

# Making a Difference



## Transplanted friendship

Former homecoming queen  
Amelia Brown finds peace of mind  
(and a new liver) through UK HealthCare.

## ALS can't silence her

Mary Lou Smith credits her  
quality of life to her caregivers.

## Markey Cancer Center

Kelly Colson experiences the  
healing power of friendship.

## Cystic Fibrosis An adult disease now

How we've helped Anne McMahan  
defy the odds.

# Making a Difference

Introductory issue | Summer 2006

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### **Transplanted friendship**

Amelia Brown was a homecoming queen in the prime of her life, but her liver was failing from a mysterious illness. UK HealthCare solved the mystery, found her a new liver and made friends for life.

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### **The Markey Cancer Center**

With its friendly feel and attentive service, it feels almost like a comfortable neighborhood bar. And when myeloma patient Kelly Colson visits, he sees a glass that's more than half-full.

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### **ALS can't silence her**

While Mary Lou Smith has lost use of her vocal cords, she hasn't lost hope. In an article she pens herself, she talks about how Dr. Edward Kasarskis and his team put her at ease.

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### **Cystic fibrosis: An adult disease now**

Now 48, Anne McMahan has surpassed the average life expectancy for a person living with cystic fibrosis. Learn how UK HealthCare's staff helped her do it.

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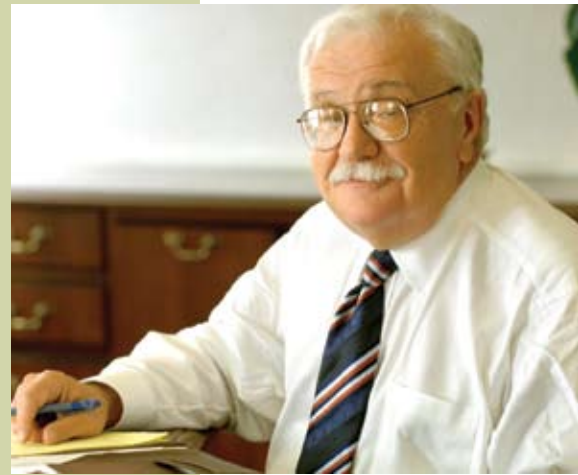
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# It all comes down to you



**UK HealthCare** is much more than our advanced medical technology. It is the physicians, nurses and technicians who use that technology correctly and effectively. Beyond our advanced capabilities, UK HealthCare is everyone who makes a difference to our patients by connecting with them on a personal level, easing their fears and offering comfort as they face conditions that are often life-threatening and certainly life-changing.

*Making a Difference* will introduce you to colleagues who go the extra mile to diagnose and treat illness while providing emotional support in even the smallest ways—recommending treatment options, providing health information, offering words of encouragement or simply remembering a name. All of these elements are meaningful.

As you read *Making a Difference*, you'll see we are focusing on members of the UK HealthCare family who are making a difference to our patients, many of whom are overcoming amazing odds thanks to our comprehensive and compassionate care. They make UK HealthCare an extraordinary organization, and it is a story worth sharing.

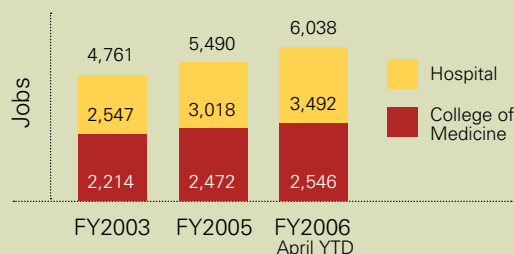
Best wishes for good health,

Michael Karpf, MD  
Executive Vice President for Health Affairs  
University of Kentucky

## UK HealthCare Statistics



**Each quarter discharges continue to increase. Annually, discharges are up 29% since 2003.**



**To meet increasing demand, UK HealthCare has created almost 1,300 new jobs since 2003.**





# Long live the Queen

Former UK Homecoming Queen  
Starts a Lifelong Relationship with  
UK HealthCare.

Even though she was a homecoming queen supposedly in the prime of her life, Amelia Brown was miserable.

A mysterious liver disease was making her sleepy and lethargic. Her skin was yellow from jaundice. She passed several gallstones. An inability to absorb calcium caused her to break her hip—and she didn't even know it. Her digestive system disrupted, she sometimes vomited between classes on the UK campus.

Worst of all was the itching—the result of too much bile in her blood. “It makes me itch now just thinking about it,” the Tompkinsville native said recently.

Brown was 19 when she found out she had liver disease, just before

Liver transplant recipient Amelia Brown with some of the cadre of staff necessary to support a transplant patient. From l. to r., Gail Starnes, RN; Liz Corio, MSW; Vicky Turner, ARNP; Brown; Lynne Polly, RN; Dana Grantz, RN, transplant nurse coordinator; Jennifer Watkins, RN; and Janet Brown, phlebotomist.

**“I was at the end of my rope. It’s a blessing to know that the donor’s family, through their pain, found a reason to let me live.”**

– Amelia Brown, Patient

starting her freshman year at UK in the fall of 2000. But doctors who initially examined her in Nashville were unable to diagnose the specific malady. When another flare-up struck that Christmas, they sent her to a prominent organ transplant center in Pennsylvania, where her name was put on a waiting list for a new liver.

Even with her condition deteriorating, Brown pressed on with her education. She not only continued taking classes, she became vice president of Delta Gamma sorority, a senator-at-large in student government and a UK Ambassador. She was crowned the UK Football Homecoming Queen in 2003, volunteered for Kentucky Organ Donor Affiliates and led UK in the Gift of Life Challenge against the University of Louisville to sign up organ donors. She graduated in December 2003—a semester early!

Through it all, she waited patiently for a new liver. And waited. And waited. More than three years passed, and still she heard nothing from the transplant center in Pennsylvania.

### **‘I just loved the people’ at UK**

“They didn’t really stay in close contact with me,” Brown said. “So finally, since I had done the Gift of Life Challenge, UK HealthCare called me and said, ‘Why don’t you come and be evaluated for our list?’ So I

went and I just loved the people. I felt comfortable with them. They assigned me a nurse coordinator and she kept a close eye on me from beginning to end.”

UK HealthCare not only made the diagnosis that had eluded doctors in Nashville—primary sclerosing cholangitis, in which a person’s immune system mistakenly attacks its own liver—it also found her the new liver she so desperately needed. Brown remembers the exact moment she got the call: 12:32 a.m. on Sunday, April 3, 2005. A family had agreed to donate a liver. The next day UK’s skilled transplant team implanted that liver in Brown’s abdomen and, after another surgery to repair her hip fracture, her long but welcome recovery was under way.

More than a year later, Brown still gets emotional about the family’s gift. “I was at the end of my rope,” she

said. “I was getting sicker and sicker every minute. It’s a blessing to know that the donor’s family, through their pain, found a reason to let me live.”

### **Nurse Dana Grantz: “We become very close....This is life and death.”**

Brown believes she would not be here today were it not for UK HealthCare—and she’s grateful to a number of people, including Dana Grantz, the nurse coordinator assigned to her. “She has a great sense of humor, and you need that when you’re going through this,” Brown said. “I was going through a lot physically, but you go through a lot mentally too, waiting on a list like that. It was comforting having people like Dana to depend on.”

Each of the four nurse coordinators in Grantz’s unit monitors about 200 patients—from the time they come



## More Than 600 Kentuckians Desperately Need Donated Organs

- More than 600 people in Kentucky are registered on the United Network for Organ Sharing waiting list for donated organs.
- Every year, an estimated 3,000 people in the U.S. die while waiting for an organ transplant.
- Transplantable organs include the kidney, heart, liver, lung, pancreas and small bowel. Transplantable tissues include bone, cartilage, skin, corneas, heart valves, saphenous veins, tendons and ligaments.
- Acceptable donors range from newborn to senior citizens.
- Organs that can be used from a living donor include kidney, liver, intestine, pancreas and lung.
- In 2005, approximately 28,000 successful organ transplants were performed. It is estimated twice as many could have been performed if more people donated organs.
- By law, donation is the right of every American age 18 and older. Hospitals are obligated by law to identify potential donors and to inform families of their right to donate.\*
- Individuals may indicate their wish to be a donor by signing a driver's license or a donor card. However, next-of-kin are still asked to give permission to donate. Therefore, individuals should inform their loved ones about their decision.
- All efforts are made to save a person's life regardless of whether he or she has signed a donor card. Doctors involved in treating a patient cannot be involved in donation or transplantation.
- There is no extra expense for the family donating organs or tissues.
- The donor's body is not disfigured by organ or tissue removal.
- All major religions approve of organ and tissue donation.

Facts excerpted from Kentucky Organ Donor Affiliates, [www.kyorgandonor.org](http://www.kyorgandonor.org).

\*UNOS (United Network for Organ Sharing), [www.unos.org](http://www.unos.org).

into the system through follow-up visits for the rest of their lives. The coordinators manage the patient's blood work, keep track of his or her overall health and serve as the link between patient and surgeon.

"Once we're assigned a patient," Grantz said, "we communicate with them constantly. We're scheduling tests, obtaining test results, explaining results and discussing infections, medications and questions regarding their illness. We become very close to the patients and their families. This is life and death.

"The relationships we build last a lifetime," she added. "From the first time they enter our clinic, to the testing that's done in order to be placed on a waiting list, waiting for the perfect match and then following them after transplant, we do not stop. We follow them forever."

"The people at UK HealthCare really keep in touch with you," Brown said. "Gail Starnes, a nurse on my floor, still calls me to make sure I'm okay. That makes me feel pretty good."

Dr. Dinesh Ranjan, director of the UK liver and pancreas program and the lead surgeon in Brown's case, said Amelia came to the right place for outstanding care. "We have an excellent team that follows patients very closely," Dr. Ranjan said. "You saw the result of that in Amelia, who started out with another center and was not doing well. She was wise enough to transfer her care here and subsequently did very well."

### **Amelia Brown: "I've never felt this good in my life."**

Brown, who now works for UK as a Fayette County cooperative extension agent, will have to take anti-rejection medication for the rest of her life. But her health now versus before the surgery "is like night and day," she said. "I've never felt this good in my life. I didn't even know what good felt like." She is also working toward a doctorate in family studies, which will allow her to research and teach in the area of family health, a career choice inspired in part by her experience.



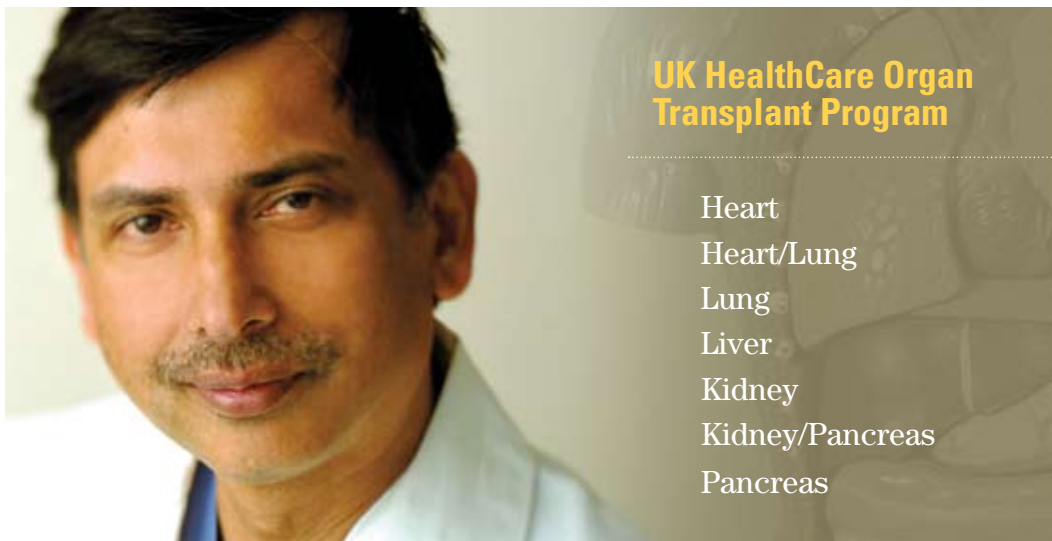
# Surgeon Dinesh Ranjan: "If There Are Any Issues, We'll Be Called and We'll Be There For Her."

Dr. Dinesh Ranjan, director of the UK liver and pancreas program, has taken part in more than 500 transplants during his career, including more than 300 at UK. He believes the program must balance high tech with high touch.

Asked how UK was able to diagnose Brown's disease when others could not, Dr. Ranjan said, "It was simply being familiar with patients who have advanced liver disease and pursuing it with the right diagnostic tests.

"She was not getting the follow-up patients like Amelia need. This was probably due to the distance, and the other program may not have been able to provide more personal attention to her as they may have too many patients. We are very involved in our patients on the waiting list as well as post-transplant. We are appropriately aggressive when needed, such as in using livers we think may suit our patients while others may have turned it down. The

Dr. Ranjan with Amelia Brown.



Liver and Pancreas Transplant Surgeon Dinesh Ranjan, MD, and his staff are available 24/7 to provide comprehensive care to transplant patients.

end result is a shorter waiting time."

Dr. Ranjan explains the more aggressive management includes a double team approach that improves the quality of the grafts, as well as aggressive intra- and post-operative management to improve outcomes with these grafts. High touch extends to the patient's referring physician and family doctor. Close contact is maintained before and after the operation because the referring physician is considered part of the transplant team. "We pride ourselves on the level of communication we have with them," said Dr. Ranjan.

For three months after transplant, the program's physicians serve as the

patient's primary doctors to monitor every health issue the patient might encounter. But if they are doing well after the first three months, transplant patients are referred back to their own doctors. "It's not cutting the cord, just lengthening it," said Dr. Ranjan.

That cord will always be there for Amelia Brown.

"We will still be checking her blood work and lab tests every month or every other month, as it may be, and the test results will be faxed to us," he said. "Amelia and her referring physician will know we are always available, 24/7. So if there are any issues, we'll be called and we'll be there for her."

The referring physician is considered part of the transplant team. "We pride ourselves on the level of communication we have with them."

— Dr. Ranjan, Surgeon

# “Some Days I Just Want to Scream with Joy.”

By Mary Lou Smith

**E**ven though I can no longer speak, my voice hasn't been silenced.

In January of 2005 I was diagnosed with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. This neurological condition, which weakens one's muscles, has attacked my throat the hardest, making it difficult for me to swallow and nearly impossible for me

to talk. Fortunately, I can still type.

My husband Bill and my daughter Emily have been a great source of strength for me as I battle this terminal disease. That's not surprising. What is surprising is how supportive Dr. Edward Kasarskis and his staff at UK have been.

To be completely honest, I was apprehensive about coming to UK. When my first neurologist, a non-UK

doctor, recommended that I visit

Dr. Kasarskis for a second opinion, I decided I would go once, and if I had a terrible experience, wouldn't return. As it turns out, I ended up making Dr. Kasarskis my neurologist instead.

I liked Dr. K's smile and immediately felt comfortable with him. When he diagnosed me in his office, he was very honest and sincere. As he broke the news to me, I began





**“Dr. Kasarskis and his whole team have one thing in common: they are compassionate and caring.”**

– Mary Lou Smith, Patient

to cry. He gently handed me a box of tissues and told me I would need to grieve. He also asked me to consider participating in a clinical trial on nutrition that he was heading up. As I was leaving, still in tears, one of the nurses in his office came over and hugged me. I knew right then what a special group of people they were.

After three days of gloom and doom, I decided to become a fighter. I enrolled in the clinical trial and started raising money for my local ALS Association chapter.

### **E-mail buddies: comforting access**

Dr. Kasarskis and his whole team have one thing in common: they are compassionate and caring. Every time I visit the office, everyone wants to see me. Well, at least my feet. That's because I have designs painted on my two big toes. The staff always seems so amazed at the designs.

Dr. K has been great about trading e-mails with me when I have questions about information I find during my hours and hours of researching ALS on the Web. He always responds and teases me, calling me his “e-mail buddy.” Having that kind of access to him is so comforting.

Mary Lou Smith (far left) with Nadine Deehan, LPN, whose hug after Smith received her diagnosis meant a lot. Deehan lost her own father to ALS and is not afraid to show compassion. Said Deehan, “If I didn't treat my patient the way I would want to be treated, why would I be doing this?”

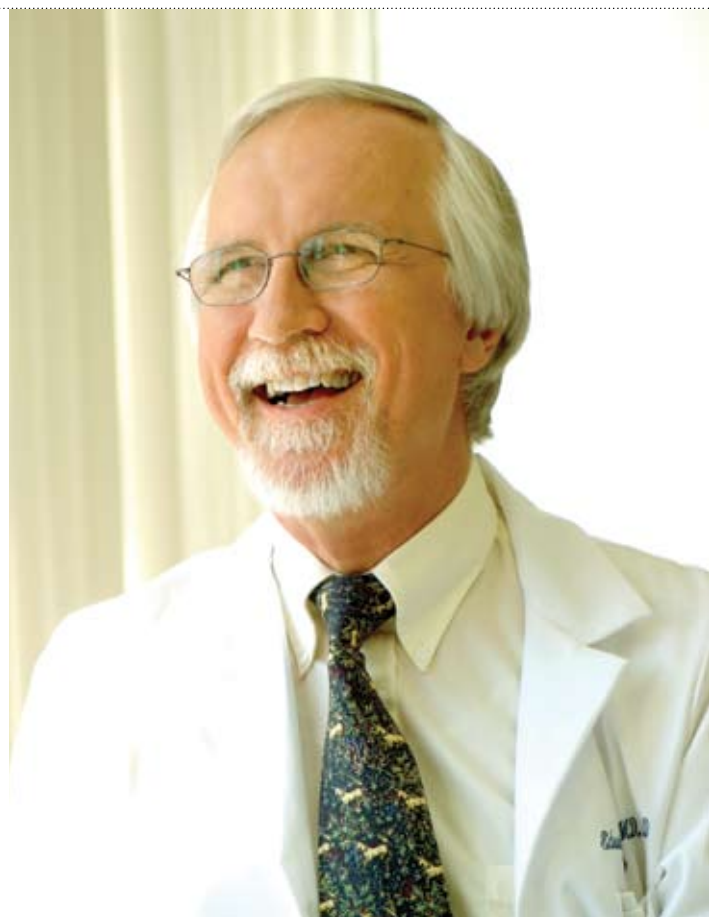
Marsha Sams, his assistant, gets a lot of e-mails from me, too. She is always so nice. Karen Kitzman, my dietitian, makes me feel proud when I do everything she asks me to do for her part of the clinical trial. Stephen Wells, the clinical research coordinator I work with, is wonderful, too. He truly cares about what he does. He has stood for what seems like hours helping me swallow fluids needed for tests during the clinical trials.

### **I still have a life.**

I have not had to give up my life yet. At this point, I still work 30 hours a week for the company I have been at for 12 years.\* I also drive, go on vacations, eat out, attend church, have functions at my house, cook and shop. I had a personality before ALS and I still do.

Last year Dr. K asked me to talk to one of his classes at UK. I laughed, but he was serious. The day of the class, I brought my laptop with Etriloquist software, which speaks what I type. With some assistance from my husband and daughter, I was able to answer a lot of the students' questions. I watched their faces and thought it went very well.

\*Mary Lou has since retired from her job and stays busy working with the local ALS chapter. In May, she and her family represented Kentucky at National Advocacy Day in Washington, D.C.



In looking for a second opinion, Mary Lou Smith was won over by UK neurologist Edward Kasarskis' smile and the fact that he made her feel comfortable.

Until UK started running television spots featuring their doctors, I thought the hospital was just for people who couldn't pay. I have talked to others who thought the same way. One of my friends has a son who suffers from seizures and she loves the pediatric department. My sister-in-law's mother had a hard-to-perform surgery here and she lives in Nevada. She's flying back here now for follow-ups.

I am so happy they are letting everyone know that there are so many good people working at UK. I certainly couldn't be more impressed with the level of personal care I've received. In fact, some days, I just want to scream with joy.

# Going to Bat Against ALS with Nutrition

For amyotrophic lateral sclerosis (ALS) patients, the best way to extend their life may not lie in new miracle drugs being developed, but in peanut butter, slices of cheese and protein shakes.

The importance of nutrition is one focus of a new national study UK HealthCare is leading entitled “Early Treatment of ALS with Nutrition and Non-Invasive Positive Pressure Ventilation (NIPPV).” In addition to nutrition, part of the study deals with medical devices that support a patient’s respiratory functions.

## A weighty matter

According to Dr. Edward Kasarskis, a UK neurologist and the study’s primary investigator, changes in a patient’s physical activity, breathing status and body composition can affect how many calories he or she burns each day as the disease takes its toll.

“We often see patients who don’t keep up with their nutrition, and they lose excessive amounts of weight... really huge amounts of weight in a very short period of time,” said Dr. Kasarskis. “It’s likely this accelerates the course of the disease.”

Research bionutritionist Karen Kitzman, RD, also involved in the study, added, “If we can keep these patients’ nutritional status up and decide early enough whether they need supplementary feeding tubes, then maybe we can prolong their healthy status.”

Kitzman noted that by the time a patient has to have a supplementary feeding tube to live, it is often too late—they are malnourished. Their

body’s energy stores are depleted and they begin to break down muscle tissue for energy. These patients may not heal well or even be able to tolerate the food going into the feeding tube.

“However, if we add a PEG (percutaneous endoscopic gastrostomy) to a healthy patient who has decreasing calorie intake, that early start can give them the extra calories needed to maintain their nutrition level through some other ups and downs,” Kitzman said.

## Increasing the calories

For ALS patients who can swallow, Kitzman often suggests high-calorie snacks such as peanut butter or cheese—foods with higher protein and fat content in them. She recommends meal supplements such as Boost, Ensure and Carnation Instant Breakfast because they taste good and can be thickened with ice cream or commercial thickener, which makes them easier to swallow. She encourages use of a liquid, flavorless calorie booster that can be added to drinks and foods. This product can be added to almost any food without altering taste.

“The people we work with have some of the best attitudes,” said Stephen Wells, a clinical research coordinator on the project. “We never run into a patient who doesn’t want to be here. They all realize they may never benefit from the information they’re giving us, but the people who come after them might.”

## Untold promise for the future

Dr. Kasarskis predicts the third phase of the research, which ends late next year, holds untold promise for the future. “The actual importance of this approach goes beyond individual patients because all clinical trials of new medications are being done without standardizing nutrition and respiratory assistance. Nutrition and support of respiratory function are probably going to be more important in extending survival than any drugs themselves.”

Stephen Wells and Karen Kitzman, RD, LD, investigate whether additional nutritional and respiratory support will prolong survival for ALS patients.

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“We never run into a patient who doesn’t want to be here. They all realize they may never benefit from the information they’re giving us, but the people who come after them might.”

— Stephen Wells, NIPPV Study Coordinator







# A New Outlook

## The Result of Positive Thinking and Top-Notch Cancer Care

**K**elly Colson has a contagious condition. But it's not multiple myeloma, the blood cancer with which he was diagnosed in 2003.

No, what Colson has that spreads so easily is a good thing. It's called optimism. Symptoms include frequent smiling, living life to its fullest, tackling new challenges and making light of his situation.

"It's just cancer," and no matter how he feels, he enjoys catching people off-guard by telling them he feels "marvelous!" Colson may grossly understate the obvious in an attempt at humor, but he is completely aware multiple myeloma

is an incurable blood disorder that is to be taken very seriously.

"We've all got expiration dates," said the 46-year-old Lexington resident. "Some are just earlier than others." The way Colson sees it, being diagnosed with an incurable cancer is no reason to turn bitter and mean to friends and family who are there to help and support you.

That attitude may literally prolong his life. His primary physician, Dr. Dianna S. Howard, a UK hematologist, said every patient has a different coping strategy when faced with a life-threatening illness. While some take a defeatist view, "others say, 'I'm going to live my life, make

the best of it and go forward.' Kelly epitomizes that," Dr. Howard said. "When people do that, they keep going a lot longer."

Charlotte English, a nursing care technician in the Markey Cancer Center since 1999, has drawn Colson's blood and checked his vital signs dozens of times. That means she's had a lot of time for small talk. "The man never has a bad day," she said. "He comes in here, and you might expect him to be down because he's in a cancer center, but he always asks how I'm doing. On my birthday he called to wish me a happy birthday and he and his wife got me a gift certificate to Rafferty's."

Cancer patient Kelly Colson is feeling well enough to turn the tables on Jason Ritchey, a patient care associate in the Markey Cancer Center, and take him for a spin.

English said Colson has also befriended and encouraged other Markey patients. "He's just a very, very positive person."

### **Excellent care and personal touch change outlook**

Colson claims he wasn't always so cheery, but the excellent care and personal touch he receives at all levels from UK HealthCare, particularly the Markey Cancer Center and its Bone Marrow Transplant Clinic, changed his outlook.

"You can be all bummed out; you can be depressed," Colson said. "But then you walk in there and you see certain individuals... like Jason (Ritchey) at the front desk... He's a great kid, always with a big smile on his face. He recognizes people. He'll see me and say, 'Hey, Kelly, what are you doing?' Then there's Charlotte English, she does your blood work and takes your blood pressure. She's as nice as she can be, real good at connecting with people.

"And Dr. Howard, she's wonderful. She has a family and can empathize with patients. She's very, very knowledgeable. She'll say, here's what I recommend but always wants me to do research, too."

### **A disturbing diagnosis**

Colson's life changed one day in late October 2003, just after he and his wife Teresa returned from a trip to Mexico.

He was mowing the grass when he felt a sharp pain in his right shoulder. "I don't know if you've ever had a broken bone, but it just snapped," Colson recalled. "I was delirious with pain."

**"I love my job, I love the patients and I love the people I work with."**

– Charlotte English, Nursing Care Technician

## ***Charlotte English: "I Never Leave This Place Feeling Depressed."***

Charlotte English has a 62-mile commute to her job as a nursing care technician for Markey Cancer Center. Each workday this single mother of five makes a 124-mile roundtrip from her home in Flemingsburg to Lexington and back.

"I love my job, I love the patients and I love the people I work with," she said. English considered cutting back to three days in order to reduce driving time, but when she realized she wouldn't get to see the patients she normally sees, she changed her mind.

"So now, they say, 'Charlotte, I thought you were leaving,' and I'll say, 'Look, I tried to leave you, but I can't!'" English now works four days a week,

four 10-hour shifts.

"I'm one of those people who just go high-speed constantly," she said. "If we have a busy day, I don't stop." A self-described "people person," English gets to know every one of the 10 to 30 patients she encounters each day, taking their vital signs, drawing blood and providing triage. And they get to know her in return.

Performing her job with pride since 1999, the year after her father died of cancer, she reflected, "You might think working in a cancer center has got to be depressing, but I never leave this place feeling depressed. The people you meet touch your heart one way or another."



“When you’re really sick and the reality sets in that you are not going to live forever, you want to be with...professionals who genuinely care about your well being and quality of life.”

– Kelly Colson, Patient

X-rays showed a fractured bone in his upper right arm. Worse, the X-rays also showed the cancer. A very aggressive tumor inside the bone had weakened Colson’s right humerus, or upper arm bone, causing it to shatter.

Treatment would not be a simple proposition. There is no known cure for myeloma, which causes an overproduction of certain proteins in the bone marrow. Myeloma—usually called “multiple” because it shows up in several bones throughout the body—can be treated with surgical removal of tumors, but they may pop up somewhere else later. Radiation, corticosteroids, stem-cell transplants, chemotherapy and other medications are also effective in managing the disease—but major bone breaks such as Colson’s complicate the situation.

The first order of business was to excise the tumor in Colson’s shoulder and replace the joint with one made mostly of titanium. The

surgery went well, but in the spring of 2004 he suffered near-fatal blood clots in his lungs, which caused him to be hospitalized for another 16 days. Follow up chemotherapy had to be delayed.

By the summer of that year, Colson was ready for another big procedure—a stem cell transplant. UK doctors extracted stem cells—the building blocks for all cells—from his bone marrow. They administered a very high dose of chemotherapy to attempt to eradicate myeloma cells and then returned the stem cells to his body to promote remission. Colson’s condition has been stable since that time.

### A new freedom

Trying to work a demanding job had become extremely difficult given his frequent health-related absences following treatments he received. Colson elected to quit work and focus

on the treatment of his illness.

That downtime didn’t last long. It was all the incentive he needed to build up a part-time consulting business in November 1999. In keeping with his sunny disposition, he named it Sunshine Services LLC. Ironically, the change has given him a new sense of freedom.

“I wish I had done it 20 years ago,” Colson said with a laugh. “Business is great.”

Stable for over a year, Colson is realistic but hopeful about his short- and long-term prognosis. Colson said he enjoys good nutritious food. His condition is being managed with a variety of medications, including a blood thinner, a bone-strengthening and thalidomide—a once-notorious drug now undergoing a remarkable rehabilitation.

Another stem cell transplant for Colson is possible, although Dr. Howard is cautious because the procedure has serious side effects and is not always effective. Other options are possible as well. (See related story.)

Whatever the future holds, Colson has forged a strong bond with the supportive, nurturing staff of UK HealthCare. “Periodically, I take four or five pizzas into the clinic around lunchtime for the staff,” he said. “Of course, if you take food to hungry people, they love you. The way I look at it, I’m investing in my future. If the doctors and staff are working hard to keep me alive, the least I can do is feed them occasionally.”

“Believe me, when you’re really sick and the reality sets in that you are not going to live forever, you want to be with knowledgeable health care professionals who genuinely care about your well being and quality of life.”

Jason Ritchey’s ever present smile is one of the first things a Markey cancer patient sees.





# Dianna Howard, MD: We're Offering the Best Possible Options for Cancer Patients

Kelly Colson has undergone one successful stem cell transplant to treat his multiple myeloma and another is possible down the road. If he does make that choice, UK HealthCare is the only center in the region where such a procedure is offered.

While a second transplant is possible, the good news is the options for Colson and other multiple myeloma patients are expanding rapidly. Although the blood cell cancer is still described as incurable, researchers have been encouraged by several developments that are letting myeloma patients live longer, healthier lives.

The median survival for patients with multiple myeloma has more than doubled in the past decade. Newer treatment options have allowed patients who once died within two to three years to think of their condition as chronic. Additionally, newer drugs that target the biologic weaknesses of the myeloma are associated with fewer life-threatening and life-altering toxicities.

A drug Colson is taking, thalidomide, falls into this category. In the 1960s thalidomide attained possibly the worst reputation of any drug ever marketed. Pregnant women given this anti-nausea/sedative medication gave birth to babies with grossly underdeveloped arms and legs, as well as other defects. Later, however, resourceful researchers began investigating the possibility that a drug that hampered limb growth in fetuses would also block tumor growth.

"This is an area where there have been incredible advances," said Dr. Howard. "In the last five to 10 years there have been at least



three new agents approved for use in multiple myeloma." As with other new anti-cancer drugs, these new agents zero in on the cancer while sparing healthy cells, she said.

With advances being made constantly, Dr. Howard believes UK HealthCare offers the best possible options for cancer patients like Colson. New drugs are usually available years earlier at an academic center than they are in other settings. As part of an academic institution, the Markey Cancer Center pairs clinical researchers with scientists to promote the translation of laboratory observations into clinical trials, which in turn provides a venue for clinical observations to raise new scientific questions and influence the direction of new research.

"We work with the College of Pharmacy in new drug development and novel therapeutics. That's something you're not going to find except in a cancer center and in an academic center," she said.

Thanks in part to novel research being conducted at UK, Dr. Dianna Howard believes the very best options for cancer patients are here.

The drug thalidomide is expanding the options available to multiple myeloma patients.



## Novel cancer drugs developed at UK

- Camptothecin (DB 67) – Brain tumors
- Hormone-coated nano-particles linked to Taxol chemotherapy – Breast cancer
- Parthenolides – New class of chemotherapy drugs
- Blackberry gel for skin tumors

# Living on the Edge

At 48, Anne McMahan has beaten the odds and is living at the leading edge of medicine.

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“I’ve had the same physicians for over 23 years. I’ve joked with Dr. Kanga to say that I’m going to live to take care of him as an old man.”

— Anne McMahan, Patient

The way Anne McMahan tells it, she and UK HealthCare have practically grown up together. Her father, a pediatric endocrinologist, took a job with the hospital when it first opened in 1962. She was four at the time.

Over the years, UK Chandler Hospital has continued to play an important role in her life. It was where





she first entered the work world as a nurse in the early 1980s. It's where she now works in the UK HealthCare call center's pediatric triage service. It's where her husband works as a pharmacist. And it's where, over the last four decades, she has received treatment for cystic fibrosis (CF).

### Long-term relationships

According to the National Institutes of Health, CF is the most common fatal genetic disease in the U.S. It causes the body to produce a thick, sticky mucus that clogs the lungs and leads to infection. It also prevents digestive enzymes produced in the pancreas from reaching the intestines where they are required to digest food.

There is no cure for CF and the present life expectancy for people affected by it is usually their mid-30s. McMahan has beaten the averages. She is 48 years old and going strong.

McMahan credits her longevity and quality of life in large part to the aggressive medical care provided by her UK physicians: Dr. Jamshed Kanga and Dr. Michael Anstead. "I've had the same physicians for over 23 years. I've joked with Dr. Kanga that I'm going to live to take care of him as an old man," she said.

Because she has a less severe form of CF and her obvious symptoms

Pulmonologists Michael Anstead, MD, and Jamshed Kanga, MD, collaborate closely to ensure a smooth transition from pediatric to adult care for CF patients.

## Michael Anstead, MD: Excited about the Improving Prospects for CF Patients

Since 1989 when the gene that causes cystic fibrosis (CF) was first discovered, the median lifespan for patients with the disease has increased by more than 10 years. And nearly half of that increase has come during just the last five years.

According to Dr. Michael Anstead, director of the adult CF Center, the median survival rate has jumped from 31.6 years in 2002 to 36.8 in 2004—up from just 26.5 years in 1989. (When McMahan was born, patients rarely made it to puberty, often succumbing to the disease as young children.)

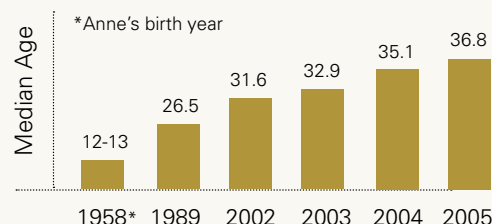
He attributes the increase in his own patients' survival to three things: 1) a more uniform use of aerosolized antibiotics that fight the bacteria that invade the lungs of many patients; 2) use of antibiotics with special properties that inhibit the ability of the bacteria to produce toxins and are anti-inflammatory; and 3) an initiative undertaken by the Cystic Fibrosis Foundation to improve the

quality of care for CF patients.

"One of the great developments in Kentucky is that we now do newborn screenings for cystic fibrosis," he said. Through the lobbying efforts of Drs. Anstead and Mabry, Anne's father, CF was included in the newborn screening tests implemented by SB 25 passed during the last Kentucky legislative session. This screening can identify 99 percent of babies born with CF. If those patients can be identified and monitored through each lung infection, the bacteria might be prevented from growing in their lungs. Once it takes hold, it is extremely difficult to dislodge.

"In Denmark, only 20 percent of teenagers affected with CF are infected with this bacteria," he said. "In the U.S., 70 percent are infected with it. Denmark's median lifespan is about 45 years. So we're starting to adopt some of the principles they've learned over time. It will help the CF patients who are children today."

**Median Lifespan for CF Patients**



Anne works at UK HealthCare, where she also receives treatment for her cystic fibrosis.





did not begin until age 8, it wasn't until she was in college (where she was finally diagnosed) that she sought treatment from Dr. Kanga, a pediatric pulmonologist. When Dr. Anstead, who is certified to treat both pediatric and adult cases, came on board at UK, he became her pulmonologist.

"Some of the therapies we've used have really benefited her," said Dr. Anstead. "We have a lot of patients who need to balance their treatments and their lives. You want them to have a good balance between quantity of life and quality of life."

### Multidisciplinary team pays off

"I have a very progressive medical team," said McMahan. "And it's not just the physicians. It's truly a multidisciplinary team." Her team includes a social worker, psychologist, dietitian, respiratory therapist, pharmacist and a nurse coordinator.

"The respiratory therapists have spent hours and hours doing percussive treatments on me," said McMahan. "It's kind of like a ketchup bottle where you turn it upside down and pound on it to make that thick stuff come out."

Due to constant lung infections and other complications, McMahan estimates she has to be admitted to the hospital six weeks out of the year. When that happens, the nursing staff

on 3 North always help get her back on her feet. "I have been a patient on that unit over 20 years. Two of the nurses have been my primary nurses for about that long. They know my quirks and preferences and I know theirs," she teased.

### New challenges

McMahan's longevity as a patient with CF has come at a cost. She has developed diabetes and osteoporosis, two conditions increasingly common in adult CF patients.

Still, she hasn't let the complications slow her down much. McMahan spends time with her family (she has two boys: one a sophomore in college and one beginning medical school), she plays handbells and continues to work for UK HealthCare as a triage nurse answering the after-hour calls of anxious parents with sick children.

"My manager has been very flexible, and I couldn't have a better situation," McMahan said. "She

Respiratory therapist Denesa Tuney works with McMahan in her pulmonary function lab.

Cathy Dudderar, RN, (left) and Lois Craigmyle, RN, are part of McMahan's care through the CF Center.

3 North nurses Rhonda Doris, RN, (left) and Diana Frankenburger, RN, have come to know McMahan so well they share news about their families.

understands my physical limitations, so I am scheduled in three- to four-hour shifts. When I get sick, she just says, 'Come back when you feel better.'"

Despite a lifetime of battling CF, McMahan has always been able to maintain a positive outlook. "It's something that's been with me from the beginning. I really don't understand when people feel sorry for me because it's not what I'm feeling at all. I feel very blessed to be in the situation I am in, even though it does require a big chunk of my life to manage my health."

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**"We have a lot of patients who need to balance their treatments and their lives. You want them to have a good balance between quantity of life and quality of life."**

– Michael Anstead, MD



## A Childhood Disease Encounters New Challenges

Forty years ago, patients afflicted with cystic fibrosis (CF) almost always died in childhood. Thanks to better treatments, many patients today are living well into middle age and encountering two new challenges

caused by the disease: diabetes and osteoporosis.

“All patients with cystic fibrosis are more prone to diabetes because secretions get stuck in the pancreas, so the patient doesn’t make as much insulin over time,” said Dr. Michael

Anstead, director of the adult CF Center. It is neither Type 1 nor Type 2 diabetes, but a separate form of the disease.

Osteoporosis develops because CF patients have problems absorbing calcium when they are young, chronic infections prevent them from building up their bones, and CF medicines weaken bones over time. Because of this malabsorption problem, chest percussions, a vital part of CF treatment, become impossible to do when patients have weakened or fractured ribs.

And ominously on the horizon, predicted Dr. Anstead, is cirrhosis

of the liver. As in the pancreas, secretions from the liver of CF patients are too thick. The resulting blockages create inflammation and scarring over time, which can lead to cirrhosis.

While CF patients are dealing with more complications the longer they live, these conditions are manageable. The best thing patients have going for them is cooperation, said Dr. Anstead. “There has been a concerted effort of patients, physicians and the Cystic Fibrosis Foundation to make sure patients are getting the best possible care. This cooperation is resulting in better treatments and is a major reason patients are living longer.”

## Genetic Testing: A Crystal Ball for Pulmonologists and CF Patients

Pulmonologists at UK HealthCare are increasingly ordering genetic tests for their cystic fibrosis (CF) patients, but surprisingly it’s not to diagnose the disease. It’s to predict what shape the disease will take over the course of a patient’s life.

A sweat chloride test is still the easiest way to confirm a patient has CF. “A positive sweat chloride test means you have CF,” said Dr. Carolyn Bay, a UK clinical geneticist. “Then we say, well, okay, which mutations? Is it going to be mild CF or severe CF?” At this point, a genetic test is performed.

“A pulmonologist wants to know how best to take care of a person with

cystic fibrosis. So we’re looking for mutations associated with certain health problems,” said Dr. Bay.

Pulmonologist Anstead added another important use for genetic testing in adult CF patients: checking a CF patient’s spouse to see if they are a carrier of the CF gene. “If their spouse is a carrier, they have a one in two chance of having a child with CF. If their spouse is not a carrier, then they know their children won’t have CF. The children will be carriers of the disease, but that’s only an issue if they marry a CF carrier down the road,” he said.



# Building the Commonwealth's **Academic Medical Center** of the Future

## **Patient Care**

The new UK Albert B. Chandler Hospital will provide the right kind of space to deliver the very best patient care. Kentuckians deserve peace of mind that no matter how complex or unusual their illness, they can be cared for in Kentucky. Partnerships with rural hospitals will help patients stay in their communities for most primary care needs, reserving UK Chandler Hospital for more complex care in a welcoming environment supportive to patients and families and conducive to healing.

## **Education**

Collaboration is a key factor in educating Kentucky's future health care providers. As one of only 11 universities in the nation to have all six health science colleges on one campus, UK is well-positioned to offer inter-professional health care education and collaborative research. A proposed Health Sciences Learning Center west of Limestone would be

shared by UK's colleges of Medicine, Dentistry, Pharmacy, Nursing, Health Sciences and Public Health.

## **Research**

The university's quest for Top 20 status among the nation's public institutions will require a significant research commitment from the

academic colleges at the medical center, which contribute more than 55 percent of UK's total research dollars.

For more information about UK HealthCare's plans, call (859) 257-1000 or toll free (800) 333-8874 and ask for our brochure: "Commonwealth's Medical Campus of the Future."

