

Acting Against Time

Disabled performing troupe provides actress with advanced Parkinson's
a stage on which to transcend illness



By John Moore, The Denver Post

THE MOMENT BEFORE she walks on stage Friday, Lucy Roucis will experience a natural rush of adrenaline that most actors soak up like applause. But unlike other actors, this normal burst of energy may very well paralyze her. It's one of the damnable consequences of living with advanced Parkinson's disease. Adrenaline can cause her body to either stiffen or flail when she needs control of it most.

"I know what I am, I know what I have, and I know that I am not scary to look at. I want to use that to get in front of people and tell them that life is OK."

Just don't mistake this momentary hesitation as stage fright. Roucis is a proud woman, a diva in the goddess sense of the word. She will share no stage with fear.

"I'll have someone backstage ready to give me a push," Roucis said, flashing a mischievous grin that shares face time with a cautionary glare, "because that's literally what it might take."

And that's all it will take. Roucis needs a hand to go from a static to a moving position, but once she gets going, just try to stop her.

Roucis is starring as Princess Winnifred in the Physically Handicapped Amateur Musical Actors League production of "Once Upon a Mattress," which opens this week at the Space Theatre in the Denver Performing Arts Complex. Now in its 13th season, PHAMALY gives opportunities to physically challenged performers.

Though she plays one on stage, Roucis is no princess. After all, Roucis was an actress and model who lived in the Los Angeles fast lane during the decade of 1980s excess. She was a wild child and a bit of a pot-smoker, a fact she admits because she thinks it's a clue that may one day help solve the mystery of why she developed the disease.

She is also a comedian with an entire routine on Parkinson's. (One of the pros she mentions: "Never being asked to babysit." Con: "Being asked to hold a kid, and he ends up in a tree.")

And, yes, she can be a diva, whether performing in Radio City's Los Angeles company of the Rockettes,

appearing in a 1983 "Porky's"-style caper that producers billed "the raunchiest film of the decade," or as the star of PHAMALY's latest musical. She is not just a handful, "Mattress" castmate Mark Dissette jokes. "She's two handfuls and a foot."

In other words, Lucy Roucis is a real person with real hopes and fears, like everyone else. But her hopes and fears are more consequential than most. She hopes that when she wakes up, she will be capable of rolling out of bed. She fears that her slow-developing disease of the nervous system will incapacitate or kill her before science can come up with a cure.

It is a wait, her doctors have told her starkly, that will last five more years at least. Five more years after a woman, now 42, might safely carry a child. Five more years of battling to stay out of a wheelchair.

"This is a progressive disease, and it is inexorably progressive," said Dr. J. William Langston, founder of the Parkinson's Institute in Sunnyvale, Calif. Parkinson's affects the area of the brain that produces dopamine, the chemical messenger between nerve cells. The lack of dopamine causes tremors, muscle rigidity and movement problems. "Eventually, it will lead to major disability, and there is no proven way to slow it down."

Before recent drug advances, Langston said, the lifespan for patients was seven years. "But we have seen that grow to 15 years," he said, "and young-adult onset cases such as Lucy's tend to be less malignant and progress slower."

This is hopeful news, until you realize Roucis first began exhibiting symptoms in 1985 - 17 years ago.

"I am afraid to look too far in the future," said Roucis, who had the word "advanced" added to her disease last year. "It wouldn't do anybody any good. I know it wouldn't do me any good."

The last good day

What Roucis remembers most about her last normal day in 1985 was the simple freedom of movement. Scratching her nose. Brushing her teeth. Clutching a cup. "It is so precious when it is taken away from

you," she said. "When I can't move, it's so hard to do anything. Your body is frozen. Your reactions are slower. You are imprisoned."

Everything prior to Parkinson's now seems fun, easy and exciting. Roucis had graduated from Loretto Heights College in Denver and was pursuing acting and modeling in L.A. She had appeared in three awful films, including John Cusack's "Better Off Dead" (as the hooker in the mink bikini) and "The Party Animal" (as a flatulent Italian sophisticate). It wasn't Shakespeare, but it paid the rent.

"It was great," she said. "Get this: I was living in a guest house on an estate. My girlfriend was having an affair with this Japanese mogul, and he liked me so much he gave me a house to live in. Now I know how that sounds, but I never ever slept with someone for any of this. I was just the friend of the girl who did."

Roucis was 26 in 1985, with all the time in the world in front of her. But then she got stomach pains that would last a year. Roucis lost 15 pounds from vomiting and diarrhea.

One day she grabbed a cup of hot water out of the microwave and her hand shook. At a party, she could not tie a balloon knot. At her Los Angeles law firm, her typing fell from 100 words per minute to 30 in less than a year. Trying to apply her foot on the brake of her car took longer.

"Then someone said, 'You know, your arm isn't swinging,'" Roucis said. "That's when I knew it was really bad. That's part of Parkinson's: Your arms stop swinging and you start losing your balance."

The first doctor Roucis saw in 1987 mentioned the "P" word, but it seemed implausible. Parkinson's mostly affects men after the age of 60. It would be six more years before it was determined to be the correct diagnosis.

"I went on the hunt to try to find out what was wrong with me," Roucis said of a trail that took her to

a healer, a past-life regressor, inspirational meetings and back to church.

By 1990, Roucis was displaying more Parkinson's symptoms. But her father, Lakewood dentist Jim Roucis, had another thought.

"He said, 'You don't have Parkinson's, you have something wrong with your thyroid, and that can make you tremor and lose weight and shake. So once you get this out, you are going to be fine.' "

Jim Roucis probably saved his daughter's life, because she did have thyroid cancer. But after the gland was removed and Lucy started hormone-replacement therapy, she didn't get better. "It just got worse," she said. "And it was heartbreaking to watch my father have to concede the fact that I wasn't going to get better. And I love him for it."

Jim Roucis calls this cruel medical twist the football equivalent of piling-on. "I denied it at first," said Roucis, a man who parked his car on the street when his daughter was 2 because she believed she was Roy Rogers and that Trigger lived in the family garage. "It was a blow."

At 31, Roucis moved home, a cancer survivor in search of a disease. She sat in Dr. Chris Filley's office at University Hospital and wept.

"I said to him, 'Who's going to love me?'" she said, crying now at the memory. "He told me, 'Survival instinct and the instinct to procreate are so strong, Lucy, that you'll be just fine.' He gave me hope."

In 1993, eight years after her first symptoms, Roucis went to see Langston, who confirmed her Parkinson's. "He said, 'Do you want it straight, or do you want it colored?' And I said, 'If I have a choice, I want the truth. How bad is this going to get?' And he said, 'Bad.'"

Langston could not tell her exactly how she got Parkinson's, but Roucis believes it was from smoking some poisoned marijuana, combined with being exposed to DDT as a kid. "I want someone - anyone - to prove I'm right or I'm wrong," she said.

About 1 million Americans have Parkinson's, which is generally believed to be hereditary, but researchers now believe there are environmental triggers found in insecticides and synthetic heroin.

"When I was a little girl, they had these trucks going

down the streets that sprayed insecticide pouring out the backs of these trucks," she said. "I would run behind the trucks down my street on West Mexico Avenue in Lakewood and say, 'That smells good.' Now you tell me that can't do something to a little kid."

Just before her stomach infection, Roucis remembers smoking marijuana that seemed like it had been soaked in something. "It was sticky, there was a chemical smell on it, and I smoked it anyway," she said. "I seriously think it gave me the stomach infection, and it knocked out part of my brain."

No one else who smoked the same pot got sick, and Langston calls it an unlikely trigger. "But would I rule it absolutely out?" he said. "No."

26 pills a day

The first thing you wonder when you walk up to Roucis' Denver apartment is why there is a lock box on the front door. Her attendant, Tracy Robinson of Accent on Independence, says it allows friends, family and caretakers entry in case Roucis is unable to get to the door.

The inside looks like a firehouse with poles in every room, "but it's not because I'm a stripper," she jokes. The poles, along with various gripping bars, have been installed throughout to help her maintain her balance and pull herself up. When she has a bad medication reaction, she sometimes spins around the poles like a whirling dervish.

Roucis experiences up to five such brain episodes a day, each lasting about 20-30 minutes. The seizures can be shocking, but friends and family have grown used to them.

"If we're at a restaurant and she has a seizure, why, I'll hold her with one arm and I'll try to eat with the other," Jim Roucis said. "It's not much fun, but it's part of the game."

Candy dishes are strewn throughout every room of the apartment, filled with medicines such as Comtan, Sinemet and Permax. "I am a drug addict," jokes Roucis, who takes 26 pills a day (six in crushed liquid form). The tab runs \$1,631.68 a month for the pills, of which

Medicaid pays all but \$10.50. The most expensive is Permax, which retails for \$884.89.

For Roucis, waking up is the hardest part of her day. She rolls over, takes some pills and waits for them to loosen her muscles. If they don't kick in, she waits alone in her bed for someone to come to her door. Sometimes Robinson, who visits four days a week, uses scare techniques to rouse her.

"I'll tell her there's a spider, because usually that will make her jump up," she said.

When people see Roucis jerk, kick and seize, they think it is because of the Parkinson's. But it's the medications, which can be debilitating and dangerous if taken in the wrong combinations. Fluctuations in drug treatments have caused Roucis uncontrollable spasms, incontinence and once a sent her heart rate racing so fast it felt like it would burst.

"The treatment," Langston said, "is often worse than the disease itself."

A stage, a world

Roucis' disability has taken her career into activism, public relations, public speaking and lobbying. "People say they want to help, but what she really needs is a job," Jim Roucis said.

But being an actress will always be a part of her identity, and every year since 1993, PHAMALy has allowed her to keep that part of her identity alive.

"Oh my God, I have to tell you that PHAMALy truly saved my life," Roucis said, "because they decided to build a company that would allow people with disabilities to work in a professional setting, to get paid to act, and have their disability be OK. It doesn't have anything to do with anything. It's just what it is."

But recently Roucis and "Mattress" director Steve Wilson butted heads on the disability issue. If Roucis can't predict how her body will react during a performance, Wilson has to be prepared for anything.

"We have blocked two versions of each scene - one for if she has good movement, and the other if she

doesn't have good movement," said Wilson, who also has created Dissette's character of Boggsbottom.

Dissette's job is solely to help Roucis if necessary. But because he will be on stage anyway, Wilson wrote him some dialogue and turned one of Roucis' solos into a duet. The change was a pill more bitter for Roucis than Sinemet.

"Boy, did I fight them on that," Roucis said. "I called Steve and I said, 'I think you are babying me too much. I just don't think I need that much help. You know that I always come through for you in performances.' But that's the thing about my disability. I have no idea, truly, what is going to happen."

"Of course, that night after I complained, I went to rehearsal and I had the worst movement I have ever had with my Parkinson's, anywhere, in my entire life. Not only could I not stand up, but once they stood me up, I could not stay stood up. I was absolutely incapacitated. I started to cry, and Steve came over and held me. I said, 'I'm sorry.' It was the hardest thing for me to say, but I really do need the help."

Roucis calls it her moment of "defeated relief."

"Needing help is the worst feeling in the world," she said. "It's, 'Darn it, I can't carry this show like I want to.'"

These episodes are her "boo-hoo" fits, and they make her tolerant of those with much less to cry about.

"I have a lot of patience for others who feel sorry for themselves, because I believe in crying," she said. "I believe in feeling how you feel, and if you are depressed and feeling icky about yourself, then feel it. Don't deny it. Then get the (bleep) over it."

Cry, courage

"It takes courage not only to talk about your misfortune, but to laugh at it in the face. In facing trials, I will remember your courage and bravery."

That message came to Roucis from Kamleh Shaban after Roucis spoke recently to the seniors at St. Mary's Academy, where she graduated 25 years ago.

When people use the word courage to describe her, she gets angry. She doesn't think courageous people contemplate suicide, as Lucy once did, before thoughts of her mother saved her.

"I'm just living my life," she said quietly. "I don't think it takes any courage to have this disease. Courage is running into a building that's on fire to get the baby on the third floor. I just don't correlate myself with having courage, because I have to get up in the morning. I have to get ready for the day. I have to feed myself. I have to go to the bathroom. I have to take my meds. But anyone with an ounce of self-love knows to do what it takes to survive."

It may be semantics, but others who do take getting out of bed for granted are more liberal with the compliment.

"She is courageous," said Langston, who is also the chief scientific adviser to the Michael J. Fox Foundation. "I think her drive and spunk and unwillingness to let this defeat her are extremely impressive and inspirational, both for patients and their caregivers. And though I can't know this for certain, I think her acting has definitely slowed the progression of her disease. As a physician, it seems to me that a patient who does the kinds of things she's doing ward off the ill-effects of the disease longer."

Roucis knows what's down the road for her. "I understand that it's total incapacitation," she said. Until that happens, she has a face - not to mention those Rockette gams - that she would like to put on the disease.

"I know what I am, I know what I have, and I know what I look like," Roucis said. "And I know that I am not scary to look at. I want to use that to get in front of people and tell them that life is OK. I hate this term, but this is my journey."

And she's ready for it. All she needs is a little push. Then, watch her go.