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Amanda Long: Back in the Saddle

Last Labor Day weekend was a somber time for the Long family. Daughter Amanda had been in the hospital for seven months and had just undergone a 21-hour operation to repair her esophagus. The marathon surgery not only caused multiple complications but ended in failure. Amanda's mother, Stephanie, was emotionally drained. "We didn't know which way to turn," she says.

Amanda was born with esophageal atresia, a congenital defect that occurs in one of 3,000 births, in which the esophagus fails to develop as a continuous passage from the mouth to the stomach. As in Amanda's case, it is typically diagnosed within the first few hours of life. Amanda had her esophagus reconnected in infancy and another repair at age 2, followed by seven quiet years.

Then she began to pool food again. "She would swallow and the food would get stuck at about the breastbone area," says Stephanie. Amanda stopped eating and started losing weight.

It marked the beginning of Amanda's lost year, when she would miss most of fourth grade, undergo five operations, and hover on the brink of death. Beginning in February 2004, surgeons at Children's



Amanda Long, age 11 and 68 pounds, went from the brink of death to riding her horse, Spot, and hanging out with friends. Recently, she told her parents that the best gift she ever got was "my life and being able to eat."

Mercy Hospital in Kansas City, where Stephanie had worked as a pediatric nurse, attempted to treat her problem. They tried dilating the area so food might pass through smoothly, until finally the tissue became too thin.

During Amanda's next surgery, her doctors found that her esophagus had fallen down to her spine. They closed her up after nine hours of exploration. Her surgeons then decided her best hope would be to remove her esophagus completely and replace it with a piece of the small intestine (jejunum). But the connection never worked. After the 21-hour procedure, Amanda was hemorrhaging and vomiting blood profusely. She still could

not swallow her own spit. She had massive bed sores that caused tremendous pain and infections from the various lines going into her body. "It was pretty devastating after all she'd been through," says Stephanie.

At one point, Stephanie thought of giving up. "She was in so much pain. I thought, obviously God wants her more than I need her, and I'm not going to put her through any more."

Support from family and friends in Higginsville, Mo., got the family through. Stephanie and Amanda's surgeon began searching the internet for other children's hospitals. Stephanie's calls to New York, Cincinnati and Los Angeles were fruitless. "No one

would touch her case."

When she called Paul Colombani's office last October, he happened to be at his desk. "She'd been told by other children's hospitals that Amanda would have to stay the way she was," says Hopkins' chief of pediatric surgery. "I said that was not an option." The Longs made arrangements to come to Baltimore.

On Nov. 4, Amanda underwent her final operation of 2004, a procedure known as a gastric pull-up that connected her stomach directly to what was left of her esophagus. It was a bloody, 12-hour surgery during which Colombani struggled to

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The Surgeon Speaks

We see a case like Amanda's every couple years.

Hopkins' pediatric surgical practice is increasingly one where patients come for a last-ditch operation. We probably see



about a dozen newborns a year with esophageal atresia, but a case like Amanda's, maybe one every couple years. I've never operated on someone who had as many surgeries as this.

When we explored her, we had to take down a lot of adhesions from the abdomen, but the stomach looked OK. Then we went up into her neck to try to find some esophagus, but only found about an inch below the vocal cords. Then we tried to disconnect the old jejunal graft that was all scarred down, but we couldn't get it out and had to cut through the thoracic cavity. It was a mass of scar tissue and inflammation. Afterwards, we pulled the stomach up into the front of the chest behind the sternum and sewed it directly to the esophagus. Just in case we had to feed her, we did a jejunostomy.

This is an example of a child with a complex congenital anomaly with failed previous surgeries coming to us for final definitive repair and rehabilitation. We don't do a lot of bread-and-butter surgery here. Our practice at Hopkins is about 70 percent inpatient, whereas most pediatric surgical practices do about 70 percent outpatient. Even compared to other children's hospitals, we have a much higher practice of complicated inpatient stays. In fact, our PICU, where more than 50 percent of patients are surgical patients, has the highest acuity—and the best survival—of any children's hospital in the nation. ■

— Paul Colombani

"She'd been told by other children's hospitals that Amanda would have to stay the way she was."



From Julie Freischlag
Director of Surgery

What's at the Core?

All around me, I see evidence of the department's core values at work. Those values—integrity, teamwork, trust, communication and respect—were voted on by staff at last year's holiday party, although it seems that they have been part of us much longer.

They came to light during our site visit from the Accreditation Council for Graduate Medical Education in February. I realize how frustrating the 80-hour workweek is for residents, who must be organized about their work to get all the experience they want. Yet they have been very thorough and honest about reporting their hours. They trust each other and sign out patients to each other. They work in teams with nurses and physician-assistant residents. Their compliance and flexibility earned us a letter of commendation from the ACGME, one of only two letters to departments of surgery in the entire country. Our residents have performed so well, in fact, that we scheduled another leadership seminar, just for them, to address how to lead during change.

In total, about 120 people in the department—faculty, nurses, administrators as well as residents—have attended these seminars to date. We are now following up with "state of the union" meetings, during which faculty and staff from each division present their vision using our core values. They tell us where they've been, where they're going and what they're going to do, and we look at what we can do to help. During the process, we've also unearthed information that divisions need to share. It's a new idea, but one we like so much that we're thinking of doing it annually. The meetings themselves bring the department's core values to the surface. ■



Reassembling a Unified Transplant Team

A divided program becomes healthy again.

The Project: A mere glance at the figures over the past five years tells of the fortunes of Johns Hopkins' Comprehensive Transplant Center. Following a spike in 2000, the numbers of transplanted organs fall increasingly downward in every category. "It was all about the fact that it wasn't a team," says Brigitte Reeb, administrative director of the CTC.

When Julie Freischlag arrived at Hopkins two and a half years ago to head the Department of Surgery, one of the most urgent tasks on her desk was to shore up the transplant program. She met with the Department of Medicine's new chairman, Mike Weisfeldt, and they began the process of handpicking new leaders—from both medicine and surgery—for each of the five organ teams and started to recruit others with similar academic interests who would interact well with them. "The rest fell out from that," says Reeb.

The Players: There are seven surgeons who perform kidney, liver, pancreas, heart and lung transplants at Hopkins and a full complement of nephrologists, cardiologists, hepatologists and pulmonologists on the medical side who practice closely beside them. Each of the organ groups has its own staff of transplant nurse coordinators and patient services coordinators who provide administrative support to the nurses. In addition, the ancillary staff—a trans-

Part of the liver transplant team meets. Clockwise from left: Denise Burrell-Diggs, transplant coordinator; Brigitte Reeb, CTC administrative director, Cindy Cohen, nurse practitioner; Pat DeBerry, patient services coordinator; Warren Maley, transplant surgeon; Suzette Walker-Allotey, patient services coordinator, and Maura Doyle, nurse practitioner.

plant psychologist, pharmacist, social worker, dietitian, as well as representatives from the immunogenetics lab—is part of the team that meets weekly to discuss patients, protocols and any problems that arise.

Other features that distinguish Hopkins' CTC are an infectious disease service just for transplant patients, an outreach coordinator who is responsible for educating community physicians and developing materials to teach patients how to prepare for transplantation, a donor advocate whose job is to increase awareness within the hospital about deceased donor donations, and a large volunteer group made up of patients who raise awareness at community events.

Hopkins' comprehensiveness is a true selling point, says Reeb. By keeping their organ programs separate, other transplant

centers don't reap the benefits of sharing resources and best practices. "We do collaborate a great deal," says Reeb, who leads Hopkins' centralized administrative structure, "not only for clinical [care] and marketing, but also for research."

The Results: Last fiscal year, Hopkins did more solid organ transplant than ever. Abdominal transplants experienced the biggest jolt, from 190 in FY '99 to 262 in FY '05. Volume isn't the only sign of health. "We've gone through a massive amount of change and turnover, but now morale has really improved," explains Reeb. "We were left with a great core of people, and the people we recruited complemented them very well, both personality-wise and career-wise. It's been very positive in the end." ■

Let's Meet: Transplant Surgeons Warren Maley and J. Keith Melancon



Melancon (left) and Maley

Warren Maley and Keith Melancon are both new to the Division of Transplant Surgery, although Maley's face may look familiar. He first came to Hopkins in 1984 to do his residency, continued on with a transplant fellowship, then joined the faculty in 1994. He left in 2000, making tours through his native Pittsburgh and Louisiana State University at Shreveport before returning to Hopkins this January. His thrust is clinical transplantation, and he has transplanted more than 40 livers in his first six months back. He is particularly keen to get the hospital's living-donor liver program running again. "We have a

lot of interested patients," he says. He remains as amazed by transplant surgery as he was in 1983, when he was the first medical student to do a rotation with the University of Pittsburgh's Tom Starzl. "It's been marvelous to be back," he says.

Fresh from a fellowship at the University of Minnesota, Keith Melancon arrived last August to become director of Hopkins' pancreas transplantation program. He performs the procedures on patients with brittle diabetes, who have kidney disease along with an array of other serious symptoms ranging from diabetic retinopathy to coronary disease. After the surgery, which is most commonly done in combination with a kidney transplant, these symptoms stabilize and even improve. "But the No. 1 thing they love is never having to have another needle injection of insulin. They're not diabetics anymore." This year he will be instituting a new protocol for kidney and pancreas patients to remove steroids like prednisone that have long been post-transplant fare from their medication roster. The next frontier for transplantation is "tolerance," he says, in which "patients continue to have an immune system to react to pathogens yet don't react at all to their transplant. That's the future." ■

Upstream Downstream: Combing the Depths of Outcomes Research

As an example of how clinical research in surgery falls short of its counterparts in other fields of medicine, David Chang cites the story of the first heart transplant. Once surgeons realize they can perform the procedure, they search for the perfect patient. Afterwards, there's a press conference, everyone assumes the operation is doable, but no one tests the treatment on the average patient. "That's not scientific," says Chang, "and yet surgical treatment decisions often get made on stuff that's not scientific."

Chang, a research associate and acting director of the new Center for Surgical Trials and Outcomes Research, speculates that that's because clinical investigations in surgery remain unregulated. Whereas pills administered by different physicians are identi-

cal, surgical procedures performed by two surgeons—or even one procedure done by the same surgeon twice—can vary widely. In fact, one study reported that two-thirds of clinical trials published in top surgical journals had drawn conclusions not supported by the data presented. "There's not a culture of evidenced-based clinical trials."

Hopkins' new center, a first of its kind in the country, will eventually be located on Blalock I2 and will be stocked with fellows and research assistants, computer software and databases to support clinical research in the department. Meanwhile, Chang already has projects under way in every one of surgery's eight divisions. A typical study is investigating recovery after surgery. Although wounds may have healed and pain may have resolved, patients can report

up to six weeks of functional limitation. "What happens to patients when they go home, given socioeconomic status, health care access and other health care delivery issues?" asks Chang.

That's where outcomes research fits in. "As simple as it sounds, it's actually very difficult to study once you leave the controlled environment of the hospital. This is a new frontier. We're not just aiming to get people out of the hospital; we're aiming to return them to their normal lives."

Chang refers to this kind of research as "downstream." One of his own projects is an example of an "upstream" investigation. He studied age bias in trauma patients and discovered that elderly patients are less

likely than younger ones with the same injury to go to trauma centers. Studies like these help "predict what kind of patient can have good outcomes so we can make appropriate treatment decisions," says Chang. "If [the elderly are] not even getting to trauma centers, there's nothing we can do, nothing we can learn and nothing we can try to improve upon."

Another of Chang's innovations is a series of research-methodology lectures being delivered to Hopkins surgery

residents. "It's so new, there's no textbook on this," he says. In addition to teaching them how to critically prepare a better paper, Chang urges them to right the wrongs of current clinical research. "Research actually makes you a better surgeon, it makes you think better. If you can figure out which tools are better for patients and how to read the literature, and know the problems out there, you can do a better job for your patients." ■



David Chang's goal is to make it easy for people to collect data, the phase at which clinical researchers often get stuck. "Then we can get people to spend more time thinking about appropriate study and data analysis."

"We're not just aiming to get people out of the hospital; we're aiming to return them to their normal lives."

On the Job

Tina Cafeo: Nurse Manager, Cardiac Surgical Intensive Care Unit, Cardiac Progressive Care Unit

Except for the briefest of detours, Tina Cafeo has spent her entire nursing career in Baltimore. After graduating from Penn State in 1984 and unable to find work near her native Johnstown, Pa., she came to Hopkins. While working on the cardiac SICU, she gradually earned a master's degree, then became a cardiac surgery case manager. Within a year, she was made nurse manager of the CSICU and took on the CPCU too in 2003. She lives in Carroll County with her two cats, Gabby and Nittany.

How many people do you oversee?

About 150 on the cardiac SICU and the CPCU. I man-

age the R.N.'s, the clinical technicians, support associates, inventory management clerks, clerical associates and the CNEs.

That seems like a lot.

I can manage two units only because I have an extremely strong leadership team. The NCIIIs and NCIIIs have groups of people they're responsible for mentoring and evaluating. Our workload is nicely distributed. They're growing and doing things that interest them, and I'm supported by them, hence able to do my job.

What changes have you seen in nursing here?

Earning Magnet status and the



hospital's commitment to being at the top of the pay scale have relieved the staffing problems here. Plus, our nursing recruitment department does a phenomenal job. When

I have holes in staffing, they've really worked with me to get people in the door. I have a wonderful group starting this year. **So there's more cohesiveness.**

We all work together to make sure, as nursing, our needs get met in all departments. I think nursing as a whole feels more empowered now. Senior leadership hears the problems in direct

patient care and is making system changes. For example, because of a SICU safety initiative, now we have a transport team that takes ICU patients to tests, rather than

have ICU nurses leave the bedside. I mean, how great is that for nursing?

So barriers have broken down.

Yes. Surgery now has the Weinberg ICU, the SICU and the CSICU. The intensivists rotate through all three. We sit in the same room and practice the same protocols that have been shown to have good outcomes for patient care. It's a big satisfier when everybody works as a team. It seems like we're all around more collaborative.

That seems like a good place to be.

It's a very challenging place to work, and you can thrive in this environment. ■

Believing in Dr. Choti

Larry Silverman had his first operation for colorectal cancer at Washington Hospital Center, but on the dark day it recurred in 2003, he took the advice of his radiation oncologist, a former Hopkins physician, and called Michael Choti. He and his family were immediately impressed by the Hopkins surgeon, not only with his knowledge but with his compassion and humility. "He has the unique gift of immediately ingratiating himself with people," says Silverman. "He's so busy, you wouldn't think he would have time for you, but he makes you feel like he has nothing but time for you."

When Choti operated, he had to perform a colostomy on Silverman, and found cancer in his liver as well. After some aggressive chemotherapy for his liver cancer, Silverman lost about 40 pounds. He needed to regain the weight before Choti operated again.

"We were hoping that would be the end of it," says Silverman, 74.

Silverman is not a complainer. He is happy that he can still



Carlynn and Lawrence Silverman of Chevy Chase. "I couldn't have made it without the support of my wife and children," says Silverman.

play golf, even if only nine holes. He was an athlete in his youth. In fact, the Jersey City, N.J., native came to Washington, D.C., on a basketball scholarship and was drafted by the NBA in 1953. Unfortunately, he recalls, "I was drafted by the Army at that time, too. They gave me an offer I couldn't refuse."

After serving in the Korean War, Silverman gave up basketball for a better salary in the real estate business. Within three years, he was a partner at Lewis and Silverman, which within a decade became the largest marketing and sales agent in the country for new communities and new developments. He still goes into the office and works at a small piece of the business. This summer, Silverman had

another recurrence of liver cancer and stoically underwent his fourth cancer surgery in seven years. "[Choti] told me he got 90 percent of it out," says Silverman. "So that's that."

Silverman and his wife, Carlynn, had already given a gift to support education and outreach after their first experience at Hopkins. Now they are supporting Choti's research in tumor immunology and experimental therapeutics of liver tumors.

"He started to explain it, but I'd be lying if I told you that's why I did it," says Silverman. "I did it because of him! I mean, I believe in him! And if he believes in it, that's good enough for me." ■

To make a gift to the Department of Surgery, contact Boi Carpenter-Mellady at 410-516-5483 or bmellady@jhmi.edu. To no longer receive information about supporting the department, contact her using the information above.

"He's so busy, you wouldn't think he would have time for you."

LARRY SILVERMAN

FACULTY NEWS

The Department of Surgery welcomes several new faculty members to various divisions: **Dana K. Andersen** joins the department as the new chief of surgery at Johns Hopkins Bayview Medical Center. Andersen comes to Baltimore from the University of Massachusetts Medical School and UMass Memorial Health Care, where he served as chair of the Department of Surgery. His clinical expertise is in pancreas and liver surgery. His research interests are in the areas of glucose metabolism and the biochemical function of the pancreas ■ **Heitham Hassoun** joins the vascular surgery division. He completed his vascular and endovascular fellowship at Northwestern University in Chicago ■ **Timothy M. Pawlik** has joined surgical oncology after completing his fellowship at M. D. Anderson Cancer Center in Houston ■ Former Hopkins chief resident **Gedge D. Rosson** has joined the division of plastic surgery ■ **Ashish S. Shah** has joined the Division of Cardiac Surgery. He comes from Duke University Medical Center ■ **J. Timothy Sherwood** has joined the thoracic surgery division after completing his fellowship at University of Colorado Health Sciences Center ■ Former assistant chief of service **Christopher Wolfgang** has joined general surgery.

KUDOS

David Chang, research associate, has won the Maryland Stars of Life: Maryland EMS-Geriatrics Award from the Maryland Institute for Emergency Medical Services Systems. He accepted the award from Gov. Ehrlich at the State House in Annapolis ■ **Christine Martin**, credentialing coordinator and surgery house staff coordinator, received the 2005 Award for Excellence in Graduate Medical Education Administration from Hopkins' Office of Graduate Medical Education. The award comes with a year's free parking and a \$500 allowance to enhance a professional meeting.

Back in the Saddle

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remove the old, densely scarred jejunal graft.

Amanda spent a mere two weeks at Hopkins, and for the first time ever had no leaks in her follow-up swallow study. Since then, her recovery has been slow but steady. The feeding tube she still uses at night will eventually be removed. This fall, she begins middle school.

She has also been riding her beloved horse, Spot, and in July, won four ribbons in the 4H Fair, placing first in horsemanship. Some days, she says dryly, "I can even eat double quarter pounders with cheese."

In between activities, Amanda wrote a letter to President Bush, telling him that because of Paul Colombani she can eat anything she wants now, and she'd appreciate it, if he had time, if he would thank him. ■

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