

Ahmanson/UCLA Adult Congenital Heart Disease Center

SUMMER/FALL 2004

ANNOUNCEMENTS

Award of Extraordinary Merit

Our own Dr. Joseph K. Perloff has been chosen to receive the UCLA Medical Alumni Association's *Award of Extraordinary Merit* for the year 2004. This award recognizes individuals for their contributions over a span of many years that have been of unusual great benefit to the UCLA School of Medicine either directly or by enhancing the reputation of the School through major advances in the medical field. He will receive the award at the 2004 Medical Alumni and Aesculapians Awards Banquet on Friday, October 22. Congratulations Dr. Perloff.



The Physician as Patient Joseph K. Perloff, M.D.

In December, three days after returning from travels to Greece, Russia, Norway, the American Heart Association Meeting in Florida, and the Texas Heart Institute in Houston, Dr. Perloff suffered a sudden heart attack that quickly catapulted him from the role of physician to patient. Following a dramatic 3am trip to the UCLA emergency room, he underwent urgent six-vessel coronary bypass surgery under the skilled hands of Dr. Hillel Laks.

Now, many months later, Dr. Perloff is fully recovered and very mindful of the realities of being a patient with cardiac disease. He and his wife Marjorie recorded their experiences from the patient and family perspective, both good and not so good, in a monograph "Coronary Artery Bypass: A User's Manual" that was published in the July issue of the American Journal of Cardiology. His vivid personal reflections have served as a lesson in empathy to each of us who look after cardiac surgery patients.

We are grateful to have Dr. Perloff back at UCLA in the role of teacher and investigator. He teaches students and post-doctoral trainees in the weekly Wednesday ACHD clinic and continues to be an inspiration to us all.

Patient Advisory Committee

The Ahmanson-UCLA Congenital Heart Disease Center has a relatively new group of people assisting them — the Patient Advisory Committee (PAC).

The PAC was formed to assist the Center in identifying programmatic needs for patients and families and in developing patient support programs and resources. The PAC is composed of ACHDC patients Marty Bieti, Kay Deeney, Tracy Livecchi (Chair) and Beth Kissinger (Co-Chair) as well as ACHDC staff members Mary Canobbio, Linda Houser and Pam Miner.

This past year PAC members helped organize the CHD Awareness Day, assisted with developing the ACHDC website and newsletter, and participated in the Camp del Corazon Family Weekend. One of our members, Marty Bieti was a speaker on a panel addressing the issues of growing up with Congenital Heart Disease.

We have some exciting projects for this next year:

- Continue updating and working on the ACHDC Website:
<http://www.achdc.med.ucla.edu>
- Planning and hosting a social mixer to give patients and their families an opportunity to meet and to get to know each other in a casual setting
- Teen/Family mentoring program
- Coordinating with the Adult Congenital Heart Association (ACHA) to put on a regional meeting

But our small group of people can't accomplish all of this on our own — we **need YOU!** We need your suggestions as well as volunteers to be a mentor. If you're interested, please contact Linda Houser or Pam Miner at (310) 794-9629 or email them at achdc@mednet.ucla.edu.

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IN MEMORIAM

This year we have lost two giants in the field of pediatric cardiology. The Ahmanson/UCLA Adult Congenital Heart Disease Center was privileged to have been the recipient of their wisdom and support.



Samuel Kaplan, M.D. **1922-2004**

In January of this year, we lost one of our most treasured leaders in the field of adult congenital heart disease. Samuel Kaplan was internationally recognized as a pioneer in congenital heart disease, and spent the latter part of his distinguished career as a pediatric cardiologist focusing on adult survivors. He joined the ACHD program at UCLA in 1987 and was an integral part of our ACHD clinic for over 10 years. During his UCLA tenure, he was active in CHD research, as well as in the training of younger generations of pediatric and ACHDC cardiologists.

Dr. Kaplan was a native of South Africa and completed his medical education in Johannesburg. He continued his cardiology training at the Hammersmith Hospital in London in 1949. In 1950, he joined the cardiology department at the Cincinnati Children's Hospital where he became recognized as one of the founders of the discipline of pediatric cardiology. His early research and experiments were instrumental in developing the membrane oxygenator. This is still an essential part of the circulatory support during open-heart surgery in both children and adults. As Chief of Pediatric Cardiology at the Cincinnati Children's Hospital, he was widely recognized as one of the top five most constructive and productive academic cardiology leaders in the U.S.

Dr. Kaplan's wisdom and patience, and his gentle presence and radiant smile will always be remembered by the countless patients and families whose lives he touched. Samuel Kaplan's role in developing the mission and vision of the adult congenital heart disease program at UCLA will be a lasting legacy to each of us.



Arthur Moss, M.D. **1914-2004**

Dr. Arthur Moss was another pioneer in the field of pediatric cardiology. In 1938, he received his medical degree from the University of Minnesota.

He joined the cardiology department at UCLA in 1952 where he held top leadership positions including Emeritus Professor of Pediatrics and Executive Chair of the UCLA department of Pediatrics from 1967-1977. Dr. Moss played a pivotal role in the formation of the UCLA Adult Congenital Heart Disease Center. Upon the arrival of Dr. Perloff at UCLA in 1977, Dr. Moss supported Dr. Perloff's vision of creating a clinic that would care for pediatric patients with CHD once they reached adulthood. Upon his retirement he gave Dr. Perloff the names of all his patients who were 17 and older. These 200 patients were among the first to be included in the Center's registry which now has over 2000 names.

HIGHLIGHTED FACULTY



Ruey-Kang Chang, **M.D., MPH**

Dr. Chang is Assistant Professor in Pediatric Cardiology at the Department of Pediatrics and Director of Pediatric Exercise Physiology

Laboratory at the David Geffen School of Medicine at UCLA. Dr. Chang's research interests include outcomes of children with heart disease, exercise physiology and cardiac rehabilitation. Other areas of interest are physical activity as prevention of childhood obesity and associated morbidities. His exercise physiology laboratory, located at UCLA's Kurlan Heart Center, is one of few laboratories in California dedicated to studying congenital heart disease. The laboratory is equipped with state-of-the-art cardiopulmonary exercise testing systems that measure metabolic parameters and interface with cycle and treadmill ergometers.

Numerous research studies are conducted in the pediatric exercise laboratory. Dr. Chang is the Principal Investigator of a research study funded by the National Institutes of Health on the effects of exercise training in children after heart transplantation or after Fontan operation. This study will investigate the impact of an 8-week exercise-training program on cardiac, pulmonary function, psychological wellbeing, and habits for physical activity. He is also the Principal Investigator of a study funded by the American Heart Association to investigate the physical activity, obesity and coronary risk factors in children with congenital heart disease. In addition, Dr. Chang and his team are conducting pilot studies on the effect of pre-exercise muscle massage on cardiopulmonary function, and the use of yoga as exercise training for adolescents and young adults with single ventricle after the Fontan operation.

Dr. Chang has authored 30 research papers, two book chapters and numerous abstracts in the field of in pediatrics and pediatric cardiology. He enjoys working with students and trainees on research and mentoring junior physicians.

FUND DEVELOPMENT

Annual Fundraising Event

The seventh annual dinner event hosted by the Hertz Investment Group and philanthropist Judah Hertz raised \$200,000 for the Ahmanson/UCLA Adult Congenital Heart Disease Center. Held at Cicada Restaurant in downtown Los Angeles on April 27, the event was attended by more than 200 people.



From L-R: Judah Hertz, The Hertz Investment Group, John S. Child, M.D., Director.

The special evening, which featured Joan Rivers impersonator Dee Dee Hanson as the mistress of ceremonies, honored Stephanie Haymes-Roven, JOWCOL, and the John Coltrane Music Foundation. In addition, this year's theme was "Honoring Our Patients and Their Families" and included a special honor for Ken and Laurie Boyko. Entertainment was Thelma Jones with the Monte Montgomery Quartet.



Special Honor Recipients Ken and Laurie Boyko and children.

"We are grateful to Mr. Hertz and the Hertz Investment Group for their ongoing support," said Dr. John Child, director of the Ahmanson/UCLA Adult Congenital Heart Disease Center and Streisand/American Heart Association Professor of Cardiology at the David Geffen School of Medicine at UCLA. "The funds raised permit us to expand our ability to not only improve care and increase the number of patients we can serve, but also to provide basis for continuing our research and education programs."

The Ahmanson/UCLA Adult Congenital Heart Disease Center is an internationally recognized patient care, diagnostic, research, and educational facility devoted to the rapidly growing population of patients with congenital heart disease who have reached adulthood. Next year the Center will celebrate its 25th anniversary.

GOLD HEART \$10,000+

Anonymous
Mr. Harry Bruni
JOWCOL and the John Coltrane Music Foundation
Mr. Judah Hertz
Mr. and Mrs. Stuart M. Isen
Mr. Anthony Jaffe
Trimont Real Estate Advisors
Mr. Jason Turner, Venbrook Insurance

SILVER HEART \$5,000+

Anonymous
Mr. and Mrs. Kenneth Boyko
Mr. and Mrs. Richard Boyko
Mr. Bruce Karatz
Mr. and Mrs. Wolfgang V. Kupka
Mr. and Mrs. Marvin Mandelbaum,
Mandelbaum Insurance Services
Mr. Todd Morgan
Erzi Namvar
Mr. and Mrs. Charles Roven
Thomas and Helene Spiegel Family Foundation

BRONZE HEART \$1,000+

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Anonymous
Mr. and Mrs. Marc Bohbot, Concept Management
Mr. Arthur Brown
Capdevielle Title Corporation/Sher Garner Cahill Richter
Chesed Foundation
Mr. and Mrs. Gerald A. Ducot
Mr. and Mrs. Simon Elhiani
Mr. and Mrs. Len Fisch
Mr. Jeffery D. Fox
Mr. Selwyn Gerber
Guidant Corporation
Mr. Mario Hernandez, Union Bank of California, N.A.,
The Private Bank-Beverly Hills
Mr. Frank Jansen, Chicago Title
Katten Muchin Zavis Rosenman
Mr. Frederick H. Leeds, Fred Leeds Property Management
Mr. and Mrs. Paul Lentz, California Market Center
Lew-El Properties
Mr. and Mrs. Joe Lumer
Mr. and Mrs. Mark Mandelbaum
Mr. and Mrs. Dan McCoy
Mr. and Mrs. David McEwen
Mr. Michael P. McNamara, McNamara, Spira & Smith
Mr. Forrest Nolin, Advance Building Maintenance
Mr. and Mrs. Gary Winnick, Winnick Family Foundation



Psychosocial Issues Affecting Adults with Congenital Heart Disease: A Patient's Perspective

By Tracy A. Livecchi, LCSW

I've often said that one must have a tough "emotional heart"

in order to endure all the challenges that congenital heart disease (CHD) presents to its patients. I know this only too well being one of the oldest living people born with complete transposition of the great vessels. Like other CHD patients, I have had to cope with receiving overwhelming medical information, experiencing sudden life-threatening symptoms, repeated hospitalizations, countless invasive procedures and a stream of medical bills. It is important for patients, family members and health care providers to be aware that psychosocial issues can exist as a result of the experiences described above. Furthermore, if these issues are not properly addressed they can have a strong impact on a person's medical care and overall quality of life.

This article is drawn from the medical literature, conversations with adult patients and from my own experiences as both a CHD patient and a Clinical Social Worker. While reading this, it is important to keep in mind that not every person with CHD is affected in the same way. The degree by which a person is affected depends on personality, diagnosis, medical history, family attitudes, overall emotional and social support, gender, age and prognosis.

As a result of their medical experiences, some of those with CHD suffer from depression, anxiety and post-traumatic stress. These symptoms can occur chronically or intermittently and can be triggered by a number of situations. Some triggers include re-hospitalization, physical symptoms, or something as seemingly simple as a regularly scheduled visit to the cardiologist. According to one study, panic attacks occurred in as many as one in ten CHD outpatients, compared with 2-6% in the general public (Jackson).

For some of those with CHD, physical

incapacity, scarring and cyanosis can lead to diminished self-esteem and social isolation (Utens). Heartfelt sadness and fright were terms used in one study to describe commonalities among the participants (Gantt). Feelings of loss, struggles over body image and the perception of "being different" from their peers are also experienced by some patients.

In addition to the psychological and emotional issues, many of the studies suggest that moving into a state of independence can also be a challenge for some patients. One study found that those with CHD more often live with their parents than on their own when compared with the general public (Utens). The reasons for this may include perceived or actual physical limitations, medical related interruptions in education and employment, insurance (both health and life), employment discrimination, the level of parental protectiveness and family attitudes.

For most people, the beginning of adulthood signifies the desire to find a significant other. Some adult patients have reported concern about how, when and what to tell their romantic partner about their illness. Since CHD is not always physically obvious to those around them, the information can come as a surprise. There can also be stress dealing with the stereotypes and preferential treatment that are sometimes placed on patients. For instance, throughout my life I found that some people feared my illness—often times treating me with "kid gloves" and lowering their expectations of my abilities. This experience definitely affects the amount of information I offer about my health.

Many women are said to be uninformed about their heart disease and reproductive matters (Gantt). As a result, they may not be aware of their options for birth control, pregnancy and minimizing menopausal symptoms. For some women with CHD, pregnancy can present an unacceptable

medical risk to both the mother and/or the unborn child. For others, with the proper medical management, a successful pregnancy is possible. Both men and women report worrying about passing on CHD as well as living long enough to raise their children (Horner).

After years of clinical stability, many adult patients experience deterioration in their health and ability to function. These patients often feel angry and betrayed by their hearts, health, physicians and families since no one had told them they would have to face cardiac difficulties again (Horner). I know only too well what this is like. Many years ago I was told that I "was cured" by surgery. Now I am being told "we don't know" what my future may hold. That information has had a strong emotional impact on me as it would on any individual.

Many patients feel isolated because they do not realize there are others faced with similar experiences. According to one study, those with CHD "often suffered silently and worried alone" and out of 29 adult patients, 79% of them had a diagnosable psychiatric illness yet none of them were receiving treatment by a mental health professional (Horner). This may be linked to the correlation of CHD and the frequent use of the psychological defense of denial (Utens). My experience has led me to believe that it could also be due to the obstacles encountered in finding a skilled mental health practitioner. Or, perhaps, could it be because some believe their fears to be too overwhelming for friends, family and even health care professionals? Whatever the reason, it is important to know that there are others facing similar circumstances and by reaching out, one can find help. Associations that may be able to assist patients and family members can be found under the "Related Websites" section of this newsletter.

In terms of the psychological and

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Psychosocial Issues

Continued from page 4

emotional issues, I cannot stress enough the importance of having access to affordable mental health services. There are many techniques and interventions that can assist patients in managing their symptoms and maximizing their quality of life. I personally have struggled throughout my life with many of the above issues and I've worked hard on a number of levels to ensure that my chronic illness does not define who I am as a person. Instead, I rejoice in the fact that I am a wife, a mother and a counselor, as well as a survivor.

Finally, we must remember that many of

those with CHD have not only survived, but they have been found to excel in many areas of their lives. Some of the research shows that, in general, we possess enormous resilience (Horner). Emotionally and socially, we appeared to be better adjusted than our peers (Utens). These findings validate my long-standing belief that by living through such adversity, one tends to become more accepting of other people's differences and appreciative of the positive relationships in one's life. On a personal note, I cannot tell you how many times I've craved "everyday" problems. And when those problems do occur, I try to navigate my life with what I see as a gift: a clear perspective on what is truly important.

Selected Bibliography

Gantt, L, Growing Up Heartsick: The Experiences of Young Women with Congenital Heart Disease, Health Care for Women International, 13:241-248, 1992

Horner, T, Liberthson, R, Jellinek, M, Psychosocial Profile of Adults With Complex Congenital Heart Disease, Mayo Clinic Proc. 2000; 75:31-36

Jackson, C, Some Psychosocial Effects of Living with a CHD, The Laurel Wreath, A Publication of the Adult Congenital Heart Association, Inc., Spring 2003

Utens, E, Verhulst, F, Erdman, R, Meijboom, F, Duivenvoorden, H, Bos, E, Roelandt, J, Hess, J, Psychosocial Functioning of Young Adults After Surgical Correction for Congenital Heart Disease in Childhood: A Follow-up Study, Journal of Psychosomatic Research, Vol. 38, No 7, pp. 745-758, 1994

ACHA CONFERENCE

ACHA 3rd Annual National Conference

The Adult Congenital Heart Association (ACHA) is a nonprofit organization founded in 1998 which seeks to improve the quality of life and extend the lives of adults with congenital heart defects. Through education, outreach, advocacy and promotion of research, ACHA serves and supports the more than one million adults with congenital heart defects, their families and the medical community.

This past April, the ACHA held its Third Annual National Conference at the Mayo Clinic in Rochester, Minnesota. It was the largest national conference for the ACHA with over 200 adults



ACHA attendees. Front: Dr. Somerville, Dr. Warnes, Mary Canobbio, RN, MSN. Back: Jim Wong, Anthony Cordaro Jr., Amy Verstappen, Karen McNulty, Robin Layman, Paula Miller, Mary Kay Klein, Kyna Ray, Donna Turransky, Anthony Pugliese.

with heart defects, members of their families, and medical professionals in attendance. UCLA's very own Mary Canobbio was one of the speakers. Some of the topics presented over this 3-day meeting included the future of valve repair and

replacement, breakthroughs in congenital cardiac care, insurance obstacles, and reproductive issues. Attendees also had an opportunity to view a couple of films on CHD including "Open Hearted," a patient's perspective documentary about Marc Ostrick's third open-heart surgery.

The next national conference will be held in 2006 in the San Francisco area. Plans are underway to hold one of three

regional conferences in Los Angeles. The dates and location for the 2005 Los Angeles Conference will be announced on the ACHA website at www.achaheart.org.

To become a member of ACHA, visit their website and click on the "Join ACHA" link. The Southern California ACHA representatives are Marty Bieti and Donna Smith. They can be contacted via email at mwbieti@achaheart.org and djsmith@achaheart.org.

RELATED WEBSITES

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/

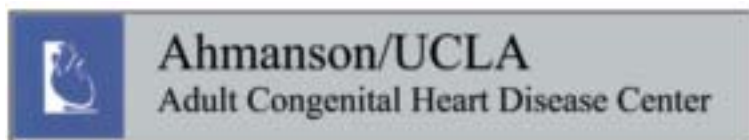
Congenital Heart Information Network (CHIN)
www.tchin.org or call (215) 493-3068

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

The 32nd Bethesda Conference 2000 proceedings
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



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FUNDRAISING 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
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Assets that can be given

- Cash
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- Real Estate
- IRAs and Pensions

To learn more about these and other ways you may give a gift of a 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 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.