

The Power of a Guitar

(from Arts for Health: Music by Eugene Beresin, pages 82-84)

“Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.” ~ Susan Sontag

In 2001 I was the mom of a teen age son who played a mean guitar, could hold his own on a drum set, fronted a band with his friends, and soloed in the jazz band at school, Nick had also just been diagnosed with cancer of the bile ducts, a rare and usually fatal disease. A life that was overflowing with friends, music, and unlimited possibility rapidly disappeared as hospital stays, radiation therapy, chemotherapy, surgeries and scans soon enveloped Nick and our family. Nick’s world as a musician, a lacrosse player, a student leader came to a screeching halt as what was most important to him and gave him joy vanished. Music was central to Nick from an early age. A precocious child, he was fascinated by the Beatles much to the chagrin of preschool and kindergarten teachers who tried to steer him toward more traditional kid singers and songs, like “Wheels on the Bus” when he was much more interested in “Yellow Submarine”. By the time he was in first grade, Nick was recording mix tapes of Beatles songs for family members with his own running commentary on the songs and lyrics. In retrospect, his study of the Beatles and their music introduced him to an ambiguous, complex and challenging world well beyond his years. Nick got his first electronic drum set while in preschool, but soon envisioned himself as much more John Lennon than Ringo Starr.

Nick learned all he could about playing the guitar, forming bands with friends and performing with panache on the stage with the middle school jazz band.

As parents, when your child is diagnosed with a life-limiting illness you quickly move into survival mode. Your world becomes focused on finding a way for your child to survive their illness. Survival is key to everything you think about night and day. My husband and I immersed ourselves in researching and obtaining the most state of the art medical and surgical treatment protocols and interventions and assembled a dream team of highly acclaimed medical specialists at one of the nation's premier academic medical centers. Nick's cancer treatment consisted of multiple inpatient stays, and when able to go home, returning to the hospital for twice a day outpatient radiation therapy, chemotherapy and frequent blood transfusions. Nick had a catheter placed in his chest to provide nutrition and medication. Nick suffered severe side effects of both his disease and its treatment. With his immune system compromised, protecting him from normal environmental germs became paramount. Several weeks into his treatment Nick said to my husband Paul and me "I just want to be a kid again." In that moment we recognized that we had all become unintended citizens of the kingdom of the sick without a map or a way to navigate back to the kingdom of the well, even for a short visit. It then became so obvious what needed to happen — Nick needed to be part of his world again, he needed his guitars, and he needed to make music.

One memorable night, after Nick had been readmitted to the hospital, I walked into his room to find his doctor, an esteemed senior leader in the field of pediatrics, with feet propped up on Nick's bed, simply listening to a 14 year old riff some Beatles tune on his

prized turquoise hollow bodied electric guitar— it was magical. For me, it was a lasting gift of the recognition of the healing power of music for all of us in the room that night. The simple, yet profound act of making and listening to music connected us all in a universal experience — and for that bit of time Nick received his passport back to the kingdom of the well. Nick died a few weeks later, but the incredible healing that music brought him and those around him remain indelible in our minds. Beatles music still plays in our house. connecting us to a boy gone much too soon and reminding us that a guitar can be powerful medicine.

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