Body Mapping

Journey through the stories of eight organ transplant patients
Dr. Michael Karpf and the UK Arts in HealthCare program partnered with Dean Michael Tick from the UK College of Fine Arts, the Kentucky Organ Donor Affiliates, the Ruth Hunt Wood Foundation and the Art2Be organization to hold a body mapping workshop and exhibition under the direction of visual artist Xavier Verhoest in February 2013.

Eight transplant patients from UK HealthCare created canvases of their bodies that described their experience with transplantation. All patients are from Kentucky and are recipients of a variety of donated organs. Verhoest of the Art2Be organization from Nairobi, Kenya, led the intimate workshop in the Tuska Center for Contemporary Art at the UK Fine Arts Building.

Thanks to the UK College of Fine Arts School of Art & Visual Studies who lent the Tuska Gallery for the workshop. Special acknowledgement to student assistants Leslie Parker and Amy Hoagland for their help to Xavier Verhoest during the workshop.
What is Body Mapping?

Body Mapping is a creative therapeutic tool that brings together bodily experience and visual artistic expression. In its basic form, it involves painting a life-size representation of one’s body onto a large surface and using colors, pictures, symbols and words to represent experiences lived through the body and show the path that one has taken through life.

Most of this method provides a creative vehicle for expression that is not dependant on literacy levels and enables participants to (re-)discover their bodies as a source of strength and healing. The painting of the body maps takes place in a safe and confidential group setting and is interwoven with personal story telling, group discussions, guided visualization and movement therapy.

Art2be has worked with adults and children living with HIV, sexual minorities, sex workers, cancer survivors, illegal immigrants, health workers and survivors of gender-based violence. This was the first time the body mapping project focused on organ transplant patients. The project uses art to allow children, youth and adults to tell their life stories, share their concerns and aspirations with their families and communities. It challenges established ways of thinking and of treating others. It campaigns for the rights we all deserve.

Impact

Body Mapping helped individuals who have undergone life-saving organ transplants connect with others who have had similar experiences. Led by Xavier Verhoest, visual artist with Art2Be, the organ recipients spent four days in a creative interpretative workshop where they shared their past fears of facing possible death without transplantation, their medical journeys through the process of waiting for and then receiving an organ transplant, their sadness for their donors, and finally, their collective joy of being alive. Ultimately, Verhoest said, Body Mapping helped the recipients realize what beautiful and strong treasures they have within.

As one of the recipients, chosen as the group spokesperson for the unveiling of their art, said, “Xavier led us through part of our healing journey through this powerful visualization process called Body Mapping. Each of us has gone through a traumatic journey and has scars not only on our bodies but also on our psyches. Our art shows that we have chosen to show our gratitude and our thanks by letting our little lights shine to others, by living joyously for ourselves and for our donors, with strength and dignity and love, knowing that deep down all people are connected.”

Body Maps express personally lived experiences and have thus the potential to break down barriers between people when the works are exhibited in public places. The vibrant colors and often surprising symbolism awaken the viewers’ curiosity. Since the individual person depicted in the body map is never reduced to a stereotype, there are many ways in which one can identify with the author of the body map.

Ultimately, you will recognize yourself in these works.
In 2006 I began to experience severe pain on the right side of my abdomen. The pain was so severe I went to the emergency room three times over the next two years. On the third trip, an octreotide scan was ordered that revealed a carcinoid tumor in my colon. In the spring of 2008 I had a colon resection to remove both the primary and secondary sites. Five of the nodes removed tested positive.

During the next three years I made numerous trips to the Mayo Clinic in Rochester, MN for a diagnosis that showed there were five lesions on the liver. In April of 2011, I had a liver resection to remove the tumors. During the operation the surgeon unexpectedly discovered I had non-alcoholic cirrhosis of the liver, NASH.

During the summer my kidneys were failing, and I was admitted to the hospital for renal failure. I was fortunate enough to meet the liver transplant team at UK. I began testing to become a candidate for a liver transplant and was placed on the transplant list in October.

My condition continued to deteriorate. But on January 19, 2012, I received a new liver. I had the loving care and support of my family. My husband stayed with me during the day and my children, who came from Tennessee, North Carolina and South Carolina, took turns staying at night. Three days after the transplant surgery I developed cardiomyopathy; my lungs collapsed requiring an additional eight days in the intensive care unit.

On January 19, 2013, I celebrated my first anniversary with my new liver. The children gave me a surprise lemonade drop-in to celebrate the occasion. Many individuals from the University of Kentucky medical center, family and friends provided continued support including Dr. Hundley, Dr. Karpf, Patty Followell, all the nurses and technicians on the eighth floor and the ICU, Dr. Dale Goodin and his staff, the transplant team, my nurse Kim Severson, PA’s, Hender Rojas, Carol Broughton Kathy Jones, Dr. Rosenau, Dr. Whayne, Dr. Anthony and Dr. Castellonos.

I will be forever thankful to the donor and his/her family. They gave me continued life. I have always been an organ donor but never dreamed that I would be a recipient. My new motto is “Save a life. Be a donor”.

My body mapping experience was a very bonding and emotional time. It gave me the opportunity to meet with others who had transplants and hear and share stories of their journeys. As others look at the body mapping and read my story it gives me hope they will be inspired to donate organs and realize how much good comes from giving.
Give life. Live life. Attitude is half the battle: I am grateful for each day that I open my eyes.

Forty-six years ago, I went from little or no hope to the most fantastic journey and a fully blessed and great life. When I needed a kidney transplant at the age of 15, my mother gave me one of hers. I did not want to accept it. I prayed nightly for God to just take me so my mother and dad could simply go home and get on with life, raising my brother and sister.

But a mother’s love is nothing to take lightly. She gave me a kidney, and I was fortunate and honored enough to have my “Wonderful Mother” with me for nearly 44 more years before she died. I think it is important for people who read this to know that both parties can live and lead normal, productive lives.

It’s what we do with the love we are given that matters all around. It brings me great joy to think of what I have accomplished so far on my journey. My calling from about the age of five was to become a nurse. I was fortunate enough to carry out my dream. And in the words of my wonderful mother, “Just look at all the people you’ve been able to help.”

My mother and I shared a love of the children’s song, “This Little Light of Mine.”

“This little light of mine, I’m going to let it shine. / This little light of mine, I’m going to let it shine, let it shine, let it shine, / Hide it under a bushel? NO. I’m going to let it shine. / Hide it under a bushel? NO. I’m going to let it shine, let it shine, let it shine.” (Composed by Harry Dixon Loes (1895–1965) circa 1920.)

My canvas is simply one of positive thinking, never give up, trudge on no matter what obstacles may get in your way, share and encourage others, try to instill the gift of hope, and simply live life to the fullest as we never know when our journey may end.

Not everyone can say their mother gave them life twice!

With much love, joy and great thanks, I am going forward still – Life is Great!
This Little Light of Mine
I Have To Let It Shine —

NOT EVERYONE CAN SAY THEIR MOTHER GAVE THEM LIFE TWICE!

HOPE
NEVER GIVE UP

BLESSED
I am a heart transplant recipient. My life was saved on December 26, 2011, by a 16-year-old named Caleb Beaver when his parents donated his organs for transplantation.

Before I became ill, I had a busy practice as a psychiatrist. I was active with my wife and two teenage sons and enjoyed sports, such as riding my mountain bike and shooting white-water rapids.

My life was nearly stolen by end-stage biventricular heart failure, caused by sarcoidosis. I learned I needed a heart transplant to survive. I closed my medical practice. Eventually, I was hospitalized at UK HealthCare while I waited for a heart to become available.

I was able to hold onto my love of family, maintain interest in learning and teaching medicine, and preserve hope. I was not afraid.

In my painting, the blue symbolizes peace, integrity and tranquility that have streamed since I received my new heart.

Red signifies energy, strength, power and determination along with passion, desire and love which now flow incessantly through my body.

Over my right arm lies “a treasure within” which suggests that two souls and one heart have allowed for enhanced resilience and ascension.

The stripe going down my body represents the inflammation, scarring and turmoil associated with the disease that destroyed my native heart and nearly took my life. Within the stripe are granulomas. These are diagnostic for sarcoidosis, which can be recurrent, but is now dormant and contained.

The bass guitar denotes a common denominator: Both Caleb and I played bass guitar in bands when we were 16.

The blue and white fingers on my right hand are the colors of the University of Kentucky. My life transitioned, was revived and saved there.

The pink and white fingers on my left hand are a tribute to Caleb as he was a strong advocate and supporter of breast cancer awareness.

The caduceus encompassed by the partial circle backslash symbol depicts my medical career being cut short but not completely eradicated. I have enhanced capacity to help and heal others by virtue of my experience.

The flower is a memorial and a harbinger: A flower was given to me on Christmas, and the next day I was given a new heart.

The Tin Man provides inspiration and linkage: He and I both needed and received hearts.

I have reclaimed my Strength and Vitality and look forward to a prolonged life with my family. I am Renewed.
I had my life all planned out by the time I was 16. I knew I wanted to be a doctor so I was going to attend Xavier in New Orleans and major in biology, go to medical school in Washington State, have four or five children, and make my parents proud, but all that changed.

Long story short, I was diagnosed with lupus. I really didn’t understand what lupus was exactly except that my diagnosis meant my parents’ worst fear had come true. By the time I was 22 I was diagnosed with rheumatoid arthritis, and at the age of 25 I was diagnosed with pulmonary arterial hypertension, a condition where the vessels in your lungs narrow, making oxygen transfer into your blood difficult.

Due to this, your heart also works harder, which caused right heart failure. My disease got so bad that I had to wear a pump that infused medicine into my pulmonary artery every three to five minutes.

This disease changed the course of my life. I had to stop working; I was passing out on the job due to shortness of air. I passed out in Wal-Mart. I would pass out just walking to the bathroom.

In April 2012, I entered the hospital. It was vital that I receive a heart and double lung transplant. I went to University of Kentucky hospital where I thought I would die, but on the night of July 6, my doctors said they had a heart and set of lungs for me.

I still am unable to fully understand how I felt that day. My mind was full of many thoughts – too many for my heart to assess, but one thing was clear: there was a family out there who had lost a loved one. My surgery began around 2am the morning of July 7, 2012, and lasted around eight hours.

I still have trouble sorting my feelings out about this whole experience. Through this Body Mapping project, I have a better understanding of what my mind is trying to tell my heart. I know I got the gift of life from strangers. Every breath I take is due to the help and selfless act of strangers. I can never fully express or show my never-ending gratitude towards them. Through my art, I hope they will see my appreciation and know that I am fully aware of the loss of their son, brother, nephew, or grandchild. I also hope that other transplant recipients will feel a connection to my art, and they will know that in this battle they are not alone.

In many ways I feel like this disease has destroyed my life, and other times I feel that I am going through these trials because God has a bigger plan for me.
I was born in the mountains of Eastern Kentucky, a little town named Hazard in Perry County, to my parents Cecil and Ethel Halcomb. My dad was a coal miner. We lived a very humble life—one that I loved very much. Our little mountain home was surrounded by the hills and all my relatives. I felt safe and content; my heart is, and always has been, in my mountains. In 1962 my family moved to Lexington, Ky. I never felt such loss or so out of place in my life. Lexington was big. I was not. Economics brought me here, economics kept me here. I would never expect anyone to understand how I feel about the mountains of Kentucky, not even my wife or children, who have never lived there. All through the sixties, I felt sure that soon we would return to Eastern Kentucky, but that was not to be—again, economics. In the late sixties, I think I made some compromise with myself and Lexington. I would stay, but I wouldn’t like it. I was sometimes content to travel back home on weekends and vacations, but as I grew older, I realize the reasons that brought my parents here would directly affect me too—economics.

In 1972 I was old enough to make my own decisions on where and how I wanted to live, but quite suddenly I was tossed a curve—I met a girl. Like most young men by the late teens, I had met and dated a lot of young ladies, but this was different. This time I was in love.

Peggy came into my life in 1972 and has been my wife for 38 years now. She was with me before I was diagnosed with kidney failure and stayed with me during some uncertain times, always cheerful, always optimistic. In 1972 I went to the University of Kentucky Medical Center for failing eye sight; I had no idea how sick I was, but in the following weeks, I would find out. When they finally put a name to my sickness and all that it implied, I was heartbroken, scared, confused, and just too damn young to be robbed this way. I looked out the window of my hospital room and home—a life—seemed so far away.

After a year of dialysis, I got “that” call. It was September 12, 1973. On the 13th, I was transplanted. Through caring and goodness of heart, in a time of great tragedy for a family unknown to me, they chose to donate the organs of someone they loved so that I could have a life. Through the vision of the wonderful doctors and researchers at the UK Hospital and the choice that a family made at a time of so much pain, I was given my life—to marry, to work, to have two children, and now to have two grandchildren.

Because of my donor and donor family, I was given a chance to live, and indeed I have.
Journey
UK
The Path to Healing
In 1990, I was diagnosed with auto-immune biliary cirrhosis – my body was attacking my liver. By 2004, I was in liver failure and in need of a transplant. How fortunate I was to receive one while I was still healthy enough to undergo this difficult surgery and recovery.

My donor was 17. In the midst of their grief, his family saved my life. It is with a grateful heart that I have been able to return to my work, to a life of love and joy, and to be able to witness my daughter blossom into her adult self.

This young man lives on in me, and I feel responsible to him and to his family to take care of myself, to honor him by continuing to live as fully and joyously as I can. I had always appreciated life, but something has shifted. I am dazzled on a daily basis by a glimpse of blue sky or the sweet smell of the earth; by the presence of those who love me and got me through this; by the opportunity to once again comfort and help others. I have learned to appreciate every moment, live the best I can for that day, and not worry about things that have not yet happened.

In my painting, the ground beneath me is cracked and uneven, representing the unexpected and unpredictable challenges to my health. Over my heart is the message I have learned, that no matter how dark things become, they will change and I will find my way. I am cradling my liver and you see the words – honor, cherish, protect. Similar to the feelings one has toward one’s child, I honor the sacredness of my donor’s life within me, cherish this amazing gift which does its job so well, and do all I can to protect my liver and my overall health.

I am dancing to convey the message that every moment matters, and regardless of the challenges, I insist on celebrating life by living joyously – both for myself, and for this young man who is unable to experience his own joy. In the photographs at the roots and top of my painting are those dear ones who supported me through this, beginning with the healing ceremony – drumming and dancing in my back yard, each adding their ribbon-figure to a trellis where they continued to keep vigil at my window during my recovery.

The body-mapping project enabled me to connect with others who have been through transplant – to bring to light the gratitude, the pain, sadness, strength and hopefulness that are part of the transplant experience.

With the help of Xavier, our gentle guide, powerful positive energy was generated which allowed us to find expression for our personal journeys. If this exhibit helps others to understand the magnitude of the gift of organ donation – the gift of life – we will be gratified.
I live joyously for both of us.

Honor
Cherish
Protect

Linda Angel
I was born in Grundy, Virginia, and moved to Kentucky where I met my husband of 42 years. We were blessed with a beautiful daughter and an awesome grandson. I also was fortunate to have a career I loved – teaching. My life seemed just about perfect until one day I learned that perfection doesn’t exist in reality.

After 35 years of teaching, I retired and planned to do volunteer work. Within four months of retirement, I was diagnosed with Goodpasture Syndrome, an auto-immune disease in which the body’s own defense system attacks the lungs and kidneys. The doctors were able to save my lungs, but the disease destroyed my kidneys. I was sent to pheresis and dialysis for approximately nine hours a day for several weeks. Once the pheresis was completed, I continued dialysis four and one-half hours, three times a week. This was my new life, connected to a machine with two large needles taking and returning my blood.

When I walked into the dialysis clinic that first day, sadness rushed through me, as I witnessed so many people connected to machines. I became part of that environment, and soon realized that the very process keeping me alive was gradually killing me. During the period of time I went to this clinic, three people passed: souls that might still be alive if they had received a Gift of Life.

Finally a miracle happened! God prepared the way for me to receive a second chance from one of his special angels who had decided to be an organ donor. On the night I received my kidney, I lay in my bed, and just like watching an angel from heaven, I watched a helicopter descend onto the roof of the hospital bringing my new life to me. Now, I was to receive the most special of gifts – the Gift of Life.

After my transplant, my life became much better. Not only could I again eat a variety of foods, but I was no longer connected to a machine. I was able once again to urinate – a bodily function I no longer take for granted. Instead every time, I thank God and my special angel for this life saving ability.

But then, within a year, my world collapsed. My husband passed, and the pain in my heart was horrific. With the assistance of my devoted family, I began the grieving process. As I remembered the promise I had made to my donor angel, I knew I had to continue living. Life has not always been easy, but I face each hurdle with an “I can do it” attitude. In the Body Mapping project, I met other transplant recipient patients who have shared their emotions and experiences. What an awesome experience Xavier led us through to express our journey through art.

In a prayer, I promised my angel – my donor – I would always treasure and take care of her special gift. I pray that her family will realize that as long as I am alive, part of her lives within me.
Pre-transplant, I was a wife, mother, daughter, sister, friend and chemical/environmental engineer with a busy full life. I had three children involved in sports, music and everything that good kids are involved in. In 1995, when my youngest was one-year-old, I was diagnosed with Alpha 1 Antitrypsin Deficiency, Alpha 1, for short, a genetic liver and lung disease. We eventually learned that my younger brother was also affected and immediately put on a lung transplant list. My other siblings were also affected but not to the same degree or as young as my brother and I.

By that time, I owned my own environmental consulting business and was doing pretty well. However, I was starting to feel very tired and began cutting back on my hours. Eventually, my world began shrinking. I began doing only what was necessary for my family to function. I was sleeping a lot. The Alpha 1 was sucking the life out of me.

I shut my business down completely. My medical procedures were increasing and getting more serious in order to save my life, and my world shrunk down to the doctors and my family.

When I got the call that UK Hospital had a donor liver for me, we jumped in the car and got to the hospital in less than 30 minutes. They rushed me in, got me prepped and did not give me much time to think, thank goodness, because I was scared. I said “I love you” to my family, and that was about all.

I woke up! I immediately realized that I had someone else’s liver in me! After a few days the doctors told me they had found quite a bit of cancer in my old liver as well as cirrhosis. If I had not had the transplant when I did, I probably would not have lived much longer.

I learned very soon after my transplant that my donor was a 19-year-old young man. His mother was very brave when she was faced with the decision of donating her son’s organs for transplant. In her grief she saved my life – someone that she did not know.

A few years have passed now and I know that I was meant to live. I have been able to do many things on my bucket list: watch my son graduate from college; be inducted into the U.S. Air Force and marry a beautiful young woman; watch my daughter graduate from high school with the highest honors and help her to decide on the college she now attends; watch many soccer games; and hopefully soon watch my youngest graduate from high school with all of her achievements. I was with my aunt and my father when they died. I was there when my brother received his life-saving double-lung transplant. I am here to help my mother as she ages. These are all things that I would not have been able to do without my donor family’s generosity and braveness.
CONNECTED
All of the paintings are self-portraits. Each tells one person’s story about their organ transplant.

This book accompanies the exhibition of Body Mappings made by UK HealthCare transplant patients in February 2013.

For more information about organ donation, visit www.kyorgandonor.org.

For more information about body mapping, visit www.art2bebodymaps.com