Parkinson’s disease literally wiped the smile from Nellie Faye Hagberg’s face.

Her smile had greeted thousands of East Africans, some of whom she tutored in English while she and husband, Ray, were missionaries for 36 years in Tanzania.

It had given hope and courage to her three children, all born and educated through high school in Africa.

Then, about 20 years ago, Parkinson’s disease began to mask her gregarious nature. “I was under the age of 60, so thought I was going through menopause,” she said.

Her face deadpanned, as muscles grew taut. Pain in her neck and shoulder lead her to a neurologist, who diagnosed the disease.

Now, her smile has returned thanks to an experimental drug taken since April through a clinical trial at UNMC.

“I feel like my old self again,” said Hagberg, 74. “I have more energy, more life. I’m smiling, joking around — even ornery. This medicine has allowed me to regain my sense of self.”

Parkinson’s disease, a degenerative disorder that kills dopamine-producing brain cells, causes tremors, stiffness, slowness and impaired balance.

About one million Americans live with Parkinson’s and there is no cure — though medications provide some relief.
At UNMC, Hagberg is one of two participants in a multi-institutional clinical trial to test the effectiveness and safety of a gel form of the drug levodopa-carbidopa. Although not accepting more patients at UNMC, the trial eventually will enroll 320 people from around the world. John Bertoni, M.D., professor of neurological sciences, is the principal investigator at UNMC.

The oral tablet form of levodopa-carbidopa is the primary drug prescribed in the United States, but may not be absorbed efficiently, said Carolyn Peterson, nurse coordinator of the trial.

The gel form, which is marketed in Europe but not in the U.S., is pumped directly into the small intestine for 16 hours a day where it is absorbed into the bloodstream.

For the trial, Hagberg had a tube inserted into her stomach. She carries the pump and medicine in a pouch the size of a videotape slung over her neck and shoulder.

Every 40 days, she travels four hours from her Spencer, Neb., home to get a supply of medicine at UNMC. This will continue for the next four years or until the drug gains approval in the U.S.

Ray, her husband of 55 years, is her driver, companion and caregiver. “He keeps track of all my medicines, helps me all day and night and is there for me all the time. He helps me through the rough spots. There’s no way I could be in this study without his help. Care givers are unsung heroes.”

Hagberg looks forward to continuing in trials for this medication.

“We can only make advances in medical care when people are willing to take a risk. Without participation, there won’t be progress,” Hagberg said.

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Nellie Faye Hagberg

Clinical trials pave way for new medicines

Before a new drug comes on the market, it must first pass through rigorous cellular, animal and finally human testing — or clinical trials.

Clinical trials determine how well new medical approaches work in people. Each study attempts to answer scientific questions and tries to find better ways to prevent, screen for, diagnose or treat a disease. Clinical trials also may compare a new treatment to a treatment already available.

At UNMC, clinical research has been expanding the past few years to improve patient care, safety and health outcomes. Two people at the forefront of this movement are Jennifer Larsen, M.D., associate vice chancellor for clinical research, and Chris Kratochvil, M.D., assistant vice chancellor for clinical research. Dr. Larsen was recently named the new vice chancellor for research effective July 1.

“We’re further developing our infrastructure for clinical research, integrating operations, and bringing together such partners as The Nebraska Medical Center, Children’s Hospital and Medical Center and affiliated institutions to provide increased resources and opportunities for clinical trials,” Dr. Kratochvil said.

UNMC is the home for the Center for Clinical and Translational Research and The Great Plains Center for Clinical and Translational Research, which is committed to innovative clinical and translational research that reduces rural health disparities and improves rural health.

Drs. Kratochvil and Larsen have created a number of research education seminars, symposia and workshops for faculty and staff to learn about different aspects of clinical trials. This fall, a six-part series will be offered to investigators on issues related to clinical research.

UNMC has specifically reached out to partner with pharmaceutical companies on new drug development and clinical trials. Recently, Quintiles, the largest clinical research organization in the world, named UNMC a prime site through which to conduct clinical trials. Dr. Kratochvil was named chief medical officer for UNeHealth to administer these agreements and connect researchers to externally sponsored study opportunities.

“This is exciting for the medical center and the region,” Dr. Kratochvil said. “We expect to eventually conduct an additional 30 to 50 new clinical trials per year at UNMC. These trials will involve a wide spectrum of patients, ranging from oncology and endocrinology to psychiatry and pediatrics.”

Drs. Larsen and Kratochvil developed a database of clinical trials being performed at UNMC available on the UNMC web site. Health care providers or patients themselves can search to find a study specific to a particular condition or disease. This clinical trials database can be found at: unmc.edu/cryptaltrials.

“Translational research links the expertise we have in the laboratory with our clinicians,” Dr. Kratochvil said. “It’s a growing area for UNMC and the National Institutes of Health.”

The ultimate goal: Move new medicines from the laboratory to the clinic more quickly to help patients.