

*"A baby who died in 1994 during birth at fullterm named Cheyenne Cacciatore was the first stillborn baby in the United States to receive a Certificate of Birth resulting in Stillbirth. Her mother, Dr. Joanne Cacciatore started the movement several years after her baby's death. In addition, a few more U.S. states have legislated a day of remembrance of the stillborn."*



Most of you know her as Dr. Joanne Cacciatore, founder of the MISS Foundation and professor and researcher at Arizona State University. Her expertise is helping those affected by traumatic death. As a mother of five, as she says, "four who walk and one who soars," she understands how these parents are affected by this tragedy. These aspects made her start this nonprofit organization with 75 chapters around the world. These chapters help aid parents whose children are in the process of dying or have already died. As an advocate of "green" mental health care, she is also a member of Associations like the American Psychotherapy Association and more. Her work has been featured in People and Newsweek magazine, the New York Times, Boston Globe, CNN and more.

**Arizona Foothills Magazine: In your words, what is your foundation and your main goal?**

Joanne Cacciatore, PhD: Every day in the United States and beyond, infants and children die. The MISS Foundation has grown from a small, local nonprofit agency, which I founded in 1996 to a huge international nonprofit with 77 chapters around the world. The MISS Foundation C.A.R.E.S. for families who are enduring life's worst tragedy- the death of a child. We can't save children, so we help save their families. We focus our efforts on counseling, advocacy, research, education, and support- thus the acronym C.A.R.E.S.

**AFM: How does it feel to do something amazing and give back and help counsel those in need?**

JC: Well, it's a bittersweet calling without any doubt. The degree of suffering I mean, can you imagine, for a brief moment, what would happen in your family if a baby or a child were to die? Unspeakable and unthinkable loss. Yet, I am able to join them in their suffering and endure the pain with them as we navigate their own unique experience of traumatic grief. Not everyone has the tragic privilege to work with these profoundly beautiful families. The children who died—those are the really amazing ones—from beyond this world, they inspire us to live more fully, love more deeply, and to more fully inhabit our own lives. I feel honored to know all these children through their parents, grandparents, siblings, aunts, uncles and friends.

**AFM: While in college, did you know this was the path you wanted to take? What pushed you into this field?**

JC: This work was my calling. In 1994, my baby daughter, Cheyenne died, from unknown causes. I was catapulted into a dark night of the soul that would literally change my entire world. I could barely get out of bed many days, and I was in deep, dark abyss for a very long time. She died on July 27, 1994, and sometime in October, I made a promise to my dead child that if I survived the pain, because I wasn't sure I would, I would make sure other families enduring this tragedy would not need to endure it alone. I started the MISS Foundation in 1996 making good on that promise to her. I hope one day I will see her again, in whatever way that might be, and that she will smile knowing that I lived up to that promise.

**AFM: Tell us about an experience or moment that has touched or moved you, something you will not forget.**

JC: There are far, far too many for me to describe. I will tell you that I have received thousands upon thousands of letters from people around the world thanking me for this work, from Romania to Africa to Italy to New Zealand. I learn something profound from every family, from every child who died. My heart grows bigger from every experience, and it's truly the most rewarding, albeit tragic, work to which a person could commit his or her life.

**AFM: This foundation is about helping others. What have you learned about yourself?**

JC: I have learned that the capacity for a human to bear suffering is equivalent to their capacity to experience love. The reason for big suffering is big love. From exploring death, from facing death every day, I have learned to truly live. That is a gift, a gift I believe few know or discover. A gift for which I am grateful.

**AFM: What is the process of helping families discover hope?**

JC: I'm not sure I see that as my role. I join them in their suffering so they do not suffer alone. I know many do experience hope as a byproduct of having a willing witness to their pain, and that is a truly magical thing—to feel despair and then to discover there may be hope. I suppose I help them be with what is true for them, moment-by-moment, and the hope and the healing come, organically, from that relationship.

**AFM: You say, "I don't want to merely survive. I want to become." How does this foundation make you "become"?**

JC: I become more fully human by being a willing student of life. Every day of my life I am becoming more fully human. I learn from my students at ASU, I learn from the ant working in my yard and the clouds moving across the sky. I learn from my work at the MISS Foundation. I hope I'm becoming and learning and growing and evolving from now until I take my final breath. I believe that hubris incites stagnation, and I never want to be in that place. Humility is key. And death keeps us very, very humble.

**AFM: You also said, “The more I am present with the reality of human suffering—my own and others—the more genuine and full life I am able to lead.” How does this make your life more fulfilled?**

JC: It is impossible for anyone to escape human suffering. Someday, someone you love very, very, very much will die. And you will experience grief; profound suffering that will bring you to your knees. No pill, no wand, no magic spell, no prayer or mantra or bottle or book will fix it. Human suffering is a part of the human experience. When I constrict my willingness to enter the dark places, to truly feel the suffering of my life and my loss, then I also restrict my capacity to feel the kind of big, rushing, capacious love and joy and passion for life. The poet, Gibran, said that only ‘he who has looked into the eyes of sorrow will ever truly look into the eyes of joy.’ I absolutely believe that. We numb or distract or evade or deflect any of our painful emotions and we risk fragmentation our true selves. Our world becomes very, very small and very limited.

**AFM: What impact do you hope to have on the future?**

JC: I hope to see many more skilled practitioners in the area of traumatic grief. I direct the Graduate Certificate in Trauma and Bereavement program at ASU to help train specialists in this area. Frankly, there aren't enough trained providers in the United States to help the numbers affected by traumatic death. I'd also love to see the MISS Foundation offices in all major cities around the world. We have a misperception that traumatic death is a ‘family’ issue. It's not. It's a social issue that affects every one of us. The effects of child death, in particular, are far more enduring that people realize. I've spoken to many families who talk about their grandmother's loss and how ‘she was never the same after that’ or how ‘our family changed forever.’ We can, together, create a more sane and compassionate world for the bereaved. But it begins with education and a willingness to tolerate very, very painful and traumatic human experiences.

So ultimately, before my own death, I'd love to see the world transformed into a more tender and compassionate place for those suffering. Those are some big aspirations, indeed!

**AFM: To those who want to help, what do you recommend?**

JC: We desperately need funding. As you can imagine, the topic of infant/child death is hardly sexy for grantors, and thus we struggle obtaining financial support from philanthropic groups. We need skilled board members who can help in meaningful ways and who have connections to key community leaders. If folks are interested in our mission, a mission of the heart, mind, and soul, please feel free to contact Kathy Sandler, MSW at [Kathy.Sandler@missfoundation.org](mailto:Kathy.Sandler@missfoundation.org) or call the office at 602.279.MISS.

Many, many thanks for reading about our organization!