



The Laurel Wreath

A Publication of the Adult Congenital Heart Association
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Every year in the month of April, thousands of people flock to Boston, Massachusetts to watch or to take part in the annual Boston Marathon. The marathon covers a distance of twenty-six point two miles from Hopkinton, Massachusetts to Copley Square in Boston. It is one of the most popular marathons in the world. The winner gains a great amount of money and on his or her head is placed a Laurel Wreath. The Laurel Wreath is an emblem of honor and of achievement.

There are many who deserve a Laurel Wreath, but they are unknown to the world. They are people who are running in their own marathon. It is not a marathon that will end in 26.2 miles; it is a marathon that will last a lifetime. It is not a marathon for money or reward; it is a marathon that is run to stay alive. They are people who have Congenital Heart Defects - CHD. Every year that they live is cause for a Laurel Wreath.

This newsletter is a Laurel Wreath for them.

---Judy Norwood (Tetralogy of Fallot)

ACHA Board Meets in Newton, Massachusetts

The ACHA board had its first annual meeting on June 12, 1999. Members of the board are pictured to the right.

Karen L. Klein is the President of ACHA. She works full time in Boston College's O'Neill Library, and is pursuing a master's degree in library and information science part time at Simmons College.

Anthony R. Cordaro, Jr. is the Vice President of ACHA. He is a pre-med student at the University of Texas - Austin.

Mary Kay Klein is the Clerk and Treasurer of ACHA. She is Karen's mother. She has a doctorate in philoso-



From left: Tony Cordaro Sr., Bonnie C. Paulsen, Kimberly C. Ochs, Karen L. Klein, Mary Kay Klein, Anthony R. Cordaro Jr.

phy and is the President of the Swedenborg School of Religion.

Bonnie C. Paulsen is the founder and co-editor of the Laurel Wreath. She is also a nursing student at Boston College.

Tony Cordaro, father of VP Anthony, is the President/C.O.O. Atlantic Pacific Communications, an interna-

tional cabling company with headquarters in Houston, TX.

Kimberly C. Ochs is a graduate of Boston College, where she was the co-chair of the AIDS Awareness Committee. She has a masters in sociology and currently works for a venture capital firm.

Interview with Michael J. Landzberg, MD

By Diane C. Clapp

Diane Clapp, our co-editor, recently had the chance to speak with Dr. Michael Landzberg, head of the Boston Adult Congenital Heart (BACH) Service. Here is what he had to say:

DCC: What is BACH?

MJL: BACH is an acronym which stands for Boston Adult Congenital Heart group or service. About ten years

ago, a bunch of cardiologists at Children's Hospital, including myself, decided that the way we in New England were caring for young adults who had grown up with congenital heart disease was not all that it should be. We felt that we were not prepared to deal with teens and adults with congenital heart disease as effectively as we dealt with them when they were kids.

DCC: Who or what makes up BACH?

MJL: BACH is made up of about 4-5,000 regularly seen patients and their

families, as well as thousands more people we deal with on a referral basis. There is an inner core of about a dozen

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A Measure of Peace

By Troy L. Meinke

In the Spring of 1991, I found myself in a hospital emergency room. This is a familiar setting for a individual with a CHD. The surroundings were the same, just a different hospital in a different town.

I had struggled throughout childhood and my early teen years constantly wondering, often aloud, "Why God why?" I knew other children who went to school all year. They did not have to spend weeks at a time in the hospital because a common cold turned into pneumonia. They could play outside in November and did not have to observe the street games from the garage bundled in a lined jacket. The whole process

seemed very unfair. These thoughts were all the more difficult when one had been brought up to believe in an all powerful God who could perform miracles at a moment's notice. Surely, I figured, He would consider my situation worthy of a miracle.

After my early teens the speculation slowly gave way to anger. As I got older, I discovered that my mother had been right, there were many things I could not do. Society limited my access due to fears about my health, fears that were realistic and many that were not. The heroic doctors that my mother often spoke of as I was growing up no longer seemed to have imparted a gift on me, but a curse. I often wondered if they really had given any thought to the life I would have after they quit patting each other on the back telling themselves what a great job they had done. I was sure of one thing--none of them had a congenital heart defect. However, since the only alternative to living with a heart condition would be to have not survived, most of these thoughts were just mental exercise.

In college I found much needed solace in alcohol. They wouldn't let me in the army, they wouldn't let me play sports, I could not get insurance, but they would let me drink. And drink I did. Though I know of no studies, I think to a large degree I (and maybe many CHDers in general) suffer from a form of Post Traumatic Stress Disorder. Years of being in school one day and being wheeled down a hospital corridor the next had taken a mental toll. Children with congenital heart defects undergo traumatizing stress, hoping one day to be chosen for the kickball team and the next day praying to God to be delivered through one more surgery. And if it isn't obvious by now, self pity was a permanent fixture along with the alcohol.

So in the Spring of 1991 I found myself in the emergency room. No, I wasn't there because of tachycardia or bradycardia (none of the "cardia" varieties); my truck had been struck by a drunk driver. This was three weeks before my college graduation; I was on my first date with the passenger. My truck had rolled one complete time after being struck (it ended on its wheels upright with me hanging half in and half outside).

My date had been life-flighted (in the Texas Hill Country this means a helicopter takes you to the BIG city where the *real* doctors are). The police were certain that I was drunk as well. They read me my rights and questioned me as much as the nurse would allow them. However, that night I was not drunk, yet. I had worked a late shift and so my evening had started late. I had a case of beer in the truck at the time of the accident and certainly planned to float my liver well before the night was over.

In the emergency room, a single realization kept running through my mind, my life had been spared **AGAIN**. I hadn't been wearing a seat belt and had survived the accident with minor cuts and a lot of bruises. The fact that the truck had not landed on top of me was a miracle. I knew that the problems that I currently had were those of my own doing.

I began to see a different God than the one I had been looking for. I looked back and saw a homebound teacher whom I admired, an uncle who had treated me as a real person (not just a heart condition with a person attached), and a Sunday school teacher that took the very few opportunities I allowed him to remind me of a better way than the current self-destructive path I felt I needed.

Why are some children born with heart defects? I do not know. Why was I born with a heart defect? I do not know. I know that God (however you perceive Him/Her) has slowly guided me through the challenges of having a congenital heart condition. My life was spared despite many operations as well as a crippling self pity that I inflicted upon my psyche over the years. I will be honest-- that night in the emergency room, the earth didn't move, I didn't see Jesus by the Coke machine, and the mop bucket didn't glow. However that evening my "congenital mental condition" began to catch up with my improving congenital *heart* condition. And it began with a realization that God would not do to me what I had been doing to myself.

You may e-mail the author at Tlmeinke@aol.com

Contributors

Editors: Diane C. Clapp &
Bonnie C. Paulsen
Copy Editor: Heidi L. Wilkinson
Layout: Karen L. Klein

Writers:

Susan Fernandes, PA-C
Karen L. Klein
Troy L. Meinke

Interview Team:

Interviewer: Diane C. Clapp
Editors: Karen Klein, Myriah
Klein, Mary Kay Klein, Heidi
Wilkinson
Transcription: Mary Kay Klein

Special Thanks to:

Nick and Jane Alfieri
Phyllis Brooks
Diane C. Clapp
Eddie Evans
Susan Fernandes, PA-C
Anna Jaworski
John and Myriah Klein
Michael J. Landzberg, MD
Robin J. Layman
Sheri Maxwell
Signal Graphics, Inc.
Laurie Tobin, Esq.
Michele Eileen Tutalo
Burton and Esther Weinstein
Karen Zimmerman

Endocarditis – Top Five Questions Every Adult with Congenital Heart Disease Wants Answered

Susan M. Fernandes, MHP, PA-C
Boston Adult Congenital Heart Service
Children's Hospital and Brigham & Women's Hospital, Boston, MA

1. What is endocarditis and how do I know if I have it?

Endocarditis is an infection of the heart and blood vessels, which carried a high risk of death and permanent damage before antibiotic treatment was available. Although endocarditis is always caused by bacteria that enter the bloodstream, only a small fraction of such infections are preceded by dental work or surgical procedures. Bacteria often enter our blood stream when we brush our teeth or chew food; the worse the state of our teeth and gums, the more bacteria enter our blood stream. This is why it is especially important to see a dentist every six months.

Endocarditis may present with flu-like symptoms that go on for a while with poor appetite, muscle and joint aches, weight loss, low grade fevers and/or nightsweats, or the symptoms may include an acute onset with high fevers, shaking chills, vomiting, and/or unusual rashes. If a low-grade fever is present for more than a few days or a high fever is present and there is no clear source of fever (e.g., sore throat, bad cold, etc.), then blood cultures must be drawn **before** antibiotics are started. This is especially important for patients with heart conditions at high risk for endocarditis (see below). (1)

2. Are all ACHD patients at the same risk of developing endocarditis?

There are predisposing factors that put some people at higher risk than others of having endocarditis. The risks of developing endocarditis are broken down into three groups- high, moderate, and low.

High Risk Category include, in part:

- Prosthetic cardiac valve
- Prior history of endocarditis
- Cyanotic congenital heart disease
- Surgical shunts from the aorta to the pulmonary artery

Moderate Risk Category include, in part:

- Most congenital cardiac malformations
- Valvular heart disease

Low Risk include, in part:

- Unrepaired atrial septal defect
- Repaired atrial or ventricular septal defect
- Repaired patent ductus arteriosus

The above categories are from the AHA Scientific Statement, Prevention of Bacterial Endocarditis.
Recommendations by the American Heart Association.

Most people with congenital heart disease will need to take antibiotic prophylaxis prior to dental and/or surgical procedures. If needed, the type, the delivery method (pill or intravenous), and the procedures for which it will be needed should be individualized. One should discuss this with their health care provider who will often give recommendations in writing that can be brought to all health care professionals. (2) (3) (4)

Continued from page 3

3. Can I avoid endocarditis by avoiding the dentist?

No. Although dental work can sometimes be a precipitant to endocarditis, most health care professionals believe that just as many cases of endocarditis, if not more, are caused by poor dental hygiene. Avoiding the dentist actually increases the risk of endocarditis.

4. Do I need to take antibiotics before body piercing or tattooing?

This is a very controversial topic. Most physicians have seen a case of endocarditis following body piercing and/or tattooing, but a single published report shows that the incidence may be very low (5). Since taking antibiotics prior to these interventions is relatively simple, our service does advise taking antibiotics to lessen the potential for the profound ramifications of endocarditis, although we have no data to support this recommendation. If one chooses to body pierce or tattoo, it is important that the skin be well cleansed beforehand. If redness, swelling or discharge is noted, then one should be seen by one's primary care provider without delay. There are no published reports showing the correlation between the part of the body that is pierced and the risk of endocarditis.

5. Does sexual intercourse put me at risk for endocarditis?

There is no evidence either negative or positive that vaginal, anal, and or oral intercourse puts one at risk for endocarditis. Unprotected sexual intercourse does put one at risk of developing sexually transmitted diseases including chlamydia, gonorrhea, HIV, hepatitis, etc. There have been reported cases of endocarditis caused by chlamydia and gonorrhea. (6)

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Future Issues

If you are interested in writing articles for *The Laurel Wreath*, we would love to hear from you. We are interested in articles from medical professionals and from adults with CHD. Stories about personal experiences, photos and original artwork would be welcome. Please include a self addressed stamped envelope if you would like photos and artwork to be returned.

All submissions should be mailed to:

**The Laurel Wreath
c/o Diane Clapp
308 Matfield St
West Bridgewater MA 02379**

Submissions may also be submitted to
Diane via e-mail at **DCC8@aol.com**.

Submission deadlines are:

- October 1 for the Fall Issue
- January 1 for the Winter Issue
- April 1 for the Spring Issue
- July 1 for the Summer Issue

Possible topics include:

- Travel
- Using oxygen at home
- Transplants
- Specific defects/procedures

Continued from page 1

people who work alongside the two physician assistant co-ordinators of the program: Sue Fernandes and Disty Pearson, both of whom run the day-to-day workings of this group on an inpatient and outpatient basis. Besides that, there are at least two dozen other consultants from all aspects of life who help patients to deal with issues as they arise.

DCC: *Are there other groups like BACH in other parts of the country?*

MJL: BACH is one of probably a dozen leading adult congenital heart groups throughout the world. Throughout this country and Europe there are many wonderful ACHD centers. There is now an international society which tries to bring all of these groups together, thereby promoting the well-being of adults who have been born and raised with congenital heart disease, and are dealing with it in their adult years.

DCC: *What are the future goals for BACH?*

MJL: Everything we're about has to do with quality of life for the people we take care of.

The goals of BACH are to provide that we don't look at somebody as just their heart, but as a unique individual with unique problems, and to be able to help solve those problems with new treatments, real cures, better support. That's the global picture, without getting into the medical subspecialties and the niches that we have.

DCC: *How is BACH funded?*

MJL: BACH is a self-sustaining, self-supported, multi-institutional, multi-hospital, multi-specialty group. Hospital staffs work together to keep it running, aided by the fees and dues paid by patients and/or their insurance cov-

erage for individual visits. It's long been said that adult patients who have congenital heart disease have not been able to be fully insured for all of their medical care. We've been blessed in that our patients, our friends, have tremendous spirit and ability, and so they have fought to the extremes of ensuring that they have appropriate medical coverage. Also, our state has blessed us with a wonderful free care program. Not that we've needed to take advantage of that very often. We have a very high rate of personal insurance that has been able to be maintained for our patients so they can afford the care. Nonetheless, our hospitals have guaranteed to us that if people lose medical insurance they will never be denied the very best care that we can provide.

The BACH Group is dedicated to providing long-term optimal continuous care to its patients. Brigham and Women's Hospital and Children's Hospital, through this framework, are committed to these ideals. As appropriate, if someone does not have insurance, they will be asked to pursue all options of insurers or medical financial assistance. If insufficient options are encountered, then the hospitals and medical caregivers will work out a payment system that will work with each individual and family, so as to ensure that no patient will be forced to jeopardize optimal health care due to financial reasons.

With regard to patients from elsewhere, seeking treatment, or advice via BACH-we will always arrange for medical consultation, either with direct contact or through review of medical records, for any person who could benefit from such. Similarly, if we feel that any person could greater benefit from the services of BACH than those of another regional center of excellence,



Michael J. Landzberg, MD
Boston Adult Congenital Heart Service

then no therapy or level of care will be denied at any time, (based upon the above outline).

DCC: *Anything you would like to add?*

MJL: With regard to anything else: I think that there's not one of us at BACH that doesn't come into work every morning saying, "I couldn't imagine a better job that I could have," and we don't always see it as a job. It is also, "I couldn't imagine a better way of fulfilling our lives." Each one of us here has a tremendous respect and admiration for every person whom we work with and take care of throughout the country. Our patients-what they've endured, their outlook on life, their ability to see the larger picture in life, their determination, their ability to get through issues that most of us wouldn't have a clue on how we could address-is what we all strive to take with us as we see each patient, as we try to come up with something new and better to guide their lives. I think that if we never lose that perspective, we will continue to achieve every goal that BACH is about.

Thanks for having me.

Contact ACHA

ACHA offers a variety of resources, such as support group information, bibliographic resources, clinic listings and information on summer camps, on its website at: <http://www.adultcongenitalheart.org/> Printed copies of our resources lists may be requested by writing to:

ACHA
c/o Mary Kay Klein
273 Perham Street
West Roxbury MA 02132
USA

Erratum

A correction is in order concerning the "BT shunt" to which Thursday Girardi alluded in her article ("Life in the Slow Lane," Spring 1999). The editor's note should have read Alfred Blalock, not Robert Blalock.

A Message from the President

By Karen L. Klein

ACHA's board had its first annual meeting this June. It gave us the opportunity to discuss our current and future directions. ACHA's purpose is to educate the public, adults with congenital heart disease, and the medical community about adult congenital heart issues. We also want to link adults with congenital heart disease together for the support and emotional gratification that comes from having contact with others who have had similar experiences.

The ten months since ACHA incorporated have been a busy time. The response to ACHA has far exceeded our

expectations. Our mailing list now includes approximately 140 individuals, organizations and clinics. Our website is viewed by people from roughly 40 countries each month, and it received about 12,200 visits in July 1999. It is always a thrill when a new membership form comes in or a new country visits the site.

One of the goals we talked about was expanding the layout of the newsletter. This issue is the first to be printed in the new format. It also has the first in what we hope will be a continuing series of articles involving healthcare professionals. Our other goals include publishing pamphlets and information sheets as well as holding a national conference.

I would like to thank the members



Karen, her boyfriend James, and Tina in Chicago-May, 1999

of the board, all of ACHA's members and donors, support group leaders, and all the professionals who have helped us during the past two years. Your support has meant a lot and has made ACHA possible.

Third Annual Gathering at Uno's Pizzeria

By Diane Clapp and Sheri Maxwell

The third annual ACHD gathering was held at Pizzeria Uno's in Dedham, Massachusetts on August 7th, 1999. These gatherings began in 1997 when Sheri Maxwell, the AOL ACHD chat co-facilitator, came to Massachusetts from Texas for her daughter's skating competition. Traveling here gave Sheri the opportunity to meet Diane Clapp, her co-facilitator and the founder of the chat, for the first time. It also gave Sheri and Diane a chance to meet other chat members who live in the area or were able to come to Dedham for dinner and conversation.

Six chat members and three guests met at Pizzeria Uno's that day. The outing was so successful that another was scheduled for the following August. Nine ACHDers and six and a half family members (including Martin Miller's pregnant wife Linda), drawn from the membership of the Boston Adult Congenital Heart (BACH) Support Group and the AOL chat, made merry at Uno's.

This year's gathering involved eight ACHDers from the AOL chat, the BACH group and the ACHD listserv,



Back Row (l-r): Nick, Karen, Tanya, Martin. Front Row (l-r): Laurie, Heidi, Sheri, Diane.

and nine guests. These meetings have turned out to be wonderful experiences, and have forged some lifetime friendships. If you have had such a meeting in your area, the ACHA would love to

hear about it. If you are interested in future gatherings in Boston, please contact Diane Clapp at 308 Matfield St., West Bridgewater MA 02379, or via e-mail at DCC8@aol.com.

Heart of a Mother, a book of essays by mothers and grandmothers of people with CHD and mothers and grandmothers who have CHD, has just been released by Baby Hearts Press.

For more information on the book or to order, please contact:

Anna Jaworski
6618 Sunrise Drive
Panama City Beach FL 32407
Phone: 1-888-222-4649 (toll free), or see
<http://www.babyheartspress.com/>

