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Op-Ed Contributor

Your Mother Would Know

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IT'S been 14 years, but I can still feel the terror that gripped me when our son's cardiologist asked my husband and me if Wolff-Parkinson-White Syndrome ran in our family.

Getting my husband's family medical history was as simple as calling his mother. But I'm adopted: I didn't know who in my family may have had this heart condition, and it wouldn't be easy to find out.

And yet, my medical history was crucial to treating our son. If the syndrome did not run in my family, the doctor counseled that my son would run an elevated risk of sudden death, and she'd be inclined to perform the corrective operation right away. But its rate of success at the time was just 50 percent. She was hoping she could postpone the operation for a few years until surgeons grew better at the procedure. The difference could mean life or death.

It had never before occurred to me that because I had no medical history, my son didn't have one either. I'd never needed a medical history. Neither did our son, until he turned 14 and began having symptoms.

As a New Jersey adoptee, I could access "nonidentifying" information about my biological family, including the vague medical histories available at the time of my relinquishment in the 1950's. But for the facts that might save my son's life, I would need to talk to blood relatives. EKG's weren't around back then; if a relative of mine had died suddenly, the doctors couldn't have known that it was from Wolff-Parkinson-White syndrome. The doctor told me that the condition "skips around in families," and that, if my son had it, it was very likely that a sibling of mine had it, too.

But I didn't know if I had any family members. I didn't even know my real last name. My birth records were collecting dust in a vault somewhere. New Jersey law forbade me or my son from opening them. If I waited for court orders and hearings, the information might come too late. For the first time, I felt inadequate as a mother. Simply because my son was the child of an adoptee, his rights were being denied.

And so I set out to find my family any way I could. I lied, stole and broke a few laws. I assumed different identities. I called agencies pretending I was someone else. I got people to do things for me that would have gotten them fired if their superiors ever found out. I slipped records in and out of police departments. I copied confidential records and no one but the official who looked the other way was the wiser. I didn't care if I got arrested. All I cared about was keeping my son alive.

I didn't care about protecting the identity of my birth parents. What was their privacy compared to their grandson's life? My adoptive parents' feelings, which had always been important to me, now dropped to the bottom of my list of priorities, too. I no longer cared that they never wanted me to search for my birth parents. Keeping my son alive was infinitely more important to me.

I was a victim of a system that was set up to protect everyone in the adoption triangle except me. And that system was now making my son a victim too.

I found my birth family the hard way and learned that I had five siblings. Luckily, all of them are healthy. But I learned that after my son's ordeal, a second cousin of mine died of a heart condition that the doctors think was Wolff-Parkinson-White syndrome. Sadly, if he had known about us, we could have helped to save his life.

Our son is doing fine now, after three heart operations. The successful one came two years into the search for my family, in response to an acute episode that required immediate treatment. By that time, the procedure was better studied than it had been at the condition's onset. Still, it was a difficult time for us - one that would have been much easier if I'd had access to my birth records.

Both birth mothers' and adoptive parents' rights should be protected. But what about an adoptee's rights? We were too young to voice our opinions and desires at the time of our surrender, so our decisions were made for us.

But we're not children anymore. We should have the same right as any other adult to make decisions. And now the New Jersey Assembly has the power to help us. New Jersey Bill A3237, which would allow adopted adults the right to obtain copies of their original birth certificates, has been waiting a year to be heard by an Assembly committee; the Senate has already passed an identical bill. The passing of this bill would give rights not only to adoptees, but to their children, too.

Carol Barbieri is a songwriter and musician.