Avera Transplant Institute
Prairie Center
1000 E. 23rd St., Suite 210
Sioux Falls, SD 57105

RETURN SERVICE REQUESTED

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Patti Swenson, RN ......................... 605-322-3017

Bone Marrow Transplant Social Worker
Melanie Hericks .................................. 605-322-3034

Bone Marrow Transplant Financial Coordinator
Shane Olivier ........................................ 605-322-3014

Spiritual Care
Mary Guth, MS LMFT ................. 605-322-3258

More Information
For more information about the Avera Transplant Institute and to view Medical Minutes and interviews with patients and physicians, go to AveraTransplant.org.

Bone Marrow Transplant
Patient Newsletter
2014 ISSUE 1
Since her diagnosis of leukemia in December 2009, Dr. Teresa Binkley of Brookings, S.D., has been able to be part of several joyous occasions – the weddings of her two children and the birth of her first grandchild – thanks to great care and a successful stem cell transplant.

At age 49, Teresa, Research Associate and Assistant Professor at South Dakota State University, Brookings, was feeling especially fatigued around the Christmas season. Normally active as a runner, Teresa thought she was just out of shape. At the same time, she visited her dentist concerning her painful, swollen gums. An antibiotic helped some but did not resolve it. She could no longer chalk her symptoms up to holiday stress, and scheduled an appointment with her doctor.

A complete blood count revealed that Teresa’s white blood cell count was 119,000. With experience as a lab technician, Teresa knew at that moment she had leukemia.

She was referred to Dr. Vinod Parameswaran of Avera Medical Group Hematology & Bone Marrow Transplant. Dr. Parameswaran confirmed the diagnosis of acute myeloid leukemia (AML), started Teresa on chemotherapy and began the search for a stem cell donor. “I have four brothers and two sisters, but no one was a 10-for-10 match,” Teresa said. In the meantime, chemotherapy was keeping Teresa in remission. “By May, I was back to work, and feeling back to normal by Christmas of 2010,” Teresa said.

Yet in April 2011, Teresa relapsed, and by then, Be The Match – a global network for bone marrow transplantation – had identified an unrelated 10-for-10 match through a universal donor database. It was time to schedule a stem cell transplant as the best possible treatment for long-term survival.

“My son, Steve, planned to be married in June 2011, and I said I needed to be out of the hospital and able to attend his wedding.” Teresa was well enough to attend the wedding before having her transplant on June 29.
The transplant went well, although I had some complications, including graft versus host syndrome. Throughout 2011, Teresa spent 117 days in the hospital. “It was a long, long healing.” Yet by Thanksgiving, she was home with her family “since she had been quite well.” Teresa said her husband, Mark, Academic Advisor at SDSU, probably spent 115 of the 117 days (and nights) in the hospital with her. “He is the love of my life, and was a constant caregiver,” she said.

Their daughter, Laura, was married in the fall of 2012 to Olivier, a friend that Steve met while studying abroad in France. In December 2012, Steve and his wife, Eileen, had their first child, Linus – the Binkleys’ first grandchild. Laura and Olivier live in New Hampshire, where they work for Dartmouth College in Hanover, and Steve and Eileen are teachers in Brookings.

“Whether you live a month or two years after a bone marrow transplant, every day holds something to be thankful for,” Teresa said. The donated stem cells came from Europe, where contact with donors is not allowed for two years. After eagerly waiting, Teresa wrote a letter to her donor, a 27-year-old man in Germany named Markus. “His little package of cells was shipped all the way from Germany to Sioux Falls to save my life,” said Teresa. “When I wrote to him, I said ‘you are my hero.’” The two have corresponded by email, and Teresa hopes to go to Europe one day and meet him in person.

With hopes that her experience with leukemia and bone marrow transplant could help someone else, Teresa received training through Be The Match to be a peer-to-peer mentor. Since then, she has visited informally with a young man who was anxious about his AML diagnosis, as well as her cousin, whose 9-year-old daughter was diagnosed with AML.

A native of Minnesota, Teresa’s family immediately wondered why she did not go to Mayo Clinic in Rochester. “I felt I was in the right place, and was getting excellent care at Avera,” she said.

She related well to Dr. Parameswaran, who also has an interest in research. “I knew my five-year survival rate was 30 percent, and that hopefully, I would be on the right side of that 30 percent. Dr. Parameswaran stayed positive, but he didn't sugar-coat anything and just gave me the facts. I really appreciated that.” Teresa said she also received great care from Drs. Kelly McCaul and Ahmed Galal.

“Avera’s bone marrow transplant program is one of those treasures we have right here in Sioux Falls, S.D., that most people wouldn’t have believed is here.”
As a caregiver, resilience is a valuable characteristic and quality to experience. It may help to think about resilience similar to a raft taking a trip down a river. On a river, you may encounter rapids, turns, slow water and shallows. As in life, the changes you experience affect you differently along the way. In traveling the river, it helps to have knowledge about it and past experience in dealing with it. Your journey should be guided by a plan, a strategy that you consider likely to work well for you. Perseverance and trust in your ability to work your way around boulders and other obstacles are important. You can gain courage and insight by successfully navigating your way through white water. Trusted companions who accompany you on the journey can be especially helpful for dealing with rapids, upstream currents and other difficult stretches of the river. You can climb out to rest alongside the river. But to get to the end of your journey, you need to get back on the raft and continue.

Resilience is the process of adapting well in the face of adversity, or significant sources of stress. It means “bouncing back” from difficult experiences.

In fact, the road to resilience is likely to evolve from these experiences.

As a caregiver for someone who is experiencing a serious illness, you may wish to find ways to continue to build your resilience. Here are some suggestions that may be helpful to you:

- **Make connections.** Good relationships with close family members, friends or others are important. Accepting help and support from those who care about you and will listen to you strengthens resilience.

- **Celebrate the small accomplishments.** Try to acknowledge and be grateful for the simple things in life.
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“My favorite part of my job is knowing I can help a patient go through the transplant process. To physically see the progress and good outcomes that patients experience is very rewarding,” Shane said.

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Accepting circumstances that cannot be changed can help you focus on establishing new goals that give you hope.

- Develop realistic goals. Do something regularly — even if it seems like a small accomplishment. “What's one thing I know I can accomplish today that helps me move in the direction I want to go?”

- Rely on your faith and spirituality. Focus on healing of body, mind and spirit for your loved one and for yourself.

- Look for opportunities for self-discovery. People often learn something about themselves and may find that they have grown in some respect as a result of this journey. Throughout the healing process, you may find more appreciation for life.

- Maintain a hopeful outlook. When it is possible, be realistic and optimistic about what is happening in your life.

- Take care of yourself. Pay attention to your own needs and feelings. Engage in activities that you enjoy and find relaxing.

Resilience is rooted in a tenacity of spirit, a determination to embrace all that makes life worth living even in the face of overwhelming odds.

Elizabeth Edwards, in the midst of her adversity, stated, “I have been sustained throughout my life by three saving graces: my family, my friends and a faith in the power of resilience and hope. These graces have carried me through difficult times and they have brought more joy to the good times than I ever could have imagined.”

Resource: American Psychological Association

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BMT CONNECTIONS

“BMT Connections,” a bone marrow transplant support group offered at Avera, is a group that welcomes anyone affected by bone marrow transplants. We especially encourage our patients and their loved ones before, during and after transplant to come join in the activities and discussion, to not only receive support but to offer it to others going through the same journey. BMT Connections meets the second Thursday of every month at 4 p.m. in the Prairie Center. The Prairie Center is located at 1000 E. 23rd St. on the Avera McKennan Hospital & University Health Center campus. Watch for invites mailed each month. We hope to see you there! Some future topics include:

- **Provider session**
- **Pharmacy topics with speaker**
- **Skin care and summary safety**
- **Healthy eating with Jessie Muth, RD, LN, and The Quarry staff**

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We hope this insert can help put a smile on your face. Whether through positive thinking or humor, Patti Swenson, RN, will be offering this entertainment section for each newsletter.

*Enjoy!*

A heavy snowstorm closed the schools in one town. When the children returned to school a few days later, one grade school teacher asked her students whether they had used the time away from school constructively. “I sure did, teacher,” one little girl replied. “I just prayed for more snow.”

“My father taught me how to swim when I was 5 years old. He took me down to the river and threw me in. I wouldn’t have minded, but people were ice skating at the time.” — Bob Phillips

**TRANSPLANT MEDICATION MINUTE: URSODIOL (ACTIGALL)**

One of the most important responsibilities you will have in the transplant process is taking your medications as prescribed. We recommend patients be engaged in their care and keep a medication card or list to use every day and bring it to each office visit to be reviewed by a care provider. Please be aware of the brand name and generic names of your medications, the purpose for each of them, what each medication looks like, which days/times and how long to take each medication, how to take the medication or special instructions (if OK to crush as needed or if need to take with food, etc.), the most common side effects, what to do if a dose is missed, if it is a prescription or over-the-counter medication, etc. This is a lot of information to keep track of so please let us help you; if you have any questions about your medications, do not hesitate to ask your friendly pharmacist or care provider. You should **never** stop taking a medication unless directed to do so by your physician. If you cannot afford your medications, let your social worker (Melanie, 605-322-3034) know and we will work on helping assist with coverage. Your medications play a huge role in your outcome! We will be featuring a different medication that is standard of care for patients before, during and/or after their transplant. In this issue, we will be featuring ursodiol (Actigall).

Medications are generally made with the intention of treating one specific medical condition. Over time, though, it may be discovered that a drug helps with other health problems as well. A good example of a drug that has more than one use is ursodiol. Ursodiol is commonly used to treat gallstones, but is now being used to protect the liver in some patients who get specific cancer medications. Despite these two uses seeming to be much different from one another, they are actually very similar.

For those with gallstones, ursodiol works by dissolving the stones that block bile from flowing out of the gallbladder. Bile’s two main uses in the body are to help the liver get rid of filtered waste and aid in the absorption of food from our diet. On the other hand, ursodiol can also help protect the liver from some specific cancer medications. The liver filters out drugs from the blood and puts them into bile to be taken out of the body. This can lead to a buildup of chemotherapy drugs in the bile, which can be harmful to the liver. Ursodiol may help prevent this damage by going into the bile and blocking the chemotherapy from causing harm. Be sure to note that not all cancer medications cause this problem, and you should talk with your doctor if you have any concerns or questions.

Ursodiol comes as both capsules and tablets. It is taken by mouth between two and four times daily. Common side effects of ursodiol include headache, dizziness, diarrhea, constipation and upset stomach. In order for this medication to work to its full potential, it should be taken with food. It is important to know that ursodiol may take time to work to its full potential, so you should not discontinue taking it without talking with your doctor first. Whether it is being used for gallstones or liver protection, ursodiol can be an effective medication for those who need it.
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AVERA’S BONE MARROW TRANSPLANT PROGRAM EARNs REACCREDITATION

SIOUX FALLS (Jan. 24, 2014) — Avera Transplant Institute was recently awarded renewed accreditation from the Foundation for the Accreditation of Cellular Therapy (FACT) for demonstrating compliance with the FACT-JACIE International Standards for the full scope of bone marrow transplant programming. This represents Avera’s fourth three-year accreditation for allogeneic (donor cells) transplant, and third three-year accreditation for autologous (own cells) transplantation.

On the Avera McKennan Hospital & University Health Center campus, the scope includes adult transplantation, donor collection facility and cellular therapy processing laboratory. Infusion of lifesaving, marrow-restoring cells follows high doses of chemotherapy and/or radiation therapy administered through the Avera Cancer Institute and Avera McKennan.

Avera continues with the only bone marrow transplantation program in the state and surrounding region. Since 2000, Kelly McCaul, MD, Vinod Parameswaran, MD, and Ahmed Galal, MD, have performed hundreds of bone marrow transplants at Avera. A consultation with a transplant physician helps to ensure plans are in place for patients to move to transplant at the precise timing before the disease progresses or complications develop. Through advanced technologies and optimal referral timing, transplantation restores bone marrow function and offers the highest overall disease-free survival rate for certain types of blood cell cancers, such as leukemia, lymphomas, multiple myeloma and myelodysplastic syndrome.

FACT-JACIE definitive standards are developed by leading experts based on the latest knowledge of the field of cellular therapy product transplantation, and utilized by on-site inspectors qualified by training and expertise. Avera has been found to be in compliance with these rigorous standards and additional governmental regulations, affirming program quality.

“We endeavored to achieve accreditation for our organization because FACT accreditation has evolved into an all-but-necessary qualification to be accepted and competitive in the field of cellular therapy,” said Dr. McCaul, Medical Director. “We believe this recognition affirms program quality, making patients aware. This recognition also serves as a reference for physicians making referrals and provides assurance to insurance companies that the program meets quality care standards for cellular transplantation.”

“The program has every accreditation and participation offered for bone marrow transplantation programs, including approval from the National Marrow Donor Program donor registry,” said Beth Plahn, Director of Transplant Services at Avera McKennan.
A Time to Heal for All Cancers
Among survivorship programs is “A Time to Heal,” a 12-week holistic rehabilitation program designed to help men and women regain physical, emotional, intellectual, psychological and spiritual health after undergoing cancer treatment. People who have completed this program say they have greater satisfaction in life and stronger feelings of well-being. Call 605-322-3000 for details.

Take Charge of Your Nutrition
Learn to maximize your nutrition and discover ways to manage side effects of treatments. The Avera Cancer Institute has a dietitian available to assist with your nutrition concerns. Call 605-322-7929 to set up an appointment.

Look Good . . . Feel Better
This program is offered to women who deal with the outward side effects of chemotherapy and radiation on hair and skin. It occurs the second Tuesday of the month from 1 – 3 p.m. and the fourth Wednesday of the month from 4 – 6 p.m. Call 605-322-3235 to register.

Spiritual Care
Spiritual Care Services can help an individual sort through complex emotional and spiritual issues. Call Mary Guth, Chaplain, at 605-322-3258.

Aromatherapy
Samples are available in patient care areas. Please inquire with staff.

Medical Acupuncture
Acupuncture is available on Mondays and Fridays. Acupuncture helps reduce stress and the discomfort of cancer treatment side effects. Call 605-322-5240 for appointment times and fees.

Therapeutic Massage
Therapeutic massages, 30–60 minutes in length, are offered on Wednesdays and Thursdays. Free 15-minute massages are offered on Tuesdays. Call 605-322-8470 for appointment times and fees.

Classes in the Mind and Body Studio
These classes use the mind-body approach, focusing on mindfulness, gentle movement, posture, breath and visualization, and are facilitated for all fitness levels. If interested, call 605-322-3241 for a list of class offerings and times.

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Yet in April 2011, Teresa relapsed, and by then, Be The Match – a global network for bone marrow transplantation – had identified an unrelated 10-for-10 match through a universal donor database. It was time to schedule a stem cell transplant as the best possible treatment for long-term survival.

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More Information
For more information about the Avera Transplant Institute and to view Medical Minutes and interviews with patients and physicians, go to AveraTransplant.org.