

Investigation into a Neurological Syndrome of Unknown Cause: An Epidemiological Summary of Enhanced Surveillance Interviews

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Cause in New Brunswick

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# **Overview and Highlights**

- The aim of this report is to provide an epidemiological review regarding a cluster of individuals identified as having a potential neurological syndrome of unknown cause in New Brunswick. It is important to note that the exploratory findings presented here do not indicate causality. These epidemiological results are also independent of the clinical review that is currently being undertaken by an oversight committee that has been established for this purpose, and no conclusions can be drawn with regard to the identification of a novel syndrome or disease from this report.
- At this stage of the investigation, based on the current findings, there are no specific behaviours, foods, or environmental exposures that can be identified as potential risk factors with regard to this cluster of cases.
- Since early 2020, three neurologists in New Brunswick have identified a number of individuals who were reported to have an unusual combination of neurological symptoms. Forty-six of the 48 identified cases were referred by a single neurologist and the two other cases were referred by two separate neurologists.
- The first of these cases was referred to the Creutzfeldt-Jakob Disease Surveillance System (CJDSS) in 2015, followed by 12 cases in 2019, 25 cases in 2020, and 10 cases in 2021. The CJDSS is managed by the Public Health Agency of Canada (PHAC) and performs nationwide monitoring for human prion diseases which cause neurologic manifestations. These referrals were made in relation to suspected diagnoses of Creutzfeldt-Jakob Disease (CJD).
- The cluster was identified by the main referring New Brunswick neurologist and its existence was first tentatively recognized by the CJDSS in early 2020. Several cases, including one that was referred to the CJDSS in 2015, were later identified through a retrospective review and added to the cluster on the recommendation of the principal neurologist, due to similarities in clinical presentation and lack of a confirmed diagnosis. The review of older files was completed on cases for which a diagnosis of CJD was suspected but later set aside. It was only through this retrospective review that the older cases were identified.
- As of April 30, 2021, there were a total 48 individuals who were identified to have some clinical signs and symptoms that were similar to those associated with CJD yet presented atypical characteristics. These patients all tested negative for known forms of human prion diseases.
- Difficulties in diagnosing these individuals led to their classification as a potential cluster with a
  neurological syndrome of unknown cause in New Brunswick in early 2020 by the principal referring
  neurologist and CJDSS. Public Health New Brunswick (PHNB) was made aware of this matter by the
  CJDSS in late 2020 and began to investigate in early 2021. The investigation regarding this condition is
  still active and PHNB continues to collaborate with local and national subject matter experts.
- The potential neurological syndrome appears to be limited to New Brunswick, with no similar cases being referred from other provinces or territories.
- PHNB is still actively investigating the cluster in order to determine whether the condition is an illness of unknown etiology, and if so, its potential causes, risk factors and prevention measures. The investigation is likely to last several months, and regular updates on the investigation will be provided. An oversight



committee, with six New Brunswick neurologists, has been established to provide a professional second opinion to ensure due diligence and rule out other plausible diagnoses.

- As of September 2021, 34 of the 48 cases (71%) participated in the PHNB enhanced surveillance interviews. Nine cases (19%) declined an interview. Five (10.4%) cases could not be contacted after multiple attempts. Interviews with identified individuals or their representatives began in May of this year.
- All of the cases that participated in the enhanced surveillance interviews were referred to the CJDSS by the same neurologist.
- Among the interviewed cases, there were 18 females (53%) and 16 males (47%). Approximately half of those cases (59%) were between 18-59 years of age, and the median age was 57 years. Overall, females were younger than males. The average age of female cases was 51 years, while the average age of male cases was 59 years.
- Among the 48 cases in the cluster, nine are deceased. Three of the deceased cases were females, the other six were males. There was one death in 2019, four in 2020, and four more in 2021. Representatives for five of the nine deceased cases agreed to participate in enhanced surveillance interviews conducted by experienced PHNB nurses as part of the epidemiological investigation.
- Most of the individuals interviewed, at the time of reported symptom onset, were living in southeastern New Brunswick, around the Moncton area, and in the northeastern part of the province, near the Acadian Peninsula. The geographic distribution of the cases may have been influenced by the catchment area of the referring neurologists.
- PHNB has adopted a thorough, transparent, and open approach and has considered a wide range of hypotheses that include food safety, environmental factors, and lifestyle practices. Further epidemiological research may be required once the clinical case reviews are completed by the Oversight Committee.



Neurological Syndrome of Unknown

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Acronyms	
Federal Organ	izations
BCCDC	British Columbia Centre for Disease Control
CJDSS	Creutzfeldt-Jakob Disease Surveillance System (PHAC)
CFIA	Canadian Food Inspection Agency (PHAC)
NML	National Microbiology Laboratory (PHAC)
OMD	Outbreak Management Division (PHAC)
PHAC	Public Health Agency of Canada
Provincial Orga	anizations
DAAF	Department of Agriculture, Aquaculture and Fisheries (GNB)
DELG	Department of Environment and Local Government (GNB)
DNRED	Department of Natural Resources and Energy Development (GNB)
GNB	Government of New Brunswick
PHNB	Public Health New Brunswick (GNB)
Others	
CJD	Creutzfeldt-Jakob Disease
Comms	Communications
HABs	Harmful algae blooms
LCL	Lower Confidence Limit
NB Rep	New Brunswick Representative
SMEs	Subject Matter Experts
SPAs	Senior Program Advisors
UCL	Upper Confidence Limit



# Definitions<sup>1</sup>

## Disorders, Diseases, and Syndromes

A disorder is a disturbance or departure—for example, of an organ or body system—from normal healthy function, (i.e., an impairment). A disease is a disorder that can be assigned to a diagnostic category; it usually has a distinct clinical course and often a distinct etiology or cause. In contrast, a syndrome is a group of symptoms and signs that tend to appear together and collectively characterize a disorder.

## Exposures

The process by which an agent comes into contact with a person or animal in such a way that the person or animal may develop the relevant outcome, such as a disease. Examples of exposures assessed by epidemiological studies are environmental and lifestyle factors, socioeconomic and working conditions, medical treatments, and genetic traits. Exposures may be harmful or beneficial—or even both (e.g., if an immunizable disease is circulating, exposure to immunizing agents helps most recipients but may harm those with adverse reactions to the vaccine).

## Causes in Public Health Sciences

In epidemiology and other population sciences, causes include contextual factors, even if such factors can seldom be manipulated experimentally to produce change, given the following facts: causes operate at upper, aggregate, and distal levels as well as across macro- and micro-levels (climate, geographic location, diet); some causes are fairly constant or immutable conditions (as gender); others show large variations across time and space in the extent to which they change in an individual's lifecourse (educational and occupational achievement, social mobility and status, income, living arrangements).

## **Descriptive Epidemiology**

Epidemiological studies and activities (e.g., surveillance) whose descriptive components are much stronger than their analytic components or that clearly fall within the descriptive area of the descriptive-analytic spectrum, that is, descriptive study of the occurrence of disease and other health-related characteristics in human populations. General descriptions concerning the relationship of disease to basic characteristics such as age, gender, race, occupation, social class, and geographic location: even such general descriptions may have analytic dimensions. The major characteristics in descriptive epidemiology can be classified under the headings: persons, place, and time. Descriptive epidemiology is always observational, never experimental; hence observational epidemiological studies may be descriptive; nevertheless, epidemiological research studies are often analytic.

## Surveillance

Systematic and continuous collection, analysis, and interpretation of data closely integrated with the timely and coherent dissemination of the results and assessment to those who have the right to know so that action can be taken. It is an essential feature of epidemiological and public health practice. The final phase in the surveillance chain is the application of information to health promotion and to disease prevention and control.

<sup>&</sup>lt;sup>1</sup> Retrieved from: Porta, M., Last, J. M., & Greenland, S. (2008). A dictionary of epidemiology (Fifth). Oxford University Press (OUP).



A surveillance system includes a functional capacity for data collection, analysis, and dissemination linked to public health programs. It is often distinguished from monitoring by the notion that surveillance is continuous and ongoing, whereas monitoring tends to be more intermittent or episodic.

## **Public Health**

The combination of sciences, skills, and beliefs that is directed to the maintenance and improvement of the health of all the people through collective or social actions. The programs, services, and institutions involved emphasize the prevention of disease and the health needs of the population as a whole. Public health activities change with changing technology and social values, but the goals remain the same: to reduce the amount of disease, premature death and disease-produced discomfort and disability in the population. Public health is thus a social institution, a discipline, and a practice.



# Background

Since early 2020, there have been three neurologists in New Brunswick who have identified a number of individuals considered to have an unusual combination of neurological symptoms. A diagnosis for these individuals has yet to be confirmed. This has led to the identification of a cluster with a potential neurological syndrome of unknown cause in New Brunswick.

Public Health New Brunswick (PHNB) is investigating if this is truly an illness of unknown etiology, and if so, its potential causes, risk factors and prevention measures. The investigation will most likely take several months to complete.

PHNB became aware of this matter in late 2020 and began to investigate in early 2021. It created an enhanced surveillance process to gather information about individuals with the potential neurological syndrome. The first step in the process was the review of preliminary symptom data provided by the notifying neurologists and the Creutzfeldt-Jakob Disease Surveillance System (CJDSS), followed by consultations with subject matter experts. The CJDSS is operated by the Public Health Agency of Canada (PHAC) and provides testing capacity and expertise for countrywide surveillance of human prion diseases that produce neurologic symptoms, such as Creutzfeldt-Jakob Disease (CJD) and are most prevalent in the brain. The identified cases have clinical signs and symptoms that are similar to those associated with CJD, yet also present some that are atypical. They have all tested negative for known forms of human prion diseases.

To better understand potential exposures, PHNB developed an enhanced surveillance questionnaire for the epidemiological investigation based on the advice of subject matter experts in Public Health, Epidemiology and Disease Surveillance, Food Safety, Environmental Health, Zoonotic and Infectious Diseases, Natural Resources and Energy Development, Agriculture, Aquaculture and Fisheries, as well as Neurologists on this investigation, (see Consultation with Subject Matter Experts and Development of the Enhanced Surveillance Questionnaire). This epidemiological survey may help determine if there is an environmental or infectious source of the reported syndrome, and if so, help identify ways to prevent more cases from occurring.

The questionnaire was designed as an exploratory tool to generate hypotheses about potential risk factors and exposures for a neurological syndrome of unknown cause. It collected exposure information based on personal experiences and focused on broad initial questions which might be further refined through subsequent inquiries. The questionnaire was administered via telephone interviews with affected individuals or their designated representatives between May and September 2021, and the responses were analyzed using a comprehensive approach involving quantitative and qualitative methods. The findings presented in this report are based solely on these responses and represent a first step in identifying potential commonalities between members of the cluster.

Along with this questionnaire, an oversight committee was tasked with providing a professional second opinion on the identified cases to ensure due diligence and rule out other plausible diagnoses. Clusters of individuals with similar presentation to this potential neurological syndrome of unknown cause have not been referred from outside of New Brunswick. However, Public Health officials across Canada have been informed of this investigation and advised to contact PHNB and the CJDSS for further information.



# Methods

# Consultation with Subject Matter Experts and Development of the Enhanced Surveillance Questionnaire

The findings in this report have been grouped by theme and correspond to the major sections of the epidemiological enhanced surveillance questionnaire which was created for the purpose of collecting data for Public Health New Brunswick's investigation regarding the potential neurological syndrome of Unknown cause in New Brunswick, Canada. The content of the questionnaire was developed and validated through the consultation process with subject matter experts (see Figure 1). The validation included both an in-depth review of the content and piloting of the questionnaire. The sections covered in the enhanced surveillance questionnaire include topics related to demographics, food exposures, environmental exposures, occupational and work details, recreational exposures, family and close contact exposures, and additional information that participants felt might be relevant to their syndrome (see Results for details).







## **Telephone Interviews**

The enhanced surveillance questionnaire for the epidemiological investigation was administered through indepth interviews conducted over the phone, with consenting cases or their designated representative referred to as their proxy—following a standardized protocol. Participation in the interview was voluntary and the respondents, including the cases or their proxies, could choose not to answer a question or to end their participation at any point. Participants were encouraged to ask for clarification if they needed to. The interviews took approximately four hours to complete and the respondents were asked very detailed questions. The interviews were conducted in the respondent's preferred official language by experienced, bilingual nurses from PHNB.

The responses collected during the interviews were entered into a secure system and were used, shared, and disclosed in accordance with all applicable legislation, policies and procedures. Participants were informed that they might be contacted in the future and asked for additional details about their condition. The findings in this report do not include any personal or identifying information.

# Quantitative Analysis for Fixed Responses and Qualitative Analysis for Open-ended Responses

Descriptive epidemiological analysis methods were employed to analyze the collected responses and were supplemented by qualitative methods for the relevant open-ended sections of the questionnaire. The main software used for the analyses was Epi Info Version 7.2.4.0, which was supplemented with MAXQDA Analytics Pro 2020 Version 20.4.1 for qualitative data analyses. This report contains descriptive epidemiological analyses of data collected from the 34 interviewed cases.

Responses to the items with fixed (closed) options have been summarized as counts and percentages. These values are presented by topic in the Results section as well as in the tables in Appendix A: Extended Tables. As individuals could choose not to respond to any of the items, the total number of responses may vary.

Word clouds and extended lexical search options were employed to analyze open-ended responses. The lexical search feature enables document exploration and, as a result, aids in the coding of qualitative data segments into common themes from the relevant open-ended responses.

## Sub-Group Analyses

Further analyses were conducted for sub-groups of individuals based on reported characteristics related to geography, age, history of head trauma, exposure to industrial sites, exposure to pesticides and herbicides, potential exposure to harmful algae blooms (HABs), and close contacts and family members with similar symptoms. These comparative exposure assessments examined response patterns between sub-groups to explore whether there were different exposure profiles. The analyses looked into variables related to drinking water, medical history, food consumption, environmental exposures, industrial exposures, occupational exposures, recreational exposures, and close contacts (except when used to define a subgroup).



# Results

This report describes the epidemiology of a cluster of individuals with what has been identified as a potential neurological syndrome of unknown cause in New Brunswick, Canada. It highlights the results of the epidemiological interviews completed using the enhanced surveillance questionnaire, specifically developed for this purpose by Public Health New Brunswick. The questionnaire included both closed and open-ended items that focused on topics related to demographics, food exposures, environmental exposures, occupational and work details, recreational exposures, family and close contact exposures, and additional information that participants felt might be relevant to their symptoms.

# 1 Case Background and Demographic Information

### Case / Proxy Information

As of September 8<sup>th</sup>, 2021, a total of 34 of the 48 cases under investigation (71%) participated in enhanced surveillance interviews for the epidemiological investigation. Nine cases declined an interview and five cases were unable to be contacted despite repeated attempts. (see Table 1 and Appendix B: Enhanced Surveillance Interview Status).

Interview Status	Cases
Completed Interview	34
Declined Interview	9
Unable to Contact	5
Total	48

#### Table 1: Interview Status Summary

Surveillance interviews with individuals identified as members of the cluster or their proxies began in May and were completed in September 2021. Each interview took approximately four hours to complete. Ten of the interviews were conducted with the case, 11 with the case's proxy, and 13 were with both the case and a representative (proxy) of their choice. Interviews were conducted with the proxies for five individuals (15%) who were deceased. Two of the deceased were females and three were males.

Among those interviewed, 79.2% of the proxies lived in the same residence as the case (Range: less than a year to 49 years). Eighteen of the interviewed cases were females (53%) and 16 were males (47%). Approximately 59% of cases were between 18-59 years of age. The median of age for all cases was 57 years (Range: 18-83 years). Overall, there were more females in younger age groups and more males in older age groups. The average age of females was 51 years (Mean: 51, SD: 18.3), and the average age of males was 59 years (Mean: 59, SD: 14.4).

Twenty-six of the 34 (76.5%) cases identified with a racial or ethnic group. Nineteen (73%) of those 26 individuals reported an Acadian ethnicity and seven (27%) described their ancestry as an unlisted option (e.g.: Irish, Belgian) (see Table 2: Demographics). Eight (23.5%) of the 34 interviewed individuals did not report an ethnic identity.



Among the cases that were interviewed, the earliest and most recent reported symptom onset years were 1997 and 2021, respectively. Twenty (59%) of the 34 interviewed cases reported a year of symptom onset between 2018 and 2021.

#### Case Residence / Travel History

At the onset of their symptoms, most of the interviewed cases were living in areas in southeastern New Brunswick around the Moncton area (Zone 1 = 65%), followed by the northeastern region around the Acadian Peninsula (Zone 6 = 23.5%) (see Figure 2).

The majority of the cases' main residence at symptom onset were located in rural areas (50%), were single family type dwellings (71%), or were located near bodies of water (76.5%). Of the 34 interviewed cases, one reported living outside the province at the time of reported symptom onset date. On average, there were 1 child and 2 adults living in the household at the time of cases' reported symptom onset date (Children Mean: ~1, SD: 1.4; Adults Mean: 2, SD= 0.8). The primary source of drinking water of the main residence at reported symptom onset date, was municipal water (53%) followed by well water (47%) and bottled water (12%). The primary sources of drinking water are not mutually exclusive.

Approximately 44% of cases had lived at more than one address during the 5 years preceding the start of their reported symptoms. This includes any address other than their main address, such as previous addresses, temporary addresses, cottages or summer homes, and secondary residences. One case reported a main address that was in another province during the 5 years prior to the onset of their symptoms. The main addresses of other cases were all located in New Brunswick.

Just under half (44%) of the interviewed cases had visited at least one country outside of Canada in the two years before the start of their symptoms. All travels were reported to be for leisure activities and vacation. The most common destinations were in the United States or the Caribbean.



#### Table 2: Demographics

Value		Frequency <sup>2</sup>	Percentage
Number of Cases	Total	34	100.00%
Respondent	Case	10	29.4%
	Proxy	11	32.4%
	Case & Proxy	13	38.2%
Respondent Relationship to Case	Spouse	14	41.2%
	Parent	3	8.8%
	Child	3	8.8%
	Self	11	32.4%
	Other	3	8.8%
Case Sex	Females	18	52.9%
	Males	16	47.1%
Case Age (Years)	Median	57	
	Min	18	
	Мах	83	
Case Status	Alive	29	85.3%
	Deceased	5	14.7%
Case Health Zone at the Date of Symptom Onset	Zone 1	22	64.7%
	Zone 2	2	5.9%
	Zone 3	0	0.0%
	Zone 4	0	0.0%
	Zone 5	0	0.0%
	Zone 6	8	23.5%
	Zone 7	1	2.9%
	Other Province or Territory	1	2.9%
Case Rurality at the Date of Symptom Onset	Urban	17	50.0%
	Rural	17	50.0%
Case International Travel	Yes	15	44.1%
	No	19	55.9%

<sup>&</sup>lt;sup>2</sup> Number of cases, except for *Case Age* which is expressed in years.



Value		Frequency <sup>2</sup>	Percentage
Case Ethnicity	Identifies with an Ethnic Group	26	76.5%
	Acadian	19	73.1%
	Other (e.g.: Irish, Belgian)	7	26.9%
	First Nations	1	3.8%
	Asian	0	0.0%
	Black	0	0.0%
	Eastern European	0	0.0%
	Hispanic	0	0.0%
	Inuit	0	0.0%
	Métis	0	0.0%
	Middle Eastern	0	0.0%
	South Asian	0	0.0%
	Western European	0	0.0%
	No Declared Ethnic Identity	8	23.5%



*Figure 2: Geographic Distribution of Cases' Main Residence in New Brunswick by Health Zone at the Time of Reported Symptom Onset*<sup>3</sup>





#### **Case Medical History**

The intent of this survey was not to collect medical information as that will be obtained through the clinical review of the Oversight Committee. Rather, the survey focused on information that is not easily obtained from medical records.

In the two years before symptom onset, 12 (35.5%) of the cases who completed interviews had received blood or blood products and 5 (15%) had donated blood. None reported donating or receiving an organ or tissue. Five cases (15%) stated that they had received an invasive dental procedure or extraction other than a filling in the two years prior to the beginning of symptoms.

More than half of the cases (56%) mentioned that, during the same period, they had used over-the-counter medications or supplements, such as analgesics, multivitamins, sleep aids, digestive aids, memory aids, allergy medications, nasal congestion medications and natural supplements.

#### Other Information

The qualitative analysis of open-ended sections from the 34 completed enhanced surveillance interviews found that, prior to the onset of symptoms, 7 cases (20.5%) had reported a history of head trauma (including concussion and motor vehicle accidents), 25 (73.5%) had reported industrial exposures in their work or living environments, 12 (35.3%) reported exposures to pesticides and herbicides, and 8 (23.5%) had potential exposures to harmful algae blooms (HABs). All of these exposures were self-reported by the interviewees. A full clinical and diagnostic review is being undertaken by the Oversight Committee for each case involved in this cluster, which will allow for a more thorough analysis into these potential risks of exposure.

## 2 Food Exposures

Food exposures refer to the intake and eating habits of certain food categories in the two years prior to symptom onset. Food categories were not mutually exclusive and may consist of consumable items that an individual hunted or harvested themselves, that were procured by neighbours or friends, or were purchased from various sources, such as marketplaces or roadside stalls (see Table 13). Cases were asked about whether the foods were imported or acquired from local sources. They were also asked about how frequently and how recently they consumed those items. Food consumption-related items were used to identify potential pattens and behaviours. Further details regarding the origins of specific products, when available, were reviewed.

#### **Dietary Preferences**

For their general food and dietary preferences, four (12%) stated that they were on a specific diet, such as a keto or low carbohydrate diet. None (0%) of the cases reported being vegetarian. Seven cases (20.5%) reported allergies to one or more food items, and 12 cases (35.3%) reported that there are foods or food groups that they avoided eating, such as gluten, dairy products, mushrooms, wild meat, seafood, and shellfish. Twelve cases (35.3.%) stated they regularly consumed local delicacies or specialty food items, such as poutine rapée or Thai cuisine. A case's typical diet consisted primarily of home-cooked meals with

<sup>&</sup>lt;sup>3</sup> n = 34



occasional outings to restaurants. Chain stores were the most common venue where groceries were purchased (97%). This was followed by independent or smaller stores (56%), local butcher shops (47.1%) and public or farmers markets (35.3%). The venues for buying groceries were not mutually exclusive.

#### Venison and Other Wild Game

Regarding venison and other wild game meat consumption, moose meat was the most frequent reported food item with 16 of the 34 cases (47.1%) mentioning that they had consumed moose meat in the two years before the onset of their reported symptoms. The moose were all reported to have been caught or hunted in New Brunswick. Of the 16 cases that reported eating moose, 15 (94%) had indicated eating muscle meat (steak, chops, roasts) and three (19%) ate the moose meet raw. Among the 16 cases who had consumed moose meat, 56.5% of the interviewed cases reported that it had been more than a year since they had last eaten it, 19% reported eating it within the last year, 12.5% within the last month, and for the remaining 12.5% of the cases could not recall whether when they had last eaten it. Most of the cases that reported eating moose ate it at least once per year (31.2%), followed by less than once per year (25%), once per quarter (19%), once per week (19%), and once per month (6.2%). Other frequently consumed wild game meat included game birds (29.4%), rabbit (23.5%), and deer (23.5%).

Eight of the 34 cases (23.5%) mentioned that they had consumed deer caught or hunted in the wild in New Brunswick during the two years before the start of their reported symptoms. All of those cases reported eating muscle meat (steak, chops, roasts), three (37.5%) of them also indicated eating processed products (sausage, jerky, etc.), three (37.5%) ate the deer meat raw, and only one (12.5%) consumed organ meat.

Value <sup>4</sup>	Frequency	Percent	LCL	UCL
Moose	16	47.06%	29.78%	64.87%
Game Birds	10	29.41%	15.10%	47.48%
Deer	8	23.53%	10.75%	41.17%
Rabbit	8	23.53%	10.75%	41.17%
Bear	4	11.76%	3.30%	27.45%
Frogs or Snakes	3	8.82%	1.86%	23.68%
Elk	2	5.88%	0.72%	19.68%
Beaver	0	0.00%	0.00%	10.28%
Boar	0	0.00%	0.00%	10.28%
Caribou	0	0.00%	0.00%	10.28%
Other Wild Game	0	0.00%	0.00%	10.28%
Squirrel	0	0.00%	0.00%	10.28%
Any Venison or Wild Game	20	58.82%	40.70%	75.35%

#### Table 3: Frequencies of Venison and Other Wild Game Meat Consumption

<sup>&</sup>lt;sup>4</sup> Fields are binary, N = 34.



#### Seafood and Shellfish

For the seafood and shellfish category, in the two years prior to symptom onset, 31 (91.2%) cases reported eating fresh or frozen lobster, followed by 26 for prawn or shrimp (76.5%), 26 for scallops (76.5%), 18 for mussels (53%), 17 for clams (50%), and 14 for lobster tomalley (41.2%).

Those who reported seafood and shellfish consumption were also asked where the food item was usually obtained from (self/family-caught/harvested, purchased or unknown) and whether it was generally sourced locally, imported, or unsure if was local or imported.

Among those who reported eating lobster, 30 cases (97%) indicated that it was typically purchased, whereas 29 cases (93.5%) acquired it locally. Among those who had eaten lobster, the most common frequency was at least once per year (64.5%), and the last consumption was most commonly reported as more than a year ago (39%).

Among those who reported prawn or shrimp consumption, 100% indicated they typically purchased it, whereas 69.2 % were unsure if the product was local or imported. Of those who had eaten prawns or shrimps, the most prevalent intake was at least once per month (46.2%) with the most common recent consumption periods being more than a year ago (31%) and within the last week (31%).

When it came to scallop consumption, 100 % of those who ate it indicated they typically purchased it, whereas 61.5 % were uncertain if the food item was local or imported. Among individuals who had consumed scallops, the most frequent rate of consumption was at least once per month (38.5%), with the most recent consumption dating back to more than a year ago (31%).

Among those who ate mussels, 94.5% stated they were typically purchased and 61.1% acquired them locally. Additionally, among those who had reported eating mussels, the most common frequency was at least once a year (44.4%), and the most recent consumption was more than a year ago (39%).

Value <sup>5</sup>	Frequency	Percent	LCL	UCL
Lobsters	31	91.18%	76.32%	98.14%
Prawn or Shrimp	26	76.47%	58.83%	89.25%
Scallops	26	76.47%	58.83%	89.25%
Mussels	18	52.94%	35.13%	70.22%
Clams	17	50.00%	32.43%	67.57%
Lobster Tomalley	14	41.18%	24.65%	59.30%
Other Seafood or Shellfish	10	29.41%	15.10%	47.48%
Oysters	6	17.65%	6.76%	34.53%
Snails or Escargots	5	14.71%	4.95%	31.06%

## Table 4: Frequencies of Seafood and Shellfish Consumption

<sup>&</sup>lt;sup>5</sup> Fields are binary, N = 34 cases.



Value <sup>5</sup>	Frequency	Percent	LCL	UCL
Crayfish	0	0.00%	0.00%	10.28%
Any Seafood or Shellfish	33	97.06%	84.67%	99.93%

#### Freshwater Fish

With respect to freshwater fish, freshwater salmon (65%), trout (32.3%), and bass (29.4%) were the most frequently consumed items. Thirteen (38.2%) cases indicated that they had eaten another type of freshwater fish not listed on the questionnaire, such as haddock or mackerel.

Freshwater salmon was typically purchased (91%) and of unknown origin (64%)—respondents were unsure whether it was local or imported—among individuals who reported consuming it. Most often the last consumption of freshwater salmon was at least once a year (68.2%), and the most recent consumption period was during the past six months (32%). Almost every case indicated that they had eaten only fillets.

#### Table 5: Frequencies of Freshwater Fish Consumption

Value <sup>6</sup>	Frequency	Percent	LCL	UCL
Salmon (Freshwater)	22	64.71%	46.49%	80.25%
Other Freshwater Fish	13	38.24%	22.17%	56.44%
Trout	11	32.35%	17.39%	50.53%
Bass	10	29.41%	15.10%	47.48%
Perch	2	5.88%	0.72%	19.68%
Any Freshwater Fish	27	79.41%	62.10%	91.30%

#### Saltwater Fish

For the saltwater fish category, 44% of cases indicated consumption of saltwater salmon. In the two years before the start of their symptoms, around 59% of cases reported eating saltwater fish other than those included in the questionnaire. Half (50%) of those individuals reported eating cod, mackerel, haddock, and smelts, and only 35% reported consuming sole. All of the cases said that they had only eaten fillets.

<sup>&</sup>lt;sup>6</sup> Fields are binary, N = 34 cases.



#### Table 6: Frequencies of Saltwater Fish Consumption

Value <sup>7</sup>	Frequency	Percent	LCL	UCL
Other Saltwater Fish	20	58.82%	40.70%	75.35%
Salmon (Saltwater)	15	44.12%	27.19%	62.11%
Tuna	2	5.88%	0.72%	19.68%
Swordfish or Marlin	0	0.00%	0.00%	10.28%
Shark	0	0.00%	0.00%	10.28%
Any Saltwater Fish	24	70.59%	52.52%	84.90%

#### **Foraged Foods**

Regarding foraged foods, wild berry and fiddleheads had the highest rates of consumption, respectively at 85.3% and 29.4%. There were also two cases that reported consuming wild herbs, one for wild edible plants, and one for wild mushrooms during the two years prior to the onset of their reported symptoms.

For those who indicated consuming wild berries, blueberries and strawberries had the highest reported intake, respectively 96.5% and 90%. This was followed by raspberries (69%) and blackberries (17.5%). Wild berries were generally purchased or foraged locally (acquired by self, family, or friend) by respectively 86.5% and 70% of the cases who ate them in the two years before the start of their symptoms. Wild berries were most frequently reported to be consumed at least once per week (34.5%), with the most recent consumption having occurred during the previous week (31%).

Further analysis of the open-ended responses found that most berries were reported to be consumed either fresh or frozen and eaten with other types of berries. Of note, several respondents indicated that they had consumed "wild fruit" even though the product was obtained from commercial sources.

#### Table 7: Frequencies of Foraged Food Consumption

Value <sup>8</sup>	Frequency	Percent	LCL	UCL
Wild Berry	29	85.29%	68.94%	95.05%
Fiddlehead	10	29.41%	15.10%	47.48%
Other Foraged Food	6	17.65%	6.76%	34.53%
Wild Herb	2	5.88%	0.72%	19.68%
Other Wild Edible Plant	1	2.94%	0.07%	15.33%
Wild Mushroom	1	2.94%	0.07%	15.33%
Any Foraged Food	31	91.18%	76.32%	98.14%

<sup>&</sup>lt;sup>7</sup> Fields are binary, N = 34 cases.

<sup>&</sup>lt;sup>8</sup> Fields are binary, N = 34 cases.



## 3 Environmental Exposures

Environmental exposures broadly refer to contacts that individuals may have had with agents in their surrounding environments. Specifically, these items focus on exposures to animals—including pets and wildlife—to industrial sites, and to bodies of water—such as streams, lakes and oceans (see Table 14). These exposures are based on self-reported information and have not been validated with clinical and diagnostic information.

#### Animal Exposures

In the two years prior to the onset of symptoms, 29 (85.3%) of the cases that were interviewed had regular interaction with a pet in their household, such as dogs, cats, or birds.

Among the people interviewed, 15 (44.1%) had exposures to wildlife or wildlife droppings. This might have been through activities such as hunting, fishing, trapping, cleaning up after pests (e.g. mice, rats), or providing animal care.

Twenty one percent of cases reported contacts with livestock in the two years prior to the onset date of their reported symptoms. Livestock included cattle, swine, and poultry, as well as less often farmed species like deer, elk, and mink.

In the two years prior to the onset date of their reported symptoms, three of the interviewed cases reported animal bites, three reported exposures to animal tissues, and eight had contact with animal carcasses. None of the cases reported tick bites.

Value <sup>9</sup>	Frequency	Percent	LCL	UCL
Pets	29	85.29%	68.94%	95.05%
Wildlife or their droppings	15	44.12%	27.19%	62.11%
Animal Carcasses	8	23.53%	10.75%	41.17%
Livestock	7	20.59%	8.70%	37.90%
Animal Bites	3	8.82%	1.86%	23.68%
Animal Tissues	3	8.82%	1.86%	23.68%
Tick Bites	0	0.00%	0.00%	10.28%
Any Animal	30	88.24%	72.55%	96.70%

#### Table 8: Frequencies of Animal Exposures

<sup>&</sup>lt;sup>9</sup> Fields are binary, N = 34 cases.



#### Industrial Exposures

In the two years preceding the start of their symptoms, some of the cases reported industrial site exposures. These sites could have been located close to their home, their place of work, the residences of their friends and family, the places they visited while on vacation, or any location where they spent a considerable amount of time. For the items with closed (fixed) response options, among the 34 interviewed cases, 10 (29.5%) reported exposures to manufacturing plants, 3 (9%) to mining sites and quarries, and 3 (9%) to refineries and energy production facilities (9%) (see Table 9). Further analyses of the open-ended sections of the enhanced surveillance questionnaire responses found that a total of 25 of the 34 cases (73.5%) had reported potential exposures to an industrial site. This difference may have resulted from the limited options for the fixed response items, the open-ended section was broader which allowed more elaborate responses. All of these exposures were self-reported by the respondents and have not been validated by clinical and diagnostic information.

#### Table 9: Frequencies of Industrial Exposures

Value <sup>10</sup>	Frequency	Percent	LCL	UCL
Factories or Manufacturing Facilities	10	29.41%	15.10%	47.48%
Mining Sites or Quarries	3	8.82%	1.86%	23.68%
Refineries or Energy Production Facilities	3	8.82%	1.86%	23.68%
Other Industrial Exposure	0	0.00%	0.00%	10.28%
Any Industrial	11	32.35%	17.39%	50.53%

#### Recreational and Environmental Water Exposures

In the two years prior to symptom onset, a majority of cases interviewed reported spending time near an ocean (79.4%), a waterpark (56%), a river (53%), or a beach (50%). Some had also spent time near a marsh (35.3%). These locations could have been related to various activities in or on the water—such as boating, fishing, rafting, or spending time at beaches, summer camps, and waterparks—and may have involved multiple locales—like primary residences, workplaces, vacation homes, friends' residences, family residences. The analyses of the open-ended responses also highlighted that only eight (23.5%) cases reported they may have been exposed to harmful algae blooms (HABs). All of these exposures were self-reported by the interviewees and have not been validated by clinical and diagnostic information.

<sup>&</sup>lt;sup>10</sup> Fields are binary, N = 34 cases.



Value<sup>11</sup> LCL Frequency UCL Percent Oceans 27 79.41% 62.10% 91.30% Splashpads, Waterparks, or Pools 55.88% 37.89% 72.81% 19 Rivers, Streams or Springs 18 52.94% 35.13% 70.22% Beaches 17 50.00% 32.43% 67.57% 35.29% 19.75% 53.51% Marshes or Swamps 12 Freshwater Lakes 29.41% 15.10% 10 47.48% Ponds 8 23.53% 10.75% 41.17% Other Bodies of Water 17.65% 34.53% 6 6.76% Other Recreational Bodies of Water 3 8.82% 1.86% 23.68% 32 80.32% Any Recreational and Environmental Water 94.12% 99.28%

#### Table 10: Frequencies of Recreational and Environmental Water Exposures

## 4 Occupation and Workplace Exposures

Occupational and workplace exposures refer to any contact that individuals may have had with agents through employment or volunteer activities, including short-term, seasonal, part-time, or full-time positions that the case may have held in the two years prior to the start of their symptoms (see Table 15). Exposures related to occupation are based on self-reported information and have not been validated with clinical and diagnostic information.

#### **Occupation History**

Most of the interviewed cases reported that they had occupied a position other than the roles specified on the questionnaire (32.5%). Examples include teacher, retail store employee, office worker, day care worker, driver, and laborer. Just as many indicated that they were unemployed or retired (32.5%). Construction (15%) and medical backgrounds (12%) were also reported.

<sup>&</sup>lt;sup>11</sup> Fields are binary, N = 34 cases.



Cause in New Brunswick

#### Table 11: Frequencies of Occupational History

Value <sup>12</sup>	Frequency	Percent	LCL	UCL
Retired	11	32.35%	17.39%	50.53%
Other occupations not already listed	11	32.35%	17.39%	50.53%
Unemployed	11	32.35%	17.39%	50.53%
Construction (e.g., trades)	5	14.71%	4.95%	31.06%
Medical / paramedical / nursing / dentistry / laboratory	4	11.76%	3.30%	27.45%
Natural Resources Industry (e.g., fishing, forestry)	3	8.82%	1.86%	23.68%
Earth-moving (e.g., heavy machinery)	2	5.88%	0.72%	19.68%
Agriculture (e.g., farmer, crop irrigation)	1	2.94%	0.07%	15.33%
Military	1	2.94%	0.07%	15.33%
Meat industry (e.g., butcher / abattoirs / rendering plants etc.)	1	2.94%	0.07%	15.33%
Mining (e.g., quarry, tar-sands)	1	2.94%	0.07%	15.33%
Other occupation involving animals or animal products (e.g. leather worker)	1	2.94%	0.07%	15.33%
Animal related (e.g., farmer, taxidermy, laboratory, veterinary medicine, wildlife)	0	0.00%	0.00%	10.28%
Funeral home worker (e.g., embalmer)	0	0.00%	0.00%	10.28%
Pest Control	0	0.00%	0.00%	10.28%
Printing Facility	0	0.00%	0.00%	10.28%
Sewage treatment	0	0.00%	0.00%	10.28%
Waste disposal	0	0.00%	0.00%	10.28%
Water Treatment	0	0.00%	0.00%	10.28%
Any Occupational History	33	97.06%	84.67%	99.93%

## **5** Recreational Exposures

Recreational exposures refer to contact that individuals may have had with agents while partaking in leisure activities, such as gardening, outdoor recreation, or personal hobbies (see Table 12). Exposures related to recreation are based on self-reported information and have not been validated with clinical and diagnostic information.

<sup>&</sup>lt;sup>12</sup> Fields are binary, N = 34 cases.



#### Gardening

In the two years before their reported symptom onset date, more than half of the interviewed cases (56%) reported spending time gardening or working with soil at home or in their community garden, nursery or farm. Two cases (6%) reported direct exposures to pesticides, having personally mixed, loaded, handled, or applied pesticides in the two years prior to symptom onset. No cases (0%) reported direct exposures to herbicides. Analyses of the open-ended questions further revealed that a total of 12 of the 34 cases (35.3%) had been indirectly exposed to pesticides or herbicides in their environment, such as living near a commercial farm.

#### **Outdoor Activities**

Seventeen of the 34 interviewed cases (50%) stated that they had spent time doing various outdoor activities, such as camping, fishing, or hiking.

#### Hobbies

In terms of hobbies, 62% of the cases said that they were involved in other activities or hobbies in the two years prior to onset date of their reported symptoms. These involved things like playing an instrument, photography birdwatching, pottery, woodworking, and painting.

Value <sup>13</sup>	Frequency	Percent	LCL	UCL
Other Hobbies	21	61.76%	43.56%	77.83%
Gardening	19	55.88%	37.89%	72.81%
Outdoor Activities	17	50.00%	32.43%	67.57%
Pesticide Use	2	5.88%	0.72%	19.68%
Herbicide Use	0	0.00%	0.00%	10.28%
Any Recreational	29	85.29%	68.94%	95.05%

#### Table 12: Frequencies of Recreational Exposures

## 6 Family and Close Contact Exposure

Information related to common activities and shared interests among family and close contacts with similar symptoms were collected to identify potential common exposures. This information is based on self-report and has not been validated with clinical and diagnostic records.

#### Family members or Close Contacts

Twelve of the 34 respondents (35.5%) indicated that the case had family members or close contacts who were experiencing similar symptoms. Seven of those 12 cases (58.5%) also stated that they had a second family member or close contact with comparable symptoms. Two cases (17%) further reported that they had

<sup>&</sup>lt;sup>13</sup> Fields are binary, N = 34 cases.



a third family member or close contact whom they described as having similar neurological symptoms. These observations have not been validated by clinical records and laboratory information.

# 7 Sub-Group Analyses

To ensure due diligence, additional analyses were performed for sub-groups of individuals based on reported characteristics related to geography, age, history of head trauma, exposure to industrial sites, exposure to pesticides and herbicides, and potential exposure to harmful algae blooms, and close contacts and family members with similar symptoms. Sub-group analyses explored whether certain individuals shared common characteristics or specific patterns. Like the main analyses, the sub-group analyses did not find any distinctive patterns.



# Discussion

Public health encompasses a wide range of activities carried out by various levels of government, in partnership with a diverse range of stakeholders, including federal and provincial agencies. The prevention and control of notifiable diseases and events is a shared responsibility. PHNB considers its highest priority to be the protection and promotion of the well-being of New Brunswickers. With the advice and input of local and national subject matter experts in Public Health, Epidemiology and Disease Surveillance, Neurology, Food Safety, Environmental Health, Zoonotic and Infectious Diseases, Natural Resources and Energy Development, Agriculture, Aquaculture and Fisheries, PHNB is leading the investigation of this potential neurological syndrome of unknown cause in New Brunswick, Canada.

It is important to highlight that the findings presented in this report should be viewed in light of certain considerations. The information represents what has been shared with PHNB, at the time this report was prepared, regarding the 34 cases that participated in the enhanced surveillance interviews. All of those cases were referred to the CJDSS by the main referring neurologist. The interviews were conducted over the phone with the cases or their proxies. The information collected during the interviews reflects their personal experiences and may be subject to limitations regarding the availability and completeness of information.

The exploratory findings reported here represent self-reported exposure information and do not establish causal links to an identified syndrome. As such, these results need to be interpreted with caution and cannot be generalized to others beyond those under investigation. The enhanced surveillance questionnaire focused on personal information, which may not reflect the current or previous clinical presentation of the cases. These results do not rule out the influence of other factors or the need for further studies once a full clinical and diagnostic analysis is available.

Despite the above-mentioned limitations, this report has a number of merits. PHNB has developed and used standardized protocols based on recommendations from national and provincial subject matter experts for the epidemiological investigation of this cluster, in particular, an enhanced surveillance questionnaire, including closed and open-ended questions, that was designed specifically for this investigation. The interviews were also conducted in the respondent's official language of choice.

Moreover, a combination of quantitative and qualitative approaches was employed for the exploratory analysis of collected interview responses. The response rate for enhanced surveillance interviews was considerable, with 71% of those who were invited having completed the interviews. This in-depth and inductive approach is useful for refining research questions, generating hypotheses, and determining the next steps of the investigation.

It is also worth mentioning that an oversight committee has been constituted to evaluate the cases in order to rule out alternate diagnoses and ensure full due diligence from a clinical perspective. These epidemiological findings should be supplemented by clinical and diagnostic information, along with the conclusions of the Oversight Committee, which will guide the direction of any future investigation activities.



# Summary

As of April 30, 2021, there were a total 48 individuals who were identified as having a potential neurological syndrome of unknown cause in New Brunswick. These individuals were referred to the CJDSS by three neurologists from New Brunswick for further testing, with all but two cases referred by the same neurologist. The first case was referred in 2015, followed by 12 cases in 2019, 25 cases in 2020, and 10 cases in 2021. The case from 2015 was included retroactively at the clinician's suggestion, due to similarities in clinical presentation and lack of a confirmed diagnosis, when the existence of the cluster was tentatively recognized in early 2020. To date, none of these individuals have tested positively for known forms of human prion diseases.

The cluster of individuals with neurological symptoms was identified by the main referring neurologist through consultation with the Creutzfeldt-Jakob Disease Surveillance System (CJDSS). The CJDSS is managed by the Public Health Agency of Canada (PHAC) and performs nationwide monitoring for prion diseases that cause neurologic manifestations in humans, such as Creutzfeldt-Jakob Disease (CJD). These diseases provoke changes in the brain that can cause rapidly developing dementia, confusion, difficulties with movement and speaking, hallucinations, muscle stiffness and fatigue.

The potential syndrome appears to be limited to New Brunswick and the majority of the interviewed cases were reported to be living in Southeastern and Northeastern parts of the province at the time their symptoms started. The geographic distribution of the cases may have been influenced by the catchment area of the referring neurologists.

Cases were asked about their food exposures and surrounding environment. The most common exposures were lobsters, wild berries, scallops, shrimps and prawns, regular interactions with a pet in their household, spending time near an ocean, and spending time near an industrial site. Details regarding exposures are presented in the Results section and in Appendix A: Extended Tables. All exposures were self-reported by the respondents and have not been confirmed by clinical or diagnostic information.

Some of the identified exposures appear to be common among the cases under investigation. However, none of these are deemed to be concerning upon further analysis of the enhanced surveillance interview responses. Many of the exposures are typical of the region, which is strongly influenced by Maritime cultural practices. For example, most cases reported consuming lobsters only a few times per year—which is well below the recommended consumption limit issued by Health Canada. In addition, lobster consumption has not been identified as a cause of illness by NBPS or the Public Health Agency of Canada in the past 10 years. As for the consumption of wild berries does not appear, these are not linked to any particular source. Furthermore, there is no evidence from this report that a particular food, such as lobster, wild berries or moose, is linked to the development of neurological symptoms, as more cases would have been identified within New Brunswick and in neighbouring provinces or states. Clinical and diagnostic information is currently being reviewed by the Oversight Committee and may help determine whether there are alternate diagnoses for the individuals included in this potential cluster or whether more investigation is required.



# Conclusion

Based on the findings of this report, there are no specific behaviours, foods, or environmental exposures that can be identified as potential risk factors with regards to the identified cluster of cases with a potential neurological syndrome of unknown cause. As such, residents should feel confident that they are not considered to be at risk of any food or environmental exposures within the province.

PHNB has adopted a thorough, transparent, and open approach and has considered a wide range of hypotheses that include food safety, environmental factors, and lifestyle practices. The surveillance interviews with individuals associated with this potential neurological syndrome is a vital first step towards understanding more about this cluster of cases. The investigation into this cluster of cases is still active and PHNB continues to collaborate with local and national subject matter experts and healthcare providers to identify potential risk factors and prevention measures for this potential syndrome. Further epidemiological research, such as an observational study (e.g., case-control study), a second round of interviews or further testing, may be required once the review of the clinical investigations is completed by the Oversight Committee.



# Appendix A: Extended Tables

Nouveau

New

Table 13: Frequencies of Food Exposures

Value <sup>14</sup>	Frequency	Percent	LCL	UCL
Lobsters	31	91.18%	76.32%	98.14%
Wild Berry	29	85.29%	68.94%	95.05%
Scallops	26	76.47%	58.83%	89.25%
Prawn or Shrimp	26	76.47%	58.83%	89.25%
Salmon (Freshwater)	22	64.71%	46.49%	80.25%
Other Saltwater Fish	20	58.82%	40.70%	75.35%
Mussels	18	52.94%	35.13%	70.22%
Clams	17	50.00%	32.43%	67.57%
Moose	16	47.06%	29.78%	64.87%
Salmon (Saltwater)	15	44.12%	27.19%	62.11%
Lobster Tomalley	14	41.18%	24.65%	59.30%
Other Freshwater Fish	13	38.24%	22.17%	56.44%
Trout	11	32.35%	17.39%	50.53%
Fiddlehead	10	29.41%	15.10%	47.48%
Other Seafood or Shellfish	10	29.41%	15.10%	47.48%
Bass	10	29.41%	15.10%	47.48%
Game Birds	10	29.41%	15.10%	47.48%
Deer	8	23.53%	10.75%	41.17%
Rabbit	8	23.53%	10.75%	41.17%
Other Foraged Food	6	17.65%	6.76%	34.53%
Oysters	6	17.65%	6.76%	34.53%
Snails or Escargots	5	14.71%	4.95%	31.06%
Bear	4	11.76%	3.30%	27.45%
Frogs or Snakes	3	8.82%	1.86%	23.68%
Elk	2	5.88%	0.72%	19.68%
Wild Herb	2	5.88%	0.72%	19.68%
Tuna	2	5.88%	0.72%	19.68%
Perch	2	5.88%	0.72%	19.68%
Wild Mushroom	1	2.94%	0.07%	15.33%
Other Wild Game	1	2.94%	0.07%	15.33%

<sup>14</sup> Fields are binary, N = 34 cases.



Value <sup>14</sup>	Frequency	Percent	LCL	UCL
Other Wild Edible Plant	1	2.94%	0.07%	15.33%
Beaver	0	0.00%	0.00%	10.28%
Boar	0	0.00%	0.00%	10.28%
Caribou	0	0.00%	0.00%	10.28%
Crayfish	0	0.00%	0.00%	10.28%
Swordfish or Marlin	0	0.00%	0.00%	10.28%
Shark	0	0.00%	0.00%	10.28%
Squirrel	0	0.00%	0.00%	10.28%

#### Table 14: Frequencies of Environmental Exposures

Value <sup>15</sup>	Frequency	Percent	LCL	UCL
Pets	29	85.29%	68.94%	95.05%
Oceans	27	79.41%	62.10%	91.30%
Splashpads, Waterparks, or Pools	19	55.88%	37.89%	72.81%
Rivers, Streams or Springs	18	52.94%	35.13%	70.22%
Beaches	17	50.00%	32.43%	67.57%
Wildlife or their droppings	15	44.12%	27.19%	62.11%
Marshes or Swamps	12	35.29%	19.75%	53.51%
Factories or Manufacturing Facilities	10	29.41%	15.10%	47.48%
Freshwater Lakes	10	29.41%	15.10%	47.48%
Animal Carcasses	8	23.53%	10.75%	41.17%
Ponds	8	23.53%	10.75%	41.17%
Livestock	7	20.59%	8.70%	37.90%
Other Bodies of Water	6	17.65%	6.76%	34.53%
Animal Bites	3	8.82%	1.86%	23.68%
Animal Tissues	3	8.82%	1.86%	23.68%
Mining Sites or Quarries	3	8.82%	1.86%	23.68%
Other Recreational Bodies of Water	3	8.82%	1.86%	23.68%
Refineries or Energy Production Facilities	3	8.82%	1.86%	23.68%
Tick Bites	0	0.00%	0.00%	10.28%
Other Industrial Exposure	0	0.00%	0.00%	10.28%

<sup>&</sup>lt;sup>15</sup> Fields are binary, N = 34 cases.



Cause in New Brunswick

#### Table 15: Frequencies of Occupational History

Value <sup>16</sup>	Frequency	Percent	LCL	UCL
Retired	11	32.35%	17.39%	50.53%
Other occupations not already listed	11	32.35%	17.39%	50.53%
Unemployed	11	32.35%	17.39%	50.53%
Construction (e.g., trades)	5	14.71%	4.95%	31.06%
Medical / paramedical / nursing / dentistry / laboratory	4	11.76%	3.30%	27.45%
Natural Resources Industry (e.g., fishing, forestry)	3	8.82%	1.86%	23.68%
Earth-moving (e.g., heavy machinery)	2	5.88%	0.72%	19.68%
Agriculture (e.g., farmer, crop irrigation)	1	2.94%	0.07%	15.33%
Military	1	2.94%	0.07%	15.33%
Meat industry (e.g., butcher / abattoirs / rendering plants etc.)	1	2.94%	0.07%	15.33%
Mining (e.g., quarry, tar-sands)	1	2.94%	0.07%	15.33%
Other occupation involving animals or animal products (e.g. leather worker)	1	2.94%	0.07%	15.33%
Animal related (e.g., farmer, taxidermy, laboratory, veterinary medicine, wildlife)	0	0.00%	0.00%	10.28%
Funeral home worker (e.g., embalmer)	0	0.00%	0.00%	10.28%
Pest Control	0	0.00%	0.00%	10.28%
Printing Facility	0	0.00%	0.00%	10.28%
Sewage Treatment	0	0.00%	0.00%	10.28%
Waste disposal	0	0.00%	0.00%	10.28%
Water treatment	0	0.00%	0.00%	10.28%

<sup>&</sup>lt;sup>16</sup> Fields are binary, N = 34 cases.



#### Table 16: Frequencies of Recreational Exposures

Value <sup>17</sup>	Frequency	Percent	LCL	UCL
Other Hobbies	21	61.76%	43.56%	77.83%
Gardening	19	55.88%	37.89%	72.81%
Outdoor Activities	17	50.00%	32.43%	67.57%
Pesticide Use	2	5.88%	0.72%	19.68%
Herbicide Use	0	0.00%	0.00%	10.28%

<sup>&</sup>lt;sup>17</sup> Fields are binary, N = 34 cases.



Cause in New Brunswick

# Appendix B: Enhanced Surveillance Interview Statuses

Completed Interview	The case or their proxy has participated in an enhanced surveillance interview for the epidemiological investigation regarding a potential neurological syndrome of unknown cause.
Declined Interview	The case or their proxy has been contacted by an interviewer and has decided not to participate in an enhanced surveillance interview for the epidemiological investigation regarding a potential neurological syndrome of unknown cause.
Unable to Contact	The case or their proxy could not be reached after multiple attempts to contact them. In instances where a case was deceased, attempts were made to contact their next of kin as proxies. Public Health New Brunswick interviewers made attempts to connect over the phone on at least four different days, with at least one attempt outside of business hours. A letter was also sent by registered mail to each of the cases in August, either to extend an invitation to participate in the interview process or to thank them for completing the interview. If non-participating individuals did not respond within two weeks of the confirmation of receipt of the registered letter and could not be reached by phone after a reasonable number of attempts were made, they were considered as unable to contacted.