

Marjorie Guthrie

Finding Our Way

*The Story of Woody and Marjorie Guthrie's
Fight Against Huntington's Disease*



Huntington's Disease
Society of America



50 YEARS OF SERVICE
1967-2017



Marjorie Guthrie

Finding Our Way

*The Story of Woody and Marjorie Guthrie's
Fight Against Huntington's Disease*



Huntington's Disease
Society of America



50 YEARS OF SERVICE
1967-2017



Reprinted by



Huntington's Disease
Society of America

HDSA.org (800) 345-HDSA

From *Counseling in Genetics*, edited by
Y.E. Hsia, K. Hirschhorn, R.L. Silverberg, L. Godmilow.
Copyright 1979 and reprint permission by
Alan R. Liss, Inc., New York, NY.
First reprinted by the Committee to Combat
Huntington's Disease as "A Personal View
of Genetic Counseling."

© 1979 Alan R. Liss, Inc.
Photos courtesy of the Woody Guthrie Archives

PREFACE

“We set out to do something, and, if possible, change how the world looked at HD,” reflected Marjorie Guthrie on the 15th anniversary of the Committee to Combat Huntington’s Disease, the group she founded in 1967.

Back then few people had ever heard of Huntington’s and far fewer knew anything about it. Those seeking to learn more were faced with a dearth of information and a good deal of misinformation. HD families had to endure the consequences: isolation, hopelessness, despair.

Today there is abundant evidence of progress. As we take heart in recent advances in research, education and care, we remember our debt to Marjorie Guthrie, whose drive and charisma gave HD families the voice which now echoes around the world.

INTRODUCTION

Many of you know that my husband, Woody, father of my children, had Huntington's Disease. I want to share with you some of our experiences in learning about Huntington's and the experiences other families have shared with me about Huntington's. I hope these experiences will help genetic counselors understand some of the joys and sorrows in the lives of families with genetic problems.

I have been amazed at the uniqueness of each person's experience, and then on reflection I see many similarities. There are common threads of fears, anticipation of fears, concerns with how individuals at-risk might react to the diagnosis, how (or if) to tell a spouse or children, how to find a way to live with the diagnosis, and whether there will be treatments or a "cure." As I have often sat and listened to these people pouring out their concerns, I try to help by listening, encouraging them to explore their feelings, observing how they speak and what they leave out. Each one has his or her own story that "leaps out," once an opening is given, to share.

Sometimes, two persons come together, a husband and wife, a mother and daughter, and reveal thoughts to each other that have been hidden a long time.

I find that someone capable of understanding and sharing things that are difficult to say can help a family face the reality of what might or might not happen with the threat of Huntington's disease. I do not consider myself a professional counselor. When someone comes to me we just talk together. Hopefully, I help by sharing my own feelings and how I have found strength. Out of all this, I, too, am helped and am finding my way. It is not a constant routine, but one that changes from person to person. As I look back, there have also been changes from year to year in my thinking as well as those with whom I speak.

HUNTINGTON'S IN OUR FAMILY ***Early Recollections***

Let us go back and begin with my earliest recollections about Huntington's and See how I came to where I am today.

In the early 1940s, I was a professional dancer. When I first met Woody, I found him to be a shy yet strong, creative, child-like fun person. He had a kind of innocence and yet when he looked at you, his gaze was direct and complete. His body, in comparison with most of my dancer friends seemed awkward but strong and sinewy. He had the coloring of the earth itself, and one had the feeling that he had slept upon the ground many nights. He carried his guitar everywhere he went, hanging on his back. Sticking out of his breast pocket, one could see a few sharpened pencils, a good pen or two, and in his pants pockets a roll of writing paper or a notebook pushed down into the back pocket. He never wore a tie, and when I met him, he didn't even have a warm coat. In the cold, wintery days, he wore an old army jacket that seemed much too big. His bony fingers stuck out, and his cowboy boots seemed to have been worn down to paper. Yet he walked with a stride - a fast walker when he had to go somewhere, a dawdly one when he was strumming and coming down the street. He talked concisely, a few short words, to the point, with a funny little laugh, as he seemed to reflect on his own words. His eyebrows always seemed to be raised in question over his small beady eyes. He had

what appeared to be leathery, tough suntanned skin, his face had smile lines, and his thin lips curled up at the ends.

I liked walking down the street holding hands. His grip was firm, and despite his “country” appearance he felt “special.” We shared hours of talk and dreams. We liked dreaming and teasing about the future. We made up stories about what our life would be about, how our kids were going to grow up and be “world changers and hope-ers” - how we were going to be the “singing Guthries”- how we would travel as a family - making this world a better place with songs and dance and that “good union feeling.” We were like any young couple in love - planning for the tomorrows and believing that we could do anything that we set out to do - as long as we were together.

Woody had been married before and already had three children. We shared a little room in a typical rooming house on 14th Street in New York City, one window, one bed, a small sink, a chest of drawers, one chair, one small closet.

When I went off in the morning to my rehearsals or classes, he would sit down with his typewriter on the chest of drawers or sit in the chair and fill up a ten-cent notepad and sip a container of coffee. Sometimes, when I returned, I would find funny drawings or notes telling me he was out walking or grabbing a bite to eat across the street or going to see Joy Homer, who was then editing his autobiography, "Bound for Glory." Those were busy, productive days. After long hours of work both of us would put our thoughts together, and either he or I would read what he had written that day out loud, so that the other one could type it up properly for Joy to read the next day.

One day he wrote about his mother, describing how she had become disheveled and neglected the house and even had temper tantrums and threw things around the house and was often found sitting in the little movie house of Okemah, Oklahoma, where the Guthries lived. After his older sister Clara died from a fire in the house, his "mama" was taken to the "insane asylum" in Norman, Oklahoma.

I asked Woody what kind of sickness this was. He said that the doctor told them she

had Huntington's chorea. I asked him if he could get sick like his mother, and he said that only females get this chorea so he did not have to worry.

And we didn't worry. We went on building our dreams, working at our professions, he writing, me teaching and dancing. Sometimes, at a party with our friends, I would feel so bad when Woody would drink too much and become angry over little things - or perhaps disappear with a friend - and I would go home crying and hurt. When I protested that I didn't see why he had to drink so much, he would explain that where he came from everybody drinks this cheap wine from the time they were four years old. His body was used to it and it wouldn't hurt him one bit and he resumed his writing, with an occasional trip to record his songs for Moe Asch at the Folkways recording office on 46th Street.

During the war, Woody and his good friend, Cisco Houston, shipped out in the merchant marine. Cisco was not one to knuckle down to anybody, but he always handled Woody so tenderly. He told us wonderful stories about Woody at sea, and we would all

laugh together about Woody's antics on the ship. Instead of setting the tables for the thousands of men who were on their way to fight in Europe, Woody would write the day's news on a blackboard with cartoons all around. This was supposed to be the day's menu, but his humor and his songs had become part of Woody that everybody could enjoy, so there were no complaints. They made three trips together and were torpedoed twice. Woody wore his medals proudly. He believed in the fight against Hitler, and on his guitar he had a large sign: THIS MACHINE KILLS FASCISTS. He wrote many songs about the defeat of Hitler - Some serious and some satire - always with hopes for a better world - a positive picture of what that world could be like, would be like. He was not one to be defeated or to let us believe in defeat.

Meanwhile, our family had grown. Our little girl, Cathy, whom Woody called "Stackabones," had died in a fire, and now we had three little ones, all of us living in three tiny rooms in Coney Island. I liked color - the linoleum floor was bright blue - the book shelves went from the floor to the ceiling, and Woody's desk was a piece of wood, cut on an angle, nailed to the wall in the corner of our

living room. Our bedcouch opened up at night and touched the little piano that I had bought during one of Woody's trips, so that if you wanted to get out of the bed at night you had to climb out either end. Our three kids slept on little nursery cots side by side, and we used a gate between their room and ours so that they could all play together, yet we could see them. Many days when I was away teaching, Woody was left in charge of the children until my friends who helped to care for them would arrive later in the day. He would write, sing, feed, tease, and read all day, alternating whenever he felt like it from one activity to another. Sometimes he would make a sketch or two or write whatever the children said about his drawing on the paper.

In the beginning, I felt good leaving him with the children. I knew he had the patience to do things with them. I also knew that my mother or my helper would be there in time. It was a good family life with all the usual ups and downs. Sometimes his anger was tough to take. There were times when we parted for a day or two – sometimes for a week or more – when he would be away singing somewhere and not return as I had expected. But there would come in the mail another ten – cent

notepad telling me how much he loved the kids and me and that he wasn't good enough for us.

He would return dirty and tired, I would set him down into a tub, wash him up, and he would dance around our little room and say how good it was to be home again. And I would sit at the piano chording the way he said his mother used to do, with him brushing my long hair down my back, as he used to do for her. I always felt that in many ways I was not only Woody's wife, but also the mother that he never had and always wanted. We had wonderful, friendly neighbors in those days. Young and old came to our apartment, listening to our records, playing chess on our tiny kitchen table. Woody enjoyed our neighbors and loved Coney Island, which was where we could live and still have "wide open spaces," something that Woody felt was missing in the city, since he identified with the wheat fields and the crops and trees and rivers where he had slept in his travels.

Signs of Huntington's Disease

I recall very clearly how one day Woody was walking in front of me and his guitar was not on his back, and yet he seemed to be walking a bit lopsided. I remember thinking “that’s funny, he looks like his guitar is on his shoulder pulling him over, but it’s not there.” (I used to carry my little bag with all of my dance clothes in my hand and I always felt so unbalanced when I did not have it. I recalled thinking, “that’s the way I feel when I walk without my bag.”)

I know now that this walk was one of the first signs of Woody’s chorea.

I thought nothing of it at the time, but little by little his uneven walking became worse. Also, in retrospect, his beautiful diction on his recordings became more and more difficult to maintain. He had a marvelous way of saying the t’s or d’s at the end of a word, and he made every effort to speak clearly. To do this, he seemed to gather his breath and words seemed to explode from his lips. I began to notice that his anger seemed longer or more severe than before. Thinking that maybe it was the pressure of the three kids

disturbing his work, we moved into a larger apartment, where Woody could have a special room nearby with his books and typewriter, where no one would disturb his thinking. We set up a great studio, using orange crates, for his writing and drawing paraphernalia. He worked there beautifully for a while. Then little by little he would bring home a book he was reading, or a few pages for me to read, then the typewriter. Little by little he soon moved back in. He worked at home and several weeks later would try moving to another place. Once we used a store around the corner and had to set up a big curtain to cover the storefront so people would not knock on the window and want to come in.

Recognizing that none of these places were working out, we moved to a new apartment, where Woody had his own room in his own home. We thought surely that was going to help him become more stable.

I was still teaching, earning a living, and had to leave home regularly. I began to leave with more and more concern as I noticed the heavier drinking, and he seemed to tire more. He would rest on our bed for longer periods in the middle of the day. When he was resting,

he seemed to be glad to be away from it all. If I wanted to ask a question, I waited until I felt he would be more responsive. I was aware of what I was doing, but one day I noticed that my daughter, who at that time was about two years old, would walk up to the bed and if he did not seem to want to talk to her, she would quietly walk away, sensing that this was not the time to talk to Daddy.

Without knowing, I think all of us were aware that there was something wrong with Woody. A young musician who loved Woody began to imitate his explosive speech as though that was his real speech pattern. There were numerous outbursts of temper, and one frustrating day Woody agreed that “there was something wrong” and consented to seek medical help.

Doctors and Hospitals

After three weeks in a local hospital for observation, we were told that Woody was an alcoholic. Later, after several weeks in Bellevue Hospital, there was still no diagnosis of his condition. Then one day Woody suddenly called. The doctor had told him to go home. They gave him a subway token and a dime to

call me. He was already on his way! I panicked. I called the hospital and asked the doctor if it were true that he was told to go home. No diagnosis! Just go home! The doctor said, "Mrs. Guthrie, your husband is a very sick man, and WE DONT KNOW WHAT TO DO WITH HIM." I replied that I didn't know what to do with him either. I was worried about my children. What could we do now?

This was the real beginning of anguish! Whom would I talk to? Whom would I consult? How should we live? Was it safe to leave him with the children?

To my surprise, Woody looked well. The food and rest in the hospital had been good for him. He seemed calm and ready to work again. He did work. He wrote songs and articles, typing away, sometimes writing with his collection of pens and pencils, sometimes drawing wonderful funny sketches. He was Woody again. It was wonderful to see him busy, active, and smiling. Yet underneath all this were my own fears. The words of the doctor were ringing in my ears, and I became more and more concerned about leaving him in the house, but I knew I had no choice. Our mother's helper was more experienced with life

than I. She handled Woody calmly and took care of the children. As the weeks went by I managed to keep up a good front with her help.

One day, Woody said that he wanted to take a trip to California, and I rushed at the opportunity to have him leave home. Our good friends Will and Herta Geer welcomed him, and I felt relieved that Woody was in good hands. He wrote regularly, notebooks full of ideas for songs, telling about life with the Geers. This was a time of respite for me. It did not last too long, and soon he was on his way back to New York.

For the next two or three years, with more involuntary movement, with more difficulty swallowing, and difficulty with speech, he signed himself in and out of Brooklyn State Hospital. The first time we went to this hospital he told the doctors that he knew something was wrong and hoped they could find out. I recounted his background and begged that they find out, for whatever it was we could find a way to face it, but the not – knowing was killing us! Eventually it was suggested that Woody should have some shock treatments, and he was moved to a ward to wait his turn

for these treatments. He and I just accepted this as a possible hope that something could be done. It was while waiting in this ward that a young physician came up with the diagnosis of Huntington's chorea.

We were stunned Woody believed that he couldn't have his mother's illness because "men did not get chorea." We were told there was no treatment.

HOPELESS. HELPLESS.

For days after, we talked at the hospital about what we should do. There was no question but that he would have to stay in the hospital. We would keep our family together. I would bring him home on weekends. We would find a way to tell the children when it was appropriate. He would try to keep writing in the hospital. We would stick by each other as best we could. We found OUR way.

We stumbled a lot over the following years. We listened to what others said, and then we did what we thought was best for ourselves and our children, and it usually was NOT what others had advised. One doctor suggested (along with most of my friends) we

should tell the children that Woody had died, so that they would not have to see him deteriorate. This was so unreal to me at the time. What would happen if they found out that I had lied? And how could I help to take care of him if we wiped him out of lives? He did not seem ill. There were many, many good days when he walked rather well and enjoyed our visits. He began to show more of the involuntary movements, but he always joked that his “vitaphones” (the loads of vitamins that he was taking) were going to make him better. When we went to our local hot-dog stand on weekends, he ordered several, ate the hot-dogs, threw the rolls away, and drank six or seven root beers. He enjoyed riding in the car, and particularly liked to lie down in the sun in our backyard. By now, I had bought a house in Queens, and while Woody never lived in this house, our neighbors knew who he was and shared in our pleasure as Woody became better known to the public.

A newspaper article told about Woody’s sickness and the Secretary of the Interior, Stewart Udall, honored him with an award for the songs that expressed his love for our country. He could not go down to Washington to receive the award, but we took his picture

as he held it, seemingly happy that people were still singing his songs.

Towards the end he was confined to his wheelchair and found speech and swallowing very difficult. He almost choked several times, and on several occasions I received a telegram telling me that he was dying of pneumonia. Each time he pulled through and each time he laughed about how he was “still here.”

All this time he was trying to write. His beautiful handwriting was deteriorating, but he still wanted me to bring long yellow pads to the hospital. He filled them up with his “scrabbles,” and I replaced them with additional tablets. He loved the feel of his pencils and tried to keep one always on him, which wasn’t easy in a ward with 40 men, mostly patients with mental disorders.

All during the years when I came to visit and to read his fan mail, there were always letters from young people. I would read parts, and he would enjoy hearing the good thoughts. I had been told that he probably did not understand one word, but his response was so evident and obvious, that I would ask him questions to prove to myself that he did

understand all I was reading and saying. He had many moments of extreme tiredness when his concentration would wane. He would show such exasperation when he waved two open fingers in the air (meaning that he wanted a cigarette placed there) and no one cared to accommodate him, even though I left cartons of cigarettes for him each week.

His inability to express a need and the frustration of being ignored were the greatest hardships of all for him. I understood his sign language and his frustration, and I began to think of ways to try to get the hospital attendants to become more responsive to his needs. I made three cards, “YES,” “NO,” and “?,” and I spread them either on his bed or on the tray of his wheelchair. I teased him and said that he must help me prove to the attendants and the doctors that he was fully competent despite his appearance, and he must answer some questions to show that he did know what I was saying. I asked a series of questions to which I knew the answers, and despite an annoyed look on his face that he had to prove his sanity, he invariably moved his arms to the correct card. This is when I began to wonder whether the doctors really knew all about Huntington’s. We “tested” him

in this way continually, and then, towards the end, we used one or two eye blinks to answer yes or no. I changed the number occasionally to be sure that we were still communicating. In this way I learned that there was a whole man locked up inside this shell of a person. I learned that he had no physical pain, although his nervous system was deteriorating and affected him in many ways. He could not feel or taste, which was why he wanted more seasoned foods, candy, and strong coffee.

He was tied into his wheel-chair to avoid falling, but this also hastened the wasting of his muscles. He could no longer stand and could no longer walk or come home. I suggested loosening his bonds in the chair, so that he might try some simple exercises to build up his thigh muscles so that he could walk. When I came to visit and asked if he had done the exercises, he replied by popping up and down in his chair. One day, another patient remarked that he had walked. Sure enough, when I untied him, he walked several steps away from the chair and then returned, collapsing into it with a big grin on his face.

It was then I began to believe there were things that we could do to help the

patient who had Huntington's. Each time I visited, I questioned and observed. For years, I came with my friend Shirley. I found that it was getting more difficult for me to converse with Woody, knowing that he could not respond without great effort. I found that if Shirley and I sat on each side of him and we talked so that he could hear all our news and hear what we were doing with the children and all the usual family gossip, he enjoyed being a part of what he was hearing and often smiled and shook his head in response.

On his dying day he heard us come into his room, opened his eyes, and made a grunting sound when I asked him if he would like some water. I fed him a spoon of water to wet his dry lips. He was still a whole person, but this person was dying and he knew it. We knew it too, and the hospital chaplain who was standing by asked if he might say a prayer. He recited the Lord's Prayer, and we all looked at each other, listening quietly. I told the chaplain that Woody had always loved to read the Bible and was more versed in the Bible than most people. He had always enjoyed studying the religions of the world, and throughout this conversation he was listening with his eyes sometimes closed and sometimes open. When

I left the hospital. I stroked his forehead. I knew it was the last time.

Early the next morning, they called. Woody had died.

HELPING OTHERS TO COPE

I began to live, however, with a new vigor and determination. I had already talked to Dr. Whittier about what I might do to help him and other scientists find families with this disease, because there was a feeling that this “rare disorder” was not so rare. Several months before Woody died, I did find three other affected families, and that is when I organized the Committee to Combat Huntington’s Disease, in 1967. I had told Woody of my plans, and I do think that he understood. Now, relieved of the care of Woody, I could devote my energy and whatever talents I had to this task of finding Huntington’s families and bringing attention to this disease, and thereby maybe even helping my own children.

With each passing year, I meet and talk with mothers and fathers, children and friends of affected families as I travel across the

country, and I hear in their stories remnants of my own. Today, there is better understanding of how Huntington's progresses. The "team approach" has been recognized as the best method for helping a patient and family through the various stages of the disease. Neurologists, family physicians, genetic counselors, social workers, nurses, and a variety of health therapists are working together, starting at the earliest symptoms, to offer better care and treatment. Now, we recognize that every member of the family is a patient whose needs must be assessed with each passing year. Huntington's is a chronic disorder which requires a great variety of care.

The Future Is Unpredictable

Each person who lives in an environment that is unpredictable develops fantasies, some unrealistic, some closer to reality. All are trying to find ways to cope with the unknown. These are common threads, but I believe the answers for coping depend on many factors that need to be explained.

When should one talk about Huntington's? When a parent has just begun to show symptoms and has young children?

Regardless of what the spouse might wish to say, one must consider the kind of person the patient was and is, the temperament of the children, their ability to cope with their friends who might visit the home, the kind of community in which the family lives, the educational background of the family, their way of coping with any problem, and who their physician is.

Each member of a family expresses himself or herself in an individual way when a family first learns about Huntington's or when a diagnosis has been confirmed. Much depends on how the doctor tells the patient, how the doctor looks when he says there is no treatment, or "there is nothing I can do, come back in a year." Sometimes a family does not go to its physician because they know what he will say, and the patient or the spouse does not want to face the facts yet. A person may have had the experience of seeing Huntington's in his or her parent as a child and may wish to protect the family from this diagnosis.

In my own family, one child thought he knew something about father's disease, but did not think that I, his mother, was truly aware of

the facts, and, wanting to spare his mother, suffered quietly and alone.

These are only some of the challenges people are dealing with in their lives.

Difficult Practical Decisions

What of practical problems? Should the patient live in an institution? Is this just an escape? Can the patient be cared for at home? Are there other places where a patient might go and still function at his or her own best level? Who can afford to pay for this kind of care? Will the family have to sell everything they own in order to qualify for medical care? What happens to the remaining family? Where will they live or find schools or work? Do you tell your employer that you seem to or might have Huntington's? What should you do about your workman's compensation form, your insurance, your will, your various legal problems? After many days and nights of anguish over these kinds of thoughts... how does a patient learn to live with Huntington's?

The Healing Effects of Time

Many people have written of the coping mechanisms which all of us eventually either do or do not develop. I have come to certain truths for me. Most important is that time is the great teacher. In time we learn many things. Our parents have told us this over and over, but it is beginning to become a reality as I think about my life. If there is time, we can hope to resolve our thoughts and our ways of accepting or finding new ways to solve problems. In talking with affected families, I find that those who begin to face their reality - not mine or yours but their own vision of what life is all about - as early as possible, make the best adjustments. If you are a child, and you know that someday you might have Huntington's like your parent, perhaps the fact that in your family the adult form may not show symptoms until 35 or 40 can help you rationalize that there is no need to worry because it is still far off.

When you are deeply worried, the fears wax and wane depending on what happened that day or that night. We bring to each day an accumulation of experiences, and they melt into feelings that change from day to day.

These are different when you are alone from when you are among friends. Sometimes we share our fears with our peers; sometimes we cannot find the words to use with them; or we try and are frustrated in the effort.

As time goes by, a child may find his or her Huntington's problems are either increasing or becoming forgotten, sunk deep into the subconscious, or they come and go depending on who or what arouses these thoughts again. The child has become familiar with his fears. The more we feel at home with our fears, the easier it is to accept the reality of what is or what might be.

I think most adults recognize this pattern of growth in all kinds of living. Being familiar with life itself helps most of us to wake up in the morning and do what must be done. Our hospitals are filled with people who could not or did not practice coping with their reality. And it takes a lot of practice and much help and inspiration and examples from the kinds of people we see around us or read about. Heroes begin to take shape when we are young, and they help us to define ourselves as we look into the mirror. We "make believe" that we are a favorite school teacher, and we

talk or walk or imitate what we like about him. Our reaction to sickness and deformity is learned early in life from those around us. What happened in a family when a grandparent dies, or becomes ill, and who does what for whom? Did the family console together, or cry at the gravesite, or was death a celebration of life? Was there something in accepting that all of us have a limited time? Who is first to talk about the “quality of life?” A parent, a teacher, or a friend? Children do talk about these thoughts and we the adults are like a mirror in which they look to learn about themselves.

Helping Myself to Cope

This is the way I thought about living with Huntington’s in my family. Woody was my mirror at first. In those early days, when our life was full of living, creating, and believing that we had many tomorrows, we saw in each other a partner toward common goals. Our dream was to make a better world. Woody came from a rural Midwest background. Each of us had parents who set us examples, gave us the courage to work hard, imbued in us faith to believe that we were here for a wonderful purpose, which we could achieve

with hard work. Woody liked to make long lists of all the different kinds of work he had done. My list was shorter, but it was there for me to reflect on; what we did together became another list; what we did with our family was another list. We extended these lists to our neighbors and our community. We saw all these wonderful opportunities because we were looking for them.

In the long years of hospitalization, one of the questions I used to ask was “Do you want to live?” and Woody always answered that he did. I guessed his desire was to see what was going to happen next. When I asked “What do you do here all day, think about the past?” he answered with a nod of his head. “Do you worry about the future?” He would smile and say no. He had enough of his life stored in his bank of memories to keep himself going.

I do not know how much of this has rubbed off onto our children. I do not know their inner fears or what they share with their partners, but I hope that time will help them too. We have talked together as a family, and whatever they say today, I know they will say it differently tomorrow. Knowing that I am

trying to do something to help may or may not be of comfort to them, if and when they ever show symptoms of Huntington's. But we are learning many things about it that we did not know yesterday. My experiences with Woody have helped me to learn that our understanding of this disorder was wrong from the start.

Professional Support for Families

Today, with help from a "team" of professionally trained persons, I believe we must begin by exploring the whole background and history of a family which has concerns about Huntington's. All the empty spaces should be filled in not only regarding those who had Huntington's in the past, but how their family responded, and how individuals who did or did not develop it conducted their lives.

I believe we should try to hold up a mirror for those who seek our help. We should help them see where they came from, how they feel about themselves and their way of life. With guidance from the professional "life-givers," We should try to draw out from each person a vision of the path which that person

might begin to walk. Every now and then, there will be a new turning, but we should try to keep our people moving along the projected path, sometimes jumping over a hurdle, sometimes stopping to catch their breath.

I am convinced that a Huntington's patient should not be hospitalized too soon. He or she needs to be able to live each day to his/her full potential. Many patients are capable of developing new skills commensurate with their handicap. They need to be encouraged to participate in every phase of family life. Relatives who are "at-risk" may choose to hide from reality for a while, but if they could be helped to sense, early in life, that living is one big "risk," they will begin the coping process early and accumulate enough strength to fill their days doing the things they can and want to do.

In our experience, learning about the possibility of having Huntington's close to the "age of onset" (35-55) can be devastating. An "at-risk" person has the least time to learn to cope and usually has the greatest difficulty in accepting the facts. Here again, we should emphasize that, despite the dreaded truth, there are still years of living to be experienced.

You do not just drop off tomorrow with Huntington's. When I look back, I marvel at the way Woody lived in a ward with 40 or more mentally handicapped people all those years and yet somehow managed to maintain his sanity. Today we encourage patients to live at home as long as possible. We believe that work and recreational day facilities should be available on an out-patient basis, instead of leaving these patients alone all day without any social contact. If it becomes necessary to live in a nursing home facility, there should be incentives for productive living for as long as possible. Even in later stages of Huntington's proper care facilities should be provided which should include social and therapeutic resources (1). Physical, occupational, and speech therapies are essential to preserve mobility, morale, and communication as long as possible.

We encourage patients to participate in experimental drug therapy for the control of involuntary movements, as well as to alleviate the depression and irritability with the newly developed drugs. Sometimes meeting and talking with a similarly affected patient has given new courage and purpose to one newly diagnosed. Now I know that Woody should

not have been strapped to a chair, without any physical exercise, those last four years. We recommend starting a course of therapy as early as possible, to prevent muscles from wasting away. We know that with speech therapy we can maintain better communication, which is itself one of the major causes of stress and frustration, and these in turn aggravate involuntary movements. Some families have learned ways to prepare foods that are easier to swallow and to design clothes that are easier to put on and take off. Enabling patients to dress and care for themselves is essential for maintaining a sense of human dignity. When institutional care becomes unavoidable, having one's loved ones close by - caring - is perhaps one of the most important strengths needed by the patient.

Recently, I have come to realize that my comments about living with Huntington's are valid for anyone living with any chronic debilitating disorder. Huntington's Disease has become a prototype for neurogenetic conditions. As the commonality of the problems in these families becomes recognized, I believe that they should speak as one constituency, as members of society.

But we do need the help of trained professionals, who should reflect a positive feeling about his or her own life. We need to transmit hope. Without giving advice, I believe in sharing thoughts and in helping people to live with their reality, remembering that this reality is constantly changing.

We need the mirror and the sounding board to see and hear ourselves. Sensitive support and counseling is becoming more urgently needed, as more inherited disorders become identified. Counseling must not create more problems; otherwise it would be better to hide our family secrets, and suffer quietly and alone, as it was for centuries. Effective counseling should help families learn to live with their problems and make wise decisions. This could strengthen family relationships, as loved ones work together to make the most of the time they have.

To this day, I have not changed my youthful dreams of wanting to be a world “changer and hoper,” but I think I have learned how to accept my reality through change and experience. Let’s help others to do so too.

References

1. Commission for the Control of Huntington's Disease and Its Consequences: Vol I: Overview; Vol II: Technical Report; Vol III Part 2: Work Group Reports - Social Management; Vol IV Part 1: Public Testimony — Summaries and Indexes; Vol IV Part 2: Public Testimony - Ann Arbor, Atlanta, Boston; Vol IV Part 3: Public Testimony - Chicago, Dallas; Vol IV Part 4: Public Testimony - Denver, Los Angeles; Vol IV Part 5: Public Testimony — New Orleans, New York, Seattle; Vol IV Part 6: Public Testimony - Washington, D.C., Wichita. Bethesda, Maryland: 1977. National Institute of Neurological and Communicative Disorders and Stroke.

POSTSCRIPT

*By Louise Vetter, President & CEO,
Huntington's Disease Society of America
September 18, 2017*

“Do you know what a hoper is? Well, that’s what your mama is, a hoper. She has more hopes per square inch than almost anybody else. Hopes about this and hopes about that, hopes about you, about me, about all of the relatives, hopes about lots of people, all people. I ought to say, she’s what’s called a planner. I guess she makes more plans in a day than fascism could tear down in a century. I really believe this was what made me like her... Every detail of her life is not only a plan, but it is a dream, and the whole plan of a better world is one that she dreams about always. And she dreams it so plain and so strong that everybody who gets close to her notices it, and picks it up like a radio taking music out of the air.”

– Woody Guthrie, about Marjorie Guthrie in a letter written to their unborn child.

It has been 50 years since Marjorie Guthrie “set out to do something” about Huntington’s disease and the hopes and plans that she dreamt about in 1967 still resonate today at the Huntington’s Disease Society of America.

Her earliest vision of an organization of families united to provide help and hope to those affected by HD still guides HDSA. Its mission - to improve the lives of people affected by Huntington's disease and their families - shapes every program and is a direct reflection of Marjorie's dogged insistence that there be more care and unrelenting progress towards a cure.

Reflecting on Marjorie's impact is as astounding as it is inspiring. At a time when communication was by mail and travel was limited, she armed herself with a typewriter and suitcase and the needs of countless families on her shoulders. Powerfully and personally, she paved the way for a new brand of patient advocacy and integrated families into medicine and science like never before.

Marjorie created a community driven to create immediate change against a merciless foe. She envisioned "there must be a strong, well supported National organization to assure the widest possible distribution of all our educational materials to the HD families, doctors, neurologists...to the whole scientific community and health professionals

everywhere.” With HDSA Chapters and Affiliates, social workers and support groups from coast to coast, HDSA has a truly national presence, so that families everywhere can connect to necessary resources.

Today, the HDSA Centers of Excellence program exemplifies Marjorie’s vision of a “team approach” to caring for HD families. At these world-class facilities located across the United States, families benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have deep experience working with families and who work collaboratively to help families plan the best HD care program throughout the course of the disease.

Marjorie brought light to families hidden in the shadows, isolated by the shame and lack of understanding of the disease. By year’s end in 1967, Marjorie had a mailing list of 35 HD families and vowed that “we must continue our search for HD families everywhere.” Today, HDSA engages more than 35,000 volunteers annually and reaches hundreds of thousands more through a vast network of national and international outreach and resources.

Today, the question HD families ask is not “if” there will be a treatment or cure, but “when”. Investing more than a million dollars annually to research programs like the HD Human Biology Project, Berman-Topper HD Career Development Fellowship and the Donald A. King Summer Research Fellowship, HDSA is fueling HD research that is patient-focused, solution-oriented and attracts new scientists to HD research.

Every member of the HDSA community is following in Marjorie’s footsteps. Like her, we travel to Capitol Hill to remove barriers to care for HD families. Like her, we gather clinicians and social workers to educate them about HD and connect their expertise to the families who depend on them. Like her, we inspire and invest in the scientific researchers who are deepening our understanding of HD and working to develop treatments. Like Marjorie, we gather with our families to support one another and dream together.

It is often said that the truest reflection of a life well lived is the family left behind. As we pause to recognize what would have been Marjorie Guthrie’s 100th birthday, the

family that is today's Huntington's Disease Society of America is a tribute to her legacy. At HDSA, family is, and always has been, everything.

Clearly, our work is not done. Huntington's disease has not yet been stopped. But because Marjorie Guthrie dreamed and planned and pushed forward to "do something" against the unrelenting foe of HD, we have one another – and we have hope.

SUPPORT THE FIGHT AGAINST HD

The Huntington's Disease Society of America's programs enable world leaders in Huntington's disease research, care, and advocacy to continue their groundbreaking work in the fight against HD. Your support is crucial to ensuring that these experts can make progress toward effective cures and treatments. To make a donation of any of the items below or to learn more, please call HDSA's national office at **(212) 242-1968**.

Donations of the following items provide valuable support in combatting HD:

- Cash
- Stocks
- Individual Retirement Accounts (IRAs)
- Insurance
- Bequests and Planned Giving
- Automobiles
- Workplace Giving

WHAT IS HUNTINGTON'S DISEASE?

Huntington's disease is a fatal genetic disorder that causes the progressive breakdown of nerve cells in the brain. It deteriorates a person's physical and mental abilities during their prime working years and has no cure. Today, there are approximately 30,000 symptomatic Americans and more than 200,000 at-risk of inheriting the disease.

Each child of a parent with HD has a 50/50 chance of inheriting the faulty gene that causes Huntington's disease.

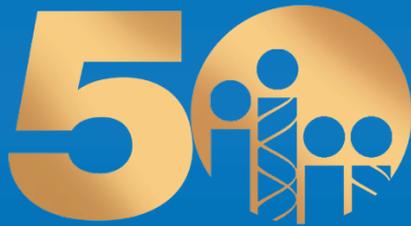
The symptoms of Huntington's disease are described as having ALS, Parkinson's and Alzheimer's – *simultaneously*.



The Huntington's Disease Society of America is the premier nonprofit organization dedicated to improving the lives of everyone affected by HD. From community services and education to advocacy and research, HDSA is the world's leader in providing *help for today and hope for tomorrow* for people with HD and their families.

In the battle against Huntington's disease, no one fights alone. **At HDSA, Family Is Everything.**

To learn more about Huntington's disease and the work of the Huntington's Disease Society of America, visit **www.hdsa.org** or call **1-800-345-HDSA**.



50 YEARS OF SERVICE
1967-2017

HDSA.org

800-345-HDSA