

where brothers and sisters are heard

THE SIBLING

VOICE

january - march 2014



aids warrior, advocate, and my brother

by leslie goldberg

He was six years older than I. My beloved older brother, Howard Jay, rocked my world. From the moment we entered each other's lives, I knew he was my Twin Flame—my soul's other half—as well as my partner in crime. He was my mentor and always made me feel safe and loved.

His sense of humor was legendary. His innate creativity and fashion sense blew others away. He was a leader in everything he did. He didn't just lead, he led with strength, grace, and compassion. He remains unforgettable to all of those he touched in his short forty years on this planet. For those of us who were closest to him, we were blessed

to have had him in our lives!

His given name was Howard. When he went away to attend the Fashion Institute of Technology in New York, he became a sophisticated "Jay." Jay graduated as a fashion illustrator with honors. His schoolmates were Perry Ellis and Donna Karan, among many now famous names in the fashion industry.

In 1987, shortly after my dad followed my mom into passing on, Jay was faced with his own mortality and decided that it was time to get the results of the blood tests he had been taking for many years but had never had the nerve to ask about. In a move that would change his life forever, he found out he was another statistic in the ever-growing population at that time of people who were HIV positive. Armed with this devastating news, he followed his heart and became a warrior to save all of his fellow warriors from this scary disease.

Jay rallied many of his friends in Chicago and became the founding member of Chicago's first TPA (Tested Positive for AIDS) group. He never waned in keeping everyone's spirits up, while trying every way to get his voice heard among bureaucrats who were trying to keep that growing epidemic hush-hush—as if this plague didn't exist. He and his fellow TPA members participated in countless rallies and nonviolent marches. They worked so hard to raise awareness of the countless people suffering the prejudices of people with AIDS in this country and to humanize the fight. The group even participated in a photography shoot for a

Jay and Leslie

Here we are with the first edition in 2014 of your Sibling Voice newsletter. It seems that I hardly had time to sleep in 2013!

Yet, as I sat down to work on this newsletter and reread over and over again the moving stories about siblings who have loved and lost, I am reminded that the sibling journey is one to be remembered and honored.

Leslie Goldberg's article about her brother, Howard Jay, an AIDS activist who eventually died from AIDS, is sweetly enhanced by the bonds that they continue to share, as Leslie keeps Howard's legacy alive. You will also be moved by all that her brother did in his short life. Read and be amazed!

Amanda Dunn (Anicich) has channeled her grief and kept her brother's memory alive by sharing her story and writing her memorable and moving book, *There Are No Monsters In Heaven*. As a sister who endured many years of watching Tony succumb to drug addictions, she reminds us that bonds of sibling love are ever strong, even when those siblings are no longer here.

As I prepare for my big trip as the keynote speaker and workshop leader in Atlanta, GA for the CURE Childhood Cancer Organization, I am reminded at how much need there is in this world for a simple gesture of love and hope.

~ Susan Whitmore
founder & president



trailblazing book that was put out by A&M University entitled *Epitaphs for the Living: Words and Images in the Time of AIDS*. Many photos from this book, including the one with my brother and his Chicago TPA group, were featured in the music montage at the end of HBO's groundbreaking movie *And the Band Played On*.

As members of the TPA group started passing away, Jay was the glue that kept them together. Sensing his time was also near, Jay decided to take part in a trailblazing study at the NIH (National Institute of Health). He was hoping to help make a difference to all of his fellow warriors who were suffering with AIDS. He was flown to Bethesda, Maryland in January of 1993 and took part in the study that invented the "cocktail" of drugs that is now saving people's lives, making the monumental difference for people now living with AIDS. After a month at NIH, Jay realized that his consent to forego chemo and radiation (which he had to sign in order to participate in the study) was a mistake, since he grew ever weaker.

Jay made the decision to fly back to Chicago and entered a hospital for aggressive treatment. I drove up from Columbus, Ohio to be with him. He tried to shelter me, his little sister, by pushing me away. I went back home but promised to be there for him. I kept in touch with him constantly.

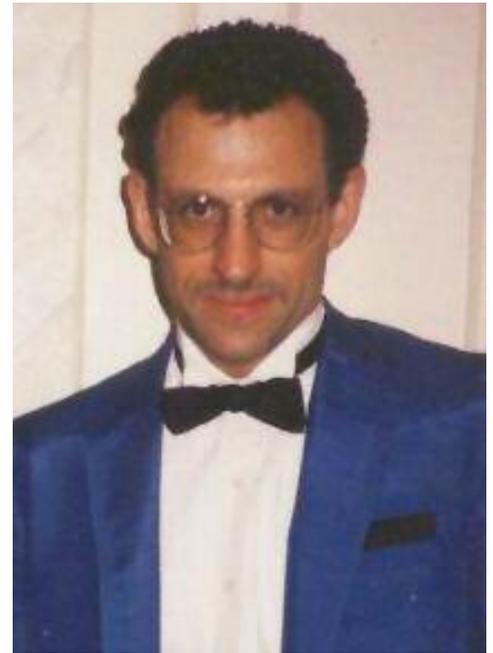
In June, I received the call that would change my life. My strong and brave brother was really ill in the hospital and finally admitted he needed me. I threw my things in my car, worried and anxious during the entire seven-hour drive. Two days later, even though Jay was bedridden, the hospital still insisted they couldn't do anything more for him, and they released him.

With the help of hospice, I turned Jay's living room into a hospital room environment, and my sister Susan and I became full-time caregivers. Soon thereafter Jay was hospitalized

for the last time. Susan and I never left his bedside. On Jay's last night on Earth, he had fallen into a coma. Susan and I stayed in an empty bed next to him and played a board game as loudly as we could so Jay could hear us and know we were with him.

"Howard Jay will ALWAYS be with me. He is a part of everything I do and will remain alive in spirit as more and more people are touched by his legacy of love."

After the funeral, I went back home. I was working for the community Hebrew school, and many of our teachers went to Ohio State University. The Hillel at Ohio State was creating its own version of the AIDS quilt. I transferred Jay's amazing drawings to fabric and created four squares for this community quilt. Two weeks before it was to be presented



Jay

running the quilt ceremony, and she asked me to be one of the four speakers that day. So, in front of faculty, media, and some very loud kids, I walked up to the bannister with the amazing community quilt as my background. As I started to speak, everyone grew silent. As I looked out over the crowd, I realized that even though Jay had passed, he was still touching people's lives.

I have given the same speech that I gave that day to many different age groups over the years. In 2005, I was asked by the rabbis of a temple I worked for to give the speech during the solemn Yom Kippur service. As I looked out over the crowd of thousands of people, there wasn't a dry eye in the house. The speech has turned out to be a dynamic educational tool—one that will keep Howard Jay touching lives for many years to come.

Losing my beloved brother, after having already lost my mom and dad, was even harder for me, especially because we were so close. However, writing this article for griefHaven about his life has been very cathartic. Writing is my favorite form of expression, and it has helped me realize that Howard

Jay will ALWAYS be with me. He is a part of everything I do and

will remain alive in spirit as more and more people are touched by his legacy of love. I encourage all of those who need a coping mechanism to pour yourselves into whatever creative outlet you enjoy. Trust me—it will help to always keep your loved one close!



Leslie and the AIDS quilt

to the community, I sat down and wrote Jay a letter. It was powerful. People didn't have to know me or Jay, but I knew they would be touched by the quilt. I sent the letter to the woman who was



Leslie, Jay and Susan

do you remember...?

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My Dearest Howard,

July 11, 1993

Do you remember when I was five years old and we did the newest dance craze "The Freddie" at your school bus stop to the amazement of your schoolmates? Do you remember that by the time your bus had arrived, we had all eight of your friends dancing The Freddie? I do!

Do you remember when I was six and we lived near a boardwalk? Do you remember that Mom left YOU "in charge" as my trusty babysitter and she forbid you to take me to the rides on the boardwalk that she knew we both loved while you were babysitting? Do you remember my pure joy when you won that adorable stuffed dog at the arcade after we rode the rides to our heart's content? Do you remember that we forgot to hide the stuffed animal when we got home and Mom found it the next morning and knew we had gone to the boardwalk? I do!

Do you remember that same year when we walked home from the beach and Mom realized she forgot the house key? Do you remember that you hoisted my small body through the open bathroom window and then had to spend five minutes patiently explaining how to unlock the front door because I was too young to understand how it worked? I do!

Do you remember when we giggled uncontrollably after a couple of sips of wine at the Passover Seder table each year and our family exiled us to the living room where we continued our laugh fest? I do!

Do you remember when I thought your Bar Mitzvah cake was a real prayer book and every photo reflected my thumb print because you caught me trying to turn the page? I do!

Do you remember my tears of joy as I walked into my bedroom and saw the gorgeous dress you had bought me, with your own money, for my eighth grade graduation since Mom and Dad couldn't afford to buy me one? I do!

Do you remember when you graduated high school and attended the Fashion Institute of Technology in New York where you majored in fashion illustration and insisted on being called by your middle name of "Jay?" Do you remember that your friends included Donna Karan and Perry Ellis? I do!

Do you remember when I finally got old enough to go out drinking and you took me dancing? Do you remember throwing me across the dance floor with the ease of Fred Astaire while people circled around us to watch you effortlessly spin and turn me in time to the beat? Do you remember when disco was alive in our bodies? I do!

Do you remember when you and Dad walked me down the aisle and you had a very serious expression on your face, which seemed to show that you took your role of giving me away with mixed emotions? I do!

Do you remember when you told my husband and me five months after our marriage that you were HIV positive? Do you remember the tender, brotherly bear hug you gave me as you told me you felt fine and that you were going to beat the odds? I do!

Do you remember when I rushed to your side and walked into your hospital room only to see your gaunt, Holocaust- type face muster up a brave smile? I do!

Do you remember when you cried over the phone two days later when the hospital you were in didn't even care if you were bedridden and were releasing you anyway the following day? I do!

Do you remember that I promised I would stay in Chicago to take care of you no matter what happened and no matter how long it might have been? I do!

Do you remember your friends calling me up two weeks later to tell me that they could no longer stand to visit you because of how you looked? I do!

Do you remember our calming, deep talks and my soothing words that helped us both get through that rough period? I do!

Do you remember that I whispered the Shema prayer in your ear as your soul slipped away from me? I do!

Do you remember if I could see anything through my tears as they laid you down to rest next to our beloved grandmother? I don't!

Do you remember your anxious plea to me that you would not be forgotten and that I vowed to you that you wouldn't be? I DO!

My dearest Howard Jay, you were a student of life and oh what a lesson you learned! Time can never erase your shining memory. You will live on in my heart forever!

Love,

Your little sister, Leslie

my funny, intelligent, big brother

by amanda dunn

My big brother. My funny big brother. My intelligent big brother lost his way. His name is Tony. It started out as innocently as going to a few parties and experimenting with some alcohol and recreational drugs here and there. That opened the door to a whole new world of addiction that at first glittered like an oasis in the desert, but only for a while. At first it was an escape from the self-doubt he felt in the real world and a high that he couldn't find anywhere else. Eventually, the addictions became too strong, and he was pulled deeper into them where he could enjoy all the spoils they at first had promised him.

As Tony became more introverted and started to live in his alternate reality, we were left to stand by and watch our dear brother and son slowly transform into someone we didn't know—a darker version of his former self, full of anger and hate. We struggled, as we could still see glimpses of the man we knew—a sensitive nod here and there, a hug, or when a random “I love you” would fall from his lips. We would receive a lucid phone call one day only to be called later that afternoon by the police asking us to come and collect him from the station or the hospital.

I believe 100% that my brother wanted to fight his demons, but they were too strong for his sensitive side. At some point there was no return for him—we had lost our beautiful brother and son to his addictions even before he finally departed this earth.

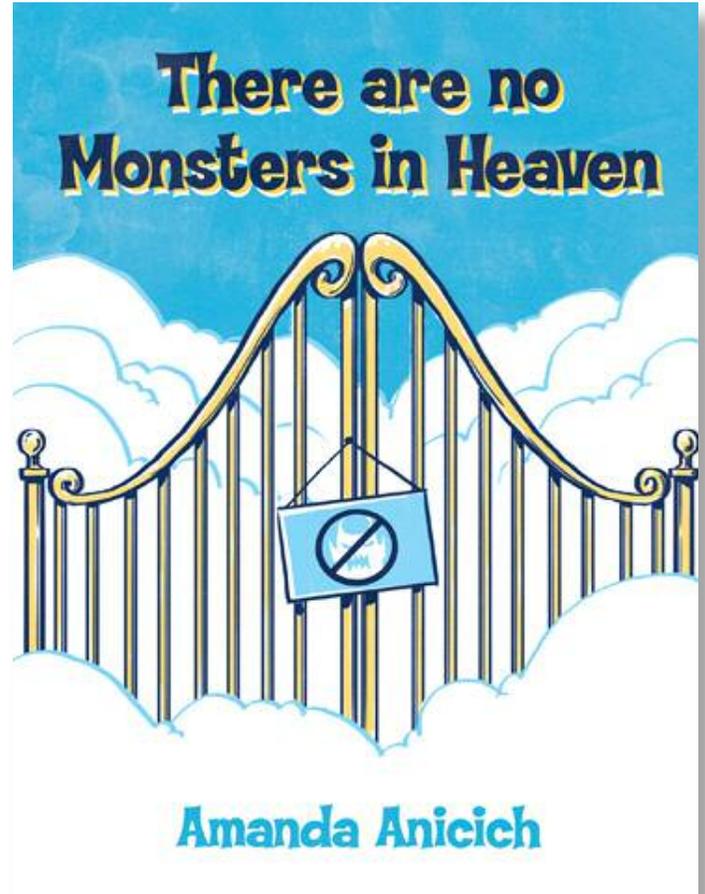
His last years on this earth were a living hell, not only for him but for our family as well. We constantly lived with the tiny flicker of hope that he could beat his never-ending fight with his addictions, all the while knowing

deep down that this was not likely to happen.

It is ironic that in the end my brother passed away from a blood clot that traveled to his heart. Even though his addictions did not take his life, they were with him that afternoon as he staggered off to the bus station on the way to a friend's house for a drink. That was the last time my parents would watch their lost son turn his back to them and venture off to find a way to satisfy the never-ending urges his addictions demanded be sated.

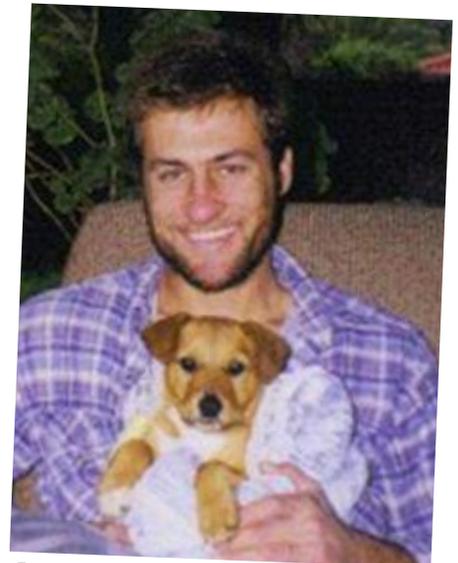
Our family was fortunate in that we were able to say our goodbyes and spend time with our brother as he lie in the hospital in a vegetative state. He could not breathe on his own, and his brain stem had been damaged beyond repair so, even if he did survive, the brain damage would have been so severe that he may never have been able to walk, talk, or recover his core functions.

There are certain moments in life that are etched into our memories so deeply they can be easily relived years later as though they just



happened moments ago. One of those moments for me is the look in the nurse's eyes as I rounded the corner of the IC unit where my brother lie moments after he had left this

I made a promise to myself to do what my brother would want, and that was to help my family throughout the difficult grief journey, while also helping other people understand the pain of addiction and how to cope with being left behind.”



Tony

earth. This memory haunts me to this day, and a feeling of guilt rises in my throat as I recall it because I was not there by my brother's side as he took his final breath. It was in that moment, seeing the compassion in the nurse's eyes, that I realized the enormity of what had been taken from me, from us: the lost family dinners, the lost achievements I

addictions forced him to live with each and every day. I made a promise to myself to do what my brother would want, and that was to help my family throughout the difficult grief journey, while also helping other people understand the pain of addiction and how to cope with being left behind.



Tony, Lisa and Amanda

would have celebrated with my brother, the lost hugs and “I love yous,” the lost words that I never got to say to him, the unborn nephews and nieces he would never meet, and the always empty chair at family gatherings. The indescribable pain and suffering that we all felt was too much to comprehend.

Even though I was necessarily grieving, I did not want my grief to be the main focus; my brother deserved more. He was a compassionate soul and would not intentionally inflict harm on anyone or anything, so all this heartbreak and sheer suffering we were feeling didn't seem right. I knew that my brother would not want us to be in such pain, the same type of pain that his

I felt helpless as I watched my parents try to process everything that had happened, from his addictions to his death. The pain and heartbreak they felt was written on their faces every day and was slowly killing their spirit. I wanted to help them realize that among all this sadness the shining light had to be my brother. The shining light is my brother, who I just know is missing all of us dearly. Yet, I also know that he is happy and with my grandparents now—that he is finally free from the burdens he had on Earth. I wanted my family to try and remember that whenever the grief gripped their hearts. Even though we all cried for what we had

lost, I wanted them to remember what my brother had gained: peace.

I decided to write about all that had happened to my brother. It started out as a simple fable that included illustrations to try and explain how my brother became an addict and how it destroyed the beautiful spirit he was. That became my book, *There Are No Monsters in Heaven*. I wanted everyone who knew my brother to remember that he was now in a better place and, although we missed him every day, he deserved a better life than the one he had on Earth. I wanted my husband and son who did not have the pleasure of meeting my brother to know what a great man he was. I wanted my family to

know that, at least in my brother's case, it seemed his addictions were not caused by anyone or anything, but that he was just too sensitive a soul to deal with the strength of the addictions. I wanted everyone to understand that, although he may have partied with his addictions and at first enjoyed them, he didn't want to live with them forever. Unfortunately, he found he just could not leave them. I now want other people who may be dealing with the heartbreak of living with an addict or dealing with the loss of losing a loved one to addiction to know that there is a silver lining. This silver lining is that the happiness of your loved one will never be lost forever—it is just put on hold for now in this place we call Earth.

To this day, I still cry uncontrollably for no reason when I hear a certain song, when I see a sunset, or just when I think of my dear brother. I suspect I always will. I let myself sob, and then I remember that he is in a better place wherever he is now and that he is watching over me telling me he is all right. Tony is soaring over all of us, enjoying his next journey.



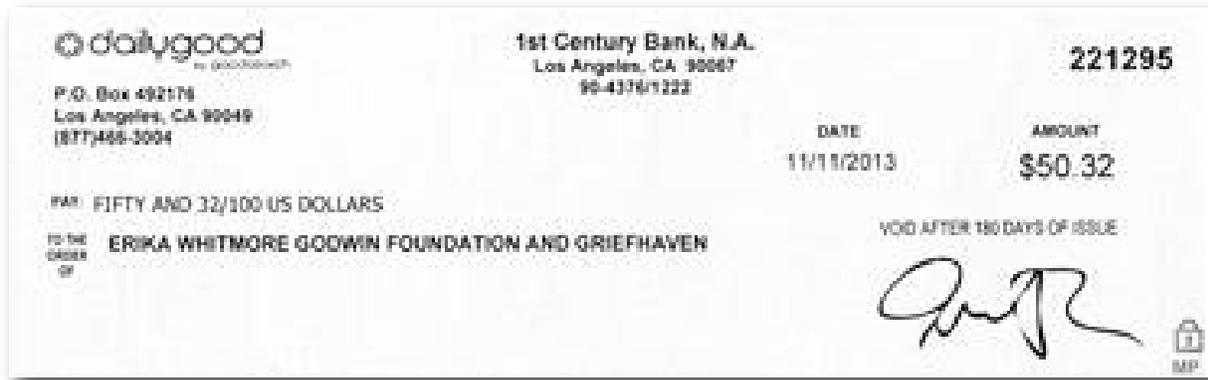
Amanda Dunn is a creative writer from Australia who lives in Southern California with her

husband and young son. After watching her older brother struggle for more than 20 years with addiction and dealing with his untimely death, she wrote about her experiences to help herself and others cope with their losses. Through her illustrated fable *There Are No Monsters in Heaven*, she encourages us to remember that those we have lost are now in a better place.

Amanda's book is available at blurb.com and as an ebook through Apple's iBook store, Barnes and Noble, Smashwords, and Kobo or on the griefHaven website.

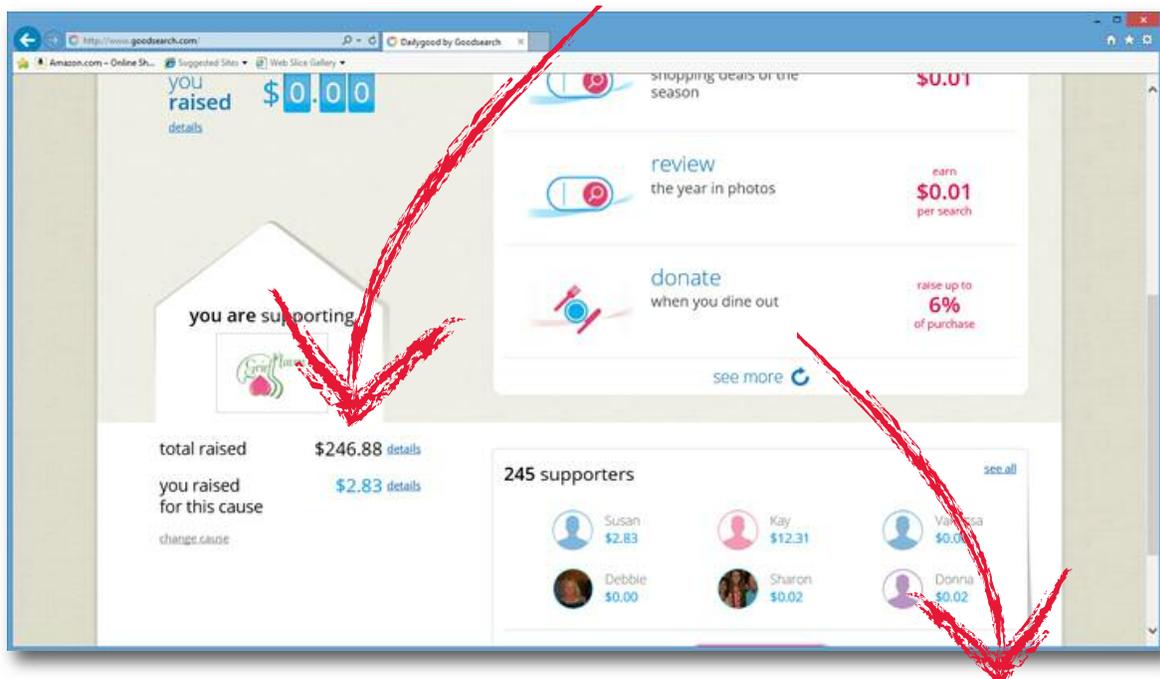
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