

Heartland
Headlines

A Special Publication
for people with kidney disease.



Managing Stress

In This Issue

- 📍 One Generous Act + One Kidney = Two Lives Changed!
 - 📍 Immune Boosting Foods for Renal Patients
- ...and more stories just for you!

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



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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.

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A Message from the Patient Advisory Council Chair



When I joined Network 12's Patient Advisory Council (PAC) almost 4 years ago, I knew little about the PAC's role with the Network. Over the ensuing years, I have become immersed in PAC activities which has led to my increased involvement in kidney patient advocacy. I'd like to share more about the Network and what they do to help people living with kidney disease.

When the ESRD Networks were first established, it was determined that the patient voice needed to be an integral part. The PAC provides the Network with the patient voice to help meet the needs of dialysis patients and their families and improve the quality of care they receive. The PAC is a diverse group of people who are on dialysis, have received a kidney transplant, or are the care partner/family member of someone with kidney disease. Members represent the states of Iowa, Kansas, Missouri, and Nebraska. The PAC brings in new members each year to ensure that new voices are part of the continuing evolution of the PAC.

As a PAC member, I act as a liaison between the kidney community and the Network. After my first PAC meeting in Kansas City, MO, I was given the opportunity to represent the Network at a national level for the next three years through the ESRD National Coordinating Center Learning and Action Networks. In addition, the Network staff holds monthly meetings with PAC members discussing topics ranging from Quality Improvement Activities (QIAs) to input into what needs to be included in educational materials for patients and families/care partners. One of the most successful projects that I was privileged to participate in, was an educational forum with patients and staff held in

the Kansas City area last year. The hope is that we can hold more of these events in the other states in the future.

As a member of the Board of Directors (BOD), I represent the PAC in the BOD's duties to oversee the operations of the ESRD Network 12 contract with Medicare. The Network also has a Medical Review Board (MRB) that gives the staff guidance on quality improvement projects and helps set the standards of care in our community. Like the PAC, the BOD and MRB members are volunteers. Members represent all fields involved with end stage renal disease (ESRD) care including kidney doctors, transplant surgeons, nurses, social workers, dietitians and patients from across the region.

Some of the topics that the BOD and MRB have discussed include the Network's handling of patient grievances, the positive influence of Network Patient Representatives on QIA participation and, most recently, the Network's approach to the COVID-19 crisis.

In this issue of the *Heartland Headlines* patient newsletter, in addition to a patient and living donor story, we have asked several people from the Medical Review Board to share with you. Until our next edition, take care and live strong with kidney disease!

Mark Johnson is currently on in-center hemodialysis in Atlantic, Iowa where he has been the Network Patient Representative since 2016. Mark has been on the PAC since 2016 and currently serves as the Chair and member of the Board of Directors.

Working to Improve Care for Kidney Patients

Qsource ESRD Network 12's focus is on improving the lives of people living with kidney disease in all that we do. Network 12 works with patients and staff at dialysis clinics and transplant centers, in Iowa, Kansas, Missouri and Nebraska to help them make care better for those they serve. The Network gets advice from our Patient Advisory Council, Medical Review Board and Board of Directors, which includes patients and family members from the area, to guide our work.

The Network does a lot to help make care better so people with kidney disease can live their best lives. We do this by:



Helping patients learn more about kidney disease, dialysis and transplant



Helping patients if they have a complaint about the care they get



Helping patients and the clinic staff work together to solve problems



Making sure patients can get the dialysis care they need



Working with staff to share ways to make care better



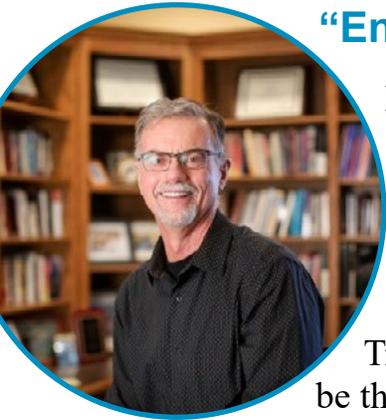
Working with the State Survey Agencies to make sure patients are safe

To learn more visit us online at www.ESRDNetwork12.org



One Generous Act + One Kidney = Two Lives Changed!

In this issue of *Heartland Headlines* we've paired our Patient-to-Patient story from Mike Bronson, a kidney transplant recipient, with a story from his living donor, Tonya Blythe. Their stories can give us all hope as it truly shows how a generous act can change lives.



“Enjoy the day and be hopeful for tomorrow.”

I was diagnosed with kidney disease in 1985, three months after I was married. End stage renal disease (ESRD) didn't arrive until 2009.

Transplantation seemed to be the best option in terms of lifestyle, life span, and the ability to continue in my vocation. Tonya contacted me that spring and offered to donate. Tonya went from the “on-deck circle” to the “batter's box.” I will always be grateful for her courage and her selfless love.

While she was being evaluated, I went on home peritoneal dialysis. I started with Continuous Ambulatory PD (CAPD), then I switched to Continuous Cycling PD. I am a pastor and desperately wanted to continue working, but my strength faded fast. If you're reading this and you're on any form of dialysis, you are a hero. It is hard, is it not? Fortunately, I wasn't on dialysis long. In October 2009, I received Tonya's gracious gift. (By the way, how do you adequately thank someone who gave you a vital organ?)

I started to feel well for the first time in years. For about two weeks, I didn't know a person could feel that well. However, two months after transplantation, my disease, focal segmental glomerulosclerosis (FSGS) returned. I felt oddly at peace, but struggled to tell Tonya. It felt like I failed her. Sometimes you must talk yourself out of false guilt.

I've had about 150 plasmapheresis treatments, four bouts with sepsis, and raised two children

while having a chronic illness. Yet here I am 10 years after the transplant and going strong. Why? First and foremost, my faith in Jesus sustains and motivates me. Second, we have dedicated medical professionals who attend to us. Make them your friend. They have struggles just as we do. If you love your neighbor as yourself, it's amazing how that eventually comes back to you.

Your state of mind is also important. As a man thinks, so is he. I struggled with depression while on dialysis, and for a time after the disease recurrence. There's no shame in that. I went on an anti-depressant for a time. It helped. Then I realized it wasn't helping. So I stopped it. It sounds simple. And it was.

My wife was also crucial in my road to better physical and mental health. Today I still work full time. I have four grandchildren I would not have met without Tonya's gift. I am loving life and seeing good days.

I want to encourage you to eat right, follow your doctors' orders, exercise as much as possible, and stay socially connected. And as much as possible, enjoy the day. Someone once said, “Yesterday is history, tomorrow is a mystery, today is all we have.” Enjoy the day and be hopeful for tomorrow!

Mike Bronson is a kidney transplant recipient and lives with his family in Tonganoxie, Kansas where he works as a pastor. Mike has served on the Patient Advisory Council since 2016, is currently the Vice Chair and in 2019, he became the Kansas patient representative on the Medical Review Board.

Talk Transplant: A Living Donor's Perspective

In spring 2009, I became aware of Mike's struggle to find a living kidney donor after a simple tweet about his blood type (O, same as mine) caught my eye. Knowing next to nothing about the living donation process (or really about organ donation at all), I sent him a message asking what someone would have to do to become a donor. I was relieved to find out that he had a potential donor who was already involved in the testing process, but vowed to make contact with Mike's transplant coordinator for more information.

Early on, my "why" was simply my faith in Jesus and a desire to help a friend in need. However, after learning more about the need for life-saving organ transplants, I was also burdened by the notion that so many people were needlessly suffering, because they weren't receiving a gift that I (and many others) could give so freely.

A few months later, Mike's potential donor was turned down due to a previously unknown medical issue and my evaluation process began in earnest. Over the course of the next three and a half months, I underwent the same battery of exams as all of his previous potential donors including lab tests, an EKG and chest x-ray, a psychological evaluation, and more. Even though Mike and I lived a few hours apart from one another, I was able to complete most of this testing locally with minimal time away from family and work until the surgery itself in October 2009.

My kidney was removed through a procedure called a laparoscopic nephrectomy; three small incisions were made in my abdomen and a camera was inserted to help guide the surgeon

throughout the surgery. Admittedly, the days following my surgery were difficult; however, I was able to return home a few days later with a return to normal daily activities after 4-6 weeks. I had a support system of friends, family and co-workers in place which helped greatly throughout my recovery (especially with an active one-year-old at home!).



For patients in need of a transplant, I can only imagine how difficult the "ask" must be. Know that your life is worth it! To those who are struggling to approach family and friends about the possibility of donating, or to those who are considering a donation, I would want them to know that while the process itself can seem difficult, the blessings I have received by giving this gift have been significant and long-lasting.

Tonya Blythe is a wife to Jon and mother to Javan, Aaron, Tiras, Elsie, Jackson and KJ. Tonya and her family live in Gladstone, Missouri where she works part-time along with homeschooling two of their children.

For more patient stories, visit our website at esrdnetwork12.org/patients/patient-stories/

To find out more about living donation and starting the conversation visit:

www.donatelife.net

or

www.transplantexperience.com



Like us on [Facebook](#) to get updates on new patient stories.

Coming soon...

VIP Renal Review Podcast





A Message from the MRB Dietitian Stay Well My Friends

During this uncertain time you are being challenged by everything around you. Being quarantined or practicing social distancing by limiting your appearances out in public makes you more susceptible to three out of the four eating cues: boredom, stress and access to foods in your stocked pantry. The fourth cue is social gatherings, since this pandemic has taken care of this one, you will need some armor to fight off the other three or you could end up gaining some unwanted weight or ending up in the hospital.

When tackling food and eating cues practice mindful eating strategies:



Really start listening to your body. Pay attention to your body cues and stop eating when you have had enough. Place a portion of food on your plate to avoid overeating making your body feel full or sluggish.



Listen to your body tell you it is hungry. Are you really hungry right now? Is your stomach growling? Is your energy low? Are you unable to focus on a project? Make sure to limit eating when your emotions tell you that you are hungry – I have worked hard, I deserve this. If you are not hungry and it is emotions getting the best of you – try taking a little walk to the end of the block and back or practice some stretching.



Eat at set times, not just randomly throughout the day. Eating planned meals and snacks throughout the day will help arm you against binge eating and random snacking. Focus on eating when you are eating. Do not sit down and watch television or play games. Be mindful of the good foods you are putting into your body.



Eat foods that are nutritional and healthful. Stock your pantry with foods that will boost your immune system (see 10 Immune Boosting Food Favorites on the next page). Foods that contain nutrient dense ingredients will stay with you and feed your body longer than foods that have more calories and sugars.



Remember to pay attention to your body cues. Choose foods that are full of vitamins and nutrients not just fillers and empty calories. This is one of the ways you can help your body defend itself against unwanted viruses and other illness.

Kathleen Upton is a dietitian at DaVita Omaha West in Nebraska. She has served on the Network 12 Medical Review Board since 2017.



10 Renal Friendly Immune Boosting Food Favorites



Apple Cider Vinegar holds special antiviral properties and contains some probiotics obtained during the fermentation process.



Black Tea contains compounds that defend your body against bacteria and viruses. Make sure to stay in your fluid recommended limit.



Cinnamon contains compounds that reduce inflammation, protect against viruses reproducing and inhibit the growth of microorganisms.



Garlic contains compounds that help to fight the viruses that have invaded your body.



Ginger contains compounds that protect the body by limiting the viruses ability to attach to other cells.



Lean Protein contains zinc and proteins that work together to strengthen your immune system.



Mushrooms contain compounds that help to limit the virus cells from replicating and assist with reducing inflammation.



Seafood contains Omega-3 fatty acids that enhance immune cell function and can enhance the activity of white blood cells to strengthen your immunity.



Vitamin C-rich foods (like bell peppers, strawberries, blueberries, lemons, broccoli and kale) are antioxidants that assist with supporting cellular function to boost your immunity.



Yogurt contains probiotics to fight viral infections that could affect your respiratory or gut systems.

Talk with your dietitian for insightful and different ways to use these nutrients to fuel your body's defense against viruses.





Medicare, Kidney Transplant, and Work

Are you thinking about getting a kidney transplant, but have questions about Medicare’s coverage after transplant? Currently, Medicare coverage for the immunosuppressant medications covered under Part B and other medications under Part D continues for at least 36 months after transplant. To be eligible for Medicare after the 36 months following kidney transplant, you must continue to pay your Part B and Part D premiums and meet at least one of the following requirements:

- be 65 years or older; or
- be disabled for a reason other than kidney disease; or
- return to dialysis within 36 months

There are Social Security Work Incentive programs that can help transplant recipients continue their Medicare beyond the 36 month period.

Continuation of Medicare

Those with transplants who work with a disability in addition to ESRD can keep Medicare if work earnings:

- are too low to count as a month of trial work; or
- after the 9-month trial work period stay below the substantial gainful activity level; or
- are above the guidelines. Social Security Disability Insurance (SSDI) payments may stop.

Continuation of Medicare extends free Medicare Part A, premium Part B and Part D for 93 months starting the month after SSDI ends.



My Life: Occupation; My Network: Medicare Part D

Continued Payment Under Vocational Rehabilitation (VR)

Those with transplants who have no other disability beside ESRD can keep their SSDI and Medicare (Supplemental Security Income (SSI), any state supplement and Medicaid) if:

- they are in a VR program before medically improved (successful transplant after one year); and
- the Social Security Administration determines the program will make it more likely the person will be no longer need disability payments forever.



SSDI and Medicare (or SSI and Medicaid) continue until the person finishes the program, stops working with VR or Social Security decides continuing with the program will not increase his/her likelihood of staying off the disability rolls for good.

Ticket to Work

Help Line at 1-866-968-7842 or visit www.choosework.ssa.gov



Vocational Rehabilitation Services

Iowa | Vocational Rehabilitation Services
800-532-1486 or <https://bit.ly/2Xku6Ay>

Kansas | Rehabilitation Services (SRS)
866-213-9079 or <https://bit.ly/2GmfaLn>

Missouri | Vocational Rehabilitation
877-222-8963 or <https://bit.ly/2Ip2xT5>

Nebraska | Vocational Rehabilitation Services
877-637-3422 or <https://bit.ly/2Zi6C0o>

Easterseals Nebraska Ticket to Work
800-471-6425 ext. 102 or email ttw@ne.easterseals.com

Department of Veterans Affairs

Contact your local VA. Call 1-844-698-2311 or www.va.gov/careers-employment/

Plan for Achieving Self-Support (PASS)

Contact your local Social Security office or call 866-592-1755 ext. 23014 or visit www.ssa.gov/disabilityresearch/wi/pass.htm

Additional Resources

"Finding work during the COVID-19 crisis" by Melanie Kahn, American Kidney Fund
<https://bit.ly/2SDfPPq>



Tips for Managing Stress

“The Only Thing That Is Constant Is Change” — Heraclitus

One thing we can always count on is that change will happen. Sometimes we will have control over it, other times we will not. Sometimes it will be positive and sometimes negative. Luckily, we have control over how we respond to change and the stress that it can bring. Here are a few ways to help deal with stress so that we can cope with change, especially during this time of living with COVID-19.



Stay connected. Set up times to do phone or video calls with your loved ones.



Get the facts. Having the correct information can help you to make good decisions for yourself. Make sure that you are getting your information from credible sources.



Set limits. Limit your time on social media and TV news. It’s important to get updates, but being connected can increase your stress.



Stay Active. Keep your mind and body active. Take a walk, practice yoga, work in the garden, read a book, do a puzzle or craft, try baking or cooking, learn something new.



Get outside. Being outside can brighten your mood.

“I enjoy baking anything out of a simple yeast dough. Working it with your hands is an excellent stress relief, and forming loafs, rolls or breadsticks is calming. Not to forget, that this tastes so much better than store-bought bread.”

-Anja Schlagel, kidney transplant recipient, PAC member from Kansas



My Life: Coping With Dialysis



Take Deep Breaths. Take a few minutes every hour to practice deep breathing. Focusing on your breath slows your body's "fight or flight" reaction to pressure or fear, and it pulls your attention away from negative thoughts.



Inhale deeply for a count of six, hold for three, then exhale slowly to the count of three. Repeat the process five to six times.



Meditate. Meditation is linked with feeling less stressed.



Listen to music. Music can help to calm you down or boost your mood.



Laugh. People who laugh heartily, on a regular basis, have a lower standing blood pressure than does the average person.



Be grateful. Focusing on what we are grateful for can help us from getting stuck in negative thoughts.



Create a Gratitude Jar. Use an empty jar or cup and small notepad. Fill it by writing notes with memories and happy thoughts, kindness and good deeds, funny moments, future plans and big and small victories.

If you are having difficulty coping or if at any point you feel overcome by feelings of sadness and hopelessness, you should talk with someone you trust such as a social worker or your doctor. To find help in your area contact **The Hopeline** at **1-800-273-8255**.

Honoring a Beloved Kidney Advocate Yvonne Steele (Oct. 30, 1950- April 18, 2020)

On behalf of the staff of Qsource ESRD Network 12, our boards and the Patient Advisory Council, we would like to honor the life and memory of Yvonne Steele. Yvonne was a huge advocate for Peritoneal Dialysis as she was able to live well on PD for over 10 years, working as a cosmetologist, doing Zumba and volunteering her time. She was a Network Patient Representative for her dialysis center since 2010 and joined the Network PAC in 2013. She also spoke to patients at Missouri Kidney Program events sharing about her best friend - her PD cyclist. Yvonne's passion was contagious and she made an impact on everyone she met. We will truly miss her smile, generous heart and passion for helping people with kidney disease.





A Message from the MRB Chair Preethi Yerram, MD

As I write this piece, I am being bombarded in all different directions with emails, news items, and ever-changing guidelines relating to COVID-19. I am certain that my patients with kidney disease are in a similar situation, and it can all be very overwhelming. Patients with kidney disease are a vulnerable group with potentially higher risk of COVID-19 complications, and it is important to protect yourself by following good hygiene and other precautions as outlined by the Centers for Disease Control (CDC) and your healthcare team. There is a lot of information coming at you during this time, and it is vital that you separate fact from fiction. One way to ensure this is by only relying on legitimate sources of information such as the CDC (www.cdc.gov/coronavirus), the National Kidney Foundation (www.kidney.org/covid-19), ESRD Network 12 (www.qsource.org/coronavirus or **1-800-444-9965**), and follow the advice given by your healthcare team.

It is important for patients on dialysis to continue their treatments during this time and stay in touch with their dialysis team. Also, talk to your friends and family about your situation, and tell them that you may be needing their help and ask for it when you do. It may be as simple as getting your groceries, picking up medications, dropping off food, or driving you to your dialysis treatments. Your healthcare team is your ally. Reach out to them for any help if you feel ‘stuck’. We are in this together and can only succeed if we take a team approach in dealing with it. I am certain that we will eventually prevail, but these are trying times, and will test all our collective resolve and strength. Wishing everyone good health!

Dr. Yerram is a nephrologist at the University of Missouri in Columbia. She has volunteered on the Network 12 Medical Review Board since 2014 and is the current Chair.

Visit TheKidneyHub.org

The ESRD National Coordinating Center (NCC) has a new patient web tool available. TheKidneyHub.org was created by patients, for patients. On the site you can find information about COVID-19, Transplant, Home Dialysis, Infection Prevention, Well Being, New Patient Education, and the Kidney Community Emergency Response Coalition.



My Network: My ESRD Network



Tips to Stop the Spread and Prevent COVID-19

Older adults and people who have underlying medical conditions like kidney disease are at a higher risk for developing serious complications from COVID-19 illness. Here are a few important reminders to help dialysis patients get through the pandemic together.



Do not miss treatment



Keep a supply of medications and food



Know the signs of COVID-19



Be flexible



Follow the CDC Guidelines:

- Wash your hands often with soap and water for at least 20 seconds.
- If a sink is not available, use an alcohol-based hand sanitizer.
- Avoid touching your eyes, nose, or mouth as much as possible.
- Outside of your home, stay at least six feet away from people and wear a mask.
- Cover your coughs and sneezes with a tissue and then discard it.
- Clean and disinfect any objects and surfaces that you touch.



Travel safely to/from dialysis:

- Bring disinfectant wipes to clean all high-touch areas.
- Wear gloves or use hand sanitizer often.
- As soon as you get to your clinic, go the closest available sink and wash your hands.
- Bring your own pen to sign in. Do not use a shared pen from your ride or at the clinic.
- After your ride, when you get home, wash your hands.



NPR Spotlight

Home Dialysis Advocate and Care Partner on a Mission

Since summer 2019, Dawn Bates has been a Network Patient Representative (NPR) for Tri-State Dialysis in Dubuque, Iowa. As a care partner for her husband Jimmy, she is not only a great advocate for home hemodialysis, but also understands the support needed for patients and their partners to be successful at home.

Patients often may feel isolated after they move from in-center dialysis to home because they miss the support they get from seeing other patients and staff three times a week. Seeing the need, Dawn has been hosting a monthly support group for home patients and their care partners. She uses the resources shared each month on the NPR Connection Calls to make sure other home patients and their partners have the information they need to live well with dialysis. For example, in February the topic was “My Wishes.” They briefly talked about the importance of sharing their wishes with family and loved ones and about quality of life over quantity of life. The group shared the positive things they have experienced by doing home dialysis.

- No early mornings
- Freedom to travel
- Less dietary restrictions
- Ability to work full-time
- Less chances of being exposed to illnesses
- Can do dialysis on my time
- Can be a homebody if I want to
- Less depressing than being in center

Everyone in the group is very grateful for the care they receive from Tri-State Dialysis Center and feels that the home dialysis nurses always go above and beyond in the care provided.



In addition to the support group, Dawn is working with the clinic staff to help educate patients about home dialysis. Dawn and Jimmy helped with a Lobby Day at their clinic by bringing in his NxStage machine and sharing their story with patients and their families. They are also working on a bulletin board with pictures from the support group sharing what they can do because they are on home dialysis and are planning a picnic for the summer.

The new social distancing guidelines haven't stopped their support group from having a conference call to share and connect! For more information about support groups including online and phone support visit the Network website at: <https://bit.ly/2y76GHA>.



Alternative Ways to Manage Pain

The Centers for Disease Control and Prevention (CDC) wants you and your doctors to think about other ways to help with chronic pain besides prescription opioids (E.g.: oxycodone, hydrocodone, morphine). Talk to your doctor to see if any of these may help you. Visit <https://bit.ly/35csLk8> for more information.

Pain Relievers



Non-opioid pain pills such as Tylenol, Motrin, or Naprosyn

Antidepressants and Anticonvulsants



Certain medications also have benefits for treating depression and seizures

Exercise



Physical therapy and exercise have been shown to lessen pain symptoms

Cognitive Behavioral Therapy



Changing thoughts and behaviors related to pain

Telehealth- A New Option to Get Your Health Care Needs Met

Telehealth is a great way to get the health care you need while still practicing social distancing. If you have a phone or a device with the internet, you already have everything you need to do telehealth. You may be able to:

- Talk to your doctor live over the phone or video chat
- Send and get messages from your doctor using chat messaging, email, secure messaging, and secure file exchange
- Use remote patient monitoring so your doctor can check on you at home

What types of care can I get using telehealth?

You might be surprised by the variety of care you can get through telehealth. If you need care — especially during the COVID-19 emergency — it's worth checking to see what your telehealth options are. For example, you may be able to get:

- Monthly visits with your kidney doctor
- General health care, like wellness visits
- Prescriptions for medicine
- Dermatology (skin care)
- Eye exams
- Nutrition counseling
- Mental health counseling
- Urgent care conditions, such as sinusitis, back pain, urinary tract infections, common rashes, etc.

Visit telehealth.hhs.gov for more information on finding telehealth options and preparing for a video visit.



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Ways to Connect While Keeping Your Distance

Living with social distancing is hard. It is easy to feel like you are alone, but you don't need to be lonely. Use the technology at your fingertips to connect with those you care about.



Phone a friend. A simple phone call may be all it takes to make someone's day better. Make a schedule and call someone every day.



Connect face to face - virtually. If you have a smartphone, download apps (Facetime, Zoom, Skype, Google Duo and Hangout) that can help you connect. It's a great way to check in, share dinner or play a game together.



Send a message. For regular check-ins, texting works great. Send photos or short videos too. Other apps that can help you stay in touch include Facebook, Snapchat, Instagram and WhatsApp. These are great ways to connect across the miles with friends and family of all ages.