

# OUTREACH

Johns Hopkins Comprehensive Transplant Center



JOHNS HOPKINS  
MEDICINE  
COMPREHENSIVE  
TRANSPLANT CENTER

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## Setting the Stage for Organ Donation



*The camera rolls as Mike Williams relays tragic news to a standardized patient family. A pastoral care team member and a nurse comfort the patient's mother, but only Williams is an actual staff member. Later, the group will evaluate the exchange.*

AS CO-DIRECTOR OF Hopkins Hospital's surgical ICU, Pam Lipsett has witnessed her share of death and the emotional toll it takes on caregivers and families alike. As chair of the Hospital's Organ Donor Council, she also knows the importance of turning death into a gift of life. But bringing up organ donation while families are struggling with end-of-life decisions, Lipsett cautions, is ripe for misconceptions about the obligations and motives of those treating the dying.

"When a life hangs in the balance," she says, "a family's worst fear is that you won't do your best to save their loved one's life, that all we care about is saving the organs. Nothing could be further from the truth."

But taking advantage of the narrow and ethically charged window of opportunity to ask a grieving family about organ donation, Lipsett emphasizes, comes down to this: How caregivers communicate with families about end-of-life decisions can open the door to organ donation discussions. Nationally, the organ shortage has reached a crisis level. Every day, 17 people die waiting for hearts, lungs, livers and kidneys.

With funding from two federal Health Resources and Services Administration grants, Hopkins has been training physicians and other care team members here and elsewhere how to speak to families about end-of-life decisions, with the aim of fostering

### The Plot Thickens

Physicians who have taken the standardized patient training say they leave with a heightened awareness of the effect of their words. "There's more science to this than people give it credit for," Williams claims. "We need to offer feedback on good encounters as well as bad ones." The following simulated patient encounter illustrates the point.

**Scene I:** A teenager is rushed to the OR after a car accident. He has a brain hemorrhage. You, the doctor, must prepare the family for the possibility that the boy will die. You assure them that you—and the team—will do everything possible to save him.

**Scene II:** In spite of heroic efforts to save the patient, he has gotten worse, and it looks like he's going to die. You explain that Hopkins performs two evaluations at least six hours apart to assess the presence of brain death. During the wait between encounters, the team interacts with the doctor and the family. All eyes are on the dynamics. The videotape is running.

**Postmortem:** At the end of the session, the "family" comes back in the room to share feedback—a crucial part of the training. A patient's husband says, "You used words I could understand, and you were calming." But, he adds: "When you were describing how organs are donated, you made a sawing motion on your breastbone. That was very disturbing to me." ■

a better atmosphere for organ donations. Studies at HRSA—and Hopkins—have found that organ donations under these circumstances increase when physicians are attentive to family needs. Neurologist and Ethics Committee Co-Chair Mike Williams points out that demonstrating compassion and integrity at the end of life builds trust between caregivers and families.

But, surprisingly, Williams and  
*(continued on page 5)*

## The View from Here Buckling Down

By Robert A. Montgomery, M.D., Ph.D.

**W**HENEVER MY CHILDREN get in the car with me, they remind me to fasten my seatbelt. They're mimicking a pervasive ad campaign that propelled the safety practice toward a life-saving law. But what strikes me is how natural it is for my kids to utter those words. By the time they're 18, buckling up will become part of their routine—right after they adjust their seat.

So imagine what could happen if our children were raised with one more reminder: to check "organ donor" on their licenses. I realize organ donation is a personal decision, but the organ shortage in the United States has reached crisis proportions, and we've got to do more to improve it. Today, 87,000 people are on waiting lists for organs. And, as more Americans are diagnosed with diabetes and hepatitis C, the need is growing exponentially.

I applaud Health and Human Services' Tommy Thomp-



son for his efforts to improve the situation, including HRSA grants (see front page). The Transplant Resource Center, too, is raising awareness with a wonderful ad campaign. And we're making great strides at Hopkins to increase living organ donation.

But it's just not enough. Fifteen years ago, Spain adopted a presumed consent policy—meaning that unless stating otherwise, Spaniards are willing to donate their organs when they die. Since then, donations there have increased by 142 percent. But it took more than legislation. The government created a network of transplant coordinators who not only direct transplant services but also provide information to the public and media. In the process, they debunk myths about transplantation. Now Spain leads the world in organ donation.

The lesson is obvious. Get involved nationally. But even conversations with family, patients or friends can make a difference. Think about it as you fasten your seatbelt. ■

## Mentors Offer Advice on Coping

**P**AT BARGET has a vivid memory of the day she thought she lost her mind: She was driving on the highway and suddenly had no idea where she was headed. Distraught, she pulled over and tried to calm down.

Eventually Barget made it home, but she wouldn't call her doctor: "I was certain he'd think I was crazy and take me off the liver waiting list." Only later did she learn encephalopathy was the culprit. If only someone had warned her toxic waste buildup from her diseased liver would lead to confusion, she thought, maybe she wouldn't have been so alarmed.

Barget received a new liver in 1999. As she recuperated, the retired Severna Park, Md., high school English teacher realized she could help others awaiting organs simply by sharing her experience. When she learned CTC social workers and several transplant recipients had already started laying the groundwork for a formalized mentoring program, Barget offered to help.

Leading the effort since 1997, liver transplant social worker Linda Darrell introduced Barget to four other suc-

cessfully transplanted liver patients: Ernie Clayton, a high school guidance counselor; Rodger Goodacre, an attorney; Tim Halloran, a lobbyist; and June Henneman, a community volunteer. They met often, recalling their own struggles. With Darrell's support, they compiled a mentoring handbook.

Four years later, the CTC's mentoring program—one of only several in the nation—boasts 13 mentors across three organ groups and provides online and in-person training. So far, the program has helped about 60 patients. "This group is becoming an integral part of the Hopkins transplant community," Darrell says.

Darrell, Angie Muir, social worker for kidney patients, and Terri Cook, nurse coordinator for lung transplant, select mentors for a three-week online training program. Red flags, like depression and encephalopathy, are covered in depth. "Our goal is to help mentors become independent but know when to seek help," Darrell says.

In the online presentation, the mentoring committee—which Barget chairs—advises other mentors to ac-



(From left) Angie Dickinson and Linda Darrell listen as patient volunteer Pat Barget describes a potential mentor.

knowledge what transplant patients are going through.

But virtual instruction isn't enough, Darrell says. At a required training session, psychologist David Edwin addresses the group, and social workers engage them in role playing and talk about specific organ groups.

A seasoned teacher, Barget keeps her eye on performance well after the training. If she gets negative feedback, she intervenes immediately. But overall, Barget knows mentoring works because "we know better than anyone else that it can be an almost unbearable time." ■

## Research Notes

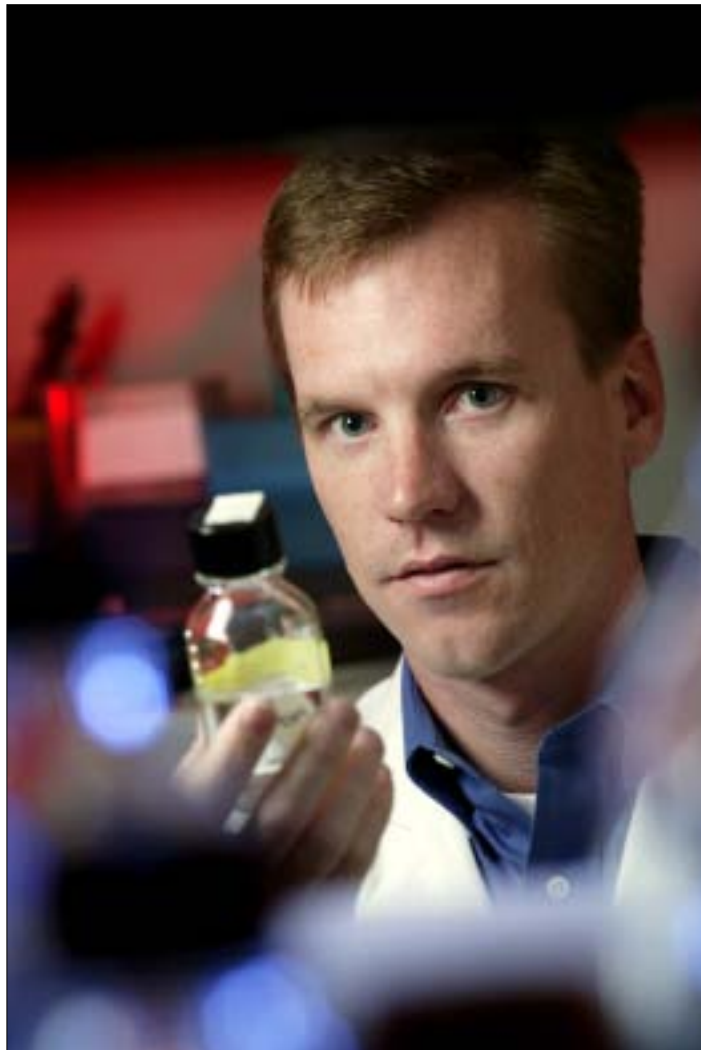
# A Few More Good Kidneys

**F**IFTY YEARS after the first successful kidney transplant, researchers still haven't gotten around the fact that the body needs to be coaxed into accepting a new organ. And that's not the only thing that keeps transplants from being ideal.

Less sophisticated problems, like keeping organs fresh, can also foil transplants. Solving these problems is critical because more than 60,000 Americans are awaiting kidneys.

In response, researchers at Hopkins' Incompatible Kidney Transplant Program (INKTP) are working creatively to find solutions. Daniel Warren, who co-directs the lab with CTC Director Robert Montgomery, studies laboratory rats because they mirror tissue incompatibility hurdles between human donors and recipients. The goal, he says, is to trick the recipient's body into accepting a mismatched organ.

With help from surgical resident Chris Simpkins and fourth-year medical student Geoff Allen, Warren is trying, for example, to grasp the science behind a standard plasmapheresis technique. The procedure removes harmful antibodies from the rats' blood before transplantation. It's effective when combined with intra-



*In pursuit of healthy kidneys, Dan Warren prepares a solution to inject rats*

venous immunoglobulin therapy (IVIG), a way to restore still-needed antibodies.

But making good matches isn't the only way to improve the kidney shortage, Warren says. He and his colleagues are also test-

ing ways to protect the kidney from damage that occurs after removal and before transplantation.

Storing organs on ice before delivery prevents some tissue damage, but it can't stop the gradual destruction that disrupting the blood supply—ischemia—causes. Also, the longer the kidney sits, the worse its function will be when transplanted. Delay courts rejection.

To overcome this problem, Warren is using new

gene therapy methods to deliver inhibitors of ischemic damage to rat kidneys. He injects gene therapy directly to the rat's donor organ prior to harvest, with hopes of preventing later injury to the transplanted kidney. Then he evaluates the results by looking for protein markers of ischemia.

Meanwhile, Warren is investigating an underused source of kidneys: those from older or less healthy donors. While they're presumed to have inferior kidneys, Warren suspects that's not always the case. He and Chris Sonnenday, coordinator of this clinical project, are studying ways to predict kidney viability. They think it's more important to look at the kidney itself than at the donor. To that end, they attach a special pump to the blood vessels of a kidney removed from a donor and monitor the ease of fluid movement. "Healthy kidneys should be easy to pump," says Warren.

Warren and his colleagues are excited about what these advances could mean for transplant patients. Even since INKTP debuted in 2000, 121 patients at high risk for rejection have been successfully transplanted. Says Warren, "Considering the average wait for a kidney is about four years, imagine how increasing the potential donor pool and getting their kidneys earlier could improve quality of life for the recipients." ■

—Diane Bovencamp

*The goal, he says, is to trick the recipient's body into accepting a mismatched organ.*

# KIDNEY, LIVER & PANCREAS *Outreach*

## Steve Solga's Gut Feeling on Flora

**M**ANAGING advanced liver disease is a delicate dance. Patients suffering from confusion and insomnia—hallmarks of the encephalopathy that typically results with ammonia buildup—find some relief with lactulose or antibiotics. But lactulose, a synthetic sugar that pulls ammonia into the gut, also brings bouts of diarrhea, says new Assistant Medical Director of Liver Transplantation Steve Solga. Antibiotics that destroy natural ammonia-producing bacteria may help, but they too have side effects. And they're expensive.

Troubled by these conventional treatments, Solga is dedicated to finding natural alternatives. His goal is to shift the balance of bacterial flora in the gut to help compensate for liver disease. "If we can change the gut from an ammonia-producing to an ammonia-excreting environment," he says, "we can treat disease in a way that's natural and well tolerated."

For the past seven years, working alongside former Hopkins' hepatologist Anna Mae Diehl, Solga's studied probiotics—microorganisms that bring harmony to gut flora—and made some startling discoveries. In a preliminary study last May, cirrhotic patients were treated with probiotics and fermentable fiber, another natural supplement that nourishes bacteria. After 30 days of treatment, half the patients treated with either the probiotic preparation or fermentable fiber showed a reversal of encephalopathy, compared with 13 percent in the placebo group. Both treatments improved brain and liver function without side effects.

But because the FDA regulates



*Steve Solga says probiotic dietary supplements ease gut-liver access—and may even improve liver function.*

drugs—not dietary supplements—Solga has had trouble finding funding for his work. At last, NIH's new National Center for Complementary and Alternative Medicine has brought change. With their support and IRB approval, Solga's been able to launch a pilot study on fatty liver disease. The six-month trial is open to adults, ages 45 to 70, with type 2 diabetes. In the coming months, he hopes to win approval for a second study on hepatic encephalopathy. Probiotics will be the centerpiece of both studies.

Solga says adding fermentable fiber and healthy bacteria to the diet hold great promise for patients with diseased livers. His hunch is that patients with minimal hepatic encephalopathy—and even those on liver transplant waiting lists—can enhance their quality of life through the treatment. "If probiotics just stabilize liver function, we can help so many people," says Solga. "But I suspect the therapy will go one step further and improve their liver disease."

With the increase in hepatitis C and cirrhosis from nonalcoholic fatty liver disease, Solga expects more people will yearn for a kinder, gentler treatment. Already, popular nutrition magazines tout the protective benefits of probiotics found in yogurt, soy products and whole grains against digestive system infection.

Solga still routinely prescribes lactulose and antibiotics, but he's optimistic probiotics will soon earn the government's blessing. "Here's a well-tolerated, natural, inexpensive therapy. And side effects are extremely uncommon," he says. "They deserve serious scrutiny."

*For more information about the fatty liver disease study, call Research Coordinator Gillian Buckley at 410-283-9388 or e-mail her at [gbuckley@jhsp.edu](mailto:gbuckley@jhsp.edu).*

### Introducing Steve Solga

Steve Solga, a Pennsylvania-born liver specialist, has been assistant medical director of liver transplantation since July 2004. After receiving his M.D. from Duke University, he trained at Hopkins in medicine, gastroenterology and liver disease, culminating with an advanced hepatology fellowship year sponsored by the American Association for the Study of Liver Diseases. In his new role, Solga balances research and patient care.

Solga, 34, is nothing but enthusiastic about the field of liver transplantation: "We've finally reached the point where we can say transplants work. It's truly gratifying to see patients 10 years after receiving a new liver do well."

He and his wife, Lisa Spacek, M.D., Ph.D., an infectious disease specialist at Hopkins, live in Baltimore. They have a 1-year-old son, Leo.

*Pam Lipsett, John Shatzer and Mike Williams hope the standardized patient program will ease end-of-life discussions between staff and patients.*



## Setting the Stage

*(continued from page 1)*

Lipsett has discovered many physicians are unable to speak frankly to families about death and dying. Director of Clinical Education **John Shatzer**, who oversees Hopkins Medicine's standardized patient program, reduces the problem to a cultural taboo. "No matter how much training we have, we're still uncomfortable talking about death," he says. "And the best way to teach doctors how to have the conversation is to let them practice communication skills."

The initial Hopkins training focused on the neuroscience intensive care unit and pediatric ICU. Physicians, nurses and other care team members practiced end-of-life communication with standardized patients. Each session was taped and evaluated to highlight each member's—or team's—strengths and weaknesses in such key elements as evoking compassion and discussing clearly the end-of-life options.

Although standardized patients also receive training for these encounters, they're encouraged to be spontaneous, responding to communication nuances from caregivers. It makes the simulations so powerful and real, Williams notes, that participants feel drained afterwards. During one training encounter, for example, an African-

American man became so caught up in the emotion of the moment that he interrupted the conversation to ask if he could pray. The attending physician later recalled the prayer proved therapeutic for everyone there because it gave them a chance to collect their thoughts.

Hopkins has used the success of its end-of-life communication program to obtain a second HRSA grant to train caregivers at other hospitals, including the University of Maryland Medical Center. The program is about to become the first accredited in-service of its kind nationally. Hopkins provides these groups with 10 taped simulations.

Improved communication skills strengthen an already established Hopkins end-of-life care protocol on brain death that gives families grieving time before considering organ donation. "Decoupling," the technical term for the family's acknowledgment of death—which includes initial bereavement—must precede the topic of organ donation to avoid any perception of conflict of interest. A strong feature of the protocol is the "huddle," when everyone on the team sets clear communication goals and breakdown of tasks.

When brain death occurs, the family receives support from one of the Hospital's eight family advocates, members of the pastoral care team who've had special training in end-of-life care. Hopkins donor advocate **Ann Vukelich**, who oversees the family advocates, says FAs handle everything from babysitting to spiritual requests, while specially trained Transplant Resource Center of Maryland representatives explain the process. But only after the family has been told their loved one has died does a representative from TRC raise the possibility of organ donation. The collaboration, Vukelich notes, provides boundless compassion, "the kind of attention everyone should have at the end of life."

Williams hopes the combination of end-of-life communication training, protocols, family advocates and assistance from the Ethics Committee and Organ Donor Council will convince patients there's no hidden agenda. A transplant hospital, he says, has two obligations: to provide support for patients in need and for patients who become donors, including those who die in spite of best efforts to save them. "At the very least," he says, "we want families to have experienced a death they won't look back on bitterly." ■

# HEART & LUNG *Outreach*

## Hands-On Cardiology: Introducing Stuart Russell

**H**EART FAILURE in the United States is rising at an alarming rate: It affects 4.7 million Americans. Blame it on heredity, longer life spans and obesity. Whatever the cause, Hopkins is bringing promising research directly to heart failure patients.

Clinical Chief of Heart Failure and Transplantation Stuart Russell is part of this bigger push for clinical cardiology. He joins several cardiologists who manage patients full time—gathering data to bolster clinical research.

After graduating from the University of Washington School of Medicine, Russell did his medical residency at Hopkins, then a transplant cardiology fellowship at UCLA. For the past seven years, he practiced his specialty at Duke University Medical Center. Now Russell, 40, is back at Hopkins.

### **What's so different about Hopkins cardiology from when you were here in the 1990s?**

In those days, as I watched superb cardiac patient care by people like Ken Baughman and Ed Kasper, I realized that so much of the field relies on monitoring even slight changes in heart function. That tradition continues, but Hopkins has beefed it up in the past 10 years. Hiring Rick Lange as clinical chief of cardiology—a brand new position—demonstrated the hospital's stronger emphasis on patient care. And, with exciting stem cell research and more heart devices, cardiologists are better able to test new discoveries on patients. I was hired to be available to patients.

### **But you still do clinical research. What's your focus and how is it**

### **helping patients?**

I'm involved in a large multi-center NIH study on exercise training, which originated at Duke. The goal is to see if a tailored exercise program can help heart failure patients live longer. Fifty percent die within five years of diagnosis. We've got to improve that statistic. Participants exercise three times a week at the hospital, using either a treadmill or stationary bike. In my own lab, I'm interested in why people stop exercising. Are they not motivated, or do they get tired? And how much is too much? We're trying to figure out if it's a psychologic or a central nervous system problem.

### **Do you think exercise plays a vital role in recovery?**

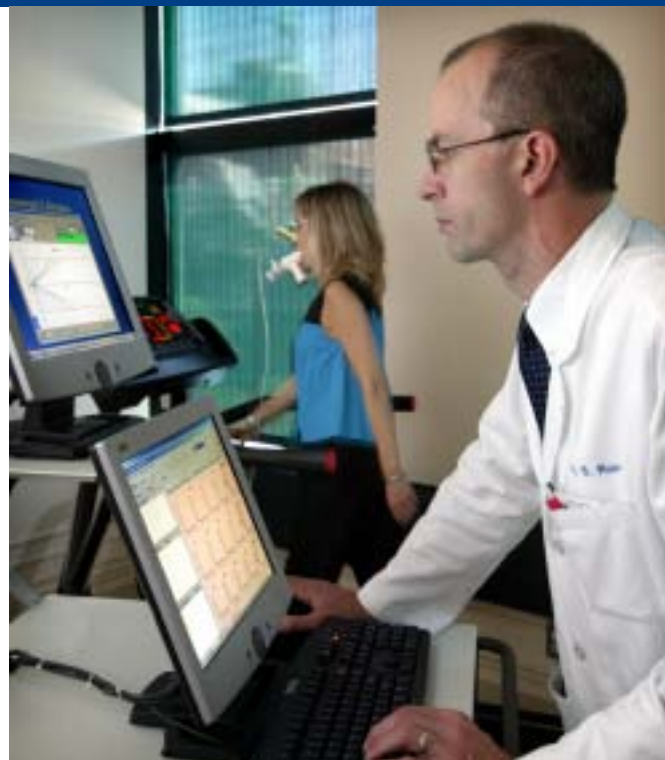
Definitely. In the old days, doctors would tell their patients who suffered heart attacks to stay in bed. Now we tell them to walk as soon as possible. It's unclear if it prolongs life, which is why we're doing the exercise training study.

### **Why do you think the number of people with heart failure rises annually?**

People are living longer, for one thing. And we do a great job of taking care of people with heart attacks, but we're not saving heart muscle. So, many of these patients will eventually get heart failure.

### **How much time do you devote to transplantation?**

Half my life is transplant; the other is congestive heart failure. It's amazing to put in a new heart, but it's equally rewarding to see a heart failure patient—who was supposed to get a transplant—succeed because clinical



*Stuart Russell measures a heart failure patient's heart rate as she ramps up speed on a treadmill.*

management worked.

### **You were at Duke when Jesica Santillan died after receiving organs with the wrong blood type. What was it like to be privy to that case?**

It was a tragic, avoidable mistake. I'm grateful I wasn't a pediatric transplant cardiologist, although they called me for advice. The media frenzy was insane—20 cameras in everyone's face for weeks. And on the day of the tragedy, we had transplanted a liver, heart and lung in a young man—a rare occurrence. He did great, but the press just wasn't interested.

### **What are your goals in your new position?**

Mainly to provide relief for patients with bad heart disease. But I also hope to find new ways to help these patients. With consistently impressive basic science and clinical research, Hopkins is bound to be among the first to unravel heart failure mysteries. ■

# For Young Cystic Fibrosis Patients, Osteoporosis Is No Old-Person's Disease

**C**YSTIC FIBROSIS patients are living much longer, with average survival up from age 5 in the 1950s to the early 30s today. The oldest CF patient in the U.S. is 76; Johns Hopkins' oldest is 65. But with this increased survival have come unexpected problems, including one associated with aging—osteoporosis.

"Many people think of it as a disease your grandmother has, not someone in his 20s," says pulmonologist Michael Boyle, director of the adult program at the CF Center at Johns Hopkins, which studies the disease in both adults and children.

But for the young CF patient, the consequences of this disease can be severe. Osteoporosis, or bone density loss, leads to painful rib, spinal and other fractures that disrupt physical therapy to break up mucus in the lungs, the hallmark symptom of cystic fibrosis. Worse, it can exclude a patient from lung transplant, the only remaining option for many patients. That's why Boyle has been targeting this problem in younger CF patients in the hope of developing new therapies to reduce CF patients' risk of osteoporosis and fractures.

Studies have already shown an association between fractures and cystic fibrosis in adult patients, but when did the bone thinning begin? And can it be delayed or even prevented? In screening CF teens, Boyle has found that up to half show signs of osteopenia, or early bone thinning. Part of the reason lies in the nature of the disease—CF patients have a difficult time absorbing vitamin D, which is critical for retaining calcium and building bones. Another contributing factor is a CF therapy itself—glucocorticoid steroids. Boyle has found that almost all young

patients on this therapy suffer accelerated bone loss.

"It's a combination of both the inflammation of the disease and the medicines designed to treat it," Boyle stresses.

Boyle suspects adolescence—when 50 percent of a person's adult bone mass is acquired—is the time when early bone thinning begins. And that may also be the time to target therapies and boost a patient's vitamin D. That's why Boyle is measuring the impact of high doses of vitamin D in young patients. The standard recommendation for those who are deficient is a twice-a-week supplement for two months, but Boyle has found that does little to increase vitamin D stores. Now he's going to higher doses to find an effective and well-tolerated level: "It turns out you have to give CF patients

whopping doses because of their difficulty in absorbing vitamin D."

Boyle is also studying the use of a class of medicines called bisphosphonates to prevent bone thinning. Being part of a national research consortium of CF centers, the Cystic Fibrosis Therapeutic Network, and working closely with Johns Hopkins pediatric pulmonologists like Peter Mogayzel, Boyle is optimistic new therapies to delay or prevent bone thinning will be developed. Patients, he adds, motivate him to find the answers.

"I really enjoy working with younger patients who are facing tough, end-of-life issues at a time when their peers are worried about college or finding a job," Boyle says. "There's a desperate need for us to help them." ■

—Gary Logan



*Pulmonologist Michael Boyle, measuring bone density in CF patient Kathy Shank.*

# Outreach Calendar

For more information, call the Comprehensive Transplant Center, 410-614-5700

## Transplant Educational Support Groups

### MULTI-ORGAN EDUCATIONAL SUPPORT GROUP

*Medications and You: Coping with and Managing the Medications We Take Before and After Transplant*

**February 1, 2005, 7 p.m.**  
Cader Room, Harvey 508  
Refreshments served

### MULTI-ORGAN EDUCATIONAL SUPPORT GROUP

*Insurance and Medicare: How to Work with Hopkins Staff, Your Insurance Company and Medicare to Help Pay for the Cost of Transplant*

**March 1, 2005, 7 p.m.**

Cader Room, Harvey 508  
Refreshments served

### MULTI-ORGAN EDUCATIONAL SUPPORT GROUP

*Life After Transplant: What Will Life Be Like After I've Had a Transplant?*

**April 5, 2005, 7 p.m.**  
Cader Room, Harvey 508  
Refreshments served

### MULTI-ORGAN EDUCATIONAL SUPPORT GROUP

*Immunogenetics and Transplant: A Visit to the Immunogenetics Lab*

**May 17, 2005, 7 p.m.**  
Details to follow

## Seminars/Conferences

### 22ND ANNUAL MEDICAL AND SURGICAL GASTROENTEROLOGY: A MULTIDISCIPLINARY APPROACH

**January 30–February 3, 2005**  
Sheraton Steamboat Resort,  
Steamboat, Colo.

### CARDIOVASCULAR TOPICS AT JOHNS HOPKINS

**February 24–26, 2005**  
Thomas B. Turner Building at  
Johns Hopkins  
Baltimore, Md.

## Outreach Events

### "GIFT OF LIFE" CTC ANNUAL HOLIDAY PARTY

**December 7, 2004, 6 p.m.**  
Turner Concourse  
Hopkins Hospital

### ANNUAL TRANSPLANT PATIENT CONFERENCE

*Presented by Hopkins staff and guest speakers*  
**May 14, 2005, 8 a.m. to 3 p.m.**  
Holiday Inn,  
Timonium, Md.

Physicians are welcome to attend all educational and outreach events.

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### Editor/Writer:

Judith Minkove

### Contributing Writers:

Diane Bovencamp,

Gary Logan

### Photography:

Keith Weller

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