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A life or death search for her family ties

By Diane Carlton
The Monmouth Journal



ATLANTIC HIGHLANDS — Carol Barbieri, a resident here, and her twin sister, Kathi, were told they were adopted around the third grade by their parents. Not having much interest in finding her birth parents, Barbieri said, “There was a part of me, as some adoptees will tell you that had a chip on my shoulder — ‘Well, she left me. Why should I look for her?’”

That is until 1991, when Barbieri’s then 14-year-old son, Jonathan, now 31, was diagnosed with Wolff-Parkinson-White Syndrome — a cardiac condition that causes the disruption of the heart’s normal rhythm. During one of Jonathan’s episodes, he presented with an excessive heart rate of 320 beats per minute.

When the cardiologist asked the Barbieris if there was a history of the illness or sudden death on either side of the family, she recognized that obtaining her husband’s medical history was as simple as making a phone call to his mother. But, being adopted, Barbieri had no way of knowing — or any easy means of finding out — about the health history of her biological family.

Whether or not Wolff-Parkinson-White Syndrome was hereditary decided Jonathan’s course of treatment and, ultimately, a life or death scenario for the young boy.

Essentially, sporadic — or non-inherited cases — cases showed a higher risk for sudden death at the time and the Barbieris were hoping for heredity. The owner of two pure-breed Yorkies, Barbieri said, “I could more easily find my dogs’ medical history than my son’s.”

The singer, songwriter, and performer, now 53, has spent nearly 20 years becoming an adoptee advocate for access to original birth certificates in the state of New Jersey, something the state has denied since 1940.

On Wednesday, April 1, Barbieri held a presentation at Borough Hall, here, to tell the story of her race-against-time quest to locate her birth family, inform other adoptees how they can help petition state legislators and present her new song entitled, “Your Secret’s Safe with Me” — a heartfelt piece that she considers her legacy.

Because the current law concerning adoption records in the state of New Jersey was passed nearly 70 years ago and continues to reflect social attitudes at that time regarding illegitimacy, shame and secrecy, Barbieri’s search was daunting one. She was told by doctors that Wolff-Parkinson-White Syndrome “skips around in families” and that, if her son had it, it was very likely that a sibling of hers would have it too. She knew that at least one of her siblings, her twin sister, and her children did not have the syndrome.

If the syndrome did not run in the family, Barbieri was told that Jonathan would run an elevated risk of sudden death and that corrective surgery should be performed right away.

The odds for survival, at the time, were 50 percent and it was advised that the family wait as long as possible to allow for advancements in treatment and procedure of the rare disease.

With the support of Jonathan, as well as son additional son Christopher — then age 10, and supportive husband, Joe, 58, on the home front, Barbieri set forth to question her adoptive relatives, petition bureaus of records and vital statistics, and explore library microfilms searching for any hint of her past.

The secrecy and privacy issues of the existing law forced Barbieri to commit slightly dishonest transgressions which included lying, cheating, stealing and assuming different identities. She did not care if she got caught, Barbieri was strictly consumed with the process of keeping her son alive.

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

After learning her mother’s maiden and married names on various documents, Barbieri could still not locate the whereabouts of her mother or ascertain if she was even still alive.

“When Social Security doesn’t know what happened to you, you pretty much fell through the cracks or are living in Australia,” she said with a laugh.

But the undisclosed tales Barbieri uncovered were no laughing matter.

She was abandoned as an infant and separated from her twin sister for nearly the first year of her life, and that was not the only secret Barbieri discovered during her search. She found out the hard way that she is one of seven “confirmed” siblings from three different fathers and, that in addition there was potentially, another set of twin siblings.

Learning about her birth mother through accounts that included arrest records, police reports, mug shots and newspaper clippings detailing child neglect, Barbieri learned about her mother’s affliction with alcoholism and was told by her mother’s friend — found on a marriage certificate, still residing at the same named address — that her mother had committed suicide 12 years prior to Barbieri’s search.

“I felt like my heart dropped to my feet ... it was stunning,” she said. “At this point I had gotten to know her through her paper trail. I wanted to meet her, but the chip was gone.”

Judy Foster has helped Barbieri’s mission through NJCARE — a grassroots organization that supports honesty in adoption through educational outreach and legislative advocacy. Foster is the state representative to the American Adoptive Congress (AAC) and is a birth mother who remained silent for 37 years, fighting diligently for adoptees to be able to gain access to their original, not amended, birth certificates.

“I am an advocate because I believe this is a civil rights issue,” she said. “Adoptees deserve the rights to their heritage and updated medical information.”

In stark contrast to Barbieri’s story, Atlantic Highlands resident Lin Howe, who attended the seminar at borough hall, had adopted her daughter through Family Options in Red Bank which specialized in “open adoptions.” “We read a lot of books and articles,” said Howe, “and felt an open adoption would alleviate some concerns about adoptees not knowing who they were.”

Stating her daughter, now in college, knows her extended birth family on both sides, including medical history, and can pick up the phone at anytime and speak with her birth parents, Howe said, “Personally, I can’t imagine not being able to find out your biological roots. I’m so happy my daughter has hers.”

After three successful heart surgeries, Jonathon Barbieri is now healthy and living in Lyndhurst. He received his most successful surgery two years after his mother’s search began when the procedure was better studied than it had been at the condition’s onset.

Ironically, Wolff-Parkinson-White Syndrome research now shows the reverse findings are true: heredity cases have a higher risk for sudden death.

After her son’s ordeal, Barbieri learned a second cousin died suddenly of a heart condition the doctors believe was Wolff-Parkinson-White Syndrome. About the advocacy towards amending the New Jersey state law, Barbieri said, “Many people believe that it’s just birth families being able to help adoptees — it’s not. Adoptees and their children have the ability to help birth families too. It’s a two-way street.”

In addition to writing her catharsis in song, Barbieri is in the process of telling her long and arduous truth in a book currently titled, "Adopted and Clueless" and will be giving her presentation on April 26 at the 30th Annual National Adoption Conference in Cleveland, Ohio.

Petitioning the state legislature each month by telling her story in Trenton, Barbieri hopes her presentations will move other adoptees to assist in getting Bill A752 passed in the Assembly.

Acknowledging the rights of both adoptive and birth parents, Barbieri questions the rights of adoptees and said, "We were too young to voice our opinions and desires at the time of our surrender, so our decisions were made for us. The passing of this bill would give rights not only to adoptees, but to their children, also."

For more information about Bill A752 or to find out how you can petition the state legislature, visit www.nj-care.org.