I had choices for medical school, and getting a scholarship reinforced my decision to come to KU. It felt great being recognized for my undergraduate achievements. William Gordon Garnett Scholarship, established by bequest in 1990.

Anne Miller, M.D.  
Class of 2011  
KU School of Medicine  

Far Above: The Campaign for Kansas

INVEST IN THE FUTURE

Consider a bequest for KU Medical Center

Benefiting students is just one of the goals of Far Above: The Campaign for Kansas. Bequests, most commonly made through a will or trust, can support scholarships, research, teaching or patient care.

To discuss a bequest that carries out your wishes for the future of the KU Medical Center, please contact Nell Lucas, (913) 588-5551 or nlucas@kuendowment.org or Andy Morrison, (785) 832-7327 or amorrison@kuendowment.org.

Bequests for the benefit of KU should be written to the Kansas University Endowment Association.

Help us rise. Help us soar.
Each year, physicians and other medical professionals in the United States spend thousands of hours in the developing world, repairing cleft palates, treating cholera and distributing medicine. While admirable, these short-term medical missions go largely unevaluated. Teams return home with a sense of satisfaction but few objective measures of the quality of their work or its lasting impact. A recent KU Medical Center study was built on the idea that good intentions aren’t good enough. The seven-year review of outcomes is among the first of its kind. Kevin Sykes, the department of otolaryngology’s clinical research director, joined a mission trip led by Pamela Nicklaus, M.D., clinical associate professor of otolaryngology and director of the pediatric otolaryngology fellowship, to Antigua, a city in the central highlands of Guatemala. While his colleagues worked in the operating suites, Sykes went looking for data. Using the logbooks maintained by the hospital staff, Sykes created a list of tonsillectomy patients who had been treated by KU’s mission teams from 2004 to 2010. He then matched the list to postoperative charts maintained by hospital staff. Sykes was looking in the charts for signs of complications. The study, co-authored with Nicklaus, Keith Sale, M.D., assistant professor of otolaryngology, and Phong T. Le, concluded that the otolaryngology team operates with adequate safety protocol. The paper was published in Otolaryngology—Head and Neck Surgery.

Innovative agreement makes it easier for RNS to earn advanced degrees

Registered nurses with an associate degree in nursing from Butler Community College in El Dorado, Kan., can now continue their training and earn a bachelor’s degree in nursing at the University of Kansas School of Nursing, thanks to a new agreement between KU and Butler. Under the agreement, RNs with associate degrees from Butler can now enroll in KU’s online RN-to-BSN program, allowing Butler graduates to complete all required general education courses at Butler Community College instead of coming to the KU School of Nursing campus in Kansas City. The two schools believe this agreement is a model of creative institutional collaboration for the advancement of professional nursing as well as each school’s commitment to lifelong learning. The most recent Institute of Medicine Future of Nursing report calls for 80 percent of registered nurses to have a bachelor’s degree in nursing or higher by 2020. In order for that to be possible, colleges and universities need to collaborate so that RNs with associate degrees can easily progress to a bachelor’s program, according to David Martin, RN, MN, clinical associate professor and RN-BSN/MS program director at KU. This prepares nurses for positions such as nurse practitioner, clinical registered nurse anesthetist, clinical nurse specialist and nurse-midwife.

The KU School of Nursing has six Butler Community College graduates currently enrolled in the RN-BSN/MS program.
THE NEW DEPARTMENT OF CANCER BIOLOGY CONFRONTS THE RIDDLES OF METASTASIS

Danny Welch, Ph.D., founding director of KU Medical Center’s new department of cancer biology, hopes his department will prove instrumental in finding better ways of pinpointing and reining in metastatic tumor cells. There are currently four faculty members in the department and plans are to eventually recruit five to 10 additional faculty. Member Animesh Dhar, Ph.D., was recently awarded the department’s first New Research Project (NRP) grant from the NCI to evaluate crocin, a compound from saffron, as a potential therapy for pancreatic cancer. An application to form a new graduate program is also in the works – a timely initiative because the Institute of Medicine is considering making cancer biology its own discipline, like biochemistry or pharmacology.

SCHOOL OF MEDICINE STUDENT WINS A 2012 AWARD FROM THE AMA FOUNDATION

Marcus Basing, a second-year student in the School of Medicine, received a Minority Scholars Award from the American Medical Association (AMA) Foundation. The AMA Foundation is committed to increasing the diversity of minority physicians to better reflect the needs of an increasingly diverse society. With a master’s degree in microbiology, Basing has conducted research into how perceptions of diabetes affect illness management among African Americans, and the evaluation of pastes and the recruitment of African American participants in health disparities research. In addition, he is the executive director of the School of Medicine Community Health Project, where he matches medical, pharmacy and nursing students with local non-profit agencies. A KU School of Medicine student has won this prestigious award four out of the last five years.

KU PHARMACOLOGISTS PUBLISH BOOK ON THE BENEFITS OF HERBAL SUPPLEMENTS

S.J. Enna, Ph.D., a professor of molecular and integrative physiology, and Stata Norton, Ph.D., a professor emeritus of pharmacology, toxicology and therapeutics, have co-authored a science-based primer on understanding the benefits and dangers of herbal supplements with regard to brain function. The book, “Herbal Supplements and the Brain,” gathers current scientific information on the effectiveness of herbal products on central nervous functions such as anxiety, insomnia, alcoholism, depression and memory. The book provides a historical perspective on the use of plant products to modify central nervous system functions and on the development of current techniques to study the effects of herbal products on the brain. The book is targeted at physicians and pharmacists interested in the use of herbal supplements in the treatment of neurological disorders.

KU’S TOP-RANKED PROGRAM GRADUATES ITS 100TH CLASS

This past May, the KU Department of Physical Therapy and Rehabilitation Science graduated its 100th class of physical therapy students. Initially organized in 1943 as a response to the polio epidemic, the program has reached high heights in the areas of research and education. Faculty and graduates of the program have earned distinction, and the department is consistently recognized as a leader by U.S. News & World Report. Beginning with just one faculty member in 1943, the program now boasts 15 faculty and has earned an international reputation in the world of rehabilitation sciences. In its 2013 rankings of public university graduate programs, U.S. News & World Report ranked the KU Physical Therapy program ninth in the nation.

RESEARCHERS ARE MAKING KEY DISCOVERIES THAT COULD PREVENT RETINOPATHY

As part of an aggressive effort to speed delivery of treatments to patients by finding new uses for approved drugs, researchers at KU Medical Center have begun a clinical trial testing the most common form of adult leukemia with a drug first approved to treat arthritis more than 25 years ago.

In late 2011, KU researchers treated the first trial participant, a Kansas City-area patient suffering from chronic lymphocytic leukemia or CLL, with the drug auranofin, which has long been used to treat patients with arthritis. Additional patients both in Kansas City and at partner-}

ing sites including the NIH in Bethesda and the James Comprehensive Cancer Center at The Ohio State University are enrolled in the trial.

The trial is one key piece of a larger collaboration between KU, The Leukemia & Lymphoma Society (LLS) and the National Institutes of Health (NIH) to accelerate discovery and development of safe, effective and affordable cancer treatments. Over the last two years, the group discovered that auranofin kills CLL cells in test tubes, and received approval to test the drug in CLL patients.

Louis J. DeGennaro, Ph.D., executive vice president and chief mission officer at the LLS, says the collaboration between KU, LLS and NIH is giving new hope to patients by reducing sharply the time and costs associated with developing new drugs and therapies. He says auranofin is a great example of what is possible through an effective public-private partnership.

Scott Weir, Pharm.D., Ph.D., director of KU’s Institute for Advancing Medical Innovation (IAMI), says the model of spending more than $1 billion and taking more than a decade to deliver new therapies to patients is simply not sustainable. The IAMI collaborative was able to move auranofin into a clinical trial in just two years and for about $1 million, representing significant time and cost savings.

CLL is currently treated with drugs that are initially effective. But patients often reach a stage where they become resistant to treatment, including chemotherapy, leading to death absent other treatments. While chemotherapy can be quite toxic, auranofin has been demonstrated to be reasonably safe and effective in the treatment of arthritis.

Developing new uses for approved and abandoned drugs – or drug repurposing – is a major focus of the KU-LLS-NIH collaboration. In addition to auranofin, researchers are currently exploring other existing drugs that may offer similar hope for patients with leukemia and other blood cancers.

Christopher P. Austin, M.D., director of the NIH Center for Translational Therapeutics, says the face of modern medicine will rapidly change if accelerated drug development like we’re seeing in the repurposing of auranofin for CLL is successful. Austin says that drug collaboration will be applicable to other cancers and diseases and has enormous potential as a new paradigm for therapeutics development.

RESEARCHERS EXPLORE PATIENT-PROVIDER EMAIL COMMUNICATION

A study by two Department of Family Medicine faculty members examines email communications between doctors and patients in a primary care setting, finding how often they communicate, what topics they discuss and more. Mugur V. Geana, M.D., Ph.D., with KU’s William Allen White School of Journalism and Mass Communication, and K. Allen Greiner, M.D., MPH, professor of family medicine and associate chair for research, examined 327 unique email messages from 49 general practitioners collected over 90 days. They included all patient identification data and performed a content analysis on top-}
ics such as message characteristics, message content, content details, message tone, empathy and inclusion of other information sources.

They found that doctors took an average of 23 hours to reply to a patient’s email, compared to about five hours for patients. Treatments and lab tests were the most common topics of discussion for both patients and providers. Some of the most interesting emails were in response to a patient’s message, while the rest were emails informing patients of appointment times, medications, test results and the like. Geana and Greiner estimate that less than 20 percent of primary care physicians in the United States regularly use email to communicate with patients, even though studies have suggested that it does improve patient-provider relationship and increases patient satisfaction. The research was presented at a conference for the International Communication Association and the French Society for Communication and Information Sciences in Roubaix, France.
How do you solve a problem like Alzheimer’s disease? “For starters,” says Russell Swerdlow, M.D., “you look to see what clues are around, even if you have no idea what those clues mean.”

One clue that has long intrigued researchers is that the brains of people with Alzheimer’s disease are riddled with plaques made of a protein called beta-amyloid and tangles of another protein called tau. “The big hypothesis here is that amyloid causes Alzheimer’s, so if we could just get rid of it or keep it from being made, we could cure this disease,” says Swerdlow, who directs the University of Kansas Alzheimer’s Disease Center, designated one of 29 centers of excellence by the National Institute on Aging last year.

The idea that amyloid causes Alzheimer’s arose following the discovery – in the early 1990s – of families where approximately half of each generation developed brain plaques and tangles, and dementia, in their 40s. Scientists found three genes that were associated with the disease in these families.

“Based on these findings, the ‘amyloid cascade hypothesis’ gained steam because it made sense,” Swerdlow says. However, he questions whether this heritable dementia occurring in middle age is, in fact, the same as the more typical Alzheimer’s seen in older patients without a clear-cut family history of the disease.

“If it’s the same disease, then the amyloid cascade hypothesis could be right; if not, it’s probably wrong,” he says. “Right now, those studying Alzheimer’s are divided very unevenly into two camps.”

Researchers in the larger camp are sure that amyloid drives the disease. Colleagues in the smaller group aren’t convinced and are exploring other possibilities – including tau tangles, inflammation in the brain, and perturbed brain energy metabolism – that could be at the root of Alzheimer’s. The dividing lines are usually evident at scientific conferences.

“Every now and then, there are attempts to have debates over different hypotheses, and those are the most entertaining,” Swerdlow says.

For Swerdlow, the real problem that needs to be solved is why protein plaques and tangles develop in the first place.

“Scientists tend to study what they can see, which is why they’re investigating both amyloid and tau,” he says. “On the other hand, I say, ‘Well, amyloid and tau are present in Alzheimer’s, so something must be driving their formation, and we need to figure that out.’”

Swerdlow is in the minority.

“I believe plaques and tangles occur not as a cause, but as a consequence, of Alzheimer’s,” he says. “You may have plaques in your brain, but that doesn’t necessarily mean you have Alzheimer’s disease. It merely indicates that your brain is aging.”

While malformed proteins such as amyloid and tau are a byproduct of Alzheimer’s and probably contribute to its deadly progression, Swerdlow believes efforts to clear them from patient’s brains won’t ultimately cure the disease.

“My pet theory is that we’ll find a fix for Alzheimer’s when we understand what regulates aging,” he says. “We know some things slow the changes that come with aging – for example, exercise improves motor function and muscle strength, while restricting the caloric "BY ALISSA PÖH"
intake of mice makes them live a lot longer. So how do we apply these concepts to the brain?”

Swerdlow and his research group are working to understand how brain energy metabolism differs between younger and older brains. He thinks metabolism in an older brain might be boosted by tinkering with its mitochondria. Mitochondria are the energy powerhouses of cells, and cells employ various biochemical pathways to maintain them. Manipulating these pathways can influence aging in animals.

“One of the big ideas I’m working on is that people with Alzheimer’s have mitochondria that function differently, although we don’t yet know why,” he says.

W. Davis Parker, M.D., for whom Swerdlow worked as a research fellow at the University of Virginia, agrees with Swerdlow’s theory. Parker believes that Alzheimer’s disease results from problems in the electron transport chain, which the brain’s energy is generated by using fuels such as glucose.

In other experiments while he was in Virginia, Parker and Swerdlow transferred mitochondrial genes from blood samples of Alzheimer’s patients into laboratory-cultured nerve cells. These cells began behaving like diseased brain cells. Among other things, they produced amyloid plaques.

Parker’s argument has yet to gain widespread acceptance, though. “Most others in the field are so entrenched in the amyloid cascade hypothesis that they ignore other ways of studying Alzheimer’s,” he says. “I’ve heard years of my work dismissed as ‘too ridiculous to even mention’ at a major international conference. I was encouraged that it had been sufficiently noteworthy to merit dismissal.”

Swerdlow’s and Parker’s observations suggest that changes in mitochondria lead the way in Alzheimer’s. “As we age, our mitochondria decline to the point where signs of Alzheimer’s are seen,” Swerdlow explains. “How quickly individuals reach that point depends on how well their mitochondria were put together in the first place. Some people might need to reach 200 years of age before experiencing real cognitive problems. Others could get into trouble at 60. A lot of this is probably genetically determined, but environmental factors could also be involved.”

Someday, Swerdlow hopes to learn how to manipulate brain metabolism to help older brains regain function. Meanwhile, Swerdlow wholeheartedly endorses the beneficial effects of exercise on the brain – which his KU Medical Center colleague Jeffrey Burns, M.D., has been studying for years.

“When it comes to working out, you’re not really exercising the brain,” Swerdlow says. “Yet, as you become more fit, your body handles hormones like insulin differently, which ultimately changes metabolism in the brain. Your muscles also churn out lactic acid during exercise, which the brain uses as fuel. We want to find ways to produce these good effects more robustly.”

Swerdlow agrees, though, that when it comes to misfolded proteins like amyloid and tau, or faulty mitochondria in the brain, “we still can’t say for sure which is the chicken and which is the egg.” Clinical trials have been designed around drugs tailored to rid the brain of protein plaques and tangles. However, success is still elusive in these trials, patients who received treatments designed to eliminate amyloid or prevent its formation did no better, and sometimes worse, than those taking placebos.

“I believe that the mice used in preliminary studies aren’t modeling the correct disease, so treatments that appear to work for them fail in people,” Swerdlow remarks. “We have to catch these trials, patients who received treatments designed to eliminate amyloid or prevent its formation did no better, and sometimes worse, than those taking placebos.”

Swerdlow isn’t willing to wait another decade or longer to see if new clinical trials show that anti-amyloid therapies are effective in younger people who aren’t showing signs of dementia. “I’m that a tacit surrender for all the people who currently have Alzheimer’s or will develop it in the next couple of years,” he says. He feels that until the true cause of Alzheimer’s is found, researchers are essentially swinging with their eyes closed.

“I have my own ideas of how I would treat the disease and they’re not proven either,” he adds. “But you do have to start somewhere. Hopefully in all this mess someone’s going to stumble across something that works.”

Contact Alissa Poh at apoh@kumc.edu
Pregnant women have known for years about the benefits of DHA, which is crucial for brain development. Studies that documented improved cognitive skills in breast-fed infants have attributed this to the DHA content of breast milk. And for those women who can’t breast-feed or choose not to, DHA is also now added to almost every brand of baby formula.

Widespread recognition of DHA as a key factor in brain development for babies in the womb and after birth is due in large part to research pioneered by Susan Carlson, Ph.D., the Al Rie Professor of Nutrition in the University of Kansas Department of Dietetics and Nutrition.

Carlson was among the first to recognize that breast-fed infants had higher amounts of circulating DHA than infants who had been given formula. She has taken an active role in the education of pediatricians, obstetricians, nurses and dietitians about the roles of DHA in maternal and infant health and has been involved nationally and internationally in establishing best practice guidelines for intake of DHA by infants and pregnant women.

Unfortunately, Carlson says, women in the United States have far lower DHA levels in their breast milk than women in other regions of the world. This can be attributed to two factors: North Americans don’t eat as much fish, as their global neighbors, and pregnant women, in particular, are warned against eating fish during their pregnancies to avoid mercury.

Carlson says there are many types of DHA-rich seafood that pregnant women can safely consume, but many pregnant women have instead chosen to augment their DHA intake through supplements. The current suggested DHA dosage for pregnant women is 300 milligrams per day. Carlson’s latest research centers around trying to ascertain whether that 300-milligram dosage is sufficient to have a significant impact on the cognitive development of infants and children.

In February 2012, Carlson and fellow researcher John Colombo, Ph.D., director of the KU Schiefelbusch Institute for Life Span Studies, were awarded a $2.5 million grant from the Eunice Kennedy Shriver National Institute of Child Health and Human Development to fund the next five years of a 10-year, double-blind randomized controlled clinical trial to determine whether prenatal nutritional supplementation with the omega-3 fatty acid DHA benefits children’s intelligence and school readiness.

Beginning five years ago, Colombo and Carlson enrolled 350 pregnant women in a study to determine whether DHA supplementation improved birth outcomes and reduced prematurity.

During the last half of their pregnancies, the women were randomly given a 600-milligram supplement of DHA or 600 milligrams of a placebo. Their babies were then followed until they were 18 months old. The children underwent intense assessments that included weight, height, blood pressure, heart rate, memory tasks and attention tests. This new grant will allow them to continue studying and measuring the children every six months until they reach age 6.

The possibility that DHA may have long-term benefits for cognitive-intellectual development, particularly on measures that predict school achievement, would have enormous implications for public policy on prenatal nutrition,” Carlson says.

Colombo says another key to understanding how DHA benefits cognitive development is the manner in which scientists test the intelligence of young children. While the Bayley Scales of Infant Development are standard measurements for the cognitive development of infants and toddlers, many observers feel that the measure lacks specificity. To advance their understanding of how DHA affects children, Colombo, whose area of expertise is in developmental cognitive neuroscience of attention and learning, is implementing alternative measurements that are more sensitive – a move he says holds great promise.

“AnyTHING I can do as a mother to make sure that my son gets what he needs to fully develop both physically and cognitively. I’m going to do it,” Rieke says.

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“What we want to know is, if you give the mothers this amount of DHA supplement during this potentially critical period of their pregnancy, do the kids show differences in cognition?” Colombo explains.

Carlson says this trial is groundbreaking in a couple of ways. First, this is an unprecedented length of time to examine children for the potential benefits of DHA.

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When James Calvet, Ph.D., came to work at the University of Kansas Medical Center in 1981, he didn’t know anything about the kidney.

Calvet’s background was genetics and cell biology. He’d just finished postdoctoral studies at the Worcester Foundation for Experimental Biology in Massachusetts, where he had been researching the mechanisms of gene expression and ribonucleic acid (RNA) structures in cultured cells – the HeLa cells made famous in Rebecca Skloot’s bestselling “The Immortal Life of Henrietta Lacks”.

“I was one of the people growing liters and liters of those cells,” says Calvet, now a professor in KU’s Department of Biochemistry and Molecular Biology. Watching as newly synthesized RNAs turned into messenger RNAs, he eventually discovered new ways to determine how messenger RNA expression and ribonucleic acid (RNA) structures in cultured cells – the HeLa cells made famous in Rebecca Skloot’s bestselling “The Immortal Life of Henrietta Lacks”.

Eventually, Calvet’s attention turned toward the kidney. Calvet says he decided to go into nephrology because “I was interested in the basis for that.” Gattone essentially figured out a way to lower levels of cyclic AMP in the kidney so that it decreases both cell proliferation and cyst-filling fluid secretion in animal models. By 2005, the first patients were enrolled in studies.

Among the patients now on tolvaptan trials is Nicole Harr, 45, who was diagnosed with PKD about 10 years ago.

“If tolvaptan works,” he adds, “it’s the first clinical treatment of PKD. We have a drug that could work for this disease.”

By C.J. Janovy
In many ways, Carolyn Harbold is a typical 11-year-old girl. The sixth-grader from Pittsburg, Kan., loves to play sports, including bicycling and swimming. Her newest interest is running track. She enjoys hanging out with friends and playing with her two sisters and brother.

Unlike the majority of her peers, however, Carolyn has spent more than half of her life in counseling for pediatric bipolar disorder and attention-deficit/hyperactivity disorder (ADHD). She’s also been in and out of the hospital — as many as four times in one year — because her behavior was uncontrollable. Carolyn

TELEMEDICINE IS HELPING CHILDREN IN RURAL KANSAS RECEIVE MUCH-NEEDED MENTAL HEALTH SERVICES

BY CARI MERRILL

ILLUSTRATION: Keith Negley
Carolyn has consistently received care from providers in Pittsburg, but her mother Marie continued to struggle in managing her daughter’s ever-changing moods. When Carolyn’s oldest sister saw an ad in The Pittsburg Morning Sun for a pediatric mood disorder telemedicine study being conducted by the University of Kansas School of Medicine–Wichita, Marie jumped at the chance to enroll Carolyn.

“It was something new and something that would hopefully help me better parent Carolyn and handle her moods,” Marie says.

PROVIDING TOOLS FOR COPING

KU School of Medicine–Wichita child and adolescent psychologist Nicole Klaus, Ph.D., was the principal investigator in the telemedicine study that enrolled Carolyn and Marie Harbold. Klaus has an extensive background in diagnosing and treating pediatric mental health disorders. Originally from Hays, Kan., Klaus left the state to earn her master’s and doctorate in clinical psychology as well as to complete a fellowship in clinical child and adolescent psychology.

“When I moved back to Kansas, I saw a real need to serve kids in rural areas who just aren’t able to drive to Wichita or Kansas City to get their mental health care,” Klaus says.

During her study, Klaus worked closely with the Center for Telemedicine and Telehealth at KU Medical Center in Kansas City. The center is a recognized world leader in telehealth services and research.

In a predominately rural state like Kansas, telemedicine is crucial. Of Kansas’ 105 counties, 102 are medically underserved. These communities are faced with retiring primary care physicians and limited access to specialists, leaving patients to travel to Wichita, Kansas City or even outside of the state.

After training with the video and sound equipment necessary for telemedicine consultations, Klaus enrolled patients from Pittsburg, Garden City, and Hays, in her study. Her patients would receive treatment from her while she was in Wichita and they remained in their towns.

During her study, Klaus worked closely with the Center for Telemedicine and Telehealth at KU Medical Center in Kansas City.

Carolyn’s bipolar disorder and ADHD are two mental disorders that often appear together. About 7 to 8 percent of children from ages 5 to 18 in a large population, such as Wichita, have ADHD, said Russell Schell, M.D., KU School of Medicine–Wichita psychiatry professor. But because there is a lack of pediatric bipolar disorder literature and education programs, it’s difficult to diagnose, and many times, the condition is underdiagnosed.

Schell says telemedicine, when used in partnership with a local primary care physician, can be beneficial for helping to treat mood disorders.

“Let’s say a patient has an anxiety disorder like agoraphobia, which is a fear of being outside; you could actually conduct a session in their home,” he says.

Telemedicine is also helping meet a need in rural towns that don’t have specialists, especially child psychiatrists, who are already in extremely short demand. But telemedicine isn’t meant to stand on its own.

“The real bonuses are when you do this in a collaborative care model – where the family medicine doctor or whoever is primarily taking care of the patient – is involved. When the doctor in the rural community remains the caregiver and takes advice and guidance from the telemedicine support person, then you get an aura effect.”

Carolyn saw the television screen as a benefit. The simple zoom feature helped focus Carolyn’s attention on Klaus rather than on her surroundings.

Klaus’ study that included the Harbolds was a pilot project funded by the Wichita Center for Graduate Medical Education and the Kansas Bioscience Authority to demonstrate the feasibility of doing psychoeducational psychotherapy by televideo. Future studies are planned to collect clinical data to show symptom improvement using telemedicine therapy.

Klaus also developed a tool kit with the Harbolds that included a number of activities to both relax Carolyn when she needs to be calmed and to stimulate her when her mood is down. All the coping skills in the tool kit were practiced during the sessions.

Since participating in the study, Carolyn has excelled at school and at home.

“We were so excited because Carolyn went from getting 60s on her school work to getting 100s every day after we went through the therapy,” Marie said.

TELEmedicine = PRIMARY CARE CAN EQUAL SUCCESS

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While telemedicine is useful for bridging distance and bringing specialists to underserved towns, it comes with challenges.

“The main difference I noticed is I couldn’t control their behavior as well on the other end of the screen,” Klaus says of her patients. “If they were going to be a little ornery in my office, I have a few more options to distract them. When they’re on the other end of the video camera, they learn very quickly they can mute the microphone or walk off screen.”

In the spring of 2012, Dr. Klaus received a one-year, $30,000 Frontier SRS pilot grant funded through the Wichita Center for Graduate Medical Education and the Kansas Bioscience Authority to further her telemedicine research. The latest project will pilot a Spanish version of the psychoeducational psychotherapy – the same therapy used with Carolyn and Marie Harbold – to include Spanish-speaking families in future telemedicine trials.

“We believe that quality care through telemedicine can reduce travel expenses, improve quality of life for the entire family, and help prevent hospitalizations,” Klaus says. “The technology is advancing so rapidly and has the potential to overcome so many of the major barriers to accessing mental health care for rural Kansas families. The possibility that more children will get the treatment they need is very exciting.”
In the fall of 2011, several months after having a malignant melanoma removed from her scalp, Mary Elizabeth Williams was told by her doctor that she had metastatic, Stage 4 cancer. Williams, a longtime writer and editor for the online magazine Salon, as well as contributor to The New York Observer and The New York Times, was told she had few viable treatment options. But her doctor mentioned a clinical trial for Ipilimumab, the first new melanoma drug approved by the FDA since 1998. After a battery of tests to determine her suitability, Williams was enrolled in the trial.

The Ipilimumab trial Williams enrolled in is a Phase I trial, where researchers test an experimental drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify side effects.

Williams says she didn’t have any hesitation in signing up for the Ipilimumab trial because she had no other treatment options. But she understands why many patients decline to participate.
Williams says researchers told her she would run the risk of a battery of side effects ranging from fever, rash and fatigue to rare but serious conditions such as heart attacks and meningitis.

She went on to chronicle her experiences as a clinical trials patient in her salon blog, “My Life as a Lab Rat.” Although Williams’ clinical trial was not at the University of Kansas Medical Center, her blog introduced a national audience to the challenges and benefits of participating in research that may help save the lives of future generations.

At any one time, there are more than 600 clinical trials going on at KU Medical Center. The trials cover most kinds of cancer, neurological conditions such as Alzheimer’s disease and Parkinson’s disease, as well as studies that target pediatric obesity, kidney disease, spinal cord injuries, smoking cessation and heart disease.

And for many of the thousands of patients who participate in trials at KU Medical Center, the experience of being a clinical trials subject is beginning to change for the better, thanks to a new center that is devoted to the clinical trials experience.

**THE UNIVERSITY OF KANSAS CLINICAL RESEARCH CENTER**

Although the new KU Clinical Research Center has been open since January 2012, the center’s medical director, Raymond Perez, Ph.D., still beams when he talks about it.

“There really is no other place like it,” Perez says.

One thing that makes the center unique is the way it has been funded. In 2008, voters in Johnson County, Kan., approved a one-eighth cent sales tax to finance the Johnson County Education Research Triangle. The tax generates approximately $5 million per year to support the KU Clinical Research Center and the same amount for two other higher-education and research facilities in Johnson County.

The KU Clinical Research Center is designed unlike any other research facility in the country. The 82,400-square-foot building, which was donated by the Hall Family Foundation, includes state-of-the-art equipment, with space, resources and manpower devoted solely to accommodate clinical trials patients and researchers. It is the home for a growing number of the clinical trials being conducted at KU Medical Center, including early phase oncology clinical trials.

“There are very few academic medical centers in the country that have free-standing early phase units like we have here,” says Perez, who came to KU Medical Center from Dartmouth Medical School last year. “The Clinical Research Center allows us to completely focus on providing the very best patient care and conducting clinical research because that’s what the center is designed for.”

Perez says the Clinical Research Center will be eventually be able to handle 25 to 30 early phase cancer trials at any given time and enroll up to 300 new patients per year. And with The University of Kansas Cancer Center’s new designation as a National Cancer Institute-recognized center, the number of cancer clinical trials in the coming years is expected to increase.

Add to that the $20 million Clinical and Translational Science Award (CTSA) that KU Medical Center received from the National Institutes of Health (NIH) in 2011 to accelerate clinical and translational research, and the Cooperative Research and Development Agreement between the NIH, KU Medical Center and the Leukemia & Lymphoma Society to develop potential new therapies for rare blood cancers, there is little doubt that the medical center will be conducting more clinical trials in the near future.

That increase in the number and scope of clinical trials positions KU Medical Center to enhance its reputation as a major player in clinical and translational research. But it also brings with it a tremendous number of challenges. “It’s an undertaking to say that conducting clinical trials is a lot more complicated than it used to be,” Perez says.

**EARLY CLINICAL TRIALS**

The concepts behind clinical trials are ancient. In the Bible, the Book of Daniel describes a planned experiment to determine the effects on two groups who either partook or did not partake of “the King’s meat.”

In 1025 A.D., Persian physician and philosopher Avicenna wrote The Canon of Medicine, laying down rules for the experimental use and testing of drugs and treatments. Among other things, Avicenna wrote that the drug to be tested must be free of any extraneous accidental qualities; it must be used on a simple – not a composite – disease; the quality of the drug must correspond to the strength of the disease; and the effect of the drug must be seen to occur consistently, because otherwise the result may just be accidental.

Many of these guidelines hold true today. But most researchers agree that, particularly in the last 25 years, designing and conducting clinical trials has become much more complicated, expensive and difficult.

Richard Barohn, M.D., is chair of the KU Medical Center Department of Neurology and program director for Frontiers, the medical center’s CTSA institute. Barohn says the days of a researcher getting an idea for a new drug or therapy and testing it with a small group of patients are long gone.

“The new reality is that the majority of the time, you need a huge team to put on a clinical trial,” Barohn says. “Clinical trials now take many more people and much more money, and take much longer to complete.”

Perez says much of the increasing complexity is due to the growth of regulations surrounding clinical trial research, as well as the fact that most trials today must be geared toward more chronic and challenging diseases and conditions.

“Cures and treatments for most of the easier diseases have already been discovered,” Perez says. “But when you are talking about more complex diseases such as cancer and Alzheimer’s disease, there are no easy solutions, because the causes are much more difficult to determine. And when we don’t know the cause, the cure is nearly impossible to find.”

To conduct successful clinical trials, Barohn says, an institution must have a talented group of researchers who are skilled in designing clinical trials; an experienced team to conduct and support trials; the money necessary to fund trials; adequate space and facilities; and the ability to recruit patients willing to participate in trials.

**DESIGNING A CLINICAL TRIAL**

When a researcher develops an idea, procedure or drug he or she wants to test, experts in the field or colleagues typically review the concept to provide feedback.

If the study idea appears to be viable, the next step is to obtain funding, which a researcher can secure from a variety of sources, including the federal government. In many cases, especially for large or long-term studies, funding may come from more than one source. Only when funding is secure can the true work of designing the trial begin.

Trial designers must be methodical to ensure the trial maintains a strong scientific foundation. “The point of clinical trial design is to develop rigorous and quantitative markers to control the risk of error,” says Matt Maya, Ph.D., the chair of biostatistics at KU Medical Center. “Only then will you discover if your hypothesis is true.”

Researchers at KU Medical Center usually work with faculty in Mayo’s biostatistics department to develop a study protocol. The protocol is a document that often includes the number of participants, the eligibility and exclusion criteria, details of the drug or therapy the participants will receive, the steps clinical caregivers will carry out, and most importantly, the study endpoints.

They also must work with KU Medical Center’s Institutional Review Board (IRB), comprised of researchers and non-scientists, to ensure that the study protocol complies with all the ethical, legal and regulatory requirements set by the Food and Drug Administration (FDA) and the Department of Health and Human Services, among others.

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**“Designing and conducting clinical trials has become much more complicated, expensive and difficult.”**

“There are some very specific criteria for getting a trial approved,” says Karen Blackwell, who is director of the Human Research Protection Program at KU Medical Center. “We go through this long approval process because we want to maintain a high degree of transparency about the research we carry out at KU Medical Center and the results it produces.”

**THE CHALLENGE OF RECRUITING PATIENTS**

Once a trial is designed and approved, next comes the daunting challenge of recruiting patients. Barohn says recruiting a sufficient number of qualified patients is often the biggest barrier to conducting successful clinical trials. According to Clinical Site Services, a company that helps many pharmaceutical and biotechnology companies manage the trial enrollment process, more than 85 percent of all clinical studies do not meet their projected timelines, primarily because they struggle to recruit enough patients for their trials.

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Reflecting the increasing complexity of trials, a 2011 report by the Tufts Center for the Study of Drug Development found that the median number of procedures in a clinical trial increased by 49 percent from 2000 to 2007. At the same time, the number of eligibility criteria for entering patients into a study grew by 58 percent, causing fewer patients to enroll in trials (enrollment rates fell 21 percent).

Blackwell says it is essential to make sure from the beginning of the recruitment process that patients completely understand the commitment and possible risks of clinical trials before they are enrolled.

"Those who are the first humans to undergo a potential new treatment can face some serious risks, no matter how much prior testing has occurred in the laboratory and in animals," Blackwell says. "Our researchers sit down with each patient and go over the informed consent documents and other materials so they have a complete understanding of what lies ahead.

Patients sign onto clinical trials for a number of reasons. Some have no other treatment options. Others enroll because their current therapies aren’t working—perhaps because they want to be the first to receive a potentially life-saving drug.

But the reason many people enroll in clinical trials is that they truly believe they are helping to advance scientific knowledge and discovery.

Mary Elizabeth Williams, the Salon writer, is one of those patients. She says in addition to the attraction of receiving a drug that could potentially save her life, she wanted to do the trial to help researchers find a cure or treatment for her type of cancer, whether it ends up helping her or not.

"On my better days, I feel connected to something very big," Williams says. "I feel like my diseased body has a purpose.

Barohn says many patients decline to participate in trials because they are reluctant to give up any other traditional treatment they are undergoing, they are anxious about possible side effects, worried about the time commitment or have concerns about being a "guinea pig."

He says a skilled researcher can often reassure a potential trials subject about those and other concerns. But many patients, no matter how dire their situation, do not want to be a part of a research trial.

It can also be a tremendous hurdle to recruit minority participants for clinical trials. Racial and ethnic minorities suffer disproportionately from diseases such as cancer, diabetes and HIV, but the difficulty of recruiting and enrolling minority patients in clinical trials has been an ongoing concern among researchers.

Perez says there’s definitely a trust issue.

"African Americans in particular have traditionally been reluctant to participate in clinical trials because they distrut the medical establishment, partly due to the legacy of the Tuskegee syphilis study in the early part of last century," he says.

But that may be changing.

A 2007 study by the online journal PLoS Medicine found that ethnic minorities in the United States, particularly African Americans and Hispanics, are as willing to participate as non-Hispanic whites, and in some instances more willing.

In fact, the study’s authors say the factors that influence participation are often related to practical issues. They include whether potential participants are medically eligible to participate and have personal circumstances that allow them to participate. Child-care demands, job flexibility and geographic proximity to research sites make a difference.

"But one thing that being part of a clinical trial showed me was that minorities in the United States, particularly African Americans and Hispanics, are as willing to participate as non-Hispanic whites, and in some instances more willing."

Perez says a new challenge for recruiting patients is that many of the drugs being tested now have specific targets. Because cancer trials, in particular, now usually focus on a specific type, cause and stage of the disease, even patients who are willing to enroll in a trial often aren’t eligible because it doesn’t fit their particular cancer profile.

"It’s becoming less frequent that a drug is being tested that could help, let’s say, any woman with breast cancer," Perez says. "It’s more likely that a drug is being targeted to a patient who has a specific genetic mutation, like the BRCA-1 gene, that likely played a role in her breast cancer."

Perez says finding a sufficient number of patients with a particular genetic alteration for a drug trial can be a challenge for researchers.

"The good news is that there has been a tremendous increase in awareness among patients about clinical trials and how they can help," Perez says. "Because of that, researchers, particularly in cancer, are finding the recruitment process a bit easier."

Another stumbling block for many researchers is getting their results published. For a variety of reasons, many trials never lead to definitive conclusions. Trials often close prematurely because there is a loss of funding. Also, unanticipated problems with the selection of patients, procedures used during the trial, or small differences between the interventions being compared can result in inconclusive results.

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Perez says the failure in many Phase 2 clinical studies is not surprising.

"This is where many drugs stumble," says Perez. "Phase 1 clinical trials are largely focused on safety. But in Phase 2, the studies are not only larger so one can discover more toxicities, but it is at this stage that the drug is usually first tested to see if it is effective in bringing about the required therapeutic effect." (In Phase III, the drug is given to an even larger group of people to confirm its effectiveness and collect information that will allow the experimental drug or treatment to be used safely. And a Phase IV trial is done after the drug has been marketed to gather information on the drug’s effect in various populations and any side effects associated with long-term use.)

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Another stumbling block for many researchers is getting their results published in a timely manner. In a study released in early 2012, Yale School of Medicine researchers looked at a sample of trials primarily or partially funded by the NIH. They found that fewer than half had results published within 30 months of completing the trial, and one-third remained unpublished 51 months after completion.

Barohn says if a researcher navigates all the challenges of getting a clinical trial off the ground and completed but then fails to publish the results, the study might as well not exist.

"You owe it to your patients to publish your research, even if the results are not what you hoped for," Barohn says.

Barohn says senior researchers at KU Medical Center have a long history of mentoring junior faculty who are just dipping their toes into the complexities of clinical trials. He says that mentoring is particularly crucial when it comes to helping younger scientists analyze their research and write up their results.

But the ultimate clinical trial success story is when a patient without hope takes a leap of faith, participates in a trial and has a miraculous therapeutic result. Williams appears to have experienced just that. Several months after enrolling in the ipilimumab clinical trial, she has seen many of her tumors shrink dramatically and, in some cases, disappear completely.

"I am an experiment, and the experiment continues," Williams says. "But one thing that being part of a clinical trial showed me was that having Stage 4 cancer isn’t what it used to be. It gave me a chance I didn’t have before."

Contact Donna Pacik at dpacik@kumc.edu
It has become a reality that any academic institution conducting clinical trials today must have an outstanding biostatistics department. Biostatisticians have become major partners in designing, conducting and analyzing clinical trials. KU Medical Center’s growing Department of Biostatistics is chaired by Matthew Mayo, Ph.D. We talked to Dr. Mayo recently about the role that his department plays in the growing number of clinical trials being conducted at KU Medical Center.

BIOSTATISTICIANS PLAY A MAJOR ROLE IN CLINICAL TRIALS

By DONNA PECK

1. How critical is it that a biostatistician be involved during the process of putting together and implementing a clinical trial?

It is becoming more and more essential. If a researcher has a question they want to test, we can help them answer that from a data standpoint, and we can ensure that it is statistically valid and is conducted in an ethical way. The more time we spend up front helping a researcher design a trial, the easier it will be for them to analyze the data and come to a valid conclusion at the end.

2. Have you ever had to tell a researcher that a proposed trial can’t be done?

Sometimes. But that comes up more often with junior investigators than it does with senior researchers. With experience, they get a clearer understanding of what is statistically required for a successful trial.

3. When you’re working with a researcher on designing a new clinical trial, what are your key responsibilities?

My job is to work with the researcher to determine the optimal design for that trial. We do things like establish what are the fewest number of subjects or patients needed for a statistically valid result. We also figure out the error rate and help the scientists identify what they want the endpoints or outcomes of the trial to be.

4. Are there times when a biostatistician and a researcher don’t see eye-to-eye on what those numbers should be?

Oh definitely. Sometimes what a researcher wants to do makes sense clinically, but not statistically. It’s not necessarily an adversarial relationship between biostatisticians and a scientist. But it’s a constant back-and-forth.

5. Do biostatisticians specialize and have expertise in particular types of clinical trials?

There are some statisticians who focus on designing trials for cancer or infectious diseases studies, but many work on all kinds of clinical trials. There are also some biostatisticians who prefer certain clinical trial designs. Maybe they prefer using a Bayesian or an adaptive design approach as opposed to a frequentist approach. Bayesians tend to be aggressive and optimistic with their modeling assumptions. Frequentist statisticians are more cautious. We are comfortable doing both here.

6. It sounds like in addition to being data experts, biostatisticians need quite a few other skills to be successful working on clinical trials?

You have to be a good communicator because you are explaining data to non-data people. You need to have excellent writing skills. And most of all, you have to be a collaborator. That’s why we have added a collaborative research course as part of KU Medical Center’s biostatistics graduate program.

7. Is this a great time to be a biostatistician at KU Medical Center?

Well, we certainly are a lot more project-rich than when I came here 14 years ago! There is so much important research going on here right now, and I know I speak for my department when I say we are thrilled to be a part of it.

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More than a Preschool

The Children’s Campus in Kansas City, Kansas offers a range of services for at-risk children

By David Martin

Phillimina Njau felt desperate and alone after the birth of her daughter. Following in the steps of her older sisters, Njau had left Tanzania to attend college in the United States. She was taking classes at Kansas City, Kansas Community College when she found out she was pregnant. Kayla arrived in early 2010. The delivery, by Caesarean section, left Njau in physical pain. She also worried about her ability to balance schoolwork with being a single mom. Isolated from friends and family, she fell into a depression. “I had given up on everything,” she says.

Njau received crucial support from a program at the University of Kansas Medical Center. Project EAGLE, a division of the Department of Pediatrics, provides early education and other services for more than 1,000 young children and families in Kansas City, Kan. The program has been such a success that Project EAGLE received the Edward Zigler Award for Innovation from the National Head Start Association in 2012.

Njau’s experience is a testament to Project EAGLE’s ability to help at-risk families. Once so overwhelmed that she considered suicide, Njau is today an honors student in respiratory therapy, while Kayla is a happy 2-year-old with a preference for macaroni and cheese over her mother’s African recipes.

Njau learned about Project EAGLE through one of its intake specialists. Each year, Project EAGLE assesses the needs of hundreds of families with young children. Njau’s intake specialist talked to her about Medicaid and other programs that were available to her and her child. The process did not feel cold and bureaucratic. Njau was touched that she was asked if she was eating well.

Kayla, Njau learned, was eligible to enroll in a unique Early Head Start program that Project EAGLE offers. Project EAGLE belongs to Educare, a national consortium of early childhood centers supported by tax dollars and private donations. These full-day, full-year centers deliver Early Head Start services in facilities designed to be showrooms for birth-to-age-5 learning.

It took six years to raise the money for the Children’s Campus. Staker discovered that potential donors were put off by the fact that she hadn’t asked them for money in the past. “I didn’t have a credit history,” she says.

But no one gave up, and the capital campaign goal was ultimately reached. Dickinson Financial Corporation donated the land for the Children’s Campus. Major donors include the Barton P. and Mary D. Cohen Charitable Trust, the J.E. and L.E. Mabee Foundation, the Unified Government of Wyandotte County, the Hall Family Foundation, J.E. Dunn Construction and Broadway Square Partners. Project EAGLE shares the building with Juniper Gardens Children’s Project, a center within KU’s Life Span Institute, and the Family Conservancy, a provider of mental health services, parenting education and other services.

Staker says visitors are often surprised by the range of services offered. On the ground floor, a physician’s assistant makes medical rounds through the various classrooms in the Educare center each day. Project EAGLE also manages a health clinic in which parents can receive screenings and referrals.

Njau tries to take advantage of Project EAGLE’s different offerings. She uses the library and has asked the cooks for tips on how to prepare food that Kayla will like. She is also grateful for the warm reception she receives on a daily basis from those at Project Eagle. Njau, who serves on a parents’ advisory council, says Staker and the rest of the staff take the time to greet her and provide advice when needed.

“If I have a problem, I will call one of them before I would call anyone else,” she says. “Because I trust them with my child, it means I trust them with my life.”

Contact David Martin at dmartin@kumc.edu

It was a 2-week-old or 1-month-old child enters this building, it’s school,” Staker says. “You’re going to learn.”

Today, more than 130 infants, toddlers and preschoolers attend the Educare center. Each classroom has at least three teachers. The classrooms connect directly to outdoor play areas and share kitchens with microwaves, refrigerators and dishwashers. The aim is to provide the best structure to help at-risk children grow up eager to learn and ready for school. Staker was the driving force behind the Children’s Campus.

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Project EAGLE’s Educare center occupies the ground floor of the Children’s Campus, a three-story, $15.8 million building in downtown Kansas City, Kan. When it opened in the summer of 2010, the center became only the 11th member of the Educare Learning Network, a partnership between the Ounce of Prevention Fund and the Buffett Early Childhood Fund founded to help very young children at risk for school failure.

Njau was blown away when she first entered the Educare center. “It was such a beautiful building,” she says. “I had been looking at day cares. This was more like a school.”

That’s the point, according Martha Staker, who served as the executive director of Project EAGLE until her retirement in June 2012. “From the time a 2-week-old or 1-month-old child enters this building, it’s school,” Staker says. “You’re going to learn.”

Today, more than 130 infants, toddlers and preschoolers attend the Educare center. Each classroom has at least three teachers. The classrooms connect directly to outdoor play areas and share kitchens with microwaves, refrigerators and dishwashers. The aim is to provide the best structure to help at-risk children grow up eager to learn and ready for school. Staker was the driving force behind the Children’s Campus. Prior to its opening, Project EAGLE had leased space in an office building in downtown Kansas City, Kan. The space did not lend itself to serving the needs of children. Looking for alternatives, Staker came upon the concept of “multi-tenant nonprofit centers” – buildings that house organizations which have similar or complementary missions.

Staker’s research led her to believe that Kansas City, Kan., would benefit greatly from a facility that offered early childhood development, parenting education, crisis intervention and other services in one place. “We saw so many children in our community falling through the cracks, and felt that if we could consolidate services under one roof, we’d be more likely to get good outcomes for children,” she says.
At Cross-Lines Community Outreach, Inc. of Wyandotte County, students and faculty in the University of Kansas Department of Dietetics and Nutrition are working to combat a serious, community-wide problem: food insecurity. Currently, more than a quarter of the children in Wyandotte County don’t have access to proper food or nutrition.

In a proactive effort, students and faculty from KU Medical Center have started a nutrition education program called Food for Your Family. Over the course of the eight-week program, Wyandotte County families and children learn about the negative effects of unhealthy foods, as well as cooking skills and healthy eating habits.
COME ON INSIDE.

Learn more about how telemedicine can help children in rural areas, the challenges of clinical trials, how doctors are gaining a better understanding of kidney cells, and much more.