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At-risk Angels pitcher Joe Smith at Huntington's fundraiser: 'I'd give every dime I have for a cure'

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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)
 - ▶ December (3)
 - ▶ November (2)
 - ▼ October (2)
 - [Huntington's disease patients get first dosing in ...](#)
 - [At-risk Angels pitcher Joe Smith at Huntington's f...](#)
- ▶ September (3)
- ▶ August (1)
- ▶ July (1)
- ▶ June (1)
- ▶ May (3)
- ▶ April (2)
- ▶ March (1)
- ▶ February (3)
- ▶ January (2)
- ▶ 2014 (24)
- ▶ 2013 (30)
- ▶ 2012 (26)
- ▶ 2011 (33)
- ▶ 2010 (26)
- ▶ 2009 (21)
- ▶ 2008 (7)
- ▶ 2007 (7)
- ▶ 2006 (4)
- ▶ 2005 (17)

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TUESDAY, OCTOBER 13, 2015

At-risk Angels pitcher Joe Smith at Huntington's fundraiser: 'I'd give every dime I have for a cure'

No one person is the face of Huntington's disease the way ALS is associated with Lou Gehrig or Parkinson's disease is linked with Michael J. Fox. But HD touches many lives, including some we know from major league sports.

Choking back tears, 31-year-old Los Angeles Angels baseball pitcher [Joe Smith](#) remembered the phone call three years ago from his father back in his native Ohio that changed his life forever: his mother had been diagnosed with Huntington's disease.

"Unfortunately, I got a call driving home from our spring training site in Goodyear, Arizona, from my dad," Joe told an audience of over 400 people at a San Diego fundraiser on October 10. "He told me: mom had HD."

Then Joe recalled when his mother Lee came on the phone on that day in February 2012, not long after she had received her genetic test results confirming she had HD.

"I'll never forget the sound of her voice," he said. "It was just empty. It was the worst. I never heard anything like it. That stayed with me for a long time, that sound, when she said, 'Hi, Joseph,' but the way she said it [...] was different. And it hurt. It still does, obviously. This time, when she got the news, I still didn't know a whole lot about HD. But obviously, when you get off the phone with the parents and got a 30-minute drive, there's a lot of thinking that goes on."

He's done a lot of thinking – and action – since then.

For his efforts to raise awareness and funds for the HD cause, Joe received the Guthrie Award of the [Huntington's Disease Society of America](#) (HDSA) at the San Diego chapter's 15th Annual Celebration of Hope Gala, held this year at the spectacular coastal residence of Craig and Rebecca Irving. [Craig](#) is a businessman and philanthropist.

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[Huntington's Disease Drug Works](#)
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Above, Joe Smith and mother Lee (photo by Gene Veritas, aka Kenneth P. Serbin). Below, Celebration of Hope Gala attendees mingling before the start of dinner and the formal program (photo by Mike Nowak).



Staring HD in the face

Joe remembered his family's four-hour drives from southern Ohio to Cleveland to visit Lee's mother, who, the family knew, suffered from HD. Seeing his grandmother's progressively worsening symptoms at each visit left Joe sad and concerned as a child and teenager.

"I think that's the scariest part," Joe continued. "It's one thing, I think, to go through life, or to have something that not necessarily you don't know about, but [...] my mom took care of my grandma, she went to doctor visits with my grandma, she was on the phone all the time with my grandma.

"When you know the road you're heading down, and right now there's nothing that you can do about it, you're just going. You're hoping there's light. You got hope. You got faith. But at the end of the day, right now, there's no cure."

Lee did not speak at the gala but talked about her symptoms in a brief [video](#) shown to the audience.

"She stares it right in the face every day," Joe said, referring several times to his mother's fortitude.

Joe ended his speech with a call to boost fundraising for HD research.

"I'd give every dime I have if they had a cure today," he declared.

You can watch Joe's speech in the video below. View other videos of the event by [clicking here](#).



Los Angeles Angels' Joe Smith: 'I'd Give Every Dime I Have for a Cure for Huntington's Disease'

from [Gene Veritas](#)

09:34 |



[Los Angeles Angels' Joe Smith: 'I'd Give Every Dime I Have for a Cure for Huntington's Disease'](#) from [Gene Veritas](#) on [Vimeo](#).

Taking public action

As the children of an HD-affected parent, both Joe and his 29-year-old sister Megan Nein have a 50-50 chance of inheriting the genetic defect.

Joe has previously talked to the press about his [fears of living at risk](#).

"My sister has three kids and she hasn't been tested," [Joe said last March](#). "I got married recently, and I'll get tested before we have kids."

He didn't speak directly about his fears at the gala, but they were palpable throughout his speech.

Both Joe's and HDSA CEO Louise Vetter's comments once again demonstrated how HD can devastate the extended family because of its genetic cause and difficult caregiving burden.

"It's not easy to come out and say you're from an HD family," Vetter said in introducing Joe. "If one of your parents has it, you don't know if you have it or not. So it takes a lot of courage to face your future."

Recalling Woody Guthrie's widow Marjorie's founding of HDSA in 1967, the organization recognized Joe with the Guthrie Award because of his "bravery" in confronting HD, she said.

Too often conversations about HD take place "behind closed doors," Vetter observed.

The Smith family has "made it public and they've created a call to action," she explained.



HDSA CEO Louise Vetter (photo by Mike Nowak)

The community emerging as its own spokesperson

For older generations of Americans, songwriter-activist Guthrie symbolized HD.

In recent decades, with younger generations unacquainted with Guthrie, many in the Huntington's community have attributed the lack of awareness about HD – ironically one of the most common of the rare diseases – to the lack of a celebrity such as Michael J. Fox in the sphere of Parkinson's disease.

Without national opinion polling on HD, we can't really know if this is the case.

What's important is that *more* HD family members are telling their stories publicly than ever before, and HD *is* gaining exposure.

Like 33-year-old filmmaker-actress [Marianna Palka](#), who revealed her HD genetic test results in an HBO film that premiered in June, Joe is emerging as a key new spokesperson for the HD cause.

Two other successful athletes – former Olympic rower [Sarah Winckless](#) and former National Hockey League player [Jake Dowell](#) – have shared their HD stories.

In June, another, award-winning film, the documentary [The Huntington's Disease Project: Removing the Mask](#), was released.

Networking for the cause

Joe's advocacy is helped by the fact that professional baseball maintains a huge fan base.

Joe and his family have started a foundation, [Help Cure HD](#), to raise money for research on deep brain stimulation (DBS) as a potential treatment for HD. (For years doctors have used DBS to treat Parkinson's disease.) So far Help Cure HD has raised nearly \$400,000.

Joe's wife is Allie LaForce, a TV reporter for CBS Sports. In January, Allie did a feature on Bill Johnston, the public relations director of the National Football League's San Diego Chargers, and his fight against HD. Bill's wife Ramona, who has HD, now lives in a nursing home.

The main mover behind the smartly produced HDSA-San Diego galas, Bill has helped raise several million dollars for HDSA through those events and numerous others.

Bill uses his contacts in the upper echelons of business and pro sports to invite speakers like Joe and garner corporate sponsors such as the B. H. Gold Insurance Agency. HDSA also honored B.H. Gold President Bill Habeger with the Guthrie Award for his support of the cause.

"May these galas soon be victory galas," Habeger told the audience.



HDSA-San Diego President Burt Brigida (left), B.H. Gold President Bill Habeger, HDSA CEO Vetter, and HDSA-San Diego immediate past president George Essig (photo by Mike Nowak)

From the heart, emboldening our community

As they arrived at the gala, I introduced myself to Joe, Lee, Joe's father Mike, and Tim Mead, the Angels' vice president for communications.

I told Joe that I was also from Ohio, that my mother had died of HD, and that I carried the genetic defect. I told him that he could rely on the San Diego chapter, HDSA, and me for anything he and his family might need in the struggle against HD.

Lee and I shared a few words about our common Cleveland connection. When she mentioned that she was 56, I said I was right there with her at 55.

At 56, my own mother had the involuntary movements typical in HD and was starting to lose her ability to reason.



Joe (left), Lee, and Mike Smith with Tim Mead, vice president for communications, Los Angeles Angels (photo by Gene Veritas)

I thought of how lucky I was to remain asymptomatic and participate fully in the gala.

After his speech, Joe asked my opinion.

“You hit it right on the mark,” I said. “You spoke from the heart.”

Later, just before the end of the gala, I spoke again with Joe. “We are brothers in this cause,” I said, putting my arm around his shoulder.

Joe raised awareness and money, but most importantly he has emboldened our fellow HD brothers and sisters to join the fight. Having every dime in the world won't bring treatments unless we have enough participants in the all-crucial research studies and clinical trials.



Joe Smith (left) and Gene Veritas (photo by Mike Nowak). Watch more videos of the gala by [clicking here](#).

Posted by [Gene Veritas](#) at 9:26 PM     

Labels: [Bill Habeger](#) , [Celebration of Hope Gala](#) , [cure](#) , [fundraising](#) , [genetic testing](#) , [Huntington's disease](#) , [Huntington's Disease Society of America](#) , [Joe Smith](#) , [Lee](#)

[Smith](#) , [research](#) , [symptoms](#) , [treatments](#) , [Woody Guthrie](#)

6 comments:

 **Jimmy Pollard said...**

As always, Ken, well done!!!!

[10:33 PM, October 13, 2015](#)

 **Mickie Toetz said...**

Excellent article!

[7:30 AM, October 14, 2015](#)



 **Unknown said...**

Love this! Our community needs more of strong, brave people like you and Joe to speak out! xoxox

[7:52 AM, October 14, 2015](#)

 **lois simons said...**

nice article, I had 2 sons that had HD thanks to their father, I found out about it after I was pregnant with my youngest and met his family for the first time, I thought his brother was just drunk the way he walked but was told that he had a disease and there was nothing to worry about. (boy were they wrong). When my oldest started falling all the time at the age of 5 the drs in TX said I was just a over protective mother, but the did some test and one dr asked the family history and told me to get out now while I could, so I contacted my mother in PA and between her and his aunt me and my 2 sons headed to PA. That was in 1993 when the genetic test came out there neurologist asked if I wanted them tested just for the peace of mind and for the SSI. The results came back 95 and 98 CAG repeats I called there father and he said so what, That just made me fight more for the boys and forget him and his family. We lived on our own till I was told by the state I had to get a job. We moved in with my mother in a 2 bedroom condo (things were tight) but we got by and they were the happiest and loving boys even with all the seizures, Stephen had over 400 one day before we got them stopped, we knew he would never wake up from that many and he never did but he never had another one. Russell suffered more joint and breathing trouble along with the seizures, and suffered more at the end. Lost them both in 2004 just 5 months apart. When I called their father to let him know Stephen had pass he said ok but just 3 days later we got a call from his aunt that my mom took cause Russy was seizing and I was helping the nurse, that he had died. I knew then what he had done. To this day none of his family has been tested and there are kids and and grandkids and great grandkids now. So please everyone who knows there is HD in the family get tested and don't pass this terrible disease on to anyone else. Thanks lois

[5:04 PM, October 14, 2015](#)

🌀 Anonymous said...

Hi Lois,

As HD is a very devastating disease, I am not sure if you are aware of the over context of your post. Personally, I find some of it to be extremely rude and lacking compassion. While I can understand your frustration with your boys father because he is choosing to live a careless life regarding his boys and that irritates any good mother, I can't understand the reason for sarcasm in your post. It is likely that maybe the father of your boys is in denial and apathy is part of the disease.

My father suffers from HD and is the oldest of 10, six of his sibilings have HD, in which 2 have already passed at young ages. Obviously I have a 50% chance of having HD. What I can tell you from the being at risk point of view is this, being at risk is enough for someone to think about. I am 27 years old and have 2 beautiful children. I had my children before my father was disgonosed, but even now knowing he has HD and there's a chance I could have it I wouldn't live my life any differently. Setting limitations on an individuals pursuit of happiness because the have this disease doesn't seem fair. I do believe that gebteic counseling is necessary and being honest with your partner is necessary, but I don't think living a life without children or unfulfilled is totally necessary either.

I believe the Lord will choose that path for individuals and while we all feel differently about it because we are affected differently, I don't think it's fair for our lives to be limited. We wake up every day and think what if and we watch our loved ones suffer just as you did.

In your post, it comes across as if all of us who aren't risk or have HD just carelessly choose to pass the disease on or make it sound as though those with HD are infected or contagious. The HD community should be a community of HOPE for a cure, it shouldn't be a community in which we are encouraged to live our life with limits. We want and deserve family too.

Ultimately, a couple with one who carries the HD gene and the significant other should seek the Lord and Genetic Counseling when it comes to their future reproductive plans, hopes, and dreams. They shouldn't be encouraged to completely give them up, as your comment sounds as though that's what one should do.

God Bless You,

Kaycee

10:11 PM, October 14, 2015

🌀 Anonymous said...

Hi Lois,

I completely sympathize with your situation and understanding of the problem and solution. With the genetic testing available, if everyone at risk behaved as a responsible parent to their unborn child and had the test in utero, this disease could be eradicated in one generation. There is no reason for this disease to still exist.

No one is saying if you are at risk, don't have children, just be responsible and don't condemn your children who as a parent you only want the best for, to die a inhumane death you wouldn't wish on your worst enemy.

I too have two beautiful kids who are at risk because of their father, who similarly won't get tested despite showing early symptoms. It is about the most selfish thing a parent could do to their child.

God clearly doesn't care, why else does this horrible disease exist and persist otherwise.

Great post Lois, more people need to think like that.

[2:28 PM, June 28, 2016](#)

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