Le **Comité des usagers** du Centre universitaire de santé McGill

The McGill University Health Centre **Patients' Committee**

ANNUAL REPORT 2015-2016



MUHC SITES:

Lachine Hospital - LH
Montreal Children's Hospital - MCH (Glen)
Montreal General Hospital - MGH
Montreal Neurological Institute and Hospital - MNI and MNH
Royal Victoria Hospital - RVH (Glen)
Cedars Cancer Centre (Glen)
Montreal Chest Institute – MCI

SUBCOMMITTEES:

Cancer Care Mission Patients' Committee - CCM
Communications
Lachine/Camille-Lefebvre Pavilion (in-patients) Patients' Committee
Montreal Children's Hospital Family Advisory Forum - FAF
Montreal General Hospital Patients' Committee
Montreal Neurological Institute and Hospital Patients' Committee
Montreal Chest Institute Patients' Committee
Glen-Royal Victoria Hospital Patients' Committee
Medical Mission Patients' Committee

ELECTED MEMBERS: MUHC PATIENTS' COMMITTEE					
MEMBER'S NAME	SITE / MISSION	REPRESENTATION	FUNCTION		
Mario Di Carlo	MNH	Patients	Co-chair		
Amy Ma	MCH	Patients	Co-chair		
Lisa Rosati	RVH	Patients	Secretary		
Douglas Burns	(Non-elected member)	Patients	Appointed Treasurer		
Pierre Hurteau	ССМ	Patients	Patient rep on MUHC Board		
Constance Goral	RVH	Patients	Member		
Eva Zietkiewicz	RVH	Patients	Member		
Paul Horowitz	MGH	Patients	Member		
Tom McCutcheon	MGH	Patients	Member		
Evelyn Seligman	MGH	Patients	Member		
Raymonde Deslauriers	Camille-Lefebvre	Inpatients	Member		
Pierrette Leroux	Lachine	Patients	Member		
Seeta Ramdass	MCH	Patients	Member		
Tomy-Richard Leboeuf- McGregor	MCI	Patients	Member		
Inactive	Geriatric Mission	Patients			
Inactive	Medical Mission	Patients			

NON-ELECTED MUHC STAFF			
Siobhan Ua'Siaghail (replacing Johanne Chryk)	Administrative Assistant		
Marie-Josée Stonely	Assistant to the Director, Clinical Operations		
Lynne Casgrain	Ombudsman		

THE EXECUTIVE COMMITTEE
Mario Di Carlo, Co-Chair
Amy Ma, Co-Chair
Lisa Rosati, Secretary
Douglas Burns, Appointed Treasurer
Pierre Hurteau, MUHC Board Patient Representative

REPRESENTATION ON THE MUHC BOARD OF DIRECTORS

Pierre Hurteau (re-elected September 2015)

CHAIRS' MESSAGE

The past twelve months have been a whirlwind of change and challenges. Spring 2015 was marked by the historic move of the Royal Victoria Hospital, the Montreal Children's Hospital and the Montreal Chest Hospital to the Glen site. Members of the various site committees were active prior to the move, whether by assisting staff in walk-throughs during activation to address deficiencies or by participating in town hall orientations. Members also volunteered on the day of the actual move, bearing witness to the start of a new era in Montreal.

Once the moves were completed, we successfully campaigned for having STM busses accessible to wheelchairs at the door of the Glen. Currently, Vendome metro station is not able to accommodate people with reduced mobility and is difficult for parents using strollers to navigate.

Parking topped the list of complaints once the new Glen site opened. Specifically, the MUHC had the most expensive hospital parking rates in the province. We confronted the parking issue by first filing a complaint with our own Ombudsman and the Ombudsman's answer left us with no other option than to escalate our complaint to the *Protecteur du citoyen*. By November, the *Protecteur du citoyen* released a 19-page report that helped bring about improvements.

Among the initiatives: 1) the MUHC collaborated with the Patients Committee and invited one of our members to join the newly-struck parking committee; 2) booklets of 7 parking passes; and 3) preferential rates to patients and families according to length of stay and not tied to a specific diagnosis. Despite these successes, nothing prevents the MUHC from increasing its rates in the future. The Patients Committee promises to keep a watchful eye on this.

Defending patient rights at the intersection of government budget compressions and a healthcare reform is trying at the best of times. We used the media extensively for public awareness on issues such as: a lack of accessible transport to the Glen, the relocation of dialysis patients to Lachine and excessive parking fees. Many conversations were also held with patients, families and clinicians to get a comprehensive view of where our frail and sick were most vulnerable, be it for cancer surgery wait times or the axing of beds in the short-stay unit. Several clinicians themselves publicly expressed concerns over budget cuts made to their departments and their effect on patient care.

Patient Committee elections, which are held every three years, took place in Spring 2016. We revised existing bylaws to reflect the new reality of the Glen site and to allow room for future growth (i.e. the emergence of new mission-based sub-committees such as the one for the Medical Mission).

Our two main goals for 2016-17:

- A successful adaptation/transition to the anticipated change in leadership with a new executive director to take helm of the MUHC in Fall 2016. Our top priority is to have a strong, healthy collaboration with this new leader, given the existing challenges of restructuring the healthcare network and budget cuts.
- Assert ourselves as a key player in helping the MUHC become a leader in consolidating the new Patient Engagement initiative.

CALENDAR OF MEETINGS

FREQUENCY: Monthly, 10 times / year

DURATION: 3 hours

IN-CAMERA: April 2015, (part of) June 2015, (part of) November 2015 (AGM), January 2016,

and (part of) February 2016.

Office RVH A1.08 move to D. 04. 7514 at the Glen - April 8, 2015. Siobhan Ua'Siaghail, the Administrative Assistant replacing Johanne Chryk (sick leave), began working on April 27, 2015.

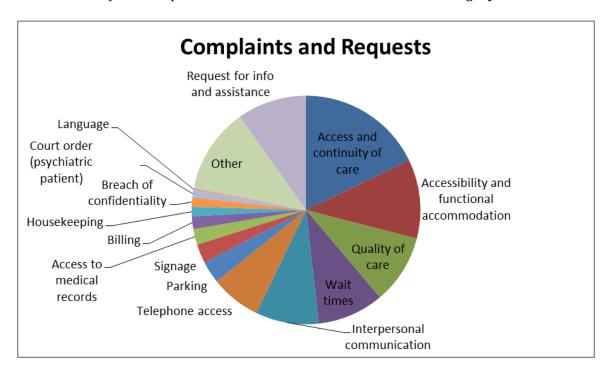
COMPLAINTS AND REQUESTS FOR ASSISTANCE

In order of frequency

Access and continuity of care:	
Accessibility and functional accommodation:	25
Quality of care:	22
Wait times:	21
Interpersonal communication:	20
Telephone access:	16
Parking:	7
Signage:	6
Access to medical records	5
Billing:	4
Housekeeping:	3
Breach of privacy/confidentiality:	3
Court order (psychiatric patient):	2
Language:	1
Other:	27
Request for assistance:	22

TOTAL: 224*

^{*}Note: Some of the complaints received involved more than one category.



ONGOING CONCERNS

- Parking fees
- Telephone access
- Test centres: wait times and delays in obtaining results
- Surgical oncology wait times
- MUHC's divestment of patients from its ambulatory clinics to other ambulatory clinics
- Status of transfer of STM Transport adapté to underground S1 level at the Glen
- Lack of accessibility at the Glen (services, ATM machines, public telephones, etc.)
- Neonatal ICU Nursing shortage
- MUHC roll-out and enforcement of the no-smoking policy
- MUHC plans for the MGH redevelopment
- Status of dialysis patients (MGH vs. Lachine Hospital)
- Operating rooms available for patients at the MGH and the Glen
- Lachine Hospital redevelopment project
- The private paediatric clinic at 5100 de Maisonneuve
- Regular Glen ER 'code purple' (over 100% saturation)
- Bills 10 and 20 (extra fees)
- Physical accessibility at the Glen
- Wait times to access documents requested from Archives
- Financing two Administrative Assistant salaries (due to sick leave) on the Patients'
 Committee annual budget
- The need to respect the MUHC Clinical Care Plan of 2007, given the challenges for patients in 2016
- Patient flow at the MCH due to technology dependency and lack of proper facilities in the community
- Impact of the imposed MUHC funding at an 85% occupancy rate is having on patient care and services
- The impact on patients continuing to need primary and secondary level services and the availability of corridors of services in the community, now that the MUHC is a designated tertiary and quaternary care centre
- Decisions being imposed by the MSSS without consultation with patients.

ACTIVITIES

April 2015: Hiring of part-time Administrative Assistant Siobhan Ua'Siaghail.

May 2015: Revision of expenditure guidelines and financial record-keeping of the Patients' Committee and its site and mission subcommittees by Douglas Burns.

June 2015: MUHC Glen Site parking issue. Due to the many complaints made by the public to the media, the Patients' Committee, the Ombudsman, the Administration, etc. regarding the exorbitant parking rates, the process of rectifying the situation was undertaken. Spearheaded by Pierre Hurteau, a formal complaint was sent to the MUHC Ombudsman, and then forwarded to the Quebec Ombudsman, *le Protecteur du citoyen*, in September 2015.

October 2016: Response from *le Protecteur du citoyen*: A 19-page report in favour of patients' concerns was sent with recommendations for the MUHC to respond to by November 30th.

September 22- October 2, 2015: Patients' Awareness Week.

Theme: Consenting to or refusing care: Your right! MCH Nurse Ethicist Dr. Franco Carnevale and Marie Serdyndska of the MCH Socio-Cultural and Interpretation Services (SCIS) presented on September 30. *Topic: What is informed consent?*

Annual voting to elect the MUHC Patients' Committee Executive (April 2015 – March 2016)

Result:

Co-Chair: Amy Ma

Co-Chair: Mario Di Carlo **Secretary:** Lisa Rosati **Treasurer:** Douglas Burns

Dialysis relocation issue: With the closure of the RVH in April 2015, a new dialysis facility needed to be established. Evelyn Seligman has been involved with the Outpatient Dialysis Committee in: (a) surveying patients to assess their needs, (b) liaising with MUHC administration and nephrologists to plan for a dialysis satellite unit, and (e) overseeing the creation of a new site. Several workgroups were involved in finalizing a decision. <u>Outcome</u>: The RVH dialysis unit would stay open until the new satellite unit was ready at the Lachine Hospital. The relocation of dialysis patients to Lachine was yet another chapter in government decisions that were made without consulting patients. The Committee requested that the location of a patient's residence be considered along with the medical criteria in determining where they would receive treatment.

November 16, 2015: Public Annual General Meeting. The Annual Report 2014-2015 was presented by Mario Di Carlo and Amy Ma. Individual site and mission subcommittee reports

were also presented. Douglas Burns presented the Financial Report. A question period followed.

January 2016 – to present: Functional accommodation and accessibility issues at the Glen. Project spearheaded by Lisa Rosati and Emanuel Kolyvas. A document with pictures illustrating the lack of proper accessibility was sent to the Administration. This project will be monitored by the Glen-RVH Patients' Committee in collaboration with the MUHC.

December 2015: Meetings were held to discuss the creation of a Medical Mission Patients' Committee and Medical Mission staff requested a patient representative on their Quality Committee and Nursing Committee.

December 2015 - January 2016: Q+ Challenge Patient Safety projects. Richard Bertozzi was the patient representative on this steering committee that awarded a staff project \$150,000 targeting the improvement of patient safety.

December 2015 – March 2016: Posters and roll-ups informing the public of our role as patient advocates were designed and then ordered to be put up at every site.

November 2015 - March 2016: Several meetings were held with members of the Patients' Committee of the *Centre hospitalier de l'Université de Montréal* (CHUM) regarding parking fees.

January 2016 - March 2016: Several meetings were held with members of other patients' committees within the Montreal area (*Réseau d'échanges des Comités des usagers du Québec* - RECUQ) to discuss their concerns regarding the lack of proper representation by the *Regroupement provincial des Comités des usagers* (RPCU). The members of the Patients' Committee unanimously resolved that the RPCU be informed of their disaffiliation from the organization.

March 2016: Meeting with Dr. Gerald Fried - Executive members met to discuss the current MUHC bed closures and the additional 'seasonal' cuts that will take place in the summer and their impact on patient care.

CORRESPONDANCE

March 23, 2016: Letter to Claude Ménard, Chair of the *Regroupement provincial des Comités des Usagers* (RPCU) The MUHC Patients' Committee described its long-standing problematic relationship with the RPCU and its concerns that they have not been supportive of patient committee interests (e.g. parking situation).

MOTIONS / DIRECTIVES

Motion (April 13, 2015): That a Special Meeting be convened with any interested site members to discuss Patient Engagement at the MUHC.

Motion (May 13, 2015): To suggest to the MUHC Administration that -- in keeping with the spirit of patient engagement, transparency and accessibility —the offices of the Patients' Committee and that of the Ombudsman be easily found by patients and in proximity to the main entrance.

Motion (September 21, 2015): That the revised Statement of Confidentiality be approved as presented.

Motion (October 26, 2015): That a letter be addressed to Normand Rinfret about the numerous complaints received from patients regarding lengthy wait times in blood test centres.

Motion (February 23, 2016): That bylaws be amended to state that Lachine Hospital be allowed only one representative and one representative for the Camille Lefebvre pavilion.

Motion (March 14, 2016): Be it resolved that the MUHC Patients' Committee disaffiliate from the RPCU.

CONFERENCES / EVENTS

Some members attended one or more of the following:

April 22, 2015: Amy Ma: St Mary's Hospital and McGill University Lectures ('Enhancing patient-centered care'). Panel discussion.

April 29, 2015: MGH Livingston Hall: Emerging Health Care Leaders. Mario Di Carlo gave a presentation ('Engaging Patients as Partners in Health Care').

May 31-June 1, 2015: Conseil pour la protection des malades (CPM) symposium: Philippe Ouaknine and Pierre Hurteau presented. ('Le Comité des usagers du CUSM en action. La dialyse, un cas d'espèce.')

March 30 to April 2, 2015: Patient Engagement Training session in Memphis - Amy Ma and Emmanuelle Simony attended this 2-day informative training session.

June 5, 2015: MUHC Communications strategy planning meeting. Douglas Burns and Lisa Rosati were active participants at this team meeting to plan Communications strategy for the next 3 years, led by the Director of MUHC Communications and Public Affairs.

June 17, 2015: Special MUHC Patients' Committee meeting at the Glen to discuss Patient Engagement.

June 20, 2015: MUHC Walk for Montreal – Mayor Coderre led a walk from Dawson CEGEP to the Glen Site (3km) to mark the official grand opening of the Glen. A Patients' Committee banner was created. Several members participated.

October 21-24, 2015: International Society of Quality of Life Research (ISOQOL) conference in Vancouver, where more than 500 scientists from around the world were in attendance. Theme: The Matrix: Quality of Life in Social Context. Mario Di Carlo represented patients and spoke on patient engagement in the context of research.

Oct 29-30, 2015: Institute for Strategic Analysis and Innovation (ISAI) conference. Theme: Partnering with Patients to Improve Care: Essential Skills and Strategies. Speakers included Mario Di Carlo, Emmanuelle Simony and Brenda MacGibbon.

GUEST SPEAKERS

April 2015 - March 2016:

Regular reports from Lynne Casgrain, MUHC Ombudsman, on the status of complaints made by patients and their families.

Regular reports from Marie-Josée Stonely, Administrative Liaison.

May 13, 2015: Anne Lynch, Director of Clinical Operations.

November 16, 2015, AGM: A 35-minute video published by the *Conseil pour la protection des malades* was presented: '*La Contestation de Claude Brunet*', about Claude Brunet, the pioneer of patient advocacy in Quebec.

December 14, 2015: Dr. Eugene Bereza, Director, Centre for Applied Ethics (CAE) gave a PowerPoint presentation on the legislated Bill 52, the Act respecting end-of-life care.

March 14, 2016: Ann Lynch, MUHC Director of Clinical Operations (by teleconference).

PARTICIPATION ON MUHC COMMITTEES

- MUHC Board of Directors Vigilance Subcommittee
- MUHC Board of Directors Communications Subcommittee
- MUHC Council of Nurses: Quality and Nursing Executive (combined) Committee
- Committee on Quality and Risk (COQAR)
- Ambulatory Care Steering Committee
- Nephrology Quality Assurance Committee
- Dialysis Transition Planning Steering Committee
- Dialysis Transition Satellite, Repatriation, and Modus Operandi work groups
- Patient Education Committee (PEC)
- Planning Committee: Institute for Strategic Analysis and Innovation (ISAI) conference
- My Toolbox: leadership /participation Self-Management workshops for patients living with chronic conditions
- Communications Subcommittee: MUHC Patients' Committee
- Patient Engagement Steering Committee
- MCI-Camille Lefebvre Transition Committee
- All respective site Patients' Committees and Mission Committees
- MUHC Dialysis and Organ Transplant Fund (DialyTran)
- Sociocultural Interpretation Services (SCIS) Committee based at the MCH
- MUHC Parking Services Committee

PARTICIPATION ON COMMITTEES EXTERNAL TO THE MUHC

- Coalition montréalaise des comités des usagers (CMCU)
- Conseil pour la protection des malades (CPM)
- Regroupement provincial comité des usagers (RPCU) and the Anglophone Network
- Strategy for Patient-Oriented Research (SPOR) (Canadian Institutes of Health Research)
- Réseau d'échanges des Comités des Usagers du Québec (RÉCUQ)

MEDIA / PUBLICATIONS

April 20, 2015: CTV News. Douglas Burns interviewed about Vendome accessibility.

April 2015: CBC Radio Daybreak. Claudette Woodgate and Douglas Burns interviewed regarding access to pediatric care and Vendôme accessibility, respectively.

April 25, 2015: The Montreal Gazette. Philippe Ouaknine interviewed. Article entitled *Kidney patients worry about treatment under MUHC reorganization*.

April 27, 2015: Press release written by Lisa Rosati on behalf of the MUHC Patients' Committee was sent out to a list of journalists: It congratulated the MUHC for a safe and successful move of patients from the Royal Vic to the new Glen Site.

May 20, 2015: The Suburban: Letter to the editor by Lisa Rosati in response to article entitled 'Perez wants Quebec to cut hospital parking rates' (May 13, 2015).

May 29, 2015: The Montreal Gazette: Douglas Burns interviewed. Article entitled: *New MUHC:* easy to see, hard to access. http://montrealgazette.com/news/local-news/new-muhc-easy-to-see-hard-to-access

June 4, 2015: Journal Métro: Mario Di Carlo interviewed on telephone call wait times.

September 8, 2015: The Montreal Gazette. Pierre Hurteau interviewed. *MUHC Committee complains to Quebec ombudsman about parking rates*. http://montrealgazette.com/news/local-news/muhc-hospital-set-to-examine-parking-rates

September 8, 2015: La Presse : Pierre Hurteau interviewed. *Les patients du CUSM portent plainte au protecteur du citoyen*. http://www.lapresse.ca/actualites/sante/201509/08/01-4898481-frais-de-stationnement-les-patients-du-cusm-portent-plainte-au-protecteur-du-citoyen.php

September 8, 2015: CJAD: Pierre Hurteau interviewed about complaint to the *Protecteur*: https://soundcloud.com/barry-morgan-show/protecteur-du-citoyen-files-complaint-regarding-parking-costs-at-glenn-site-september-8-2015

September 8, 2015: CBC: Pierre Hurteau interviewed by Steve Rukavina about complaint to the *Protecteur du citoyen*.

September 8, 2015: Global TV: Pierre Hurteau interviewed by Gloria Henriques: http://globalnews.ca/news/2209139/muhc-users-committee-takes-high-parking-fees-complaint-to-quebec-ombudsman/

September 10, 2015: CBC Noon: Pierre Hurteau interviewed on call-in show.

September 25, 2015: The Montreal Gazette. Evelyn Seligman interviewed by Aaron Derfel regarding decrease in dialysis services by Aaron Derfel. http://montrealgazette.com/news/local-news/muhc-struggling-with-decrease-in-dialysis-services

October 20, 2015: CBC: Mario Di Carlo interviewed re new express parking fees. http://www.cbc.ca/m/touch/canada/montreal/story/1.3280991

October 29, 2015: The Montreal Gazette: Amy Ma interviewed by Aaron Derfel about private clinic for children next to Montreal Children's Hospital.

http://montrealgazette.com/news/local-news/legal-scholar-raises-questions-about-new-private-clinic-opening-next-to-childrens-hospital

November 4, 2015: La Presse: Mario Di Carlo interviewed about parking rates. http://www.lapresse.ca/actualites/sante/201511/04/01-4917149-le-protecteur-du-citoyen-somme-le-cusm-de-revoir-ses-tarifs-de-stationnement.php

December 10, 2015: CTV: Mario Di Carlo interviewed regarding parking passes/rates. http://montreal.ctvnews.ca/video?binId=1.1810301 (3.40 mark)

December 10, 2015: The Montreal Gazette: Mario Di Carlo interviewed by Aaron Derfel regarding new parking rates for frequent users.

http://montrealgazette.com/news/local-news/muhc-maintains-25-daily-parking-fee-but-lowers-rates-for-frequent-users

December 18, 2015: CTV: Mario Di Carlo interviewed regarding a new Vendome tunnel to be built by 2019. http://montreal.ctvnews.ca/video?clipId=773367

December 18, 2015: The Montreal Gazette: Mario Di Carlo interviewed regarding a new Vendome tunnel to be built by 2019.

http://montrealgazette.com/news/local-news/accessible-tunnel-between-vendome-muhcgets-provincial-funding

December 18, 2015: Journal le Metro: Tomy-Richard Leboeuf-McGregor interviewed about organ transplants. *Don d'organes: les refus augmentent.*

http://journalmetro.com/local/mercier-anjou/actualites/893225/don-dorganes-les-refus-augmentent/#

December 2015 - January 2016: The Montreal Gazette. Letters to the editor by Douglas Burns, Lisa Rosati and Amy Ma (separately) regarding the challenges patients face as a result of Bill 10.

January 22, 2016: Communiqué signed by CHUM and MUHC sent out February 25. http://cuchum.ca/wp-content/uploads/2016/02/2016.02.25 Communiqu%C3%A9CU-CHUM-et-CUSM Fraisdestationnement R%C3%A9action.pdf

February 4, 2016: CBC TV: Mario Di Carlo interviewed on geriatrics acute care issue. http://www.cbc.ca/player/play/2683085808

March 21, 2016: Montreal Gazette: Amy Ma interviewed regarding bed closings. http://montrealgazette.com/news/local-news/bed-closings-at-muhc-much-worse-than-disclosed-document-shows

March 23, 2016: CBC News: Mario Di Carlo interviewed by Loreen Pindera and Leah Hendry. MUHC seasonal bed closures will mean longer waits for surgery, doctor warns. http://www.cbc.ca/news/canada/montreal/muhc-cancer-surgery-seasonal-bed-closures-1.3503156

March 31, 2016

Tarifs de stationnement dans les hôpitaux : Les usagers du CHUM et du CUSM continuent de penser qu'ils paient trop cher

http://cuchum.ca/wp-content/uploads/2016/02/2016.02.25 Communiqu%C3%A9CU-CHUM-et-CUSM Fraisdestationnement R%C3%A9action.pdf

Financial Report

This financial report covers the first fiscal year following the realignment and reorganization resulting in the closing of the Royal Victoria, Montreal Children's and the Montreal Chest Institute facilities, and the opening in April 2016 of the new "super-hospital" at the Glen. The reorganization has necessitated some changes in the structure, responsibilities and scope of the MUHC Patients' Committee.

Due to (i) the uncertainties of the required funding for the Committee and its subcommittees, (ii) different challenges in a totally new environment, and (iii) an unforeseen abnormal charge for Leave of Absence Insurance (explained below), its normal operating expenditures were constrained during the fiscal year.

From the authorized budget allocation of \$82,000, the Committee's <u>normal operating</u> expenditures totalled \$65,163 during the fiscal year, which included:

- i) Salaries, and fees for professional services of \$39,539;
- ii) Costs of local meetings and conferences of \$5,791;
- iii) Conference registrations, travel and accommodation costs of \$9,930;
- iv) Printing, illustrations and graphics of \$7,647;
- v) Postage, telephone and purchased services of \$1,298; and
- vi) Office supplies, subscriptions and sundry of \$958.

In addition, prior to the beginning of the recent fiscal year, the Committee's long-time Administrative Assistant left the Committee on long-term, insured sick leave for an indefinite period. She was replaced beginning in May 2015 by a part-time salaried Administrative

Assistant. The full year's cost of the Leave of Absence Insurance of \$32,252 was charged as a Committee expense.

Thus, the total balance of all costs incurred and charged to the Committee during the year was \$97,415, and after applying a surplus of \$22,465 carried forward from prior fiscal years, the balance of the Committee's expenses for the fiscal year 2015-16 was \$74,950. After crediting the budget allowance of \$82,000, the Committee's account balance was a credit of \$(7,050) which may be carried forward to the 2016-17 fiscal year.

For the Committee's 2016-17 fiscal year, the Committee may be relieved by the MUHC of some of the continuing Leave of Absence Insurance costs.

With a greater concentration of medical activity now at the Glen, a significant realignment of clinical services at the Montreal General, and the transfer of a significant number of the outpatient dialysis patients to Lachine in November 2015, it is expected that the role of the Patients' Committee will be more significant, and close control over budget expenditures will need to be exercised in the new fiscal year.

Submitted by: Lisa Rosati and Siobhan Ua'Siaghail (September 2016)