

TO KAREN MCNULTY

by Donna Turransky

Karen (Klein) McNulty was a co-founder and the first president of the Adult Congenital Heart Association. She was also the first chairperson of the newsletter committee and was one of the original editors of this newsletter and Co-Chair of the first ACHA national conference in September 2000.

Karen passed from our world on August 31, 2005. The suddenness of this is still overwhelming for her husband James, her parents and brothers, friends and the many others who were touched by her. So many expressions of love and words of appreciation and generosity have been made since that day. Some of these will be shared in this edition of Heart Matters.

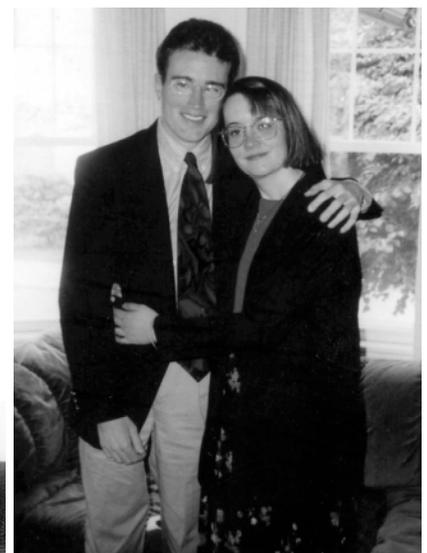
Karen was kind to us all in many ways. Reading the posts on the ACHA message board, one message highlighted this. The person spoke of the Christmas cards Karen had sent even though they had never met in person. She said that there would be a void this Christmas without that card. Many people on the message board voiced how grateful they were that Karen had helped to start the ACHA because they got to meet others like themselves and see that they were not alone in the world.

There are other things that Karen will be remembered for. She was a wife as well as a daughter, sister and aunt. The words "awe inspiring" come to mind when thinking of Karen. The inspiration for this may have been witnessed at Karen's funeral when her mother, Mary Kay Klein, gave the eulogy. Mary Kay told the mourners that she would remember the love Karen shared with her husband James. "She loved him more than I can express. The years with James were the happiest of Karen's life. Their beautiful marriage makes her sudden and untimely death all the more devastating." Mary Kay told us that Karen was a fighter. "As most of you know she was born with a serious heart defect, a CHD. She was very little and very ill. We were told that she would never walk never be strong enough to go to school...but with the help and prayers of many people...Karen got stronger instead of weaker as she grew older. I was so proud of her as she went to her first day of school. She later graduated from high school, from Boston College and Simmons College with a Masters Degree in Library Science. She loved her job as a librarian (her official title was digital resources reference librarian and bibliographer) at Boston College and being part of that community."

Mary Kay also told those gathered about the emails she received, "Her best friend from Ohio (where Karen was born), Alicia Titus, was a flight attendant on one of the planes that hit the World

Trade Center on 9/11. Karen reached out to Alicia's family after her death. After Karen's death Alicia's parents wrote to tell us, 'Karen was a special angel who brought much to us all in the way of hope, compassion, peace and goodness.' Linda Miller wrote to me about how Karen helped her after her husband Martin died. Martin also had a congenital heart defect, and was very involved in the early stages of ACHA. Linda and Martin have a wonderful son, Ben. Linda wrote 'about 2 years ago Martin's computer crashed and I lost all of his correspondence. I told Karen about it and she went through her archives and emailed me all of the correspondence that Martin had with her. Included was Martin's first email to her introducing himself and telling about his story with CHD and growing up with CHD, a letter that I will cherish because it is in his words and when Ben grows older he will be able to read them'. It was so like Karen to do something like that."

I would like to echo Mary Kay's last line of her eulogy. "As I reflect on Karen's life today there are three things that are important to me. I am thankful that God created this special person and for the years we had with her. I am grateful that she showed us how to live every moment of life to the fullest and to make the most of what we have as she did right up to the end. If you can hear me Karen, what I'd like to say: well done kiddo, well done..." In this dedication we have reprinted Karen's first President's Message. As you read those words remember the inspiration and awe that was Karen McNulty.



left: Karen with her niece, Willow.
Above: Karen with her husband James McNulty.

A TRIBUTE TO MY COLLEAGUE, FRIEND, AND SPIRITUAL ASSOCIATE, KAREN MCNULTY

Dr. Kwasi Sardokie-Mensah of Boston College

photo provided by Boston College



I made sure to let Karen know that she was a colleague. I think sometimes when we know people in a different capacity before they become librarians, we tend to look and treat them as interns, or whatever positions they were in before. It was important for me to let Karen know that. So after a few minutes on the first day, Karen asked, "But can I ask you questions when I have them?" And from then on we asked questions of each other and talked about everything under the sun.

One Friday, I had so much energy after working out I was putting on my right foot sock I ripped it into two unequal pieces. I had a presentation at Noon. I decided that if I sat down through the presentation, my ripped sock would not be the center of attraction for the students. So I get into the office, say hi to Karen, and sit down to prepare my handouts. I heard Karen say, "Kwasi, I think you need a new pair of socks." So that was the end of my plan to sit down during the presentation. I made sure that I put the projector and laptop bags on the instructor's seat to avoid any temptation of sitting down. Thanks Karen.

One thing that my pastor says in Church is, "You better be careful what you ask of God. You may get it." Well with Karen, it is you better be careful what you ask of Karen because you will get it RIGHT away. If you worked with Karen on a committee, or on an individual basis you know that she did not like wasting time at all. Time was of essence to her, and came through in all her dealings—work with students, work with faculty, work with fellow librarians, work with everyone.

I sent an e-mail to all library subject specialists to send me their business cards that I was to place on the table at the graduate student open house. The e-mail went out around 10:30AM. At 10:33, Karen was in my office with a bundle of her business cards all nicely wrapped up with a rubber band. I said "Karen, I just sent out the message". And she said "I know—I just received it. Here are my cards." Of course one of the most painful things I had to do on the day of the open house, September 6, was to keep that pile inside my pocket. So painful.

Karen did a fair share of instruction classes. I was always amazed at the amount of time and effort she put into preparing for these classes. In fact the day before Karen passed away, I was using one of the big study tables in front of her desk to assemble the handouts for the graduate student orientation. She pulled up a seat, helped me with my handout assembly, and started talking to me about the class she was going to do for Father Blake on September 22, I think. I said, "Karen, the class is about three weeks away". Then she said, "I have everything ready to go for the class. I will send you the link, and you can tell me what needs to be changed 24 days ahead of time". And she was so excited about doing the class. You would think the class was the next day. That was the Karen I knew. Always prepared. Always

ready to go. As a devoted Boston College citizen, Karen was on duty all the time. It could be an e-mail message very late at night, very early in the morning, or just teaching a class after 5PM. She was on duty all the time.

A colleague, Mark sent me this e-mail about Karen. "Michelle has asked Karen for help finding videos, but also she told me that she was looking for some Star War figures for a friend's birthday. Not only was Karen happy and ready to help with finding the videos, but she also went to Toys R Us with James that evening and found the figures for Michelle and purchased a few for herself and James". In Mark's words: "Perfect example of the loving, generous and helpful person that Karen was."

When I think of Karen, I always think of this individual who loved everyone. But I also was fascinated by her fascination for children. Several people here may have received Karen's last e-mail—pictures of Ellen's children. Karen's e-mail has a date stamp: Tue 8/30/2005 2:56 PM.

When I first started my program for the children in Ghana, one of the things I asked people was to pick up any pens and pencils they found as they walked across campus, because I could take these to Ghana and give them to the children. So many times people dropped off all kinds of materials that we were able to take to Ghana. There was not a single week that Karen did not bring something in for the children of Ghana; pens, pencils, appointment books, telephone chords, network adapters, and freebies from the American Library Association. The week of her passing she brought back two photo albums that she had taken from Cleansweep with a note one on my desk and the other by e-mail, "I am sure the children in Ghana could use them".

I will now conclude with these words, Karen, and it is about the things we had in common regarding our faith.

Karen, you and I shared many moments of our faith and belief. You and I were never afraid to talk about some of the issues that surrounded our faith—the hopes, the fears, the challenges, and even death. I mentioned to you how burying my Mom gave me so much energy and took from me forever the fear of death, for why will a person who believes be afraid of death? Your answer was "Your Mom does not want you to die now. We all have a lot of work to do in this world." Yet you just left all of us, Karen. May your love always stay in our hearts. May your smile forever remain indelible on our faces. May your kindness forever be our strength and our hope, and may your courage continue to be the wind beneath our wings. We are weak now from your death, but your spirit is aflame in us. It propels us to always live each day as if it was the last day of our life. Thank you Karen.

When I came back from my Mom's burial, I walked around humming a tune. You once asked me what that tune was, Karen. In Ashanti it goes: "We thank you, our best friend. We praise you our best friend. May God take you home safely."

Let me sing that song for you, Karen.

Messages

Karen McNulty's vision of a national organization for adults with congenital heart disease, her passion for our cause, and her tireless dedication were instrumental in building ACHA into the organization that it is today. She will be sorely missed.

Jim Wong, Board Chair, ACHA

Karen McNulty was a truly extraordinary person, who never let her cardiac issues get in the way of what she wanted to achieve. Kind, thoughtful, capable, level-headed, and deeply intelligent, she was also just a terrific human being. She taught me a tremendous amount about bravery and hard work. As an organization, ACHA owes its solid foundation to Karen's vision, intelligence, and dedication.

Amy Verstappen, President, ACHA

Karen touched the lives of all she met. I knew her as an advocate for ACHA and as the wife of one of my patient's. She brought the same zeal to her work with ACHA as she did to the rest of her life and her marriage. She inquired, she asked health care professionals to perform at their best, she would not take "no" for an answer, she asked much of herself, she asked the questions that could not be answered. She brought enthusiasm to the infancy of ACHA. She helped me understand the world and the perspective of the "unrepaired" adult with congenital heart disease. My life is better for having known her.

Dr. Frank Cetta

Karen Klein McNulty, my friend, my patient, my hero, always remarked that her world was much larger than any of us could ever imagine. Her impact on neighbors, family, companions, fellow adults with congenital heart disease, and the world at large was soft in demeanor and yet strong in its building of mission and confidence. With heartfelt sadness, personal loss, and with deepest admiration for her goals and determination, we all miss Karen. There was no one that connected with her who was not influenced by the opinions, hope, inspiration and strength displayed in tandem by Karen and her soul mate and spouse, James. There is clear recognition that the entire field of care for adults with congenital heart disease has been moved forward and for the better by the dreams and work of my friend, Karen Klein McNulty. Hopefully we all continue these dreams and works to expand our world.

Dr. Michael Landzberg, Director, Boston Adult Congenital Heart Center

It's been a little more than a week since Karen's mom called my mom and told us about her sudden passing. Right away my mother broke down in tears, but I just sat there in total disbelief. I didn't know what to do. So I got on the phone and called some mutual ACHD friends of mine and Karen's to give them the news. I did not want them to read it on the Internet.

It wasn't until the funeral service when I finally broke down and cried. You see the funeral was at the same church where Karen and James got married. I was Karen's maid of honor, which WAS an honor.

I found Karen to be one of the most intelligent people I have ever met. A fact that I found a bit intimidating and yet very useful. If someone asked me a question about CHD and I didn't know the answer I knew Karen would. If I had a problem with my computer Karen would help. Whenever I tried to write something to the old list service or for the newsletter I would send it to Karen first. She would fix any grammar, or spelling errors. (I sure could use her now.)

I didn't realize when I met Karen in 1997 the effect she would have on my life and all of us ACHDers. It will be up to all of us to make sure that the ACHA organization continues on. And stays on the track of her and Anthony's dream of being an organization for ACHD, and run largely by ACHDers.

There is a TV show on Bravo called, Inside The Actor's Studio. At the end of the show they always ask the celebrity what would they want God to say when they got to heaven. Well I know what God said to Karen... "You did good kid!!"

Karen, I will miss you very much.

Diane Clapp (DCC8) September 8, 2005

Messages

I wanted to write just a little bit about Karen as one of the "old timers" who remembers her when the ACHA was just a vision. Karen happened to stay at my house after an initial visit to Anthony Cordaro in Austin TX wherein she described discussions she had had with him regarding starting a national organization for adults that would be an advocacy group for all of us. I will never forget the spark in her eyes and the determination she possessed and the sheer single-minded purposefulness she displayed in moving forward and not letting it remain a "pie in the sky" dream. I envied her "youthful" enthusiasm but never dreamed it would go on to become all that the ACHA has become today. This same visit also saw a "spark" of a different kind happening between her and James in IM's online. They met in a chat started on AOL by Diane Clapp and co-hosted by yours truly and watching them become a twosome was also something. My heart goes out to James and Mary Kay and Ted and the rest of Karen's family – the loss is staggering to say the least. For us, as a community, Karen leaves behind a huge legacy of volunteerism, dedication and an organization that will continue to advocate for adults with congenital heart defects long, long after all of us are gone, That's quite a thing to say about someone who was only 31. A short time on earth – but a legacy that goes on and on. I'll borrow words from Oprah Winfrey – she truly lived her "best life." *Sheri Maxwell (Texas Sheri)*

I will always think of Karen and chuckle as she told her tales of how to walk with someone, not let on that she was short of breath, but get them to stop and look at an interesting plant or bird long enough to catch her breath. I love that story particularly as it not only showed her great sense of humor, but the tremendous will and determination to be all that she wanted to be with very few accommodations. Even when she allowed herself accommodations she made them so subtle that one would not even know that it was not really the flower or bird that was of interest, just the time. Karen was and is a tremendous inspiration to all who believe in people being treated equitably. She was a model of persistence, working continuously and only accepting the absolute best - first from herself and then from others. She brought the ACHA into a new age with the first international conference here in Boston. Her efforts will benefit others for many years to come and the ground work she developed is the strong foundation from which the ACHA will grow. It is from the people that we have the honor to guide that we learn the most. Thank you Karen. *Disty Pearson PA-C, Boston Adult Congenital Heart Center*

This is a reprint from the first edition of the ACHA newsletter formerly known as The Laurel Wreath printed in Fall 1998.



A message from the President by Karen (Klein) McNulty

I am one of the approximately one million people in the United States with congenital heart disease. There are many different forms of CHD, ranging from mild to life-threatening. CHD is a largely invisible condition. The restrictions it has imposed on my life, and the lives of all of us with CHD, are often not obvious to the rest of the world.

Growing up, I often felt alone as I did not know other people with CHD. It was not until I joined the adults with congenital heart disease (ACHD) email listserv, sponsored by the Children's Health and Information Network (CHIN), that I was really able to connect with other adults with CHD (ACHDers).

I had been on the ACHD list for a week or so when I started corresponding with Bonnie Paulsen. We quickly became close friends, and she introduced me to the ACHD chat on America Online (AOL). She also is the person who proposed starting a newsletter for ACHDers. I was excited about the idea and offered to help. We were joined by Anthony Cordaro Jr., whom we had met through the listserv and chat. We soon discovered that existing CHD organizations focus primarily on parents of children with CHD, and on the needs of small children. The three of us made a decision to start an ACHD organization, called the Adult Congenital Heart Association. The ACHA hopes to address ACHD needs through publishing a newsletter, forming support groups, establishing a web presence, and maintaining a national ACHD resource directory (including clinics, camps and bibliographic sources). The newsletter is already posted online at www.adultcongenitalheart.org/laurel.html. We also want to educate the general public about CHD, and encourage more research.