



Heartland Headlines

A Special Publication
for people with kidney disease.

In This Issue

- ♥ Medicare Open Enrollment for 2019
 - ♥ 10 Tips to Deal with Holiday Stress
 - ♥ PACTivate: 2018 PAC Summit
- ...and more stories just for you!

**Patient
Insight**



Edition 2 | 2018
www.heartlandkidney.org

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



Heartland Kidney Network
920 Main, Ste. 801
Kansas City, MO 64105

Phone: **800-444-9965**

E-mail: net12@nw12.esrd.net

Web: www.heartlandkidney.org

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.

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. 18.Q-ESRD12.11.095

KEPROs Patient Navigation Program for People with Medicare

KEPRO's Patient Navigation Program is a free program that can help you figure out what care you need and to better understand your care.

KEPRO can:

- Coordinate your care
- Help you think about questions you may want to ask your doctor at your next scheduled appointment
- Give you tips on how to manage your medications
- Help you understand your treatment plan or diagnosis
- Provide resources and information to help keep you healthy

For more information or to apply for the program, call **855-408-8557** and enter extension 8770 when prompted.

Visit KEPRO online at www.keproqio.com.



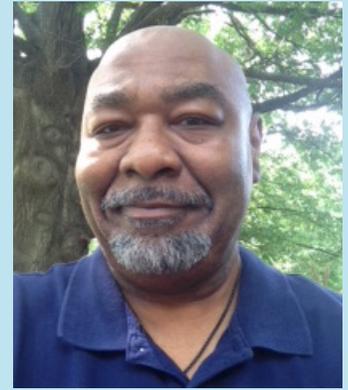
Intro from the PAC Chair

On behalf of the Heartland Kidney Network and the Patient Advisory Council (PAC), we are pleased to present the second edition of the patient newsletter for 2018.

As the PAC Chair, I hope that the articles will be helpful for your journey with kidney disease. In this issue, you will find quotes from PAC members as they share tips and advice on how they stay positive on dialysis and active in their care.

I encourage you to share this newsletter with other patients, family and friends – because with knowledge we have the power to do great things. Enjoy!

Sincerely,
Delmer Esters, PAC Chair



Delmer Esters

We're Here for YOU!

Who is Heartland Kidney Network?

Heartland Kidney Network is part of the End Stage Renal Disease division of Qsource.

We have a contract with Medicare to improve the quality of care for people living with chronic kidney disease in Iowa, Kansas, Missouri and Nebraska.

Under Medicare's direction, we act as a go-between for Medicare, dialysis and transplant centers and conduct quality improvement activities to improve patient care and outcomes through staff and patient education and engagement.

We help patients by making educational resources and increasing patient engagement through the Patient Advisory Council (PAC) and Network Patient Representative (NPR) programs.

In addition, Heartland Kidney Network is here to help you if you have a concern about your clinic. The Network can talk through your concerns with you and then work with you and the clinic to address the problem.

You can always contact us. You do not have to go through the clinic's grievance process first and you have the right to be anonymous.

The Network also works with dialysis clinics and hospitals to advocate on behalf of people who need outpatient dialysis treatment.

Call the Network with your questions or concerns at 800-444-9965.



**My Network:
Heartland Kidney Network**



Medicare Open Enrollment: Time to Make Changes for 2019

Medicare Part D Open Enrollment runs from **October 15-December 7, 2018**. Now is the time to compare plans for 2019 and make sure you have the coverage that's right for you.

Choose Your Part D - Prescription Coverage

Medicare has an online program to help you find the best prescription plan for you.

Have your current medication list with you and visit "Medicare Plan finder" at: <https://www.medicare.gov/find-a-plan/questions/home.aspx> and it will help you to:

- Pick a plan
- Check for formulary (covered drug list) changes
- Check for cost changes

Choose Your Medicare Coverage

Unless you already have a Medicare Advantage Plan before starting dialysis then Original Medicare is your only option (with some exceptions).

Unlike Medicare Advantage plans, Original Medicare allows you to choose your health care providers (ex. allowing for travel out of state and choice of dialysis and transplant center).

You can return to Original Medicare (and add a Part D Plan) during annual Medicare Advantage Disenrollment Period January 1-February 14, 2018.

Each state has a State Health Insurance Program that can help you to find a plan that will work well for you. Make sure to tell anyone helping you that you have kidney disease (ESRD-End Stage Renal Disease).

If you are having trouble paying for your health care you may also want to check to see if you qualify for one of the Medicare Savings Programs assistance programs. Qualified Medicare Beneficiary (QMB), Specified Low Income Medicare Beneficiary (SLMB) or Qualified Individual (QI) can help pay all or some of Medicare's cost sharing amounts (ie. premiums, deductibles and co-payments). To qualify you must have Medicare and meet certain income guidelines that change every year on April 1. Apply through your state Department of Social Services.

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.missouricclaim.org

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

Patient to Patient

Advice to Patients on How to Control Your Dialysis

Greetings to all readers of Heartland Headlines.

My name is Barbara Briggs and my journey with kidney disease began in 1997. At the time I was working and I did my peritoneal dialysis treatment in the lactation room. I hung on to work until I just couldn't do it anymore. I was tired all the time, so I quit work and started using my Social Security Disability benefits.

I received my first kidney in March of 2000.

I was happy as a little lark in a pool of water. My kidney lasted eight years then I started in-center hemodialysis. After the loss of my kidney transplant, I became despondent, depressed and just angry. Finally, I decided "it is what it is". I discovered I could travel to other cities and still get my treatment, so I was good and happy again.

In May of 2017, I received a call at 3:30 am stating there was a kidney available for me and told that it was high risk. I thought it was a prank call or a joke. The nurse assured me this was no joke, so I accepted. "Hallelujah!"

I am happy again and active in my community, I can sleep late and pretty much do whatever I please.

The things that keep me motivated are my family, friends and the support I receive from my church family. I was asked to be a Network Patient Representative (NPR) by my dialysis Social Worker in 2016 and before I could blink I was on every committee possible.

I enjoy what we do because I am able to help others that are having issues, questions and concerns about dialysis.



**Barbara
Briggs**

Medical Review Board
Grievance Committee
PAC NE Representative
NPR-DaVita Dialysis Omaha South

I have several members of my church and friends that are on dialysis. It gives me a sense of pride to be able to help folks and have them come to me for advice.

My advice to dialysis patients or patients preparing to begin dialysis is to **“control your dialysis; do not let dialysis control you or your emotions”**.

At times it gets rough. Don't let the fear of the unknown and or myths you may have heard about dialysis get you down, ask for more information and get the facts. Stay in touch with your doctors, social worker and form a support group or find someone you can bounce things off of.

My final advice to patients would be always ask questions, follow your diet and trust God.

Thank you for allowing me to share my story.



NPR SPOTLIGHT



This year, many of the Network Patient Representatives worked with their clinics to educate other patients on all the treatment options available.

Debra Breckenridge (left) from FMC-Ottumwa, Iowa helped with a kidney transplant awareness bulletin board.

Melinda Sanchez (right) from Garden City Dialysis Center in Kansas helped her clinic with a lobby day on home dialysis options.

Keep up the good work!



**My Network:
Network Patient
Representative (NPR)**



Front Right: Dan Westcott. **Front Row (L-R):** Amelia Warner, Laura Novy, Mark Johnson, Wallace Brown, Carmen Reinke, Yvonne Steele, Ardy Boucher and Jimmy Boucher. **Back row (L-R):** Marcus Chatman; Barbara Briggs, Jerry Ribbing, Mike Warner; Jeramy LaFollette, Chris Eichmeier, Richard Woods, Mike Ashley, Delmer Esters, Gayle Wallace, Avery Wills, Fred Krejci, Mike Bronson. **Not shown:** Denny Burgess, Doug Carrell, Kendra Deike, Steve Langton, Doug Lehman, Kim Lyles, Sean Noble, and Nam Troung-Tran.

PACtivate 2018

Active Patients. Active Advocates. Improving Lives.

On October 12-13, 2018 the Heartland Kidney Network held its annual Patient Advisory Council (PAC) Summit in Kansas City, Missouri.

The PAC guides the Network as we work to improve care for people living with kidney disease. The PAC includes people from Iowa, Kansas, Missouri and Nebraska that are on dialysis, have a kidney transplant or are a caregiver or family member of a current kidney patient.

The current PAC membership has a combined total of 324 years of experience with kidney disease treatments (dialysis and kidney transplant)!

Twenty-three members of the PAC met together to learn more about the Network, celebrate our progress in 2018 and to begin planning for 2019.

It was a great success and we left the Summit with plans for resources to improve the lives of people living with kidney disease in Iowa, Kansas, Missouri and Nebraska.

Thank you to all our PAC volunteers... you all truly make a difference!



NOTE: Permission to share their name and image has been granted by patients depicted for photo usage.

Patient Insight

We asked patients to share their thoughts about dialysis and living as a kidney patient. We hope you enjoy their answers.



Mark Johnson
Iowa



Kim Lyles
Nebraska



Jeremy LaFollette
Missouri



Jerry Ribbing
Missouri



Richard Woods
Missouri

1

How do you stay positive on dialysis?

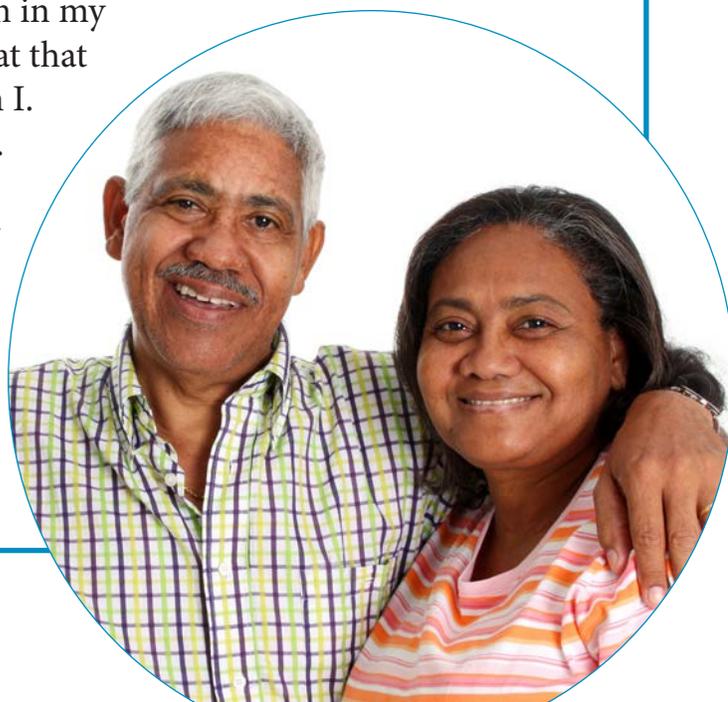
Mark: I do not allow myself to be defined by my disease. I am a person who has kidney failure, not a kidney patient.

Kim: Staying positive on dialysis is easy in that my support group is always there for me. Aside from my family, the staff at my clinic are always cheerful, helpful and have a wonderful sense of humor. They have truly become my “second family”.

Jeremy LaFollette: I try and stay busy and I am learning to find things to do like cleaning my truck out. God, family and friends also keep me positive.

Jerry Ribbing: I choose to stay positive, I am in my situation for a reason. I may never know what that reason may be, but if God is ok with it, so am I. When life deals you lemons, make lemonade.

Richard Woods: It's important for me to stay positive as a patient representative. Lead by example. The unit that I'm part of makes it very easy to be positive. The atmosphere is very welcoming. Being positive becomes contagious!



2 How do you stay active in your care?

Mark: I lean heavily on my support group. My family is actively involved in my physical and emotional well-being, my friends are always willing to listen to my journey, and my dialysis staff keep me focused on the right path.

Kim: I stay active in my care by regularly monitoring my fistula, keeping my doctor appointments and (trying) to get some sort of exercise on non-treatment days. This also helps keep my stress levels under control.

Jerry: I strive to help others, which means to practice what I preach. If I say it, then I must show I do it.

Richard: Being active with my own care is a no-brainer. I informed the staff of any changes that may occur between dialysis sessions. Without a constant line of communication with the nursing staff it would be very difficult for them to have a plan of treatment that best suits my needs.

3 Is there a tip or insight you'd like to share?

Mark: I was never a joiner before dialysis. Now, I joined a church, exercise at the YMCA, help at the local food bank, am on our local library board, and volunteer at a museum. More importantly, for the past 3 years, I have been actively involved with Heartland Kidney Network, the National Patient and Family Engagement LAN and the Kidney Community Emergency Response (KCER) patient workgroup.

Richard Woods: If you're new to renal disease ask questions. This is all new to you. There is a plethora of resources available. Talk to your patient representative or the social worker within your unit. They can point you in the direction in getting answers.



Tools & Resources



My Life, My Dialysis Choice.

This online tool will help you choose the right treatment for you so you can feel your best and live the way you want. It's available in both English and Spanish from the Medical Education Institute (MEI).

Visit : <https://mydialysischoice.org>



My Transplant Coach

This online tool helps patients learn about and understand their condition and to assist them in making the decision for transplant. Developed by Explore Transplant.

Visit : <https://exploretransplant.org/my-transplant-coach/>



KidneyX: Accelerate Innovation for People with Kidney Disease

The Kidney Innovation Accelerator or KidneyX is a partnership between the U.S. Department of Health and Human Services and the American Society of Nephrology. The goal of KidneyX is to speed up the progress of drugs, devices, biologics and digital health tools across prevention, diagnostics and treatment to give patients with kidney failure better treatment options.

To learn more about KidneyX visit <http://www.kidneyx.org>



“It Only Takes a Minute to Save Your Lifeline”

Taking care of your dialysis access is important to keeping you healthy. Here are a few quick steps you can take to check you AV Fistula or Catheter.

If you notice any of the “Stop” signs during your daily access check, contact your dialysis clinic staff.

Download here: <https://bit.ly/2PJcGwZ>



GO!

It Only Takes a Minute to Save Your Lifeline



STOP!

The skin over the access is all one color and looks the same as the skin around it.

LOOK



There is a redness, swelling or drainage. There are skin bulges with shiny, bleeding or peeling skin.

Bruit — the hum or buzz should sound like a “whoosh”, or for some, may sound like the beating of a drum. The sound should be the same along the access.

LISTEN



There is no sound, decreased sound or a change in the sound. Sound is different from what a normal Bruit should sound like.

Thrill — a vibration or buzz in the full length of the access.

FEEL



Pulsatile — the beat is stronger than a normal pulse. Fingers placed lightly on the access will rise and fall with each beat.

Pulse — slight beating like a heartbeat. Fingers placed lightly on the access should move slightly.



My Choices: What I Should Know About Fistulas

10 Tips to Deal with Holiday Stress!

The holiday season can be a stressful time. Use these ten tips when you're faced with a stressful holiday situation!



Keep up healthy habits including your diet, getting enough sleep and exercise.



Take some time to just relax. Try breathing exercises, listening to music, taking a walk or getting a massage.



Planning ahead can help spread out activities such as shopping, cooking and cleaning for family gatherings.



Feel free to say no to additional activities if you are feeling overwhelmed. Pick the most important outings or gatherings to you and politely decline the rest.



When going to gatherings or eating with family you can share why it is important to you to continue your healthy lifestyle.



If alcohol is served at gatherings remember beer is high in phosphorus and mixed drinks are generally high in sugar. Always talk to your dietitian to make sure you are celebrating safely.



Sometimes the holidays can bring up feelings of sadness or grief. It's ok to reach out and share your feelings and get support.



Reaching out to your community by going to events or volunteering can help you feel more engaged and lift your spirits.



Decide on a gift giving budget and stick to it. Talk to your family about doing a gift exchange or making gifts for each other to reduce cost.



Being realistic and flexible about your holiday expectations can help to reduce stress. As we go through life, our expectations and traditions may change, knowing and accepting this may help you to enjoy the season.





healthy. holiday. eating.

Shredded Brussel Sprout Salad with Cherries and Goat Cheese

Submitted by Carmen Reinke, Kansas. Reviewed by Danita Miner, RD.

Serving size: 2/3 cup | Servings: 8

Ingredients

For the salad:

- 1 16oz bag of Brussel Sprouts, trimmed and shredded or thinly sliced
- 1/3 cup dried cherries
- 1/3 cup crumbled goat cheese
- 1 apple chopped (Granny Smith recommended)
- 2 large shallots, thinly sliced
- 1-3 tbsp. olive oil

For the vinaigrette dressing:

- 3 tbsp. olive oil
- 3 tbsp. balsamic vinegar
- 2 tbsp. pure Maple syrup
- 2 tsp. spicy brown mustard
- Freshly ground black pepper, to taste.

This would be acceptable as a medium potassium vegetable serving on a renal diet.

Nutrients per serving:

| | |
|------------|--------|
| Calories | 185 |
| Protein | 4 g |
| Sodium | 75 mg |
| Potassium | 275 mg |
| Phosphorus | 95 mg |

Preparation

1. Place shredded Brussel sprouts, dried cherries, pecans, goat cheese and chopped apple in a large bowl; toss very gently to combine.
2. In a skillet over medium heat, add a bit of olive oil; when oil is hot, add shallots and sauté until a light golden-brown in color, two to three minutes. Transfer shallots to a paper towel-lined plate to drain; let cool.
3. Meanwhile, combine vinaigrette ingredients.
4. Add sautéed shallots to salad ingredients in a bowl, then pour prepared vinaigrette over salad as desired, tossing to coat. Serve at once.

Be Safe! Be Prepared!

While nobody likes to think about being involved in an emergency, being prepared can make a big difference if one hits you.

Most emergencies are minor and pass without major problems (such as a brief power outage), but as a dialysis patient it could be life saving to know what to do in an emergency lasting long enough to affect your health.

The following tips are just a few of the things you should do in order to prepare for an emergency or a life-threatening situation. Heartland Kidney Network has Emergency Preparedness resources for dialysis patients.

Call the Network at [1-800-444-9965](tel:1-800-444-9965), visit our website at www.heartlandkidney.org or check out the My Plan section of the My Kidney Kit.

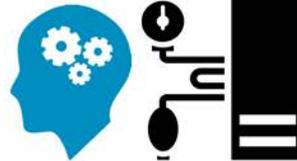
Emergency Tips



Make sure your dialysis clinic has your current phone numbers, for both you and your emergency contact. Remain at home and wait for the dialysis clinic to contact you.



Maintain a week's worth of your medications at all times.



Know how to care for your dialysis access.



Remain at home, but if you must seek shelter, take your week's worth of medication, emergency supplies, personal items, blankets and Medic Alert ID information.



Know your dietary guidelines for emergency preparedness and maintain appropriate dietary supplies. Follow the Emergency Diet provided by your dietitian or download the 3-Day Emergency Diet (Diabetic/Non-Diabetic/Pediatric) that right for you.



**My Network:
My Plan**

Weighing Your Dialysis OPTIONS

Deciding which type of treatment is best for you isn't easy. Your decision depends on your medical condition, lifestyle, and personal likes and dislikes. The key is to learn as much as you can about your choices. The following chart lists some of the pros and cons related to each option.



In-Center Hemodialysis

Pros

- Dialysis centers are widely available.
- You have trained professionals with you at all times.
- You can get to know other patients.

Cons

- Treatments are scheduled by the center and are relatively fixed.
- You must travel to the center for treatment.

Home Hemodialysis

Pros

- You can do it at the times you choose- but you still must do it as often as your doctor orders.
- You don't have to travel to a center for every treatment.
- You gain a sense of independence and control over your treatment.
- Newer machines require less space.

Cons

- You must have a helper.
- Helping with treatments may be stressful to your family.
- You and your helper need training.
- You need space for storing the machine and supplies at home.

Continuous Ambulatory Peritoneal Dialysis (CAPD)

Pros

- You can do it alone.
- You can do it at times you choose as long as you perform the required number of exchanges each day.
- You can do it in many locations.
- You don't need a machine.

Cons

- It can disrupt your daily schedule.
- It is a continuous treatment, and all exchanges must be performed 7 days a week.

Continuous Cycler-Assisted Peritoneal Dialysis (CCPD)

Pros

- You can do it at night, mainly while you sleep.
- You may be free from exchanges during the day.

Cons

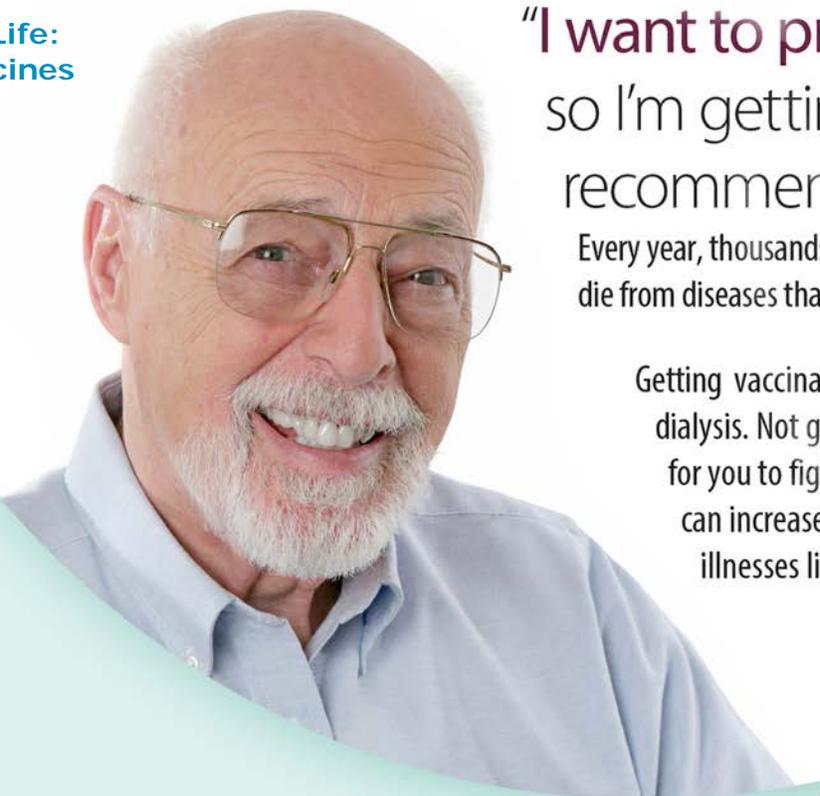
- You need a machine.
- Your movement at night is limited by your connection to the cycler.

Facebook Groups | Connect. Learn. Support

Finding a support group in your area may be difficult but some patients have found Facebook groups to be helpful to connect and learn with each other. Below are a few reviewed and recommended by members of our Patient Advisory Council. While you are there, make sure to Like and Follow Heartland Kidney Network (<https://www.facebook.com/heartlandkidney/>).

All Facebook Groups have this preceding address: [https://www.facebook.com/groups/\[enter group\]](https://www.facebook.com/groups/[enter group])

- Chronic Kidney Disease Support Group [[CKDSupport](#)]
- Dialysis Uncensored [[DialysisUncensored](#)]
- Home Dialysis Central [[HomeDialysisCentral](#)]
- Kidney Disease, Dialysis, and Transplant [[2229039880](#)]
- Kidney Disease and Diet Ideas and Help [[kidneyhelp](#)]
- Peritoneal Dialysis Support Group [[peritonealdialysissupportgroup](#)]
- S.T.R.I.V.E. Kidney [[1922819084599979](#)]
- Woman's Renal Failure Support Group [[womansrenalfailuresupport](#)]



"I want to protect my health, so I'm getting the vaccines recommended for me."

Every year, thousands of adults suffer, are hospitalized and even die from diseases that could be prevented by vaccines.

Getting vaccinated is even more important for people on dialysis. Not getting vaccinated means it may be harder for you to fight off certain diseases - like the flu - and can increase your risk of serious problems from illnesses like pneumonia.

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



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