

“Alzheimer’s Disease: Calling for a Breakthrough”

By David B. Oliver, PhD

Assistant Director, University of Missouri Interdisciplinary Center on Aging
Board President, Alzheimer’s Association Mid-Missouri Chapter

This story is not my story. Instead, this is the story of dedicated researchers who rode bicycles across the country more than 4,500 miles to shed light on an important topic – making Alzheimer’s disease a national priority. I, along with more than 55 researchers, left our classrooms and labs, trading test tubes for water bottles, lab coats for bike jerseys, safety goggles for helmets, and projectors for the horizon ahead. The ride started on July 17th in San Francisco and ended on September 21st, World Alzheimer’s Day, on Capitol Hill in Washington DC. Our goal along the route was to build awareness and gather 100,000 petition signatures to support the Alzheimer’s Breakthrough Act (H.R.3286/S. 1492), which will increase funding for Alzheimer’s disease research to \$2 billion per year, and other key legislation. In addition, we rode over every hill and around every corner in support of individuals living with Alzheimer’s disease and their families and friends.

I was one of the breakthrough riders. Little did I know that I had joined a distinguished group of dedicated scholars who had committed time and energy trying to unravel the mysteries of this cunning, baffling disease. During countless hours of training for a 70+ mile segment, my focus was on building muscles and stamina that would sustain rather than embarrass. Close to age 69, I figured I would need to try harder than my fellow riders; but during my focused training, I rarely focused on the important goal at hand.

I am Board President of the Alzheimer’s Association Mid-Missouri Chapter. We provide information and services to over 14,000 persons and their families in a 29-county area in Missouri. It is an awesome and rewarding responsibility. I have had the privilege of leading a Men’s Support Group, walked many Memory Walks, presented educational programs, written articles, and advanced the cause on countless occasions. My great aunt and grandfather who raised me died in my arms of this disease and it pains me to see others who experience the notorious 36-hour days. Caregivers, often more than those with the disease, are the ones who need the hope for a better day. My research had been driven by my personal experience with Alzheimer’s disease, but since September 21, my view has broadened.

At the end of the 4,500 mile ride across the country, the cycling scientists gathered in Washington D.C. to bike the last 14 miles to the Capitol together to deliver in person 110,000 petitions calling on Congress to take make Alzheimer’s disease a national priority. It was during the social contagion with these kindred souls that I realized the importance of our collective work. We really do care, it is not just a job, or a career; it is a mission to make a difference in the lives of millions of Americans and their caregivers who will enter a world of confusion, bewilderment, pain, suffering, and more.

Dr. Bruce Lamb originated the idea of a cross-country bicycle ride of researchers. A scholar at the Cleveland Clinic, he quickly received support and backing from Harry Johns, the CEO and President of the Alzheimer’s Association and its entire staff, and more importantly stirred the imaginations of the rest of us to begin training for this marathon of all marathons. Riders began to sign-up, agreed to ask colleagues and friends to sign breakthrough petitions and raise money to support the cause. From California to New York and Wisconsin to Texas, researchers, most of whom only knew one or two other riders, joined the movement. It was novel, it was fun, it was a challenge, and clearly a

break from routine. Little did we know that nearly all of us would be moved to tears at the culmination of the ride on the grounds of our Nation's Capital.

After visiting congressional leaders the day before, the importance of our words of encouragement to these legislators became all too clear. As we stood on risers to be recognized, we held up pictures of persons who have died of the disease and looked out upon a crowd of knowing friends, relatives, and advocates who had suffered and some of whom were currently suffering at the hands of dementia. We watched those watching us, and as tears began to slide down their faces, we were moved in concert with them. The facts and figures are convincing, but the human drama of love and grief is even more overwhelming. We all left that day feeling more committed than ever to our respective roles in combating amyloid plaques and neurofibrillary tangles. Yes, there is much work to be done.

The Congressional Visits

There were four of us in my group. We visited the offices of two representatives and one senator. At this time in the political season our elected servants were campaigning back home to be re-elected, or were on the stump in support of their respective party colleagues, but all three of these offices were busy with considerable activity. As they accorded us their time and interest, customer service was at its highest level; receptionists and office staff met with us without any sense of rush or urgency.

They were most interested in the National Alzheimer's Project Act (NAPA) that would make Alzheimer's Disease a national priority and prepare the way for the larger \$2 billion Alzheimer's Breakthrough Act. All three, two of whom had indicated earlier support, made special notes about this possibility. We were left with the impression that the third, a representative from Illinois, would be supportive as well.

The statistics we shared were enough to quiet the room. They had no idea that 50% of persons age 85 and older will develop Alzheimer's disease and that deaths from Alzheimer's have increased 46% since 2000. The financial burden on the country seemed less important as I am sure they get these kinds of figures from most advocates of various causes. More important was the human cost on caregivers and the staggering number of new cases that will be developing as our Baby Boomers age.

The Breakthrough Riders

Bruce Lamb described our group of riders as "family," and in so many ways we became one. Name tags did not identify people by their professorial rank, titles, or even university affiliation; only our names were scrolled across our tags along with "Alzheimer's Association" at the bottom. We spent the majority of our time sharing stories of our adventures across America. It was common ground on which we stood and created a bond of understanding, mutual respect, and celebration. Few spoke of mice and microscopes, successes or failures; instead, we focused on our experiences that when sewn together tell quite a story.

Stories floated through us like a breeze: Climbing to a summit of 7,500 feet by one rider only to be met by a thunderstorm and lightening; temperature changes in one day that fluctuated up to 50 degrees; small towns and farms, rich and poor, historic and not; cows and camels, goats and horses; dogs and more dogs; corn and soybean fields; hills and more hills, and then still more hills; deserts, mountains, valleys, and hollers; funny signs, national monuments, roadside markers; urban centers, traffic, people, supporters, volunteers; sights and sounds that will remain in the collective conscience; all contributed to a remarkable trek across these United States.

Along the ride there were ceremonies and recognition events. They were held in large and small cities as the baton, so to speak, was passed from one segment of riders to the next. One rider, Steve Berger, rode 270 miles over four days from Albuquerque, New Mexico to Abilene, Texas; Tim West pedaled 300 miles from Wichita, Kansas to Sedalia, Missouri; and Bruce Lamb completed a total of 600 miles spanning many segments. There were other heroic accomplishments but I cannot recall them. My own segment was Sedalia to Jefferson City, a windy road with several hills – each of which I remember distinctly.

We were greeted warmly in Jefferson City with a petition signing event at Subway. A proclamation by the Missouri Secretary of State Robin Carnahan was read to a gathering of supporters, board members, staff, volunteers, community leaders and citizens. Supporters came out to cheer us on and sign the petition. Larger assemblies were experienced in big cities from San Francisco to Oklahoma City, Kansas City, Madison, Cleveland, and more. The ceremony at the end of the last 14 miles in Washington D.C. on September 21st was indeed the most moving and memorable of all.

The final hill to climb

On the eve of the last day, riders began to arrive in the District of Columbia from parts East, West, North, and South. Half the group went to “the hill” for congressional visits described earlier, and that evening we all gathered for a reception in our hotel headquarters in Bethesda, Maryland. It was a wonderful occasion. Meeting the rest of the breakthrough family was special. Some brought family including children, others were joined by relatives. A father who lives in upstate New York traveled by train through New York to Baltimore and to D.C. to be with his son who is a researcher in California. Add to this the breakthrough ride support team “Eventage” and officers and staff of the Alzheimer’s Association and you have the gala occasion that it was.

The next morning was not unlike our individual segments. Up early to breakfast, instructions, and departure, only this time we had rental bikes to which we needed to be fitted. It was a cool 58 degrees at the beginning and remained in the 60s for most of the time. In short, it was a beautiful clear blue sky day for a bike ride. Once through Bethesda, we traveled down Rock Creek Park on a beautiful tree-lined asphalt path. At the bottom of this long stretch we found ourselves riding along the famous Potomac River; it too was beautiful, blue, and clear.

When we finally started uphill we were overwhelmed to see the Lincoln Memorial right before us with the Washington Monument looming overhead. We were at the Washington Mall and close to our destination. Chills ran up my spine. Several riders stopped to take pictures. I enjoyed seeing Einstein sitting on rocks in the bushes. We continued on until we made our final push up the toughest hill of all, Capitol Hill.

Just before entering the Upper Senate Plaza, the location of the ceremony, Bruce took the lead along with Harry. As we passed into the plaza hundreds of well-wishers applauded, whistled and cheered. Each of our names was being read over a loud speaker. We left our bikes and climbed up the risers with the Capitol in the background. We were each given a large picture of person who had died of Alzheimer’s with signatures of well-wishers on the back side. Later we used these to great effect.

Remarks were made by Terry Moran of ABC’s Nightline News; Harry Johns; Bruce Lamb; and Elizabeth Gelfand Stearns, Chairperson of the Judy Fund, a family foundation that helped support the project. As we listened to each speaker, we looked out upon the audience only to see tears in their eyes. Helen spoke of each person pictured in our

hands. I realized at that moment what this ride was all about – the importance of joining together to save our most valuable people.

And when Harry Johns held up the large binder of 110,000 signatures – single-spaced, both sides of each page, and five inches thick – I really understood the magnitude of what we had accomplished. Following our event, he was to deliver the signatures to the United States Congress and then to the White House.