

**MIND Clinic - Key Messages (Q&As)**

ABOUT THE MIND CLINIC	
<b>What is the MIND Clinic?</b>	Horizon’s Moncton Interdisciplinary Neurodegenerative Diseases (MIND) Clinic is a tertiary care service that <b>assesses, diagnoses, and provides ongoing care/treatment to patients with progressive neurodegenerative diseases</b> to improve their quality of life, and provide family support.
<b>Is the MIND Clinic specifically for patients with the “mystery disease”?</b>	The MIND Clinic has provided an array of care and services to patients identified as part of the cluster of a neurodegenerative disease of unknown origin being investigated by New Brunswick Public Health, but <b>that is not its sole purpose.</b>
<b>What kind of patients does the MIND Clinic treat?</b>	Horizon’s Moncton Interdisciplinary Neurodegenerative Diseases (MIND) Clinic is New Brunswick’s only cross-specialty collaborative clinic for <b>all progressive neurodegenerative diseases affecting adults of any age.</b>
<b>Has every referral been a suspected case of the “mystery disease”?</b>	<b>No, every referral to the clinic was not identified as part of the cluster of a neurodegenerative disease of unknown origin.</b>  All patients referred to the clinic have a combination of signs and symptoms that are progressive and difficult to assess, diagnose and care for by a single physician. The types of diseases (“neurodegenerative diseases”) that are assessed are those that cause changes in the brain and spinal cord that lead to progressive problems with mental functioning and physical movements.
<b>What professionals work in the MIND Clinic?</b>	The MIND Clinic, located at Horizon’s The Moncton Hospital, has a dedicated team of geriatricians, neurologists, registered nurses, neuropsychologist, social worker, research manager, and an administrative assistant. Associates of neurology and psychiatry also help the team.

<b>DIAGNOSES</b>	
<b>What happens when a patient is first referred to the clinic?</b>	<b>The first step is assessment.</b> The MIND Clinic team gathers as much information as possible about the patient’s health history, family health history and symptoms, and orders brain imaging and other laboratory tests to aid in the diagnosis.
<b>What happens after a patient has been diagnosed?</b>	The MIND Clinic team continues to <b>provide ongoing care/treatment to patients and provides assistance to patients and families in accessing community resources and supports.</b>
<b>What if a patient/family isn’t confident in a diagnosis?</b>	We ask patients and their families not to hesitate to discuss their concerns with staff involved in their, or a loved one’s, care.  But <b>if patients are having difficulty expressing their needs or concerns, they or their family can contact Patient Representative Services.</b> A Patient Representative will listen to patients’ concerns with compassion, in confidence, and in their best interest.
<b>How does a patient obtain a second opinion?</b>	<b>Patients have a right to make decisions about their own health and may seek a second opinion.</b> Patients who wish to seek a second opinion must speak with their primary care provider first and ask them for a referral to another specialist who works in the field.  Note: if a patient wants to obtain a second opinion from a specialist in another province, they may be billed for services. Claims can be submitted to New Brunswick Medicare for consideration, but reimbursement is not guaranteed.
<b>RESEARCH</b>	
<b>What type of research does the clinic do?</b>	The MIND Clinic will be conducting research to <b>improve our understanding of neurodegenerative diseases</b> in New Brunswick and will study the <b>ways we identify and treat these conditions</b> so that patients can receive optimum care at all stages of their illness.
<b>Will you collaborate with national experts?</b>	The MIND Clinic <b>will collaborate with local, provincial, and national experts on research projects that are applicable to</b>

	<p><b>the conditions impacting patients and families associated with the clinic.</b></p> <p>All potential research studies will undergo a feasibility assessment by the MIND Clinic, a review by Horizon’s Human Research Protection Program, and then approval will be obtained from Horizon’s Research Ethics Board (REB) and any research partner REB.</p> <p>With research ethics approvals in place, the informed and voluntary consent of potential research participants will be sought from patients at the MIND Clinic.</p>
<b>THE GNB REPORT AND “THE CLUSTER”</b>	
<p><b>What is the report that was released about the cluster of patients with the “mystery disease”?</b></p>	<p>The cluster in New Brunswick was investigated by Public Health New Brunswick – not Horizon’s MIND Clinic team.</p> <p><b>Clinical and diagnostic information was reviewed by an oversight committee to determine whether there are alternate diagnoses for the patients who were included in the cluster or whether more investigation is required.</b></p> <p>The six neurologists on the oversight committee have concluded that the individuals who were included in this cluster do not represent a neurological syndrome of unknown cause and that no such syndrome exists.</p>
<p><b>How does the release of the report change the care that these patients receive?</b></p>	<p><b>The MIND Clinic team will continue to provide the best possible care and support through this time and well beyond the release of the report.</b></p> <p>The clinical care and expertise that our MIND Clinic team provides will continue to focus on each of its patients’, and their families’ individual needs.</p>
<p><b>What happens to these patients now?</b></p>	<p><b>Some of these patients have serious known conditions that are impacting their lives in profound ways and several patients need follow-up testing, assessment, and care.</b></p> <p>As each case review was completed, the oversight committee sent a letter to the patient’s primary care provider with its conclusions</p>

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	<p>and/or recommendations for further clinical review, and then sent a communication to the patient directly.</p> <p>All of the patients were asked to follow up with their primary care provider and will continue to have access to a specialist at the MIND Clinic in Moncton.</p>
<p><b>Patients say the oversight committee didn't see or test them. How did the committee decide on a conclusion or recommendation?</b></p>	<p>The clinical information was obtained from several sources including the patients' primary care physicians and specialists, the Government of New Brunswick electronic health record, and the hospital electronic medical records where patients were assessed, followed, or received treatment as an inpatient or outpatient. This included all the information that could be obtained about the patient's health history, family health history and symptoms, and ordered brain imaging and other laboratory diagnostic tests.</p> <p>This information, and the oversight committee members' clinical experience and expertise, was used to help determine whether there are alternate diagnoses for the patients or whether more investigation would be needed.</p> <p>This is not unique to this situation. It is not uncommon for referrals to be reviewed and potential diagnoses identified without a patient being seen in person.</p>
<p><b>What about patients who don't have a diagnosis yet?</b></p>	<p>Although it was determined by the oversight committee that no such syndrome of unknown cause exists, <b>several patients who were identified as part of this cluster do need follow-up testing, assessment, and care.</b></p> <p><b>The MIND Clinic is continuing to provide this ongoing care and treatment to these patients, as well as assistance to their families in accessing community resources and supports.</b></p>
<p><b>What happens to the MIND Clinic now?</b></p>	<p>The MIND Clinic will continue to be New Brunswick's only cross-specialty collaborative tertiary clinic for all progressive neurodegenerative diseases affecting adults of any age. It will continue to provide an array of care and services to patients to improve their quality of life, and family support.</p>

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	<p>Horizon is prepared to expand the multi-specialty clinic to be able to provide care to even more patients throughout New Brunswick.</p> <p>The MIND Clinic <b>will also be conducting important research to improve our understanding of neurodegenerative diseases in New Brunswick</b> and will study how we can identify and treat these conditions so that patients can receive optimum care at all stages of their illness.</p>
<b>Media Inquiries</b>	<p>ALL media inquiries should be directed to Horizon Media Relations: <a href="mailto:media@Horizonnb.ca">media@Horizonnb.ca</a>.</p> <p>Phone: 1-877-499-1899</p>