One Sunday night in October 2019, Gabrielle Cormier set her alarm and fell into a deep sleep. The first-year student at Mount Allison University woke to someone knocking on the door of her dorm room. Confused, she pulled out her phone and saw the time: 5:30 p.m. Cormier had slept 20 hours—through the night and the next day, missing her classes.

Cormier stumbled out of bed, groggy and unbalanced. When she opened the door, a friend stood on the other side. He asked if she wanted to get something to eat. Cormier fumbled for words in response. Her actions seemed so odd that he took her to the hospital instead.

There were no answers for Cormier that day, or in the days that followed. Even now, no one knows what is happening to her, what caused her symptoms or how to help her.
Something is wrong with Cormier’s brain. She forgets things and becomes easily confused. She watches the same television shows on repeat because she can’t retain new information. She’s losing control of her muscles. The girl who used to be able to dance en pointe now needs a cane or a wheelchair to travel any distance.

Cormier, 20, is one of 48 people in New Brunswick who are part of a cluster of cases of a progressive neurological syndrome with no known cause. At least six people have died. Their ages range from 18 to 85, and most live in the Acadian Peninsula and Moncton areas. They have an unusual mix of symptoms—combinations of anxiety, dizziness, hallucinations, pain, memory problems and progressive loss of mobility.

For months, the province has been leading an investigation into the cluster. The work is still in the first stage: confirming that, amid the COVID pandemic, people in the province are falling ill with a neurological disorder of unknown cause.

The Public Health Agency of Canada (PHAC) triggered an alert about a high number of unusual neurological cases in the province late last year. The agency provided specialized expertise early in the investigation by interpreting diagnostic and autopsy results, and worked with a New Brunswick neurologist to establish a case definition for the cluster.

But over the past three months, PHAC refused multiple requests from *Maclean’s* to speak with its scientists—including scientists who gave interviews last spring and have since gone silent. PHAC says that the province of New Brunswick is now leading the investigation, and the federal agency’s role is a supportive one.

A federal public servant, who was not authorized to speak on the record, says: “PHAC is no longer in the cluster investigation business.”

Currently, no scientists are performing environmental testing as part of the investigation.

The patient safety organization Blood Watch says it is concerned by the lack of environmental testing. The group wants PHAC to take the lead on the investigation, and is calling on the federal agency to “immediately resume its investigation into the root cause” of the cluster. In a letter addressed to federal Health Minister Patty Hajdu and Chief Public Health Officer Dr. Theresa Tam at the end of September, Blood Watch wrote that “families in New Brunswick deserve answers, which are supported by full scientific rigour, as to why their family members have perished and why patients are becoming ill from painful and debilitating neurological diseases.”

ABOVE: Some scientists want to investigate whether an environmental toxin called BMAA, found in blue-green algae, could be causing the syndrome

PREVIOUS PAGE: At 20, Cormier is one of the youngest patients suffering from the unusual mix of symptoms of an unidentified illness
Cormier grew up in the village of Balmoral, a francophone community that takes up a narrow stretch of land just south of New Brunswick’s northern shore. Her parents divorced when she was eight. She’s close with both of them, as well as with her sibling and step-siblings. As a toddler, she suffered one seizure during a fever; as a teen, she struggled with anxiety, but never had other major health issues. She figure skated, skied, danced and acted in school plays. She developed a deep devotion to the band Green Day, sparked by the way her dad would pluck out their hit *Time of Your Life* on his guitar.

Cormier excelled in school, particularly in math and science. Growing up, she asked for science kits and anatomy books for Christmas, and set her sights on becoming a pathologist, the kind of doctor who specializes in diagnosing disease through body tissues and fluids. She received high marks, earning bursaries that covered most of her university tuition.

It’s impossible to pick out the exact moment when whatever is hurting Cormier’s brain began its destructive path. In hindsight, a few odd things stand out to her from her last year of high school. That spring, as she put her books away before drama practice, she passed out. A friend found her on the floor and called an ambulance. At the hospital, says Cormier, a doctor dismissed her episode as a panic attack, even though she told him that she knew what a panic attack felt like — this was not that. She says the physician told her to get off her anxiety medication or she’d struggle to complete her classes. At the time, she thought she’d somehow faked an illness, thinking it was a fluke. She began looking for a different pathologist, one who could help her.

In March 2021, as Canada’s third wave of COVID-19 began its wicked climb, New Brunswick’s chief medical officer of health sent an internal memo to doctors and nurses, alerting them to a cluster of 42 patients with a neurological syndrome of unknown cause. The December 2020 alert came after scientists at the CJDSS, where a lab conducts testing to confirm a diagnosis. Of the patients in Canada, about half — 1,156 — have received a definite or probable CJD diagnosis, including 37 people from New Brunswick.

The first alert about something being amiss in New Brunswick went out in December 2020, when experts at Canada’s Creutzfeldt-Jakob disease (CJD) surveillance system, which is operated by PHAC, notified the province’s chief medical officer of health about an unusually high number of cases of something in the province that looked like CJD but was not.

A quick-moving and fatal neurodegenerative disorder, CJD is the most notorious member of the family of prion diseases. Prions are abnormally folded proteins capable of making normal proteins also misfold. They lack DNA or RNA, so they are not expected to replicate in the way that viruses do. Yet they propagate and cause damage that leads to neurodegenerative diseases that have no cure.

Health agencies worldwide began tracking CJD in the 1990s, when a new prion disease — known as variant CJD, or vCJD — spread in the United Kingdom after people ate meat from diseased cattle. In Canada, physicians report anyone with suspected CJD to a national surveillance system (CJDSS). Between 1998 and August 31, 2021, doctors in Canada referred 2,324 cases to the CJDSS, where a lab conducts testing to confirm a diagnosis. Of the patients in Canada, about half — 1,156 — have received a definite or probable CJD diagnosis, including 37 people from New Brunswick.

The December 2020 alert came after experts at the CJDSS noticed a jump in the number of cases of suspected CJD from New Brunswick: 12 cases in 2019; 29 in 2020. The trend continued into 2021 with another 24 in the first seven months. Tests ruled out CJD in the majority of cases, but scientists at the CJDSS decided that the unusual pattern warranted investigation.

In March 2021, as Canada’s third wave of COVID-19 began its wicked climb, New Brunswick’s chief medical officer of health sent an internal memo to doctors and nurses, alerting them to a cluster of 42 patients with a neurological syndrome of unknown cause. (Since then, the cluster under investigation has grown to 48 cases and six deaths.) People in the cluster became sick with rapidly progressing dementia, issues with gait and muscle coordination, memory loss and brain atrophy that was worse than expected for their age. Doctors were asked to be on the watch for patients with these symptoms and no obvious diagnosis.

Within days, Radio-Canada received a leaked copy of the memo. The story made headlines around the world. People reached out to Canadian neurologists, worrying that they, too, had this condition, or that a family member did. On the other side of the country, the inbox of Valerie Sim, an associate professor of neurology at the University of Alberta and an expert on prion disease, lit up. “I’m getting emails from people all over the world saying, ‘Oh, I have this,’” she said in a July interview.
Sim says it’s not clear to her that patients in the cluster are suffering from a single syndrome. She has not seen data on patients, but has read public reports and talked to experts familiar with the investigations conducted by the CJD surveillance system. “I’m not in any way trying to say that there isn’t a syndrome. I’m not trying to say that they couldn’t all be the same,” she says. “I’m just putting it out there that there’s no reason we have to think that this is anything.”

Sim says health-care providers and scientists have a responsibility to communicate with the public and not hide information. Instead, she says, the way the story became public “has caused harm, where perhaps there’s not even a story.”

Gabrielle Cormier went home at Christmas in 2019, and her family physician referred her to a neurologist in Moncton, Dr. Alier Marrero. As Marrero checked Cormier’s blood pressure on that first visit, her leg jerked involuntarily. He asked if that happened often; she realized it did.

Cormier returned to university after Christmas, but she felt worse. In February, she quit university. Later that month, as she underwent her first spinal tap, she told Marrero that she’d dropped out. It was probably a good idea for now, she remembers him telling her. Over the next year, she says he told her that there were other patients similar to her.

Born in Cuba, Marrero completed his training in Quebec before settling in New Brunswick in 2013. He has a long-standing interest in neurodegenerative diseases like amyotrophic lateral sclerosis (ALS), and rare diseases. Both Quebec and New Brunswick are good places to study rare conditions. Many residents descend from French settlers who colonized Quebec and the Acadian Peninsula beginning in the 1600s. Founder mutations—genetic alterations that emerge in geographically or culturally isolated populations—have been identified in these areas. Sometimes founder mutations are linked to rare diseases, including neurological ones. In the 1970s, a neurodegenerative disorder known as ARSACS was first described in 200 families in the Saguenay-Lac-St-Jean area of northeastern Quebec. Its name—short for autosomal recessive spastic ataxia of Charlevoix-Saguenay—reflects the region where it was discovered, and where incidence is higher than the rest of the world.

Marrero and his colleagues have identified genetic conditions stemming from unique mutations among the population of New Brunswick. They’ve published three case reports and have several more not yet published, Marrero says. Because of this kind of work, he receives referrals of patients with unusual neurologic symptoms—including many over the past three years whose condition made him think of CJD. The patients had neurodegenerative symptoms, often quickly progressing, but despite the usual workups, he had no diagnosis for them.

Neurodegenerative diseases remain a mystery in the scientific world, Marrero says. “This is a territory where we have a lot to do in general in science because neurodegeneration [causes] the diseases of our time,” including dementias and Alzheimer’s disease, he says. “We don’t have a cure for any one of them.”

LEFT: Cormier was an avid figure skater, dancer and science student before the unexplained illness began to affect her mobility and memory.
Marrero reported his patients to the federal surveillance system for CJD. The province says 46 of the 48 patients under investigation were reported by Marrero, and a 47th was co-reported by Marrero and another physician. (When *Maclean’s* contacted Marrero in late September to confirm these numbers, he said he was required to refer all media requests to the province.)

Many of the patients experience a similar pattern of symptoms, Marrero says. First, they have mood and behavioural changes, along with sleep disorders. They become very anxious, maybe for the first time in their lives. Some have hallucinations or terrifying dreams. A few have delusions where they think their loved ones have been replaced by imposters. They lose the words for things or people they know. Some have echolalia, a condition in which a person repeats the same word or sentence. Many develop blurry vision and dizziness. Nearly all the patients in the cluster have myoclonus, or involuntary muscle jerks. They have pain in their arms and legs, and lose weight rapidly. As they worsen, they lose motor skills and functional capacities, but they deteriorate at different speeds. Some have received therapies like intravenous immunoglobulin, steroids and medications for Parkinson’s disease and epilepsy, but unsuccessfully.

Marrero has seen some cases within families, but does not believe this is a genetic syndrome. There are cases of “biologically unrelated” patients who live together and have similar symptoms.

As word spread about the cluster, Steve Ellis thought the patients sounded like his dad. Roger Ellis, a 63-year-old retired industrial mechanic who spent his career working in mines, went to the hospital one summer weekend in 2019 as he and his wife were celebrating their 40th wedding anniversary. Roger worried that he was having a heart attack. He underwent tests and was sent home, twice. But on the Sunday evening, Roger began vomiting and passed out with a seizure. Steve’s sister called an ambulance. At the hospital, Roger’s seizures improved, but other symptoms emerged. Doctors ruled out epilepsy, CJD, autoimmune encephalitis, exposure to lead, rare cancers and brain tumours, Ellis says. But Roger did not recover, despite a variety of treatments. He spent 366 days in hospital before being moved to a care home. Roger, who has been a patient of Marrero’s since April 2021, struggles with speech, memory and hallucinations. His son says he shuffles rather than walks and has lost his mechanic’s dexterity. “It’s been horrible to watch. He’s changed in every single way,” says Ellis.

Ellis set out to find families in the cluster, looking for people who might understand what his family was going through. He created a Facebook group, which has grown to more than 400 members. Some joined because they worry that they or someone they care for might have this condition; many are from outside New Brunswick. Only a handful, including Cormier, have come forward as part of the cluster.

Ellis was shocked when he learned how young she was. “That’s the thing that I’m so puzzled about,” he says. “What is this that can get two people so far apart in age so sick?”

**ABOVE:** Neurologist Marrero has seen more than 80 people at his Moncton, N.B., clinic since April: “I see our condition as a canary in the coal mine.”
In May, the province’s public health experts began interviewing people in the cluster as part of an epidemiological investigation, asking them about things like their environment, eating habits, past illnesses and travel, using a questionnaire developed in collaboration with PHAC. By the end of July, 23 patients had been surveyed, Cormier and Roger Ellis among them.

The results of these questionnaires are being analyzed, according to the province.

Édouard Hendriks is co-chair of the province’s committee of six neurologists who are overseeing the investigation. Their first step is to confirm that no one in the cluster has a missed diagnosis—like Lewy body dementia, a progressive dementia associated with abnormal deposits of the protein alpha-synuclein in the brain—that could explain their sickness. Hendriks says he expects some patients will be found to have known conditions and will be removed from the cluster.

All other possibilities, including a novel prion disease, are “still on the table,” he says.

In an interview in July, New Brunswick Health Minister Dorothy Shephard said that she expected there would be no answers for at least four to six months. “The most important thing to know is that not only have we not ruled anything out, but we haven’t ruled anything in,” she said.

PHAC’s involvement is currently focused on investigating and ruling out CJD, the province confirmed. “As there are no cases reported by other neurologists or health-care providers from other provinces or territories within the identified cluster of cases, the investigation is a provincial matter currently,” Bruce Macfarlane, a spokesperson for the New Brunswick department of health, said by email in early October. “However, as with any situation where public health risks are identified, it is common practice for our provincial public health officials to collaborate with PHAC colleagues.”

Neil Cashman, a professor of neurology at UBC who is an adviser to PHAC and the CJD surveillance system, says he offered to provide on-the-ground support in New Brunswick but was turned down by the province. He says he is pleased that the province is taking steps to verify whether an outbreak of something unusual is happening. But he wants outside scientists involved—scientists who can begin investigations into possible environmental factors. “I can see the value in starting at square one. I also worry that we need to get started on this research ASAP,” he says.

Cashman says he believes that this syndrome could be caused by exposure to BMAA, or β-methylamino-L-alanine, a neurotoxic amino acid. After the American capture of Guam in 1944,
a neurologist with the U.S. Navy noticed extremely high rates of an ALS-like syndrome among the island’s indigenous Chamorro people. The Chamorro even had a word for it: lytico-bodig. By the 1950s, ALS incidence was 100 times higher in Guam than elsewhere in the world. There were other presentations of the syndrome, too, in people with symptoms similar to Parkinson’s and dementia.

Early on, researchers tied the syndrome to the cycad plant, which islanders ground up for flour when imports were restricted during the Second World War. But it took another two decades of research to isolate BMAA as a possible cause. BMAA is in the cycad plant and also in cyanobacteria, or blue-green algae. BMAA concentrates as it moves up the food chain, accumulating in some seeds, bats, shellfish, lobsters and other seafoods.

In humans, some studies have suggested BMAA is correlated with different kinds of neurological disorders, though the association remains controversial. There is no definitive study showing that BMAA causes neurological disease in humans.

Paul Cox, an ethnobotanist at the Brain Chemistry Lab in Jackson Hole, Wyo., who spent years studying the people of Guam, says it isn’t clear to him that any environmental toxin is at play in New Brunswick. Still, Cox says chronic exposure to BMAA could possibly trigger types of progressive neurodegenerative illness, as could many other toxins that cyanobacterial blooms produce. As the climate changes, algae and cyanobacteria bloom more often and in larger size—meaning people are more likely to be exposed, he says. “We believe BMAA is a trigger in susceptible individuals for certain neurodegenerative diseases. So just living near it does increase your risk,” he says.

If BMAA or other environmental toxins were to be investigated as a potential cause of the illness in New Brunswick, detailed epidemiological investigations would need to be carried out, Cox says, along with regular sampling of cyanobacterial scum over time and lab tests on tissues from people who died with the syndrome. “There’d be no problem with fielding a dream team that could do that in Canada,” says Cox.

Susan Murch, a professor of chemistry at the University of British Columbia, is one of Canada’s leading experts on BMAA. She says BMAA could be a factor in New Brunswick, but so could other environmental toxins. “So I think it’s important to start analyzing some tissues from the ecosystem,” she says. “What we do know about New Brunswick is that they are having both an unusual cyanobacterial bloom and an outbreak of neurological illness at the same time. That’s very unusual.”

Blue-green algae is spreading in New Brunswick, appearing for

ABOVE: Cormier with her father, André-Marc Cormier; she says she has faith in Marrero but knows “there’s a very real possibility that I’ll never get better”
the first time this year in some lakes and rivers and reappearing in others, according to a CBC report in August.

Murch says that during her research in Guam, Chamorro people said that they were tired of being treated as test subjects without receiving answers about what was making them ill. She hopes Canadian scientists, governments and journalists show respect to people who are suffering in the midst of uncertainty. “Be kind to these patients. Having an illness that isn’t well understood is a terrible thing,” she says.

Marrero believes that what is happening in New Brunswick is related to the environment, although he does not have evidence as to what factors might be in play. He thinks the so far inexplicable neurological changes in his patients are an indication that people are not adapting as quickly as the climate is changing. “I do see our condition as a canary in the coal mine,” he says.

He believes that this syndrome is affecting people outside of New Brunswick, pointing out the province’s proximity to Quebec, Nova Scotia, P.E.I. and the state of Maine. “We’re surrounded by the same ocean, the same kind of weather and climate and everything,” he says.

Although the investigation is centred on the 48 people in the cluster, more than 80 people have been seen at Marrero’s clinic since this spring.

**At the heart of this mystery** are the people who are very sick or have died, and their families. They are afraid, and desperate for answers. Ellis wants more information from the provincial government. “I believe they’re hiding something,” he says.

The New Brunswick Public Health department is “committed to sharing the findings of this investigation to patients and their families as well as the public as soon as they become available,” Macfarlane told Maclean’s.

The province has not provided any details on the six people in the cluster who died, or acknowledged any others who may have died.

Neither has the province released information on where people in the cluster are located. Most of the people under investigation were living in the southeastern and northeastern regions of the province when they were referred. Still, Macfarlane said that “so far, our investigation has not found any evidence suggesting that the residents of these regions are more at risk than those living elsewhere in the province.”

The province has also not released information on the results of the autopsies that were completed. Autopsy reports are considered personal health information and their results cannot be shared, said Macfarlane, but the findings will be summarized in the final report.

In an email to Maclean’s, PHAC confirmed that five autopsies have been completed through the CJD surveillance system and that they showed no evidence of prion disease. The province’s oversight committee has met with the pathologist to review the autopsy findings, said Macfarlane.

Three individuals familiar with the investigation told Maclean’s the autopsies revealed no unifying pathology among the patients. Instead, these individuals suffered from varying disease processes before they died, said sources.

But those results do not rule out the possibility that an environmental trigger is causing neurodegenerative illnesses in these patients, says Kat Lanteigne, co-founder of Blood Watch. The organization wants testing performed for BMAA, given the blue-green algae in some of the province’s watersheds. “What the federal scientists bring to the table is not only world-renowned expertise . . . but it also commands a level of transparency,” says Lanteigne. “That is so critical when you’re dealing with an emerging public health crisis, which is what this is.”

In July, Shephard, New Brunswick’s health minister, said she understood people’s anxiety, but added that no one wants the province to jump to conclusions. “We have committed to doing this research and reviewing the information in a very quick manner, in four to six months,” she said. “We’re doing that because we want to give New Brunswickers peace of mind. And hopefully that’s what we’ll get at the end of this.”

The province did not rule out BMAA testing as part of the investigation: “Once the investigation is completed and potential causes and risks are identified, we will follow up as appropriate,” said Macfarlane.

In early October, Maclean’s asked when the province planned to share any findings or next steps with the public. Macfarlane said, “Results of the epidemiological investigation will be shared as soon as they become available. Further clinical findings will be shared once the investigation is completed.”

**In the meantime**, patients are getting sicker. They show up at their appointments, full of questions that don’t have answers.

Marrero says he sometimes pauses between visits with patients. He reminds himself that he must start from zero with every person, that their story is not the same as that of the last patient, that every person in the cluster needs their own answer. “I am hoping for these patients to find something, and I’m really working for that,” he says.

Cormier still sees Marrero, as well as a psychologist and a physiotherapist. She misses her friends, who are now in their third year of university. They video-called her over the summer as they played board games. She laughed during the call, but wept after it ended. She’s tired of being home alone; she dreams of seeing Green Day in concert and doing the kinds of carefree things that people her age are supposed to get to do. She doesn’t know if she’ll get a chance.

“I have faith in Dr. Marrero, but I am a realist. And there’s a very real possibility that I’ll never get better or not survive this,” she says. “I am hopeful that the third option, which is getting better, happens.” The third option is heavy with dreams, including travel, concerts and a career in pathology.