

Heartland Headlines

A Newsletter for Kidney Patients



In Memory of James Annuschat

Heartland Kidney Network would like to honor the memory of James for his years of service to the kidney community. James served on the PAC since 2013 and was the Chair 2015-2016. He was a tireless patient advocate and wanted all patients to know they could live a good life with dialysis. He will be missed dearly. We hope that you will find this newsletter helpful to you on your journey. Be sure to check out the video and website links throughout the newsletter for more information.

Patient Advisory Committee members during a recent meeting in Kansas City from left: Back row: Darrell Sunderman, Fred Krejci, Sean Noble, Mike Ashley, Mike Bronson, Bill Thieret, Delmer Esters. Middle row: Carmen Reinke, Mike Warner, Barbara Briggs, Judy Robbins, Ardy Boucher, Kendra Deike, Jeff Walser, Yvonne Steele, Avery Wills. Front: Denny Burgess and Mark Johnson.

 [My Network: PAC](#)

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Patient to Patient **Living with Faith, Gratitude and Hope**

My name is Mike Bronson. I was diagnosed with idiopathic primary focal or segmental glomerulosclerosis (FSGS) three months after my wife and I were married. (If you know of former NBA stars Alonzo Mourning or Shawn Elliott, we share the same disease. We do not share the same basketball talent!) The Lord blessed me and I didn't enter ESRD for 24 years. A woman I baptized in another city learned on Twitter that I needed a transplant. After four months of peritoneal dialysis in 2009 she gave me the gift of life. You can read more about my story at <http://mbcpathway.com/2009/11/24/organ-donor-saves-life/> or <http://www.nebraskamed.com/article/172/thanks-and-giving-transplant-story>.



The FSGS recurred a month later. Since then I've undergone seven or eight subclavian catheter placements, over 120 plasmapheresis treatments and all the financial and emotional expenses that accompany this terrible disease. But take heart! You can live a full life with renal failure. God has given me three grandchildren. I continue to carry out the work God called me to do as a pastor. My

wife and I are knit together in love more than ever before. The sanctity, transiency, and fragility of human life are crystal clear. It increases motivation. It grows gratitude. There is great clarity in sorting out that which does not matter and that which has eternal value.

The encouragement I want to extend to you is that you can do this! Regardless of your treatment modality, there is a life ahead of you. You will experience stages of denial and fear and despair. Lean on family and friends for emotional support. Never let fear get the best of you. Listen and learn about your disease. You have an entire army of incredibly skilled and dedicated professionals who will help you not only find the best treatment modality but to help you live to the most normal extent possible. Because of what you may be enduring as you read this, you may think you have no purpose in life but you do! Find it, follow it and finish it! God bless you!

- Mike Bronson
PAC Member, Kansas

**All individuals in this newsletter have provided consent to release their name and images.*



Common Transplant Myths Set Straight

Myth: You can't get a transplant if you're over the age of 60.

Fact: Your overall health is more important than your age. People over age 75 have received transplants.

Myth: Since I am an ESRD patient and on dialysis, I am automatically on the transplant waitlist.

Fact: You must get evaluated and accepted by a transplant center to be on the waitlist. If you are unsure if you are on the list, contact that transplant center directly.

Myth: If I am denied by one transplant center, I will not be able to get on the list at any other center.

Fact: Each transplant center has their own criteria for transplant eligibility.



My Choice: Talk Transplant

Be Informed: Use Medicare's 5 Star Rating

Medicare has developed the **5 Star Rating** system to help patients compare the care given by dialysis clinics throughout the country. Clinics can earn between one and five stars. The more stars a clinic has, the higher the quality compared to other clinics and the higher the quality when compared to the current national average. A rating of 3 stars means a clinic is providing a quality of care equal to the national average.

What do the stars mean?

- 1: much below average
- 2: below average
- 3: average (national average)
- 4: above average
- 5: much above average

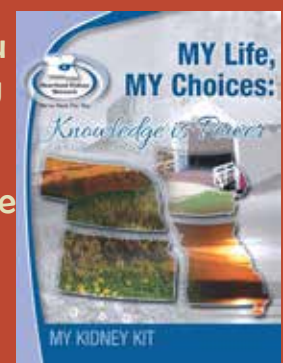
If you are thinking of changing clinics or planning to travel, you can use the Star Ratings and Dialysis Facility Compare to get more information. Visit <http://www.medicare.gov/dialysisfacilitycompare/> to compare clinics by Star Ratings, learn what questions to ask and more! To learn more about the Star Ratings visit the National Kidney Foundation website at www.kidney.org for a great **article** or visit the Renal Support Network at www.rsnhope.org for a **podcast** on the topic.



My Network- Dialysis Facility Compare



Throughout this issue you may notice a "magnifying glass symbol" at the end of certain articles. This symbol indicates that you can find more information about the topic located in the MY KIDNEY KIT at your clinic, visiting www.mykidneykit.org or by clicking the link.



Be Healthy Be Happy!

Seasonal Affective Disorder (SAD) is real for many people especially during the winter months. Everyone can benefit from knowing the signs to look for and how to keep your mood bright when the days get shorter.



Brighten up.

Let in natural light.

As the days get shorter, you may feel down. You might feel blue around the winter holidays, or get into a slump after the fun has ended. However, some people may have more serious mood changes every year that require more help. SAD is a type of depression connected to changes in the seasons. SAD is more common in the winter because of shorter days and less sunlight. It can cause moodiness, decreased



Keep calm.

Try yoga or meditation.

energy, irritability, appetite changes, sensitivity, sleep changes or loss of interest in activities.

SAD can be caused by:

- Shorter days during the winter months. Your biological clock changes due to less sunlight, which may lead to feelings of depression.
- Less sunlight may also lessen serotonin, a chemical in your brain that may trigger depression.



Be active.

Exercise, socialize or volunteer.

- A chemical in the brain called melatonin helps you sleep. More dark hours during winter can affect production of melatonin, affecting sleeping and mood.

*For More Information visit <https://newsinhealth.nih.gov/issue/Jan2013/feature1>



My Life

Talk with your doctor or social worker if sadness doesn't go away or interferes with your daily life. These "self-care" tips might help with seasonal depression:

- **Go to a movie, take a walk or do other activities you enjoy.**
- **Get out in the sunlight or in brightly lit spaces.**
- **Spend time with other people, socialize or volunteer.**
- **Keep a regular sleep/wake schedule.**
- **Eat healthy foods and avoid too much sugar.**

Your feedback is important to us!
Please visit:
https://www.surveymonkey.com/r/HKN_HH
to tell us what you think about this newsletter.

Take on Needle Fear

As part of one of the Network projects in 2016, we asked patients why they do not have their dialysis catheters removed. Over 400 patients responded and told us that fear is the number one reason. Here are some ways that have worked for others to train your body not to react to the fear:

TIP 1: Bring more blood to your head - Lie flat, or tilt the chair so your legs are above your head when you get a needle stick.

TIP 2: Kill the Pain - Use a pain killing cream or gel to numb the site.

TIP 3: Get Therapy - Ask your doctor or social worker to refer you to a therapist who can help you work on ways to lessen your fear.

TIP 4: Take Charge of Your Needles. Sticking yourself puts you in control. It distracts you from the pain, so you feel it less, and helps your access last much longer.

TIP 5: Avoid Needles - Choose peritoneal dialysis (CCPD or CAPD), treatments that don't use needles.

For more information visit: <http://www.homedialysis.org/life-at-home/articles/dialysis-needle-fear> Reference: Dialysis needle fear: Easing the sting. 2005, Medical Education Institute, Inc.

Stay Healthy: Get the Flu Vaccine

The flu, or influenza, is a serious health threat. This is true especially for people on dialysis who are at high risk for hospitalization and complications. Most dialysis clinics will give your vaccine while you are there, saving you a trip to the doctor.



[My Life: Vaccines](#)

Medicare Open Enrollment

Open October 15th -
December 7th

Every year, people on Medicare have a chance to make changes to your Medicare plan including Part D- prescription drug coverage. Now is the time to make any changes for 2017. For more information visit www.medicare.gov/part-d.



[My Network: Medicare D](#)

Be Ready!

An emergency or a disaster can occur at any time. As a kidney patient you need to know ahead of time what you can do to stay healthy during an emergency. Having an emergency kit and plan can help you be prepared.

Tell your family, doctor and clinic what your plan is. Make sure your clinic has your correct address and phone numbers including emergency contacts and out-of-state contact numbers. Visit <https://www.ready.gov/prepare-for-emergencies> for more information.



[My Plan](#)

Programs that Work for YOU



Are you interested in continuing to work, returning to work or entering the workforce for the first time? There are free programs available to help increase financial independence and self-sufficiency for people living with disabilities like kidney disease. Vocational Rehabilitation (VR) is available to help people with disabilities keep working through job training and educational programs. Social Security's Ticket to Work program is a free and voluntary program for people ages 18-64 who are blind or have a disability and who get Social Security Disability (SSDI) and Supplemental Security Income (SSI) benefits. To learn more about Ticket to Work call the Help Line at (866)968-7842, visit <https://choosework.net/> or watch a video at <https://youtu.be/VOq5hf0MsHg>.



[My Life: Occupation](#)

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

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Qsource
 ESRD Network Strategies



We're growing!
 We've partnered with Qsource
 to form QSource ESRD
 Network Strategies. Together,
 we're making
healthcare. better.

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 #HSM-500-2016- 00012C. The contents present do not necessarily reflect CMS policy.

Life Beyond the Chair: NPRs at Work



Dirk Huston, Omaha, NE



[My Network: NPR](#)

Ardy Boucher, Des Moines, IA

Throughout the Network, patients are helping improve care in their clinic everyday for everyone. Dirk and Ardy are both active as Network Patient Representatives at their clinics. This year, they worked with their clinics as part of a 2016 Network quality improvement project. They both helped by providing ideas and made some fun and educational bulletin boards. Thanks for all you do!!!