Renowned Quebec scientist Guy Rouleau to take the helm of The Neuro

AFTER IN INTERNATIONAL SEARCH, THE NEOURO HAS FOUND ITS NEW DIRECTOR RIGHT HERE AT HOME

Guy Rouleau, a prominent Quebec scientist recognized around the world for his research into such brain disorders as epilepsy, autism and schizophrenia, will succeed the late David Coleman at The Neuro as Director of the Montreal Neurological Institute and Associate Director General of the Montreal Neurological Hospital. His appointment takes effect January 1, 2013.

“As Neuro Director and Wilder Penfield Professor of Neuroscience, Dr. Rouleau will have endless opportunities in which to invest his passion for neuroscience, his creativity and his leadership,” said Normand Rinfret, director general and chief executive officer of the McGill University Health Centre. “As the talented professionals at The Neuro continue to map and share their understanding of the brain, as well as provide exceptional care and training, we will also be charting a bright future at the Glen site that will support even more collaboration and benefits for society.”

Dr. Rouleau comes to The Neuro from the Université de Montréal, where in addition to his own research laboratory, he directs the

Martine Alfonso: new leader at The Montreal Children’s Hospital

Martine Alfonso, who was selected with the support of both the Council for Services to Children and Adolescents and the Board of Directors of the McGill University Health Centre (MUHC), will take on the role of Associate Executive Director of the Montreal Children’s Hospital (MCH), effective January 7, 2013.

“I am confident that Martine will ensure the MCH enhances its leadership position within the Quebec healthcare network and she will be a strong advocate for The Children’s within the MUHC,” said Normand Rinfret, director general and chief executive officer of the MUHC.

“Martine personifies our commitment to ensuring that children have timely access to care in a compassionate environment, while remaining at the forefront of advances in teaching and research.”

In her new position Alfonso will work with her MCH colleagues on preparing for the move to the Glen in 2015 and deploying the associated services for patients and their families.

“It is with much enthusiasm that I have accepted the children’s AED position,” says Alfonso. “It will be a privilege to contribute to the ongoing success of this important institution. I very much look forward to joining their team in the New Year.”

For 14 years, Alfonso worked as a physiotherapist before becoming part of the management leadership at the Institut de Readaptation Gingras-Lindsay de Montréal in 2003. By 2009, she

MUHC kicks into action during Code Orange Simulation

At 8:35 a.m., October 24th, a simulated emergency incident was declared in Montreal. More than 100 actors dressed and made-up as injured patients were brought to the Emergency Departments of the MGH and MCH by ambulance and bus. This simulation was designed to evaluate the emergency preparedness of Montreal services should a major event really occur. The MUHC was invited to participate in this unique opportunity with the Agence de la santé et des services sociaux de Montréal, the Corporation d’Urgences-Santé, le Service de police de la Ville de Montréal, the Montreal Transit System and the Canadian Forces. The MUHC was lauded by the Agence for its efficiency and professionalism – a testament to the dedication and team work of all our staff. Keep an eye out for the December issue for a photographic account of the event.

Continued on page 2

Continued on page 2
The night of Saturday, November 17 was truly special. Over 900 members of the MUHC family came together to eat, dance and celebrate our successes at the fourth annual Director General’s (DG) Awards Gala.

In presenting the awards to the ten individual winners and the team, I was once again struck by the talent we have at the MUHC, as well as the professionalism and commitment of our colleagues. Through the various testimonials, we got a clear sense of their impact on care, teaching and research. This impact resonates throughout our community, through relationships with colleagues and through collaborative efforts with partners. We are justifiably proud of all of the winners and grateful for their leadership.

The winners represent the best of the best. Regardless of the category, making a final choice in each was difficult. After all, the contributions of the nominees illustrate that we have a broad team with many strengths.

As such, on behalf of the MUHC, I also wish to thank all who took the time to nominate a colleague or team. In doing so, you reflected on what excellence means to us as an academic health centre and helped inspire all of us to do our very best.

A gala evening such as last Saturday night does not happen overnight. It involves many hours of hard work by a large and diverse group of people. Your thoughtfulness is most appreciated and I thank you for going the extra mile.

Finally, the DG Awards Gala was a night to remember in more ways than one. Not only was it an entertaining and moving soirée, but it also served as a reminder that we are all truly privileged to work with each other. Indeed, we can all learn from each other.

MESSAGE OF NORMAND RINFRET

In a joint statement, McGill Principal Heather Munroe-Blum, Vice-Principal (Health Affairs) and Dean of Medicine David Eidelman, and Norman Rinfret stated that, “We are confident Dr. Rouleau will help create and strengthen ties with community, academic institutions and hospitals across Quebec, Canada and around the world.”

“I have dedicated my career to advancing neuroscience and neurological care,” Rouleau said. “To increase the impact of this work in Quebec and beyond, The Neuro is the place to be. Staying true to Dr. Penfield’s vision, scientists and physicians work hand in hand so that problems encountered in the clinic inspire research and new findings from the labs are directly applied to patients’ medical needs.”

His landmark achievements are his contributions to the identification of more than 20 disease-causing genes and his discovery of new mutational mechanisms. He is also a recipient of many honours, including most recently the 2012 Prix du Québec – Prix Wilder Penfield, the Henry Friesen Prize and the Margolese Prize. Rouleau is also an Officer of the Ordre national du Québec.

In the role of the Neuroscience Mission’s Director, Alfonso will oversee the planning and execution of the move of the Neuro to Glen which is scheduled for 2019.

Alfonso is a registered nurse and has experience in both acute care and research settings. She has held several management roles at the MUHC in the areas of ambulatory care and inpatient services. Most recently, she joined the MUHC team and became Administrative Director of the Neuroscience Mission. In this role she was responsible for the administration of clinical activities at The Neuro, neuroscience activities at the Montreal General Hospital and related ambulatory services.

Two years later, with the passing of Dr. David Colman, Alfonso was named Interim Director of the Montreal Neurological Hospital (MNH). In this capacity, she has provided steady and effective leadership during a challenging period and she has played a key role in developing the transition plan for the period leading up to the anticipated move of The Neuro to the Glen in 2019.

As Guy Rouleau assumes his new position, Martine Alfonso will be bringing her experience as a healthcare practitioner and manager to her new assignment.

“The decision to leave The Neuro was a difficult one,” says Alfonso. “For the last four years, I have worked with clinicians, Montreal Neurological Hospital and Institute leaders and the whole Neuro community in support of integrating cutting edge research and outstanding clinical care. With interest, I will continue to follow the successes of their many projects under the capable and dynamic leadership of Guy Rouleau.”
LOGIBEC—driving a new era

THIS NEW SOFTWARE TOOL WILL PROVIDE AN INTEGRATED APPROACH TO MODERNIZING ADMINISTRATION AND MANAGEMENT TOOLS ACROSS THE MUHC

By Chantal Beaudry

At each site, perhaps even to the level of every team, of the McGill University Health Centre (MUHC) management practices are unique when handling schedules, recall lists, patient record numbers, invoicing and so on. The systems are not harmonious, but perhaps even more glaring is how outdated they are; in many cases only portions of information can be processed electronically, while the rest must be inputted manually. Enter: Logibec.

Logibec is a software suite that several MUHC teams are now preparing to integrate as their administrative and clinical management system. The new tool allows for electronic monitoring of patients (admission, discharge, transfer, bed chart), employees (training, schedules and replacements, attendance records, payroll) and suppliers (material management, budget, income, invoicing and electronic payment).

The software suite was acquired in February 2011 and has been used for issuing users’ invoices since October 2011. This month, the application will be used to set up the MUHC general ledger, which is the final repository of accounting records and data. This will be the starting point to eventually improving the quality of the financial reports to managers.

Logibec will be implemented across all teams of the MUHC over the next two years. The overall harmonization of the management and administrative practices will pave the way for many new opportunities and services that will contribute to improved efficiencies, accuracy and even best care.

Accreditation 2013 is launched!

Accreditation Canada is on their way back to the MUHC in September 2013. Under the theme “Working Together”, Accreditation Canada’s QMENTUM program will aim for a wide participation from our MUHC teams as we strive for continuous quality and safety improvement.

In anticipation of the visit, the MUHC will undergo a series of preparatory phases, the first of which is called “self-assessment”.

QUESTIONS & ANSWERS

1. What is QMENTUM?
Qmentum is a program from Accreditation Canada that ensures quality and safety improvement activities are part of the day-to-day activities of the MUHC.

2. What does QMENTUM consist of?
The four phases of the Qmentum process are Self-assessment, Roadmaps (results) Preparation for Tracers (mock tracer activities), and the Accreditation Visit.

3. What are Required Organizational Practices (ROPs)?
ROPs are essential practices that minimize risk and improve patient safety. Examples of ROPs include medication reconciliation, reporting and disclosure of incidents/accidents, and staff education on hand-hygiene or the prevention of falls.

4. How do staff and doctors participate in QMENTUM?
In the first phase, Self-assessment, many of you will be asked to complete one questionnaire. Staff will be given the questionnaire that best suits their work responsibilities.

5. How much time does completing a QMENTUM questionnaire take?
Depending on the questionnaire, it will take between 15 minutes to an hour.

6. If I work in more than one service, how should I respond?
You should answer based on the service in which you spend most of your time.

7. What happens to the QMENTUM questionnaires once completed?
Each MUHC team will quickly receive results of the questionnaires in the form of a Roadmap, highlighted with red, yellow or green flags. The red and yellow flags identify areas that need improvement. Each team will decide where to focus its improvement efforts, create an action plan, and begin to make changes as necessary. We will have six months to work on these improvement plans.

8. What happens during the Accreditation Visit?
During the Visit, the surveyors will use the Tracer method to gather information. This means they will tour all over the MUHC hospitals, talking to many different staff, reviewing documents, and observing a variety of activities to evaluate quality and security of care.

Our goal is to make quality improvement a part of the MUHC’s day-to-day operations and culture. The Qmentum Self-assessments, Roadmaps, Tracers and Visit will help us do just that, by asking all of you to participate. Share your ideas, help put your ideas into practice, and contribute to better patient care!
HIV patients face new reality

As this patient population ages, secondary health issues are surfacing. Cognitive impairments could now be linked to years of living with this once deadly virus.

By Julie Robert

Twenty-four years ago, Robert (not his real name) was infected with HIV. With the right combination of treatments he has been able to live a healthy life. However, a few years ago, Robert started to experience concentration and memory problems. Holding something and not remembering where he wanted to put it, or opening the fridge and not remembering why, are not uncommon events for this active 59-year old.

Robert is one of the participants in an innovative study conducted by the McGill University Health Centre (MUHC) and the Montreal Neurological Hospital and Institute that is assessing cognitive function in patients living with HIV. He decided to take part to help the cause and advance science. "I don't know if my problems are related to age, the virus or something else," he says. "But if I can help, I will."

THE NEW FACE OF HIV

Thanks to the availability of highly effective antiretroviral therapy (HAART), deaths from AIDS plummeted by over 90%. per cent after 1995.

The face of HIV seemed to change overnight. Today, people infected with HIV are now living into old age, but as a result secondary health problems are surfacing, such as possible cognitive decline.

"At the beginning of this epidemic, people with HIV had to stay home from work because they were sick," says Marie-Josée Brouillette, a psychiatrist and researcher at the Research Institute of the MUHC, who is spearheading this project. "Thirty years later, a problem now is they want to continue their professional lives, but if there are issues with concentration this can lead them to feel less effective mentally."

In partnership with Clinique Médicale l’Actuel, the study’s multidisciplinary team—composed of psychiatrists, neurologists, neuropsychologists, epidemiologists and HIV physicians—is currently developing a new tool to measure cognitive abilities in patients infected with HIV. The goal is to develop a battery of computerized tests that are free and remotely accessible, and that can reliably measure cognitive ability in just a few minutes.

"Our statistical analysis method (called a Rasch analysis) is a clinical epidemiology model, which in this case represents an innovative approach," says Dr. Brouillette. "We are shedding new light on the relationship between cognitive symptom complaints and test results."

The research project involves approximately 100 patients, who go to either Clinique Médicale l’Actuel or the MUHC to take a series of online tests, which they take again three and six months later. "Many studies have documented that between 30 and 50 per cent of people living with HIV have mild cognitive impairments," says Dr. Brouillette. "These impairments manifest as problems with attention, concentration and memory."

FINING AVENUES FOR TREATMENT

According to Dr. Brouillette, some patients get the HIV virus in their brains in spite of good viral control as measured in the blood, and these people may experience cognitive losses. The only test that can screen for HIV in the brain, currently, is a lumbar puncture—a procedure that is quite invasive and not appropriate in all cases.

"An outcome of this study is we may be able to measure cognitive decline that could suggest presence of the virus in the brain," says Dr. Brouillette. "The challenge for researchers is to develop a battery of reliable tests that are easy to administer to larger cohorts of study participants so that scientists can expand their knowledge in this emerging field and can potentially identify interventions that could mitigate the negative impact of the virus on patients’ cognitive ability, earlier rather than later."

This project is a collaboration between Marie-Josée Brouillette (Psychiatry); Lesley Fellows (Neurology); Lisa Koski (Neuropsychology); Nancy Mayo and Lois Finch (Clinical Epidemiology); the MUHC’s Chronic Viral Illness Service; and Réjean Thomas and Sylvie Vézina from Clinique Médicale l’Actuel. With the support of the MUHC’s Warren Steiner, Psychiatrist-in-Chief, Richard Lalonde, Director of Research, and Norbert Gilmore, Medical Director of the Chronic Viral Illness Service.
The smallest victims of HIV  
– MCH clinic treats patients from birth to 18

By Christine Zeindler

As we mark World AIDS (Acquired Immunodeficiency Syndrome) Day, we may not consider the youngest victims of this disease. The reality is, there are approximately 3.4 million children living with HIV (Human Immunodeficiency Virus, which leads to AIDS) worldwide and more than 4,000 of them live in North America. For more than three decades, The Montreal Children’s Hospital (MCH) of the McGill University Health Centre (MUHC) has been one of two Montreal centres treating HIV-infected children from Montreal and its outreach environment.

“Currently, we are following 21 HIV-infected patients, the majority of whom we have known all their lives,” says Dr. Christos Karatzios, co-director of the MCH HIV clinic. “Most of these children, now in their preteen and teenage years, were vertically infected by the virus from their mothers, who were HIV positive while they were pregnant. We are also following a few patients who have been recently exposed to HIV through birth but who hopefully are not infected thanks to strategies we use to prevent transmission of HIV.”

FROM HEMOPHILIA TO HIV

The MCH HIV clinic, which includes physicians, nurses, psychologists, nutritionists and child-life therapists, first started treating patients in the early 80’s.

“Some of our first patients with HIV were those who were receiving regular blood transfusions,” says Dr. Karatzios. “Mostly, these were patients who had hemophilia, a blood clotting disorder.”

Prior to 1992, blood and blood products were not screened for HIV. Since hemophilia patients or others receiving transfusions were given blood, which was not tested—the very blood that was saving their lives was putting them at extreme risk of contracting HIV.

ACCEPTANCE IS BEST APPROACH

“Life is not easy for our patients,” says Dr. Karatzios. “These kids have a serious chronic illness and they usually have been orphaned by at least one parent. The biggest challenge for families is to accept that their child is infected. After that, parents need to come to terms with feelings of guilt, especially in the setting of mother to child transmission. It is our job to support these families using a multidisciplinary approach.

Helping children face their disease is another important role of the clinic. Many medical and psychosocial issues have to be prevented or dealt with. Adherence to the drug regimen is also an important issue. If medications aren’t taken properly, the patients risk becoming susceptible to other infections and serious consequences may follow. Also, by 14 years of age, the children need to know and understand their disease. We start informing them early and when they are around 16 years old, we prepare them for a move to an adult facility.”

TRANSITIONING TO ADULT CARE

By 17 years, the clinic staff encourages the child and his/her family to make a choice about which adult health facility they will regularly attend. After they turn 18, they attend their first adult clinic accompanied by a MCH nurse.

“We try to make the transition an easy one,” says Dr. Karatzios. “We offer a lot of support, but after 18 they are mostly on their own. It is critical that these young adults continue with regular clinic visits, but sometimes they don’t and they put themselves at risk. We are looking at ways to improve this transition process.”

According to Karatzios, for the most part, the patients are well-adjusted. “Some of our earliest patients are now having children of their own,” he says, “a testimony of treatment success and their own optimism.”

Looking after Canada’s newest arrivals

MCH Multicultural Clinic provides services for immigrant and refugee children

By Christine Zeindler

According to Dr. Louise Auger, the main mission of The Montreal Children’s Hospital Multicultural Clinic is to ensure immigrant and refugee children don’t fall through the cracks.

“We have five pediatricians who see newly-arrived children to Quebec, who are referred from The MCH Emergency Department, other departments, CLSC’s or community organizations,” says Dr. Auger, the director of the Clinic. “In addition to addressing the problems for which the child is referred, we carry out full assessments of their health status. Included is a screening program for the detection of anemia and infectious diseases, such as HIV, tuberculosis, hepatitis and intestinal parasites. We also arrange for further treatment within the hospital if required or will facilitate referrals to community resources.” The team provides consultations for children adopted from other countries as well.
In 2010 a decision was made to merge the McGill University Health Centre (MUHC) Human Immunodeficiency Virus (HIV) clinics of the Montreal General and Royal Victoria hospitals (the latter is located at the Montreal Chest Institute, Immunodeficiency Service). The new merged clinic is known as the Chronic Viral Illness Service (CVIS). We asked Dr. Norbert Gilmore, the director of the CVIS, to provide some history about HIV and Acquired Immunodeficiency Syndrome (AIDS) at the MUHC, his insight into the new service, and his thoughts on the much-changed face of this once deadly disease.

Tell us about HIV in the early years at the MUHC.
DR. GILMORE: “In 1981 I was at the Vic working in Allergy/Immunology and we started to see people come in with an odd disease. I took over an allergy clinic in order to accommodate these patients. A year later they were sitting on the floor because there simply weren’t enough chairs.

There was a great sense of unease at that time, and nobody really wanted to deal with something that seemed so dangerous and scary. The situation at the Montreal General was the same at that time. Dr. Chris Tsoukas was studying patients with hemophilia, many of whom were ill, and he began seeing a lot of gay men afflicted with this daunting disease. But thanks to the general goodwill in the immunodeficiency world here, people rallied, despite the fear and uncertainty that marked the early days of HIV.

By 1984, an HIV/AIDS clinic at the Vic—which moved to the Montreal Chest by 1990—opened under the leadership of Dr. Richard Lalonde, while Dr. Tsoukas continued to see patients with HIV at the MGH. Both clinics have multidisciplinary teams that include psychologists, psychiatrists, nurses and more working together to provide the best care possible to patients with HIV/AIDS.

We went from having no drugs to treat HIV—almost running a palliative care service as a result—to an oncology mode, where some people would do well on HIV medications and others wouldn’t, no matter what we did. Then, thanks to evolved research and as a result the introduction of new drugs, the disease entered a chronic mode where almost everybody could do well if they took their meds.

What are we doing for patients today?
DR. GILMORE: “Today, we have highly effective therapies, so people starting treatment for the first time over the last year or two have a life expectancy close to that of other Canadians. Much like diabetes, however, where the disease is well controlled for years and then chronic side-effects turn up, we’re seeing the same problem in the HIV world. This is where the multidisciplinary care teams become essential.

HIV patients also now have the opportunity to take medications that can help prevent the infection of others, especially if taken the day before and a couple of days after having sex. If a condom breaks and the partner is infected you can give the healthy partner the highly effective anti-HIV meds for four weeks to stop infection from developing.”

When and where will the new clinic be located and how will services be improved?
DR. GILMORE: “At the moment, we hope to be fully operational by spring 2015. The CVIS will be located at the Glen Campus and will be able to accommodate all of the clinical work we’re presently doing. We will also continue to conduct clinical research, which we will be given space for so our research nurses can work and follow patients who are involved in studies.

At the end of the day our work is very rewarding, and it is great to see that we can make a difference.”
Living with HIV, cared for by the MUHC

By Maurice Crossfield

You wouldn’t expect someone with HIV to call themselves lucky, but that’s how Stephen sums it up when he looks back at nearly three decades of managing the disease. “Ninety-nine point nine per cent of the time I stick to the medical regime," he says. "I also watch my diet very closely. I have a tremendously high activity level, and I’ve been able to maintain that."

Stephen (not his actual name) learned he had HIV in 1987, a time when a diagnosis was a virtual death sentence. Through the years of upheaval that followed he remained focused on staying alive, first to see his children finish high school. Then college. Today, at age 65, he’s focused on being there for his grandchildren.

The same year Stephen was diagnosed, Dr. Norbert Gilmore began working as an infectious disease specialist at the Royal Victoria Hospital. As such he has been a front-line witness to the transformation in HIV treatment.

“It has been a huge human journey,” he says. “I have gone from seeing people die to now, where with the right combinations of drugs people can stay alive and live normal, active lives.”

Today’s antiretroviral drugs are highly effective and have transformed HIV treatment. The right combination of medications and lifestyle, along with good doctor-patient communications can produce lasting results.

But HIV treatment is about more than just the virus: Patients may see their world turned upside down. In Stephen’s case, it eventually resulted in the end of his marriage, his job, and huge changes in his family relationships.

That’s where the team at the Chronic Viral Illness Service can step in to help people with HIV or hepatitis C. A dedicated team of social workers, a psychologist, a psychiatrist, nurses, outreach workers, pharmacists, a dentist and even a lawyer, the team provides necessary support to patients who may need help in many aspects of living with these illnesses.

“We want to try to bond with people, to make them feel supported,” says Gilmore. “I tell people I love success, and this is a great service.”

The basics of HIV/AIDS

• Human immunodeficiency virus (HIV) causes acquired immunodeficiency syndrome (AIDS), AIDS is a progressive condition that impairs the body’s ability to fight infection and tumour (cancer) growth
• HIV infected patients have weakened immune systems and are susceptible to infection from other organisms, including bacteria, viruses and yeasts
• HIV is treated with specific anti-viral therapy
• There is no cure for HIV/AIDS, but anti-viral therapy, can keep the virus from multiplying and has turned HIV/AIDS into a chronic disease
• HIV can be transmitted by;
  - contaminated blood or blood products from mother to child (during pregnancy or breastfeeding)
  - sexual intercourse
• While mother to child transmission remains the most common method of transmission to children, unsafe sexual intercourse is now the most common method of adolescent-onset and adult HIV transmission
Our Glen site: ready to open its doors in summer 2015!

A The Glen site sits on 43 acres of land and is a 2.4 million square foot facility. It is located at the nexus of three neighbourhoods: Notre-Dame-de-Grace, Sud-Ouest and Westmount.

B View of the Cancer Centre under construction. The Cancer Centre at the Glen site will consolidate all MUHC ambulatory cancer care. This will encourage interdisciplinary care and exchanges between colleagues, allowing our professionals to treat the disease and guide patients through the healing process.

C Students, professionals, patients and visitors will have access to two health information resource libraries: one will be located in the Adult Hospital (The Royal Victoria Hospital and the Montreal Chest Institute) the other in The Montreal Children’s Hospital. Both libraries will be welcoming spaces filled with natural light where people can work or do research. A special section at the back of the library in the Adult Resource Centre will be reserved for residents and doctors and it will be equipped with workstations and Wi-Fi.
**Fundraising Flash**

**Recent Results:**

$61,290 – Macquarie Private Wealth Softball Tournament: What happens when a former Montreal Chest Institute (MCI) patient is up to bat with his physician pitching on the mound? Some friendly competition and lots of laughs at the first annual Macquarie Private Wealth Softball Tournament. Funds raised went to the MCI Foundation, with every donation being matched by the Macquarie Private Wealth Foundation. A special thank you to Positano and Sodexo, the event’s generous sponsors.

$45,000 – Cedars Festival of Fine Wine and Food: Some of Burgundy’s finest wines were sampled at the Cedars Cancer Institute’s Festival of Divine Wine and Food on November 1, which raised more than $45,000 to support sarcoma cancer care, research and education at the MUHC.

**Coming Soon:**

**Wednesday, December 5:** The Annual Cedars Raffle and Abracadabra Auction – This event has become a tradition for thousands of supporters who look forward to the pre-holiday event for their chance to win over $80,000 in cash and prizes. Proceeds will go towards the acquisition of a state-of-art PET-CT scanner for the new Cancer Centre at the Glen site. Location: Le Windsor (1170 rue Peel). Time: 6 p.m. Tickets: $125. Contact: 514-934-1934, 71230 or cedars.ca/events

---

**D** The Glen site will house two Emergency Departments, one for adults and one for children; the two departments will share one main sheltered entrance that will protect patients and their loved ones from the elements.

**E** An intuitive design and bright, welcoming spaces create a better patient experience.

**F** Installing the coloured glass that will enliven the Glen site hospital.

**G** The 1,700 workers currently on site are installing plumbing and electrical systems, as well as medical gas piping.

*Please note that all renderings are works in progress*
Live well with COPD

WEB-BASED SELF-MANAGEMENT PROGRAM EQUIPS PATIENTS TO TAKE CHARGE OF THEIR LUNG HEALTH AND IMPROVE THEIR QUALITY OF LIFE.

By Margo Vizbara

Henri Tremblay has lived with COPD for over two decades. But it wasn’t until 12 years ago that he reached a critical point where he had to be hospitalized and treated at The Montreal Chest Institute (MCI) of the McGill University Health Centre (MUHC). That was the beginning of the journey he has taken to learn how to manage and live well with his disease.

COPD (Chronic Obstructive Pulmonary Disease)—which encompasses the better-known conditions emphysema and chronic bronchitis—is the fourth leading cause of death in Canada and is expected to eventually rise to third place. It affects some 750,000 Canadians, and many more may unknowingly have it, according to the Canadian Lung Association.

“It’s a progressive disease,” says Tremblay. “It creeps up on you without really noticing too much at first and eventually it becomes debilitating.”

Tremblay’s rehabilitation included access to a then relatively new educational program called Living Well with COPD, which arms patients and healthcare professionals with myriad tools to achieve self-management of the disease. While COPD is incurable, it can be controlled substantially through changing behaviour, including quitting smoking (the main cause of COPD), taking medication properly, exercising regularly and learning breathing techniques.

Developed at the MCI, the program was rolled out in 1998 in response to a lack of structured services and tools for COPD patients—COPD exacerbations (when symptoms flare up) represent the number one cause of hospitalizations. In 2006, the Web site www.livingwellwithcopd.com was launched in an effort to provide worldwide accessibility to the program’s tools.

The goal of this comprehensive self-management program is to create a personalized action plan to coping with the illness on a day-to-day basis, all under a healthcare team’s guidance. The program focuses on strategies to manage symptoms (breathing difficulties, excessive phlegm and frequent or lingering colds) by adopting and maintaining new healthy behaviours.

“We’re seeing fewer visits to the physician, a reduction of about 40 per cent in hospital admissions and emergency room visits—and an improvement in the quality of life of these patients,” says Dr. Jean Bourbeau, director of the COPD and Pulmonary Rehabilitation Program at the Montreal Chest Institute of the MUHC. “Even with advanced disease, people can avoid a hospitalization through a phone call with their case manager. It’s very powerful.”

Today, Living Well with COPD is the standard COPD self-management program across Quebec, and is used throughout Canada. The program has been adapted to other countries, building on its international reputation. A new and improved Web site will be launched this month at the inaugural Congrès québécois de recherche en santé respiratoire taking place November 21-22. Additions include a public section with background on the disease and the program, learning videos and educational tools. The new Web site also features an interactive section for patients and health professionals (access code required) and access to the international adaptations of the program.

Meanwhile, Tremblay says he has been able to manage his illness. He can read his symptoms well, using medication and adapting his lifestyle as needed. For example, he had to give up skiing three years ago, but replaced it with other exercises.

“The program provides you with sufficient ability to make your own diagnosis and gives you autonomy. Before that, I had to reach for medical help whenever I had problems. It was not a proactive stance,” Tremblay says. “The framework of the program is an absolute blessing toward knowing what to do and organizing your management of that situation.”

To learn more about Living Well with COPD, visit www.livingwellwithcopd.com