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An angel fighting for the cure (Huntington’s disease and abortion - Part I)

Kenneth P. Serbin

University of San Diego

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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.

SUNDAY, DECEMBER 11, 2011

An angel fighting for the cure (Huntington’s disease and abortion – Part I)

Lying in a hospital birthing room, Christina Wright held her premature infant son Timothy John awhile in her arms and, after he died, handed his tiny body over for research that might help save her husband and thousands of others from Huntington’s disease.

On August 28, 2011, Timothy became an “HD angel,” yet another mourned but deeply loved victim of this killer brain disease. His brain was donated to a tissue bank at the University of British Columbia’s renowned research program on Huntington’s.

After the fetus tested positive for the abnormal gene that causes Huntington’s, Christina and her husband Michael prayed at their local church in Coral Springs, FL, and then decided to abort their child in the 22nd week of the pregnancy. Hoping all along that they might carry the baby to term, they had already given him a name.

For more than ten years, Michael has helped care for his 54-year-old mother Gail Suvino, now residing in a nursing home with late-stage HD. In October 2010 Michael himself tested positive for the disease. He is 34, and he worries constantly about when his own symptoms will start.

Blog Archive

- ► 2021 (12)
- ► 2020 (16)
- ► 2019 (19)
- ► 2018 (16)
- ► 2017 (14)
- ► 2016 (13)
- ► 2015 (24)
- ► 2014 (24)
- ► 2013 (30)
- ► 2012 (26)
- ▼ 2011 (33)
  - ▼ December (2)
    - Kate's untested baby (Huntington’s disease and abo...
    - An angel fighting for the cure (Huntington’s disea...
  - ► November (4)
  - ► October (4)
  - ► September (2)
  - ► August (1)
  - ► July (2)
  - ► June (2)
  - ► May (4)
  - ► April (4)
  - ► March (3)
  - ► February (3)
  - ► January (2)
- ► 2010 (26)
- ► 2009 (21)
- ► 2008 (7)
- ► 2007 (7)
- ► 2006 (4)
- ► 2005 (17)

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Christina and Michael Wright (family photo)

The 'toughest decision'

Christina and Michael could not bear the thought of their son facing the threat of a life burdened with severe disabilities and ultimately cut short by years, if not decades.

"It was very hard for me," Christina said with great emotion in a phone interview on December 8. "I didn't know that he was going to be born alive. He was strong and a fighter and wanted to live, and that breaks our hearts."

"He looked just like me when he was born," said Michael, who had stood by Christina during the birth. "He had my big feet and chicken legs."

"This was the toughest decision we ever had to make," he continued. "I bring it up every day. A lot of people don't know what this disease does to a family. It does massive damage to a family."

A birth with a research goal

With medical assistance, a baby delivered at 22 weeks would have a 10 percent chance of survival, explained Christina, a pediatric nurse. Because this was an abortion, the medical team did not intervene to save Timothy. He died of heart and lung failure.

"I did not have a clinical abortion," Christina said, noting that in a standard abortion the mother is put under anesthesia and the fetus terminated and removed in pieces with the help of forceps. Under those circumstances, the brain could not have been used for research.

"I went through the birth to be able to donate the brain," Christina continued. "The doctors did insert pills into my cervix to induce my labor. I pushed him out. I delivered my son with the purpose of fighting this disease.

With great pain in her voice, Christina spoke of how she will miss her son.

"No one wants to hurt their child," she said. "We loved him so much. We always will. Even if we have ten children, we're always going to be missing one. He was our son and always will be. We have pictures of him. We have his ashes in an urn. He will live in our hearts forever.

"I feel like he's fighting in a different place," she added. "He's my husband's angel. My son can help save my husband. He's a warrior. I couldn't be more proud as a mom, to know that my son helped find a cure to beat this. Some moms want their children to be a doctor or a lawyer. Mine might help find the cure for a disease that destroys families."

Painful memories of another test

When I read Christina's Facebook posting about Timothy on August 29, I felt terrible. I decided immediately that I would soon write an article for this blog about their plight. This is the first of two articles about HD and abortion.

Never an easy decision, abortion is even tougher for people of faith like the Wrights and a pediatric nurse like Christina. The disabling, ultimately deadly nature of HD further complicates that decision.

Interviewing the Wrights was one of the most difficult moments in my 13-plus years as an HD activist.

Listening to them sent my mind reeling back to the winter of 1999-2000,

Huntington's Disease Society of America
International Huntington Association
Huntington's Disease Drug Works
Huntington's Disease Lighthouse
Hereditary Disease Foundation
Huntington's Disease Advocacy Center
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when my wife and I tested our own baby for HD in the womb six months after I had tested positive for HD. As I told the Wrights, their experience closely resembled ours – except for the all-important fact that our daughter tested negative.

As I pictured Christina holding Timothy, I imagined what it would have been like if our daughter had died in her mother’s arms immediately after birth.

I can’t find the words to describe the pain I felt. I shared our family’s story with Christina and Michael. I told them that I supported their decision and thanked them for donating Timothy’s brain for such a worthy cause. “I appreciate that,” Christina said.

In recounting the interview to my wife, I explained how the Wrights had oscillated between continuing and terminating the pregnancy. I then recalled our own situation. “Nobody knows for sure until they’re actually faced with the decision,” my wife said. I agreed.

An HD-free child

I am immensely relieved that our “miracle baby” is HD-free.

On several evenings this past week she and I happened to watch a recording of *The Heart of Christmas*, a new feature film based on the story of Dax Locke, a toddler whose battle against a rare form of leukemia mobilized the community to support his family and celebrate Christmas early so that he could enjoy it one more time before he died in 2009. Thinking of the Wrights, I felt so privileged to share these moments with her.

Last Saturday morning, after we accompanied her to a testing center for a private school entrance exam, I reflected on her progress in life and her immense potential.

The most powerful drive in life – more than the sex drive or anything else – is the need to nurture and protect a child. No calamity wounds a family more than the death of a child.

An imperfect situation

The Wrights’ story reveals the tragedy of HD, the wrenching decisions it forces upon families, and the imperfect conditions under which they must make and carry out those decisions.

After meeting through Match.com and dating awhile, Christina and Michael married on St. Patrick’s Day of this year. Michael, a beverage merchandiser who had to quit college in part to help care for his mother, had revealed to Christina that he had tested positive for HD but so far had not symptoms. Christina witnessed the tough reality of HD by meeting Gail.

“A lot of people would run the other way,” Michael said. “She really loves me.”

Christina, now 38, had been told by doctors that she couldn’t get pregnant because of an irregular menstrual cycle since the age of 14 and, later, ten years of failed attempts to conceive in a prior relationship. She and Michael didn’t use contraceptives.

The pregnancy caught the Wrights completely by surprise. Thus they hadn’t had the opportunity to seek genetic counseling, nor could they resort to PGD (preimplantation genetic diagnosis), which would have allowed them to choose embryos without HD for implantation into her uterus.

Pondering the results

An amniocentesis was done on the baby at sixteen and a half weeks, the earliest possible moment. But the results of the HD test took three more weeks to arrive.

Michael’s abnormal gene has 42 CAG repeats, whereas a normal huntingtin gene has only ten to 29. Those extra repeats cause the disease. Timothy had 40 repeats. Statistically speaking, Michael, who is 34, will probably develop symptoms sometime in his forties or fifties. Someone with 40 repeats might develop them a bit later, although, according to Michael, Gail’s symptoms started around the age of 36 or 37, and she has only 36 repeats.

Although they are finding more clues, scientists still don’t know exactly how and when the disease starts. Anybody with 40 repeats or more will definitely develop symptoms at some point.

The Wrights had learned that the child of a gene-positive man has a much greater chance of developing juvenile Huntington’s disease, which can start as early as the toddler years. But that’s because the father can often pass on *more* repeats, whereas a mother usually passes on her number. In this case, Timothy actually had fewer repeats.

“I almost don’t want to know that, if that’s the case,” Christina told me after I explained my understanding of that connection between repeats and juvenile HD. “We very much wanted our baby. We feel that we gave him back to God, especially because we’re Catholic.”

‘We were bonding’

The process of learning about their child’s fate was awkward. The Wrights received the results of Timothy’s HD test from an on-call obstetrician, rather than from their regular doctor, who was out of town. No social workers or geneticists were on hand to help clarify the information, and it was the first time the obstetrician had ever advised a patient on an amniocentesis involving HD.

The Wrights faced additional time pressure because in Florida a fetus at 24 weeks is considered viable, Christina explained. Had Timothy reached that age, the couple would have had to travel to another state for an abortion.

“We were both crying and both devastated,” she said of the impact the news of Timothy’s gene-positive result. “It was very difficult for us. I didn’t think God would give us more than we could handle, and so I wanted to have our son.

“It wasn’t just a pregnancy at that point. It was our son. We saw his picture on the ultrasound. I was gaining weight. I could feel him move. We were bonding with him. We started picking names. It was just very hard.”

Medical advice

But the obstetrician told her that she “was being selfish and not considering the life of the child” if she went through with the pregnancy, she said.

Other doctors that the Wrights knew at the University of Florida in Gainesville – where Michael travels regularly to participate in an HD research study – couldn’t tell the couple when the symptoms would occur and how bad they might be.

“We wanted to consult with them,” Christina said, explaining that they spoke with these physicians via cell phone. “Their opinion meant more than an obstetrician's. They agreed that it would be better not to have the child."

She added that these doctors did not mention the relationship between the CAG repeats and the age of onset.

All of the doctors led the Wrights to conclude that they would have a "sick baby," Christina said.

Timothy's purpose

Sitting in a pew at their church, the Wrights prayed and cried for more than an hour. The parish priest appeared and asked what was wrong, and, without mentioning HD or a genetic test, the couple explained that they had gotten "bad news" at the doctor's office and would have to deliver their child prematurely.

"He came into our room (at the hospital) and said a prayer and held our son and put some holy water on him and christened (baptized) him," Christina said, adding that Timothy was probably dead at that point. "It was very touching for us."

Timothy lived for about 90 minutes. The medical personnel needed to get his brain on dry ice in 30 or so minutes, and they shipped it to the University of British Columbia's Huntington Disease BioBank. There scientists study tissue samples to understand "the way DNA changes associated with Huntington's disease affect the actual physical characteristics and proteins of the brain and tissues."

"That was one thing we were adamant about," Christina said. "If we were going to lose our son, we wanted something to come from this.

"We're not ashamed of what we did. We just want to help find a cure."

The couple wants to share their story to raise awareness about Huntington's and support the quest for a cure not just of HD, but other devastating neurological conditions such as Alzheimer's and Parkinson's, Michael added.

Timothy is now part of that quest.

"We felt that was his purpose," Christina said.

Opinions on testing

The Wrights still want a child and are now saving to afford PGD, which can cost upwards of $10,000 and even twice that amount, depending on the circumstances. Their insurance doesn't cover it.

They believe that PGD is "the responsible thing to do," Christina said. She strongly disagrees with families that, when pregnant, choose not to test for HD via amniocentesis.

"With all that science has to offer, it's (also) the responsible thing to do," she said.

"Just think about the long-term effects if they don't do the right thing," Michael said. In using the latest scientific techniques, he and Christina aren't seeking the "perfect baby, but a healthy baby," he added. "You owe it to your family" to assure healthy genes, he said.

"God gives us these vessels, these instruments, this technology to guide us and help us along, especially in the medical field," Michael said. "Don't go through it blind-folded."

More HD families need to “come out of the closet,” Michael continued. HD is “not something to be ashamed of. People look at Mom and think it’s a stroke. It hurts."

Learning from the Wrights’ example

In concluding the interview, I told Michael that he and I were “brothers” in the fight to stay healthy and support the cause for the cure. I told Christina that she was my “sister” in the cause.

I’ve been meditating on Timothy and his parents. I pray that others don’t have to face their terrible predicament, although many surely will until the medical community achieves greater awareness of the genetics of HD.

Ultimately, effective treatments or a cure would liberate people from this predicament.

We can learn much from Timothy John Wright. His parents gave us his brain for research – to serve the greater, common good. Understanding the bigger picture, Christina and Michael committed the ultimate act of human solidarity.

We in the HD community also need to see the greater good. Whenever possible, we need to participate in research. To do so, we must exit the terrible “HD closet.” I myself remained pseudonymous, in the closet until 2010, and in February of this year I came out by delivering the keynote speech to HD specialists from around the world gathered at a key conference in Palm Springs.

As Michael pointed out, we need to rise above the difficult feelings surrounding HD and gain heart from the fact that our participation in the quest for treatments and a cure is helping to create the dawn of a new era. Along with the scientists, we are taking a quantum leap in the study of the brain. We are the pioneers pointing the way to better brain health. We are doing something profoundly good and important.

From suffering to progress for all

In the past, many people – including my own family – have viewed HD as a matter of suffering. But today, with scientific progress, HD is about the human quest for a longer and more fulfilling life for all.

In the Bible, Abraham was willing to sacrifice his own son in a sign of complete commitment and love. Our collective human sorrow is captured In Michelangelo’s *Pietà*, with Mary holding the body of her son Jesus after his crucifixion.

Michelangelo's Pietà, *in St. Peter's Basilica in Rome*

The mini-urn containing Timothy's ashes (family photo)

We in the HD community are all Timothy John Wrights in our mothers' arms.

Indeed, we in the HD community endure great suffering. "You think, 'God can't be that cruel,'" Michael said.

But, like the Wrights, none of us should feel ashamed. This community has lots of love – and it shows it just as the Wrights have done.

(The second part of this series will tell the story of Katelyn Sandbulte, a 20-year-old juvenile Huntington's disease patient in the first trimester of pregnancy.... At this special time of year, please remember to donate to the Huntington's Disease Society of America.)

Posted by Gene Veritas at 9:35 PM

Labels: abortion , activist , brain , cure , DNA , gene-positive , HD closet , Huntington's , juvenile Huntington's , love , PGD , pregnancy , research , symptoms , tested negative , treatments

35 comments:

Anonymous said...

Dear God, I do not think this is the way to go in fighting HD...

4:36 AM, December 12, 2011

jemi456 said...

This comment has been removed by the author.

5:01 AM, December 12, 2011

jemi456 said...

This comment has been removed by the author.

5:16 AM, December 12, 2011

Stella said...

Excellent post, Gene, about a very difficult situation. I really absolutely admire your bravery in exposing this disease in a realistic and un-apologetic way.
As for this family, I wish I could just hug them all.

8:35 AM, December 12, 2011

Eileen said...

How sad that a precious life created by God has been murdered. There is nothing noble about donating his brain to research other than to appease the parents' guilt. Maybe Timothy could have lived long enough to grow up, go to school and discover the cure for Huntington's. I am mourning for Timothy today.

9:14 AM, December 12, 2011

Grannyjan said...

While I can partly understand this couple's decision, I don't agree with it, and not for any religious reasons, but from having raised a JHD child and knowing the absolute joy she brought to all who knew her.

And yet, when my beautiful 17-year-old Keely died of JHD last Christmas Day, I was unable to donate her tissue for research, as we had so desperately wanted, because no pathology staff could be found to remove her tissue, due to the holidays. And we live a short ferry ride from UBC, where the tissue bank is. I am still very frustrated and angry about that! What a total waste of an opportunity to aid in finding a cure for HD and JHD.

10:15 AM, December 12, 2011

Anonymous said...

This is so incredibly sad. I am at risk for HD and have 2 children, one of which is only 7 months old. I could not imagine my life without my children. Huntington's is a horrible disease, but it should have been left in God's hands. Life is precious. Children die every day from a variety of different illnesses. Timothy could have lived a very productive life. 30 or 40 years is a long time to have a full life before being faced with the symptoms of HD. I will pray for that baby's soul.

10:21 AM, December 12, 2011

Anonymous said...

With a CAG of 40, that child could have lived to 60 without symptoms. There isn't much chance of JHD with that repeat,

even if from the father.
Also, there WILL be treatments in the next few years. I cannot understand what they have done. It has disgusted me.

11:27 AM, December 12, 2011

Anonymous said...
I completely understand. I am also presymptomatic for HD and I plan that this disease stops with me.

Although I hope that there will be a cure there is none yet, so I would rather ensure that my child will not have to go through what I might have to when the symptoms begin. Plus since I know I have the gene it seems cruel to continue the terrible cycle.

If everyone who tested positive could stop the disease with them, the next generation would not be inflicted (aside from the cases where it randomly starts).

3:07 PM, December 12, 2011

Anonymous said...
I cannot believe the medical community condones or recommends the above practices. This has disgusted and disturbed me and the fact that you as a resource in the Huntington's Community do not have any issues with this is even more concerning. Calling it god's will is even more disturbing.

A 22 week old baby is almost viable - to kill an otherwise perfectly healthy baby because of a disease that will not hit for 40 + years (which means 40+ years of research for a cure and normal life) is not right. These standards need to be CHANGED.

Illness and death is part of life weather it is Huntington's disease or cancer or simply old age. Every family has their own struggles. My mother-in-law passed away of cancer before my Huntington's Diseased mom even had symptoms. Should someone's life be terminated if they test positive for cancer as well? Where does this all stop.

I honestly had to read the story three times because I could not believe it was true.

3:13 PM, December 12, 2011

Anonymous said...
Obviously this topic is going to be heavily debated due to how it is seen as controversial, hopefully people will keep their negativity and rude comments to themselves. I would not want to be in that position and it is not my place to judge others on

actions when I have no frame to begin to compare that type of decision. Thanks for writing about it.

3:40 PM, December 12, 2011

Anonymous said...

You mention Mother Mary holding the body of her son Jesus after His crucifixion and how this shows our collective human sorrow.

I agree, contemplating the life of Christ through the eyes of His mother Mary helps me in my struggles with HD. I pray the Rosary "The Seven Sorrows of Mary." Through this I can understand the suffering she and her Son went through for our salvation. I can also imitate their example when dealing with HD in my life.

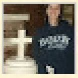
It is advent and we wait the coming of Christ. What if Mary had said "no" to God's request to be the mother of Jesus? What if she had killed her Son to save herself and her Son from a life with suffering? Jesus died a horrible death in his 30's. Wasn't this His Father's plan?

5:45 PM, December 12, 2011

Anonymous said...

Shame on ALL of you that criticize them. None should judge unless you have been in their shoes and personally know them. I have the wonderful privilege to know them and they are the most loving and gracious people I have ever met. This decision was hard for them but good parents make what they think are the best decisions for their children. I support them and stand by them 110%. They are, in my eyes, WONDERFUL parents.
Shame on all of you for judging them.
I love you both and God bless

7:32 PM, December 12, 2011



Kate's Kronies said...

i have a child with JHD... i know the family of my daughter father who passed away at age 33.. she is 20..
I cant even think of life without her. But i cant judge the wrights either.. instead when they posted it I prayed for them and for their pain.. it is sad every way around.. I dont 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 child or children living with JHD and HD.

7:41 PM, December 12, 2011

Anonymous said...

I expected to read comments about the Wright's murdering their baby. I respect there decision. They made the most difficult choice a parent could make. But what kind of life would they have knowing that Timothy would develop the disease. When you go through pre-symptomatic testing, you are made aware that if you have a positive result, you could become paranoid that every little tremor or unusual movement and think that it is the disease. Can you imagine going through life like this. It is bad enough for an adult to face the fact that they will develop HD. They have done more than enough donating Timothy's brain to research to help find a treatment and hopefully a cure. They do not need holier than thou calling them murderers to add to the pain. Even if they are working on treatments, the progress with HD has been slow. You do not know if there will be a treatment by the time Timothy developed symptoms or not. The Wright's did what they felt was the right thing to do. They wanted to protect him from possible suffering as any parent would.

This topic is not always black and white and it is easy for someone to talk and call someone else a murderer if they have never been in that situation. Maybe you shouold walk in their shoes before ever opening the mouth. You cannot understand until you have been there or experienced a family member go through this disease.

9:02 PM, December 12, 2011

Paul Ware said...

My heart breaks for the Wrights who were failed by the medical system. Unlike them, I was informed of the risk of passing on my possible HD to a future generation and the appropriate tests after my vasectomy to guarantee some child would not pay for my genetic pool. I was tested twice after my surgery to make sure my mother's HD would end at me (I've since tested HD+). The Wrights deserved the best modern science could give them in a world where procedures such as PGD-IVF exist, not the the worst of modern science as they had to endure.

10:56 PM, December 12, 2011

Anonymous said...

HD is one of the worst diseases out there. I can't understand why anyone would risk having a child that could inherit HD. That is cruel.
The Wrights had to do what they did. Thank God they had the courage.

7:25 PM, December 13, 2011

Anonymous said...

sad so sad...HD sucks no matter what.. and we all should support each other.. it totally sucks

9:42 PM, December 13, 2011

Anonymous said...

I have pre-symptomatic HD and I am disgusted by the idea that this parents used me as a reason to murder their innocent child. I have choose to have a tubal ligation to prevent this from happening in the beginning. These parents used their child as a pawn because they were to scared to deal with it. That is disgusting.

10:16 AM, December 14, 2011

Anonymous said...

Clearly this is a very difficult situation for all of us, but the HD community must work together. There are just too few of us to condemn each other. Each individual family deals with the disease the best they can. Even when we disagree, we must enfold other HD families in our arms and hearts. We will find a cure for this disease, but as a community we must all work for that end. The Wrights did that with much heart break. The rest of us need to support them even if we would have chosen differently.

10:17 AM, December 14, 2011

Anonymous said...

Gene,
I have read and reread your blog for 2 days and have had 2 sleepless nights because I was not sure how to respond.
I think that posting this article glorifying the killing of a baby is irresponsible of you. As a leader in our HD comm...unity you should be more responsible in your writing. It makes me as a leader realize that we are failing as a community when the facts that this family had to base their decision to kill their child were so wrong. The baby had a 40 repeat, with that repeat the risk of Jhd is not there. Chances are the child would not show symptoms until way later in life. He would have most likely lived a full life. Is makes me sad to hear that there were doctors that would participate in the killing of this baby. It makes me realize that we need to be educating our health care providers of the facts. We need to be valuing the life of everyone in our HD community.
You are a powerful voice in our community and I am disappointed in your blog especially around the Holiday season.
Why are we not highlighting the wonderful stories of caregivers that dedicate their lives to caring for their family members or the families who are so brave to live with HD everyday knowing that some day they will have symptoms, but still living everyday to the fullest. It is sad that a family who kills their baby because it has the gene for HD is glorified.

God Bless,

Kendell Aitchison

1:49 PM, December 14, 2011

Christina Wright said...

WOW!!!
To those who's comments were kind and understand, Thank you <3
To those of you that called me and my husband a "murder"... o.k.!!
If you feel better, congrats!!
But know this, you did NOT hurt me or my husband, cause we aren't ashamed of what we did!!
We are proud of Timothy John's purpose to the world, helping science fight HD. and as parents, we loved him enough to give him back to God and save him from a life of suffering.
Every couple with a HD-positive partner has to make choices regarding the risks of passing the gene on... and I commend those like us that will NOT pass the gene on to a child... that is guilt we couldn't live with!! But no, we do NOT feel guilty for giving our son back to God. or planning to use IVF with PGD in the near future.

5:23 PM, December 14, 2011

Susan Blankenbecler said...

Gene,

I read this post with tears streaming down my face for the Wrights and for all who have been at risk or who have tested positive and wanted to start a family. I know the pain of that struggle personally, but was blessed to test negative then have children later in life.

Each couple has to make these decisions for themselves and none of us has any right to cast judgement based on what may be right for us.

For me, I did not have my children until I knew my status but my sister did not make the same choice. She has two beautiful daughters who are very active in the HD community, one who is studying to be a neurologist the other is in high school. My sister is in the early stages of HD. Was she wrong? I cannot imagine life without those girls! Life would not be the same without them but I could not have done the same.

Clearly the Wrights felt the same way. Maybe we should all keep our opinions and judgement to ourselves and wish them peace and comfort in this holiday season.

7:14 PM, December 14, 2011

Anonymous said...

Unexpected pregnancies happen. It is important that the HD community be educated on its options for clear decision making in cases such as these. You have read above about testing with amniocentesis at 16 weeks with results returned at 19 weeks. My partner and I had an unplanned pregnancy and we are + for HD. We were able to test the fetus at 11 weeks through CVS (chorionic villus sampling) and knew the results before 13 weeks. Should other HD+ couples find themselves in a similar situation, please consider the following:
-facilities that complete HD testing via CVS will require documentation of parental diagnosis of HD
-many facilities will not complete the CVS unless it is certain that the parents would terminate the pregnancy should the fetus test +. The medical community's resasoning is that it is unethical to allow a child to be born knowing this medical information without his/her consent and before the child is of age 18.
-There is the chance that the collected DNA from the CVS will not give clear determination of an HD+ or HD- diagnosis of the fetus.

To all who have had to "stand in our shoes", I am so sorry.

12:13 PM, December 15, 2011

jemi456 said...

I feel the need to apologize to The Wright's, Gene Veritas and to everyone else that may have read my earlier posts on this matter. I had no right to say the harsh things that I said. I have deleted these post's and will not be commenting any further on this matter. Timothy John is wrapped in God's loving arms right now.

9:53 AM, December 16, 2011

jemi456 said...

Don't speak evil against each other, dear brothers and sisters.*
If you criticize and judge each other, then you are criticizing and judging God's law. But your job is to obey the law, not to judge whether it applies to you. God alone, who gave the law, is the Judge. He alone has the power to save or to destroy. So what right do you have to judge your neighbor?
(James 4:11-12)

12:23 PM, December 16, 2011

Anonymous said...

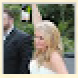
My heart is breaking. Truly breaking. As an at risk person with 4 siblings with HD (2 angels) I can't imagine not having had them in my life and what a huge impact they made on so many in their lives. Having unprotected sex, or any sex for that matter carries the risk of pregnancy. It is NOT the childs' fault for being conceived. As a matter of fact, he very well could grown up to be a huge contribution to eradicating this horrible disease. What you're saying is that we should just kill everyone now that has HD because they are suffering too much. OMG!!! The choice was taken away from that precious angel, and NOBODY has that right, only God and the individual. I am disgusted by the medical community for allowing this to happen or even make it a choice. And believe me, I know the pains of HD. I hate this disease. Who's to say there wouldn't have been a cure for him?Where's the hope? Our hope is in the Lord, and we cannot be the ones to take that away. Even though I don't support abortion, it would have been better to terminate the moment the pregnancy was discovered. Not that it's any better, but it seems less cruel. I know that his precious little soul is in His arms and now that is all that matters. But please, can we try and prevent this situation from happening again?? Don't play with God.

10:17 AM, December 17, 2011

kelley said...

I think it is very disrespectful and rude for all of you to write nasty comments about their decision. Huntington's is a horrific disease. If these parents felt that they made the right decision, we need to support them. You can talk about how aweful you think they are and disagree with their belief with God. Being judgemental is not the answer. I am 22 years old and am at risk for having HD. It affects my life every single day! This disease runs my thoughts and my life constently. I refuse to have children until I am tested and if I have it I would never have children naturally and risk it. Whether you live a healthy life until you are 40 once this disease hits it ruins a life and it ruins a family. And once you know you are at risk, its no way of living. It amazes me how negative you all are. My prayers are with this family. God Bless. Hopefully your son will be the answer to a cure!!!

1:55 PM, December 17, 2011



Valerie Berry said...

Thank you so much for posting this! I have always been and always will be pro-choice. I have so much respect and admiration for this family for what they did.

- Valerie

2:50 PM, January 12, 2012

Anonymous said...

My cousin is Michael Wright, we grew up together as children, we have both suffered the fall out form HD. Having to watch my grandmother and our aunt and his mother withstand the pain and turmoil that involves this disease. As of today 12/26/12 Michael's mother has passed this morning. And hopefully with their sacrifices and belief in science rather than succumb to a life not knowing what will happen to their son, and instead give up their son to the greater good of helping families like then and yours is the most selfish display of courage. So save your bible scripts and wake up to realize that (God) can't help us understand how to eliminate this horrible disease. I have watched this disease take 3 lives slowly over years. I support my cousin and his wife 100%. Rest in peace my beloved aunt Gail and my wishes and love is with the Wrights in their time of grief.

Wednesday, December 26, 2012 06:35 PM by Gary brown

7:12 PM, December 26, 2012

Unknown said...

This comment has been removed by the author.

12:40 AM, June 24, 2013

Unknown said...

This comment has been removed by the author.

1:00 AM, June 24, 2013

Anonymous said...

I am compelled to share my story after reading about the Wrights and Kate. Two years ago my husband underwent testing for HD because his grandfather had the disease and we were starting to think about a family. It was done with no genetic counseling at a routine check-up by his primary care doctor. He found out his results through an email.
He tested positive with a CAG repeat of 41. The good news is that his grandfather also had a 41, and didn't have symptoms until his early 80s. We hoped that my husband would follow the same pattern, however were determined not to pass this disease on to our children. Our plan was to have IVF with PGD.

A few months ago, we were surprised to find out that I had gotten pregnant. We debated all of our options and decided to move forward with having CVS; I knew the risks of passing on a much higher repeat to our child and didn't want to take that chance. I went for my first doctor's appointment, thinking I was 6 weeks pregnant but learned that I was actually 9 weeks pregnant. Since CVS is done between 10-12 weeks, we knew that we had to get the ball rolling. It was two weeks before they could get me in for the CVS appointment.

When I finally did go in, we met with the genetic counselor and were told that they would only do the procedure if we were planning on terminating the pregnancy based on the results. We were told that it could take up to four weeks to get the results since they sometimes have to culture the sample. I had the procedure done vaginally and had some complications. I actually ended up in the ER the next day because I was leaking amniotic fluid. Luckily, everything healed after two weeks of bed rest. Overall, the CVS process was not nearly as simple as I had imagined.

It took a total of three weeks before we learned our results. I was just about 15 weeks when we finally got the phone call from the genetic counselor. We were saddened to find out that our baby girl tested positive for HD with a repeat of 41, exactly the same as my husband and his grandfather. Even though we had initially decided to terminate an HD positive pregnancy, I was already in my second trimester and we felt that we really needed to think through our decision.

It took about an hour for us to decide. We had seen our babies head, hands, and feet on the ultrasound; she was moving around and growing, we loved her and wanted the best for her. My husband looked at me and said, "32 years ago, if my mom knew everything that we know now, there is not 1% of me that wishes I hadn't been born. This baby deserves a chance." According to the current research, she will be at least 55 before she has any symptoms, maybe older based on our family history. Fifty years is a long time in regards to research and medicine. It is also a long time to live a good life. She will have a
healthy childhood, a chance to go to college, a career, and maybe even a family.

Each year, on the anniversary of the date my husband found out his results, we share a bottle of champagne and toast to another year that we still have together. We count our blessings instead of our losses. Our daughter will now be with us each year as we make this toast and we will answer her questions honestly as they come. I pray everyday that we find a cure for this disease, but if we don't, I still know we are making the right decision. If we decide to have more children, there is no question that we will 100% go through IVF with PGD, regardless of the cost. It is the responsible and right thing to do, especially knowing what we know now; I also encourage others to do the same. However, my husband is right, our daughter does deserve a chance, Huntington's is part of who she is, her DNA, without it she would not exist and we would never get the chance to meet this unique and wonderful person.

10:09 AM, June 07, 2014

Unknown said...

I'm just as shocked!!!

5:16 AM, October 21, 2016

Unknown said...

I have walked in their shoes!!
Timothy could have lived 30,40,50,60 years without showing symptoms !! That's a life worth living!!

5:21 AM, October 21, 2016

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