



LIFELINE

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A Healing Soundscape in Sophia's Garden: Sound Therapy Supports Family Challenged by Daughter's Lysosomal Storage Disease

An Interview with Karen Herzog and Richard Sachs, parents of Sophia Herzog Sachs

By Shelley Zulman

A baby girl with soulful brown eyes summons sounds of survival in Palo Alto, California. Sophia Herzog Sachs suffers from an extremely rare lysosomal storage disorder called Niemann–Pick Type A. Sadly, life expectancy for babies like Sophia is 3 years. Still, at 27 months, Sophia is holding on, and her parents are doing everything they can to change her diagnosed destiny.

Karen Herzog and Richard Sachs, Sophia's parents, radiate inspiration, strength, love, and hope. They have resolutely deflected sorrow and have worked relentlessly to create a nurturing environment for their daughter. They have openly shared intensely personal experiences with a growing community of more than 400 people—including friends, family, health practitioners, researchers, social service agencies, and volunteers—who have rallied around Sophia. With their community, they have grown an organic vegetable garden; decorated their home with symbols of Eastern and Western prayer and healing; and welcomed the sounds of a powerful therapeutic tool: music.

Sophia's parents credit Herb Moore, a close friend, musician, and creative explorer in the realm of sound, for much of the outpouring of music into Sophia's life. Wishing to evoke positive metaphors for Sophia's disease, Moore correlated the DNA sequence of the gene responsible for

making the enzyme Acid Sphingomyelinase (ASM) with musical notation. (In Sophia's case, a mutation in this gene has deprived her of enough ASM to effectively break down lipids.) He used synthesizers and also recorded and applied Sophia's own vocal sounds to create nurturing music for her. His goal was to both capture her playful spirit and creatively symbolize healing energy. The result is an artistic composition of personalized music on a CD called "Sophia's Garden." Community healing, says Herb, is about applying each contributor's



particular skills and talents “from a place of passion or joy.” He explains, “My passion is music. That’s the place where I feel personally, emotionally, and spiritually connected.” When he plays guitar for Sophia, Herb notices the calming effect of the music. “That’s probably a big part of healing: relaxing,” he says. His goal in creating the CD for Sophia was first of all to soothe her as the primary audience and second to support family and community.

Recently, Karen and Richard have established “Sophia’s Garden Foundation” to advance their vision of a global approach to healing. In the following interview, Karen and Richard discuss their personal experiences with sound therapy as a healing tool.

Q: When did music first play an influential role in Sophia’s life?

Karen Herzog: I sensed that she was musically inclined from birth. For the first 17 months of her life, I breastfed her to music: lullabies, classical, Reggae, Latin, African, Indian, and Brazilian. I said to Richard, “I think she’s either going to be a musician or a dancer.” Sophia would rhythmically move her hands and arms to music, especially to Fred Astaire’s Top Hat. We often danced around the house while I carried Sophia in a Baby Bjorn or sling. Music deeply comforted and moved her.

Q: Your family friend Herb Moore composed unusually personal music for your daughter. What was the significance for you and Sophia?

Karen Herzog: When Herb created the Sophia’s Garden CD, we were thrilled. We had been using sound and movement therapies for palliative care and Sophia’s sleep apnea. Herb’s music felt like a missing link. Until late 2002, Sophia never napped and was frequently up during the night. When she did start napping, we continuously played the first track. She slept so soundly to Herb’s music. I have often imagined the music filling the room with

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ASM—the enzyme she is missing—and her body responding by producing it naturally. I feel that the music reaches her on a spiritual level, thereby supporting the healing process. Sophia's CD has given me strength and is important to our community's continued hope for a cure.

Q: Does Sophia prefer particular musical styles?

Karen Herzog: Sophia's Garden CD is a particularly important one because it actually addresses her disease. We also rotate different styles of music that resonate with Sophia. For example, I started playing Cesaria Evora and Bebel Gilberto for her when she was an infant. We were amazed at her sophisticated taste. It turns out that one of her genetic defects is a rare Portuguese stop-codon mutation that we jokingly believe accounts for her taste in Brazilian music.

Q: In what ways does Sophia respond to music?

Karen Herzog: Music is a healing balm that reaches Sophia in a way that other therapies cannot. Most of the time, Sophia remains motionless in a supported, reclining position, but music moves her in profound and subtle ways. She responds to motion therapy performed to musical rhythms she likes. When we play calming music and massage her with therapeutic essential oils, she relaxes her body and quiets down. When we play upbeat music, her spirit and energy level rise. She subtly moves her feet and hands to sounds. The gleam in her eyes, the window to the soul, also reveals her emotion.

Q: How does music influence Sophia's communication with you?

Karen Herzog: Sophia primarily expresses herself through her voice and eyes. She has a beautiful musical voice described by Herb to be in perfect pitch. She absorbs and mimics sounds like a sponge, cooing to indicate contentment. When she is upset, she can cry out and seem to be saying, "Ma ma." People comment on Sophia's incredible, penetrating, deep brown eyes. Some have said that Sophia can look right into your soul and see exactly who you are. We call this connection the "Sophia Effect," since it prompts a flurry of creative energy. Music is intuitive and powerful.

Q: Can you describe how music supports you personally?

Richard Sachs: Music has enhanced my spiritual connection to our supportive community. Many people in our community have found Sophia's CD to be inspiring. They say that it helps them navigate through life's challenges.

Karen Herzog: Music not only has soothed my grief and welcomed peace into my life but also has helped bond Sophia and me in a warm and healing relationship. Music is transformational. It allows me to actualize and understand my feelings at a core level. At times, I've consciously played sad music because it has helped me to reach the sadness deep inside me. I want to touch that sadness and thereby touch my humanity.

Q: Do you recall a particular incident when music changed the atmosphere?

Karen Herzog: A Pathways Hospice intern and Stanford medical student was so enthusiastic about Sophia's integrative healing circle and Herb's

music that he ordered the Sophia's Garden CD online from my computer during his housecall. He said that he would never forget his visit with Sophia.

Q: What are your thoughts for other families interested in sound therapy?

Richard Sachs: We hope our story will inspire families to explore music as a healing tool. Turning our experience into something that can be helpful to other people adds to the positive energy in our family and our effort. That's a big part of what's kept us going: knowing that we can pass on what we do to other people.

Karen Herzog: Other families may want to engage music to stimulate internal movement, cause relaxation, or reversely, encourage stimulation. Sound therapy adds to the quality and integrity of our life and strengthens connections. Don't get me wrong; Richard and I have our down times, but we continually reframe what's happening. That reframing is helping us to cherish our time and to live by our values and by example. Sophia has a strong purpose in her life, as we all do. This experience has forever changed all of us who are touched by Sophia and her story. That's life, and that's beauty. Sounds lyrical, doesn't it?

For additional information on Sophia's story and how you can help Sophia, please visit www.sophiasgarden.org. To purchase Sophia's CD, please visit <http://www.melosync.com/ntsad>. Shelley Zulman is a freelance writer/editor and consultant in Santa Cruz, CA.

She can be reached at shelley@publishconsulting.com.