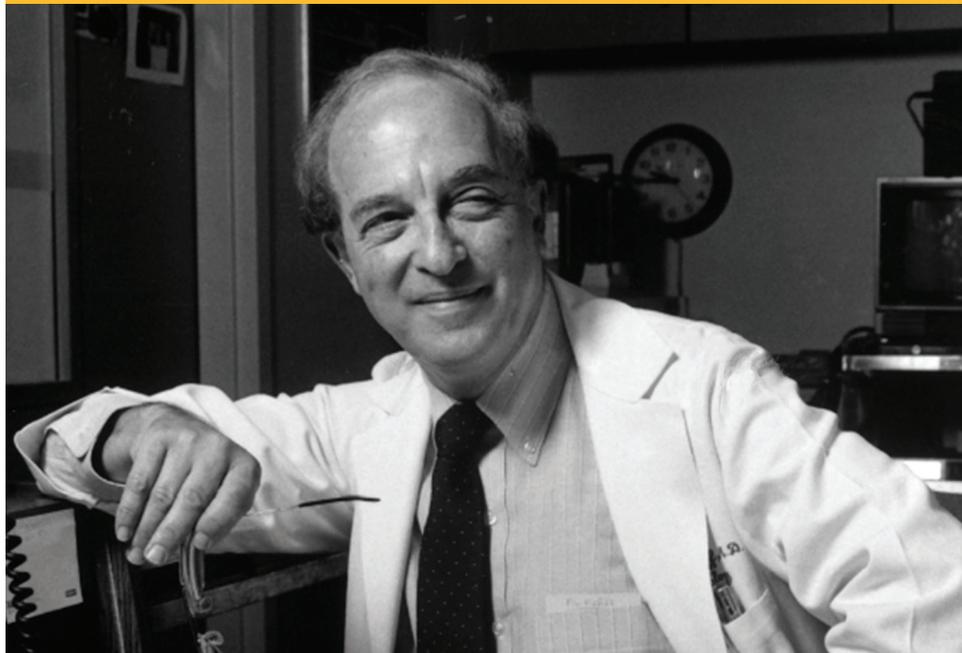


# Ahmanson / UCLA

## Adult Congenital Heart Disease Center

FOR THOSE TOUCHED BY CONGENITAL HEART DISEASE

Winter 2015



### In Memoriam

## Dr. Joseph K. Perloff (1924 – 2014): Memorial Tribute

As many of you know, our founding director Dr. Joseph Perloff passed away in August at the age of 89. His legacy is not only that of a master clinician, teacher and researcher, but he quite literally is credited with fathering an entire field of medicine; that of adult congenital heart disease.

On September 28<sup>th</sup>, 2014, we celebrated Dr. Perloff's life in a fitting memorial tribute at the Luxe Hotel in Bel Air, attended by 200 colleagues, friends, family, patients and many of the cardiologists that Dr. Perloff trained. His ACHD colleagues traveled from as far away as Japan, Germany and Montreal to pay their respects. We shared this celebration with Dr. Perloff's family, including his wife Marjorie Perloff, two daughters Carey and Nancy Perloff, and his three grandchildren. Speakers ranged from esteemed colleagues, students, family members and closed with readings from his grandchildren. On November 16<sup>th</sup> 2014, during the American Heart Association meetings in Chicago, the International Society of Adult Congenital Heart Disease posthumously awarded their first "Lifetime Achievement" award to Dr. Perloff. During the award presentation, Dr. Jamil Aboulhosn presented a touching chronicle of Dr. Perloff's career and his remarkable contributions to the care and well being of adults with congenital heart disease.

Please visit our website at <http://heart.ucla.edu/ACHDC> for our full tribute to Dr. Perloff. If you are interested in making a memorial donation in honor of Dr. Perloff, please contact Yvonne Jose at [yjose@mednet.ucla.edu](mailto:yjose@mednet.ucla.edu) or (310) 825-2019.

### Sapien Valve

## New Transcatheter Valve Being Utilized in ACHD Patients at UCLA

The Melody valve (Medtronic Inc.) was the first transcatheter valve used at UCLA; the initial implants were performed in October of 2010. Since that time, we have placed over 150 transcatheter Melody valves in children and adults with congenital heart disease. Most of these implants have been in the pulmonary position, but we have also successfully implanted this valve in the aortic and tricuspid position. The main limitation of the Melody valve is that it malfunctions when expanded to a diameter > 24 mm. Many ACHD patients have existing valves, conduits, or native outflow tracts that are larger than 24 mm and they would not be candidates for treatment with the Melody valve.

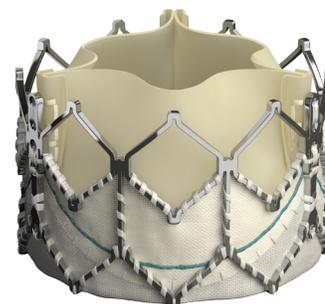


Photo: Edwards Lifesciences LLC

*Sapien XT™ transcatheter valve*

The Sapien XT™ (Edwards Inc.) transcatheter valve is currently commercially available in the United States and is FDA approved for replacement of narrowed aortic valves.

*Continued on page 7*

## Faculty and Contact Information

### Faculty

#### Ahmanson/UCLA ACHDC Faculty

**Jamil Aboulhosn, MD**, Director, Streisand Chair

**Leigh Reardon, MD**, Congenital Cardiology

**Jeannette Lin, MD**, Congenital Cardiology

**John Child, MD**, Emeritus Director

**Daniel Levi, MD**, Interventional Cardiology

**Kevin Shannon, MD**, Electrophysiology

**Jeremy Moore, MD**, Electrophysiology

**Kalyanam Shivkumar, MD, PhD**, Electrophysiology

**Pamela Miner, RN, NP**

**Linda Houser, RN, NP**

#### Surgical Faculty

**Hillel Laks, MD**

**Brian Reemtsen, MD**

**Reshma Biniwale, MD**

**Richard Shemin, MD**

#### ACHDC Staff

**Jennifer Doliner, RN**, Nurse Coordinator

**Yvonne Jose**, Administrative Manager

**Veronica Olmedo**, Clinical Coordinator

**Evelyn Garcia**, Patient Administrative Support

#### Research Coordinators

**Abbie Hageman**

**Rachel Bolanos**

### Contact Us

#### How to Contact the Center

Patient Scheduling (310) 825-9011

Nurse Coordinator (310) 794-5636

Fax Numbers (310) 825-6346 or (310) 825-9012

Email: [achdc@mednet.ucla.edu](mailto:achdc@mednet.ucla.edu)

Website: <http://heart.ucla.edu/ACHDC>

#### Information & Resources

Adult Congenital Heart Association (ACHA)

Website: [www.achaheart.org](http://www.achaheart.org)

Call (888) 921-ACHA

Email: [info@achaheart.org](mailto:info@achaheart.org)

#### International Society for Adult Congenital Heart Disease (ISACHD)

Website: [www.isachd.org](http://www.isachd.org)

## ACHDC Fellowship Program

### Ahmanson/UCLA ACHD Fellowship: Improving Access to ACHD Care

Every day, many of our patients drive hundreds of miles to UCLA, understanding the importance of seeing experienced adult congenital heart disease specialists. However, due to the long commutes and traffic, patients arrive late or miss echocardiogram appointments, can have high blood pressure from the stress of the commute or fall asleep in the waiting room because their drive started before sunrise. There is clearly a shortage of ACHD specialists. While patients within driving distance of a major metropolitan area are usually able to seek care at their local centers, others live in smaller cities or rural areas and do not have access to trained ACHD specialists at all. The Adult Congenital Heart Association works with patients and providers to draw attention to this problem and to set training standards and goals for training ACHD providers.

At the Ahmanson/UCLA ACHD Center, we are committed to improving access to quality ACHD care both nationally and internationally. Graduates of the Ahmanson/UCLA ACHD fellowship are now caring for ACHD patients in California, Nevada, Oregon, Massachusetts, Canada, and Japan, and hundreds of graduates of UCLA's pediatric and adult cardiology fellowship programs have rotated through our clinics.

Our patients not only motivate us to expand access to care, but are also an essential part of this effort. Our ACHD fellows learn from our patients, and will use this knowledge to help patients in their communities in the future. If you would like to donate to our ACHD training fund, please contact Yvonne Jose at 310-825-2019. In the meantime, please read on to get to know our current fellows!



*Gentian Lluri, MD, PhD*

Dr. Gentian Lluri received his MD/PhD degree in 2008, followed by internal medicine internship and residency at the University of Illinois at Chicago and an adult cardiovascular disease fellowship at UCLA. Dr. Lluri has embarked on two additional advanced fellowship training years in ACHD at the Ahmanson/UCLA ACHD Center. Dr. Lluri has a long-standing interest in molecular biology pathways that guide cardiac development and the disturbances of these pathways that can lead to congenital cardiac malformations, and continues to actively study these mechanisms in the lab. In addition, Dr. Lluri is actively involved in clinical studies, with the goal that the knowledge derived from laboratory and clinical findings will lead to potential new treatment options for a variety of congenital heart diseases. His research has been presented in national meetings and published in several peer-reviewed journals. In addition, Dr. Lluri is the recipient of the 2014 ACHA-Actelion

Fellowship award to specifically support his training in ACHD. He is fluent in several languages and likes to go for walks during his spare time with his wife and seven-month-old son.



*Todd Roth, MD*

Dr. Todd Roth joined our team on September 1<sup>st</sup>, 2014 for advanced ACHD fellowship training. He completed his pediatric cardiology fellowship at Virginia Commonwealth University in 2012, and practiced for two years in the Fort Lauderdale, Florida area. Upon completion of his ACHD training, he will serve as the South Florida ACHD specialist for Pediatrix Medical Group and co-director of the ACHD program at Joe DiMaggio Children's Hospital. Dr. Roth has a special interest in quality of life measures among adult patients with congenital heart disease and is currently interested in investigating the impact exercise endurance has on quality of life in adult patients with congenital heart disease. In his spare time, Dr. Roth has enjoyed exploring the California landscape with his wife and three young boys.



### Congenital Heart Walk

## 3<sup>rd</sup> Annual Greater Los Angeles Congenital Heart Walk a Record Success

The third annual Los Angeles Congenital Heart Walk was held on June 29<sup>th</sup>, 2014. Once again, organizer Barbara De Maria and her dedicated team demonstrated their talent at putting on a first class event on a beautiful Sunday morning in Griffith Park. Nearly 1200 walkers comprising 81 teams participated, and this represented an approximately 200% growth over 2013! The event raised over \$100,000, ranking second place nationally among the Walk events, with funds divided between the Adult Congenital Heart Association (ACHA) and the Children's Heart Foundation. Team Ahmanson/UCLA was once again one of the top fundraisers and the Ahmanson/UCLA

Adult Congenital Heart Disease Center a proud co-sponsor of the event.

ACHA uses walk funding to support its many activities in education, outreach, advocacy and research to improve the quality of life and extend the lives of adults with congenital heart disease. The Children's Heart Foundation uses the funds to help support the most promising research to advance the diagnosis, treatment and prevention of CHD. For more information and to view the many wonderful pictures of the 2014 event, visit [www.facebook.com/CongenitalHeartWalkLA](http://www.facebook.com/CongenitalHeartWalkLA). All of us at UCLA look forward to continuing this success in 2015, so stay tuned for more info!

### Contributions

## How You Can Help

The Ahmanson/UCLA Adult Congenital Heart Disease Center (ACHDC) relies in large part upon donations in order to pursue the goals of the Center. This support is vital to the ACHDC's ability to continue providing high-quality care for adult patients with CHD. Your tax-deductible contributions directly support:



- Patient programs focused on enhancing quality of life, such as newsletters, informational websites, support groups, and psychological counseling
- Research programs aimed at improving life expectancy
- Training programs integral to preparing future providers to carry on the highest level of care

You can learn more about how to support the ACHDC by visiting <http://heart.ucla.edu/ACHDC> and clicking on "ways to give".

To discuss specific gift options, or for more information, please call 310-825-2019.

Your contribution helps to ensure that the ACHDC remains a leader in clinical care, research, education, and training.

### Contributions

## The ACHDC Board of Advisors has pledged \$180,000 to fund advanced training in Adult Congenital Heart Disease

The ACHDC Board of Advisors has pledged \$180,000 to fund advanced training in Adult Congenital Heart Disease. The gift to the UCLA Division of Cardiology will support an inaugural 2-year Fellowship for an American Board of Internal Medicine approved ACHD specialist. This will meet a critical gap in our national health care system. There is a shortage of specialized cardiologists who are properly trained to care for adult patients with complex CHD. The Ahmanson/UCLA ACHDC has traditionally been and continues to be a leading institution for the training of ACHD specialists. We are very grateful to the board members: Thomas Bliss, Kenneth Boyko, Judah Hertz, Delphine Lee, Nora McGarry Arian, Michael McNamara, Douglas Praw and Deborah Spander for their generosity and continued commitment to the Center.

# Three UCLA Congenital Heart Patients Share Their Stories



## Jeni, Age 29

### Giving Hope to Others

When I was born with Hypoplastic Left Heart Syndrome (HLHS) in 1985, there were no known survivors of this heart defect. The future had a giant question mark over it; my parents did not know what would come of my life, but they did trust that God would see us through it. I had the Norwood procedure at less than 24 hours old, the Fontan at 17 months old, and a pacemaker placed in my abdomen when I was three years old. I've had multiple catheterizations and ablations, and the obligatory pacemaker battery changes. Needing to have a heart transplant one day is a possibility for me, but so far, by God's grace my heart is still going strong.

I'm thankful that I've gone through all this in my life, because I have learned so much and it has given me the opportunity to give hope to others when hope seems so far away. It came down to a choice: I could either sulk in self-pity and be angry because of all the challenges and pain I face with my heart condition, or I could take the blessings and the trials God has allowed in my life in order to help others. I devote much of my time to reaching out to families worldwide with children who have HLHS or other CHDs. Being one of the oldest living survivors of HLHS, I do what I can to give parents hope that their child will be able to grow up, be an adult, and get married. It's a beautiful thing to help parents feel comfortable planning a long-term future for their child,

instead of being afraid to look past tomorrow because of the constant fear of death at a young age. I am truly humbled and honored to pave the way for these children.

Working to give hope to these families has opened up some amazing opportunities. In April 2011, an independent Christian film company made a documentary on my life entitled "Journey's Beginning." In the film, the director and I travel to Colorado to meet a family whose 7-month-old girl had HLHS. It was an incredible experience, as the family thought the oldest HLHS patient was still a toddler. When they heard there are adults with HLHS, you can imagine how emotional our time was together!

In June 2011, my husband Nick and I joined Nels Matson on Bike4theCHF, a fundraising event for the Children's Heart Foundation. They rode their bicycles from San Francisco to Manhattan in six weeks, visiting children's hospitals along the way. My mother Jill and I drove a support vehicle and were able to meet many heart families that we had only known through social media. The highlight of the trip for me was on my 26th birthday. We visited the pediatric cardiac ICU at Children's Hospital in Omaha. While there, I asked a new mother what type of CHD her baby had. She replied, "Hypoplastic Left Heart Syndrome." I said, "I have HLHS as well and I'm celebrating my 26th birthday today." You could see tears well up in her eyes. She couldn't imagine thinking beyond the next hour let alone 26 years down the road.

Today, Nick and I do our best to unite the community of CHD couples. In the spring of this year, Nick started a video blog, "Loving a Broken Heart," (<http://lovingabrokenheart.wordpress.com/>). He noticed that, while there are many resources for CHD parents, there really are no resources for the spouse. Our goal is to provide a space where CHD couples can share their stories, ask or answer questions, give advice, and have the confidence that they are not alone.

It's easy for people to think that HLHS brings nothing but hardship and pain. I'm confident that no matter what I face in my life, the trials are never out of God's control and they will bring forth a blessing that will help others.



## Adam, Age 35

### From Patient to Nurse

As I type this article, I find myself very lucky to be where I am. I was born with Transposition of the Great Arteries (TGA), as well as atrial septal defect (ASD) and ventricular septal defect (VSD). Three days after I was born, a nurse was listening to my heart and heard a murmur. At the time, patients with TGA had a very low survival rate. When I was 18 months old, the decision was made to go with a tried and true method – the Mustard procedure, which was believed to be my best option.

My childhood was good, although I did have problems with stamina. This made it challenging to keep up with the other kids when playing sports, a difficult emotional hurdle to overcome as a boy. After high school I started flying, I went to school and earned my pilot's license. I am not sure which was harder, earning the license or getting the FAA to grant me the approval to fly. I love flying; the freedom of flight gave me a feeling of normalcy and allowed me to leave my worries on the ground.

When I was 20, I found out that my heart was failing. I was scared; it was an overwhelming feeling, being told that with medication management I would only have another three years to live. I was told I had two options: heart transplant or a late arterial switch

procedure. The risk of the arterial switch was that very few had been done on adults at the time and patients undergoing a late arterial switch in adulthood had a low survival rate. I gambled and went for the switch, thinking that at least I had a backup plan in a heart transplant.

The process was very frightening on several levels. This was going to be a series of three open heart surgeries, I wondered if I would survive. I also thought about the fact that my one and only brother passed away from Non-Hodgkin's Lymphoma when I was 15. I saw how my parents were affected; I had to hand feed my mom because she wanted to die as well. It was hard going into these surgeries knowing how my parents would react if things went south. I "sailed" through the first two pulmonary banding surgeries with little difficulty. After the third surgery in the series, the challenges set in. I was on ECMO (heart assist device) for two weeks, and while I was placed in a medically induced coma, I hallucinated and I could hear everything. It was a very scary and stressful time. I suffered from depression after I was transferred out of the ICU. I had the benefit of the ICU nurses coming to my room after their shift and spending time with me, trying to lift my spirits. This selfless action left a huge and lasting impression on me.

2009 was a turning point for me. My pediatric cardiologist had retired and I was looking for a new doctor. I met with Dr. Aboulhosn, and it was the only time that anyone took a comprehensive approach. It was discovered that I had an aortic aneurysm. While it was large, it was stable, but I'm not one to sit idle; I underwent open heart surgery for the fifth time. I had a Bentall procedure, done to replace my aortic root with placement of a new mechanical aortic valve. I am now on Coumadin, which I find challenging at times. With the help of Pam Miner and Linda Houser, the ACHDC NPs, I am able to monitor and balance the Coumadin and my diet.

It was also in 2009, when I was laid off of work. I thought back to the nurses who had worked so hard helping me to survive, not just physiologically but psychologically. I decided to use the opportunity to go back to school, and I entered a vocational nurse program. After graduating, I worked in a skilled nursing facility. It was when I started

working at the UCLA Cardiovascular Center in 2012 that I really was able to apply my personal experience and bring comfort to patients. UCLA has been very good to me as a patient and as a place to work. I am currently completing my prerequisites and I have applied for the nursing program here at UCLA. I hope to elevate my skills and ability to help more patients through my nursing and personal experience.



## Meredith, Age 50

### Conquering Obstacles, Looking Ahead

This past April, I turned 50 years old. It was an age milestone I never thought I would see. "I made it, I survived, I outlived the heart condition," and everything now is "icing" on the cake after making it to that number.

In 1964 I was born with tricuspid atresia and a ventricular septal defect. My parents found out when I was three months old after a few episodes of me turning blue and gasping for air. The prognosis at the time was grim; I wouldn't live to see my tenth birthday they were told. When I was a year old they performed a Blalock-Taussig anastomosis to help get more oxygenated blood to my lungs and brain. And when I was nine they tried a risky operation called a Glenn shunt. I recovered well and spent the next 18 years of my life pushing myself to achieve as much as I could but learned to stop when I was out of breath or feeling light-headed. I wasn't able to participate in any strenuous activities but

quickly learned that it didn't mean I couldn't chase goals and dreams in other ways.

As in all lives, I've faced challenges, tragedies, triumphs and victories. I lost a baby at 8-months gestation when I was twenty-four. It was the most devastating time in my life and the "heart break" was unforgiving. At twenty-six I was working part-time and going to school part-time; I started to get dizzy spells. My heart was failing. I felt like my life was stopping before it really got going. Two days after my twenty-seventh birthday I was at UCLA for a "Modified Fontan" procedure, Dr. Hillel Laks was my surgeon. Once again I had a full recovery and life started marching forward at an even quicker pace.

I graduated with a BS in management at thirty-eight and entered into the pharmaceutical industry as a sales rep at age forty! A strenuous and active job of driving, lifting, moving, working non-stop, airports and flights and training and moving and working, working, working; I could never have imagined this life for myself until I tried. The years of medical progress for my heart made me better and stronger and I didn't want to stop. Every time I had thoughts of doubt I told myself to try and proved I could do more than I ever thought possible.

At age forty-five I had to put on the brakes; my heart started having arrhythmias. I kept pushing myself as much as I could and the UCLA team gave me a few options. It seemed surgery was the best one for me even though I was in doubt that I'd make it through a fourth. It was the first time I had to worry about Coumadin and monitoring what I was eating. The UCLA team was great – I wasn't. It was a weekly struggle not to yell at the anti-coagulation team member when they asked me if my diet had changed at all in the past week. "Are you kidding? I have to eat the exact same amount of lettuce, broccoli, vitamin k, etc... each week?" I wasn't nice. This was not going to work for me. At this point I saw surgery as the only hope of ever being off Coumadin, although the UCLA team never promised that would happen. I hoped to be back up working and living life as soon as possible; so at age forty-seven I had another modification to the Fontan procedure, once again under the great care of Dr. Laks. And just to make airport security more interesting, the team added a pacemaker too!

*Continued on page 7*

## The Nurse Practitioner in ACHD

Nurse practitioners are recognized by the American College of Cardiology as key members of ACHD facilities. NPs take comprehensive histories, perform physical examinations, order and interpret diagnostic tests, implement or modify treatment regimens and furnish prescriptions. They also counsel and educate patients, collaborate in research and assume administrative responsibilities.

Nurses have played an important role in the UCLA ACHD Center, since its inception in 1980. Dr. Joseph Perloff, our founding Director, had the foresight to recognize the advanced practice nurse as a critical member of the ACHD team, integral to providing seamless continuity of medical care, as well as providing the important link to informational needs of our patients and their families, and key to recognizing and addressing the psychological and social issues that impact those living with CHD. Dr. Perloff's vision for the ideal team to provide care to adults with CHD was emulated to all subsequent national ACHD centers, making the advanced practice nurse part of the fundamental provider group across the US, and now internationally.

The UCLA ACHD Center benefited from the pioneering efforts of the first two clinical nurse specialists, Mary Canobbio followed by Mava Day, who were formative in the development of the Center in the 1980's. Thanks to their guidance and inspiration regarding this "new specialty of adult congenital heart disease", their successors Pam Miner and Linda Houser chose ACHD as their specialty of choice. As Nurse Practitioners, Pam and Linda play an important role in assessing and diagnosing patients and work collaboratively with the ACHD attending cardiologists to plan care, with the primary responsibility of being the ongoing link for patients as issues arise or changes in management are necessary between office visits. Years of ACHD experience have cultivated their clinical instincts, and made the NPs a crucial link between patients and their physician providers.

### Pam Miner, NP

Pam Miner joined the Center in 1991. Her undergraduate degree was from Mount St. Mary's College in Los Angeles and her Master's degree was from UCLA. Her background in nursing prior to 1991 was adult cardiology and critical care, so she learned congenital heart disease under the mentorship of the Center's founding Director Joseph Perloff, and then under the two subsequent Directors of the Center, John Child and Jamil Aboulhosen.

Pam was fortunate to be at the table during the American College of Cardiology's 32nd Bethesda Conference in 2001 on "Care of the Adult with Congenital Heart Disease", as a task force member defining the "Workforce and Education" for future ACHD care. She also was on the writing committee for the 2008 ACC/AHA Guidelines for "Management of Adults with Congenital Heart Disease." She has been on the Medical Advisory Board of the Adult Congenital Heart Association since its inception over a decade ago, and is a dedicated advocate for patient education and the virtues of peer support between patients with this shared disease.

Pam has always played a collaborative role in UCLA's robust ACHD research program, and in 2008 became one of the charter members of the Adult Congenital Cardiac Care Associate Research Group, and was



Linda Houser, NP, (left) with Pam Miner, NP.

appointed Co-Chair in 2013. This research group consists of advanced practice nurses, physician assistants, and psychologists and focuses multi-center research efforts on topics central to the care of adults with CHD, including "contraceptive practices of women with CHD", which Pam is the principal investigator on.

On a personal note, as a native Californian, Pam still lives near the community she grew up in, Thousand Oaks. She admits that her career trajectory has taken precedence over other more conventional pursuits like marriage and children, but she has no regrets. She has a very close relationship with her family, and loves being an Aunt. She is a passionate home chef and wine collector, and an unapologetic dog lover.

### Linda Houser, NP

A native of New Jersey, Linda received her baccalaureate degree in nursing from the University of Pennsylvania. She began her career working for the Veterans Administration in Boston, MA in the department of general surgery. She then relocated to Southern California and embarked upon a long career at UCLA, first as a staff nurse in cardiothoracic surgery, and later in neonatal intensive care. In both areas she found herself taking a special interest in children with congenital heart disease and, perhaps as a natural outgrowth of this, ultimately developed a desire to learn more of the outcomes of these children as they grew into adulthood. In 2003 she received a masters degree in nursing from UCLA and thereafter became certified as a nurse practitioner. During her final quarter of the program, she had the good fortune to be assigned to the Ahmanson/UCLA Congenital Heart Center, then under the direction of Dr. John Child. Working with Dr. Child, Dr. Joseph Perloff, Dr. Aboulhosen and Pamela Miner she broadened her knowledge of congenital heart disease in the adult and was offered a position with the center in 2003. Linda has enjoyed a long and very rewarding career in this her first and only NP position, participating in clinical care, writing, teaching, research and collaborating with a group of people she considers to be the finest health professionals she's had the opportunity to know, and working with a patient population that continues to challenge, inspire and motivate her every day. Much to her delight, she is beginning to see patients in her adult clinic that she first met as newborns! This has truly brought her UCLA experience full circle and is testament to both UCLA's clinical excellence and Dr. Perloff's vision.

In her spare time, Linda is an avid distance runner, enjoys music and theater, and shares her home in Ventura County with her husband Erik and two furry felines, Sabrina and Josey.

## The DASH Diet: A Common Sense Approach to Healthy Eating

The DASH (Dietary Approaches to Stop Hypertension) diet is a heart-healthy, easy to follow and nutritious diet plan – recommended by the Centers for Disease Control (CDC) and the American Heart Association. According to the CDC, the DASH diet can help prevent or lower high blood pressure, reduce your risk of heart attack, heart disease, stroke and other diseases. For adults with congenital heart disease, a heart-healthy diet is especially important in terms of preventing acquired health problems such as high blood pressure, obesity, heart attacks, and strokes which can complicate one's underlying heart condition. Things that lead to high blood pressure include: carrying extra weight (BMI>25), salt (sodium) intake, lack of exercise, sleep apnea, ibuprofen (and similar "NSAID" pain relievers), birth control pills, age, and family history of high blood pressure.

The DASH diet is low in sodium, cholesterol, saturated and total fat, and high in fruits and vegetables, fiber, potassium, and low-fat dairy products, and a variety of foods rich in nutrients that help lower blood pressure, such as potassium, calcium and magnesium. By following the DASH diet, you may be able to reduce your blood pressure by a few points in just two weeks. Over time, your blood pressure could drop by 8 to 14 points, which can make a significant difference in your health risks.



### Tips to begin making gradual changes towards the DASH diet:

- Add a serving of vegetables at lunch one day and dinner the next, and add fruit at one meal or as a snack.
- Increase your use of fat-free and low-fat milk products to three servings a day.
- Limit lean meats to six ounces a day — three ounces a meal, which is about the size of a deck of cards. If you usually eat large portions of meats, cut them back over a couple of days — by half or a third at each meal.
- Include two or more vegetarian-style, or meatless, meals each week

Because the DASH diet is a healthy way of eating, it offers health benefits besides just lowering blood pressure. The DASH diet may offer protection against osteoporosis, cancer, heart disease, stroke and diabetes. While the DASH diet is not a weight-loss program, you may lose unwanted pounds because it can help guide you toward healthier meals and snacks. The DASH diet can be found at [http://www.nhlbi.nih.gov/health/public/heart/hbp/dash/dash\\_brief.pdf](http://www.nhlbi.nih.gov/health/public/heart/hbp/dash/dash_brief.pdf)

### Patient Stories (Continued from page 5)

I feel better at 50 years old than I have at any other time in my life. I exercise by walking, taking Cardio Barre classes or practicing Pilates to keep my body fit. I don't know if or when I'll need more cardiac procedures and I've learned not to worry about it. I was given the okay to stop taking Coumadin last year. I'm living in the moment and so grateful to my parents, family, childhood doctors and nurses, and the UCLA doctors and nurses who've helped me get here; Dr. Perloff, Dr. Laks, Dr. Child, Dr. Reardon, Dr. Aboulhosn, Dr. Shannon, Mava Day, Linda Houser and Pam Miner. I'm so saddened to hear of Dr. Perloff's passing this last August. He was a very kind man who forever changed my life due to his dedication and efforts in his field. I am so grateful to have been his patient.

One final thought: my best friends throughout my life have been dogs; Lady, Rosie, Scarlet, Moose, Pudgie, Peaches, Muffy, Emmy, Dolly, Chanel and Rigby. They've forced me into walks when I haven't felt like it. They've licked away tears and made me smile. They've kept me company on long days and nights of recovery. If you don't have a dog, consider adopting one from your shelter. In return for your kindness, they will be your most trusted and loving friend.

### Sapien Valve (Continued from page 1)

The Sapien XT comes in various diameters (23, 26, 29 mm) and consists of bovine (cow) tissue within a cobalt chromium frame. The valve is not FDA approved for use in other positions, however, Drs. Aboulhosn, Levi and their colleagues have received UCLA institutional review board (IRB) approval to use the Sapien XT valve in patients with congenital heart disease. Starting in July of 2014, the 29 mm Sapien XT valve has been successfully placed in six patients with congenital heart disease; four valves have been implanted in the pulmonary position, one in the tricuspid position and one in the mitral position.

The availability of the Sapien XT has expanded our armamentarium of transcatheter valves and we are now able to perform nonsurgical transcatheter valve replacements in ACHD patients whose anatomy would have precluded use of the Melody valve. We are still utilizing the Melody valve for many cases but in those with larger diameter valves, conduits or native outflow tracts, the Sapien XT is an excellent option.

## Ahmanson/UCLA ACHDC Research At-A-Glance

### Clinical Trials

**Melody transcatheter valve replacement studies** on use, outcomes and safety.

**Macitentan in Eisenmenger Syndrome to Restore Exercise Capacity (MAESTRO)**

randomized clinical trial using Opsumit in Eisenmenger Syndrome patients.

*Now enrolling*

**Efficacy of Remodulin in Adults with congenital heart disease and pulmonary hypertension** on use of Remodulin therapy in CHD patients with severe pulmonary hypertension (or Eisenmenger syndrome).

*Now enrolling*

**Closure of atrial septal defects with the Amplatzer Atrial Septal Occluder (ASO)**

Surveillance Study on erosion rates after use of Amplatzer atrial septal occluder (ASO) device.

**Pulmonary Artery Repair with Covered Stents (PARCS)** on effectiveness and safety of covered stents used during Melody transcatheter valve replacement.

### Multi-Center Collaborations

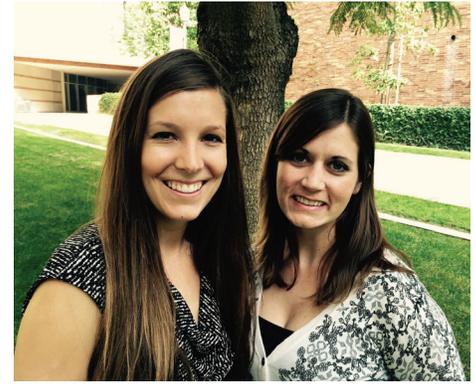
**Adult Congenital Heart Disease/ Eisenmenger Syndrome Quality Enhancement Research Initiatives (ACHD/ES QuERI)**

on patients with atrial septal defect/ventricular septal defect/AV canal defect or Eisenmenger syndrome to identify risk factors that may lead to development of pulmonary hypertension and clinical prognosis.

*Now Enrolling*

**Alliance for Adult Research in Congenital Cardiology (AARCC) Study – Medical Therapy for Pulmonary Hypertension in Unrepaired Atrial Septal Defect**

on use and effectiveness of pulmonary hypertension drugs in patients with atrial septal defect.



*Abbie Hageman (left) and Rachel Bolanos, UCLA ACHDC Research Coordinators*

**Bicuspid Aortic Valve Aortopathy: Feasibility of a Compared Effectiveness Study** NIH-funded study on treatment and prevention of aorta enlargement in bicuspid aortic valve patients.

### Translational Research

**Mechanical Circulatory Support for the Fontan Circulation** on the use of ventricular assistive devices (VAD) in patients with failing Fontans using an animal model. For more details visit the Ahmanson/UCLA ACHDC website at <http://heart.ucla.edu/ACHDC>



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