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‘Alive and Well’ captures struggle against untreatable brain disorder

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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)
    - It's playoff time – and a reminder that brain heal...
    - Creating a Christmas memory for a Huntington's family
    - 'Alive and Well' captures struggle against untreat...
  - ► November (3)
  - ► October (3)
  - ► September (3)
  - ► August (2)
  - ► July (1)
  - ► June (1)
  - ► May (3)
  - ► April (4)
  - ► March (2)
  - ► February (3)
  - ► January (2)
- ► 2012 (26)
- ► 2011 (33)
- ► 2010 (26)
- ► 2009 (21)
- ► 2008 (7)
- ► 2007 (7)
- ► 2006 (4)
- ► 2005 (17)

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GENE VERITAS

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WEDNESDAY, DECEMBER 11, 2013

'Alive and Well' captures struggle against untreatable genetic brain disorder

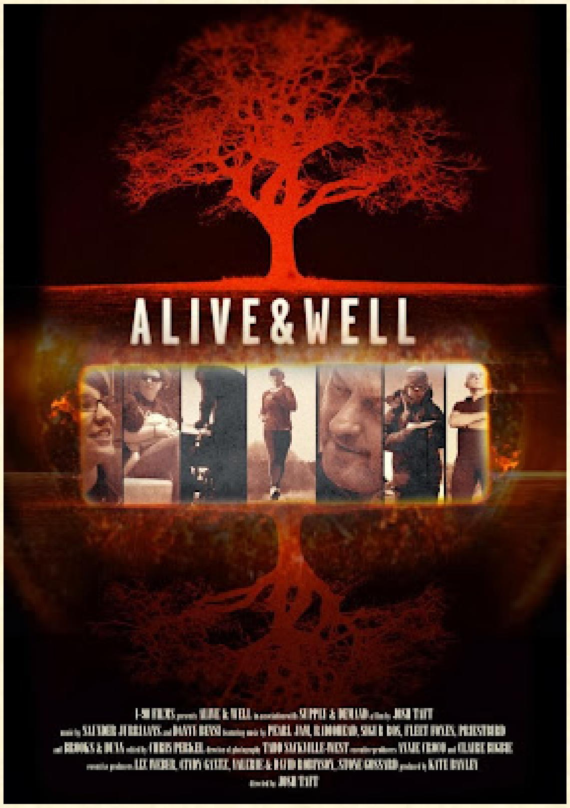
Watching the recently released documentary film *Alive and Well* this past Monday evening, I re-experienced the torrent of emotions involved in the fight against Huntington's disease.

Filmed on three continents, the 75-minute *Alive and Well* takes us on an odyssey through the lives of six families affected by HD and one HD researcher whose "reason for getting up in the morning is just to do something to solve this problem."

The stories embody the deepest fears and highest hopes of the HD community.

Alive and Well portrays the utter helplessness of HD patients in the final stages of the disease. The filmmakers visit a medical facility where several HD patients reside. Their bodies appear almost lifeless as they sit in chairs, unable to care for themselves. Their faces are half-frozen, revealing only a wisp of the personalities they once expressed.

These HD people are in a movie, but they cannot even speak their lines.



HD Links

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
Thomas Cellini Huntington's Foundation
HDSA Orange County (CA) Affiliate
HD Free with PGD!
Stanford HOPES
Earth Source CoQ10, Inc.

HD Blogs and Individuals

Chris Furbee: Huntingtons Dance
Angela F.: Surviving Huntington's?
Heather's Huntington's Disease Page

Honoring HD people, creating an advocacy tool

"Huntington disease has been described as the most devastating disease known to man, and it's devastating because it robs you of who you are," says world-renowned HD scientist Dr. Michael Hayden, interviewed in his native South Africa. "You lose the ability to speak. You lose the ability to communicate. Yet your perception is fine. You can perceive things around you."

Dr. Hayden uses "Huntington disease," the way people spell the term in Canada, where he has spent much of his career.

"The other devastating part of this is that it's progressive," he adds. "There is no way to intervene in the course of the illness. And what's particularly ironic is that it's continuous from one generation to the next."

In their struggles, Huntington's families provide great inspiration for humanity, "so-called ordinary people doing extraordinary things," Dr. Hayden continues.

"If people knew the stories that are in these families with Huntington disease, these would fill books and books of adventures and sources of inspiration for the rest of the world. The stories are really profound."

As the filmmakers say, *Alive and Well* is about a disease that exists everywhere but is still unknown. It's also about human resilience.

"We made this film to honor the people who trusted us with their stories, to have this film seen by as many people as possible and to raise awareness of Huntington's disease," says director Josh Taft, first introduced to HD by Seattle advocate Liz Weber, in a press release. "We wanted a way to share these very personal stories with compassion, strength and beauty. We wanted to create a solid tool for the community to share their stories and to be proud of."

No regrets

Viewing the film in a downtown San Diego movie theater at a screening organized by Misty Oto of the local chapter of the Huntington's Disease Society of America (HDSA-San Diego), *Alive and Well* carried me through the peaks and valleys of my own experience with HD.

My mother was diagnosed with HD in 1995 and died in 2006 at the age of 68. I tested positive in 1999; thankfully, I have yet to show any of HD's classic symptoms. Our daughter tested negative in the womb and is today a thriving eighth grader.

In the first profile, of 19-year-old Heather Alimossy of Medford, OR, I saw how innocence is lost and life changed forever when someone tests positive for the HD mutation – confirmation that Heather will follow in the footsteps of her HD-afflicted mom.

As shown, Heather forges on in the quest to live a full life. She continues to ride her dirt bike – and she lovingly cares for her mother.

"I don't want to regret anything," she says, the film then showing her on a ride through the countryside.

Taking a chance

I was heartbroken by the story of Katy Bradley and her family, of Olympia, WA. Katy married Scott despite learning that his father had HD. At one point, the couple visited him in a nursing home in California.

"I knew by then, especially, what this could turn into," Katy says. "I guess I took a chance."

The couple refused let HD "ruin" their lives. They decided to bear children without Scott getting tested. However, without their knowing it, Scott passed on the HD gene to their son Matthew. Scott's symptoms didn't begin until well into his adult years, but Matthew developed juvenile HD as a toddler.

In a matter of a few years, Matthew's symptoms worsened to the point where he was "in a constant state of seizure," Katy says. "His brain is constantly firing."

"Today's it," says Katy. "So let's have fun today. So let's do what we can. Let's make muffins."

The vignette finishes with people quietly attending Matthew's burial. The couple's small daughter Anna is also at risk for HD. Meanwhile, Scott continues to decline.

A very hopeful note

The other profiles in the film focus on Courtney Rifkin, a gene-positive woman shown climbing Mount Kilimanjaro to raise awareness about HD; Brooks and Dunn drummer Trey Gray, portrayed in his desperate struggle to maintain his skills after HD onset; Mandy Kipfer, a young woman who wants to start a family, filmed as she receives her HD-negative test result; and the middle-aged former NBC News war correspondent Charles Sabine, presented in his role as the HD community's global advocate while striving to avoid onset.

I could empathize deeply with Trey, because I fear losing my ability to write. I felt terribly jealous of Mandy, although ultimately happy for her, because I want to be free from the shackles of HD. I felt strengthened by Courtney and Charles, because they refuse to give up and are willing to share their stories with the world.

During the film, I sat next to HDSA-San Diego president George Essig, whose extended family is affected by HD. He, too, was moved by *Alive and Well*.

"It's been the best representation really of the disease I've seen on a variety of levels – physical, emotional, and in terms of the devastation," George said afterwards, as the audience of 140 filed out of the theater.

The film features an original score plus songs from Radiohead, Pearl Jam, Fleet Foxes, and Sigur Ros. The overall effect is saddening but also upbeat.

"I would also say it has a very, very hopeful note," George said.

HDSA-San Diego president George Essig with daughter Julia and wife Theresa at the screening of Alive and Well *(photo by Gene Veritas)*

Spreading the word

George added that he is "anxious to get copies out, because I think we could spread this virally as well as in movie theaters and a part of the whole education process and awareness process for the Huntington's community."

Alive and Well is not yet available on DVD and currently can only be viewed in small screenings, but event organizer Misty pledged to advocate for greater distribution of the film.

Alive and Well has shown in a number of other U.S. cities. Advocates can arrange for showings in their communities by contacting the Theatrical on Demand organization GATHR.

"We're incredibly proud that Liz Weber and the team in Seattle developed this film," said HDSA CEO Louise Vetter in a phone interview today. "There are a lot of multimedia tools to raise awareness about HD. We're supportive of all the efforts."

The producers aim to "bring the film to life" by encouraging HD families to share the opportunity to view it, Louise added. It's also a way for HD community to "learn how to be alive and well with HD," she said.

"That's a very powerful effort," she observed of the film's promotion, which has relied heavily on social media. "They've been very committed to that grassroots effort from the beginning."

In recent years, a number of advocates have been producing other films on the disease. Notable examples include: Chris Furbee's just-completed, 89-minute *Huntington's Dance*, chosen to appear at the 2014 edition of the highly competitive Slamdance Film Festival; Kristen Powers' still- in-progress *Twitch*; and James Valvano's still-in-progress *The Huntington's Disease Project: Removing the Mask*.

(To read more on HD's place in the news and entertainment media, click here.)

Yesterday, polio – tomorrow, HD?

Alive and Well begins – and ends – with a message of hope from Dr. Hayden.

“For each of us, we have to find our own passion,” he says at the outset. “That’s what makes life meaningful.”

We all *can* and *must* contribute, Dr. Hayden urges us.

“When you grow up in (apartheid) South Africa, you learn very quickly not to accept dogma,” he recalls of his youth in the closing minutes of the film.

Nobody believed HD existed in Africa, he adds. “Unfortunately, it’s alive and well throughout Africa.”

He recounts how, in conducting his Ph.D. research on HD in South Africa, he visited every mental hospital in the country to attempt to measure the frequency of HD among the populace.

Today Dr. Hayden is focused on the pathways to treatments that, although they may not cure the disease, could delay onset to offer people a longer life. (In 2012, Dr. Hayden became the president of global research and development and chief scientific officer for Teva Pharmaceuticals, Inc., a large, Israel-based drug firm, where he continues to promote HD research.)

“I’m really hopeful that we are going to be able to change the course of this illness,” he concludes, “and I think it’s in the near as opposed to distant future. I don’t know what ‘near’ is, but I’m convinced that with the … incredible donations of organs and blood and stories and financial support that’s come from so many quarters that we’ll be able to do something….

“Who would have thought in the late ‘50s there’d be treatment for polio? We can and will overcome this.”

Posted by Gene Veritas at 12:50 PM

Labels: advocacy , Alive and Well , diagnosed , documentary , HD-negative , HDSA-San Diego , Huntington's disease , juvenile HD , Michael Hayden , mother , onset , Pearl Jam , resilience , symptoms , tested positive , treatment

1 comment:

Anonymous said...

This is a great blog post! I am currently trying to bring "Alive and Well" to a nearby town, I hope you don't mind if I "share" your post as a informational and promotional tool. I believe knowledge and understanding of the disease will lead to more support and funding. :)

6:48 AM, January 21, 2014

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