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Huntington's disease and the perils of adoption

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

Blog Archive
- ► 2021 (12)
- ► 2020 (16)
- ► 2019 (19)
- ► 2018 (16)
- ► 2017 (14)
- ► 2016 (13)
- ► 2015 (24)
- ► 2014 (24)
- ▼ 2013 (30)
  - ► December (3)
  - ► November (3)
  - ► October (3)
  - ► September (3)
  - ► August (2)
  - ► July (1)
  - ► June (1)
  - ► May (3)
  - ► April (4)
  - ► March (2)
  - ► February (3)
  - ▼ January (2)
    - Junior Seau, Super Sunday, and our most important ...
    - Huntington's disease and the perils of adoption
- ► 2012 (26)
- ► 2011 (33)
- ► 2010 (26)
- ► 2009 (21)
- ► 2008 (7)
- ► 2007 (7)
- ► 2006 (4)
- ► 2005 (17)

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FRIDAY, JANUARY 18, 2013

Huntington's disease and the perils of adoption

Because Huntington's disease is inherited, its sudden appearance can send family relationships into a state of shock.

Many HD families can trace the disease back over generations, but in some, like mine, it appears unexpectedly.

Adoption of gene-carrying children generates another kind of surprise for both the unknowing adoptive parents and the adoptee.

The story of four HD-stricken daughters born to Dianne M. Travers, who died of HD in 2010, reveals the almost surreal perils of adoption when HD is involved. Their story also highlights how genetic testing, increasingly common in the biotechnological era, can open up unexpected and disturbing doors.

Figuring out a puzzle

The story of these women came to light because one of the sisters, an adopted child who is today the 47-year-old Lisa Davenport Boudreau, in March 2012 discovered the identity of her birth mother after an 18-year search.

An Army combat veteran, Lisa commenced her search at the age of 30 in 1995 after retiring from the service on disability resulting from post-traumatic stress disorder.

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Lisa Boudreau during Army days (personal photo)

“It was like a puzzle, putting a little piece together at a time,” Lisa told me in a series of recent interviews from her home in Wilmington, NC. She and her sisters were willing to share their both exhilarating and painful story in an effort to raise consciousness about both the tragedy of HD and the challenges of adoption.

Lisa’s adoptive parents had told her that they raised her in a closed adoption, which withholds the identity of the birth parents. Knowing her parents would be reluctant to help, Lisa at first proceeded on her own, without knowing the name of the agency that had handled her adoption.

Acting like an investigative reporter, she sought her roots by compiling a list of women who’d gotten pregnant around the time of her birth in 1965 in Fargo, ND. She also looked for Fargo babies born that year and poured over census reports and microfiche of area newspapers, hoping somehow to find a scrap of news about her entrance into the world.

In 2007, with her four children from two previous marriages old enough to allow her more free time, Lisa devoted herself to the task full time. She first contracted a private investigative firm specializing in assistance to adoptees. Despite paying a $2,000 fee, she got no results.

Lisa was finally able to obtain from her adoptive mother the name of the agency that had handled her case, Catholic Charities of North Dakota, to which Lisa paid $500 in fees for a document certifying her nationality and birth weight and for the agency to begin a search for her birth mother. This crucial step allowed Lisa to intensify her search.

As Lisa explained, since the 1960s adoption laws have changed to make it easier for adopted children to find their biological parents. “A lot of adoptees want answers,” she said.

However, Catholic Charities delayed in obtaining results, Lisa said.

“I had to have someone put a fire under (their social worker), because in three years they did absolutely nothing,” she explained. “And then, all of a sudden, when I told them I would sue them, in a month they found my mother. I really think Catholic Charities is using the adoption industry to make money."

Catholic Charities told her Lisa that she had no siblings. To this day, she has still not obtained a copy of her birth certificate, which remains sealed in an archive in Fargo.

An identity – and a disease

"Towards the last year of looking for mom, there was something in my gut," Lisa recalled. "For the last three months, I didn't sleep two hours a night. I knew something was wrong. I could feel her pain, even though I never met her."

Finally, on February 27, 2012, Lisa received a call from a social worker at Catholic Charities who had been able to track down her birth mother.

What came next was not just the joyful revelation of her biological mother's identity, but also the shocking news that would instantly transform the lives of Lisa, her husband Bob, her children, and the relatives she had yet to discover.

Lisa learned from the social worker that her mother Dianne had recently spent seven years in a nursing home and had died of a disease of which she had never heard: Huntington's.

"After the call, I got on my laptop," Lisa remembered. "I pulled it up online and read it to my husband and said, 'what is this?!' It was very shocking. Then I had to tell my kids. It was very emotional."

Searching for roots

In piecing together her and her mother's past, Lisa would learn that Dianne, a Native American, had gotten pregnant with her at the age of 16. Later in life, Dianne became an alcoholic and a bit of a drifter, spending time in California, Utah, and North Dakota. When HD killed Dianne in November 2010, she was 62.

Dianne Travers (family photo)

“I missed her by one year,” Lisa said regretfully of her quest to meet her mother.

Lisa would also discover the identity of her birth father, Byron Johnson, an artist and architect of Norwegian descent. He had died at the age of 52 in 1993 after falling off a roof in a work accident.

Yet Lisa’s burning desire to know about her mother’s life only grew. She tracked down Dianne’s second husband, 96-year-old Jim Travers, who recalled that his wife had had a daughter. Lisa discovered both a birth certificate *and* a death certificate for this woman, Sabrina Del Rio, her half-sister, deceased at the age of 31 in 2003.

Querying the nursing home where Dianne had spent her last years, Lisa learned that a California woman named Donna Scott had handled her mother’s funeral arrangements.

Lisa set out to call every Donna Scott in California phone directories. She said she made about 3,000 calls.

“I was searching for someone who knew my mother and might be able to tell me about her,” Lisa explained.

Lisa also wondered if she might have more siblings.

On March 5, 2012, a Donna Scott in Los Angeles received a message from Lisa. Donna phoned her sister Lisa Hein in Alpine, near San Diego, to discuss the mysterious caller who claimed she might be a sister.

Opening up ‘a rattlesnake’s nest’

Despite her suspicions, Lisa B. was no less shocked by what ensued.

Returning the phone call for herself and Donna, Lisa Hein revealed that Dianne Travers was their mother. Both she and Donna were Lisa Boudreau’s half-sisters. Their father was Dianne’s first husband.

"I'm 47, jumping up and down on my bed, when I got the call from Lisa!" Lisa B. said. "My husband looked at me like I was kooky."

Lisa B. spoke to each sister in separate calls. It did not take long for them to broach the subject of HD. The two California sisters recalled their mother's struggle with HD. They also explained why their sister Sabrina had died so young: she had juvenile HD.

Sadly, the two sisters also revealed that they, too, were in the early stages of HD.

"How crazy that her name is Lisa!" Lisa H. told me. "We talked for hours that night, till 4 in the morning California time."

Lisa H., a nurse, spoke enthusiastically about the joy of connection moment but also felt "a giant pit in my stomach" because of the "rattlesnake's nest" of Huntington's that she and Donna presented to their sister.

"It was bittersweet," recalled Donna, who that same day had left her job as an insurance underwriter because of her disability resulting from HD. "We spoke for almost five hours that night. I have the message (from Lisa B.) saved. I will never get rid of it. She said, 'I think we're sisters.'

"We found her on adoption sites and Facebook sites. We said, 'holy cow, she looks like our mother!' You never know what a person is reaching out for."

Donna Scott (left), Lisa Boudreau, and Lisa Hein (family photo)

In May, Lisa B. visited her sisters in California. In July, Donna spent two weeks with Lisa B. in North Carolina.

"When we met, it was incredible," said Lisa B. "We looked at each other and touched each other and poked at each other. Back at the house we took our shoes off and looked at toes and fingers. We all had the same kind of birthmark on our leg. They both were upset at me because I have no wrinkles, and they have more wrinkles than I, and I'm older. They were upset that I had no gray hair, and they did."

Their mother's story

Lisa B. was finally learning about the mother and the family she had always wondered about.

Donna, Lisa H., and Sabrina were raised by their father Salvador Del Rio, who divorced Dianne and remarried. Whereas Lisa B. had spent her life up to March 2012 without knowledge of her sisters, Lisa H. and Donna had known since they were children that somewhere they had another sister, beyond Sabrina.

But nobody yet knew that Dianne's father had died of HD, nor that she, too, was at risk for the disease.

Donna, who spent her summers as a teenager with Dianne and Jim Travers in Utah, talked with her mother about the daughter she put up for adoption. Later, in the late 1980s, when Dianne entered a rehab facility for alcoholics, she wrote a mini-autobiography as part of her therapy.

Reading her mother's writing, Lisa H. understood that "it destroyed her and broke her heart" to give up Lisa B.

Lisa H. was excited about getting to know her mother better and reconnecting with her lost sister. In the hopes of finding the adoptee, she planned to have Catholic Charities send a letter to Lisa B.

Dianne, too, seemed ready for a new life. Around 1988 or 1989, she finished rehab in Utah. She took a plane to San Diego, with a connection in Las Vegas.

But at the Las Vegas airport, Dianne started to drink. She missed her connection and never made it to California.

Crestfallen, Lisa H. didn't mail the letter that might have reached Lisa B. She didn't want her to know that her mother was an alcoholic.

Although Donna had earlier enjoyed spending the summers with her mother, she said that Dianne became "a very mean alcoholic." In the early 1990s, Donna cut herself off from her mother to protect herself, her son, and her husband.

Dianne was diagnosed with HD in the late 1990s. In Donna's thinking, the alcoholism could have been both a cause and effect of the HD.

Sabrina's short life

As Dianne exited her daughters' lives in the 1990s, and with the family still unaware of HD, Donna and Lisa H. became increasingly worried about their younger sister Sabrina's health and behavior.

"Looking back now, we see that Sabrina had the symptoms during juvenile years," Donna said. "She was a dork and klutz in high school. We would call her 'clumsy.' She spoke with a slur. But in fact it was the HD. She started acting differently."

In her 20s, Sabrina frequently forgot to pay her bills, and she neglected to deposit checks. Her car was repossessed for failure to make loan payments.

Lisa H., who has a substantial background in neurological research, paid special attention to Sabrina's symptoms.

When Sabrina could no longer function normally, Lisa H. and her husband Andrew tried to discover the cause of her difficulties.

Sabrina Del Rio (family photo)

“She came to visit us one day in San Diego,” said Lisa H. “It was late 1998. She had had ten accidents and totaled like three cars in the two years before that. I would call her house and the line was dead. Sabrina said the was power out in her neighborhood.”

In fact, Sabrina’s phone had been disconnected for failure to pay her bill.

“She was walking staggering in front of us. Andrew said, ‘There’s something so wrong with her.’” Lisa. H said. “I sat there and watched her walk: ‘Oh my gosh, she has a brain tumor!’

“I had just gotten married, and Sabrina got sick six months later,” Lisa H. continued. “She was sleeping on our couch and trying to figure out what was wrong with her. She had severe depression and anxiety. She had trouble at work.”

Sabrina left her job in Los Angeles to move in with the couple. In 1999, Sabrina tested positive for the HD gene. She was in her mid-20s.

“Lisa, nobody’s ever going to marry me like this,” Sabrina told her sister as she cried after receiving her test results. According to Lisa H., it was the only time she shed tears about her condition.

“I looked at my husband and said, ‘I’m going to have to take care of her. She’s my child. I release you. Go and get married,’” Lisa H. said. “And he said, ‘Nope, we’re going to do this together.’”

Within six months Sabrina was in a wheelchair. A year and half later, she became bed-ridden.

“Andrew and I did it 24/7,” Lisa H. recalled. “We staggered ourselves to take care of her.

“She never complained. She always had a smile and was thankful. She handled it all very graciously. A lot of times people get bad tempers and are grumpy. She stayed her sweet self. She was very grateful. She went into the wheelchair, and said, ‘Oh, what a pretty wheelchair.’”

Sabrina died in 2003, just 31.

Struggling with symptoms

Today the three remaining sisters struggle with the early symptoms of HD.

Donna has battled the depression and anxiety caused by HD. Sometimes she goes more than a day without sleep.

“I’m a very, very patient person,” said Donna, who is 46 and whose adult son is at risk for HD. “For that to change in my character, it blows me away. That’s not me. I’m not one to fight.

“I’m living moment by moment right. I honestly don’t look into the long-term future, because I know it’s not there for me.”

Donna Scott (personal photo)

Like Donna, Lisa H. had to leave her job, where she was “triple- and quadruple-checking” herself to avoid making mistakes.

“I feel like I have a lot of difficulties with memory and organization,” said Lisa H., who is 43 and the mother of two adopted boys, whom she devotedly shuttles back and forth to school and baseball and football practices. “Everything seems like it takes me so long. I can’t even remember my nursing school graduation.

“It’s funny how your desire to have kids is so strong and crazy. Now that they’re here it makes me sadder and makes the disease harder because I wonder what I’ve done to them. We’re so happy but I don’t want them to have to see me like my sister was and spend their lives caring for me. I said to Andrew, ‘We can do this, but I want your focus to be them and not me.’ I was 100 percent fine having me go someplace when it starts to affect the kids.”

A passion for helping others

Lisa B. decided to test for HD. She felt compelled to help her four children map out their lives regarding the disease and family planning. In May 2012, her results came back positive.

“I was getting on the plane to California, with my paperwork,” Lisa B. said. “I didn’t tell my husband the results. The first people I told were my two sisters. I handed them my results after we had lunch. Back home, I told my husband. We cried and cried. I didn’t know about HD, but my sisters watched it happen. If I had found out younger, I wouldn’t have been able to handle it so well.”

Lisa believes she has experienced early symptoms such as depression, but also thinks her perceived behavioral issues could result from the post-traumatic stress disorder and gunshot wound to the head she suffered while in the Army.

“I’ve survived so much with the military,” she commented. “I’m not going to let this bring me down. It’s your attitude.”

Lisa Boudreau (personal photo)

Lisa B. has fought back by becoming an HD advocate. On January 7, she led the very first meeting of the Wilmington-area HD support group that she founded.

Another of her passions is to help reform adoption laws so that adoptees have greater access to information about birth families and are informed of potential health risks.

“A felon has more rights to their documentation than I have as an adoptee,” Lisa B. observed.

Finding her family has brought her “inner peace,” she added. “It’s a very powerful feeling to finally feel that you’re part of something.”

However, she also recognizes that this knowledge is a two-edged sword.

"I love the family I've found, but now I have to carry the burden of knowing about Huntington's and helping people understand how to handle this information," Lisa B. explained. "I also did find my 84 year old grandmother who was married to the grandfather who had it, who passed it on to my mom."

Thus Lisa B. is attempting to track down the many newfound aunts, uncles, cousins, and other relatives who are at risk for inheriting the HD gene.

"My grandfather had 15 more kids, the granddad who died of HD," Lisa B. continued. "Four of my birth family uncles were incarcerated. I'm in the process of making a list and contacting these people. My aunt tells me, 'You came back and stirred the pot.' You have to have a tough skin when you take approaches like this."

Any day now, Lisa B. expects to receive a package sent by her grandmother containing a painting Byron did of Dianne pregnant.

"Something that both my father and my mother touched would be incredible for me, for someone who never had my mother or saw my mother or touched her," Lisa B. said. "If someone offered me a million dollars for that picture, I would say no."

Throughout her quest, Lisa has had to juggle her desires with her relationship with her adoptive mother, Meredith Davenport. (Her adoptive father, Ed Meredith, died in the late 1990s.)

Meredith Davenport (left) and Lisa Boudreau (family photo)

"She wasn't too on board with me looking," Lisa B. said. "And I didn't want to step on her toes. I waited until our relationship was strong enough. I wanted to look, but it affected so many people. It's very hard mixing all these people together."

Lisa kept Meredith "in the loop" throughout her search, she said. Meredith became upset when she learned of her daughter's risk for Huntington's disease, she added.

Above all, Lisa B. worries about her own children, all in their late teens or early twenties. They now face their own decisions about testing for HD.

"I told them, "You need to have this information,'" Lisa B. said of their newly revealed at-risk status. "'Knowledge is power. You have the information I didn't have when I was adopted.' It's a very personal decision. They need to make it on their own what they want to do with the knowledge they have."

Posted by Gene Veritas at 2:38 PM

Labels: adoption , anxiety , at- risk , brain , daughter , depression , family , father , gene-carrying , grandfather , grandmother , Huntington's , juvenile HD , memory , mother , sister , support group , symptoms , tested positive , wheelchair

1 comment:

Anonymous said...

Just to set the story straight.... Byron was not an architect, nor was he an artist. He was a painter and later a roofer. He died at the age of 51. I am sorry about the struggles with Huntington's disease this family is going through. I hope a cure is found for it just like I hope a cure can be found for cancer.

3:45 PM, April 10, 2013

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