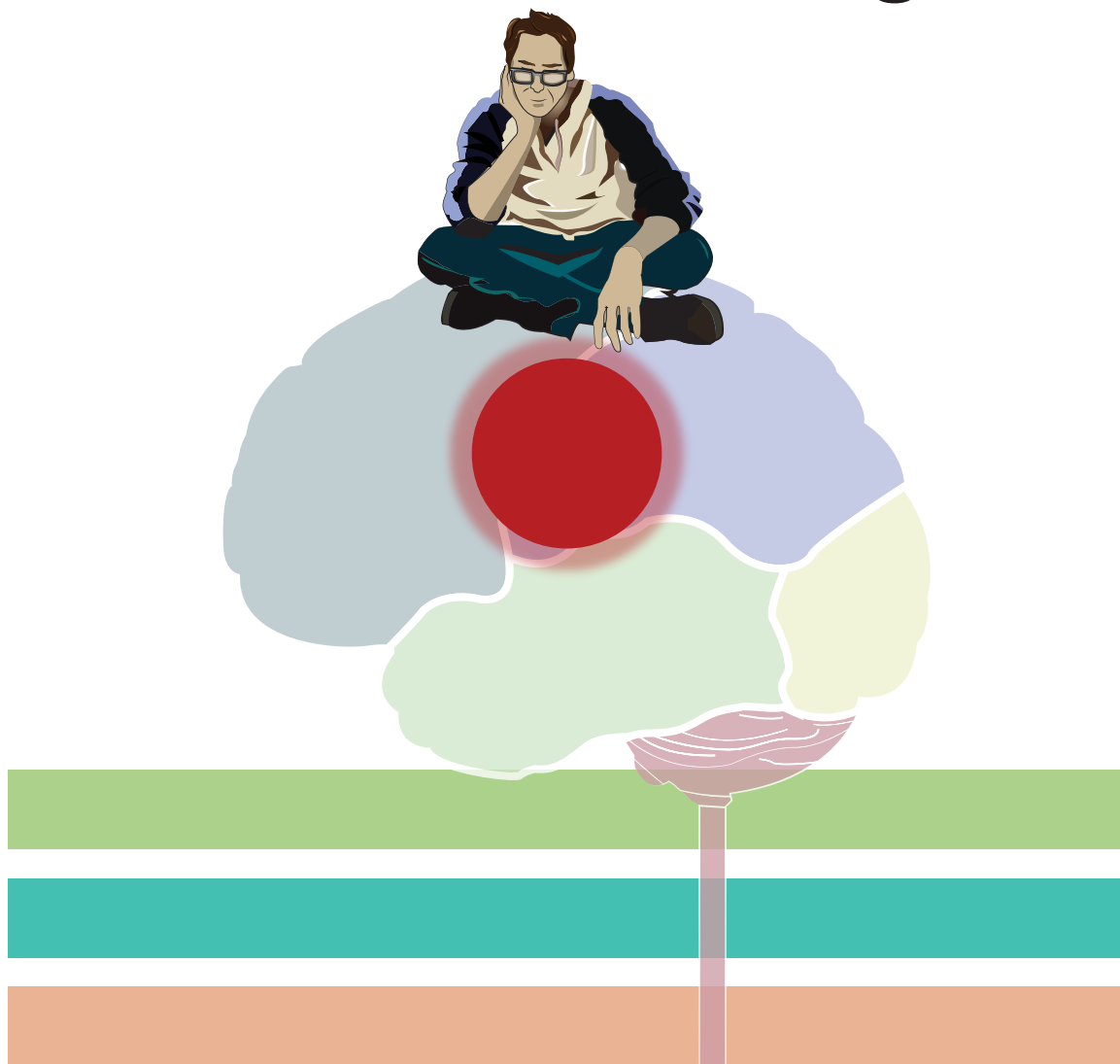


Brain Tumour Program



Centre universitaire
de santé McGill



McGill University
Health Centre

Office d'éducation des patients
Patient Education Office



Institut et hôpital neurologiques de Montréal
Montreal Neurological Institute and Hospital

FONDATION DU
CANCER DES
CEDRES



CEDARS
CANCER
FOUNDATION

Welcome to the MUHC Brain Tumour Program

The MUHC Brain Tumour Program is a large group of medical professionals dedicated to providing the best care for patients and their families with the diagnosis of a brain tumour.

Learning that you have a brain tumour is challenging for you and your family. There are many types of brain tumours and they are not all treated the same way. Having a brain tumour may affect many aspects of your life. We invite you to be an active partner in your care and ask questions about your specific brain tumour and how it will be treated. We hope this general pamphlet will help you to be involved in your care and to better understand:

- The Brain Tumour Program team
- Your care at home
- What to do when you have questions
- Resources



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Who is involved in your care and how to reach them

Brain Tumour Program and Clinic
3801 University Street Room 201
Montreal, Quebec
H3A 2B4

Tel: 514-398-5937

Fax: 514-398-7195

To book an appointment or or be referred to a nurse, please call the clinic at 514-398-5937



Members of your care team:

Your Neurosurgeon:

Name: _____

Office Phone Number: _____

Follow-up Appointment: _____

Location: _____

Your Nurse:

Name: _____

Phone Number: _____

Other specialists involved in your care:

Name: _____

Appointment date: _____

Name: _____

Appointment date: _____

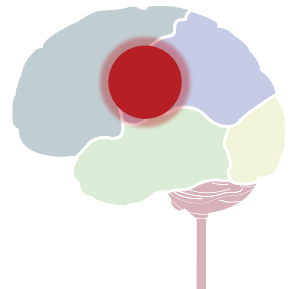
Name: _____

Appointment date: _____



What the Brain Tumour Program offers

- **Diagnostic tools and imaging**, such as CT scan, PET scan and Magnetic Resonance Imaging (MRI)
- **Specialized surgeries**
- **Radiotherapy** and **chemotherapy** treatments
- Access to **clinical trials** of promising new treatments
- **Full-time nursing care and social work**
- **Specialists for your spiritual and psychological needs**
- **Post-treatment care and rehabilitation** with physiotherapists, occupational therapists, speech language therapists and nutritionists according to your needs
- **Access to educational and support activities**, such as the Network of hope, the Glioma Module, and the Neuro-Patient Resource Centre



Who is who?

Your care may involve a variety of different health professionals. Each team member has their own expertise that they bring together to provide the best care possible for your own unique case.

Doctors

Your neurosurgeon will make the diagnosis of your tumour and perform surgery if needed. Your neurosurgeon will speak with other doctors from other specialties when needed and will follow you over time. If you need further treatments after surgery, you may be referred to a medical oncologist who provides chemotherapy and/or a radio-oncologist who provides radiotherapy treatments. Each doctor involved in your care is a specialist in his or her field and they will discuss your case and develop a treatment plan as a team.



Nurses

The Brain Tumour Program has nurses who are specialized in caring for brain tumour patients and their families. They are your main contact for questions and concerns about your health and treatment plan. If you have not yet met a specific nurse but have a question or concern, please call the clinic (514-398-5937) and ask to speak to one of the nurses. While you are in the hospital, the nurses caring for you on a day-to-day basis will be your main link between you and the other members of the team.



Social Workers

The social workers are there to support and listen to you. They will help you and your loved ones cope. The social worker will also help you plan for your needs in the community. They can help you make decisions about your goals and expectations and about your return home after you leave the hospital. They can organize and refer you to resources in the community.



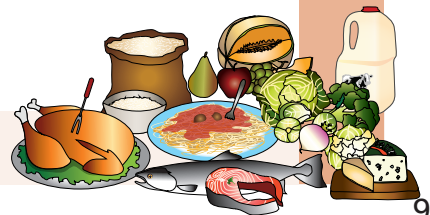
Rehabilitation team: Occupational Therapist, Physiotherapist and Speech Language Therapist

A brain tumour can affect different aspects of your functioning, such as speech and your ability to do physical activities. While in the hospital, you may be evaluated by rehabilitation therapists. Working with you and your doctors and nurses, the rehabilitation team will plan your care and decide what rehabilitation therapy you will need after you leave the hospital.



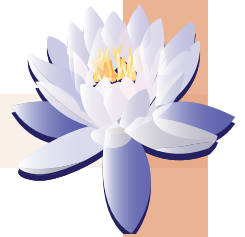
Nutritionist: Clinical Dietician

The clinical dietician can help you deal with problems related to eating and nutrition, if you have any.



Spiritual Care

The spiritual care counselor will provide emotional and spiritual support to you and your family. For many people, illness can change the way that they see themselves and the world. You may have questions about your beliefs and values. You may be asking important questions about what is happening to you and what your illness will mean to your friends and family. Talking to the spiritual care counselor can help you find inner strength to live with illness.



Brain Tumour Board

The Brain Tumour Program team members regularly discuss patient cases and decide on treatment plans together. The Brain Tumour Board is a weekly meeting that formally reviews patient cases and discusses latest research and results. Your doctor may plan to discuss your case at the Brain Tumour Board before deciding on your treatment plan.



Clinical Research

The Brain Tumour Program is a teaching unit at McGill University. We participate in important research to find new reliable and safe treatments for brain tumour patients. The Brain Tumour Program is a leader in the development of new treatments for malignant brain tumours. You are invited to ask your doctor if you are eligible for any clinical trials.



Going Home After Surgery or a Hospital Stay

It is important for you to feel confident and comfortable while you recover after being in hospital. Below, we will look at how you can manage your care after going home following surgery.

Pain / Discomfort

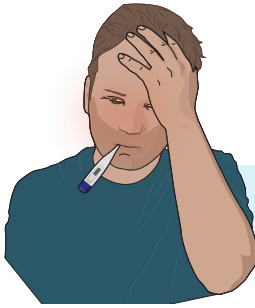


You may have mild head pain after your operation. If need be, use the pain medication that was prescribed for you by your neurosurgeon. If you have strong or long-lasting pain after going home, please call the clinic to speak with a nurse. You will feel some numbness or tingling in the area of your operation or incision (wound). This is normal and it may take months to go away.

Leg Swelling or Pain



You may have pain and swelling in a leg. If you have pain or swelling or redness in one or both legs, please contact your nurse in the program or the clinic (514-398-5937). Being as physically active as possible may prevent this problem. This may be a sign of a blood clot.



Fever

A slight fever during the first few days after an operation can be normal.

Please call us if you have a fever that continues longer than a few days or is higher than 38.0°C (100.4°F).

If you develop a fever and have pain when urinating, check with your nurse or family doctor since this may mean that you have a urinary tract infection.



Change In Function

If you develop a new weakness or numbness in your arm or leg, if you lose your ability to speak properly, or if you become drowsy or less alert, please call us immediately or go to the emergency room.

Appetite and nausea/vomiting



You may feel weak and a bit nauseated after surgery. Call your nurse if the nausea continues or increases or if you have repeated vomiting. You may not feel like eating much after your surgery. It is important that you drink 6 to 8 glasses of liquids per day after you leave the hospital. It may be easier to eat 5 or 6 small meals of healthy foods throughout the day. Good nutrition is important for healing the wound and getting your strength back.

Fatigue (tiredness)



You may feel tired after your operation. You may need rest breaks, naps, or relaxation exercises throughout the day. We encourage you to exercise. An example would be taking short daily walks for 10–20 minutes a day.



Activity Restrictions After Brain Tumour Surgery

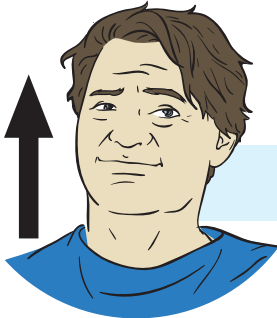
Ask your neurosurgeon about driving a motor vehicle, participating in contact sports, swimming, diving, airline travel and riding a bicycle after your operation. Do not hesitate to ask a member of your health care team about resuming sexual activity after your surgery. You may notice that you need more periods of rest after surgery.

Constipation

Constipation can sometimes be a problem after surgery. Opioid pain medications (such as codeine) can make this problem worse. If possible, try to avoid these. Increasing your activity level as much as you are able can help as well as eating foods such as bran, prunes, fresh fruits and vegetables and drinking water. You can also use the laxatives that have been prescribed by your doctor.

Wound (Incision) Care and Monitoring

Your incision wound will heal best if left open to the air. Some swelling and some redness of the wound are normal after this surgery and may take 2 to 3 weeks to get better. As you become more active, the area of swelling may change as fluids move and are absorbed into your body.



Keep your head raised to bring down swelling.

Watch your wound for signs of infection such as: swelling or discharge.



Fever could be another sign that your incision wound is infected.



If any of these happen, please call your neurosurgeon or the clinic to speak with a nurse immediately.

Cleaning The Incision Wound



Do not wash your hair until 3-4 days after surgery. Then, please wash your hair daily with mild shampoo. It is important to gently wash over the wound and to allow water to run over it. The wound should not be rubbed until it is fully healed.

Sutures (stitches)

There are two types of sutures that may be used:



Regular stitches

or



Staples

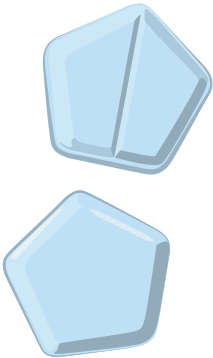
Your neurosurgeon will tell you when to have your stitches or staples removed. Your nurse during your hospital stay will tell you where you can have them removed. (At a follow-up visit or at the CLSC).

Date: _____

Where: _____



Never Stop your Dexamethasone (Decadron™) suddenly - always respect the tapering schedule.



Medications

Anti-seizure medications:

If you are taking anti-seizure (anti-convulsant) medication, please continue to take it as your doctor has prescribed.

You may need to have a blood test in order to check the level of seizure medication in your blood.

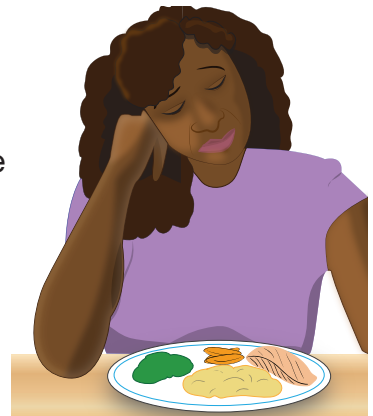
Your anti-seizure medication is:

Dexamethasone (Decadron™)

You will be given a prescription for dexamethasone (also known as a corticosteroid or Decadron™) when you leave the hospital. Usually this medication is tapered (lowered slowly) over a number of weeks. You will be given a prescription explaining the tapering schedule.

Please see the table to help you understand your tapering schedule at the back of this booklet.

Ranitidine (also known as Zantac™) or other antacids (Pantoloc™) will also be prescribed to prevent the dexamethasone from irritating your stomach lining. When the dexamethasone is stopped, this medication is also stopped.



The following is a list of side effects you may or may not notice, which could result from lowering your dosage of dexamethasone (Decadron™).



Worsening headache (report any headaches which are not controlled with Tylenol™ or similar medications)

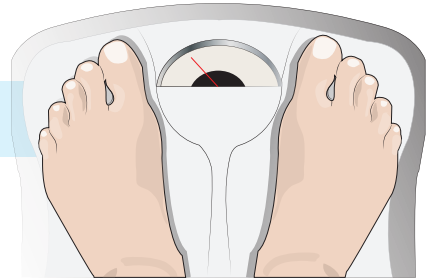


Low energy level, fatigue (tiredness)

Nausea or vomiting



Weight loss



Return to Work

Discuss with your doctor about when you should plan to return to work after surgery or during treatments.



Follow-up Care

When you leave the hospital, we will have booked a follow-up appointment for you at the Brain Tumour Clinic or at your neurosurgeon's office at the Montreal Neurological Hospital.

Depending on your diagnosis, you may also have an appointment to be seen by the Radiation Oncology and/or the Medical Oncology Service.

Your appointment is: _____

If you did not receive a follow-up appointment with your neurosurgeon before leaving hospital, please call our clinic at (514)-398-5937 or your neurosurgeon's office to arrange an appointment.

Please keep any appointments you have arranged with other physicians.

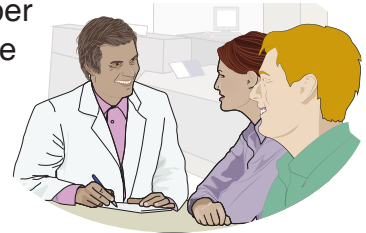
It is suggested you return to see your family doctor 2 – 3 weeks after your surgery to have him/her check on your recovery.



Coming to the clinic

Please bring a member of your family or a loved one with you to the clinic. During your visit, you may receive lots of important information for your treatment plan.

Having someone with you may help you remember and better participate in your care. When possible we try to organize your appointment so that you see different team members on the same day.



To your clinic appointment, you should bring:

- Your Medicare and your Montreal Neurological hospital cards. If you do not have a green hospital card, please go to the admitting office at room 165C behind security on the 1st floor to make a new card before your appointment.
- Your updated list of medications, available from your pharmacy
- A snack and something to do while you wait. Your first visit to the clinic may last half a day.
- Your list of questions for your treating team



Signs to watch for:

Problems rarely happen after you leave the hospital, however, it is important for you to know what is normal and what is not normal. We strongly hope that you will carefully read the Adult Brain Tumour Handbook which talks about possible complications. If you have not received a copy of this handbook, please ask a member of your health care team.

Please call us if you have any of the following problems:



Dizziness that doesn't go away

Have a **temperature**, higher than 38 degrees Celsius or 100.4 degrees Fahrenheit



Continuous **nausea** or **vomiting**

Notice the **wound has become red, swollen or hot** and there is **leakage** from the wound



Signs to watch for:

Please call us if you have any of the following problems:

Headache (with no relief from medication prescribed by your doctor)



Speech problems (slurred speech or unable to say words or make sounds)

Double vision and /or blurred vision



Stiff neck

Signs to watch for:

Please call us if you have any of the following problems:



Increased weakness in your muscles, trouble using your arm, leg, hand or foot.

Drowsiness



Seizure

Trouble keeping your **balance** or **walking**



In the event of an emergency, go to Montreal General Hospital Emergency or the nearest hospital's emergency department. If you don't know whether you should go to the Emergency room, you can call a brain tumour team nurse for an evaluation and referral or call 811 to speak with a nurse at Info-Santé who will evaluate you.

If you are concerned about your health, please call your nurse directly during business hours (8am to 4pm) or call the clinic at 514-398-5937 to be referred appropriately.



Useful Resources:

Neuro-Patient Resource Centre – room 354

Health Information for Patients and Families: 514-398-5358

The Centre is available to help you and your family find further information concerning your type of brain tumour, living with a brain tumour, caregiving, and other related topics. Also you and your family members can get access to the hospital wireless network, use one of our computers, print, fax, photocopy and find out about community resources. Feel free to drop in to the Centre anytime.

You or your family members may visit the Centre while your are in hospital. You may find it helpful to visit their website after you go home:

www.infoneuro.mcgill.ca

The Glioma Online Guide:

A powerful resource for brain cancer patients and their families

This interactive online resource developed by the Brain Tumour Program and the MUHC Patient Education Office empowers patients and their families by giving them the information they need and want to know about their cancer and care. It will help you and your family ask the right questions so that you are prepared for every part of your treatment and recovery.

www.muhcpatienteducation.ca

Search: Brain Cancer



Network of Hope

The Brain Tumour Program has organized educational and support activities through the Network of Hope, a group of patients and loved ones who have faced a brain tumour diagnosis. Call the Neuro-Patient Resource Centre at 514 398-5358 for details on upcoming events.

Cedars CanSupport

The Cedars CanSupport at the MUHC provides free, bilingual compassionate care and support to cancer patients and their families.

Their experienced team of trained professionals and volunteers provide not only practical, financial and educational services to cancer patients and their families, but also support groups, programs for young adults, and complementary therapies.

You can reach Cedars CanSupport at the Cedars Cancer Centre at 514-934-1934 extension 31666.

The website is www.cansupport.ca



General health questions (non-emergency)

Info-Santé: 8-1-1

24 hours a day, 7 days a week

Dexamethasone (Decadron™) Tapering Schedule

Current Dosage Schedule: _____ (milligrams) _____ (times per day)

Date	Dosage	Morning _____	Noon _____	Evening _____	Night _____

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This material is also available at:
Neuro-Patient Resource Centre www.infoneuro.mcgill.ca
MUHC Patient Education Portal www.muhcpatienteducation.ca



IMPORTANT: PLEASE READ

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

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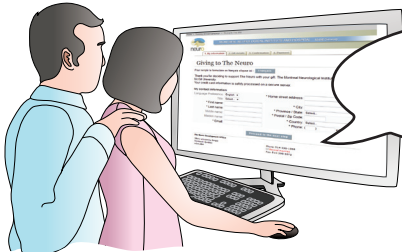
Institut et hôpital neurologiques de Montréal
Montreal Neurological Institute and Hospital



You Can Make A Difference!

Your donation to The Neuro's Brain Tumour Program helps us provide support for brain tumour patients and their family through education and teaching, and allows us to bring new and more efficient treatments to our patients.

Make a donation through the Neuro's Development Office today:



Online:
theneuro.ca

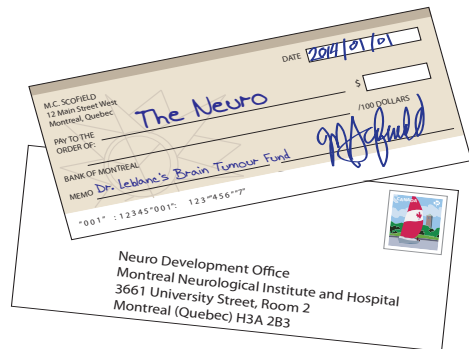
**Dr. Leblanc's Brain
Tumour Fund**



Institut et hôpital neurologiques de Montréal
Montreal Neurological Institute and Hospital



By Phone:
514-398-1958



In Person / By Mail: 3661 University Street, Room 2
Montreal (Quebec) H3A 2B3

Thank you for helping us to help others!

Patient materials are also available online at www.infoneuro.mcgill.ca.

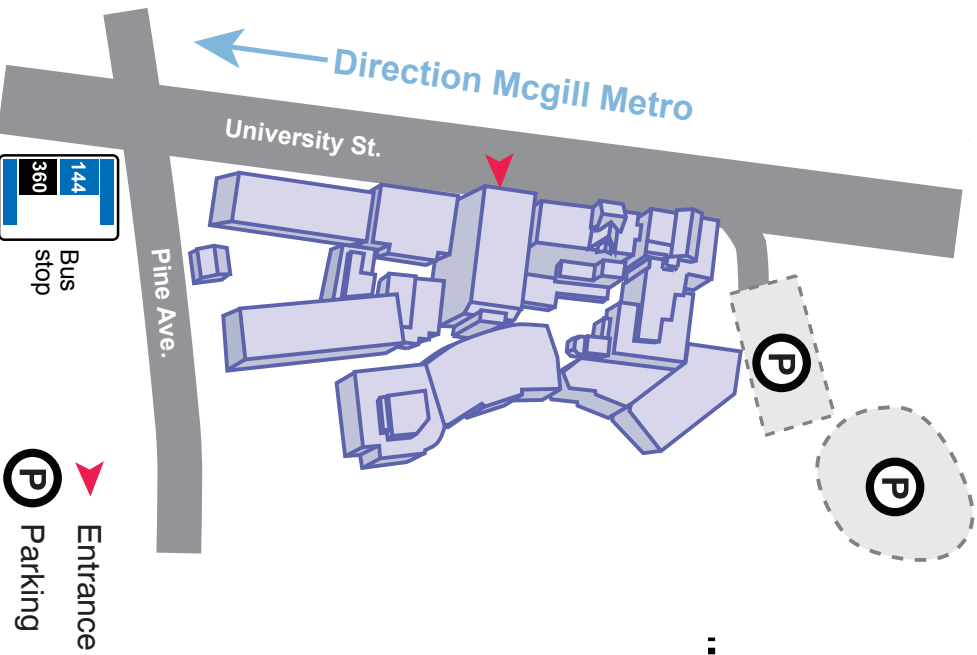
For more information contact:

The Neuro Patient Resource Centre at infoneuro@muhc.mcgill.ca

The Neuro

3801 University street
Montreal, Quebec H3A 2B4

Brain Tumour Program and Clinic: Room 201
Neuro Patient Resource Centre: Room 354



Cedars Cancer Centre

(located at the MUHC Glen site)

1001 Decarie Boulevard
Montreal, Quebec H4A 3J1

Cedars Cansupport Resource Centre: D.RC 1329

