

Fighting the control of Huntington's disease

By Larry Luebke

My earliest awareness of Huntington's disease was as a young child, when it affected my mother and one of her older sisters. Even to a youngster, their behavior was strange. They had involuntary, jerky movements; lack of balance; and difficulty communicating. It is hard to remember exactly when I became aware, but by age 10 or 12, I knew something was not right. A remark by a classmate would haunt my childhood years. A

remark similar to, "Your mother must be crazy" made me feel isolated and alone. My father's attempts to explain what was happening with my mother only confused me and reinforced a sense of fear. For me, it became a family secret that I could not share. I did not talk about it and tried not to think about it, but it was always there. I was in a denial of sorts, holding onto a terrible secret. My mother was institutionalized in 1951, around the time I was 14, and she died some 10 years later.

By the time I was 40, the disease reappeared in my family. This time, it was in individuals of my generation—siblings and cousins. Over the next few years, two sisters, one brother and four cousins developed symptoms. They all passed away in their 40s and mid-50s. When a younger sister became unable to take care of her two daughters, another sister and myself took them into our homes when they were in high school. One of these girls, now age 45, is in a nursing home, no longer able to live at home with her husband and three

children. Currently, three nieces are affected and five grandchildren of my siblings are at risk to have inherited the defective gene. This disease continues to haunt our family today, but is no longer a secret.



Larry Luebke inherited Huntington's disease through family genetics.

HD is a degenerative brain disorder caused by a defective gene that is inherited. Each child of an affected parent has a 50% chance of inheriting the gene and is born with the defective gene.

However, most commonly, the symptoms do not appear until middle age.

Over time, the defective gene causes destruction of brain cells, ultimately resulting in uncontrolled movements, loss of balance, changes in personality, loss of communication and intellectual faculties. Also, there is progressive difficulty with swallowing, walking and talking, and eventually death. It is a devastating disease to both the individual and the family, who most often become the primary caregiver. It is financially and emotionally stressful for the victim and family. Depression is common.

There has been substantial progress made in the understanding of HD in the past 20 years. It is now possible to diagnose an individual for the defective gene through a simple blood test (although some at risk choose not to be tested). There are a number of

ongoing human trials to measure the effectiveness of therapies. Research breakthroughs are being made in the lab using various lab animals. However, to date, no cure for the disease exists. Treatment today is confined to symptoms such as depression and involuntary movements. There is hope and optimism that a more effective treatment or possibly a cure will result from ongoing trials and research.

In 1967, Marjorie Guthrie, wife of famed folksinger Woody Guthrie, who passed away from HD, brought together a few friends at her kitchen table, which evolved into today's Huntington's Disease Society of America. Visit their website at www.hdsa.org.



Riding for Huntington's disease

Charlotte Reicks, 76 and Marie Nemas, 68 have become known in Grand Junction for their cross-country rides to raise funds for research and to help people with HD. This year, these "Bicycling Grandmas" are riding to Las Vegas, Nevada, leaving Grand Junction on Sunday, May 27 and arriving in Las Vegas on June 7 to attend HDSA's annual convention.

This will be their 14th cross-



Charlotte Reicks, 76 (left) and Marie Nemas, 68, (right) are bicycling grandmas for a cure.

country trip for HD. Sherri Kole, whose son has HD and Gary Heiman, whose wife is an HD social worker, will join them. This year's ride is dedicated to Scott Lambert from Grand Junction, who had HD and died in January.

There will be a send-off breakfast from 8:30

a.m.-10 a.m. at Sherwood Park on May 26.

All are invited to enjoy a breakfast of fruit, juice, coffee and muffins, generously provided by Home Style Bakery, City Market and Safeway.

To make a contribution, purchase a T-shirt, or be a sponsor, contact Nemas at 250-5997, or visit www.firstgiving.com/bikeforcure.

There is a Huntington's disease support group that meets at 6 p.m. on the last Tuesday of every month at the First United Methodist Church, 522 White Ave. in Grand Junction. ■

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