

## *Turning Poison into Medicine*

A Speech Written by Margaret H Baker For The 2000, Annual Alopecia Conference

I opened the little white box, and behind my great grandmother's engagement ring there was a heart-shaped piece of paper that said, "White Clouds Embrace Mystical Stone." My husband has practiced Buddhism throughout much of his adult life and this Zen koan summed up our growing relationship, and the gift of the diamond ring. But to me, this phrase holds additional meaning: I truly believe that my alopecia Areata has been something of a mystical stone-and certain people and events have embraced this mystical stone. It protects me from being lost in life. Most of us have asked the "Why me?" question throughout much of our lives. Why did this have to happen to me? No one else around me seems to have this condition, why am I alone? What did I do to deserve this? Why can't I just be normal?

Along the way, most of us slowly learn to accept the difficult hand that life has dealt us. Life goes on like a winding road with its twists and turns bringing joys and sorrows. What is to be learned from this road that we have set foot upon? How do you stay strong when the path is steep and unsteady and your soul is frail from the pain in your heart?

So how does one turn a bunch of philosophical questions into answers? I want you to stop and think for a moment. Think about what your alopecia Areata has taught you what are the recurring themes in your life and existence?

My life has been about adapting to change and teaching compassion. Early on, I had to accept that I was losing my hair to alopecia Areata and then Totalis. Physically, I wasn't like the other kids. My hair had fallen out in huge clumps, exposing my scalp. When I turned to wigs to fit in, I still stood out from my peers. I was vulnerable and fragile. In high school, I learned that my dad was epileptic and then mentally ill. A year later he left my mom and started a new life. This event turned out to be a bittersweet blessing, forcing me to become more independent. As I approached my senior year, I encountered another big change-I went to Chicago to study music. And with this came the shedding of my "second skin" of twelve years-the wigs that I had come to know and accept as part of my identity.

I came upon this peak with great anticipation, as I knew that this was the only key to unlocking my true self. Freedom from conformity. I was finally becoming okay with who I was (internally and externally) and my need to share it with the alopecia Areata community.

Now I was in the clear ... or so I thought. Little did I know that I would be tested again, four years later. However this time would be different. Two weeks after moving to New York to pursue a modeling and acting career, a seizure revealed a cyst in the left ventricle of my brain and I had to have brain surgery. This life-altering twist appeared at an exciting, though very uncertain, time in my life. Not only had I just given up the wigs, I was learning to adjust to a new city. Moving to

New York was like a breath of fresh air for me. It really seemed like a place where anything might be possible. I felt honored to be able to walk the crowded streets and turn heads. I had turned my poison into medicine, so why was I being stopped? Was this a reminder that I am not invincible? Was I so wrapped up in my own life that I had forgotten the people that care for me? Mysterious blessings often appear as obstacles that test our character. Their reward is immeasurable. Alopecia Areata has acted as the mystical stone in my life and the clouds have always been there to embrace me: countless people that have touched my life-my husband Tony, family, friends, and teachers, and each and every one of you. What have the "clouds" been in your life? We all have these angels... When I look around at all the people at the NAAF conference, I see tremendous beauty. I also see pain and incredible courage. You are my family and I love you, so I am going to share my secrets for turning the "poison" of alopecia Areata into medicine.

My life with alopecia Areata was not always a happy one. Like most of you, I had years of suffering before I realized the incredible advantage that had been put before me. I came into this family when I was seven. The eight-month period in which I lost the hair on my head seemed like twenty-four hours, and I felt powerless. My sister had a full head of hair. Why did this happen to me? The other kids in my class had concerns of their own: "How did this happen? Can I catch it?" I had no answers, and with every passing day more questions came...Will my hair ever grow back?

After beginning a new elementary school, I had to adjust to the growing number of bald spots on my head. They were becoming harder to hide, and the various treatments stimulating hair growth only worked for a short time after a few days, a new spot would appear. I remember blaming my mom for the very last haircut she gave me. I was eight years old and desperately wanted to hang on to every surviving lock. My hair was coming out in the shower, on my pillow, in the hairbrush, and in my hands! Suddenly my pigtails were nothing more than a few strands of scraggly hair. This was emotionally devastating as a little girl entering the age of sleepovers, hair, and makeup! Soon, wigs became my only option.

There were some great hats and it would have been nice to go natural, but this didn't seem possible seventeen years ago. Besides, wigs gave me the option to have hair like the other kids. One of my fondest memories is of visiting the wig shop after a bad day at school. I'd go in and try on all the different hairstyles, and I'd look in the mirror, smile, and feel beautiful. My mom always tried to make the best of the situation. Laughter pulled us through the toughest of times! I attribute much of my current confidence to Mom's continued support over the years, and today, the support of my husband, Tony.

Unfortunately, back when I was in grade school, I still stood out from my peers and had to answer to more questions and ridicule. My sister was embarrassed if I walked around the house without my wig when she had friends over. She also had to answer to people asking her if I wore a wig. We are only eighteen months apart and have had many moments of sibling rivalry! At least she couldn't pull my hair, but I

could pull hers! My sister has remained a loyal friend and I am thankful for our relationship.

Although it was tough at times, I always knew who my real friends were. For many of my childhood years, my mom was my best friend, and today we are both eternally grateful for the bond that we share. I carried on through school, slowly adapting to my surroundings and changing body. As I got older, the wigs got better. The synthetic-net-base wigs were eventually replaced with custom-made human-hair vacuum prosthetics. But as my collection of these things grew, so did the weight of my insecurities. I felt heavy with the fear of being found out and teased even more so. The boys were especially cruel. They liked to corner me on the school bus and say, "Is that a WIG?" or my favorite, "Do you have horns growing under there?" Kids have such colorful imaginations! It's never easy being confronted with a physical difference, which tests human compassion on a daily basis. Friends and family are so important and we mustn't take them for granted.

I believe that we meet one another for a reason; so many people have made such an impact on my life. One of these people was a high-school friend of mine. On a hot summer day while swimming in the ocean, an enormous wave pulled me under the water, taking my wig with it. "Oh no," I thought, feeling trapped and embarrassed. There I was completely exposed for the entire world to see. Boy, was I timid! I called my friend, who brought a towel to the rescue. We laughed, thinking of the shock that would come to the person who stumbled across the wig while combing the beach for shells and other treasures! After the swim, while watching me apply makeup in the mirror, she said, "You look really beautiful without your wig." I remember feeling slightly embarrassed, but that moment became a turning point in my young life.

Two years later, while in my senior year of high school, I began to contemplate what it might be like to lose the wigs and bear the world bald. It began with dreams...What would it be like to share my difference? Could the poison that haunted me for so many years actually be used as medicine? After all, it is supposed to be good luck to rub a baldhead! But how would others react to me? Suddenly the unknown became unbearable. I had to give my self and the world a test. It was scary at first; I felt exploited and raw, like a blank canvas waiting for the paint-but I found strength through writing about my experience. It gave me a tremendous sense of hope. All of a sudden I began to believe in my beauty and to see it in others.

One of the ways in which beauty is best defined is through the soul! I am always touched when I meet an open soul. An open soul to me is someone who has learned to overcome an obstacle by using it to their advantage-they test the odds and show others that anything is possible. I have been blessed by many open souls in my life. When I attended a big dinner benefiting America's Athletes with Disabilities, I met a lady who was setting out to become the first deaf African American lawyer! Then there was the man who was a world-class climber though he was missing one of his legs! Or I am reminded of my actor friend, Mark, who suffers from cerebral palsy but works in films and television along with his helper dog, Broch. Everyone of these people uses their "poison" in a positive way, and the life they lead is rich and

rewarding. Nobody is perfect, but some of us are created different because we are capable of teaching.

My lesson is one of compassion. I go to NAAF conferences to raise awareness, to teach the world about alopecia Areata. There was the time in a New York City subway when I noticed some teens laughing at me. Although I could've easily ignored them, I thought, "No, I have a chance to make a difference." So I turned around and said, "Actually, I lost my hair to an autoimmune condition when I was little." "Oh, my sister's friend has that," one of them said. The conversation concluded with the fifteen-year-old boy, waving goodbye to me from the subway platform. I smiled and waved back thinking, "That was worth it!"

Now there are times when I don't say anything, and I later end up wishing that I had. There was an incident just the other day: I was walking my dog past an elementary school and this girl shouted "Ewwww!" at the top of her lungs. I just didn't have the strength to turn around and set her straight, so she will probably continue to be rude to people who are different, without thinking twice about it, until someone teaches her to have compassion. Some people may not ever understand, and we must be willing to accept that. We need to be tolerant too. If we use anger, then hate and ignorance can never be stopped. Of course, it is much more fulfilling when someone wants to listen, and often people do—curiosity is a part of human nature.

Being able to talk about my alopecia Areata gave me an incredible sense of empowerment! I began to hold my head high in public, feeling confident and not looking back. Suddenly, people started giving me compliments! Was I actually exuding beauty?

I feel that by using what God gave me, I can become a latter-day Rosa Parks. After all, she turned the poison of racial discrimination into medicine and became a legend! Being part of this family is a gift! When I arrived in New York in 1998, I was modeling for artists and photographers. This was a way of performing in a community where I was fully appreciated. Today I still model but my primary focus is film and television. I became a member of The Screen Actor's Guild in 2000 after doing a commercial for Mt. Sinai Hospital.

Since then I have been featured in many films, the latest being Spiderman in which I play Punk #2, Lucy Lawless's sidekick. Being bald on the job gives me the chance to tell people about alopecia Areata.

They often want to know how long I've been shaving my head and then I tell them "Actually it's natural. I have a condition called alopecia Areata. Have you heard of it?" By being up front, I have found that people are more receptive. If they know that you are comfortable talking about it, there is little to criticize; and often you end up outsmarting them!

Although my unique look is an asset, I will plop on the wigs for certain character types. Once when I was working on the set of Ed, I brought four different wigs with me. At the beginning of each scene, I would change my hair. Pretty soon I had the

cast and crew in stitches! It was so much fun. I am kind of known amongst some casting directors as "the bald girl with all the wigs." I don't mind. It is really nice to be remembered in "show biz."

Hopefully someday I will be starring in films. Entertainment is my passion and I feel extremely fortunate to have the opportunity to use alopecia Areata to my advantage. It has become a therapeutic way of life for me. I will share my story with anyone who will listen. And I often see a brother or sister with alopecia Areata-at least once every two weeks and sometimes even on set! While working on the set of Zoolander, I sat two seats away from a guy with alopecia Universalis. Being afraid to assume that I had a similar condition, he asked me how often I shaved my head. When I told him it was alopecia Totalis he responded with excitement and a sigh of relief. There is also Michael, the bike messenger I met while walking on Madison Avenue. He stopped me and confessed that he had never seen anyone else with the same condition he had. "Well, there are certainly a lot of us;" I replied. He was one of the first friends I made after coming to New York. And just the other day, as I was putting on my costume in the wardrobe trailer, my friend was conversing with one of the crew who happened to have alopecia Universalis! I looked at him with excitement and tore off the blonde wig shouting "You're a brother! We've got to talk!"

So you see, although we feel lonely and isolated at times, we are never alone. There is a vast sea of Alopecians in the Land of Big Hair! We are the future!

And people do care. Everyone suffers from the poisons of humanity. It's not what you have that matters, as much as the choices you make along the way. We are all on an incredible journey! As teachers, we can give so much back to our communities-whether we choose to talk about our experience or assist others with a different one (such as terminal illnesses, feeding the homeless, or becoming a mentor). The heart is full of compassion-by exercising your heart muscle, through compassion, you can heal!

Of course, you do not have to be vocal all of the time. Even heroes need their downtime. This is when I call upon my support team-my husband Tony, friends, and family. After all, they are there to remind us who we are and what there is to love about ourselves. If we don't do our part, the hate will continue to spread. Is that what any of us want? Being bald in the Land of Big Hair is a glorious gift. So join me in teaching compassion. We have the chance to make a real difference in the world. If you change your thoughts, you can change your way of living. Why waste it?