FREDERICTON * Dr. Colleen O’Connell noticed an unusual number of people showing up at the Stan Cassidy Centre for Rehabilitation with the devastating motor neuron disease ALS, more commonly known as Lou Gehrig’s disease.

O’Connell, rehabilitation physician and research chief at the Cassidy centre in Fredericton, knew the disease was rare with an incidence generally of one or two cases per 100,000 people. But the numbers seemed higher in New Brunswick.

“Just in the course of doing our work in our day-to-day clinics, we seemed to be seeing a high number,” O’Connell said in an interview on Tuesday.

“As well, patients themselves and their families would say, ‘You know, I have friends or family with this. I thought this was a rare disease.’ So we have looked at 10 years of our own data … and we recognize our incidence is actually closer to two to three per 100,000, and in some small pockets of the province even higher than that.”

O’Connell, who also does research at the University of New Brunswick, wants to know why this province seems to have a higher incidence of ALS, a fatal disorder that gradually robs patients of their ability to move, speak, swallow and, finally, to breathe.

She said that thanks to a new institute officially launched at UNB’s Fredericton campus, she is going to be able to get access to the health and population data she needs to try to answer that key question.

“It is a fantastic initiative,” O’Connell said on Tuesday at the launch of the New Brunswick Institute for Research, Data and Training.

“It is a long time coming and it is greatly needed. You cannot do appropriate population-based health research, you can’t do any analysis of disease trends, or tracking and management, without appropriate data. We always have been limited in terms of access to reliable data … Now we will have a robust platform from which we can better evaluate and monitor disease patterns.”

Ted McDonald, director of the institute, described it as a policy-oriented research facility that will allow government to make evidence-based policy decisions.

“We are looking at identifying policy priority questions from government,” McDonald said.
Initial research and data collection in the super-secure institute has focused on health issues, but McDonald said other departments are being helped, including Social Development and Education.

“A lot of the problems New Brunswickers face transcend government departments,” he said. “Education policy can have health impacts, so it is critical to have the ability to look at data across government departments.”

Premier Brian Gallant attended the launch on Tuesday and announced the Liberal government will give the institute $100,000 per year for the next three years, continuing support started by the previous Tory government.

The institute has been in the works for the past few years but only officially opened on Tuesday. The province is just one source of funding for the facility, which also gets grants and contracts from organizations like the Canadian Innovation Foundation.

“Our government has a diversified plan for creating jobs that focuses on seizing all opportunities for economic growth,” Gallant said. “This project will aid in this by supporting smarter, more cost-effective policy development.”

The institute will provide the physical and database infrastructure necessary to conduct population research on health and wellness, education and training, economic development, crime and demography.

Gallant said it will also play an important part in the government’s plan to harness the power of big data and contribute to its open government/open data initiative, while guaranteeing that the right to privacy and the protection of personal information is maintained.