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Kate's untested baby (Huntington's disease and abortion - Part II)

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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.

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SUNDAY, DECEMBER 18, 2011

Kate's untested baby (Huntington's disease and abortion – Part II)

Kate Sandbulte, a 20-year-old woman who lives in Iowa, long lived life to the fullest.

Her mother, Tara Hansen, recalled that Kate was “was always doing ten different things at one time.” For example, as Tara has written, Kate was a “very fast learner and was able to capture the hearts of anyone who crossed her path. She learned to walk at nine months of age and was speaking in full sentences by the time she was a year old. She grew into a feisty little girl.... She was very smart and was often found to be a peacemaker and could be found defending anyone who was hurt or sad” ([click here](#) to read more).

Kate loved painting, played basketball and the clarinet in junior high, and adored the 1960s, from Janis Joplin and heavy metal to peasant blouses and flare jeans. She helped raise three half-brothers.

“She’s always been the kind of kid who can roll with the punches,” Tara added with pride. “She never gets too upset about anything.”

Two big blows

However, Kate has faced some of the biggest blows that life could possibly level. For the past five years, Kate has had juvenile Huntington's disease. Now she is pregnant with an unexpected child, who has a 50% chance of being gene-positive.

Although Kate could test the first trimester fetus for HD, she has decided not to. She plans to have her baby, even though both she and the child might not live beyond their mid-30s, and she and the baby's father do not plan to marry. Fortunately, Kate can rely on her mother, who's still in her 30s and has pledged to do all she can to take care of Kate and the child.

“She was on two forms of birth control, and it was not planned,” Tara told me in a Facebook message after I had seen her November 26 post announcing Kate's pregnancy. “She always said that if she had HD, she didn't want a baby because of the chance of passing it on. She cried for a week after reading the pregnancy test. She worried just as any mom would about the baby's health and the effects of the (HD) meds she was on.”

“But then she saw the heartbeat of the baby,” Tara continued. “She cried tears of joy and is now taking better care of herself and now has hope for her baby. She said, ‘Perhaps this child can offer you comfort when I am gone, Mom.’ She knows God gives life for a reason. And no matter what – HD or not – this child will be loved, just as she is.”

[Huntington's Disease Society of America](#)
[International Huntington Association](#)
[Huntington's Disease Drug Works](#)
[Huntington's Disease Lighthouse](#)
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HD Blogs and Individuals

[Chris Furbee: Huntingtons Dance](#)
[Angela F.: Surviving Huntington's?](#)
[Heather's Huntington's Disease Page](#)



Kate (left) and Tara at the HDSA national convention in Minneapolis in June (family photo)

Personal thoughts

Kate's decision to risk passing on juvenile HD represents the other side of the coin of the wrenching decision made by the Wright family of Florida to abort their gene-positive, premature infant son and donate his brain for research towards treatments and a cure.

The first of this two-part series on HD and abortion – my article on Christina, Michael, and Timothy John Wright – provoked the most heated reaction by readers since the blog's inception some seven years ago. ([Click here](#) to read the article and reader comments.)

Both families cited deep religious convictions as guideposts for their decisions. The Wrights are Catholic, and Kate and her family belong to a non-denominational Christian church that stresses love and the equality of all people.

As I interviewed and wrote about the two families, it stirred difficult memories of my wife's and my decision to test our daughter in the womb in the winter of 1999-2000, just six months after I had tested positive. [Luckily, our "miracle baby" tested negative.](#) She is a thriving sixth grader now applying to college-prep schools.

I told the Wrights that I supported their decision.

I also support Kate's decision. During my phone interview with Tara, I

congratulated her and her family on the pregnancy and expressed my wishes for a healthy baby.

Kate can still talk but preferred that her mother answer my questions. HD has already compromised her ability to communicate clearly, Tara said. "I'm kind of like her safety net," she added.

Along with the rest of the HD community, I sincerely hope Kate's child is HD-free.

"Both stories need to be told," Tara said. "They bring up a lot that people don't want to talk about."

Rejecting rigid views

My support for both families may appear contradictory to some with rigid or black-and-white views, but, as I pointed out in the previous article, "the disabling, ultimately deadly nature of HD further complicates" decision-making. As my wife put it, "Nobody knows for sure until they're actually faced with the decision."

Indeed, all of our stories reveal the tragedy of HD and touch on larger controversies about abortion, [suicide](#), and mercy killing.

One participant in the debate over the Wrights subsequently recalled on Facebook the case of [Carol Carr, a Georgia woman who in 2002 shot dead two sons](#) who had been confined to a nursing home with late-stage HD. She was convicted of assisted suicide and released on parole two years later. (You can view a documentary about the Carr case by [clicking here](#).) The Facebook commentator seemed to become less rigid in her critical view of the Wrights.

Dead at 33

Living in a small town, Tara and her ex-husband Jeff Sandbulte had Kate when they were, respectively, just 18 and 16. Jeff had told her that his parents had died. In reality, Jeff's father was already in a nursing home with HD, Tara said. He would eventually die in his forties.

Jeff also had juvenile HD. "We started dating," Tara said. "I got pregnant with Katelyn. I didn't know a whole lot about the disease. I had never even heard of it."

Tara didn't perceive Jeff's symptoms at the time, but in hindsight she now understands that he clearly had HD. "Knowing what I (now) know about HD, yes, he did show signs, like lack of impulse control, losing weight, sleeping a lot, and loss of temper," she said.

Jeff and Tara married in 1993, but the relationship became rocky, and she left him a year later. According to Tara, Jeff went to prison for a number of

years and had virtually no contact with Kate and Mikey, the couple's second child. Mikey, in fact, only saw his dad once. The couple officially divorced in 1996.

In 2000 Tara, a veterinary technician, remarried to Mike Hansen, a cement truck driver. They have three children together, six-year old Landon, five-year-old Shawn, who has Asperger's syndrome, and four-year-old, Gabe, who was premature but is now thriving. Tara also suffered a miscarriage of twins in 2007.

Jeff died in 2006 at the age of 33. Other members of the extended family have also fallen victim to HD, including a deceased cousin of Kate whose symptoms started at 14 and another cousin, now 30, who resides in a nursing home.

Struggling with risk

More than Kate, Mikey grew up worrying about HD, because of his biological father's situation. She showed more concern for him than for herself.

"She was very supportive of him as he was going through it," Tara said. "Her deepest fear was that Mikey would have it. He was sure he had it because his biological father had it."

Even Mikey's doctors thought they saw signs of the disease. (Untested, at-risk people often act out symptoms, as do gene-positive, asymptomatic people like me.)

Perhaps because he saw his future compromised, Mikey hung out with people who were bad influences and letting his grades slip. After he became addicted to pain killers, Mikey had to enter a treatment program, Tara said.

An HD-free brother

HD testing centers usually advise against testing minors for HD because of the severe psychological impact of the potentially devastating information. However, in Mikey's case, the family decided to test him in July 2009, when he was 16, because the prospect of HD had subjected him to enormous psychological pressures.

However, the medical profession has not fully grappled with the need to provide genetic testing information with sensitivity and competence. As I pointed out in the previous article, the Wrights received their baby's test results in an unprofessional manner. Mikey suffered a similar fate.

A staffer from the doctor's office called the family and asked for "Mike," not identifying him by his last name. But it was not Mikey Sandbulte who answered the phone, but Mike Hansen. He was abruptly told his test

results were “negative. If you have any questions, please call.” The staffer then hung up.

“They didn’t even make sure they had the right person on the line,” Tara said with indignation, noting that the proper procedure would have involved visiting the testing center and meeting with a geneticist and social worker so that the information – even happy information like a negative test – could be processed in person. The social worker became “irate” when she learned what happened, Tara added.

Luckily, Mikey was still at the drug rehab clinic. The family took his girlfriend Andrea to the clinic so that she could break the good news.

“He hit the ground on his knees and kept saying, ‘Oh, my God!’ He said, ‘I can’t believe it.’ It was like this big weight lifted off his shoulders. His whole demeanor changed – everything.”

Today, free of the spectre of HD, Mikey not only went through rehab successfully but has remained drug-free.

Kate’s onset

Like her brother, Kate also showed symptoms starting at the age of 15. In her case, she wasn’t acting out.

“That’s when her personality changed,” said Tara. “When she turned 16, she went through a terrible weight loss. She was at 130, and she went down to 98 pounds in a three-month period. We as parents are thinking, ‘She has an eating disorder.’ She would eat all the time.”

Her family also noticed periodic tremors in her hands.

HD patients typically lose weight, as did Kate. Scientists suspect the cause stems from energy shortages in the body’s cells caused by the defective huntingtin gene, as well as chorea, the constant shaking and dancelike movements most patients develop.



Kate (family photo)

Kate struggled in high school and ended up attending an alternative school. She had difficulty remembering things, too. “Hindsight is 20-20,” Tara recalled, “but at the time we thought Kate was just an airhead.”

“I look back now and I can remember struggling in school and being angry that I could not ‘get it,’” Kate wrote in her [blog](#). “We had meetings with my teachers and I would tell everyone I was trying. I was sleeping a lot and skipping school. I was trying but for some reason it just would not stay with me. I know I was mad about that. I got mad at Mom and Dad for not understanding. Up to this point I had been an honor role student in all but math.”

Still the same person

Just a few months after Mikey’s genetic test, Kate and her family braced themselves for another test.

In October 2009, at the age of 18, Kate received her results, which confirmed the symptoms she had been showing and pointed to an ominous fate. Whereas a normal huntingtin gene has only ten to 29 CAG repeats, Kate’s has 57, a number that most surely will doom her to an early death like her father, grandfather, and other relatives.

However, Kate took the test result in stride.

“‘Hmm. Thanks.’ That is all she said,” Tara recalled. “She said, ‘It doesn’t change anything. I’m still the same person I was yesterday.’ She was working part-time at a local gas station. She went into work. She said that her test had come back positive. They said to take off and go home to be with her family.”

As for the family’s reaction, “we followed Kate’s philosophy,” Tara added.

Experiencing life

It wasn't that easy, however. Two weeks after her test, Kate lost her job because of her difficulties with memory.

Despite the progression of the disease, Kate graduated from high school.

"She walked across the stage and got her diploma," Tara said with pride.

After high school, the family helped Kate move into her own apartment so that, in Tara's words, she could "experience life the best she could" before the symptoms worsened. To avoid the chance of an accident resulting from the loss of coordination typical in HD, Kate started driving less. Yet she still enjoyed being a "typical young adult," spending time with friends.



Shawn (left), Gabe, and Kate (family photo)

Kate and her family then moved into another home equipped with features that would facilitate future caregiving needs, including a large bathroom and wheelchair accessibility.

With the help of Iowa's Center of Excellence for Family Services and Research of the [Huntington's Disease Society of America](#) (HDSA), the family obtained Social Security disability benefits for Kate. She now receives a monthly payment of \$426. Medicare and Medicaid cover her medical bills.

Failed birth control

At a town celebration, Kate met a 29-year-old man named Billy. They started dating.

"The average person wouldn't know that she's disabled," Tara said,

explaining how it was natural for Kate to relate to men. “She has chorea and twitches, and she’s terribly forgetful. Other than that, she’s just a typical 20-year-old kid.”

To avoid pregnancy, Kate took Depo-Provera, a birth-control shot. She also took a low dose of a birth control pill in order to help reduce cramping and regulate her menstrual cycle.

Then both Kate and her mother took note of a missed period.

“I pulled into Walgreen’s and got a pregnancy test as a joke,” said Tara. “I didn’t think she was going to take it. She came out of the bathroom. She said, ‘It’s positive,’ and she started crying. I gave her a hug, and we just sat there.”

Kate’s baby is due on July 4, 2012.

‘In God’s hands’

Kate, Billy, and Tara met with a genetic counselor. Tara mainly stayed “in the background,” letting the young couple experience the happiness and worries of first-time parents, she said. The counselor informed them of the 50-50 chance that the baby would inherit the HD gene, but he did not advocate a course of action. The counselor said there was “no right or wrong answer,” Tara recounted.

Kate made a firm decision against both testing and an abortion.

“Even if she did test the baby, she wouldn’t terminate the pregnancy,” said Tara. “It was a struggle at first, after learning of the pregnancy. Once she saw the heartbeat, it was okay.”

Tara reviewed the options with her daughter, including abortion. “I don’t hide things from her,” Tara said. “I tell her that with juvenile HD, it could come on stronger and earlier in the baby.” Kate told her mother she was being “negative,” but Tara responded by emphasizing that she was simply laying out the facts.

“We just leave it in God’s hands,” she continued. “I can’t control HD. We all wish we could, but we can’t. In dealing with my little boy with autism (Asperger’s syndrome), people ask me if I knew, would I terminate my pregnancy. I say no.”

As for how the family will deal with so many potential caregiving burdens, Tara said that “we trust in God. The baby may not have HD. Shawn is high-function and our goal is for him to be a productive member of society. We will deal with the issues as they come up.”

Avoiding another pregnancy

After the baby is delivered, Kate and her family will take decisive action to avoid a future pregnancy.

“Kate is going to be sterilized,” Tara said, explaining that her daughter will undergo a tubal ligation, a procedure Tara also had after her last child's birth. “She asked for this, and the doctor and I both support her choice – and even agree with it.”

Tara stressed that Kate initiated this plan and was not manipulated in any way. In fact, before Kate got pregnant, the mother and daughter had already discussed this possibility, although Kate declined at the time to have the procedure.

“It's a choice that she's making, because of the birth-control failure,” Tara explained. “She doesn't want to go through the stress again of worrying about another baby.”

I wanted to know if, in Tara's opinion, sterilization violated God's will in any way. She didn't think so. On this point she agreed with the Wrights, who believe that medical technology and procedures are “instruments” of God.

‘Preparing for war, praying for peace’

I wanted to explore more deeply the risk Kate is taking by not testing the baby. I asked Tara: wouldn't a negative test put your minds at ease? And, without an abortion, wouldn't a positive test help Kate and the family provide the best care possible for a diseased child or teenager?

“We did talk about this,” Tara responded. “Kate asked, ‘What would you do to prepare? What would the father do to prepare?’ He said: learn more about HD.”

Tara met with Billy and his mother to discuss the pregnancy and plans for raising the baby, especially because he and Kate will not marry.

“We as a family group need to be able to support that child,” Tara told me. “I said, ‘It doesn't make a difference if it has HD or not.’ The end result of caring for the child and loving the child is going to be the same.”

In August, Tara obtained legal guardianship and conservatorship over Kate. These legal powers will also allow her to make decisions for the baby.

“In the end, I could force the issue if I wanted to, as her guardian,” said Tara. “But I'm going to respect her. Katelyn had 18 beautiful years without knowing (about HD). Life was what it was. Even now, she doesn't think every day, ‘Oh, I have Huntington's.’ That's the way she wants her child to be raised.”

She summed up their strategy with these words: “We prepare for war, but

we pray for peace. We prepare for the worst, but pray for the best.”

A plea for togetherness

After posting the news of Kate's pregnancy, the family saw messages of support, but also what they termed “unkind remarks.”

For example, the Wrights criticized Kate for not testing the fetus and exploring their options.

Tara believed that the Wrights were “judging Kate.” According to her, they thought Kate was “selfish and hateful to carry a baby to term without getting it tested, that Kate had no right to give birth to a child that may or may not carry the HD gene.

“Kate was angered and hurt, as I was, from the post. When the other lady terminated her baby at 20 weeks, we supported her. We offered our prayers and love.”

When the Wrights received harsh criticism for their decision, Kate and her mother still stood by them. “I don't agree with their choice but I ask our HD family to show the Wrights the same love you do to those of us who have a child or children living with JHD or HD,” the mother and daughter wrote.

Facing such extremely difficult situations, Tara told me, each family should make its own decision. She felt sad that “people showed anger and almost hatred toward somebody, especially when we're fighting this horrible disease. The disease affects us all, and we should stick together.”

“In the end, it's nobody's business,” she said. “At the end of the day, it is up to the families, and each family has their own set of beliefs and morals. It is really up to the families to make the decisions for their loved ones, with or without society's okay.

“I just want people to know: there are other options (other than testing and abortion). Do I understand where the Wrights come from? No. But I don't judge them.”

A special gift from Landon

Kate, Tara, and the rest of the Hansen family are now turning their attention to welcoming a new member. Tara reports that Kate is doing well, although she consults with an obstetrician-gynecologist specializing in high-risk births.

“We're planning on Kate doing what she can and us helping out where we can,” said Tara of the family's post-birth plans.

They also hope to raise awareness about the need to cure HD in order to

end the suffering endured by Kate, the Wrights, and the thousands of families afflicted by the disease.



Landon, the "Button Boy Fighting Juvenile Huntington's" (family photo)

Yesterday an early Christmas gift arrived at my home from six-year-old Landon. Landon makes HD bracelets and key chains. He sells them, as well as buttons promoting the HD movement. Last June, he even joined Kate and Tara at the annual HDSA convention in Minneapolis. Since then he's raised \$1,500 for the cause.

Tara told me that Landon is determined that his dollars "will find the cure."

Landon sent my family a box with a couple bracelets, about a dozen buttons, family photos, and pamphlets and business cards for his work as the "Button Boy Fighting Juvenile Huntington's Disease." (You can contact Landon's family at tanyon_24[at]yahoo.com. To donate, make checks payable to Landon Hansen and mail to 102 1st Avenue, Doon, IA 51235. All proceeds go to juvenile HD research at the University of Iowa.)







My daughter and I inspected the package's contents.

"How old is he?" she asked incredulously.

"He's six," I responded.

She selected for herself a mini-button with the words "I Love Someone with Huntington's Disease."

“We have to spread the word,” Landon told his mother about his gift to us.
“The more people understand, the better.”

Posted by [Gene Veritas](#) at [11:52 AM](#)      

Labels: [abortion](#) , [at-risk](#) , [CAG repeats](#) , [gene-positive](#) , [genetic testing](#) , [Huntington's](#) , [juvenile Huntington's](#) , [sterilization](#) , [symptoms](#) , [testing](#)

8 comments:



 **Kate's Kronies said...**

Gene,

We thank you for both stories you have wrote about.

We are all family in fight HD and JHD.. We thank you for your time that you spent writing these. We are all Warriors in this fight against HD, and we are brothers and sisters in arms in our war against HD..

So we thank from our hearts for what you do to raise awarness and hope in our "HD family"

[5:06 PM, December 18, 2011](#)


 **Christina Wright said...**

I'm soooo truly sorry that my FaceBook comments hurt this family.

I admire this family's courage, love and support for each-other. Sending prayers to Kate, Tara, baby and the family.

[6:01 PM, December 18, 2011](#)




 **Grannyjan said...**

Good for you, Kate! My daughter had Keely when she was only 17. We didn't know about HD being in the father's family at that time, but it wouldn't have changed the decision to have Keely and it wouldn't have changed the way we loved her. In her short 17 years, she brought me more joy than I can express. I was honoured and privileged to raise her (my daughter was unable), just as it will be an honour and privilege for you and your Mom to raise your child, whether he/she has HD or not. Sending you lots of love and hugs.

Jan

[8:15 PM, December 18, 2011](#)



 **Unknown said...**

Thank you for sharing both stories...love and thoughts and prayers to both families...lots of love to Kate!!!

[6:14 PM, December 19, 2011](#)



 **Kate's Kronies said...**

thank you all for u r commentsof love and hope
thanks kate and tara

8:50 PM, December 19, 2011

❁ **Jan said...**

As always, excellent post, Gene. I love how you show both sides of this very controversial coin.

My prayers and best wishes go to Kate and her family.

9:14 AM, December 21, 2011



❁ **Kate's Kronies said...**

Christina, we thank you for your kind words. and for your thoughts and prayers . God Bless you and your husband. Thank you

tara and Kate

9:12 AM, December 29, 2011

❁ **Anonymous said...**

Thank you for sharing these stories. This disease also runs in my family. A miracle is happening with my mother. I want to share this story with as many people as I can. My mom is 58 and has been in a rest home for 5 years. She hasn't been able to walk, talk or eat real food for a few years. In June 2011 the neurologist diagnosed her with the final stage and we started planning a funeral. We found this supplement made from 5 different herbs that goes into you and helps your body restore its own cells with healthy ones. We started giving it to her, 2 a day, at the end of November and if you can believe it she is standing and walking by herself. She is eating and has said a few words too. All of my siblings and I are also taking it, there is hope for everyone with Huntington's. Please take a few moments to watch this video that ABC Primetime did on this product. www.abchealthreport.com

If you would like to buy some go to www.mylifevantage.com/cindykrshul

If you have any questions feel free to contact me at ckrshul@yahoo.com

5:16 PM, February 15, 2012

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