

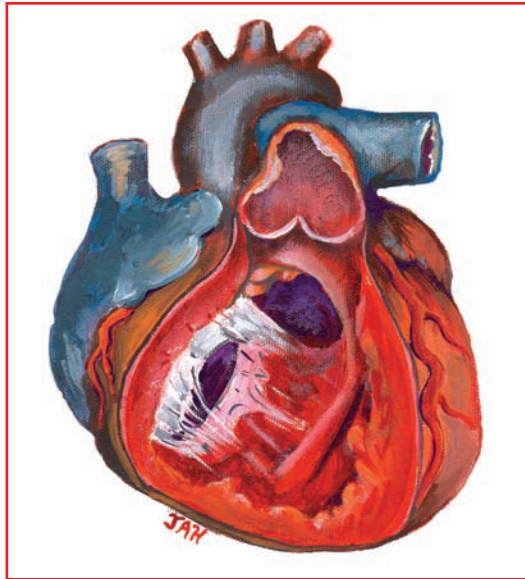


Ahmanson/UCLA Adult Congenital Heart Disease Center

WINTER/SPRING 2006

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New Treatment Options for Patients with Pulmonary Hypertension and Eisenmenger Syndrome

A small percentage of adults with congenital heart disease are afflicted with Eisenmenger syndrome. This progressive disease develops as a result of large cardiac defects that cause increased blood flow to be delivered to the lungs. If surgical correction of these cardiac defects is not accomplished early in life, this increase in blood flow to the lungs may result in damage to and increased resistance to blood flow within the small vessels of the lungs. Over time, blood pressure in the lungs becomes elevated (pulmonary hypertension) ultimately leading to shunt reversal and diversion of oxygen poor blood into the general circulation, causing cyanosis (bluish discoloration of the skin and mucous membranes). Symptoms related to Eisenmenger syndrome can include progressive fatigue, breathlessness, decreased energy and activity tolerance and an overall reduction in quality of life.

Recently, a class of drugs known as pulmonary vasodilators has emerged as promising therapy for patients with Eisenmenger syndrome. Pulmonary vasodilators have been used successfully for many years to treat patients with primary pulmonary hypertension

(elevated blood pressure in the lungs of unknown cause). Two drugs with different mechanisms of action have been investigated. Sildenafil (Revatio) is a medication that increases production of nitric oxide, a substance that enables relaxation and expansion of the vessels of the lung, resulting in decreased resistance to blood flow. Bosentan (Tracleer) directly inhibits substances that constrict lung vessels, resulting in lowered pulmonary pressure. In a recent clinical trial known as BREATHE-5, Bosentan was shown to decrease resistance of the lung blood vessels as well as improve overall exercise ability in patients with Eisenmenger syndrome.

Because of these early promising results, the Ahmanson/UCLA Adult Congenital Heart Disease Center is currently offering these therapies to patients with Eisenmenger syndrome with short-term goals of improving symptoms, increasing exercise capacity and the long-term goal of potentially stabilizing the disease process and improving overall quality of life.

If you would like more information please contact the Center at (310) 794-9629.

ANNOUNCEMENTS

ACHA Southwest Regional Conference

By: Donna Smith, ACHA Member

The first Southwest Regional Conference of the Adult Congenital Heart Association (ACHA) was held on October 22, 2005 at the Marriott Hotel in Manhattan Beach. Over 75 participants, including patients, parents and spouses, gathered to learn about the advances in medical, diagnostic and surgical updates from medical professionals in two general sessions and breakout sessions that ranged from defect-specific overviews to life style issues and coping with congenital heart disease (CHD).

The general sessions included a look back at the surgical milestones in CHD, presented by UCLA cardiac surgeon **Dr. Mark Plunkett**, advances in arrhythmia management, and a panel reviewing future trends for adults with CHD. Panel members included Dr. David Atkinson from Harbor-UCLA Medical Center, **Dr. Joseph Perloff**, Emeritus Director of the UCLA Adult Congenital Heart Disease Center, Dr. Masato Takahashi from Children's Hospital Los Angeles and Amy Verstappen, President of ACHA.

Morning breakout sessions were defect specific with presentations on tetralogy of Fallot, single ventricle, transposition of the great arteries, bicuspid aortic valves and coarctation of aorta, and cyanotic CHD. Speakers included our own **Dr. Jamil Aboulhosen**, Dr. Frederic Leong, Dr. Masato Takahashi, Dr. Michael Criley of Harbor-UCLA Medical Center, and former UCLA ACHD fellow Dr. Reema Chugh of Kaiser Permanente.

Afternoon breakout sessions took on a wide array of issues including women's health, making sense of medicines, an update on diagnostic modalities, and advances in valve replacement surgery. Sessions speakers included Dr. Juan Alejos



Bottom row: R to L: Mark Plunkett, MD; Pamela Miner, NP; Joseph Perloff, MD; Reema Chugh, MD; Masato Takahashi, MD; Top row: R to L: Martin Bieti, Jim Wong, Ph.D.; Juan Alejos, MD; David Atkinson, MD; Craig Cohen, MD; Amy Verstappen, John Michael Criley, MD; Jamil Aboulhosen, MD; Enrique Ostrzega, MD; Mary Canobbio, RN; John Nigro, MD; Donna Smith

from Mattel Children's Hospital at UCLA, Tracy Livecchi, Licensed Clinical Social Worker, and advanced practice nurses **Mary Canobbio** and **Pamela Miner** from UCLA.

While the sessions were given rave reviews, it was the shared stories of diagnoses, treatment and personal achievements that kept the noise level humming throughout the day. While most participants had spent a lifetime managing their defect, others described their shock at having been diagnosed well into their adult life. Patients and family thanked the "pioneers" such as **Dr. Joseph Perloff** for having the vision of developing programs such as the Ahmanson/UCLA Adult ACHD Center to care for the growing number of adults with CHD.

Amy Verstappen and ACHA Board Member Jim Wong closed the day with a rousing call to action for the heightened quality of life for those living with CHD through medical research, proper care, insurance coverage, and knowledge.

First Annual National Congenital Heart Disease Lobby Day

On February 8, 2006, adults and children with congenital heart defects, their friends, families, and concerned medical professionals traveled to Capitol Hill to speak out about long-term needs of congenital heart defect survivors and to educate congress on the importance of using federal health research dollars to study the life-long conditions of CHD survivors and ask for Congressional support for establishing an Adult Congenital Heart Disease Registry which would ultimately serve to extend the lives of all heart defect survivors.

Meetings were held with members of the Congress and their representatives, including and Congressman Tom Price of the state of Georgia. Congressman Price introduced House Resolution 169, which recognizes February 14th as "A Day of Hearts: Congenital Heart Defect Awareness Day".



ACHA member with their local representative

National Congenital Heart Lobby Day was sponsored by the Adult Congenital Heart Association (ACHA), Congenital Heart Information Network (CHIN), and the Children's Heart Foundation. To learn more please visit www.achaheart.org



Congenital Heart Disease Awareness Fair



From left to right: Preeti Kulkarni, Beth Kissinger, John Miller, Kim LaTour, Virginia Ettinger, Barbara Sousa, Cherie McDermott, Kay Deeney

Throughout the month of February, a coalition of patients, families, non-profit organizations, and health professionals participated in a national campaign to increase public awareness of Congenital Heart Defects and Childhood Onset Heart Disease. As part of this effort, the Ahmanson/UCLA Adult Congenital Heart Disease Center participated in a Heart Fair on Thursday, February 16, 2006. The event took place in the Main Lobby/Courtyard of 200 UCLA Medical Plaza from 10am – 2pm.

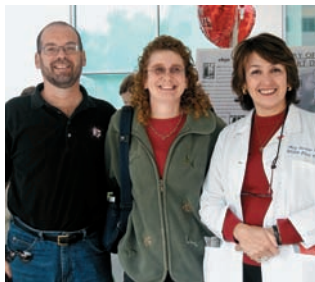
This year's event was a great success thanks to the efforts of the Patient Advisory Committee (PAC) and the support of the Center's staff. The event was targeted towards individuals interested in learning more about Congenital Heart Disease, as well as more general heart related issues through participation by other UCLA Departments. Displays included general cardiology information, risk factor screening, as well as historical information on Congenital Heart Disease. Specific exhibits on Anatomy, Diagnostics/Imaging, Women's Health/Reproduction and Valve Technologies were made available to the many individuals who attended. To see more pictures from the event, please visit our website at www.achdc.med.org under "patient resources-calendar of events".



Preeti Kulkarni, Linda Houser, NP; Veronica Olmedo



Lonnie Seavey and Dr. Jamil Aboulbosh



John Miller, Beth Kissinger, Mary Canobbio, RN



Veronica Olmedo and Yelba Castellon



From left to right: Cherie McDermott, Barbara Sousa, Lonnie Seavey, Heather Bovee, Beth Kissinger, Kay Deeney

PATIENT SERVICES

Counseling Services Available for ACHD Patients and Families

Counseling Services are now offered to patients and family members of the Ahmanson/Adult Congenital Heart Disease Center. Since patients with adult congenital heart disease are more likely than non-patients to experience depression, anxiety and increased stress, we believe that these services are a valuable addition to our Center.

Payment for these services can be made through most insurance plans and sliding scale payment is available, if needed. For more information on this service or to receive a referral for counseling, please call Pam Miner or Linda Houser at (310) 794-9629.

SOME COMMON REASONS TO SEEK COUNSELING INCLUDE:

- Change in mood, energy level, sleep, appetite and/or ability to concentrate—not caused by medical condition.
- Feelings of sadness, anxiety, fear or low self-esteem.
- A desire to prepare for upcoming surgery or other medical procedure.
- Change in lifestyle due to CHD, such as employment status, relationship shifts or physical limitations.

Patient Advisory Committee: New Patient Support Program

The Ahmanson/UCLA Adult Congenital Heart Disease Center and the Patient Advisory Committee (PAC) conducted its first Patient Support Program training on Monday, December 5, 2005. Led by Tracy Livecchi, Beth Kissinger and John Miller, eleven “trainees” participated. Catherine Mitchell from the UCLA Medical Center Volunteer Services was a guest speaker.

Through this program the Center is now able to offer support, advice and encouragement to interested adult patients, family members and parents of children with congenital heart disease. When requested by a patient, family member or parent, the Center staff will match the individual to a trained patient volunteer. The volunteer selected will have either a similar diagnosis, undergone similar medical procedures or may be someone who has gone through similar medical related/life style changes. This connection provides



PAC members: Tracy Livecchi, Julie Spangler, Preeti Kulkarni, Kim LaTour.

the referred patient with the opportunity to ask questions, discuss their fears or concerns, talk about their medical experiences, gain insights and feel less isolated.

If you are a patient and are interested in being connected to such a volunteer or would like to learn more about attending the next volunteer training, please contact Linda Houser or Pam Miner via email at achdc@mednet.ucla.edu or by calling (310) 794-9629.

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).

CALENDAR OF EVENTS

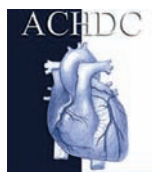


ACHDC 10th Annual Fundraiser, May 16, 2006

The 10th Annual Fundraising event for the Ahmanson/UCLA Adult Congenital Heart Disease Center will be held on May 16, 2005 at the Luxe Hotel Sunset Boulevard, in Los Angeles, California. We are privileged to announce Sally Bennett, Marjorie Fasman, and Jason Turner as our honorees this year.

Situated on seven acres of tranquil gardens, the Luxe Hotel provides a perfect setting to celebrate another year of care the Center has provided for those adults living with congenital heart disease.

We would like to express our appreciation to the Hertz Investment Group for once again graciously underwriting this special event. If you wish to purchase a ticket or tribute ad please call Mann Productions at (323) 314-7000 for more information or visit our website at www.achdc.med.ucla.edu.



ACHDC UCLA ACHD Symposium for Physicians and Health Care Providers, September 28-30, 2006

This year's ACHD symposium for physicians, nurses, and health care providers will be held from September 28-30, 2006 at the Luxe Hotel in Los Angeles. The two-day course will include a new half-day symposium for nurses and allied health professionals interested in learning how to manage adults with congenital heart disease (CHD). The remaining day and a half will cover medical and surgical management issues and clinical controversies in the care of adults with CHD. Special topics will cover heart failure and pregnancy in ACHD, as well as state of the art management of cyanotic heart disease and new strategies in managing Eisenmenger's syndrome.

For more information please visit the Center's website at www.achdc.med.ucla.edu under "Professional Resources".



CAMP DEL CORAZON
A non-profit organization



Family Symposium Saturday, May 20, 2006

*Come Hear the Truths About
Congenital Heart Disease.*

Camp del Corazon's 6th Annual Family Weekend Symposium is a free-of-charge one-day event at the Universal Sheraton Hotel, which allows adults and the families living with congenital heart disease a

unique opportunity to spend the day with experts in the field. This year they will be presenting speakers who are leaders in the advances and treatment of heart disease, as well as a follow-up question-and-answer panel discussion that may dispel many of the myths regarding living with heart disease. While the adults are attending the symposium, children ages 6-17 are invited to spend the day at Universal Studios with the outstanding volunteers of Camp del Corazon. Space is limited so please call the camp office for more information.



Camp del Corazon's Camp Sessions in 2006

The Camp del Corazon is excited to be expanding and adding a third camp session over Memorial Day Weekend at Cotton Tail Ranch in Malibu which will allow for an additional 100 campers to attend their program this year. They will also be holding their two traditional camp sessions on Catalina Island at the end of August thru the Labor Day weekend for 300 children living with congenital heart disease. To become involved or for more information, please contact Amy Larsen at the camp office at 818-754-0312 or alarsen@campdelcorazon.org or visit their website at www.campdelcorazon.org.

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/.



ACHA National Regional Conference for Patients and Families September 15-17, 2006 San Francisco, CA

The Adult Congenital Heart Association (ACHA) is planning its 2006 national conference for patients and families from September 15 – 17, 2006 in the San Francisco area at the Crowne Plaza Hotel, San Francisco International Airport. More details will be posted soon on the ACHA's website at www.achaheart.org.

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



Ahmanson/UCLA Adult Congenital Heart Disease Center

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Los Angeles, California 90095-1679

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 gifts of legacy, 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.