

MYELOMA briefing

A PUBLICATION OF THE MYELOMA INSTITUTE FOR RESEARCH & THERAPY AT THE ARKANSAS CANCER RESEARCH CENTER

MYELOMA INSTITUTE MOVING TO NEW HOME ON UAMS CAMPUS



A construction crew works on the area that will be used as the main waiting room for the Myeloma Institute.

The Myeloma Institute for Research and Therapy will be moving its clinic and the majority of its offices to a new location on the University of Arkansas for Medical Sciences (UAMS) campus during the first week of November.

The move from the Arkansas Cancer Research Center (ACRC) to the nearby Jackson T. Stephens Spine and Neurosciences Institute will take place beginning Nov. 5, according to Stanley Whitbey, the Myeloma Institute's chief operating officer. Moving to the new building, located merely yards from the ACRC, will allow the institute to consolidate its operations while adding clinic space, Whitbey said.

"The biggest help will be for our busy clinic. We'll be expanding from 11 exam rooms to 14 exam rooms plus four interview rooms," Whitbey said. The move will also allow us to consolidate from four floors (of the ACRC) to two floors (the

fourth and fifth) in the Spine Institute. Patients won't have to go to multiple floors of the ACRC anymore; they will go to one place. So much of our program will now be located in one comprehensive area: the clinic, new patient intake and triage, insurance and case management. Even visits with clinical trials nurses and study coordinators can now take place in the clinic. It will be a lot more efficient."

In addition to the fifth floor clinic and the fourth floor administrative and clinical trials operations, the Myeloma Institute's new home will include access

to a first-floor lounge area. The spacious room, which will accommodate patients and family members who need a place to rest throughout day-long diagnostic testing regimens, will include phones and public access computers, as well as other conveniences and recreational activities.

Myeloma Institute physicians will move to new offices in the Stephens building, Whitbey added. Basic science research staff will remain in laboratories on the ninth floor of the ACRC.

The move, expected to take place over three days, will not cause any disruption in services or cancellation of appointments, Whitbey explained. "Main phone numbers

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RIDING AND RAISING MONEY COMES NATURALLY FOR WOLFSON

Alan Wolfson knew he had to do something. Exactly what, he wasn't sure, but he wasn't going to take the news of his diagnosis sitting down. Not seated comfortably, at least.

A real estate developer in Bradenton, Fla., Wolfson, 56, underwent a blood test in 1995, expecting to hear bad news about his cholesterol level. "They found that I had high levels of certain proteins, which could possibly indicate that I had a problem," Wolfson said.

That problem was eventually diagnosed as monoclonal gammopathy of undetermined significance (MGUS), a condition involving abnormally high plasma cell

levels. However, these plasma cells do not form an actual tumor or mass and do not cause any symptoms. MGUS usually does not affect a person's health and, unlike myeloma, it doesn't cause bone weakening.

MGUS may eventually develop into multiple myeloma, but the chances of it happening are unknown. The risk of myeloma may be higher in those patients like Wolfson, whose protein levels are particularly high.

"When I first found out what I might be facing, everything was suddenly turned upside down," said Wolfson, who began researching his condition on the Internet,

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COLLEAGUES PITCH IN TO SUPPORT FIREFIGHTER

He was fit and ready for action. As a 29-year veteran of the Hollywood, Fla. Fire Department, Peter Robinson was no stranger to physical exertion. So, when he felt a sharp pain in his back in May 2003 while fighting a blaze, he knew that something wasn't right.



Firefighter Peter Robinson remains active in his profession, although he no longer battles blazes.

The Workman's Compensation physician suspected arthritis, maybe even scoliosis. But X-rays indicated nothing out of the ordinary. Heat therapy didn't help. The pain persisted. Finally, three months after the first fiery pang, MRI revealed lesions and compression fractures.

Now there was an explanation for the 3-inch loss in stature. An internist referred him to a local oncologist, who in turn referred him to the Myeloma Institute.

Fortunately, Robinson had not received any myeloma treatment, so he was a prime candidate for the Total Therapy II protocol, then the flagship clinical trial for newly diagnosed, untreated patients. Always a fighter since his youth (he started out training to be a pilot before life-guarding buddies convinced him to try fire fighting), Robinson approached a tandem transplant with his usual determination. The first transplant was done in November 2003, followed by a second transplant in January 2004, with good results. He has attained near complete remission and is

on maintenance therapy. His fractures are stabilized, his energy is good, and his trips to Little Rock are less frequent.

What happens when a key member of the fire fighting force is suddenly off the job? The answer, in Robinson's case, is truly heartwarming. Firefighters belong to a unique family of colleagues. They look out for one another. Over 40 fellow firefighters stepped in to cover his hours and keep his job on the clock while he was in Little Rock undergoing treatment. They didn't receive extra pay; their time was put in to keep his paycheck coming steadily. They never missed a beat. In addition to the firefighters in his Hollywood station, men from the four other Hollywood stations pitched in. And fellow colleagues from as far away as Connecticut, Michigan,

Texas and Arizona – even Vancouver – contributed funds to help with the expenses required for traveling to and from Little Rock and lodging away from home.

Although he no longer rushes to the scene of the blaze, Peter is still an active member of the force. His efforts are now focused on logistics, truly the foundation for keeping all aspects of the fire department operating. He uses his knowledge gained over the years to the fullest, and he brings a new perspective of compassion and caring to a family of colleagues who, indirectly, have reaped tremendous benefit from his personal experience with myeloma. Robinson's family is truly a family of heroes.

PROGRAM FOCUS: IMPROVING MYELOMA SURVIVAL

Since its inception in 1989 and under Dr. Bart Barlogie's leadership, the overriding goal at the Myeloma Institute for Research and Therapy (MIRT) has been to unravel the genetics and biology of multiple myeloma and to develop curative therapies.

The myeloma program at UAMS has treated more than 5,800 patients afflicted with myeloma and related disorders (MGUS, plasmacytoma, amyloidosis, Waldenstrom's macroglobulinemia, Castleman's disease). In 2004 over 600 new patients presented at the Myeloma Institute. Eighty-five percent of these new patients came from outside Arkansas. Seventy percent of all the institute's patients come from states other than Arkansas and from abroad.

Unique to the Myeloma Institute is the long-term follow-up of patients. This provides data that is unavailable at other institutions and that serves as a statistically significant foundation for development of curative therapies.

Another unique aspect of the institute's program is its primary focus on one disease family and its pursuit of the most appropriate therapies, ranging from monoclonal antibody treatment for Castleman's and Waldenstrom's, to high-dose therapy with autologous or allogeneic transplantation for myeloma, and novel agents for advanced and high-risk disease.

These treatments are administered within the context of the most refined diagnostic tools in radiologic imaging (MRI, PET-CT) and in molecular genetics profiling (DNA micro-array, interphase FISH, PCR for residual disease). This translates into improvement in survival.

The distinguishing features of the Myeloma Institute set it apart from other centers and ensure collection and analysis of data that in turn lead to novel treatment regimens.

- Enormous patient data base with long-term follow-up and instantaneous access to outcome data in the context of unique patient characteristics, so

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where he found inspiring information about the Myeloma Institute for Research and Therapy (MIRT) and its director, Dr. Bart Barlogie.

Though he was living in upstate New York at the time, Wolfson quickly scheduled an appointment with Barlogie, who told him that his condition might never progress into full-blown myeloma, but that it required regular monitoring.

“I was so impressed with (Dr. Barlogie) as a person. He’s obviously brilliant, but he’s also one of the most empathetic people I’ve ever met,” Wolfson said.

The fact that he had a young family and might not live long enough to see his children grow up was sobering, he added. “I had a sense of fear, of dread, that suddenly it was all going to end. But by going to the (MIRT) clinic, I found a place where people who have these kinds of concerns could have them addressed so completely, so thoroughly.”

Wolfson’s confidence level rose with every visit to the Myeloma Institute. Quarterly trips to Little Rock for testing confirmed that his condition was not advancing to the early stages of myeloma. Knowing that he was more fortunate than most of the patients he saw each time he visited the institute, Wolfson decided he wanted to do something to help raise public awareness about the center and the disease it is dedicated to fighting.

A bicycling enthusiast, Wolfson felt it was natural to incorporate his pastime with efforts to raise funds for the fight, and began asking co-workers and business associates to help sponsor a long-distance bicycle ride. “But instead of raising a lot of money with a few people, I wanted to raise a little money with a lot of people,” said Wolfson, who convinced a number of his fellow real estate executives to donate a total of \$12,000 to MIRT in connection

with the 2000 solo journey he made from Buffalo, N.Y., to Pittsburgh, Penn., a trip of nearly 200 miles. “That way, the news of the good that the clinic does would be more widespread.”

The money and the experience were not enough to satisfy Wolfson, however. Three years later, he made a second ride, from



Alan Wolfson takes a break during his ride through northeastern Pennsylvania in April 2005.

Toronto to Ontario’s Algonquin Provincial Park, accompanied by close friend Jake Reiter, a banker in Swarthmore, Penn., who contributed to Wolfson’s first trek. Making the first trip during a heat wave was not a good idea, admitted Wolfson, who chose late fall as a more appropriate time for the second journey. “It was extraordinarily beautiful, watching the leaves change. We even got a little snowfall.”

Inspired by the success of the ride, Wolfson and Reiter soon made plans for a third fund-raiser and rode from Pittsburgh to Buffalo earlier this year. In all, the three trips have raised \$33,000 to fund research at the Myeloma Institute.

“I tell the people that they can be 100 percent certain that their \$500 donation has saved lives and ask them what satisfaction could be greater than that,” Wolfson said. But what does he get out of it, aside from sore muscles? “A terrific time spent in some beautiful countryside and the opportunity to make a small contribution to the great work done by

Dr. Barlogie and his staff at the Myeloma Institute.”

Not to mention an opportunity for some really good exercise, said Wolfson, who continues to visit the Myeloma Institute once a year for a battery of extensive tests. “While my condition could still be dangerous, my attitude is that every year you gain, you’ll have a better chance of coping with it. Multiple myeloma and related conditions are better understood every day, and the methods of dealing with them are constantly improving. Staying in shape is a good way of improving the odds. It just stands to reason that if I have to fight something off, it’s going to be easier if I’m in good shape.”

New Home (continued from page 1)

will stay the same. Changes in secondary service lines will be communicated to patients, referring physicians and UAMS staff.”

Part of a series of changes, the move to the Stephens building comes on the heels of the recent relocation of outpatient infusion/transplant services from 7A to 7C, a newly renovated unit in the hospital. Another anticipated change is the expansion of the ACRC chemotherapy center. All non-myeloma chemotherapy will move to a different location in mid-November, thereby creating more space in the current center for Myeloma Institute patients. This change is expected to be in place two weeks after the Spine Institute move.

Phone Number Alert!

Some of the current phone numbers will change when the myeloma clinic moves to its new space in the Spine Center. Information about new phone numbers will be posted on the MIRT Web site. Please consult the Web site periodically at www.myeloma.uams.edu.

Program Focus (continued from page 2)

that every new patient's prognosis can be forecast based on actual treatment data.

- Identification of myeloma subgroups, especially via genetic tools such as gene expression profiling, using random bone marrow samples obtained from the pelvic bone and also from focal tumors identified by MRI or PET, with the purpose of "identifying the enemy."
- Closely monitored follow-up of patients when away from Arkansas, through mailed-in samples for myeloma protein analysis, by a dedicated team of nurses.
- Comprehensive discussion of all newly referred patients and patients with ongoing treatment challenges by the entire health care team, including faculty from multiple specialties.
- Weekly research/clinical conferences to interpret success/failure of ongoing programs and identify the most promising research/treatment avenues for high risk patients.
- Warm, loving care provided by a dedicated nursing team with 10 to 15 years of myeloma management experience.

Patient volume and scope of diagnostic testing ensure statistically significant results that are incorporated into development of more effective therapies.

- MIRT sees more patients with myeloma and related diseases each year than any other institution in the world.

- On any given day there are 173 myeloma patients in Little Rock for diagnosis and treatment of their disease.
- The number of physicians immediately involved in myeloma diagnosis and therapy at MIRT is higher than at any other facility in the world. They have in-depth knowledge and unprecedented expertise in the management of myeloma.
- Over 2,000 patients participated in clinical trials in 2004. Clinical trial participation at MIRT is higher than at other facilities.
- MIRT performs significant numbers of diagnostic tests annually for myeloma patients, including 2,767 MRIs, 2,337 PET scans, 4,718 bone marrow tests and 4,896 cytogenetic exams each year.
- MIRT is the only facility in the world that routinely offers gene-array analysis for every newly referred patient and utilizes this information for patient management.
- In 2004, MIRT performed more stem cell transplants overall (524) and for myeloma in particular (483) than any other facility.
- MIRT patients always have plenty of back-up frozen stem cells for future transplants.
- In addition to tandem transplants, MIRT has performed more third (160) and fourth (10) transplants than any other institution.
- MIRT has detailed long-term follow-up on 5,806 patients. This is a larger patient population than at any other facility. Length of follow-up ranges from one to 264 months, with a median of 31 months.
- MIRT has followed 256 patients for more than 10 years. Of these 256 patients, 231 have never experienced a relapse.
- MIRT has a comprehensive data base on 5,806 patients with myeloma and related diseases. Detailed baseline and follow-up information on 14,000 parameters is unsurpassed and is used effectively to model new patients' predicted outcome.
- MIRT is the only facility that has a dedicated supportive care service that monitors all inpatients and outpatients on a daily basis.

As treatment regimens have been refined and improved, survival rates have increased. The Myeloma Institute constantly reviews treatment results with the overall goal of developing even more effective therapies that are individualized, based on each patient's risk factors.

Medicine is both science and art. The Myeloma Institute has the data to guarantee true scientific discovery. It also has the vast breath of experience that enhances the art of caring for each patient in a manner that is marked by compassion and the application of broad knowledge.

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