



Ahmanson/UCLA Adult Congenital Heart Disease Center

FALL/SUMMER 2005

INSIDE THIS ISSUE

Announcements	3
Patient Advisory Committee..	3
Upcoming Events.....	3
Feature Article	4
Websites, Information, Resources	4
Fund Development	5
Fund-raising Options.....	6



Celebrating 25 Years of Excellence: Part II

As we celebrate our 25th year anniversary, we look at the present and future to continue the legacy set forth in 1980. In 2001, Dr. Perloff stepped down as Director but has continued an active role as teacher and researcher. Since then, Dr. John Child was named the new Director. In 2001, Dr. Child was awarded the Streisand/American Heart Association Chair. Today, the Ahmanson/UCLA Adult Congenital Heart Disease Center's core staff includes Dr. Fabian Chen; nurse practitioners Pamela Miner and Linda Houser; Mary Canobbio, administrative coordinator of programs and fund development; Veronica Olmedo, patient affairs coordinator; and Yelba Castellon, administration and fund management.

In addition to the primary Adult Congenital Heart Disease team, the Center has a number of non-cardiac consultants who have expertise with congenital heart disease and provide specialty care in the following disciplines: genetics, obstetrics and gynecology, hematology, nephrology, pulmonary medicine, anesthesiology, and radiology.

Patient Population

Today, our patient registry approaches 2,500 patients, 3/4 of whom are followed as primary cardiac patients or in regular consultation with area physicians who are cardiologists, internists, or in family practice. Our patient population is made up of four groups: those who have never had cardiac surgery, those who have had cardiac surgery, those who have had a temporary or "palliative" procedure in anticipation of corrective surgery, and those whose conditions are inoperable—many of which will require heart transplantation and/or lung transplantation.

Since we have long recognized the impact of congenital heart disease (CHD) on quality of life issues, the Center provides education and counseling in a number of areas including genetics, contraception, vocational or career guidance, and information regarding insurability.

Education and Research

The Ahmanson/UCLA Adult Congenital Heart Disease Center has always assumed a major role for the training and education of cardiology fellows, residents, and advanced practice nurses who will be the next generation of Adult Congenital Heart Disease professionals. Today, graduates of our fellowship and international visiting fellow programs are found throughout the United States, Canada, Europe, and Japan.

In collaboration with other disciplines including basic science, the Center also supports an active and much respected program of clinical research in hematological disorders, gene therapy, developmental biology, cholesterol metabolism, coronary artery circulation, renal involvement, pulmonary circulation, aortic wall abnormalities, ventricular function, arrhythmias, and reproductive issues including pregnancy outcomes, among others.

Continued on next page

Celebrating 25 Years: Part II *Continued from front page*

The Future

The Ahmanson/UCLA Adult Congenital Heart Disease Center is committed to continuing the mission set forth by Dr. Joseph Perloff, to provide the highest level of medical and surgical care for adult survivors of congenital heart disease. However, as the number of patients reaching adulthood continues to grow, the need to provide a program that is more expansive has been recognized. In 2002, Dr. Child set forth a strategic plan to begin expanding the Center's clinical, research, and training agenda.

New programs to be developed over the next five years include a transitional care program for adolescents and a women's heart health program. Expansion of educational programs for health professionals and for patients and their families has been started.

With the increasing interest in the new subspecialty of ACHD, the demand for well-trained congenital cardiologists is rising. Our hope is to be able to increase not only the in-residence fellowship program, but also the visitor/international fellows program. To that end, in 2005, initial steps were undertaken to establish an endowed fellowship in Dr. Perloff's name, thus assuring the continuation of his legacy. Additionally, in order to provide an educational forum for area and community-based physicians in caring for these patients, an annual symposium was successfully initiated three years ago.

Moreover, a series of patient and family activities have been developed to provide patients the opportunity of coming together to share and learn more about how to deal with their congenital defect. For that reason, a patient advisory committee (PAC) was organized. The mission of PAC is to direct the development of future educational and support programs for our patients and their families.

Summary

The Ahmanson/UCLA Adult Congenital Heart Disease Center was the first formalized program in the United States for the emerging population of adults born with CHD. Today, it is one of the leading programs in the world, serving as the prototype for most programs. In 25 years, our mission has remained unchanged, and our commitment to patient-care firm. We look to a future that promises hope for continued growth in order to meet the needs of all patients with congenital heart disease. For more information regarding new programs, contact Mary Canobbio at (310) 825-3091.

IN MEMORIAM



**WILLIAM F.
FRIEDMAN, M.D.**
1936-2005

In August, we lost one of our great leaders in the field of pediatric cardiology. In 1961, Dr. William Friedman earned his medical degree from State

University of New York Downstate Medical Center where he graduated cum laude.

Dr. Friedman is internationally recognized for pioneering one of the most important therapeutic advances for the care of thousands of premature babies born with the congenital heart defect known as *patent ductus arteriosus*. In 1972, he demonstrated that medical therapy could be used to treat patent ductus arteriosus noninvasively, through the application of a prostaglandin inhibitor.

Dr. Friedman joined the David Geffen School of Medicine at UCLA in 1979, where he continued his distinguished career in pediatric cardiology. There he rose to Executive Chairman of the Department of Pediatrics, and senior adviser to the Provost and Dean of the School of Medicine. Dr. Friedman died on August 25, 2005 after a long illness. The Ahmanson/UCLA Adult Congenital Heart Disease Center is privileged to have been the recipient of Dr. Friedman's wisdom and support.

New On-line Giving Site

Making a contribution is a meaningful and personal way to show appreciation, recognize a special occasion, or pay tribute to a family member, friend, or colleague. Our new and secured on-line site is an easy and convenient way to make a donation to the Center. The Center is entirely dependent upon its own fiscal resources, and thanks to the generosity of patients, their families, and friends, it is able to meet its programmatic and research needs. To visit our on-line giving site, please go to: www.giving.ucla.edu/heartcenter/.

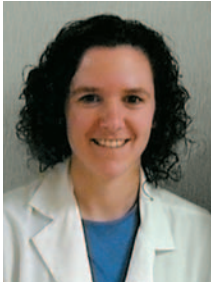
We'd like to hear from you!

We are interested in knowing your ideas and suggestions for our newsletter. If you would like to submit an article to be published in an upcoming issue, please write to us. Articles should be no more than two double-spaced, typed pages. Pictures and artwork should be submitted via email at achdc@mednet.ucla.edu as image files (.tif, .gif, or .jpeg).

ANNOUNCEMENTS

Faculty and Staff Updates

Faculty changes that have taken place this year include the departure of **Dr. Michelle Gurvitz**, who left earlier this fall to join the faculty of The Heart Center at Children's



Dr. Michelle Gurvitz

Hospital and Regional Medical Center in Seattle. Dr. Gurvitz completed her pediatric cardiology fellowship at UCLA in 2003 and since began a concurrent faculty appointment with the Ahmanson/UCLA Adult Congenital Heart Disease Center and the Division of Pediatric Cardiology. Among her interests were the transition of care from adolescence to adulthood. It was a great experience to have worked with Dr. Gurvitz, and we miss her. We wish her all the best in her new endeavor!



Dr. Jamil Aboulhosn

In accordance with our mission to train the next generation of adult congenital heart disease specialists, on July 1, 2005, **Dr. Jamil Aboulhosn** began his fellowship with the Ahmanson/UCLA Adult Congenital Heart Disease Center. Dr. Aboulhosn was chosen as the most qualified cardiologist and will work under the Direction of Dr. John Child to complete the Center's one-year advanced subspecialty-training program. His research interests include the use of new imaging modalities in CHD such as cardiac CT, MRI, and four-dimensional and intra-cardiac echocardiography. We are pleased to have Dr. Aboulhosn on our team and would like to welcome him aboard!

PATIENT ADVISORY COMMITTEE

Patient Support Program

Members of the Patient Advisory Committee (PAC) have been busy this summer working on the manual and outline for the Peer Support Program training. Tracy Livecchi (Chair), John Miller, and Kay Deeney have met to add to, modify, and revise the document.

The Patient Support Program will focus on offering peer support to adults with congenital heart disease, and to the

parents, spouses, and significant others of adult patients who have asked for support. Volunteers will be asked to phone or e-mail other patients who need peer support or to visit hospitalized patients confronting major stressors. Volunteers are asked to make an initial two-year commitment to the program and must attend an orientation session.

If you are interested in participating in peer support training, please contact Pam Miner or Linda Houser at achdc@mednet.ucla.edu or (310) 794-9629.

UPCOMING EVENTS



Southwest Regional Conference in Los Angeles for Patients and Families on October 22, 2005

The Adult Congenital Heart Association (ACHA) will be hosting its southwest regional conference on October 22, 2005, at the Manhattan Beach Marriott. This event will bring together top adult congenital heart specialists from throughout the region to provide information on the latest in adult congenital heart research, treatment, and resources.

Presentations will begin at 9:00 a.m. and will cover topics ranging from heart rhythm abnormalities to pharmacology, new imaging modalities, coping strategies, and much more! In addition, defect-specific breakout sessions and an expert panel will also be available. This conference is sure to be an

informative experience for adults born with heart defects, their families, and interested health professionals. We look forward to seeing you there!

For more information or to register, please visit www.achdc.med.ucla.edu or www.achaheart.org. You may also call 215-849-1260 or email info@achaheart.org with any questions.

CLINICAL UPDATES

Transcatheter Valve Replacement

By: Daniel Levi, MD

Just as atrial septal defect (ASD), patent ductus arteriosus (PDA), and ventricular septal defect (VSD) closures are being performed using minimally invasive transcatheter methods, valve replacements are now also possible without any surgery. Both pediatric and adult interventional cardiologists have begun trials utilizing transcatheter heart valves for either the pulmonary or aortic position. Phillip Bonhoeffer, et al, recently demonstrated the use of a stent-based transcatheter valve for pulmonary valve replacements in a series of patients with congenital heart disease (more than 70 patients to date). All of these patients, both older children and adults, had right ventricle to pulmonary artery conduits which had become either stenotic (narrowed), insufficient, or both. In this initial series of European patients, excellent short-term resolution of both stenosis and insufficiency was obtained with only minimal complications. All patients were discharged from the hospital within several days and required little intensive care and no rehabilitation (0-9 days with median of 0 days in the ICU). Figure 1 demonstrates the ability of the

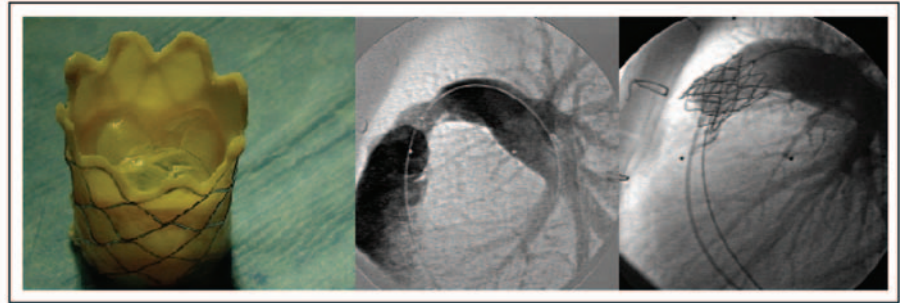


Figure 1. A valved stent is used to relieve conduit insufficiency.

valved-stent used by Bonhoeffer to relieve regurgitation in right ventricle to pulmonary artery conduits. Cribier, et al, also demonstrated feasibility of human aortic valve replacement in a series of large adult patients with calcific aortic stenosis where percutaneous, sub-annular, stent-based valve replacements were performed.

While the transcatheter heart valves used by Bonhoeffer and Cribier have many limitations, dozens of novel transcatheter valves for use in the aortic, pulmonary, tricuspid, and even mitral position are being developed. The range of technologies currently available and in development was presented at the 2nd Annual Transcatheter Valve Symposium in Chicago, March 2005. In their present state, both Bonhoeffer's pulmonary valve and Cribier's aortic valve are far too bulky to be used in neonates or even smaller children. Nevertheless, they may prove to be perfect for adults

with congenital heart disease. Furthermore, the sheaths required for use of the Bonhoeffer and Cribier valves are prohibitively large to be considered for use in the majority of the pediatric patients. Hence, much lower profile valves are being developed.

Because of the phenomenal results from surgically placed heart valves, transcatheter valve replacement is far from the standard of care. In fact, only a handful of transcatheter valves has been used in the United States. Nonetheless, a transcatheter pulmonary valve intended for use in right ventricle (RV) to pulmonary artery (PA) conduits (made by Medtronic and based on Bonhoeffer's valve) will soon enter an FDA trial in the United States. UCLA hopes to be one of the early trial sites for use of this valve in larger patients with RV to PA conduit insufficiency.

INFORMATION & RESOURCES

Ahmanson/UCLA Adult Congenital Heart Disease Center
www.achdc.med.ucla.edu or call (310) 794-9629

Adult Congenital Heart Association, Inc. (ACHA)
www.achaheart.org or call (919) 861-4547

Mayo Clinic Congenital Heart Disease Clinic
www.mayoclinic.org/congenitalheart-rst/

Congenital Heart Information Network (CHIN)
www.tchin.org or call (215) 493-3068

Camp del Corazon
www.campdelcorazon.org or call (888) 621-4800

The 32nd Bethesda Conference 2000 proceedings
<http://www.acc.org/clinical/bethesda/beth32/dirIndex.htm>

Canadian Adult Congenital Heart Network
www.cachnet.org/ or call (416) 417-6523

Kansas City Congenital Heart Disease Diagrams
www.kumc.edu/kumcpeds/cardiology/pedcardiodiagrams.html

Health Insurance Information
<http://www.healthinsuranceinfo.net/>

Medic Alert
www.medicalert.org/amb or call (888) 633-4215

FUND DEVELOPMENT

25th Year Anniversary Gala

In commemoration of the Ahmanson/UCLA Adult Congenital Heart Disease Center's 25th year anniversary, the theme for the 8th annual fund-raising dinner was "Celebrating 25 Years of Excellence." The gala celebration, generously hosted by Hertz Investment Group and philanthropist Judah Hertz, was held on May 8 at the Luxe Hotel in Bel-Air. Dr. John S. Child and Judah Hertz paid special tribute to the 2005 honorees, Thomas Bliss, Michael McNamara, and Anthony Jaffe. Mr. Bliss is the executive producer of such hit films as *Dawn of the Dead*, *Air Force One*, and *Spy Game*. Mr. McNamara formed the legal firm McNamara, Spira & Smith on the Westside in 1993. Relocating from New York in 2002, Mr. Jaffe is managing director of IXIS Real Capital Inc.



From L-R: Thomas Bliss, Honoree, Dr. John Child, Director, and Michael McNamara, Honoree.

Dr. Child and Mr. Hertz were event co-chairs. The Honorary Committee included Sally and Paul Bennett, Ken and Laurie Boyko, Marjorie L. Fasman, and Mimi Perloff. The master of ceremonies for this special evening featured Marcel Forestieri, a Jay Leno impersonator. Entertainment was Lois Albez with the Monte Montgomery Quartet.

Dr. Gerald S. Levey, Vice Chancellor for the UCLA Medical Sciences and Dean of the David Geffen School of Medicine at UCLA, praised Dr. Joseph Perloff, the Center's founder, and recognized Mr. Hertz for hosting the first fund-raising reception in 1992. Shortly thereafter, The Ahmanson Foundation named the Center with a generous, visionary gift.

The anniversary celebration dinner was a huge success, thanks to all of the new and ongoing supporters of the Center! The event brought in nearly \$250,000 in support of patient care, research, and educational programs, all of which enable the Center to continue to meet the needs of the rapidly growing population of adult patients with congenital heart disease. Dr. Child also announced the establishment of the Joseph K. Perloff Fellowship Endowment that will provide vital funding for advanced-subspecialty training to postgraduates interested in pursuing careers in adult congenital heart disease. Clearly, this year's guests had a lot to celebrate!

GOLD HEART \$10,000+

Simone & Stuart Isen
Mr. Anthony Jaffe, IXIS Real Estate Company
The Galter Foundation
R.W.H. Holdings
Mr. & Mrs. Jason D. Turner, Venbrook Insurance
Mr. Judah Hertz

SILVER HEART \$5,000+

Mr. Marc Abraham, Strike Entertainment
Mr. & Mrs. Eliot Bliss
Mr. Thomas Bliss & Ms. Merrily Weiss
Alice Coltrane, JOWCOL Music
Mr. & Mrs. Frank Jansen, Chicago Title Company
Jewish Community Center
Thomas and Helene Spiegel Family Foundation
Holliday Fenoglio Fowler
Mr. Bruce Karatz, KB Home
Jonathan and Faye Kellerman Foundation
Mr. & Mrs. Marvin Mandelbaum, Mandelbaum Insurance Services
Mr. Jerry Friedman, Marvin Engineering Co.
Mr. & Mrs. Michael P. McNamara
Mr. Forrest Nolin, Advance Building Maintenance
Stephanie & Charles Roven
The Winnick Family Foundation

BRONZE HEART \$1,200+

Mr. & Mrs. Kenneth Boyko
Mr. & Mrs. Richard Boyko
Mr. & Mrs. Michael Croft
Mr. & Mrs. Hugo De Castro
Mrs. Dolores M. Denecour
Mr. Kenneth Doran
The Ezralow Company
Marjorie L. Fasman
Mr. & Mrs. Benjamin Feingold
Mr. Selwyn Gerber, Gerber Financial Management
Ms. Adrian Goldstein
Mr. Mario Hernandez, Union Bank of California, N.A.
Mr. Alan Hewitt, Hewitt Financial Group
Mr. Wolfgang V. Kupka, Vista Affordable Housing Corporation
Mr. Joe Lumer, Five Star Parking
Mr. & Mrs. David Mc Ewen
Mrs. Diane B. Paul
Mr. William S. Price III
Shirvanian Family Foundation
Mr. & Mrs. John Swenson
Mr. Jeffrey H. Tamkin

A special thanks to all of our corporate and private sponsors for all of your support!



Ahmanson/UCLA Adult Congenital Heart Disease Center

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FUND-RAISING OPTIONS

A Legacy of Giving:

A gift planned today secures our mission to continue to serve you in the future.

Endowment Opportunities

- Teaching Fellowships
- International Scholars Program
- Research Funds
- Patient/Family Educational Fund

Planned Giving

- Gift by Will or Living Trust
- Charitable Gift Annuity
- Charitable Remainder Trust, Pooled Income Fund

Assets That Can Be Given

- Cash
- Appreciated Securities
- Real Estate
- IRAs and Pensions

To learn more about these and other planned gifts, contact Yelba Castellon, Administrative Manager, at (310) 825-2019.

Joseph K. Perloff, M.D., Endowed Fellowship

The Ahmanson/UCLA Adult Congenital Heart Disease Center has launched a fund-raising appeal to create the Joseph K. Perloff, M.D., Endowed Fellowship as a lasting tribute to Dr. Perloff. UCLA is inaugurating this distinguished fellowship to benefit the Center's mission of research, education, and patient care. The endowment will provide permanent funding to recruit the best applicants in order to advance the field of congenital heart disease in many of the areas originally initiated by Dr. Perloff.

Should you wish to contribute or have any questions, please contact Yelba Castellon, Administrative Manager, at (310) 825-2019, or you may contact the Center directly at (310) 825-2019.