

A Special Bus for Special People Heads For New York Last of April

BY NAT WORMAN

SWANTON -- On April 27, a bus will carry a special group of people from St. Albans to New York for a Broadway show and a celebration in Central Park. They'll be greeted by Michael J. Fox.

In past years, they've met the daughter of Mohammad Ali, and Janet Reno, the former attorney general of the U.S.

Some youthful-seeming faces in the group won't smile. You'll see in the thousands they join a dovetailing of body movements, as each shows concern for the other, almost like dancers.

They are the Parkinsonians, a noun that embraces victims of the disease and their caretakers. Fox, Ali, and Reno are fellow sufferers.

Leg or arm movement will be slower or faster than normal, perhaps awkward; a hand may tremble, small steps may be taken to correct someone's balance and a walker may pause – and freeze.

Withal, the American Parkinson's Disease Association's Unity Walk in Central Park on April 28 will demonstrate the sympathy that binds Parkinsonians from all 50 states and 15 countries.

And mixed with the music of bands and buzz of talk will be the sound of laughter.

Kathy Chase and Shirley Jacobs talk about the need for a sense of humor when they appear on a People of Franklin County Special tonight, April 18 at 6:30 on Northwest Public Access TV Channel 15.

The show is part of The Vermont Chapter of the American Parkinson Disease Assn. campaign to remind people that April is Parkinson's Awareness Month.

What to do when a Parkinsonian freezes?

Jacobs: "Drop a handkerchief to the floor" since stepping over it sends a signal to the brain that it's O.K. to walk on.

The bus leaves from Diamond Jim's at Highgate Shopping Center at 7 a.m. with pickups as far down as Bristol costing \$99, and those interested may phone Shirley at 524-5461.

James Parkinson, an English physician, gave the first description of the disease in 1817. Chase and Jacobs talk about modern treatment, improved even in the short time between Melvin Jacob's first signs of Parkinson's in 1975, when he was 34, and Jim Chases's in 2001, when he was 61. He had been at IBM for 37 years.

Former State Sen. John Finn, 84, was diagnosed in 1991 when former governor, Dr. Howard Dean, noted his walk and suggested he see a neurologist, said Betty Finn. It is thought the disease hit him ten years before that, at age 58. Betty Finn visits him two and three times a day at Franklin County Rehab Center. He knows people, she said, but has difficulty talking.

For Melvin, there was the twitch of his little finger, for Jim, a stiffening of his face that prevented smiling, and a cough. Doctors diagnosed Melvin's first visit, and Jim's after several, believing at first he had bronchitis. After surgery, Jim's eyelids would close without warning and he would need to pry them open. Often, the disease makes the face distorted.

Both the closing eyelids and the face are treated with botox, a drug that gives many Parkinsonians a youthful look.

Doctors prescribed other medicines for both men. Shirley Jacobs said that, at first, the doses were too strong, causing an increase in a major symptom of the disease, tremor.

Both women learned fast how to help their husbands with the disease. The physicians themselves were a major source of help in understanding what to do, they said. And the support group, begun by former Sen. John Finn and his wife, Betty, was another source of help.

And though both Jim and Melvin had surgery, the latest method, for Jim, makes Shirley wish it had been available during Melvin's illness, whose treatment consisted of surgery on the brain itself.

For Jim, Deep Brain Stimulation is accomplished through currents from a battery implanted in the chest that sends currents to the brain through electrodes fixed in the skull. It reduces the tremors, and in some cases helps to restore balance.

Though a sense of humor is always needed, Chase and Jacobs stressed the need to remain optimistic and upbeat.

"Sometimes you have to smile when you want to cry," Jacobs said.

But they both burst out laughing when asked about moods. Because the disease reduces the ability to speak clearly, irritation may mount in speaker and listener. Both, however, learn to live with it and the irritation is seldom long-lasting.

And though the tremors or the facial expressions may change, Chase and Jacobs say that the personality of the person they married didn't change at all.

"Jim told me he is the same person trapped in his body," Chase said.

She added, thinking about a term known to Parkinsonians: "The 'stone face.' People noticed that he hadn't smiled much, that he looked sad or he would choke on his own saliva" though he could always take care of the problem himself.

"Some of the meds cause a lot of saliva," Jacobs said.

In fact, both wives agreed that the disease didn't faze their husbands' self-sufficiency. Melvin exercised regularly and put in eight-hour shifts at Missisquoi Pulp and Paper in Sheldon (now RockTenn).

He faced one crisis: when because of tremors the rumor spread that he was drunk on the job, the company nurse, Bee Bartlett, put a stop to it immediately, letting those who should know where things stood.

After two surgeries to quiet the tremors, one in 1980 at 39, and, after another in 1986, Melvin woke up one morning and sat for a few minutes on his side of the bed, trying to summon up energy. Then he said to Shirley, "I don't think I can go to work anymore."

He was 45 years old. Later, at his retirement party, Shirley sat with tears in her eyes. She was hearing a man praised whom she had met at a party at the Moose Hall, when he was 14 and she was 16. When he saw her in her red dress, he told his buddy,

"That girl is going to be my girl."

He died on January 17, 1997, of cancer, in the living room of the house he had built himself, on the land at Greens Corners that had been part of the farm on which he grew up.

Jim Chase keeps cheerful and motivated. He rakes leaves, goes to market, drives a car, and looks forward to the evening when he can watch Fox news with Kathy. Her days are long; she works the 7 a.m. to 7 p.m shift at IBM. During the day, they talk on the phone. Jim can cook his own meals.

Kathy has been at IBM 30 years and Shirley retired 16 years ago after 19 years with Dr. Henry Wirts he retired (before then she worked at Kerbs Hospital, now Northwest Medical Center), she volunteers at NMC, works part time for Century 21 and in the Tyler Place Gift shop in the summer. She also heads up the Foreign Students Exchange Program.

The center of her life is the Vermont Chapter of the American Parkinson's Association through which she met Kathy. The annual Rock-a-Thon in Montpelier on which they both work, raised \$15,000 last year. The Unity Walk in New York is expected to raise over \$1 million.

The money helps people in state of Vermont who have the disease, with travel, to Boston if they need rooming, and scholarships, so people can attend meetings.

The money also goes medical assistance devices; and for research too, and for research and medical assistant devices. Experts predict a cure is about 15 years away.

"When you live through something like that you have a special passion for it, and somehow he (Melvin) knows he I have that spirit," Jacobs said.