scary Emotions Into Hope for a Wonderful Life

by Lori Hartwell



Many people with chronic kidney disease (CKD) ride an emotional roller coaster. When we are first diagnosed with a chronic illness, our emotions flare up as we try to answer questions that are often unanswerable, such as “Why me?”

Our emotions typically are triggered because of a fear of the unknown and how living with CKD will affect our lives and those that we love. People often become extremely emotional during times of emotional stress, and we can be happy one minute and tearful the next. If this sounds like you, the first thing to realize is that you are not alone! Research has shown that most people go through many emotional stages when they are first diagnosed with an illness. In my case, I have had CKD since I was a small child, and my lifelong journey has been heralded by many changes in both the status of my disease as well as how I deal with it emotionally.

I have always believed that a disease is too demanding if you don't have hope, and that hope is a key to living a happy, long, and productive life with CKD. Hope is seen in the everyday examples provided by the hundreds of thousands of individuals who live a wonderful life despite having a chronic illness such as CKD. These people (I count myself among their ranks) are not defined by their disease—they define themselves and live full and wonderful lives.

That being said, emotions are common when living with a chronic

disease—and emotional upheavals should be recognized and treated like any other comorbidity. Emotional pain is often more difficult to deal with than physical pain. Since physical pain is easy to recognize, we are more likely to bring it to the attention of our healthcare team. Emotional pain, on the other hand, is often difficult for us to self-recognize, and may be more difficult to deal with.

One of the most powerful emotions humans experience is fear.

*“Although I always strive to be eternally hopeful, I experience the same emotions as everyone else”.*



Fear is an emotional reaction to danger. Fear triggers a basic survival mechanism that is often referred to as the fright, fight, or flight response. This response is thought to be a natural protection against physical dangers. When we are fearful, our thinking can become distorted and we see everything as a possible danger. We are stuck in survival mode, and do not think rationally—it is often difficult or impossible to make clear choices and recognize the consequences of those choices.

In modern society, a prolonged “fright, fight, or flight” response can be triggered by the stress of everyday living and ongoing emotional strife. When you learn your kidneys are failing and you will need dialysis or a transplant to survive, a million

potentially fearful images and thoughts pop up in your mind. Will I live? Will it hurt? Will I lose who I am? Will I be a burden? Will I have the will to survive?

The key to dealing with these emotions is to recognize that you are still in control of your own life, and that the hope of living a full and wonderful life is exemplified by thousands of role models. The signs of hope are all around us—you just need to recognize them when you see them (several examples are listed in the accompanying table).

While hope is very powerful, it is also vital that we all recognize that we may need some additional medical help to deal with our emotions. Depression, for example, is a commonly recognized

clinical condition in individuals with chronic illnesses. The table on page 3 lists some of the potential symptoms of depression, and it is important that you (and your loved ones) know about these symptoms. Decision-making is altered if you are depressed, and it is important that you do not make potentially life-changing decisions unless you are emotionally sound. The good news is that depression can (and should) be treated! Although many of us try to deal with our emotions on our own, it is important that you immediately notify your healthcare team if you are experiencing any symptoms of depression.

Although I always strive to be eternally hopeful, I experience the same emotions as everyone else. I

**weKAN Live & Give** is a publication of the Renal Support Network, a patient-run nonprofit organization whose mission is to identify and meet the non-medical needs of those affected by chronic kidney disease.

**weKAN Patient Activists** serve to mobilize, educate, motivate, and empower fellow chronic kidney disease survivors to advocate for themselves and for one another. Together we can make a difference.

## Newsletter Staff

### Editor-in-Chief

Lori Hartwell

### Managing Editor; Layout & Design

Jodie Younse

### Editorial Coordinator

Dawn Dungan

### Distribution

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## Contact Information

### Renal Support Network

866-903-1728 Toll Free  
9 AM–5 PM Pacific Time, Mon-Fri.

### Address Changes & Submissions

Live & Give Distribution Dept.

Renal Support Network

1131 N. Maryland Ave.

Glendale, CA 91207

[info@RSNhope.org](mailto:info@RSNhope.org)

### Web Version (PDF files & archives)

[www.RSNhope.org](http://www.RSNhope.org)

have lived with my kidney transplant for almost 20 years, and am well aware of the accompanying emotional rollercoaster. However, for the past couple of years my kidney has been pattering along, and my medical team has told me that it may not last much longer. I have had to start thinking about my options. At first—even with all of my experience—I was in denial and did not want to recognize how my labs slowly started changing and the additional medications I needed to control my blood pressure, anemia, and PTH levels. It is like the game I played as a young girl—if you are under the covers, the monster can't see you and if he can't see you he can't get you.

But then I sat back and started to think about my wonderful lifelong journey. Sure I have CKD, but it has not defined me. I have lived a wonderful life on dialysis before, and I know I can do it again. I have had thousands of mentors, and continue to be amazed and proud of the examples being set by others with CKD.

And so, although I may soon be reinitiating dialysis, I have a great hope for the future. I have started the planning process to ensure that I am ready for dialysis, and reached out to others who provide a shining example of how to dialyze to live—not live to dialyze.

I encourage all of you to look for mentors who can help you in your emotional journey, while simultaneously mentoring those that can benefit from your experience. That is why I created the Renal Support Network and why the organization will continue to prosper—we all need to connect with others who understand what we are going through as we progress through the different stages of our journey. The inspiring examples of our peers with CKD have proven to me that if you turn on the lights and talk about the monster, he often disappears or isn't as big and bad as you may have thought!

Chronically Yours,

Lori Hartwell

*President & Founder*

*of the Renal Support Network*

## Signs and Symptoms of Hope and Depression

### HOPE

### Depression

(www.mayoclinic.com)

Looking forward to a new day	Loss of interest in normal daily activities
Feeling joyful	Feeling sad or down
Feeling positive	Feeling hopeless
Finding it easy to smile and laugh	Crying spells for no apparent reason
Sleeping through the night	Problems Sleeping
Being able to finish projects	Trouble focusing or concentrating
Feeling comfortable with one's decisions	Difficulty making decisions
Having a healthy appetite	Unintentional weight gain or loss
Being accepting and patient	Irritability
Being able to remain calm	Restlessness
Feeling content	Being easily annoyed
Feeling energetic, ready to go	Feeling fatigued or weak
Feeling appreciated	Feeling worthless
Having a healthy interest in sex	Loss of interest in sex
Excited about being alive	Thoughts of suicide or suicidal behavior

**Fear less, hope more; whine less, breathe more; talk less, say more; hate less, love more; and all good things are yours.**

~Swedish Proverb

# Immunosuppressant Drug Therapy & Generics

by Jacqueline Harris, RN, BSN, CCTC

Generic medications are being offered or substituted for brand name medications. There are many generics on the market currently for blood pressure and lipids as well as organ transplant rejection meds. Several transplant medicines are losing their patent protection so your pharmacy may send you a generic without any prior warning. The aim of this article is to make you more aware of your transplant immunosuppressive medication and what you need to do to understand what steps you need to take if your transplant medication is

switched to a generic.

Immunosuppressant medication falls under the narrow therapeutic index (NTI) category of medications. NTI meds are those that your physician monitors by blood levels (meds such as Prograf, Cyclosporine, etc), they are dosed based on body weight. These drugs work best when the blood level falls between a certain range. If that level is too high, it can be toxic; too low and not enough medication is in your body to prevent rejection.

Many people, including myself when I was a transplant coordinator, think that if the FDA approves a medication, it's been tested in patients that have the disease or condition that it's treating,

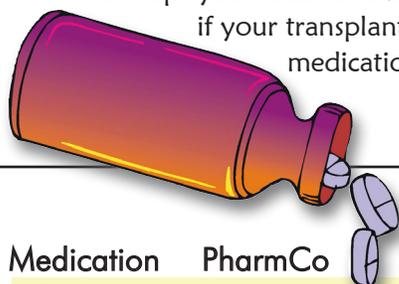
this is a major misconception!

Generics only need to be proven safe in the general population and tested on 24-36 healthy volunteers. They also have a "range" that they can fall between for effectiveness that can be from 80-125%.

You could get different generics each time you fill your prescription, so if those vary, say 85% one month and 120% the next, you can see where issues can occur. To be approved by the FDA as "equivalent" to the original brand name drug, a generic manufacturer only has to prove that it falls within this range.

Needless to say, when your transplant organ is on the line, you

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## Medication Financial Assistance Programs

Medication	PharmCo	Program Name	Phone
Epogen	Amgen	Amgen Patient Assistance Programs	Reimbursement Connection® Hotline: 800-272-9376
Aranesp	Amgen	Amgen Patient Assistance Programs	Reimbursement Connection® Hotline: 800-272-9376
Sensipar	Amgen	Amgen Patient Assistance Programs	Reimbursement Connection® Hotline: 800-272-9376
Procrit	Ortho Biotech	Partnership for Prescription Assistance (PPA)	NeedyMeds Website only* PPA: 1-888-477-2669
Zemlar	Abbott	Partnership for Prescription Assistance (PPA)	NeedyMeds Website only* PPA: 1-888-477-2669
Renagel	Genzyme	Genzyme Renassist	Together Rx Access 1-800-444-4106
Renvela	Genzyme	Genzyme Renassist	Website only*
PhosLo	Fresenius	PhosLo Patient Assistance Program	1-877-774-6756
Prograf	Astellas	Prograf Value Card Program	866-492-0060
Cellcept	Roche	Roche Patient Assistance Program	877-757-6243
Fosrenal	Shire	Fosrenal On Track	866-470-5858
Myfortic	Novartis	Myfortic Financial/ Reimbursement Programs	Patient Savings Program: 866-693-6784 Reimbursement Hotline: 877-952-1000 Novartis Patient Assistance Program: 800-277-2254

\*Websites for all assistance programs can be found by going to [www.RSNhope.org](http://www.RSNhope.org) scrolling over Resources and clicking on Medication Assistance Programs.

Some of the programs listed above also cover other drugs not listed here.



# Ticket to Work Program

by Diana Headlee-Bell

## What is Ticket to Work?

The Ticket to Work Program and Work Incentives Improvement Act was initiated in 1999 by the Social Security Administration. The initial regulations were published in 2001. It is a voluntary program created to help beneficiaries get back into the workplace and not rely solely on Social Security benefits.

## How Will the Ticket to Work Program Help you?

The program allows you to get free training, job referrals, and other services you need to find work. You can give your "ticket" to an Employment Network (EN). An Employment Network is an organization approved by the Social Security Administration (SSA). You and the EN work together to create a work plan that best fits your schedule and abilities; the goal is to help you return to the work place, and to achieve financial independence.

## Are you a Candidate for this Program?

If you receive Social Security or Supplemental Security Income disability benefits, you may be eligible for paid work. The jobs available to those with disabilities are at various skill levels including entry level positions.

Ticket to Work ticket holders, are those beneficiaries that were issued a ticket by mail. Ticket holders may

choose to assign their tickets to an employment service of their choice. The service in return would help them to find work and maintain employment. The services can include vocational rehabilitation services or other services that will help achieve the work goal. If you receive disability benefits and have not received a ticket but would like to, contact the ticket to work program (see info at the end of this article.)

Recent regulations have been set in place to enhance the Ticket to Work program. The new proposals are to encourage the service providers, educational programs, and employers to join an approved Employment Network. Recently, the number of Employment Networks has experienced an increase in enrollment from an average of five per month to an average of thirty four per month. While these new proposals are too early to assess, this is an encouraging sign for those who are disabled and wanting to return to work. This increase in the number of approved agencies will hopefully increase the chances of employment for those individuals with disabilities.

## How do I Participate?

Take your ticket to an approved provider of your choice. This provider can be either an Employment Network or a State Vocational Rehabilitation Agency.

To find an approved Employment

Network see a list of organizations provided by MAXIMUS, Inc. This is a company that helps Social Security manage the Ticket to Work program. The website is [www.yourtickettowork.com](http://www.yourtickettowork.com) or you can call MAXIMUS toll free at 1-866-968-7842.

Your participation in the Ticket to Work program begins when you sign an agreement with an Employment Network or State Vocational Rehabilitation Agency. With their help, you develop an employment plan. While you are in the program, they will review your progress in achieving the goals of your employment plan every 12 months.

You can also attend a free Work Incentive Seminar Event (WISE). WISE are community events held by Work Incentives Planning and Assistance (WIPA). These events are held for beneficiaries with disabilities and their families to learn more about available work incentives through accessible, informal, learning opportunities.

WIPA staff will help you understand how work affects the beneficiary payments, find the right network to help you go to work, and explain what other federal, state and local supports are available to help working people with disabilities.

To see if there is an upcoming WISE in your area, please go the following website: [www.cessi.net/WISE/](http://www.cessi.net/WISE/)

For more information about the Ticket to Work Program go to:

[www.socialsecurity.gov/work](http://www.socialsecurity.gov/work)

[www.yourtickettowork.com](http://www.yourtickettowork.com)

[www.ssa.gov/pubs/10060.html](http://www.ssa.gov/pubs/10060.html)

or call toll free 1-866-968-7842



## Your everyday shopping can help the Renal Support Network!



At [www.iGive.com/RSN](http://www.iGive.com/RSN), you can buy everyday items at over 650 stores at the Mall at iGive.com, like Barnes & Noble, Lands' End, Best Buy, and Neiman Marcus. It's FREE, no invisible costs or tricky obligations. A percentage of each purchase is donated to the Renal Support Network.

Join now at [www.iGive.com/RSN](http://www.iGive.com/RSN)

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*Diana Headlee-Bell was diagnosed with kidney disease in 1978 at the age of 15 as a probable result of glomerulonephritis due to strep throat. She has received two transplants, her second in 1981, which lasted for 18 years. She currently does in-center nocturnal hemodialysis. Diana is active in her state ESRD Network, serving on the Rehabilitation Committee and the Board of Directors, as well as co-chairing the Patient Advisory Committee. She is currently an RSN PEPP speaker, HOPE-line operator, and KidneySpace moderator.*

# Coping Tips from People on KidneySpace

*"Freestyle dance in the living room."*

The question began with a post from a member in Florida: "I'm sure we all feel down sometimes. What do you do to cheer yourself up?" Here are some of the responses:

*"Something that ALWAYS cheers me up is shopping. A nice shiny mall will always perk me up!"*



*"I like to sew and knit."*



*"My favorite thing in the whole wide world is to spend time with my nieces and nephews."*

*"When I feel down, I tend to clean. I don't know why, but it always helps me."*

*"If I have a little extra money, I buy a new book."*

*"If I'm in the hospital and I'm down, I will visit our garden; it has small treasures. You can see all kinds of interesting people, from patients to doctors, enjoying this piece of nature nestled between big concrete buildings. It's a nice getaway."*

*"Mow the lawn."*

*"I go on my balcony to sit amongst my flowers."*

*"Listen to good music."*



*"I love to cook and create new recipes."*

*"Sometimes just getting outside makes me feel better!!"*

*"Walking on the beach is a great stress reliever."*



We know here at RSN that "One friend can make a difference." So, where do you fit in? Did you find your coping tip on the list? If not, we hope we've been able to provide you with some fresh ideas from fellow patients.



*"I love comedy shows and movies."*

*"I call my family because they make me laugh."*

*"The greatest thing is cuddling up with my dog and cat!"*



*"Do something with crafts."*

*"Helping others makes me happy."*



*"Visit Kidney Space."*

*"When I am down the thing that cheers me up most is to get with other people."*

## Immunosuppressant Drug Therapy

*Continued from page 4*

want to make sure you're getting the right amount of medication – every dose, every week, month after month. Your medication can be substituted even among the generics, if there are multiple companies making that particular drug, depending on the best price that the pharmacy gets that month. You may receive generic "A" one month and generic "B" the next. And remember the difference between "A" and "B" can be within that 80-125% range. One may be high, the other on the lower end.

For many, especially transplant patients, they believe that using generics will save them money. This is not always the case, and frequently, there is incentive for the pharmacy to make significant money on their end with only a slight savings benefit offered to the patient. There are significant financial benefits to a pharmacy to dispense generics over name brand drugs as they make a higher profit on their end. For Medicare Part B patients, your medication costs are the same whether it's for generic or name brand. The many insurance companies have varied prices and co-pays, but there are discount cards available to cover any differences in your out of pocket costs.

This is a significant issue that you need to discuss in-depth with your healthcare provider and transplant team. Be aware of what medications you are taking and notify your physician or transplant coordinator should you receive a different color or shaped pill, as you may have received a generic substitution. Your healthcare team will need to be aware of that, as it could affect your blood levels. You may need to have additional blood tests done to monitor this very closely. The best course of action for a patient with a stable transplant is to continue using the prescribed medication from the same manufacturer.

Your physician can help prevent substitutions by making sure that your prescription states "DNS" on it or the wording "do not substitute". This can vary by state and needs to have the words marked clearly on the prescription or verbally told if the prescription is "called in" to the pharmacy. If it's a written prescription, double check this before leaving the office with a new prescription! Also, if you are getting refills, those outstanding refills can be substituted with a generic at any time if it's not marked do not substitute. There are many pharmacy assistance programs and value cards available that can assist you should there be any co-pay difference, which, in some cases makes the name brand cheaper than the generic. Your transplant social worker is a wealth of resources in this area and should be called upon for any needs that you may have. You can be your own best advocate as well and speak to your pharmacist and inform them that your transplant drugs should not be changed without consulting your physician.

Talk with your physician and stay current on the transplant educational materials available. Attend support group meetings and stay informed! Remember, a healthy patient is an educated, well-informed patient! 



Jacqueline Harris is a Senior Executive Healthcare Specialist with the Immunology division of Astellas Pharma US. She is an RN, Clinical Nurse Specialist & former transplant coordinator at Cedars-Sinai Medical Center & UCLA Medical Centers. She has over 20 years of ICU, critical care & Nephrology experience. She is a board member & volunteer with RSN. She is also a private pilot & enjoys flying whenever able. She lives in La Canada, CA.

and the prohibition of any “pre-existing conditions” as a reason to deny coverage; currently, many people cannot afford or access health insurance or are discriminated against by insurance companies and denied any coverage at all.

Last year, Congress passed PL 110-275 the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA). MIPPA is changing the reimbursement structure of dialysis to bundle the costs of medications and labs into one composite dialysis payment rate. Following the passage of such a law, Congress leaves it up to the Centers for Medicare

and Medicaid Services (CMS) to create the specific regulations governing the implementation of that law, and this is called the Proposed Rule. We are at this moment waiting for CMS to publish the proposed rule regarding the dialysis reimbursement portions of the MIPPA law. Once published the public and renal community will have 60 days to comment. RSN will be working diligently to help ensure that we let CMS know what people on dialysis need to survive and thrive.

You can get involved and comment on these proposed regulations as well! As soon as they are published in the Federal Register, we will make the provisions available on our website. We will also have links to the appropriate sites so you can file your response with CMS. Being part of the law implementation process is the best way for people with kidney disease to benefit from the new law. To comment on the proposed rule visit our website, go to [www.RSNhope.org](http://www.RSNhope.org), scroll over programs and choose weKAN. ☞



*Diagnosed with kidney disease in 2004, Kathe LeBeau began home hemodialysis in April of 2007, and is presently on the kidney transplant waiting list. She is the Project Manager for RSN's weKAN group, and is also a PEPP speaker and HOPEline operator. Kathe lives in the Capital Region of New York State with her husband of 11 years, Loren Fadding.*

### Spotlight On You

## Love, Marriage, and Yes...Dialysis

by Anthony Brown

Every story has a beginning as does every relationship. My relationship with Cyndi began in high school after I had been diagnosed with glomerular nephritis at the age of 15. We met at our church's youth group and I have always said that she had me from “Hello.” We went to prom together in 1985 as friends, but never crossed the line of friendship in high school.

I went into full renal failure in September 1996 and started peritoneal dialysis in October of that year. As we tried to keep in contact through the years, Cyndi learned of my health problems, but never truly understood what was going on. I received a transplant on Mother's Day, 2000 and hoped my life would begin again, but it was not to be. For the longest time, I tried to blame everyone else for the failure of my transplant, but in truth, the fault lies completely with me and the way I chose to live at that time. I restarted dialysis in 2002, doing in-center hemodialysis which works very well for me.

It wasn't until 2007 that Cyndi and I reconnected again. It was only by chance that her name came up in a

conversation with a mutual friend. We started talking again and spent New Year's Eve together that year, seeing



each other for the first time in almost seven years. After that, our relationship continued just as it had been in high school with one big difference—now there was true love involved that took us both by surprise.

Cyndi realized very soon that she had a lot to learn about dialysis and everything involved with it. She attacked it vigorously, especially after having seen me do dialysis when we met again for the first time. We continued to meet and she continued to learn more about dialysis. It was during one of our trips to see each

other that she asked me to marry her. That simple question brought tears to my eyes as I really didn't think anyone would want to put up with the strain of dialysis on a relationship.

That was in April 2008 and on April 25, 2009, we were married at our house in Portage, Michigan. To say that I have found the perfect caregiver and partner is an understatement. She strives to understand all she can and encourages her children to do the same, just as my daughter has done for years. Though she is still very nervous about dialysis-related things, I believe that will pass in time.

We continue to be happy and I am transferring to the Michigan transplant list so that hopefully I can receive another transplant, even though my life has already begun again. ☞



*Anthony Brown is a 12 year veteran of dialysis having done both peritoneal and hemodialysis after being diagnosed with CKD in high school. He received a transplant in 2000 that eventually failed and returned him to dialysis. He keeps active with his new bride Cynthia as a domesticated house husband. He is also striving to become more involved in weKAN and RSN. Anthony also advocates for the education of others on CKD and Donor Registry. Anthony and Cynthia reside in Michigan.*

# Vitamin D and CKD

by Nadiya Lakhani, RD, LD

It seems that everyone is talking about vitamin D, and for a good reason. Long winter months indoors and use of heavy sunscreen are some of the reasons that keep our bodies from absorbing the UV rays necessary to make healthy amounts of vitamin D which leads to vitamin D deficiency. But for people with chronic kidney disease it's not just an issue of vitamin D deficiency but a deficiency in active vitamin D as well.

## Where Does Vitamin D come from and what does it do?

Vitamin D is naturally found in food and is made in the body with the help of sunlight. In addition to sun, foods (fish, egg yolks and milk) and dietary supplements are other sources of vitamin D. Still, to work in the body, vitamin D must be activated by the kidneys. It first goes through the liver and then the final stage of activation is completed by the kidneys. Next, this active vitamin D hormone works as a messenger telling the kidneys, bones and intestines to balance calcium and phosphorus in the blood. Keeping calcium and phosphorus at the right balance is important to keep bones healthy and strong and to keep nerves and muscles working properly. When there is not enough active Vitamin D, the calcium in the body is not absorbed appropriately and bones get weak and brittle.

## What is Parathyroid Hormone (PTH)?

PTH is another messenger needed for calcium and phosphorus balance. PTH is released by the parathyroid glands when 1) active vitamin D levels are too low or 2) when calcium levels are too low or 3) when phosphorus levels are too high. These glands continue releasing PTH until these levels are normal. PTH works by telling

the kidneys to filter out extra phosphorus and to activate vitamin D. PTH also works on the bones to add calcium into the blood.

## What Happens in Chronic Kidney Disease (CKD)?

As kidney function declines, the kidneys don't respond to PTH and they are less able to balance calcium and phosphorus or activate vitamin D. Low calcium, high phosphorus and low active vitamin D levels trigger the parathyroid gland to work "overtime" and continue releasing PTH in the blood.

As the parathyroid gland continues to work overtime, this leads to too much PTH or a condition known as Secondary Hyperparathyroidism (SHPT). SHPT can be harmful to the body and if not treated early can lead to bone pain, nerve problems, itching, weak or brittle bones, calcium build up and resistance to therapy. SHPT begins early in chronic kidney disease – well before dialysis is needed. So ask your physician about checking your PTH levels. Research shows that calcium and phosphorus levels are normal in CKD but this is only at the expense of PTH. PTH levels should be checked every three months and more frequently as kidney disease progresses.

## How Should SHPT Be Managed?

During the early stages of CKD, the Nephrologist may check Vitamin D levels, known as "25-hydroxy" as well as PTH levels and prescribe a vitamin D supplement, such as ergocalciferol or cholecalciferol. This is not active vitamin D. The body still needs to convert it to its active form in order to work properly. These supplements may not work to lower PTH, especially in those people with more advanced CKD. The nephrologist



may then prescribe active vitamin D, such as Zemplar (Paricalcitol), Hectorol (doxercalciferol) or a branded generic known as Rocaltrol (calcitriol). These medications work to control the buildup of PTH. These are different from ergocalciferol or cholecalciferol (or from over the counter supplements you get at GNC stores) because they are not active and do not correct active vitamin D deficiency. Zemplar, Hectorol and Rocaltrol all activate the vitamin D receptor but all have different side effects or impact on minerals such as calcium and phosphorus. Talk to your doctor about which one is best for you.

In addition to taking your active vitamin D, it's also important to follow your diet. You play the most important role in managing your SHPT and preventing bone disease. If you are not yet on dialysis, ask your doctor about medical nutrition therapy or dietary counseling. A registered dietitian (RD) can talk to you about ways to slow down the progression of kidney disease and manage your SHPT. ☞



Nadiya Lakhani, RD, LD works for Dallas Nephrology Associates as the Pre-Transplant dietitian along with seeing patients with CKD in Office Practice. Nadiya's background includes working as a Renal Dietitian for Fresenius Medical Care and as Clinical Dietitian for various hospitals. She is also active within the renal community and serves as the Regional Representative for National Kidney Foundation, Council for Renal Nutrition and American Dietetic Association, Renal Practice Group.

## Blood Pressure

Continued from page 1

large memory that can store many past readings, voice announced readings, and compensation for the effects of an irregular heartbeat.

The BHS gave a double “A” grade to several arm cuff monitors, the first being the A&D Medical LifeSource Quick Response UA-787EJ (\$70) a top choice with both owners and reviewers for its ease of use and extended cuff size. It holds 60 readings, has an average reading feature and also measures users with an irregular heartbeat. Lastly it can rate your pressure based on height and weight.



UA-787EJ

The second monitor is the A&D UA-767T (\$120). The American Foundation for the Blind's Access World recommends this monitor because it has voice announcements.



Lifesource UA-767

A&D also carries the UA-767 (\$55). This monitor has 7.5, 12, and 17 inch cuff to choose from.

Next is the A&D UA-767 Plus (\$60) also known as the LifeSource UA-767. It does not have an audible readout though it has a lot of good features. It

holds 30 readings for both pulse and blood pressure and also includes the feature for irregular heartbeat.

Lastly, is the A&D UA-767PC (\$220). This monitor is very advanced because of its PC interface which transmits data to your doctor over the phone.

Four other monitors by Omron HEM were reviewed. The 790IT (\$75) is good for users with large arms and can store 60 readings, while the 711AC (\$55) and the 712C (\$45) tend to have a tight cuff though small and large cuffs are sold separately.

Omron also makes one wrist monitor the HEM-650 (\$40) that gets excellent reviews at Amazon.com and Epinions. Some experts say a wrist monitor is not as accurate as an arm cuff but the HEM-650 has included features to secure correct measurements.

To conclude, the A&D Lifesource UA-767 is the best basic monitor with your choice of cuff size. It does not record past readings nor have the irregular heartbeat feature but should work well for most people. If in fact you like an easier cuff to maneuver and a memory function the A&D UA-787EJ would be a good choice. 



Julie Glennon received a successful kidney transplant in 1999 after being diagnosed with both lupus and chronic kidney disease in 1988. She keeps active by volunteering with The Kidney Association of South Florida. She is also a weKAN patient activist and HOPEline operator with the Renal Support Network. Julie and her husband live in Florida.

## KNOW YOUR TARGET RANGE

Blood Pressure  
120/80

Blood Sugar  
80-120

Talk to your doctor to know what is right for you.

**KidneyTimes™**  
Health Information Beyond The Ordinary

## Why Do Patients Have Bouts of Low Blood Pressure During Hemodialysis?

EasyLink Access #: 161

Maintaining a healthy blood pressure is extremely important for people with kidney disease. However, it is not always about high blood pressure, low blood pressure is an issue too. Read the article by Dr. Dean A. Kujubu on KidneyTimes.com.

## Important Information for People with Compromised Immune Systems



Some people may be more vulnerable to contaminants in drinking water than the general population. Immuno-compromised persons such as persons with cancer undergoing chemotherapy, persons who have undergone organ transplants, people with HIV/AIDS or other immune system disorders, some elderly, and infants can be particularly at risk from infections. These people should seek advice about drinking water from their health care providers.

The EPA/Centers for Disease Control (CDC) guidelines on appropriate means to lessen the risk of infection by *Cryptosporidium* and other microbial contaminants are available from the Safe Drinking Water Hotline (1-800-426-4791).

# Give the gift of health, happiness & hope!

- Yes!** I would like to receive a free subscription to the *weKAN Live & Give* newsletter.
- Yes!** E-mail me *renALERT*, RSN's electronic update! (Please provide your e-mail address.)
- Yes!** Please send me \_\_\_\_\_ additional copies of *weKAN Live & Give* to distribute.

Name \_\_\_\_\_

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City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

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Phone \_\_\_\_\_  home  work  cell

## METHOD OF PAYMENT FOR CONTRIBUTIONS:

- Check or Money Order (payable to Renal Support Network)
- Credit Card:  MasterCard  Visa  American Express
- Total billed to credit card \$ \_\_\_\_\_ Billing Zip \_\_\_\_\_
- Card #: \_\_\_\_\_ Exp. Date: \_\_\_\_\_ / \_\_\_\_\_
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- Signature \_\_\_\_\_ Date \_\_\_\_\_

All donations are tax-deductible. EIN#95-4672679

- YES!** I would like to help RSN continue the programs that help educate and motivate those affected by chronic kidney disease.

Enclosed is my gift of:

\$ \_\_\_\_\_

## Please check all that apply:

- Patient—I have experienced:
  - transplant  PD  hemo
- Family Member  Administrator
- Physician  Nurse
- Dietitian  Social Worker
- Technician  Company Rep
- Other \_\_\_\_\_

Cut form on dotted line and mail or fax to the Renal Support Network. Thank you!

## Renal Support Network

1311 N. Maryland Ave.  
Glendale, CA 91207

toll free 866-903-1728 ♦ 818-244-9540 fax

# RSN Programs & Services



## weKAN: Wellness & Education Kidney Advocacy Network

A national group of people with kidney disease who advocate on behalf of fellow patients. *Live & Give*—weKAN's bi-annual newsletter for patients—informs, inspires, and educates patients, family members, and healthcare professionals.



## PEPP: Patients Educating Patients & Professionals

PEPP patient-speakers are trained to give educational presentations about kidney-related issues to patients and professionals. To learn about the presentations offered or to schedule a PEPP speaker for a meeting of patients or professionals, go to [RSNhope.org](http://RSNhope.org) and click on Programs, then PEPP.



## KidneyTalk

Online radio talk show hosted by Lori Hartwell & Stephen Furst, covering a wide variety of kidney-related topics. Listen at [RSNhope.org](http://RSNhope.org) or download podcasts from [iTunes](http://iTunes).



## RSN Renal Teen Prom

Annual prom held in the Southern California area each January for teenage kidney patients. Young people with CKD ages 14 to 24 come from across the United States to enjoy a night of glamour.



## HOPEline

A toll-free call-in line offering patient-to-patient encouragement and support from operators who have lived successfully with chronic kidney disease. Call **800-579-1970** Monday - Friday, 10:00 a.m. - 8:00 p.m. (Pacific Time).



## Regional Patient Lifestyle Meetings

Based on the theme of "*Health, Happiness & Hope*," meetings offer a setting where people with kidney disease and their families can learn about issues related to their illness in a relaxed, friendly atmosphere. See the RSN Calendar on page 12 and at [RSNhope.org](http://RSNhope.org).



## KidneyTimes

An online resource with articles written by kidney patients and professionals on medical, social, nutritional, and lifestyle issues. Home of the annual "*KidneyTimes Essay Contest*." [KidneyTimes.com](http://KidneyTimes.com)



## KidneySpace

An online discussion forum to air your questions, thoughts, and opinions on lifestyle issues related to diabetes and kidney disease. Go to [KidneySpace.com](http://KidneySpace.com) to join the conversation!



*In this issue of Live & Give...  
Coping with Emotions*

You Are Our **HOPE**

*Our mission at RSN is **you**. We strive to build a bridge of understanding and respect between the patients and the professional renal community.*

*Because we believe so strongly in our mission and the work we do on a daily basis, we are asking you to believe in us too.*

*We are a not-for-profit, patient-run, patient-focused organization. We're working for you whether we're sponsoring patient lifestyle meetings, publishing newsletters, or advocating to Congress about better healthcare for kidney patients.*

*Please remember RSN in your donations. We humbly and gratefully appreciate your support. As we say, "An illness is too demanding when you don't have hope." **You give us hope.***

NON-PROFIT ORGANIZATION  
U.S. POSTAGE

**PAID**

GLENDALE, CA  
PERMIT NO. 94

**Calendar**

RSN Renal Teen Prom  
January 17, 2010  
Notre Dame High School  
Sherman Oaks, CA

Upcoming  
RSN Regional Patient  
Lifestyle Meetings

- Salt Lake City, UT - Oct. 10, 2009
- West Chester, OH - Oct. 11, 2009
- Seattle, WA - Oct. 17, 2009
- Indianapolis, IN - Nov. 15, 2009
- Las Vegas, NV - Nov. 22, 2009
- Anaheim, CA - Feb. 21, 2010
- San Diego, CA - Mar. 14, 2010
- Pittsburgh, PA - Apr. 11, 2010
- Albany, NY - May 23, 2010
- New York City, NY - Jun. 13, 2010

All cities and dates subject to change.

To find out specific meeting dates join our mailing list (see page 11) or go to [RSNhope.org](http://RSNhope.org). On our website you can also register for a meeting, or download a meeting flyer.

Thanks to our sponsors!

