

# Tracing Woody Guthrie and Huntington's Disease

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## ABSTRACT

Tracing the outlines of Woody Guthrie's life can be maddening. His outpouring of songs, words, and images attests to the rare creative spirit which possessed him like a devil, or angel, more often both. He was a figure which many of us hold dear as an emblematic American symbol of outspoken and independence-minded social consciousness. Drawn from Guthrie's collection of published and unpublished material in the Woody Guthrie Archives, including song lyrics, poems, prose, artwork—in short, every imaginable form of manuscript—the shadows that form and delineate Guthrie's life keep moving, much like dancing flames reflecting off a wall, illuminating some details while obscuring others.

Guthrie, of course, had no choice about Huntington's disease (HD) or how it would impact his life. Characteristically, he moved with it, sang with it, and even danced with it. When HD finally silenced Guthrie in 1967, it nevertheless spurred his second wife, Marjorie Mazia, to action—action which continues today with the commitment and work of the Huntington's Disease Society of America (HDSA). Was it tragic? Or just the natural course of the disease? The interplay between artistry, inspiration, and devastation is what we explore here.

**KEYWORDS:** Woody Guthrie, Huntington's disease, chorea, folk music, history of neurology, huntingtin protein, intermediate alleles, anticipation, caspases

**Objectives:** On completion of this article, the reader will be able to discuss the clinical aspects of Huntington's disease as it affected Woody Guthrie and also appreciate the significance of Mr. Guthrie's musical talent and the interaction between his illness and his art.

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Describing Okemah, Oklahoma, the small frontier town in Okfuskee County where he was born on July 14, 1912, Woody Guthrie writes:

Okemah was one of the singiest, square dancingest, drinkingest, yellingest, preachingest, walkingest, talkingest, laughingest, cryingest, shootingest,

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Arlo, Woody, and Marjorie Guthrie at Creedmoor State Hospital, 1966. Photograph by John Cohen. Photo-1, Series 4, #42. Courtesy of the Woody Guthrie Foundation and Archives.

fist fightingest, bleedingest, gamblingest, gun, club and razor caringest of our ranch towns and farm towns, because it blossomed out into one of our first Oil Boom Towns.

The second-born son of Charles and Nora Guthrie, Woody was the son of a cowboy, land speculator, and local politician. His Kansas-born mother profoundly influenced Woody in ways which would become increasingly apparent as he grew older. Slightly built, with an extremely full and curly head of hair, Woody was a precocious and unconventional boy from the start, with a wry sense of humor. A keen observer of the world around him, during his early years in Oklahoma, Woody experienced the first of a series of tragic personal losses, including the death by fire of his older sister Clara, the financial and physical ruin of his father, and the institutionalization and death of his mother, which seemed to haunt him throughout his life.

In a deleted paragraph from *Bound for Glory*, Guthrie's semi-autobiographical account of his early years, Guthrie writes:

"In the other house," Mama was talking into a cloud of hot steam over the stove, "Everything had its place. Everything was clean and every stick of furniture, and every little piece of silverware, and every little rug on the floors made you think of somewhere, where you was, what you were doing on the day that you bought it. That's what a home is. That's what a home

does. Make your mind stay straight. Instead of everything all dirty, and everything all twisted and all mixed up." The cold sweat oozed out on mama's face.<sup>1</sup>

With increasing concern, Woody continued to note ruptures in his mother's behavior:

"Jest sets. Looks. Holds a book in 'er lap most th' time, but she don't look at where th' book's at. Jest out across th' whole room, an' whole house an' ever'wheres."

"Is that right?"

"If Papa tells Mama somethin' she forgot, she gits so mad she goes off up in th' top bedroom an' cries an' cries all day long. What makes it?" I asked Grandma.

"Your mama is awful bad sick, Woody, awful bad. And she knows she's awful bad sick. And it's so bad that she don't want any of you to know about it . . . because it's going to get a whole lot worse."<sup>2</sup> (p. 65)

By 1930, Nora had passed away. The last time Woody paid her a visit at the asylum in Norman, Oklahoma, she didn't even recognize him.

With Okemah's boomtown period over, Woody headed West. In the panhandle town of Pampa, Texas, he fell in love with and married Mary Jennings in 1933, the younger sister of a friend and musician named Matt Jennings. Together, Woody and Mary had three chil-

dren: Gwen, Sue, and Bill. It was with Matt Jennings and Cluster Baker that Woody made his first attempt at a music “career,” forming The Corn Cob Trio. It is also during this time that, according to Guthrie biographer Joe Klein, Woody recounts the following conversation with Matt:

Slowly, quietly, he told Matt the family history: the fires, the death of his sister, the insane asylum. “When I went to visit my mother, she didn’t even recognize me,” he said. Then he talked about the disease: it ran in the family, crossing from father to daughter and mother to son.

“Does that mean you could get it?” Matt asked.

“No. There’s no way I’m gonna get that disease,” he said, and in the whiskey haze, Matt believed him.

It was the only time they ever talked about it.<sup>3</sup> (p. 49)

Although this is the earliest published mention of the yet unnamed “disease” which would later claim him, it demonstrates Guthrie’s awareness, and denial, of what would become an increasing and lasting fear.

If the Great Depression made it hard for most people to support a family, the Great Dust Storm, which hit the Great Plains in 1935, made it impossible. Due to the lack of work and driven by a search for a better life, Woody, much like the mass migration of “dust bowl refugees,” or “Okies,” headed for California. These farmers, agricultural and unemployed workers from Oklahoma, Kansas, Tennessee, and Georgia had also lost everything, their homes and land, setting out with their families in search of new opportunities. Like them, hungry and broke, Woody hitchhiked, rode freight trains, and even walked to California, developing a deep appreciation for the people he met along the way. As a result, Guthrie’s penchant for traveling the “open road” would become a lifelong practice.

By the time he arrived in California in 1937 Woody had experienced the intense discrimination and antagonism of resident Californians opposed to the influx of “outsiders.” Guthrie’s identification with “outsider” status would become part and parcel of his political, social, and musical positioning, a position which worked its way more and more into his songwriting, as evidenced in his *Dust Bowl Ballads* such as *I Ain’t Got No Home*, *Goin’ Down the Road Feelin’ Bad*, *Talking Dust Bowl Blues*, *Tom Joad*, and *Hard Travelin’*.<sup>4</sup> Guthrie’s 1937 radio broadcasts on KFVD, Los Angeles and XELO—just over the border in Mexico—brought Woody and his new singing partner, Maxine Crissman (a.k.a. Lefty Lou), wide public attention, while providing him a forum from which he could develop his talent for provocative social commentary and criticism of topics ranging from corrupt politicians, lawyers, and businessmen to praising the humanist

principles of Jesus Christ, Pretty Boy Floyd, and Union organizers.

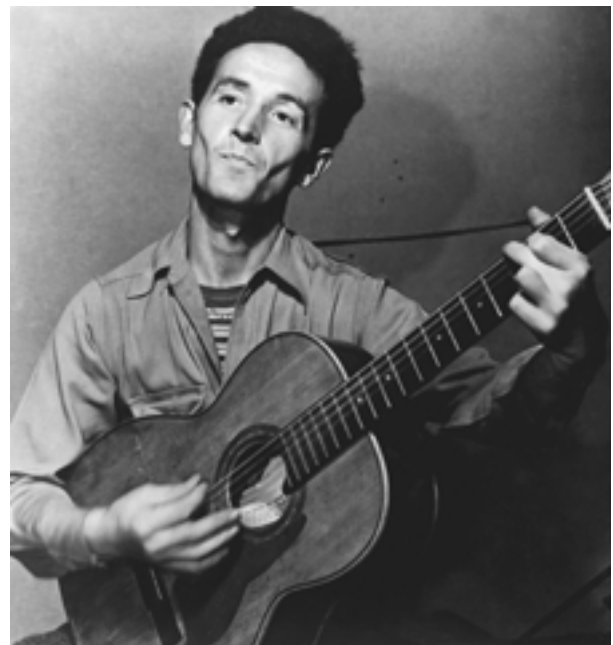
Never one to get too comfortable with success, or staying in one place for too long, in 1939 Woody headed East for New York City where he was embraced for his Steinbeckian homespun wisdom and folksy “authenticity” by leftist organizations, artists, writers, musicians, and other intellectuals:

... I sang at a hundred IWO (International Workers’ Order) lodges and met every color and kind of human being you can imagine.

Leadbelly, Cisco Houston, Burl Ives, Pete Seeger, Will Geer, Sony Terry, Brownie McGhee, Josh White, Millard Lampell, Bess Hawes, and Sis Cunningham, among others, became Woody’s friends and collaborators, taking up such social causes as Union organizing, anti-Fascism, strengthening the Communist Party, and generally fighting for the things they believed in the only way they knew how—through political songs of protest. However, becoming increasingly restless and disillusioned with New York’s radio and entertainment industry, Woody writes:

I got disgusted with the whole sissified and nervous rules of censorship on all my songs and Ballads, and drove off down the road across the southern states again.

After leaving New York City, traveling in his large new-bought Plymouth, Woody received an invita-



Woody Guthrie, playing and singing, circa 1938. Photograph by Sid Grossman. Photo-1, Series 1, #58. Courtesy of the Woody Guthrie Foundation and Archives.

tion to go to Oregon, where a documentary film project about the building of the Grand Coulee Dam sought out his songwriting skills. The Bonneville Power Authority placed Guthrie on the Federal payroll for a month, and there he composed yet another remarkable collection of songs: the *Columbia River Songs*, which include *Roll on Columbia* and *The Grand Coulee Dam*.

By this time, Guthrie had begun to increasingly distance himself from many of his friends, musical partners, and family. His marriage to Mary had dissolved, and although Guthrie tried to maintain communication with his family, he visited them only sporadically, offering financial support whenever he could. Not surprisingly, Guthrie was often considered irresponsible, adolescent, even destructive. Woody Guthrie's gradual unraveling had begun.

Returning East in May of 1940, in an historic series of recordings of songs and conversations conducted with folklorist Alan Lomax for the Library of Congress, Guthrie alludes to his mother's illness publicly for the first time:

And my mother . . . that was a little too much for her nerves, her *something*.<sup>3</sup> (pp. 158–159; author's italics)

Throughout the 1940's, Guthrie recorded numerous sides for Victor Records and Moses Asch's Folkways Records. Many of these recordings, which have been reissued under the Smithsonian Folkways label, continue to be "touchstones" for young folk music singers/songwriters everywhere.

In spite of constant traveling and performing during the 1940's, Woody managed to strenuously court and win the heart of an already married young Martha Graham dancer named Marjorie Greenblatt Mazia, whom he met in 1941.

With the beginning of World War II, moved by his strong anti-Fascist convictions, Guthrie served in both the Merchant Marine and the United States Army; first, shipping out to sea with his buddies Cisco Houston and Jimmy Longhi, and then drafted into the Army on May 7, 1945.<sup>5</sup> In one of Guthrie's many anti-Fascist songs written during the war, Woody writes:

We were seamen three,  
Cisco, Jimmy and me:  
Shipped out to beat the fascists  
Across the land and sea.  
—Seamen Three

During his tours of duty, as in civilian life, Guthrie's copious writing and drawing continued un-

abated. His energy and capacity for creative self-expression seemed inexhaustible whether on land or sea. It was on-board the *William B. Travis* in 1943 that Woody allegedly first broached the possibility that he might have inherited the same disease that killed his mother:

When the nervous back-and-forth subsided, Woody took over and began to tell them, very calmly and in surprising detail, the story of his family and the fires and his mother's illness. And then, in conclusion: "And I'm pretty sure I've got the same thing my mother had. . . ." "That's a crock," Jimmy started, then: "How do you know." "Dunno, just feel *queer* sometimes."<sup>3</sup> (p. 279)

Guthrie's Army stint at the tail-end of the war seemed a particularly pointless and unnerving exercise for him, as he struggled to overcome both boredom and frustration while awaiting discharge. In his letters he seems to wrestle with unresolved personal conflicts and mounting tensions while languishing at the Scotts Field, Illinois, Army base.

"Confused states of mind, a kind of lonesomeness, a nervousness stays with me no matter how I set myself to reading, painting or playing my guitar. Without trying to make it sound too serious, it never does get quite straight in my head."<sup>3</sup> (p. 314)

In the following excerpt, from a lengthy letter to Marjorie Mazia, Woody writes about venereal disease, a topic with which he had become curiously intrigued:

You worship nervousness. You believe in vulgar. You see only the law that you made for your own suicide. Your sex gets out of balance. Your brain functions wrong and your nerve ends are irritated for months or for years. Your tissues and organs get weakened, strained, irritated, and run down. The germ comes and he finds himself at home. The poisons from your glands did not work right because you kept the nerves all upset, cramped, overly taxed. Your defense fails. The germ lives. He makes your body his rotten log to breed his city of germs in.<sup>6</sup>

After what seemed an interminable tour of duty, Guthrie was finally discharged from the Army in 1946 and returned to Marjorie, who had by then divorced her husband. The relationship would provide Woody with a degree of domestic stability, security, and encouragement that he had not previously known. Together with their daughter, Cathy Ann, the Guthries settled down in Coney Island, New York. The peace he



had fought so hard for seemed finally within his reach, and, yet again, Guthrie's productivity reflected his surging creativity, enabling him, for example, to complete and publish his first novel, *Bound for Glory* (1943), a semi-autobiographical account of his Dust Bowl years. Guthrie's considerable literary talents met with significant critical acclaim, even while echoes of Whitman and Steinbeck were being invoked. As cultural historian Craig Werner put it: "If Woody's importance in American culture generally rests on his music, his place in the populist literary tradition rests largely on his ability to infuse his writings with the communal energy that powers his best songs."<sup>7</sup>

It was also during this time that Woody composed *Songs to Grow On*, a collection of children's songs which were inspired by Cathy Ann and, later, their first son Arlo. Woody's knack for understanding and communicating with children through music gained him a great deal of success for such memorable songs as *Put Your Finger in the Air* and the *Car Car Song*. It seemed as if all the tension and confusion of the military years were behind him, his life was back on track, and the future looked bright.

During the postwar years Guthrie continued to write songs and perform with Pete Seeger and the Almanac Singers, the politically radical singing group of the late 1940's, some of whose members would later regroup as the Weavers to become perhaps the most commercially successful and influential folk music group of the late 1940s and early 1950s. Managed by Harold Leventhal, a trusted friend and confidante, and with the help of music publisher Howie Richmond, the Weavers helped establish folk music as a viable commercial entity within the popular music industry.

In February of 1947, however, tragedy once again struck the Guthries. Cathy Ann, their four-year-old daughter, died from severe burns from an electrical fire in their home. The accident devastated Woody and Marjorie. Guthrie, in fact, was never the same. Stunned, Guthrie wrote in one of his notebooks:

And the thing you fear shall truly come upon you . . .<sup>3</sup> (p. 350)

As Klein notes, by 1949 Guthrie's work from this period seemed to have lost its sense of humor, his musical performances were inconsistent, and he was drinking:

The level of tension was higher than ever before. Woody was drinking more heavily again, and behaving very strangely at times. One afternoon he lost his temper and came charging at Marjorie with a kitchen knife. She screamed, "Woody!" which shocked

him back to his senses, after which he apologized profusely . . . but the incident stayed in her mind.<sup>3</sup> (p. 366)

In a discussion of Woody's artwork from this period, Ellen G. Landau quotes Guthrie from a notebook of the late forties:

The old head I've got seems to be all cluttered up with trash and garbage and crazy moving pictures—that whirl around all of the time and never see anything quite clear enough—and never feels [*sic*] anything quite plain enough. Never knows anything quite sure enough. Maybe something ought to happen to me to make me born again brand new.<sup>8</sup>

Woody's behavior and health continued to deteriorate, becoming visibly erratic and creating tensions in his personal and professional life. Repeatedly leaving Marjorie and their three children—Arlo, Joady, and Nora Lee—it became increasingly apparent that Guthrie was undergoing a personal crisis that nobody knew how to respond to. His "problem" seemed for many of his acquaintances and friends simply a result of alcoholism, which Guthrie may have used as an escape or shield against his fears. Guthrie was even willing to admit this much to himself, writing to Marjorie from a hotel during a final visit to his hometown Okemah:

I'm positive that 99% of our trouble is caused by my drinking; it only comes over me to hate and fight and to be so unreasonably jealous about you when I'm drinking. The drinking causes every damned ounce of trouble between us, mainly because it causes my brain to imagine a whole world of things about you that are not true.<sup>9</sup>

A hopeful Guthrie further explains:

I know that, if I can stop using liquor and tobacco that my head will stay clearer . . . The use of alcohol and tobacco both are a dizzy kind of a sickness and they make me weak enough without your pushing me out. . . . Liquor causes every ounce of these crazy fits of blind jealousy that come over me.<sup>9</sup>

Eventually returning to New York after a series of "road trips," Woody admits himself into the detox center at Kings County Hospital in May of 1952 after a particularly frightening episode with Marjorie. This was the first of several institutions that he would go in and out of for the next 13 years. From this point on, Woody Guthrie's life is a tale of struggle with HD.

In June of 1952, he voluntarily transfers to Brooklyn State, where the examining doctor, a Dr. Marlowe concludes: "This is one of those cases which stubbornly defies classification. In it, it has elements of schizophrenia, psychopathy and a psychoneurotic anxiety state, not to mention the mental and personality changes occurring in Huntington's chorea, at this patient's age." Klein writes this "offhand inclusion of Huntington's chorea . . . was the first official suggestion that Woody might, indeed, be suffering from the same disease that killed his mother."

He continues:

But the young examiner obviously was confused about the nature of the illness, since he didn't realize that the "psychoneurotic anxiety state" and all those other conditions he was describing were *symptoms* of Huntington's chorea. But then, he'd probably never seen a case of it before. It was so rare that it existed, for most doctors, merely as another oddity in their medical school texts.

and concludes with this projection:

Woody was told about none of this. All he knew was that groups of doctors were inspecting him periodically, and that they asked about his mother on several occasions. It was odd, he thought, that they were so curious about his mother, since he was absolutely convinced that his problem was alcoholism, pure and simple, and it was his *father* who'd been the drunk in the family.

During his stay in Brooklyn State Hospital, Woody continually wrote personal notes, letters, songs, and ideas for songs, filling numerous notebooks. In a lengthy letter to Marjorie, dated July 1952 from Brooklyn State, Guthrie begins with a tone of optimism:

I'll have myself back under control in another minute, another hour, another week or so;

before going into greater detail about his feelings and symptoms:

Feel terribly restless always. I get here and I want to be yonder. I get over yonder and I want to be back over here. I get out west and I crave to be back east. I get down south and hope to get back up north. I feel dissatisfied with myself no matter where I'm located.

. . . I don't trust anybody I see. . . .

It's worse when I feel hungry, and I feel hungry every minute, even after eating a big double helping and getting up from the table. . . .

Disoriented. That's the book name for what I am. Useless to a point where my pain is all but unbearable. Not needed. Not wanted. No good to myself nor no good to anybody else, a derelict of a failure. A wreck not worth the salvaging. . . .

Yet in some odd way since my hernia operation over at Bellevue, I feel better in my head and all over (in general) than I've been feeling for many a dizzy-headed year. . . .<sup>9</sup>

In a notebook from early August 1952, from Brooklyn State, Woody scrawled the following:

I see myself as a long scientific experiment to prove the indestructibility of my humanly seed.<sup>10</sup>

Among the seemingly endless ramblings on loose-leaf notebook paper, all addressed to Marjorie, he includes this description of his feelings (and how he hides them), dated August 21, 1952:

Here's my funny feeling over me again. That lost feeling. That gone feeling. That old empty whipped feeling. Shaky. Bad control. Out of control. Jumpy. Jerky. High tension. Least little thing knocks my ego down below zero mark. Everything cuts into me and hurts me several times more than it should. Everything hits me. A word or a look or an action of anybody here deals me a misery. I've not got strength to go on, nor to see things in the light as they should be. No bodily (physical) pains; just like my arms and legs and hands and feet and my whole body belongs to somebody else and not to me; so ashamed of myself I want to run hide away where nobody can find me nor see how bad I feel. Can they tell by looking at me how useless and weak and flimsy and artificial (and how foney) I feel? [*sic*]

Worse than this, I ask myself what makes me [break my head] to try to hide my weak jitters? Why don't I break down and spill them out all over to the first person I see? Why don't I? Why?

It would all be over (the worst of it) if I could only cave in and fall down and tell everybody how I feel. My trouble isn't in the dizzy spell nor the pains not in my [weakly] feeling, but my worst pains come because I spend every drop of my bodily strength trying to hide my trouble away so you can't see it; trying to keep you from reading it in my face, or my eyes, or in any words I'd say or in that stumbly way I walk around.

We never try to help our coal miners till our mine caves in; we never can let you help us till our pride caves in, and till our fears cave in.

This business of trying to hide our weaker feelings surely surely must be in all of us. Surely I'm not the only man on this ward that hides all this as long as he

can. Everybody does it; everybody tries to hide it so's you'll never guess how bad and how empty we feel. Some of us hide it more (and longer) than others. Some of us break down under it sooner than others; some talk it out, some weep it out, some yell and scream and curse it out, some battle and fight it out. All of us drive it out in our own way, but all of us must get your help, must borrow your bosom to cry on, must ask you to help us, must break our damnfool secrecy and our damnfool pride on your shoulder. Why do I stall off my own breakdown like I do? . . . Could be partly because I've just never been in a hospital like this before and my own crazy pride keeps holding me back from breaking down and letting you know how thin and how bad and how miserable I feel.

A few pages later, it turns paranoid, with Woody accusing Marjorie of being an FBI spy simply because she tries to figure out what pains and symptoms he is actually hiding.

The pages and pages of notebook rambling continue, all dated from August. At one point, Woody in a lengthy letter to Marjorie includes this description of his health:

I feel mentally, physically, economically, neuro-physically, bodily, soulfully, economically, theoretically, esthetically, mathematically, scientifically, hygeinically [*sic*], psychologically, religiously, numerically, philosophically, and sexually, and socially, and schizophrenically better this morning than I feel most mornings here. I feel politically better, too; and musically, better, also; and husbandly and fatherly, and manfully better.<sup>11</sup>

After being released from Brooklyn State Hospital on September 22, 1952, Woody heads to Pete Seeger's house in upstate New York. Pete is away in California, as Woody discovers, and so Woody stays with Pete's family and wife, Toshi, writing this letter to Pete:

I fit [*sic*] my way past all the doctors and psychofolks they could muster against me to get out from that Brooklyn State Mental Observatory. They analyzed me as being partly in the first pains of alcoholic's withdrawal period, plus a certain percentage of the mental disease my mother had, Huntington's Chorea. They're not plumb sure about my dizzy spells I feel now twice every day because I ain't got no bodily pains of any kind. All of us alky boys go through some odd sorts and flavors of craving (liquor) spells from a mild dizzy feeling on up (or down) to the worst of aches and shakes you nearly ever saw or seen.

There are lots of kinds of chorea and nobody is plumb sure about what kind I'll most likely have if any. They say it aint deadly nor fatal, so, my days in yonders

hospital weren't quite wasted if they got me off my bottle or helped me to get strong enough to bypass old Whiskey Town.

Chorea keeps me just as dizzy and a good bit cheaper. I feel a thousand million times better now that I'm a old dry drunk AA man.

Doctors all told Marjorie to get a divorce from me for the safety of the kids, which is the hardest part of my troubles at the time. She's willing to talk later about a rematch between us if my chorea stays mild enough for a few seasons, which is the best word of good news I've got to offer you at today's dawning. . . .<sup>12</sup>

In a letter to Marjorie from Topanga Canyon, California, Woody refers to his condition as *chorea* and discusses its worsening:

My chorea sure isn't kidding these days. I feel it as a nervous fluttery heart condition along with a slight lack of control over my body at times. I feel it sort of steady now at all times and a bit moreso sometimes than at other times. I don't entirely lost nor entirely gone but partly so part of the time. I'm pretty sure that I do need companionship like you say but I'm not any to posolutely certain about who'd be foolish enough to shack up with me when it gets down to bare facts.<sup>13</sup>

Meanwhile, Woody's connections to the Communist Party in America attracted the attention of the FBI. As anti-Communist paranoia escalated in 1953, the agency began reporting on Woody's actions and whereabouts, classifying him as a potential security risk. A summary report from Woody's FBI file, dated October 9, 1953, summarizes Woody's biographical details before reaching section number 7, "Status of Health." Here, the unidentified agent brought J. Edgar Hoover pretty well up to date on Woody's health, thanks to a mysterious but at least knowledgeable informant at Brooklyn State:

———\* [at] the Brooklyn State Hospital for the Mentally Ill, at 681 Clarkson Avenue, Brooklyn, New York, was interviewed on April 10, 1953 by S.A. ———advised that the subject entered the hospital on a voluntary basis on July 22, 1952, and was discharged on September 24, 1952.

——— advised that the subject was diagnosed as suffering from Huntington's Chorea, which he described as a chronic neurological condition with occasional psychotic manifestations. ——— said that this is

\*The lines here substitute for names blacked-out by the FBI before releasing these files.

a disease concerning which very little is known and for which there is no known cure. He explained that the disease appears to be inherited, noting that it had been determined that the subject's mother had died of a mental disease which appeared to have been Huntington's Chorea. He said that the disease usually strikes men in their late thirties or early forties and follows a rather distinct pattern of periods of neurotic and psychotic behavior followed by periods of apparent complete rationality. This disease is a deteriorating disease in that periods of being rational get shorter and the periods of emotional unbalance get longer until the patient is finally a hopeless mental cripple and finally dies.

——— said that it was impossible to determine the length of the disorder because there was so many varied factors involved, but that a patient could live from five to twenty years with the disease. He said that the disease manifests itself in the fortieth year and that most patients have succumbed by the time they are 55 or 60 years of age.

——— stated that the clinical record indicates that Guthrie's case was fairly well advanced and that hospitalized [*sic*] would have been recommended but that because the subject was a voluntary admission, he could not be held without a court order which would have had to be [signed] for by the subject's wife. The records indicate that Guthrie was released in the custody of his wife at the 49 Murdock Court address.<sup>14</sup>

On September 16, 1954, Woody checks himself back into Brooklyn State Hospital. In November, he writes this poem:

“No Help Known”<sup>15</sup>  
Huntington's Chorea  
Means there's no help known  
In the science of medicine  
For me  
And all of you Choreanites like me  
Because all of my good nurses  
And all of my good medicine men  
And all of my good [attenters]  
All look at me and say  
By your words or by your looks  
Or maybe by your whispers  
There's just not no hope  
Nor not no treatments known  
To cure me of my dizzy[??]  
Called Chorea  
Maybe Jesus can think  
Up a cure of some kind

In December 1955, Woody finally writes a letter to his father, admitting that he has his mother's disease:

I've got the 1st early signs and symptoms of a dizzy disease called Huntington's Chorea, same disease that Mama had which lets me stay dizzy in my head everyday without paying my barman one penny.<sup>3</sup>

On May 25, 1955, an unidentified FBI agent updated the information in Woody's agency file, explaining: “——— explained that the subject is not insane but is afflicted with severe mental depressions which cause him to go on severe alcoholic binges. —— advised that the subject will be paralyzed eventually, but could not say when this would happen.” The next report in Woody's FBI file is dated June 3, and it recommended canceling Guthrie's Security Index card “in view of the subject's health status.”<sup>14</sup>

A manuscript from Brooklyn State dated simply 1955 titled “Chorea and Me” may be Woody's most frank discussion of his disease and the link to his mother:

I got my first good early look at my chorea on back several years ago as I watched how it worked on my mother, Nora Belle Guthrie, back in my old homey town of Okemah, Oklahoma. I got myself such a good clear look at it (chorea) that I want to try and show you what things it caused her to do and how I fell heir to it through her.

I'm still glad I did fall heir to my chorea because it makes me stay dizzy and drunk all time without gulping down your [??] or without paying my bartender one little blue cent.

It's been a couple or three good years ago when I headed my own rambling self in here to the door of my good Brooklyn State Hopeystial [*sic*] and give myself up to be looked at, observed, examined, checked over, digested, analyzed, and score boarded from my head on down to try to see if I could find out and see what makes me walk around so dizzy as I do.

And just what its been that makes me walk around dizzy every day. I stumbled in here just one hop ahead of it, but when you told me how it was that my mother passed it on to me, I guessed I'd better go on back towards old Okemah Town one more time and try to tell you how I seen it hit her away on back before I even knew what name you called it by.

Some of you experts called it by one name and some of you called it by some other [nomiere??]. I just saw how odd it made her act and do around our house and I seen her lots more every day than my Dad ever seen her. He'd get up real bright and real early every morning and he'd [scribble ???] down his little bit of a breakfast and he'd go saddle up his horse and he'd ride on off to his office down in town. Then she'd throw all of our furniture and all of our fixings, our chairs and our tables and our beds and our bookcases and our



dressers all around over our whole house while she had one of her bad spells, and after her fit had worn itself off and gone on and left her, us kids would all go and pitch in and we'd help her straighten our whole place up again and get it all fixed up nice and pretty again by the time we heard Papa's foot heels scrape on our front porch for our supper time.

I could see my mother get worsen and worsen every little passing minute of all of my passing years even before I saw her get really bad enuff and really loud enuff for any of my next door neighbors to get wind of what she done or even for my very own Daddy to get very wise to it all. I learnt how if not why it is that my people spend a good ninety nine and nine tenths of their earthly hours here on my worldly planet just trying to hide the simple little facts and truth of life from one another.<sup>16</sup>

Woody left Brooklyn State of his own decision on May 23, 1956. The next day he was arrested for apparently "wandering aimlessly on [the] highway." Unfortunately, he was in New Jersey at the time, and the Morris County court delivered him to Greystone Park mental institution in Morris County, NJ. A nurse made these notes upon Woody's admission to the hospital: "Ambulatory from Morris Co. Jail—arrested for wandering aimlessly on highway. Involuntary movements of body—states he has Huntington's chorea—also says his mother had it—well-oriented to time and place."<sup>17</sup>

The actual commitment papers from the Juvenile and Domestic Relations Court of Morris County, NJ, dated June 6, 1956, include the following notes as justification for this allegation; signed by George W. Comeau, they proclaim:

It appears that Woodrow Wilson Guthrie, hereinafter designated as "patient," is alleged to be insane. . . .

The following are the facts as to the insanity of the said Woodrow Wilson Guthrie upon which my opinion is founded:

1. The patient said: "I got \$3000 for writing a song, I left Brooklyn State Hospital on May 23, 1956. I wanted to find the orphans to give them the money—I wrote about 8000 songs and I got \$10,000 for writing."
2. The patient: untidy, unkempt, kept talking all through interview about all the money he has.
3. Other facts perceived by me indicating insanity: Lacks insight and judgment, Grandiose ideas, untidy & unkempt, wanders about the highways.<sup>18</sup>

The Greystone medical staff got around to logging an official diagnosis on August 4, in which a "medical staff record" states:

. . . Dr. Dolinsky presented a diagnosis of SCHIZOPHRENIC REACTION, PARANOID TYPE, which was unanimously accepted by members of the staff.<sup>17</sup>

In an October 22<sup>nd</sup> letter addressed to "Joadsy," Woody rambles on about God; then, links his own disease to his mother's:

My mother Nora Belle did have my very own huntingtons chorea along with Joe's Saint Vitusy dance and my doctors say she had spells of epilepsy also at the very same time God is just giving me here my real perfect kind of a chance to just see and to just feel exactly how my own Mother saw and felt.<sup>19</sup>

On January 8, 1957, doctors at Greystone changed Woody's diagnosis. A "medical staff record" note reads: ". . . It was also the unanimous opinion of the staff that the diagnosis be changed from SCHIZOPHRENIC REACTION, PARANOID TYPE to CHRONIC BRAIN SYNDROME ASSOCIATED WITH DISEASES OF UNKNOWN OR UNCERTAIN CAUSE; CHRONIC BRAIN SYNDROME OF UNKNOWN OR UNCERTAIN CAUSE: HUNTINGTON'S CHOREA WITH PSYCHOTIC REACTION." A memo sheet, with the same date, marked for "record room" and closed out by "Clinical Doctor," also notes the official change: "From: SCHIZOPHRENIC REACTION, PARANOID TYPE (22.3x) To: CHRONIC BRAIN SYNDROME, ASSOCIATED WITH DISEASES OF UNKNOWN OR UNCERTAIN CAUSE; CHRONIC BRAIN SYNDROME OF UNKNOWN OR UNSPECIFIED CAUSE: HUNTINGTON'S CHOREA WITH PSYCHOTIC REACTION (19.11)."

Doctors at Greystone kept Woody on Thorazine. Medication lists show that Woody received 100 mg of Thorazine each day, at least from May 22 through May 28, 1958 and from December 1, 1959, to April 4, 1961.<sup>20</sup> An "Occupational Therapy Progress Note," dated August 7, 1959, records Woody's latest artistic achievements: two belts and a pot holder. Dr. John H. Fudge comments: "He has to wait for the therapist to give him instructions before he continues with his work . . . He seems to enjoy his work in spite of his trembling difficulties."<sup>21</sup>

In April 1963, Marjorie composed an open letter to Woody's friends and fans. The letter was published in that month's *Woody Guthrie Newsletter*. She included the following description of Woody in the hospital:



Woody Guthrie at Greystone Park Hospital, 1958. Photograph by Louis Gordon. Photo-1, Series 4, #24. Courtesy of the Woody Guthrie Foundation and Archives.

Actually, Woody's muscular condition continues to deteriorate. I find it more and more difficult to understand him when he speaks . . . and this is when his fiery temper jumps out . . . but when I finally get the words, it usually is some funny remark about something or somebody! His memory remains uncanny but he just hasn't got the muscular control to "mouth" the words. His balance is very poor . . . he looks like he is about to fall any minute . . . but he remains standing! Actually he spends most of his time in the hospital or at home lying on his back . . . smoking away . . . forever lighting up a new cigarette because the old one fell out of his mouth! To see him light a cigarette is really to see a man fighting for his life. Yes, he wants to live!<sup>22</sup>

Through it all, Marjorie continued to acknowledge Woody's courage and to care for him. His acceptance of HD was inspiring, but nonetheless painful. Klein adds:

By 1965, he had stopped speaking entirely and could only communicate by pointing a wildly flailing arm at "yes" and "no" cards that Marjorie had made for him. Then, after a while, he could no longer even do

*that*. All he had left were his eyes, which he blinked in recognition when Marjorie entered the room and, sometimes, when she asked him a question or told him something. The real horror, Marjorie was convinced, was that Woody could still understand what she was saying. He could still think and know. There was an active mind trapped inside the tumultuous decrepitude of his body.<sup>3</sup>

In Klein's summation of the discovery of Huntington's, as explained to Marjorie by a doctor, he writes:

And while it would be absurd to suggest that Huntington's disease *made* Woody Guthrie a brilliant songwriter, Dr. Whittier (and, later, Marjorie Guthrie herself) would wonder aloud if the disease hadn't worked like a drug on Woody, as a creative spur (in much the same that some artists use alcohol and other drugs), enhancing his natural rhythmicity, forcing the brain to continually rewire itself as cells died, forcing new, wonderful, and unexpected synaptic pathways to open (which also led to some unexpected and not so wonderful behavior), forcing the brain to become—in effect—more creative to survive; and then, after a point, exhausted and starving for energy, the synapses and ganglia short-circuiting . . . preventing him from *concentrating* on anything, making him fidgety, antsy, causing him to lose perspective and, eventually, his creative sense of himself.<sup>3</sup>

And, lastly, Pete Seeger's final remembrance of Woody:

About eight months before he died in 1967, I visited him once more, this time with Sonny Terry and Brownie McGhee. Woody was in a wheelchair. He couldn't walk anymore, so the hospital attendant wheeled him out onto a porch where it was warm. Sonny, Brownie and I played some music for Woody. We did "Rock Island Line," with Sonny blowing his his harp, sending beautiful notes into the air. Woody must have liked what he heard because you could see how much he wanted to be part of our little group. He tried to get his arms going, but they were just flailing around like a windmill. It got to the point where it looked as though he might hurt himself, so the attendant said, "You better quit playing that loud tune. He's tryin' to join you and he can't." So we stopped "Rock Island Line" and played some quiet blues instead.<sup>23</sup>

Woody passed away on October 3, 1967, at Creedmoor State Hospital in Queens, New York. The

certificate of death lists the cause as “natural causes” and notes that his body was cremated the following day.<sup>24</sup>

### WHAT MESSAGES FROM WOODY'S LIFE CAN WE APPLY TO OTHERS WITH HD?

The disorder referred to as Huntington's chorea during the era of Woody Guthrie is now more generally called Huntington's disease (HD). Although chorea certainly is a hallmark of the disorder, personality changes and cognitive dysfunction often appear before involuntary movements. And, as will be discussed below, children with HD may have little or no chorea.

In reviewing the life of Woody, as so eloquently summarized by Jorge Arévalo, one readily identifies themes that apply to any family afflicted with HD. For anyone who cares for these patients, it becomes immediately clear that this disorder not only compromises the individual with manifest HD but has a tremendous emotional impact on all those close to the patient.

Woody's experience with HD began when his mother, Nora, became affected. He and his siblings watched the gradual transformation of an otherwise normal functioning and nurturing mother into someone who became detached, erratic, and unpredictable. As her behavioral problems escalated, the Guthrie children never knew in what mood they would find their mother.

Very early in Woody's life story, we see what is probably the largest tragedy of HD, namely the powerful impact upon a child as he witnesses the mental and physical deterioration of a parent. In families with HD, divorce is common and the children are frequently raised by other family members or given up for adoption. Affected mothers often cannot care for their children due to depression, apathy, and volatility. Sooner or later, the HD parent requires full care and is typically placed in a nursing home. Families struggle with whether to allow small children to see the parent in the later stages of the disease.

At some point during the parent's illness, children learn about the hereditary nature of HD, especially if other family members are affected. Woody perhaps sensed that he was at-risk for developing the illness of his mother. He carried this within himself quietly and only rarely discussed it with others. Persons at-risk for HD often experience a period of denial that may be short lived or lifelong. It is not uncommon for families to conceal the family history of HD from their children. We may diagnose a 50 year-old-person with HD (with a strong family history) only to find that he has never told his children (who often have started their own families) that they were at-risk. Since there is no cure for HD as yet, most patients decide not to undergo presymptomatic testing, a process that eventually reveals to the at-risk person whether or not they harbor the HD gene. Presymptomatic testing should be per-

formed at a medical center that has genetic counselors and physicians who are familiar with HD. If an at-risk individual has a normal neurological examination, then a second meeting with a genetic counselor is arranged to discuss the implications of genetic testing. The results are later disclosed to the patient (who is always to be accompanied by a friend or relative) during the third clinic visit.

For those who carry the HD gene, the onset of the illness is always insidious and it is impossible to pinpoint exactly when they become symptomatic. It is particularly difficult to determine when Woody began to experience HD symptoms because, at baseline, his lifestyle tended toward impulsive, sensory, and momentary experiences. It was after the tragic death of his beloved daughter, Cathy Ann, that Woody became inconsolable. As drinking became more of a practice for Woody, there was growing uncertainty regarding which aspects of his behavior were from alcohol and which were from HD.

Concurrent substance abuse often masks the early cognitive or behavioral symptoms of HD making it even more challenging to determine if a person has become affected. With time, however, it became clear that in Woody this was more than simply depression and alcohol abuse when motor control deteriorated and chorea was documented. By 1952, when Woody was 40 years of age, the physicians at Brooklyn State Hospital suspected he was suffering from HD.

Denial of the at-risk status is often followed by denial of being affected with HD. From the time of a tentative diagnosis in 1949 until 1955, it appeared that Woody may have held out hope that many of his problems were alcohol-related. The letter to his father informing him that he was suffering his mother's illness seems to indicate that Woody had accepted the diagnosis, at least at some level. It is suspected that a patient's denial of their illness may be a psychological defense mechanism but also appears to be related to the neurobiology of caudate nucleus dysfunction that interferes with awareness of self. Patients with early and even moderate HD often lack insight into their cognitive dysfunction, and may not even be aware that they have chorea.

One learns about disease processes not by reading medical textbooks and journal articles, but by caring for patients, by observing their illness in real time, and by listening to their reports of what they are feeling and how the illness is affecting them. Once HD began its course in Woody, it proceeded to disrupt his personal and professional life. Woody's description of HD is brutally honest, unadulterated, and piercing. Through his writing we bear witness to the unraveling of an individual with the restlessness, the flight of ideas, the self-condemnation, the paranoia, the complete loss of control, and the pure undistilled misery.

The type of intellectual deterioration that occurs in HD includes slowed mental processing, impaired se-



quencing of multiple tasks, and delayed retrieval of information. In deciphering his very late writings, it may have been a surprise to learn that his compositions still retained Guthrie's signature clarity, focus, and depth. Arévalo writes, "If anything, Guthrie's always inordinately profound and prolific level of introspection, over the lengthy course of the disease's manifestation, seems to have taken on an increased spiritual and humanized dimension (personal communication)." Further inquiry into Woody's work during this period suggests that many of the complex neuronal pathways involved in creativity were preserved even at a time when he could not speak or write legibly.

In the late stages of the illness, Marjorie Guthrie reminds us that Woody could still understand life around him, and appreciate the company of loved ones and the playing of good music. She reminds us that the person inside the failing body is still very much alive and active, still having the same emotional needs as before HD, if not more.

Woody Guthrie died at the age of 55, after battling the disease for over 15 years. Throughout his life Woody was an advocate for the homeless, the hard physical laborers, the dirt poor, the politically incorrect, and any group that was misunderstood, unappreciated, or exploited. He spent his life trying to spread the word about injustice and suffering through his music and writings. I would imagine that he would be pleased to know that, two generations later, we continue to reflect upon his life and maintain an interest in the disease that devastated him. Woody would be extremely proud knowing how much his family contributed to the decades of education and organization of research funds that have brought us so close to a cure for HD.

(We believe) Woody would be delighted to know that his words may have some impact on the attitude and understanding of health professionals who come in contact with HD patients whether they are nurses, therapists, social workers, psychologists, or physicians. If any of us will carry with us a bit more patience, a bit more compassion, and a bit more respect to our next meeting with a person suffering from HD then this collection of writings was compiled for good cause.

### WHAT HAVE WE LEARNED ABOUT HD SINCE THE DAYS OF WOODY GUTHRIE?

When the genetic basis for HD was identified in 1993 by the Huntington's Disease Collaborative Research Group,<sup>25</sup> the world applauded. We learned that HD is caused by an expanded and unstable CAG (cytosine, adenosine, guanine) sequence in the gene coding for the *huntingtin* protein. The CAG expansion is located in exon 1 of the HD gene, and is translated into an extra polyglutamine segment at the N-terminal end of the mutant *huntingtin* protein.

HD is an autosomal dominant disorder. Children of HD patients have a 50% chance of inheriting the gene. Most normal individuals have between 11 and 26 (median 18) CAG repeats in exon 1 of the HD gene. Those who inherit at least one allele with 40 or more repeats will have a 100% chance of developing clinical signs and symptoms of HD in their lifetime (complete penetrance). The range of 36 to 39 repeats is associated with variable penetrance and referred to as *intermediate alleles*. The relationship of trinucleotide repeat length to the risk of developing manifest (symptomatic) HD is as follows: 36 repeats with a 25% risk, 37 repeats with a 50% risk, 38 repeats with a 75% risk, and 39 repeats with a 90% risk.<sup>26,27</sup>

The neurological manifestations of HD include behavioral changes, cognitive dysfunction, generalized incoordination, and chorea. These abnormalities may appear in any order and evolve in a pattern unique to the affected individual. The average duration of disease is 21 years with a range of 1 to 40 years.<sup>28</sup> The clinical course is extremely variable even among people who have the same number of CAG repeats within the same family. This point is illustrated in a report of monozygotic twin boys with HD.<sup>29</sup> The age of onset was similar between the boys yet one had primarily cognitive problems while the other had prominent motoric dysfunction. This also highlights the fact that there are many unidentified disease-modifying factors that influence the expression of the HD gene.

HD symptoms typically develop between 35 and 45 years of age (range: 2 to 80 years). The number of trinucleotide repeats predicts approximately 60% of the variability in the age of onset and is not clinically useful in predicting the age of onset in an individual patient. For this reason, disclosure of the CAG repeat length must always be provided by someone who can explain to the presymptomatic patient what information can be gained from the gene test, and at the same time clearly state the limitations of the test.

It has long been recognized that children who inherit the HD gene from their father may have onset of symptoms in childhood or adolescence. This is consistent with the phenomenon of *anticipation*, which is an increase in disease severity or earlier age of onset in successive generations. When HD begins prior to 20 years of age it is referred to as the *juvenile form* of the disease. Symptoms include rigidity, bradykinesia, dystonia, myoclonus, and seizures with little or no chorea. (I would mention that Woody Guthrie had two children from his first marriage who developed juvenile HD.) Most juvenile HD patients have CAG lengths over 70 whereas the majority of adult-onset patients have between 40 and 55 repeats. The upper limit of repeats in HD used to be considered approximately 120 until Nance et al<sup>30</sup> reported a boy with 250 repeats who became symptomatic at age two and a half years.

The genetic basis for anticipation in HD is meiotic instability, which has historically been observed in



paternal transmission. During spermatogenesis in men with HD, there is often expansion of the repeat length so their children have a younger age of onset. Recently there has been a single report of anticipation occurring with maternal transmission of HD; however, this is considered a rare event.<sup>43</sup> In this case report, the mother had a CAG length of 36 and the two daughters had 66 and 57 repeats, respectively.

Individuals with intermediate HD alleles (repeat lengths of 36 to 39) also have meiotic instability. This may explain many of the previously described "spontaneous mutations." When a diagnosis is made in a patient with no family history and both parents lived to 70 years without exhibiting signs of HD, one should suspect that one of the parents had an intermediate allele that expanded into the 40 or greater range. Other explanations to consider (in a tactful manner) when assessing patients with a negative family history are the possibility that the patient was adopted or that there was false paternity. Repeat lengths of 27 to 35 may also be susceptible to meiotic instability. Individuals with alleles in this range will never develop manifest HD but expansion may occur during gametogenesis. Thus their children may be at-risk both for developing HD and for having meiotic instability. Individuals with 26 repeats or less are considered stable in this regard.

Models of HD (in mice, *Drosophila* and *Caenorhabditis elegans*) have provided important clues regarding the mechanism of cell injury in this disorder and have facilitated the study of potential therapies. Although the function of *huntingtin* is unknown, it appears to be involved in embryogenesis. When both copies of the HD gene are inactivated in a "knock-out" mouse model, the embryos die at 8 days gestation.<sup>32</sup> When the human mutant HD gene is placed into transgenic mice, the animals develop weight loss, brain atrophy, and behavioral abnormalities (including jerky movements) that resemble some of the major phenotypic characteristics of human HD.<sup>33</sup>

According to the transgenic mouse models, it is believed that the initial step in the cascade of events leading to disruption of neuronal function is the splicing of the mutant *huntingtin* protein within the cytoplasm. This process separates the N-terminal portion (containing the polyglutamine expansion) from the rest of the protein. *Huntingtin* is cleaved by enzymes typically involved in apoptosis known as *caspases*. The truncated *huntingtin* is then transported into the nucleus where, in the later stages of the disease, it aggregates forming intranuclear inclusions.<sup>34</sup> Similar appearing inclusions have also been identified in the cortex and striatum of HD patients.<sup>35</sup>

It remains to be determined what role these inclusions play in the pathogenesis of HD.

Discovery of the potential role of caspases in HD led to the first significant breakthrough in developing agents that could alter disease course. In 1998 it was

demonstrated that caspase inhibition could delay onset of disease and slow progression of abnormalities in the mouse model of HD.<sup>36</sup> In addition to the presumed toxicity of the mutant *huntingtin* fragment, other mechanisms may be involved with the pathophysiology of HD, such as glutamate toxicity and mitochondrial dysfunction. It has long been recognized that the striatal neurons that are injured early in HD are those with N-methyl-D-aspartate (NMDA) receptors.<sup>37</sup> Additional evidence of excitotoxic injury includes the observation that the NMDA agonist, quinolinic acid, produces neuropathological changes similar to those seen in HD.<sup>38</sup> Defects in mitochondrial electron transport and oxidative metabolism have been demonstrated in HD patients.<sup>39-41</sup> The mitochondrial toxin, 3-nitropropionic acid, induces striatal lesions similar to those of quinolinic acid<sup>42</sup> and MRI spectroscopy shows increased lactate production in HD.<sup>43</sup>

This basic science information has provided the rationale for ongoing clinical trials testing caspase inhibitors (such as minocycline and tetracycline), NMDA antagonists (such as ramacemide), and mitochondrial supplements (such as coenzyme Q10 and creatine) to determine if they can slow progression of HD or reduce symptoms.

In a clinical setting, a great deal can be done to help patients with HD. Explanation of the clinical and genetic aspects of the disease are an essential part of every encounter with new families. Depression and irritability typically respond to any of the antidepressants, with selective serotonin reuptake inhibitors (SSRIs) being first choice agents. Although tricyclic antidepressants are effective in treating depression and inducing sleep in HD, they often cause cognitive side effects and are potentially lethal in overdose situations. Many HD patients have anxiety requiring benzodiazepines or buspirone. Chorea is reduced by both atypical and typical neuroleptics, which also help with behavioral problems and psychosis. Atypical agents such as risperidone, quetiapine, and olanzapine have the benefit of being more sedating than haloperidol and are associated with a lower incidence of extrapyramidal effects. The weight gain of the atypical neuroleptics is often desirable since HD is a wasting disease. Valproic acid can lessen chorea and serve as a mood stabilizer. Riluzole may also reduce chorea<sup>44</sup> but the cost is often prohibitive. Insomnia can be treated with sedating antidepressants, trazodone, sedative/hypnotic agents, or benzodiazepines. Mirtazepine is a particularly helpful drug because it serves four functions: it reduces anxiety, treats depression, induces sleep, and promotes weight gain. As the disease progresses, most patients with HD are on a combination of these drugs often taking an SSRI, a benzodiazepine, and an atypical neuroleptic. Those with juvenile HD frequently require levodopa to treat rigidity and often need anticonvulsants given the high incidence of seizures and myoclonus. Physical

therapy, occupational therapy, and speech therapy are often helpful to those with moderate to severe disease. What patients need most of all is a caring and compassionate clinic team. This is an exciting era in HD research and clinical therapeutics! We never miss an opportunity to remind patients that a cure for HD is just around the corner.

### CLOSING COMMENTS

When Woody was eventually diagnosed as having Huntington's disease, Marjorie was trying to cope with the illness while still working as a dancer, rearing her three young children, and taking care of her husband. Unfortunately, there was no one with Huntington's disease in their family to talk to or provide support, and Marjorie made a personal commitment to rectify this tragic situation.

In 1967, the year of Woody's death, Marjorie founded the Committee to Combat Huntington disease (CCHD). She soon discovered influential individuals who had HD in their families or who had an interest in the disease. She began to attend neurological meetings to make scientists aware of this inherited disorder and to encourage physicians to diagnose it correctly.

She formed CCHD chapters throughout the United States to help HD families know they were not alone, and also to raise funds for lobbying. Marjorie clearly understood the power of lobbying. With minimal resources, she plied the halls of Congress and took the HD message to all that would listen. At her urging, Congress formed a commission to investigate and make recommendations for research on the control and cure of this dreaded disease. This led to significant increases in funding for research on HD, which eventually led to the discovery of the HD gene.

Unfortunately, Marjorie died in 1983 just months before the HD gene was mapped to human chromosome 4, a discovery in major part due to the fruits of her labor.

An excellent source of information about clinical, genetic, and research aspects of HD can be easily accessed on the Huntington's Disease Society of America website: [www.hdsa.org](http://www.hdsa.org).

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