

A Man with Heart

by Emmeline Domingo

It's just past noon on a warm Wednesday in early January, and Ron Wilson is sitting at a table outside the campus Starbucks. Ron does not drink coffee; he is meeting a former student of his, Henry, who is in line waiting for his drink. Ron considers Henry a son, in fact, Ron has "adopted" many students who grew close to him while he worked as UCI's campus ombudsman. Students with troubled living situations have even stayed with Ron and his family at their home. He has been a *ninong* – godparent – at several weddings of his Filipino students, and Henry adds, will be a *ninong* at his own later this year. Henry sits close to Ron to hear him above the lunchtime bustle, his voice, although upbeat and cheerful, sounds strained, like someone getting over a case of laryngitis. This is because, in 1988, Ron underwent surgery to repair his aorta, in which one of his vocal cords had to be cut; this is just one instance of Ron's complicated medical history.

Despite the soft hoarseness of his voice, Ron loves to talk. His genuine character can be detected the moment upon sitting down with him. It seems he could be intimidating if he wanted – standing tall at 6'7" – but this isn't the case. It doesn't take much to get Ron's attention and once you have it, he speaks with you as if you are the only person around. His kind focus and calm demeanor are what made him so fit for the job as UCI's campus ombudsman. Former colleague and longtime friend, Professor William Schonfeld comments, "Ron did his job as ombudsman better than anyone before or after him, he had a large presence on campus that didn't come from his height." Now, most UCI students are not even aware that the campus ombudsman even exists. Schonfeld adds, "Seven years ago while Ron was still working here, you would have known who the campus ombudsman was. With that position, he was confronted with the task of ameliorating problems with anyone associated with the school; faculty, students, etc. But he never waited for problems to come to him, he didn't sit in his office, he was always out and about,

talking to people, making sure things were running smoothly. He has the amazing ability to listen, and to make people listen; that's what made him so great at his job.”

Former colleagues always beam while recalling Ron's accomplishments at UCI, claiming that the university would have been different if not for him. However, when asked himself what UCI would be without him, Ron humbly responds, “All my experiences here, and all the people I've met have enriched my life so much... What would I be without UCI?” Ron now holds the title of Assistant Vice Chancellor Emeritus; campus ombudsmen are rarely given this title upon retirement.

However, as an African American youth growing up in the crime ridden neighborhood of Harlem, New York, Ron did not have a linear path to such a successful future. After dropping out of high school because of his dangerous environment – characterized by drugs and gang violence – Ron worked as a mail clerk. He worked under a man named Turk, who became his good friend and mentor. Turk encouraged Ron to go back to school to pursue a college degree. Despite being too poor to afford a college education, guidance from Turk, and a renewed sense of determination allowed Ron to complete two BA's in three years at Bard College, with majors in Drama/Dance, and English Literature. Ron eventually learned that Turk had secretly funded his education.

Also while a student at Bard, Ron spent two summers volunteering in a community betterment and youth outreach program at the University of Southern California where he met his wife, Carol. After graduating, Ron moved from New York to California to be with her in 1975; they married that summer. He then earned his masters degree from California State University Long Beach, and went on to dedicate his professional career to improving educational environments and helping struggling students here at UCI.

Ron and his wife Carol have three kids: their son Jascha was born in 1977, their daughter Shanta in 1980, and their youngest daughter Alina in 1990, all now ages 31, 28, and 18. While it seems that

Ron's is the typical story of a struggling youth who achieved success, there is a little more to it. Ron is one of roughly 2,000 people in the United States living with someone else's heart.

After a surprise party filled with teary-eyed students and faculty, and over 25 years working as the campus ombudsman, Ron officially retired in June 2002. The following December, Ron received a completely new heart. He had been told by his doctor, a year earlier, to retire after being diagnosed with Congestive Heart Failure.

"Around 2001," Carol recalls, "We were planning to go back to New York for Christmas, and the doctor said, 'If you want to go back and visit, you should go this year.'" Even with such warnings, Ron continued working, settling faculty disputes and counseling students, up until his heart was working at only 20-25 percent. "The strangest thing started happening," Ron says, "For a while, I started feeling better; it was the endorphins from working with students. Doctors thought that as long as I was working with students, I was getting an extra kick."

"But it all started going downhill from there," adds close friend and former colleague, Donna, "there was a lot of pressure that last year Ron worked."

"We had administrative meetings every Tuesday and I'd keep getting up to leave to get water or to go to my office to sit because I was gasping," Ron says. "Meredith (former Dean of Undergraduate Education) followed me one day and goes, 'What's going on with you?' And I say, 'Nothing.' She says, 'You keep leaving, you don't look well, there's something going on with you.' I say, 'Meredith, I'm fine, now excuse me.' I reach for the waste basket and throw up. And then I put it back down and say to her, 'You're just imagining things'" Ron says laughing. He adds, "I didn't want anyone looking at me thinking, poor Ron."

Congestive Heart Failure is a syndrome, not a disease. That is, CHF is a set of symptoms of conditions that occur together and can be brought about by several causes, while a disease is an established entity with a clearly identifiable cause. Possible causes of CHF include exposure to toxic substances such as alcohol and cocaine, unhealthy habits such as smoking, lack of activity, and obesity. With heart failure, the pumping of the heart becomes less and less powerful. When this happens, blood does not move efficiently through the circulatory system and gets backed up, clogging the heart and stretching it out, while also increasing pressure in the blood vessels and forcing fluid into body tissues. Because of this, the body is weakened from lack of circulation and build-up of excess liquids. Patients diagnosed with CHF take diuretics to eliminate the amount of fluid in their bodies, and limit their intake of sodium (salt) and water which could overwhelm the process. Heart failure is more common among those aged 85 years and older; it only affects one percent of people aged 50 years old. Ron was part of this one percent.

“I would sit up in the hospital room late nights thinking, how did this happen to me?” Ron recalls, “I ran, I danced, I never experimented with marijuana, I don’t drink, I don’t even drink coffee. I did everything right.”

There are however, some causes of CHF that correspond with some of Ron’s physiological characteristics. Himself an African American, CHF happens to be more common among African Americans than whites, and especially among those with weakened heart muscles, and/or damaged heart valves. Although not the direct cause of CHF, Ron has had a history of heart complications, including multiple aneurysms and the implantation of an artificial heart valve, all resulting from Marfan Syndrome which he was diagnosed with as a child. Marfan Syndrome is a connective tissue disorder. Connective tissues – which provide substance and support to tendons, ligaments, blood vessel walls, cartilage, and heart valves – are weakened, affecting the major arteries. Besides having heart problems, people with

Marfan Syndrome are often tall and thin (President Abraham Lincoln is thought to have had it); at 6'7", Ron's figure is characterized by long, slender limbs.

Ron's lengthy history of hospitalizations began when he was 11 years old with rheumatic fever, and Marfan Syndrome shortly after. From the very beginning, Ron's life expectancy was short. "When I was hospitalized [in New York], the doctor took me into a room with other doctors and began pointing to all my joints and different parts of my body; he made me feel like I was freak. The doctors then told my mother that I was going to die, or at best live until I was 20-23 years old. My mother said no, she went to St. Patrick's Cathedral, took some holy water, and had it mounted over my bed. She said to them "You don't know my son, he isn't going anywhere."

At that point, Ron was in the hospital for six months, before returning for another nine months, then again for seventeen months, and another point for six months. The first year of his hospitalizations, he spent most of his time at St. Luke's Convalescent Hospital in Connecticut where children were sent to rehabilitate their hearts. There, life for Ron consisted of Penicillin, bed rest, bed pans, and the wheelchair until at twelve years old, he got tired of it.

"Back then they had these big wheelchairs made out of wood. Every now and then someone would push me outside to get some sun. So I was outside watching kids race, and I said to myself, 'I know I'm faster than them,' One of the kids yelled out, 'On your mark, get set, go!' And I threw my blanket off, jumped out of my wheelchair, ran down this slope, and beat them. They were ahead of me and I beat them. I was tired after that," Ron remembers fondly.

Throughout his youth and adolescence, aside from running, Ron also danced, took karate, and even joined the Marines, but got kicked out because of his heart condition. "I did everything I wanted to do because I wanted to do it, because I was tired of being an invalid. I never regretted it but I always

ended up back in the hospital because I did things I was told not to do. I remember my mother yelling at me one time, ‘Are you trying to kill yourself?’”

Ron just wanted to live. His key piece of advice for achieving goals consists of making three decisions, “What it is you want, what it is you’re willing to sacrifice for it, and what it is you’re willing to settle for.” Ron wanted life, and wasn’t willing to settle for anything less. Throughout his life Ron has abstained from drugs and excessive use of alcohol. Even throughout his numerous physical ailments, it seemed that his determination to live was what kept him going, along with tremendous support from friends and family.

In 1985, Ron underwent open heart surgery to have an artificial heart valve implanted after one of his valves began to malfunction. Artificial heart valves are prosthetic devices designed to replace the natural valves of the human heart in order to maintain unimpeded blood flow through and from the heart into the major blood vessels. A working artificial heart valve sounds like a watch ticking.

In 1986, Ron had his first major surgery to repair his aorta. The aorta, the major artery that leaves the heart, is often affected in those with Marfan Syndrome. When this occurs, it gets bigger (dilates), weakening the aortic wall which can tear. Blood can leak through these tears into the aortic wall, separating its layers and possibly forming an aortic aneurysm, which is a ballooning in the wall that could potentially break. This is exactly what happened to Ron. “I have a high threshold for pain but the aneurysms killed me,” Ron recalls. He had another aneurysm further down the aorta in 1988. For this one he was sent to Texas for the surgery because no hospital in California was willing to operate so low in the aorta. This second operation in Texas was a success, the only negative result being that one of his vocal cords had to be cut, resulting in his weakened voice.

Finally, in August 2002, Ron was hospitalized once more because his heart, working at only 15-20 percent, was literally failing. But this time, Ron did not expect to come back out.

August 21, 2002

Dad is doing rather badly again. He couldn't keep anything down again last night. I spoke to Dr. T this morning about it... he thinks the problem might just be the way Dad manifests his heart failure, that the blood gets backed up in the abdominal organs simply because the heart isn't pumping very well, and his body just tries to relieve the pressure. He has also spoken with the transplant team up in LA to see if Marfans patients are a bad risk for transplant, and they said no. I told Dr. T that that was scary to me, that if they take out the old heart, the new one just better work, and he said that it does, but that it still is a final (and scary) step. To me I think it was always sort of in the world of science fiction, or futuristic medicine or something.

Anyway, after he is accepted as a candidate by UCLA (assuming he will be), there is an average of a four month wait for a heart. It has to match his blood type, O pos (not a problem), and the donor has to be approximately the same size as him (a problem). Anyway, we'll cross that bridge when we come to it. (Email from Carol to their daughter Shanta)

Once it is agreed that accepting a donor heart is an option, there are multiple tests to see if the body can handle the new organ, and if the patient him/herself can maintain the strict regimen of taking multiple drugs and going to regular check-ups. Tests include, but are not limited to: skin tests, chest x-rays, electrocardiogram (checks heart rhythm), pulmonary function test (checks lung function), arterial blood gases test (checks amount of oxygen in blood), a dental exam, a CAT scan (for tumors), blood testing, and psychological and sociological testing (involving family.) Aside from physiological complications, the transplant team is ultimately testing for full commitment.

“They ask you all sorts of questions,” Ron recalls, “Are you prepared for this? Do you know what this means? Can you follow through with instructions?” The sociologist wants to make sure that the person's not going to be depressed, that they have support.” Aside from fearing that the new heart will again fail them, some transplant patients have trouble accepting the fact that someone else's heart is

beating in their body; they come up with strange illusions that they are not the same person, and experience a sort of identity crisis.

“The questions from the psychologist cover different ground, they ask you questions like, ‘If an Asian’s heart becomes available, would you be willing to take it? If a white male or female’s heart becomes available, would you be willing to take it?’ Believe it or not, some people, from what I’m told, mostly white males, will say no if asked to take a black male’s or a female’s heart. I, on the other hand, if you could put Rin-Tin-Tin in me, I’ll take it; give it to me, and I’m ready to go” Ron says laughing. Himself a black man married to a white woman, the father of biracial children, friend, and mentor to many people of various ethnicities, Ron is the last person to care about his donor’s race or gender.

Because of the limited number of hearts – in the United States, approximately 4,000 people are in need of transplants every year with only around 2,000 donated hearts available – there are four priority levels on the waiting list to be placed on, Status 1A, Status 1B, Status 2, and Status 7. Ron was on Status 1A, the highest priority, which is for patients who must stay in the hospital, require IV drugs, a heart assist device, and a ventilator; or those who have a life expectancy of less than a few weeks. However, because of a urinary tract infection, Ron was temporarily taken off the waiting list. Roadblocks to heart transplant approval include any infections, cancers, ongoing substance abuse, and organ damage. The risk of medical complications needs to be minimized as much as possible before the surgery to prevent fatal results. Patients with other health complications, such as infections, must first recover before undergoing surgery because a transplant recipient’s immune system is suppressed with medications to keep his or her body from rejecting the new organ. If not free of illness before undergoing surgery, the illness could potentially worsen and prove fatal after the surgery because of the weakened immune system, and in such a case, the transplanted organ would be useless.

To keep him from becoming completely discouraged, his son Jascha, 25 years old at the time, spent almost everyday at the hospital with him.

November 26, 2002

Jascha is going to take some time off work, go up to see him as often as he can, and the two of them will “work out” together to try to build Ron up. Jascha took a CD and tape player to the hospital so he can listen to some of his favorite music, and also to messages, jokes, poetry, whatever his friends and family want to tape and send to him. You know Ron is energized being around people. So send something to me.

(Email from Carol to friends and family)

“I was there trying to keep my dad oriented” Jascha comments. “What I realized from being in the hospital with him and even experienced myself, is that when you’re in the hospital for so long and on so many drugs, a form of dementia takes place. You start to forget what day it is, and where you are; you lose all sense of time because constantly, people are walking in and out, and poking and prodding at you. So I would come in and say ‘Good morning dad,’ tell him what day it was, read him the newspaper, and remind him where we were. Doctors would come in and ask him questions to test his coherence because they don’t want to waste a heart on a person who is so far gone. When he couldn’t answer what day it was, and didn’t know where we were, I would show the doctors and nurses he was still coherent by asking him questions he knew, like ‘Where did Shanta graduate from college? What actors starred in ‘It’s a Wonderful Life? Who is your favorite musician?’ Questions like that he could always answer.”

After months of being in the hospital, on December 9, 2002, Ron finally underwent heart transplant surgery. Carol recalls the day, “Everyone – all our kids, and some very good friends – was in the lobby of the hospital waiting during the transplant. They first called me at home at 6 a.m. to say there was a heart available. We got up to UCLA Medical Center at about 9 o'clock, and they wheeled him to the operating room at about 10. There's a lot of prep work in getting the patient ready that needs to be done before they actually put in a new heart. Every couple hours the circulating nurse would call the lobby from the operating room to update us on his status... Our waiting, though stressful, was like a party because it was what we had all been waiting for. When I was outside the hospital at about 3pm, I saw a

helicopter taking off from the roof, and I suspected that it had just delivered Ron's heart. That was exciting. I think he went into a room at about 6pm. They had left his chest open, covered with a sterile covering that looks like plastic wrap, just in case they had to go in again for any problems in the next day or so. They did that because it had been such a long surgery, and they didn't want to have to re-open him should there be any bleeding or other problems. We had seen his chest open before when they put in the Ventricular Assist Device, so it wasn't quite as shocking as it might have been.”

The heart transplant procedure consists of three operations. The first operation is harvesting the heart from the donor; this takes optimally less than six hours. Afterwards, the organ is transported on ice by airplane or helicopter to the recipient's hospital. The second operation is removing the recipient's damaged heart. The third operation is the implantation of the donor heart. It involves the creation of only five lines of stitches, or “anastomoses,” which connect the large blood vessels entering and leaving the heart. Heart transplant surgery usually takes a total of 4-10 hours. A team of anywhere from 8-14 doctors work together, with the head surgeon directing and performing most of the actual harvesting and implantation while the others help to make incisions and control bleeding.

December 10, 2002

We have a new heart in the family! Ron had his transplant yesterday and all went well. The doctor said it was a strong heart; it started right up when they hooked it up. It was a wonderful, unbelievable day... When I went in today, Ron felt so warm. I asked the nurse if he had a fever, and he said no, it was just that his blood was “circulating so well.” Thank God, Thank God, Thank God! It's a thrilling, humbling, awesome, humanizing thing. I just haven't the right words. Thank you all for the shared joy, agony, fear, prayer, anguish, support, celebration. I sure feel a whole lot more like celebrating Christmas now, don't you?

Love to all,

Carol

“It was funny after I got my heart transplant, my youngest daughter Alina (who was 12 years old at the time) gave me a hug, and she stopped and said ‘Who are you and what have you done with my father?’ My father ticks and you don’t tick.’ All her life I had the artificial heart valve.”

What Ron’s ordeal has demonstrated is that while the heart with all its valves and vessels can fail, a person’s true heart and spirit never fails with the support of loved ones. Eighty percent of heart transplant recipients live an average of two years after the surgery. It has now been six years for Ron. Ron is enjoying a normal, happy, healthy lifestyle, but of course, with quite a few modifications, mostly his strict regimen of taking different medications. Right after being discharged from the hospital, Ron was on nineteen medications. As Carol observes, “It’s a small trade-off for being alive.”

Many of the drugs Ron is on are immunosuppressants, including Cyclosporin, Prednisone, and Cell-CEPT, to prevent organ rejection. Rejection occurs when the body's immune cells recognize the transplanted heart as different from the rest of the body and attempt to destroy it. If not suppressed, the immune system would damage the cells of a new heart, eventually destroying it, and the heart would again fail the patient. Risk of rejection is highest within the first few weeks and months after the surgery. Because of this, the patient must undergo an average of three to six heart biopsies – removal of a small piece of heart muscle for examination – throughout the first year in order to check for signs of rejection. At least 40% of heart transplant patients have at least one rejection episode in the first year after surgery. It has been six years without a single inkling of rejection; true to his nature, Ron’s body seems to have fully accepted his new heart as a part of him.

Because the immune system is suppressed, the patient is more vulnerable to illnesses that a human being with a normal, healthy immune system could easily fight off. In addition to the immunosuppressants are vitamins, aspirin, and antacids – which must be taken because all the medications can upset the stomach. Since the surgery, Ron has gradually been taken off certain

medications, now taking only around 12 throughout the day. He carries a small pill organizer in his pocket at all times; only instead of containing a compartment for each day of the week, his pill organizer is made up of four containers for different times in a single day. Carol, a retired nurse, helps Ron keep track of all the medications he has to take.

“I tell people,” Ron says jokingly, “that if I die suddenly, I want you to tell everyone that the last word I said was ‘autopsy,’ because my wife is going to kill me someday. For a long time I would say to her ‘Can you get me this? Can you get me that?’ And she’d say, ‘There’s nothing wrong with your legs, you can get up and get it.’ And I’d say, ‘But I’ve had open heart surgery,’ and she’d reply, ‘Do you want it open again?’”

More than the return to his good health, Ron’s family is more appreciative of his unchanging character despite the replacement of his heart. Jascha recalls thinking his father would not be the same after the transplant, “I had gotten this crazy fear that with the new heart, would he love us the same? I had a long talk about this with my godmother. She had to remind me that love wasn’t in the flesh.”

Aside from his love, what also stayed constant after the surgery was Ron’s sense of humor.

February 25, 2003

He is home! And they did surprise me. Jascha arranged for the hospital to have him discharged two days prior to when I expected him, so when I went home from work last Wednesday, he was there. And lying on the bed, cool as anything, he asked me “Do you know where the remote is?”

The only major change in Ron’s personality is his new fondness for country music. “Before my heart transplant I listened to almost every genre of music except for country western. I really like listening to it now. Some time after the transplant I was listening to country music my room, and my son Jascha comes in and says ‘Man, I don’t even know who you are anymore,’” Ron shares, chuckling.

A few months after the heart transplant, Ron's eldest daughter Shanta put together a scrapbook of letters and all the frequent emails Carol had sent to update friends and family on Ron's condition. Carol recalls that writing and talking through the details of the ordeal were therapeutic for her. The final email included in the scrapbook ends the entire journey on a light-hearted anecdote about Ron.

April 4, 2003

It's been a long time since I've updated you all on Ron's condition. And that is because (I suppose) of the old adage "no news is good news." And it is very good. Now, all this good news doesn't mean Ron has any more sense than he had before the transplant. For example, this morning he was trying to clean the house up before the housekeeper who comes every other week got here. He stayed up till 3AM to get the towels all washed and dried, then was bustling all around this morning so tired that he fell down. Now, how much sense does that show? But, all in all, he's doing great.

The first page in the scrapbook reads "You are our miracle" while the final pages are letters from Carol and each of Ron's children, Jascha, Shanta, and Alina. Each of the letters details their worrisome thoughts while waiting for the new heart, not able to imagine a life without their father and husband.

Jascha writes, "I try and remember driving and sitting next to you, the strongest man I have and will ever know; my hero, my role model, my leader... I can't tell you how much you mean to me and this family. To see you get stronger and stronger every day, to walk with you and see movies with you again, to have my father back, there are days where I just think about it and marvel in it with disbelief. You have always helped me find my way when I'm lost, and given me the advice that I need when I need it. I am at a loss for words. All I can say is thank you, thank you, thank you, for not giving up on us, for not giving up on your self, and for always believing in me. I really don't know what I would do without you. Thank you for being the best father. And thank you for being my best friend."

It seems that Ron's deep sense of gratitude is not only inherent in him, but in each person in his family as well.

After months of rehabilitation and reclaiming the rest of his life, Ron continues many of the hobbies he enjoyed before the transplant. A lover of art and music, he collects old records, which accumulate across almost an entire wall of shelves in the family living room, and takes photographs. To show his gratitude for his heart donor, Ron took a photograph of the sun setting over a lake, its reflection glistening on the water, and sent it to his donor's family. At first, they refused to see it, the memory of their lost loved one being too painful to bear. Eventually, doctors were able to convince them to take a look, and they decided to keep it. Ron had written on the bottom, "To the family that will always be a part of me."