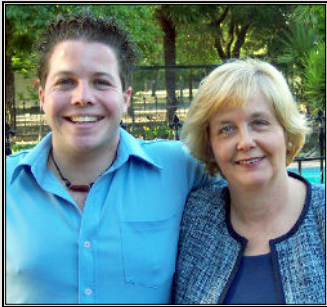


## THE MOTHER'S BOND

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My son Alex suffers from hydrocephalus, an uncommon condition that forces an abnormal accumulation of fluid inside his brain. His condition is treated with insertions of shunts into his skull to let the excess fluid drain. If the shunts should fail, Alex could lapse into a coma and even die. Quick and appropriate intervention for my son and other hydrocephalus patients is critical.

Since Alex was diagnosed more than 20 years ago with his condition he has had endless encounters with the health care system. Between ages 6 and 16, Alex had some 20 surgeries, most to replace or repair his shunts. When he was 7 Alex wasn't playing baseball, he was receiving hospice care.

But Alex is a survivor. There are many people, doctors and caregivers to thank for this, particularly one man who was willing to look at a problem in a different way. Because of this man, a bio-engineer, I didn't lose Alex when he was a child in hospice care. That, in turn, spurred me to challenge the status quo.

### A Mother's Story in the Era of Paper Medical Records

Any parent who raises a chronically ill child knows the constant worry a family endures. Our family was always on call as Alex challenged death throughout his childhood. Small changes in Alex, such as mood swings or failing memory, were signals of possible shunt failure.

Worry was also my companion whenever we interacted with the medical system. I prayed the binders that made up copies of Alex's medical record made it to the numerous doctors involved in his care.

Quick access to Alex's voluminous medical history is crucial for his caregivers, whether or not they are familiar with my son's case. His medical record and brain scans detail the nuances in caring for Alex's hydrocephalus and other ailments, which have included seizures, dangerous allergies and pituitary gland problems. Whether or not a treating doctor readily has Alex's full medical record available can literally mean life or death.

I realized this five years ago when Alex was out of state in a small mountain town and had an accident. Having memory problems and feeling out of it, Alex suspected that one of his shunts was failing. He went to the local hospital.

The small hospital treating him didn't have any of his information, including his neurosurgeon contact, allergies and medical history.

Feeling ill and confused, Alex called me from the hospital. But emergency room personnel told me since my son was over 18, I couldn't interfere with his case. No one, including me, could get a hold of his neurosurgeon. I had all his brain scans and medical information, but I was here in Sonoma, California, and he was hundreds of miles away. I could only hope that Alex or the emergency room clerk would convey to the treating doctor that laying my son flat on his back or even giving him antibiotics posed a threat to my son.

It was a terrifying experience and potentially dangerous for Alex. When Alex was a child I was his walking medical record. I always had copies of it, and would grab a copy of every piece of paper a provider ever wrote about Alex's case. But I won't be around forever to do that for Alex. I realized as a mom that Alex's information needed to be easily available to anyone who might need to treat him, especially in an emergency.

The problem is that the health care system is dependent upon easily lost paper records and physician notes and orders that often are too sloppy to interpret. The paper medical record is still the standard. Medicine itself is advancing at mind-boggling rates—and is the big reason why Alex is among the first generation of hydrocephalus patients to reach adulthood—but the nation's health care infrastructure is mired in the past. It's closer to the industrial revolution than to the information age.

To help my son, I did what I could do. I took out a second mortgage, hired some programmers and developed an electronic medical record that a patient or a patient's doctor could access any time and any place. The program, called FollowMe, now helps more than 400 other families, many of whom have children who have hydrocephalus. It's also being used to keep personalized health records for migrant farm workers throughout the western U.S.

While Alex's small town emergency room visit motivated me to take a chance to create an accessible electronic medical record, my inspiration came years earlier.

When Alex was in hospice care instead of second grade, his nurse told her brother, a Hewlett Packard bioengineer, about her patient. In those days, a single shunt was the practice to drain excess fluid from a hydrocephalus patient's brain. But to Jim Rounds, also a parent, common practice wasn't necessarily the best practice. He dusted off old anatomy textbooks, put his engineering skill to work and came up with a better system, devising two independent shunts, to help Alex.

The difference in Alex ever since has been dramatic. Because of the two-shunt approach, which is standard practice today, hydrocephalus patients can lead normal and productive lives that include school, work, extracurricular activities and family vacations. For Alex, who is now 28 and a college graduate, it also meant surfing camp, soccer and now a career in hotel restaurant management.

Just as Jim Rounds helped save my son's life by improving "the standard," I too hope FollowMe can ease the pain of those who suffer from chronic conditions and soften the worry of these patients' families.

It amazes me that even with overwhelming evidence that electronic information systems reduce mistakes and save lives, the majority of doctors today are not using them.

Hopefully, that will change. With personal electronic health records, gone are the days of mothers having to become walking human medical records, keeping binders and boxes of detail close at all times in order to dodge looming slip-ups and medical mistakes that too often cut lives short or cause needless anxiety.

Now, the bond Alex and I share is not mired in constant worry but enhanced by the potential for a better life for him and other kids.