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Woody Guthrie, Huntington's disease, and our duty to improve caregiving

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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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GENE VERITAS

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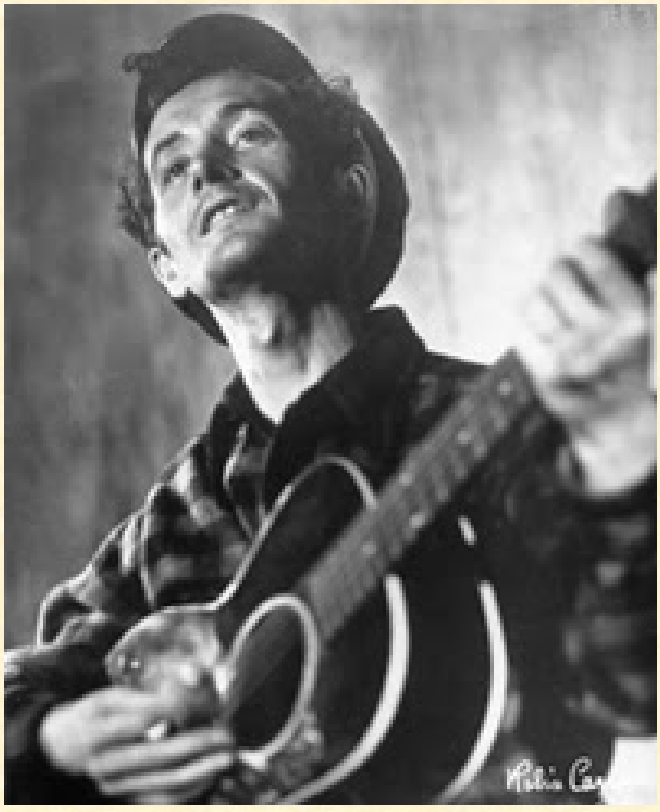
THURSDAY, APRIL 17, 2014

Woody Guthrie, Huntington's disease, and our duty to improve caregiving

By revisiting the huge, long-abandoned New Jersey mental hospital where radical songwriter and performer Woody Guthrie struggled for five years with the symptoms of Huntington's disease, photographer and author Phillip Buehler provides us with a valuable new perspective on the crisis in care for people disabled by neurological disorders.

In *Woody Guthrie's Wardy Forty: Greystone Park State Hospital Revisited* (Woody Guthrie Publications, Inc., 2013, 162 pages), Buehler, a specialist on derelict buildings, captures the rooms, corridors, and grounds of the psychiatric facility that housed Guthrie between 1956 and 1961. It had over 6,000 patients and had some 2,000 employees at its height in the 1960s.

A companion volume, *Woody Guthrie's Wardy Forty: The Interviews*, provides background from those who knew Guthrie or are involved in the campaign against Huntington's. (Click here to purchase the books.)



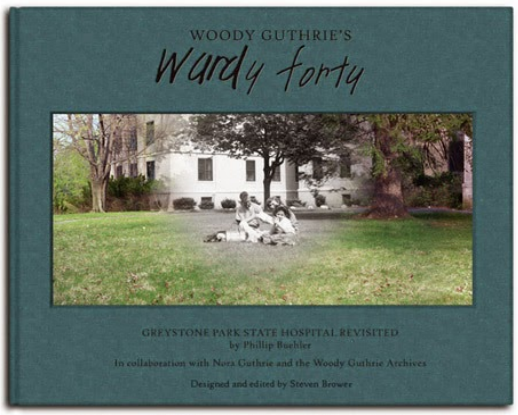
Woody Guthrie (above) and the new books about his time at Greystone Park State Hospital (below) (photos from www.woodyguthrie.org)

HD Links

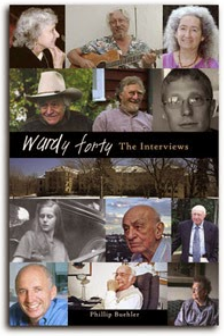
Huntington's Disease Society of America
International Huntington Association
Huntington's Disease Drug Works
Huntington's Disease Lighthouse
Hereditary Disease Foundation
Huntington's Disease Advocacy Center
Thomas Cellini Huntington's Foundation
HDSA Orange County (CA) Affiliate
HD Free with PGD!
Stanford HOPES
Earth Source CoQ10, Inc.

HD Blogs and Individuals

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



Woody Guthrie's Wardy Forty



Wardy Forty: The Interviews

Utterly debilitated and unable to speak, Woodrow Wilson Guthrie, the composer of "This Land is Your Land," died of Huntington's at Creedmoor State Hospital in Queens, NY, in October 1967 at the age of 55.

Today the United States has an estimated 5.4 million Alzheimer's disease patients, and an additional 14.9 million family members and friends cope with the disease as caregivers or in other ways. About one million people suffer from Parkinson's disease.

Huntington's disease (HD) patients number 30,000, with an additional 150,000-250,000 at risk. The government classified HD as an "orphan," or rare, disease because of the relatively small number of people affected (fewer than 200,000). Numerous other disorders have similar symptoms. By mid-century, as many as 120 million people worldwide will suffer from dementia.

The world must shoulder a massive caregiving burden. Most people affected by such illnesses will require care ranging from in-home assistance to admission to a nursing home.

While researchers have made strides studying the symptoms, causes, and treatment of these conditions, caregiving has not advanced. Professional caregivers typically earn very low wages and receive little training. Even many doctors cannot properly diagnose rare disorders such as HD.

"Long term care remains a scandal in the United States," Alice Wexler, Ph.D., a board member of the HD-related Hereditary Disease Foundation and author of two books on the disease, writes in a brief history of the disease included in Buehler's book. "Persons living with HD and their loved ones – and all those with chronic neurodegenerative and psychiatric illnesses – still struggle mightily to find appropriate and affordable support and care, at home while they are still able, in facilities when they are not."

In a case that shocked the HD community, in May 2013 a 49-year-old, late-stage HD patient was allegedly strangled in an Oregon nursing home by another patient whom police described as suffering from "severe dementia."

To complicate matters further, the Genetic Information Nondiscrimination Act does not provide protection to people seeking life, disability, and long-term care insurance. Thus, as genetic testing, including full DNA sequencing, promises to become ubiquitous, people run the risk of not getting the coverage they will most need as they live ever longer lives. Only three states (California, Oregon, and Vermont) prohibit this type of discrimination.

Lives instantly transformed

My own family has struggled with Huntington's disease since the late 1980s, when my mother Carol Serbin started having strange swings in mood. A few years later, she developed chorea, the involuntary movements most Huntington's sufferers develop, causing some to appear as if they are dancing.

Nobody in the family understood what was wrong until in 1995 a neurologist suspected Huntington's. Just two years before, researchers had concluded a two-decade quest to find the disease-causing gene, which they called "huntingtin," like the disease named for the American physician George Huntington.

In 1872, Dr. Huntington published an article describing HD's symptoms and definitively establishing it as a genetically transmitted condition. Everybody has this gene, which is essential for life, but when it expands beyond its normal size, it causes brain cells to die. The discovery of the gene allowed for a definitive test for the disease, though, unfortunately, science has yet to provide effective treatments, much less a cure.

Receiving the news of my mother's diagnosis the day after Christmas 1995, my wife Regina and I saw our lives transformed before us in an instant. With no treatment or cure, HD was fatal. All children of an affected parent had a 50-50 of inheriting the condition. Most people experience disease onset between the ages of 30 and 50, and *everybody* with a certain degree of gene expansion or greater will develop the condition.

My mother's diagnosis and the fear that I might carry the genetic expansion compelled me to fight back in any way I could. Regina and I immediately started attending the local support group of the Huntington's Disease Society of America (HDSA), and I became an HDSA advocate.

I began writing about my experiences in this blog. Because of fear of genetic discrimination, until recently, I performed all of this behind the scenes, for example writing under a pseudonym, Gene Veritas.

The fear that I carried the mutation led Regina and me to postpone starting a family. By 1999, however, we agreed to try. First, I decided to get tested. I was especially worried about transmitting the mutation, because sometimes men pass on an even longer expansion, resulting in an early-onset form known as juvenile Huntington's.

Our worst fears were confirmed: I had the same expansion as my mother and would likely develop the disease in my forties or fifties.

We then embarked on the most difficult decision of our lives: the testing of our daughter in the womb (so-called preimplantation genetic diagnosis was not yet available). After weeks of waiting for the results, we received the happiest news of our lives: our "miracle baby" was HD-free! Today Bianca is a thriving middle school student.

The genetic mirror

Throughout this period, I juggled my roles as college professor, father and husband, and Huntington's disease advocate – all while watching my mother's inexorable decline. In addition to her psychiatric symptoms and chorea, she suffered from the third manifestation of the HD triad: cognitive loss and dementia.

"Each encounter with my mom became a view into a nightmarish genetic mirror," I wrote to a physician friend who included my story anonymously in a September 2005 *Washington Post* article on HD. "I watched her body jerk, head bob, and fingers fret. One night I found her wandering around our house confused and half naked. Within a year she lost most of her capacity to speak. She ate clumsily with her hands."

Around that time, because my "HD warrior" and caregiver father Paul could no longer care for my mother at home, he placed her in a nursing home. She died quietly in her sleep in February 2006, at 68.

Paul and Carol Serbin (photo by Gene Veritas)

Finally seeing the beauty

Following Guthrie through the pages of Buehler's books, I was prompted to reflect on my relationship with my mother as she struggled with HD as well as on how our system of caregiving must improve.

Disease communities are used to emphasizing the devastation of the their particular conditions. The devastation is real. But there is more to the person than the illness. I regret not having the emotional strength and presence of mind to have seen my mother more as a person and less as a mind and body racked by the symptoms of Huntingon's. Because I had tested positive for the mutation, often "my fear of HD kept me from sitting down with her and attempting to converse," I once wrote.

In the "Foreword" to *The Interviews*, Guthrie's daughter Nora recalls her own hesitancy as a 15-year-old to reach out to her father and how she ultimately learned to appreciate the man who, despite HD, understood his daughter's feelings, a man who possessed "twinkling eyes and a mischievous grin, releasing us all to live our own lives completely and wonderfully, taking each day and each situation as it comes." Her father "lived with this disease, but he never became Huntington's disease."

"As I turn these pages, I can finally see a beauty that has taken me over fifty years to recognize," Nora writes of Buehler's photographs of the hospital where she, her mother Marjorie, and brothers Arlo and Joady visited Guthrie on the weekends and held picnics on the lawn, the children often playing in a large tree their father dubbed the "magicky tree." "These images are merely ruins, the gross leftovers, the little pieces, chipped and peeling fragments of a life felt and lived so vividly and boldly."

Discrimination and misdiagnosis

The Guthries' story became my family's story, too. I remembered how I had travelled from my home in San Diego to visit my mother in the nursing home in suburban Cleveland shortly before she died. She shared a room with a woman paralyzed from the neck down. The attendants tried to feed my mother but didn't give her much more than a few spoonfuls before quitting. Always patient, my father had done a better job of feeding her when she was still at home. He would feed her once a day at the nursing home, too. Still, she was losing energy, slowly slipping towards death.

As the books recount, Guthrie faced the kind of discrimination still faced by HD people today: police officers and member of the general public often believe that HD people are drunk. In 1956, Guthrie was picked up by New Jersey state troopers, who thought he was a vagrant. Only after a phone call from a friend did the troopers comprehend that he needed medical attention.

At first, the medical personnel at Greystone refused to believe Guthrie's claims to have written thousands of songs. Instead, they described him as "delusional" and diagnosed him as a paranoid schizophrenic. HD is frequently misdiagnosed, in part because many doctors have little or no knowledge of the disease.

"Paranoid schizophrenia was a very common misdiagnosis – as were others including Parkinson's disease, Alzheimer's, all kinds of psychiatric illnesses and people were just locked away," says Dr. Michael Hayden, a world-renowned HD expert and leader in the quest for treatments, in an interview with Buehler.

It took years to discover the cause of my mother's difficulties. She, too, had received different diagnoses, and some of her doctors seemed indifferent or unwilling to get her to the right specialist. At first she was put on Haldol, an anti-psychotic also used to try to control chorea in HD. I quickly learned, however, that neurologists who understood HD avoided Haldol because of negative side effects, so we got her off of it as quickly as possible.

A difficult environment

The first two images in Buehler's work are Guthrie's Greystone intake photographs, which Buehler found in the basement of the admissions building, shown on the next page in a recent shot by the author. Later we come across Guthrie's bed in Ward 18 of the clinic building.

Images of Greystone Park State Hospital and a letter written there by Woody Guthrie (photos from www.woodyguthrie.org)

"I remember one time walking through the entire ward with beds lined on both sides to get to my father's bed at the very end," Nora recalls in the accompanying text. "The walk seemed to take forever. All around us were strange people yelling, talking to themselves, uninhibited or somber."

I've learned that most HD patients are mixed in with individuals with other conditions in facilities where personnel have little, if any, knowledge of HD. HD family members must often educate health

personnel about the disease. Perhaps my mother would have lived longer had there been a nursing home with appropriate enrichment activities for her condition.

Guthrie lived most of the time in Ward 40, which, with his typical mirth, he nicknamed "Wardy Forty," as in the 1956 letter that appears in the book. Although HD by this time had robbed Guthrie of his ability to play guitar, he continued to write frequently, although ever less legibly.

My mother was always in charge of balancing the family checkbook and writing Christmas cards. For a while after HD struck, she continued these activities. She used a ruler to make perfectly straight lines on which to write addresses. She eventually lost the ability to write.

A caregiver's dedication

In a 1956 play titled "My Forsaken Bibel [sic]," written at Greystone, Guthrie responds to a friend's question about how he inherited HD from his mother: "Hit my mother Nora Belle when she was about 40. Made her just go into such violent fits and such violent kinds of spasms that, well, she just wreckd [sic] and just wracked every single house we did live in. My cardiographer over yonder in Brooklyn just told me my mother's chorea sorta passled [sic] on to me here." Nora Belle died in an Oklahoma mental hospital in 1929.

My mother loved to sew. I remember the Halloween costumes and other clothing she made for me. One day she just stopped. She left scores of patterns unused. Like Guthrie, I love writing. I have already passed my mother's age of onset. How much longer before HD erodes my ability to express myself? Will I need to go into a nursing home? Will a treatment be found?

Marjorie loved and cared for Guthrie despite the fact that they had separated about a decade earlier because of strains over the disease. They eventually divorced. Near the end of *Wardy Forty*, Buehler places photographs of the couple at her Queens home, where she would take her husband for visits.

"She stripped him of his clothes and scrubbed him in the bath, sprinkling him with talcum powder and singing, 'Doesn't he smell sweet now!'" Nora recalls in the accompanying text. "She would wash and iron his clothes, sew up the tears, and dress him like a mother dressing her child for a first day of school."

Once my father, daughter, and I went with my mother to a park. My mother needed to use the rest room. We had to lift her from her wheelchair and maneuver her clumsy and unresponsive body into the stall. It was like moving dead weight. She nearly fell. When she was finished, we had to repeat the process in reverse. Later, in her final months of life in the nursing home, my father visited her every day. Dejected by her death, his own dementia worsened dramatically. A year after she died, he started taking a large, beautiful, framed picture of her wherever he went, including restaurants. In 2009 he, too, died in a nursing home

Time to stop 'throwing away' people

The final two images of Buehler's book are of Guthrie's Greystone discharge photos from April 1961, which contrast with the 1956 frontal intake photo. Initially, Guthrie looks into the camera. His expression is sad, but he appears relatively healthy. Upon discharge, however, he casts his eyes downward, typical of the difficulty HD-affected individuals have with visual focus. He appears to have lost much weight.

Arlo was 19 when his father died. That same year, he released the song "Alice's Restaurant," a protest of the Vietnam War draft. In 1969 he starred in the Hollywood movie based on the song and performed at the Woodstock Festival. Arlo himself never tested for HD and has not shown symptoms.

In *Wardy Forty*, Arlo has a strong message about Greystone and its residents: "These places were built so that they wouldn't be a burden on society. You could throw away your odd child, put him in one of these towns, almost like sending people to Australia from England years ago. Penal colonies. And so it's no wonder why they ended up in this sort of notoriously bad scene. They were set up from the very beginning to be away from the world, and not be part of it. Greystone is a real monument to that."

The idea behind Greystone still largely governs our outlook on care for the neurologically disabled.

People across the country are acting to correct the situation. Maria Shriver and former Supreme Court Justice Sandra Day O'Connor – both lost loved ones to Alzheimer's – have warned the public of the Alzheimer's "tsunami" about to hit America.

In Vermont, HD activists successfully advocated for state laws preventing inappropriate transfers of nursing facility residents and requiring public assistance for home-based and community-based care. At the national level, HDSA is pressuring Congress and the Social Security Administration to update long-outdated and inaccurate disability criteria for HD and to waive the two-year waiting period for patients to receive Medicare benefits.

Responding to press reports of corruption and abuses and requests from advocates, California state legislators in January announced twelve bills aimed at addressing the inadequate care in the state's assisted living facilities and nursing homes.

Indeed, the time has come to develop a more compassionate society by valuing both the person cared for and the caregiver.

Posted by Gene Veritas at 2:40 PM

Labels: Alzheimer's , caregivers , caregiving , Carol Serbin , compassionate , Greystone Hospital , Huntington's disease , long-term care , misdiagnosis , nursing home , Parkinson's , Paul Serbin , Wardy Forty , Woody Guthrie

5 comments:

Anonymous said...

Ken!

I'll never be accused of shilling for the American nursing home industry. I am very cognizant of American "nursing home culture." That said, the lives lived in them, by both residents and staff, are just as fulfilling, gratifying, challenging, frustrating, worrisome and joyous as the one that I'm living. Woody left a voluminous paper trail to make that point in his case. I had the pleasure of meeting and speaking with a nursing home resident of 6 years in Rochester, NY just yesterday. Her comments reflected it too. She was upbeat to meet and finding as much to engage her in her life as I am these days in mine.

There are plenty of horrible features of HD. Among them are

fear of loss of independence, dependence on others and lack of assistance to remain in your home. And more. I wonder sometimes if our responses (Scandalous! And the litany of the outraged) contribute to more and more fear that, in the view of thousands of nursing home residents across the country, some with HD and most without, is unnecessary or overstated by those of us not living in these settings.

There have been advances in long-term care, significant ones. Ironic, isn't it, that our culture looks to physicians based in acute care, office practices, consultants to long-term care settings or research to recognize them and pass them on. In fact, there's great hope to be found in what we know about long-term care these days.

We'll get there, though!

Jimmy Pollard

7:17 PM, April 17, 2014

Nancy Liccione said...

Ken,

Also known and loved as Gene Veritas. I read every word with bated breath. You are so very much a warrior for the truth. My mother was a very true example of what can happen to any one with this disease. Much like Woody Guthrie , sh did not have any correct information about the Huntington's Disease that started killing her at conception. Her mother was also unaware.The disease was hidden by telling my grandmother a lie. As a four year old girl, she was told the crazy woman dragged out of her house was a relative(NOT HER MOTHER). This person, my great grandmother died in a mental Asylum in 1905.My great grandmother survived 5 years in this horrible place. You would think that American Care giving Medicine has come a long way from that time 1905. This is absolutely not true. It is nearly as archaic as that date and time. We had no idea what was wrong with my mother. She began to walk in front of moving cars. I petitioned her , as a danger to herself. The "home" allowed her to leave and she walked into rush hour traffic. I still did not know what was wrong with her, BUT I can tell you that I knew what was right for both of us. I kidnapped her out the back door of this mental health care home. I arranged for a room in a Alzheimer lock up ward..The idea that our nursing homes are doing a good job of taking care of the neurologically impaired is ridiculous. I have heard that there are many refusals to even admit Huntington's patients, to this very day. This is discrimination. In a way it is a good thing that the nursing homes refuse. This is because they are almost all incompetent regarding the level of care needed.It is comparable

to 1905, or the time after,when Woody Guthrie was in "Wardy Forty, 1956.That is 50 years later from 1905. Or lets jump ahead to 2004. This is the year my mother died from the beating, hanging upside down from her restraints and assault in the nursing home. I was called that morning and told she was dying from pneumonia. When I made it to her room , I found her hanging upside down from her bed. Bruises on her face. I tried to help her as two of my children looked for any medical personel. The male orderly verbally tried to prevent my son from entering the room. He continued to the point of verbal assault on my young daughter and my son. I told my son to call 911. When the Paramedics arrived they were also threatened!!! THEY WERE TOLD that she could not be removed by the medics.The Chief Paramedic called for police escort out. He was trying very hard to stay calm and keep his crew calm.

My point here is that everyone wants to think that it is all going well. The horrible story here , is that it really is not going well for those who are institutionalized with this Huntington's disease and other diseases like this. As America is confronted with the true numbers of those with Alzheimer's and Huntington's Disease,it must face reality. It is not 1905,1956,or 2004. Do not settle for the mediocre standards of care.

5:58 PM, April 21, 2014

Anonymous said...

SO SAD! my family suffers from the disease and not much has changed.

8:00 PM, November 08, 2014

Edith Ann said...

I support your effort to teach and raise awareness of this Terri le disease. I find the biggest problem to be finding good places for people to live. Caregivers wear out, and if you can find a good home, are critical in seeing that their loved ones are seen as people, not just a patient. Love ones are most effective in this role once their person has reached the point that one or 2 people cannot bare the strenuous and emotional needs of the person. Visitors are so critical as representative speakers for those with HD.

3:05 AM, May 21, 2017

Anonymous said...

I just found out my adult child has HD. Her father died from it 2 yrs ago(his siblings all have HD). Now I have to wonder if her minor child has it. I wish there was a way to test him before 18 (regardless of symptoms). I am blind and in failing health. I simply don't know how to get them through this. I am already struggling to care for a terminally ill husband and mother. LOST and SCARED.

7:45 AM, June 18, 2017

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