

## ***Brief Encounters with the Taos Institute***

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### **The Power of Patient Advocacy: An Example of Relational Healthcare**



By Kathy Clark

I write briefly to highlight the power of patient advocacy, in this case, the power of both the patient and his mother. Anthony, his mother and father, physicians, nurses, administrators, and other healthcare practitioners worked with, questioned, listened to, taught, demonstrated, and, most of all, appreciated each other to not only save Anthony's life, but to ensure that he have a bright future.

Anthony Galarza was diagnosed with acute lymphoblastic leukemia in 1997 when he was 8 years old. Diana, Anthony's mother, became his primary advocate, vigilant always as she worked with Anthony's healthcare team to fix any mistake, clear up any misunderstanding, coordinate Anthony's care, keep the channels of communication open, and always express her gratitude to all those healthcare practitioners who worked tirelessly to care for Anthony. Although the focus of Anthony's treatment herein took place five or more years ago, his story is instructive, very powerful and timeless.

Kaiser provided Anthony's medical care from his 1997 diagnosis to the present. After Anthony's diagnosis, he began a three-year course of chemo, followed by maintenance chemo, after which he was taken off all drugs. Four months later, Anthony required a stem cell transplant, with his sister as the stem cell donor. Following that, Anthony was cancer free for almost five years, at which point he was diagnosed again with the same leukemia, stage 4. Anthony and his family were told that a second transplant could be attempted, but the chances of success would not be great. Aside from a second transplant, there wasn't much that could be done. At that point, Anthony had the good fortune to be accepted in an experimental University of Minnesota umbilical cord transplant program, using stem cells from umbilical cords of two infants (two umbilical cords were necessary since one couldn't provide enough stem cells for a teenager). The transplant, although delayed, as explained below, was very successful for Anthony.

In July, 2008, shortly before his second transplant, Anthony developed pneumonia and was hospitalized at Kaiser, Oakland. Difficulties with Anthony's care in the hospital became immediately apparent. Fortunately, Diana was at Anthony's bedside constantly, observing problems and questioning his care. Some of the problems she observed included equipment not working in emergency situations; wrong medication; inedible, non-nutritious food; insufficient patient follow-up; hospital-acquired infections, resulting in repeated pneumonias; cross-contamination; and the combination of too many patients and not enough nurses.

Diana, upset because Anthony continued to have many avoidable and unacceptable problems during treatment at Kaiser, arranged a meeting to address all the problems in Anthony's healthcare, none of which was attributable to Anthony's cancer; instead, inadequate care and unsatisfactory conditions were her concerns. Diana and her husband, vigilant advocates, led a series of meetings with Anthony's healthcare team, all listening intently, unafraid to address any and all issues as they arose, and making

changes whenever necessary to the entire system. Diana never sought to litigate any issues associated with Anthony's care or get anyone fired. What she wanted for Anthony, she got: listening, learning, communicating, compassion, teamwork, and improvements.

When Anthony reached 17, he began acting as his own advocate, familiarizing himself with many procedures. During one visit to the ED, the nurses didn't know how to deal with central lines and did not know the protocols for cancer patients. To prevent infection, Anthony's blood needed to be drawn in a specific way. Anthony, knowing all the steps, told the nurses what to do. He wound up drawing his own blood, creating a learning moment for the nurses. At another time, Anthony, watching nurses bring him antibiotics on an open tray, told the nurses that antibiotics, due to their light sensitivity, needed to be covered. Perhaps because of the culture of healthcare, because of his age, because he was a patient, or some combination of all three, Anthony had to be assertive to be heard and respected. But heard he was.

Diana, alone at first, later with Anthony (after he moved into adult care), speaks at quality conferences and to the Kaiser Leadership committee. Both the president of the Kaiser Board of Trustees and the Director of Health and Quality have interviewed both Diana and Anthony. Kaiser calls on them as one of its "expert" families, bringing them into the system to work together with healthcare providers to improve the quality of patient care.

Diana said the physicians and administrators have been very caring and genuinely interested in their experiences and recommendations. Anthony is part of many research studies. Diana says: Something will be learned about what he went through. Diana said, quite simply: Anthony is still here. When physicians can see the face of the child, of Anthony, and hear from him, they "get" the patient experience.

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