



Ahmanson/UCLA Adult Congenital Heart Disease Center

WINTER/SPRING 2005

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Celebrating 25 Years of Excellence

This year, we are pleased to be celebrating the 25th anniversary of the Ahmanson/UCLA Adult Congenital Heart Disease Center. It is one of the first centers dedicated to the care of adults with congenital heart disease, and the past two-and-a-half decades have seen tremendous accomplishments along with challenges, but through it all, our patients and their families have been the focus of our program. This newsletter has made the history of the Center our lead story. Part one emphasizes the past and how Dr. Joseph Perloff's vision became reality. In part two, to be published in the fall, we will feature our current programs and what's in store for the future. Our annual fund-raising event, to be held on May 8, will be the highlight of the year. We hope many of you will join us, as we celebrate 25 years of excellence!

PART ONE: Memories from the Past

In 1970, congenital heart disease (CHD) was a pediatric specialty. For Dr. Joseph Perloff however, CHD was considered a continuum from birth to adulthood, a view that was the result of his work with Dr. Paul Wood during his Fulbright fellowship at the Institute of Cardiology in London.

A plenary lecture, *The Pediatric Congenital Cardiac Becomes a Post-operative Adult* delivered by Dr. Perloff at the 1972 Scientific Sessions of the American Heart Association, followed by publication in *Circulation* in 1973 served as the backdrop for a new cardiovascular subspecialty. It was the outgrowth of remarkable advances in diagnostic techniques and in the surgical and medical management of infants and children with CHD.

In 1977, when Dr. Perloff arrived at UCLA, the time and place were ripe for establishing a facility dedicated to adults with CHD. Dr. Kenneth Shine, who was Chief of the Division

of Cardiology, applauded the idea, and just as important was the enthusiastic support of Dr. Arthur Moss who was Chief of Pediatric Cardiology, then Chair of the Department of Pediatrics. During his many years at UCLA, Dr. Moss had cared for hundreds of CHD patients who had reached adulthood and had no where to go for follow-up. These patients became the core of the new Adult Congenital Heart Disease Clinic.

The Clinic began by meeting once a month. Dr. Perloff and a Cardiology Fellow saw patients. As the program began to evolve, Dr. Perloff recognized the need for a more comprehensive approach and invited Dr. John Child, newly appointed to the UCLA Division of Cardiology faculty, to join him. Dr. Child not only provided crucial clinical support, but also was an expert in the emerging field of echocardiography, which was shortly to become pivotal in the management of

Continued on next page

PART ONE: Memories *Continued from front page*

CHD in any age. Mary Canobbio, a Clinical Nurse Specialist, soon joined the Clinic, assisting with program and research coordination and providing patient and family education and counseling.

By 1980, the Clinic had expanded to once a week and now included a Pediatric Cardiology Fellow. A change in name from the Adult Congenital Heart Disease *Clinic* to *Center* underscored expansion beyond patient care to include teaching, research, and a fellowship in ACHD. In 1981, Hillel Laks joined the medical school faculty as Chief of Cardiothoracic Surgery—a truly seminal appointment that ensured the Center had all the ingredients of success.

Pivotal to the Center's success has been the fiscal support received over the years. In the late 1980s, state funds to UC medical schools sharply declined, as defense spending in California declined, and the meager funds to the Adult Congenital Heart Disease Center vanished. Notices were received from the Chair of the Department of Medicine that the Center was not generating sufficient income to justify the time and space it occupied in the outpatient clinic. It was apparent that unless money was raised from private extramural sources, the Center would cease to exist.

Throughout these early years, the Center received a number of bequests to support Dr. Perloff's vision of ACHD. Key among them was the Streisand/American Heart Association Streisand Chair that was awarded to Dr. Perloff and provided the foundation to continue the Center. In 1992, an Advisory Committee of patients and civic-minded citizens was assembled to help with fund-raising. Judah Hertz sponsored

the first major event in the penthouse of his vintage Oviat building to promote interest in the UCLA's Adult Congenital Heart Disease Center. It was there that Dr. Perloff met with Dr. Franklin Murphy, Jr., who arranged a lunch in Beverly Hills with the Chair of the Board of The Ahmanson Foundation, Mr. Robert Ahmanson. Advised that there was no point in asking for the needed \$1 million, Dr. Perloff requested half of the amount required, and Mr. Hertz pledged to match the rest by annual fund-raising events sponsored by his Hertz Group.

The following Friday, Dr. Perloff's office phone rang. Dr. Murphy's voice told him to sit down. The Ahmanson Board meeting had just ended, "Franklin informed him that they did not get the half-million asked for." After a pause that lasted an eternity, he said that the Center had been awarded *the entire million!*

A few days later, when a pile of routine mail arrived on his desk, Dr. Perloff opened an ordinary envelope that contained an extraordinary item—a check from Mr. Ahmanson. The Ahmanson/UCLA Adult Congenital Heart Disease Center was born! Fiscal security was ours at last, but equally important was the enormous credibility and visibility the Ahmanson name brought to the Center.

The Center is now an international referral resource providing not only long-term care for the growing number of patients reaching adulthood, but also providing specialized services in a variety of disciplines including Ob/Gyn, Genetics, Hematology, Nephrology, and Anesthesiology.

ANNOUNCEMENTS

AWARD OF EXTRAORDINARY MERIT



Dr. Joseph K. Perloff received the UCLA Medical Alumni Association Award of Extraordinary Merit for 2004. It recognizes contributions that have been of unusually great benefit to the David Geffen School of Medicine at UCLA by enhancing the reputation of the School through major advances in the biomedical sciences. Dr. Perloff was honored with the award at the UCLA Medical Alumni & Aesculapians Awards Banquet on October 22. Congratulations, Dr. Perloff!

Faculty and Staff Updates

The Ahmanson/UCLA Adult Congenital Heart Disease Center assumes a major commitment to train and educate the next generation of leading physicians in CHD in adults. The Center offers a one-year fully affiliated fellowship program designed specifically to develop the high levels of clinical and research expertise required for a career in ACHD.



This year, we are pleased to announce a key addition to our team for 2005-2006. **Dr. Jamil Aboulhosn** has been selected to complete the Ahmanson/UCLA Adult Congenital Heart Disease Advanced Subspecialty Fellowship Program, under the Direction of Dr.

John Child. Dr. Aboulhosn is currently a third year cardiology fellow at Harbor-

UCLA Medical Center. In fall 2004, we were fortunate to have him with us at UCLA for a four-month rotation. Since then, he has been actively involved with the Center's research efforts and continues to attend conferences. We look forward to having him join our team in June!



We are also pleased to announce the addition of our new administrative manager, **Yelba Castellon**, to our staff. Her role is to provide support in carrying out the Center's day-to-day administrative and financial duties, including assisting with the annual fund-raising benefit, publishing the annual newsletters, and maintaining the Center's Website. This year, as a new

staff member on the Patient Advisory Committee (PAC), she helped coordinate the CHD Awareness Event. Feel free to contact Yelba at y Castellon@mednet.ucla.edu or (310) 825-2019 to discuss fund-raising options or any other administrative matter. Welcome aboard, Yelba!

25th Anniversary Patient Tribute Book

As part of our 25th anniversary celebration, we would like to invite patients and their spouses, children, and parents to share their thoughts about being part of the 25-year history of the Ahmanson/UCLA Adult Congenital Heart Disease Center.

We also would like to identify patients who have been followed here since 1980. If you have an "early" photo you'd like to share, please feel free to send it to the Center's office. We will require a written/e-mail statement indicating your willingness to print the photo. Please send a "copy" of the photo, as it will not be returned.

If you wish to send a statement or memorable event highlight to the tribute book, you may do so by e-mailing or sending your tribute to the Center. Please include your full name, telephone number, fax, and e-mail address. The tributes will be published in the program brochure of our annual fund raiser event on May 8, 2005. *The Deadline for submission is April 8.*

Please send c/o Yelba Castellon, Ahmanson/UCLA Adult Congenital Heart Disease Center, Division of Cardiology, Room 47-123 CHS, 650 Charles E. Young Drive South, Los Angeles, California 90095 or e-mail to achdc@mednet.ucla.edu. Visit our Website at www.achdc.med.ucla.edu for more information.

PATIENT SERVICES

Support Services for ACHDC Patients: The Role of the Clinical Social Worker

Often, ACHD patients feel a need to speak with someone objective, someone other than a family member or close friend, about feelings relating to lifestyle changes and in preparation for upcoming medical procedures. A licensed clinical social worker (LCSW) can help ACHD patients by providing psychotherapy services to assist in dealing with medical related stress, anxiety, depression, loss, anger, and/or relationship issues.

Psychotherapy provided by an experienced LCSW can be short or long term in nature, depending on the needs of each individual. It can also assist patients and/or family members

in feeling less isolated, more in control, and empowered when needing to make important decisions. This therapeutic process can help strengthen coping skills, increase support systems, and develop valuable ways of managing stress, as well.

Moreover, social workers can be helpful in strengthening patients communication skills, in addition to assisting them in collaborating with other health care professionals and involved agencies. Advocacy is also a role many social workers take on, sometimes assisting clients in letter writing or by making telephone calls on their behalf (with their client's authorization). For referrals, please contact Pam Miner or Linda Houser via e-mail at achdc@mednet.ucla.edu, or you may call them at (310) 794-9629.

Patient Advisory Committee: New Patient Support Program

The staff members at the Ahmanson/UCLA Adult Congenital Heart Disease Center and the Patient Advisory Committee (PAC) are in the process of developing a patient support program. Its goal is to offer support, personal insight, and encouragement to ACHD patients and their families, via specially trained patient volunteers.

Through this program, interested patients and/or their family members can be connected to an adult patient with a similar diagnosis, who has undergone similar medical procedures or has gone through medically related lifestyle changes. This contact could then provide the opportunity to ask questions, talk about medical experiences, and gain insights, thereby hopefully reducing feelings of isolation. Although the staff often receives requests for this type of



PAC members: Kay Deeney, Tracy Livecchi (Chair), John Miller, Virginia Ettinger, and Martin Bieti.

meeting, it will be the first time a formalized program will be in place to make it happen.

If you are interested in learning more about this program or joining the PAC, please contact Linda Houser or Pam Miner via e-mail at achdc@mednet.ucla.edu, or you may call them at (310) 794-9629.

CALENDAR OF EVENTS



Patient Advisory Committee: CHD Awareness Event

On February 13, 2005, the Ahmanson/UCLA Adult Congenital Heart Disease Center's PAC hosted the 6th Annual Congenital Heart Disease Awareness Day. It was held at UCLA's Sunset Canyon Recreation Center.

Speakers from the Ahmanson/UCLA Adult Congenital Heart Disease Center included PAC members Tracy Livecchi, Kay Deeney, Martin Bieti, and John Miller. Also present were Dr. John Child and Dr. Joseph Perloff, who presented the history of CHD in commemoration of the Center's 25th Anniversary. The luncheon celebration provided an opportunity for CHD patients and their family and friends to meet one another, mingle, and share experiences. The event was a great success thanks to the efforts of the PAC and Center staff!



Ahmanson/UCLA Adult Congenital Heart Disease Center's Annual Fund-raising Event

This year, our 9th annual fund-raising event celebrates the 25th Anniversary of the Ahmanson/UCLA Adult Congenital Heart Disease Center, and will be held on May 8, 2005, at the Luxe Hotel on Sunset Boulevard in Bel Air, California. We are privileged to announce that Thomas Bliss, Anthony Jaffe, and Michael McNamara are our honorees.

Situated on seven acres of tranquil gardens, the Luxe Hotel provides a perfect setting to recognize the extraordinary contributions the Center has made to the field of CHD over the past 25 years.

We would like to thank The Hertz Investment Group for once again graciously underwriting this special event. If you would like to purchase a ticket or a tribute ad, please call Yelba Castellon at (310) 825-2019.

ACHDC Symposium for Physicians and Health Care Providers

The third UCLA symposium on ACHD will be held on April 29 and 30 at the Luxe Hotel in Bel Air. This program is designed to provide community cardiologists and health care providers with continuing medical education focused on the complex medical management needs of adults with CHD. This year's program highlights the challenges of managing heart failure and arrhythmias in patients with CHD.

For more information, please see the UCLA CME website at <http://www.cme.ucla.edu>, or call (310) 794-2620. Also you may download this year's program on the Center's Website at www.achdc.med.ucla.edu.



CAMP DEL CORAZON

A non-profit organization



2nd Annual Gala del Sol

Camp del Corazon, a non-profit corporation providing summer camp for children with heart disease, is hosting its 2nd Annual Gala del Sol fund-raising event to be held on Saturday, April 9, at the Globe Theater at Universal Studios, Hollywood. This

year, the honoree is Dr. Joseph Perloff, as he has been so instrumental in the care of many of the campers, families, and counselors. This fun-filled event will also include an incredible silent and live auction; McKenzie Westmore and Seven as the hosts; musical entertainment by Chuck Negron; and a special appearance by Tom Arnold.

For more information, please contact Ronya Waters in the camp office at (818) 754-0312.

5th Annual Family Weekend



The 5th Annual Family Weekend at Universal Studios is set for Saturday, May 14, 2005. Join Camp del Corazon and the American Heart Association at an event for the whole family! This free symposium allows the parents of children with congenital and acquired heart disease and adults living with CHD a unique opportunity of spending the day with Los Angeles experts in the field. While the adults are attending the symposium at the Universal Sheraton Hotel, the children will be exploring Universal Studios/Hollywood theme park with the outstanding volunteer staff of Camp del Corazon.

For more information, please call the Camp del Corazon office at (818) 754-0312.

ACHA CONFERENCE



Regional Conference in Los Angeles for ACHA

This year, the Adult Congenital Heart Association (ACHA) is planning one of its three regional conferences in Los Angeles. The LA Conference is scheduled for Saturday, October 22, 2005. It will be a one-day educational conference for patients with CHD. A number of speakers from various ACHD programs will be giving updates on numerous clinical issues. For more information, please visit our website at www.achdc.med.ucla.edu, or e-mail us at achdc@mednet.ucla.edu.

Other regional conferences scheduled for 2005 will take place in New York and Florida. Visit the ACHA Website at www.achaheart.org to become a member or for the latest conference information. The Southern California ACHA representatives are Martin Bieti and Donna Smith. They can be contacted via e-mail at mwbieti@achaheart.org and dsmith@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/>



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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 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 Aly Shoji, Senior Associate Director of Development, at (310) 267-1826, or you may contact the Center directly at (310) 825-2019.