www.heartlandkidney.org

Heartland Headlines

A Special Publication
for people with kidney disease.

Issue 2 | 2019

In This Issue

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- Tips for Coping With Dialysis
- Thinking About or Waiting for a Transplant?

...and more stories just for you!

Patient to Patient

For more information, to request a printed copy of this newsletter or to file a grievance, please contact:

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Resource: **www.mykidneykit.org**
Social Media:
www.facebook.com/heartlandkidney

Your feedback is important to us! Visit **http://bit.ly/2DjNTas** to tell us what you think of this newsletter.

Throughout this issue, you will see a magnifying glass symbol.

When you see that symbol, you can find more information in the MY KIDNEY KIT (at the dialysis clinic) or online at **www.mykidneykit.org**.

NOTE: All individuals featured in this publication have given consent to release their name, image and information in regards to discussed content.

This resource was developed while under contract with the CENTERS for MEDICARE & MEDICAID SERVICES (CMS), a Division of the Department of Health and Human Services. Contract #HHSM-500-2016-0012C. The content presented does not necessarily reflect CMS policy. 19.Q-ESRD12.08.156

New Patient Advisory Council Chair

In this issue of the Heartland Headlines patient newsletter, we would like to introduce Mark Johnson, the new Patient Advisory Council (PAC) chair for ESRD Network 12.

Mark has been a member of the ESRD Network 12 PAC since 2016. He is also a member of the Board of Directors and has served as a Network Patient Representative (NPR). Mark represents the Network on several national groups. We are so happy to have him in this leadership role. Be sure to read Mark's story in our Patient to Patient article on page 3.

We would also like to announce and introduce the winner of the first Ardyth M. Boucher Legacy Award: Susie Atterberg from Keukok, Iowa. See page 11 for her story.

This award was developed to recognize patients who are engaged in their own care, strong advocates in the community and give hope to others by their example of living well with kidney disease.

The Network had a great response to this new award. Thank you to all who submitted nominations and congratulations to Susie!

We hope you will enjoy reading this issue and find new information and ideas to help you continue to live well with kidney disease!

Sincerely,
DeeDee Velasquez-Peralta, LMSW
Patient Services Manager

In Case of Emergency... What Kidney Patients Can Do to Be Prepared

Use the following as a checklist to prepare for an emergency.

Make an emergency supply kit to include:

☐ A copy of your current medication and allergy list
☐ A copy of your current dialysis prescription
☐ A list of important phone numbers (keep a printed copy in case you lose phone service).
Include the name, address and phone numbers for:

- Dialysis Clinic: ______________________________
- Back-up Dialysis Clinic: ________________________
- Back-up Transportation: _______________________________
- Kidney Doctor: ____
- Pharmacy: ____
- Utility Contacts: ____
- Emergency Contact(s): ____
  ____

☐ Emergency diet (3 Day Emergency Diets are available in the **My Kidney Kit**)
☐ Emergency supplies (for a full list see **My Plan: In Case of Emergency**)
☐ List of dialysis clinics in the area (Visit Dialysis Facility Compare at **www.medicare.gov**)

Consider the following questions as you make your personal emergency plan:

- What is your back up transportation?
- Where you will go if you must evacuate, your home, your city?
- What will you need if you cannot leave home? Or if you must leave home?
- Who will you need to contact?
- How will you manage your diet and fluid if you miss dialysis?

Share your personal emergency plan with the dialysis clinic.

☐ Make sure your clinic has the right contact information for you and your emergency contacts including any out-of-state contacts.

If you must get dialysis at a different clinic, try and follow as close to your regular scheduled number of treatments and time. Services may be harder to find so don't wait too long to start looking. Following the emergency diet can help if you can't get to services for a day or two.

For more infomation or a Patient Identification Card: **https://kcercoalition.com/en/patients/**

My Plan and My Network:
Dialysis Facility Compare

Patient to Patient

“When one door closes, another opens.”

Mark Johnson

Patient Advisory Council Chair, Network Patient Representative Atlantic, Iowa

My name is Mark Johnson, the new chairperson for the Network 12’s Patient Advisory Council. Ten years ago, I visited my local medical clinic, complaining about an inexplicable large weight gain over the past few months. Without doing any tests, the doctor informed me that I just needed to control my appetite. A week later – Memorial Day 2009 – I was rushed by ambulance to the ER, where I was diagnosed with end stage renal failure. During the next several months, over 170 pounds of fluid were siphoned from my body.

Six months later, I found myself being a patient at the Atlantic, Iowa DaVita hemodialysis center. I was a very angry patient. At the time, I owned a very successful restaurant; dialysis and frequent hospital stays simply got in the way of my career. I was continually demanding to shorten my treatment time in order to operate my business. I had spent the past 20 years cooking over a hot grill and fryer, so I was use to drinking a pitcher of water every hour. Now, I was emphatically informed that the 7-8 kilos of fluid gain between sessions was unacceptable. The food I loved to eat was no longer allowed. And, worse of all, my taste buds changed: the taste of bacon made me nauseous!

By the end of 2012, despite all my efforts, I was forced to close my restaurant. A few months before, I had switched to home hemodialysis at the insistence of my nephrologist. My mother, a retired ER nurse, became my caregiver. During the next several years, I slowly got my fluid gains and my dietary habits under control. My anger was gone; now, I was severely depressed. Enormous amounts of money and time was being spent to keep me alive, yet I was contributing nothing to justify this tremendous effort.

During this time, my mother turned 80 and was no longer able to keep cannulating me. I decided to try peritoneal dialysis. Unfortunately, I was not a good patient and did not adequately practice the sterilization methods I had been taught. After two bouts of peritonitis, I reluctantly went back to the unit.

A few months later, as I unwillingly dragged myself to my dialysis chair, I noticed a poster asking for volunteers to become a member of Network 12’s Patient Advisory Council. As a bonus, a trip to Kansas City was included as part of the deal! I asked my unit administrator if she thought I would be a suitable candidate. She actually thought I was right for the position! I did not realize that my life was about to turn completely around!

During the past three years, I have been an active member of the PAC and represent the Network on the national level as a Subject Matter Expert with the National Patient and Family Engagement Learning and Action Network (NPFE-LAN). I have been encouraged to join patient advocacy organizations such as the American Kidney Fund and the Dialysis Patient Citizens. I have been privileged to be invited twice to Capitol Hill in Washington, DC to advocate for my fellow kidney warriors. I have been involved in giving my input as a patient for the KidneyX project and participated in a CMS (Medicare) Technical Expert Panel.

Ten years ago, I thought my life was essentially over. Now, I have a renewed will to thrive, not just survive. When one door closes. Another opens.

Tool for Patients by Patients: Depression Toolkit

Whether you are just starting your journey, have been on dialysis or living with a transplant for years, coping with it can be hard. It is very common for people on dialysis to deal with depression at one time or another. As patients themselves, the Kidney Patient Advisory Council (KPAC) for the Forum of ESRD Networks has made a toolkit for people living with kidney disease to help patients cope with depression.

According to the Kidney Patient Advisory Council, "This toolkit was designed BY patients and FOR patients but there are important contributions by professional collaborators who graciously joined our workgroup. It is important to remember that we are not alone. Even if we are on dialysis and coping with anxiety or depression, we can still have loving and productive lives. There are no limits to what we can achieve with determination and the right tools. Many, many people have gone through the same things and we would like to share some of the things that helped us cope."

To download a FREE full copy of the "Dialysis Patient Depression Toolkit" please visit: **www.esrdnetworks.org/resources**

A Look Inside the Toolkit

Chapter 1
The emotional demands of dialysis

Chapter 2
Signs of anxiety and depression caused by overwhelming stress

Chapter 3
Do I need help?

Chapter 4
What type of help is out there?

Chapter 5
Picking a treatment provider and how to prepare for a mental health visit

Frequently Asked Questions

The Facts About Fluid

Q Why do I have to limit the amount of fluid I have each day?

A
- Dialysis only removes some of the fluid
- Greater and undesired fluid gain between treatments increases risk of cardiovascular death

Q What are the different types of fluid?

A Examples of where you find fluid:

- Water, juice, milk
- Coffee and tea
- Soups and broths
- Watermelon and other fruit
- Ice cubes, ice cream, popsicles
- Puddings, yogurt, gelatin
- Lettuce

Q What are potential symptoms of fluid overload?

A
- Shortness of breath
- Headaches
- Stomach bloating
- High blood pressure
- Heart failure
- Swelling

Q What can happen during treatment if you remove too much fluid?

A
- Low blood pressure
- Cramping
- Nausea/vomiting
- Headache
- Dizziness
- Fatigue

My Treatment: What is Fluid Weight?

Tips to Help Control Fluid

Keep Track

- Write down your fluid intake in a notebook
- Include liquids with meals, snacks and medications
- Use a water bottle that's marked with your daily goal
- Measure fluid amounts
- Download an app on your phone that allows you to track
    - My Food Coach (android/iphone) Visit **www.kidney.org/apps**
    - H2Overload - track fluid/weight/BP, NKF (iphone)

Control Thirst

- Limit sugar
- Limit salt intake
- Limit caffeine and alcohol
- Suck on ice chips, crushed ice or popsicles
- Suck on frozen fruits like blueberries and grapes (1/2 cup)
- Spread fluids throughout the day
- Sip don't gulp
- For dry mouth
    - use spray bottle
    - swish and spit to moisten your mouth
    - brush your teeth
    - use moist swabs
- Chew gum or suck on hard candy (sugar free)
- Keep your mind busy
- Stay cool
- Adjust dialysis to meet your individual needs

Set Fluid Goals

Talk to your doctor and dietitian about setting goals for you

Tips for Coping

To be successful with dialysis or a transplant, you should keep your life as normal as possible. You may need to adjust your time schedule or activity level, but you should try to stay involved in the activities that you enjoyed before your kidneys stopped working.

Be Involved

- Many people on dialysis or transplant continue to work or go to school. Others travel, attend church, are active in their community or stay busy with clubs, hobbies or volunteer work.
- You might want to become active in your dialysis or transplant clinic as a patient representative, or start or become part of a clinic support group.
- In your own healthcare, being informed will make you feel more comfortable with your treatment.

“I am involved in helping my community through my church and the Ministerial Alliance”. – Jerry Ribbing, PAC Member, Monett, Mo.

“It’s important for me to participate in my care and get out in the community and stay active.” – Chris Eichmeier, NPR and PAC member, Clinton, Iowa

“I ask for copies of my treatment sheets weekly and I keep track of my blood pressure and medications.” – Laura Novy, PAC Member, Omaha, Neb.

“The PD cycler will give you the information you need for your treatments so you can keep track of your numbers.”
– Yvonne Steele, NPR and PAC Member, St. Louis, Mo.

Be Active

- Exercise at least every other day, even if you just walk around your house several times.
- Talk with your doctor about the kinds of exercise that will work best for you.
- Your local YMCA has programs to help people if cost is a concern. Some insurance plans offer help with health club memberships and classes.

"I enjoy taking Zumba and kettle ball classes in my community."
– Yvonne Steele, NPR and PAC member, St. Louis, Mo.

My Life: Being Active

Be Positive

Look at the positive things in your life and try not to focus on the negatives. Do things that make you feel happy!

"Be grateful. My dad always told me to, 'stop and smell the roses'."
– Laura Novy, NPR and PAC member, Omaha, Neb.

Connect

- Talk about how dialysis or transplant is affecting you with your family and friends. Sharing can help them understand more about you and your life so they can give you support when you need it.
- Talk with other patients. Whether it is just chatting before and after treatment in the lobby, talking to a peer mentor, your Network Patient Representative or through a support group or online community it can be helpful to hear how others cope.
- Talk to your doctor or social worker. It is normal to feel sad after starting dialysis or getting a transplant. This sadness may stay for a long time or it may get worse and turn into depression. If you feel sad all the time or think about ending your life, you need to talk to your doctor or social worker right away. Your doctor and social worker can work to connect you with people who can help

Medicare Part D - Medicare Drug Plans

Medicare prescription drug coverage is an optional benefit offered to everyone who has Medicare. If you decide not to get Medicare Part D when you're first eligible, you will likely pay a late enrollment penalty if you join later.

There are two ways you can get drug coverage:

1. Medicare Prescription Drug Plan (Part D). These plans add drug coverage to Original Medicare, some Medicare Cost Plans, some Medicare Private Fee-for-Service (PFFS) Plans, and Medicare Medical Savings Account (MSA) Plans.
2. Medicare Advantage Plan (Part C) (like an HMO or PPO) or other Medicare health plan that offers Medicare prescription drug coverage. NOTE: If you are just starting Medicare since beginning dialysis, then a Medicare Advantage Plan will not be an option, it is only available if you started the plan prior to starting dialysis.

Tip: Have your list of medications handy when you use the Plan Finder. It can show you the costs for each plan.

When can you get or change your Medicare Part D

- Initial Enrollment Period: starts three months before you are eligible and lasts for seven months.
- Annual Enrollment Period: **Oct. 15 - Dec. 7**
  - During open enrollment you can pick a plan, check for cost changes, and changes in your plan's formulary (list of drugs covered).

To find the plan that is right for you check out "Plan Finder" at: **https://www.medicare.gov/find-a-plan/questions/home.aspx** or contact your state's Health Insurance Program listed below.

What will it cost? Your actual drug plan costs will vary depending on:

- The drugs you use
- The plan you choose
- Whether you go to a pharmacy in your plan's network
- Whether the drugs you use are on your plan's formulary
- Whether you get extra help paying your Medicare Part D costs

Tip: Make sure to tell anyone helping you find a plan that you are a dialysis patient.

State Health Insurance Programs:

Iowa: Senior Health Insurance Information Program (SHIIP)
1-800-351-4664
www.theRightCallIowa.gov

Kansas: Senior Health Insurance Counseling for Kansas (SHICK)
1-800-860-5260

Missouri: Community Leaders Assisting the Insured of Missouri (CLAIM)
1-800-390-3330
www.missouriclaim.org

Nebraska: Nebraska SHIIP
1-800-234-7119
www.doi.ne.gov/shiip/

ESRD Medicare Timeline

Medicare Entitlement and 30 Month Coordination Period Begins

- Medicare starts on first day of fourth month of Hemodialysis
- Medicare goes back to 1st day of month that Peritoneal Dialysis began
- Medicare goes back to 1st day of month that kidney transplant is received
- Medicare pays after your insurance does, it pays deductibles and copays
- Medicare Part B covers outpatient dialysis, you may pay a late penalty if you wait to enroll

*30 month coordination begins whether or not you sign up for Medicare

30 Month Coordination Period Ends

- Medicare starts paying before your group/employer based insurance plans
- Patients need to make sure Medicare knows about their group coverage and that group plan knows the patient has Medicare as the first payer
- Medicare always pays first before Medicaid, Children's Special Health Care Services and TRICARE

End of ESRD Medicare

- Medicare will stop paying 36 months after the month you have a kidney transplant (If the patient is not getting Medicare because of age or another disability)
- If patient recovers kidney function and is no longer on dialysis or stops getting treatment, Medicare will end 12 months after the month you stop dialysis

Medicare will be extended if:
- You start dialysis again or get a kidney transplant within 12 months after the month you stopped dialysis; or
- You start dialysis or get another kidney transplant within 36 months after the month you get a kidney transplant

For more information on Medicare for people on dialysis you can download it at:
https://www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf.

And the Winner Is...

On Behalf of the Qsource ESRD Network 12 Boards and Patient Advisory Council, we would like to recognize Susan (Susie) Atterberg as our first winner of the Ardyth (Ardy) M. Boucher Legacy Award. Mrs. Atterberg was nominated by Southeastern Renal Dialysis - Lee County in Keokuk, Iowa, and her nomination and story is a wonderful example of the spirit of hope and generosity that Ardy shared with all those she met.

Pictured left to right: Russell and Linda James, Susie and Mark Atterberg

In her own words, we'd like to share Susie's story.

I am Susie Atterberg, age 69 and have been married to Mark for 50 years. We have one son and daughter-in-law and 3 grandchildren that are the joy of my life. I was a bank manager for 25 years, retiring in 2012. We enjoyed traveling, boating and having fun with family and friends. Four and a half years after retirement, I acquired an auto immune disease called Anti–glomerular Basement Membrane (Anti-GBM) that killed my kidneys. After a life-saving experience at the University of Iowa hospital, I was immediately placed on dialysis and remained there for 18 months until a kidney became available.

It was an emotional time for me, going from a healthy person to one fighting to live. Dialysis was foreign to me, but with the love, caring support and expertise of the staff, my life was maintained very well until transplant. One of my long-time friends was selfless, gracious and generous enough to offer her kidney, after my cousin had tried but was unsuccessful. We were blessed with a match and on Feb. 22, 2018 a successful transplant was performed in Iowa City that prolonged and brought normalcy back to my life.

Our family and friends organized a benefit and celebration of life in August 2018. I chose the Southeastern Dialysis Center of Keokuk to be the recipient which is where I spent my time. It was important to me to show my appreciation and love to both the staff and patients. Through the generosity of family, friends and Keokuk community, I have been able to give back to those who cared for me and those experiencing dialysis. I find joy in seeing smiles on the faces of those trying to overcome and endure the obstacles in life.

On August 3, we held our second event to benefit the dialysis staff and patients. I am blessed and want others to feel blessed and cared about as well. This event brings awareness of the importance of dialysis and the significance of organ donation to the public.

My motivation in life is, and always has been, my husband, children and grandchildren. They have loved and supported me every step of the way. I strive to be a good role model and hope it demonstrates to them what results when kindness and generosity are shown toward others.

Every Day is a Blessing!

Susie Atterberg

Thinking About or Waiting for Transplant?

Mike Bronson received a kidney on Oct. 27, 2009 from a living donor. He became a member of the Patient Advisory Council in 2016, and in 2019, became the PAC Vice Chair and the Kansas patient representative for the Medical Review Board. Since Mike has kept his kidney healthy for almost 10 years, we asked him what patients should do to stay as healthy as possible while they wait for transplant and he shared the following checklist:

- ☐ Follow your medication schedule
- ☐ Exercise as much as possible
- ☐ Follow the diet that your doctor recommends
- ☐ Build relationships with your healthcare team
- ☐ Communicate often with your pre-transplant coordinator
- ☐ Don't miss any doctor's appointments
- ☐ Get your labs updated quickly when asked for
- ☐ Consider listing at multiple transplant centers
- ☐ Stay hopeful
- ☐ Once on the list, keep a travel bag ready at all time. Be sure transportation is lined up.
- ☐ If you are on dialysis, don't miss any sessions
- ☐ Stay as socially active as possible. Avoid the temptation to isolate yourself
- ☐ If you are depressed or anxious, don't hesitate to talk to your healthcare team.
- ☐ If you believe you have a legitimate grievance, contact QSource ESRD Network 12

What Every Patient Needs to Know

The *What Every Patient Needs to Know* patient booklet has information on kidney transplant including some ideas to make sure you are ready for your transplant once you've been listed. Working with your transplant team, keeping all your appointments and building a strong support system are all important to be "call ready". The booklet gives some ideas on how to prepare yourself for your transplant:

Medical

Emotional

Financial

Practical

Educational

Spiritual

To learn more visit the United Network for Organ Sharing's Transplant Living website at: **https://www.transplantexperience.com** to download the booklet or contact their customer service line to order your copy at 1-888-365-7411 option 2.

Heartland Kidney Network has transitioned to a new identity.

Heartland Kidney Network is transitioning to a new identity. While we will still provide the same support, educational opportunities and resources as we have in the past, we will be now be known as Qsource ESRD Network 12, reflective of our parent company's identity and inclusion of ESRD capabilities.

The name transition aligns with a national trend to have End Stage Renal Disease (ESRD) Networks identify by their Network number rather than a specific name that depicts location or service area. We will continue to serve the ESRD patients and clinicians in Iowa, Kansas, Missouri, and Nebraska.

We're still the same Network – only now you have access to a broader array of services and educational opportunities through our collaboration with other ESRD Networks, Quality Improvement Organizations and national partners.

Contact Us
for information about living well with kidney disease or if you have a concern about your care.

We provide free information, assistance and confidential mediation to the ESRD community.

We're Here for You!

Patient Toll-Free Line
1-800-444-9965

For more information or to file a grievance, please contact:
Qsource ESRD Network 12 | 920 Main St., Ste. 801 | Kansas City, MO 64105 | net12@nw12.esrd.net

www.Qsource.org | www.heartlandkidney.org

Qsource
ESRD Network 12

My Network:
Qsource ESRD Networks

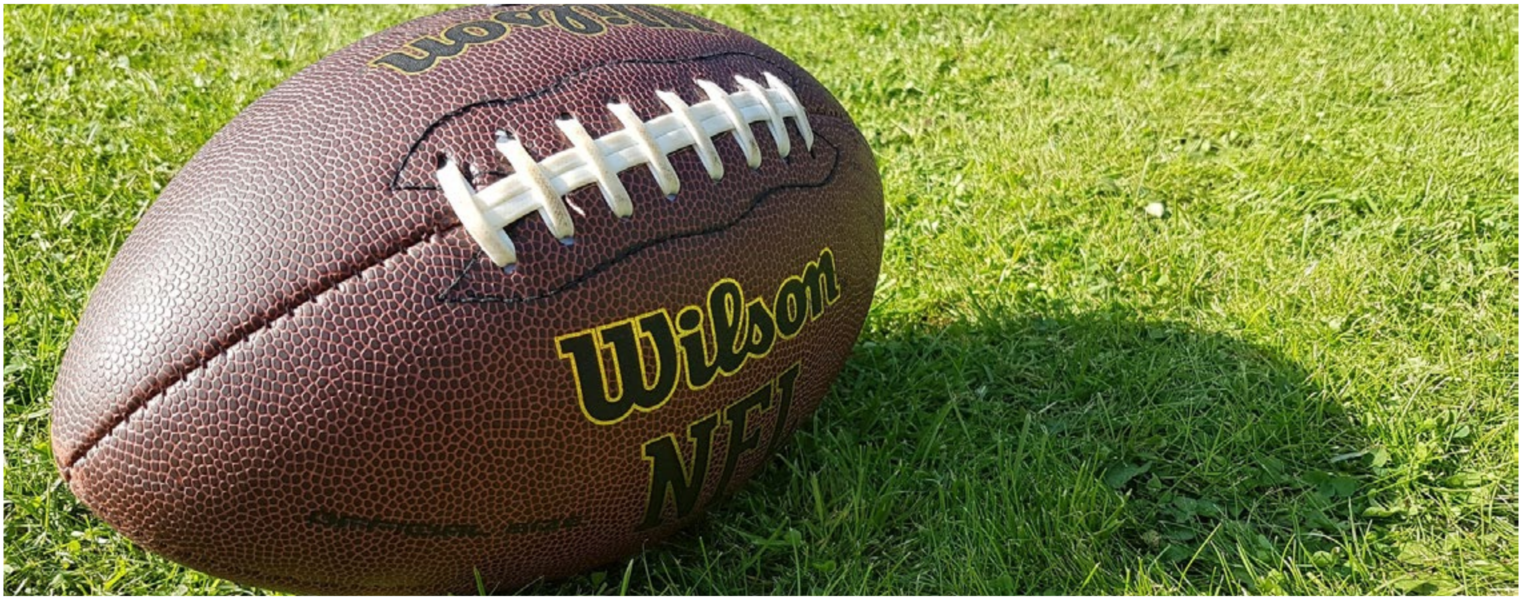
Kidney Disease Makes the News!

An Executive Order was signed July 10 to launch Advancing American Kidney Health, a bold new initiative to improve the lives of Americans suffering from kidney disease, expand options for American patients, and reduce healthcare costs.

The initiative provides specific solutions to deliver on three goals: fewer patients developing kidney failure, fewer Americans receiving dialysis in dialysis centers, and more kidneys available for transplant.

To read the Executive Order in full, visit: **https://www.whitehouse.gov/presidential-actions/executive-order-advancing-american-kidney-health/**

Source: **https://www.hhs.gov/about/news/2019/07/10/hhs-launches-president-trump-advancing-american-kidney-health-initiative.html**



A Low Phosphorus Treat for Game Day!

Herb Cheese With Low Sodium Crackers

Ingredients

2 packages (8 oz each) cream cheese, softened
1/4 cup margarine, softened
2 Tbsp dried chives
2 Tbsp parsley flakes
1 tsp garlic pepper
1/2 tsp dill weed
1/4 tsp thyme leaves
1/2 cup chopped red bell pepper
Low-sodium crackers

Nutrition Facts

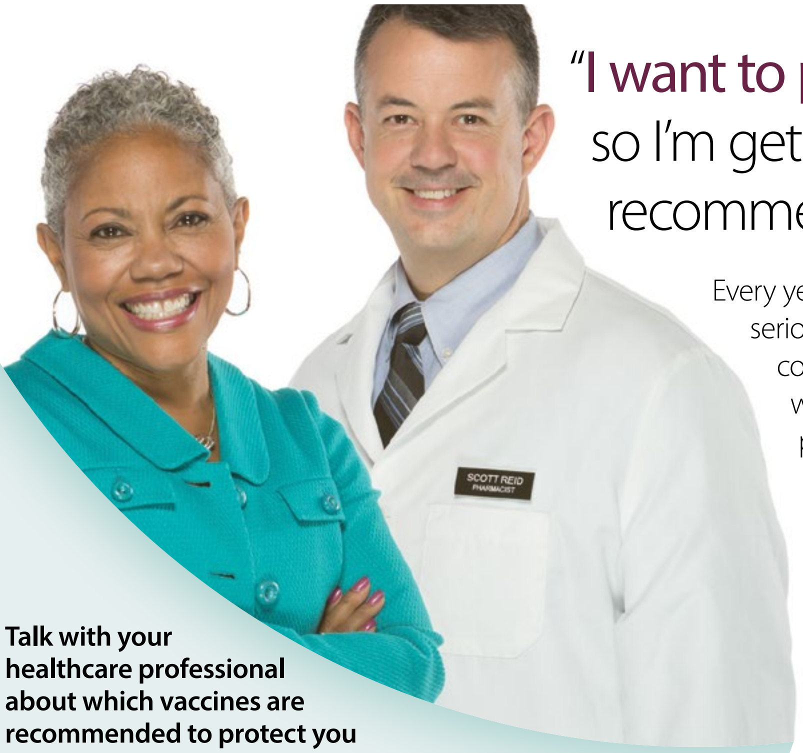
Serves 24
For each 2 Tbsp serving:

Calories	86
Protein	2g
Fat	9g
Carbohydrate	1g
Sodium	83 mg
Potassium	26 mg
Phosphorus	15 mg

Directions

With an electric mixer, beat together cream cheese and margarine until fluffy. Add chives, parsley, garlic pepper, dill weed, and thyme, beat well. Place a piece of plastic wrap in a small bowl. Spoon cheese mixture into plastic wrap. Fold plastic wrap over the cheese to cover. Refrigerate until cheese is firm, about 4 hours or overnight. Unwrap cheese. Turn bowl upside down onto serving platter. Smooth entire shape with knife. Sprinkle with chopped red pepper. Cover and refrigerate until serving time. Serve with your favorite low sodium crackers. Enjoy!

InBalance Low-Phosphorus Recipes. 2010. Genzyme Corp.



“I want to protect my health, so I’m getting the vaccines recommended for me.”

Every year, thousands of adults in America suffer serious health problems from diseases they could be vaccinated against like shingles, whooping cough, hepatitis A and B, flu, and pneumococcal disease.
Some even die.

Talk with your healthcare professional about which vaccines are recommended to protect you and your loved ones.

Learn more at **cdc.gov/vaccines/adults**
or call **1-800-CDC-INFO (1-800-232-4636)**.

DON’T WAIT. VACCINATE!

U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

Qsource ESRD Network 12
920 Main St., Suite 801
Kansas City, MO 64105