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IN THIS ISSUE

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The Humanitarian Heart

Following transplant, a career shift reflects new priorities.

Most of us probably would not consider starting an ice cream company a serious humanitarian gesture. But for Adrian Pace, leaving a lucrative profession as a hedge fund manager to start a healthy gelato company was just that.

This is the story of Adrian Pace: a husband and father of two from Connecticut and a lifetime heart patient at NYPH/Columbia. He was born in 1969 with congenital heart disease, which caused his aorta, the largest blood vessel in his body, to be narrowed (called supravalvular aortic stenosis). At that time, the source of his problem had yet to be identified—a genetic mutation impairing the production of elastin in his body.

Because surgical techniques to correct his narrowed aorta were not very well advanced in 1969, his doctors at NYPH/Columbia waited until he was five years old before performing surgery. In the meantime, his heart overcompensated to push blood through the constricted vessel, damaging his aortic valve and heart muscle. Combined with the elastin problem, which interferes with normal elasticity of his tissues, this damage set the stage for a lifetime of continual heart problems.

Valve repairs at age 36 were initially successful, though the stitches in his mitral valve detached due to all the scarred tissue, leaving Adrian with a severe mitral valve leak. "This was the most difficult surgery I ever recovered from," Adrian recalls. During the next 40 days his heart rhythm fluctuated wildly as he suffered ongoing multi-focal PVCs (premature ventricular contractions — extra, abnormal heartbeats) and heart block. Adrian was unable to lie down or sleep. Breathing was difficult at best, and he gained many pounds of fluid while the numerous medications made him feel even worse. "I didn't sleep for ten consecutive days and nights. All I could do was stare out my window at the George Washington bridge, fighting to survive. Those were the absolute worst 40 days of my entire life".

From day one, Adrian's life was filled with medications, procedures, and devices, as well as repeated major open-heart surgeries:

- surgery at age 5 to open the narrowed aorta;
- surgery at age 13 to replace his aortic valve with a mechanical valve;
- open heart surgery at age 20 to replace Adrian's aortic valve and aorta;
- surgery in his early 30's to replace his worn-out aortic homograft with a mechanical valve and synthetic aorta;
- surgery at age 36 to replace his tricuspid valve and repair his mitral valve, which was leaking badly.

Between these milestones, Adrian underwent literally hundreds of additional smaller procedures, took countless medications, had two implantable devices, and lived with ongoing physical restrictions and illness.

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But Adrian persevered, and experts in defibrillation were at last able to regulate Adrian's heart rhythm. Repairing the leak was not an option at this point, however. As Adrian explains, "That would have pushed the limits of what my heart could take." So after about a month recovering at home, Adrian returned to NYPH/Columbia to begin testing required for heart transplant surgery—the only remaining option—along with a grueling ten month regimen to remove the antibodies from his body in preparation for a donor heart.

Photo courtesy of Laurie Wright.

Adrian Pace with his daughter, Olivia; wife, Jenny; and son, Max.

By June 2008, his antibodies had been reduced to about 50%, enough that he could potentially accept a donor heart without rejecting it. At this point he checked in to the hospital, where he would remain until a donor heart became available.

Adrian waited over seven months in the hospital, his heart's pumping action strengthened by medications called pressors. Potential donor hearts came and went virtually daily, none of them a match. He missed that summer and the first half of his children's school year, waiting month after month. Intravenous immunoglobulin and chemotherapy treatments continued weekly to suppress his body's production of antibodies. Still it was estimated his odds of finding a match were less than 5%. Then, after over seven months, it finally happened. A compatible heart became available, and **Yoshifumi Naka, MD, PhD** performed the transplant January 27, 2009. "Because Adrian had such extensive scar tissue and so many complications from prior treatments, this was one of the most complicated transplants our hospital has ever performed," says Dr. Naka. "I don't specifically remember many of the surgeries I perform, but I'll remember this one."

It was during the long wait for his heart that the seed for Forte Gelato was planted. Adrian had closed his hedge fund at the end of 2007, and knew he'd do something different after receiving his new heart. The NYPH staff and transplant team, who met with him daily, encouraged him to invent something for his fellow patients, and this became part of his daily thinking while waiting: Adrian wanted to help other patients, but how? A sharp thinker and innovator, he considered a range of ideas from developing new medical devices to creating various food products. As time wore on, Adrian began to focus on the idea for high-protein foods for patients like himself.

Adrian explains, "In the hospital, it was important to have a lot of protein because of muscle wasting issues. I was given an ice cream-like product that had eight grams of protein, with lots of unnatural additives and most of its calories and sugar coming from high-fructose corn syrup. And it tasted awful, I tried to make milkshakes out of it and it didn't work, and I found it didn't even dissolve in milk." He would eat protein bars that people brought from outside the hospital instead. "I started thinking, this is terrible. Patients are people too—they deserve something better."

Despite a longer than normal recovery and some additional complications, Adrian was elated to have his new heart. Once at home, Adrian got to work on his new business ideas. He settled on the idea of gelato, because it would likely appeal to patients who couldn't eat regular food or whose sense of taste had changed due to illness or treatments. He began experimenting in his kitchen, researching ways to make this Italian form of ice cream with very high protein and low fat. The process was tedious; "I tried about 150 formulas before I could find a way to create a worthy heat-stable protein blend," says Adrian. But in time, he developed his high protein gelato using premium ingredients: egg yolk instead of stabilizers, agave instead of corn syrup, hormone-free cream, high quality vanilla from Madagascar, and "very good" cocoa. "Having endured countless hospital stays, I know how important the little things are; seeing my family and eating were the highlights of the day."

At his three-year annual post-transplant exam, Adrian's coronary arteries were "perfect," his heart function was that of a healthy 21-year-old, and he had no signs of organ rejection or other problems. "I had always viewed my surgeries as time-outs to get back to my regular life," Adrian says. "My transplant was more of a "reset," because I didn't go back to my career—but I started a new one, and for the first time in my life I was unrestricted from physical activities and sports. My transplant gave me a future that is brighter than ever before."

As for his company, Forte Gelato has begun supplying hospitals on the east coast. "The response to our gelato is fantastic," says Adrian. "People absolutely love it, and once they taste it, they keep ordering more." Many patients tell him Forte is the only thing they can eat. Although Adrian did not originally intend to sell Forte Gelato as a retail product, it has been picked up by Stew Leonard's, Whole Foods, and other retailers. Adrian is now pursuing additional retail sales so he can sell Forte Gelato to hospitals at the cost they are willing to pay, so that patients who need it the most can have it.

In a degree far beyond "making lemonade out of lemons," it seems fair to say that creating Forte Gelato from the depths of his health crisis is nothing short of remarkable. But Adrian is just happy to be back with his family and more active than ever before, and would prefer to focus on the future rather than dwell on the past. Indeed, his future does look sweet. ■

Learn about heart surgery and transplantation at www.columbiasurgery.org

First Ex Vivo Lung Transplants at NYPH/Columbia

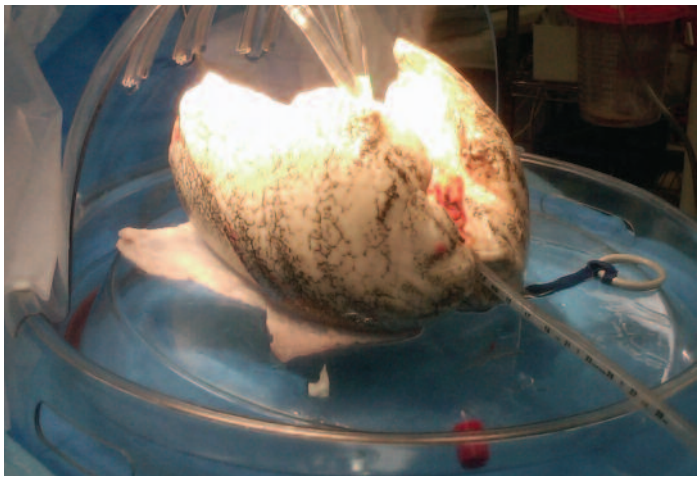
Ex vivo perfusion improves condition of donor lungs prior to transplantation and could increase access to transplantation.

Thanks to the recent initiative by Facebook to encourage users to list their organ donation status, the public may gain more awareness about the urgency of organ donation. Many people—patients, families, and physicians alike—hope the effort will bring tangible results: enough organ donors to meet the needs of over 100,000 patients on the transplant waitlist each year.

While the absolute number of organ donors is fundamentally far lower than those in need, an even smaller percentage, just 15-20% of donor lungs, is usually deemed acceptable for transplant, according to **Frank D'Ovidio, MD, PhD**, Associate Surgical Director of the Lung Transplant Program and Director of the Ex Vivo Lung Perfusion Program at NYPH/Columbia. Most lungs sustain too much damage at the time of death, he explains, which precludes them from transplantation. A relatively new approach called ex vivo lung perfusion could help to improve those odds, however.

In June 2011, the Lung Transplant Program at NYPH/Columbia began enrolling patients in an important new multicenter FDA trial with the acronym of NOVEL (Normothermic Ex-Vivo Lung Perfusion as an Assessment of Extended/Marginal Donor Lungs). The complicated name belies a simple but vital concept: evaluating and preparing donor lungs outside the body prior to transplantation. Called Ex Vivo Lung Perfusion (EVLP), the process entails removing the lungs from the donor's body and placing them in a special see-through dome, where they are warmed to body temperature, renourished with fluids, nutrients and oxygen, and carefully examined for a period of hours to access their functionality. Developed in Sweden, EVLP has been studied and successfully used in Europe and Canada for the last decade, but it has only recently become subject to study in the United States.

"Since the multicenter FDA trial began, we have assessed at our site seven sets of lungs, all of which would have been considered ineligible for transplant before this trial," says Dr. D'Ovidio, Principal Investigator. "We determined that of those seven pairs of lungs, three were in fact suitable for transplant." These went to Nancy Block, Patricia Kingsbury, and most recently to Steven Davis, who says, "I am so grateful for this program. Without it, I likely would not have been able to receive a lung transplant." The other four sets could not be adequately reconditioned during EVLP and were deemed unsuitable for transplantation. "In this limited time period, EVLP allowed us to perform three transplants that otherwise would not have been possible," Dr. D'Ovidio says.



Donor lungs during ex vivo assessment and perfusion

Although that figure is just a small start, the NOVEL trial will continue across all the centers until 42 patients receive lung transplants with ex vivo perfusion, and 42 controls are transplanted without use of the process.

"We know the process is not harmful to donor lungs. It allows better assessment of and potentially improvement in the quality of lungs that would otherwise be turned down for transplant," says Dr. D'Ovidio. "There is also indication that lungs already considered acceptable may potentially function better after transplantation if they are treated with EVLP. This will be examined more closely in additional research."

"Overall, we aim to meet the need of patients listed for lung transplantation, as well as to improve their long-term health after transplantation. Ex vivo lung perfusion won't be a solution to all of the challenges facing lung transplant patients, but it will help to increase the number of transplants performed each year. Even if we see a gain of 10-15% from this method, that could mean ten more patients at NYPH/Columbia would receive lung transplants each year. And if it proves to be more successful than that, we'll be even happier," comments Dr. D'Ovidio. "It's not that EVLP will be a magic bullet, but every step helps."

EVLP is being studied widely at this time in many countries, as evidenced by the number of presentations on the topic at the 2012 Annual Meeting of the International Society for Heart and Lung Transplantation. Based on the successes achieved so far, researchers are also investigating the possibility of using EVLP as a platform from which to deliver targeted therapies to actively repair donor lungs. ■

Learn more about the NOVEL trial at: columbiasurgery.org or by calling 212.342.1518.

Taking Endocrine Disease Seriously

Section of Endocrine Surgery recognized for its expertise

Endocrine disorders are some of the most complex and challenging conditions to treat because of their effects on multiple systems of the body. At NewYork-Presbyterian Hospital/Columbia, patients can be sure they are receiving care from physicians and surgeons who are among the very finest in their fields. Four multidisciplinary centers at the Section of Endocrine Surgery provide care for the full spectrum of endocrine diseases: the Adrenal Center, the Neuroendocrine Tumors Center, the New York Thyroid Center, and the Center for Parathyroid Disease. The directors and faculty of these centers are regarded as leaders in clinical care and research in endocrine disorders, as clearly evidenced by a steady stream of accolades, publications, and contributions to professional societies and media.

In recognition of superior care for patients with pheochromocytoma and paraganglioma, the PheoPara Alliance has designated the Adrenal Center as a "Center of Excellence," and named Co-directors **James A. Lee, MD** and **Salila Kurra, MD** as "Physicians of Excellence." The PheoPara Alliance, a nonprofit organization formed to raise awareness about pheochromocytoma and paraganglioma, provides the latest research and information about these rare diseases to both physicians and patients.

Other achievements during the past year have included numerous invitations to moderate and present at the professional conferences of the American College of Surgeons, the American Society of Nephrology, The Society for Surgery of the Alimentary Tract, and other national physicians' associations. **Dr. Lee**, **John D. Allendorf, MD** and **John A. Chabot, MD**, Director of the Pancreas Center, were chosen as the content experts for the neuroendocrine tumor section on

James A. Lee, MD; John A. Chabot, MD; and John D. Allendorf, MD

Uptodate.com, which is one of the premier educational resources that doctors use to help care for patients across the world. Faculty have also appeared on radio and television shows as visiting experts on thyroid disease, including "*The Dr. Oz Show*" and WAMC's "*Speaker's Corner*".

According to James A. Lee, MD, FACS, Chief of the Section of Endocrine Surgery, "We take our mission very seriously: to provide superior care for every patient, and to advance the treatment of endocrine disorders through basic and clinical research as well as physician education." ■

To learn more about treatments for adrenal disease, neuroendocrine tumors, thyroid conditions, and parathyroid disease, please visit the new Endocrine Surgery web site at columbiasurgery.org/endocrine/index.html or call 212.305.0442.

SAVE THE DATES

Annual Breast Cancer Awareness Day
November 11, 2012
New York, NY

This patient education program will include discussion of breast cancer prevention, screening, diagnosis, treatment, healing, sexual health, nutrition, fertility issues, relieving stress, and integrative approaches to care and wellness.

For information and reservations: Christine Rein
Telephone: 201.346.7014 Fax: 201.346.7011
E-mail: cmr2146@columbia.edu
Register online: www.columbiasurgery.org

Annual Pancreatic Cancer Awareness Day
November 3, 2012
New York, NY

Learn about treatment options and sources of support with the experts of NewYork-Presbyterian Hospital, Columbia University Medical Center, The Pancreas Center and The Muzzi Mirza Pancreatic Cancer Prevention & Genetics Program.

For information and reservations: Christine Rein
Telephone: 201.346.7014 Fax: 201.346.7011
E-mail: cmr2146@columbia.edu
Register online: www.columbiasurgery.org

These events are free and open to the public, but reservations are required.

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