ANNEX 2

MCGILL UNIVERSITY HEALTH CENTRE
USERS’ / PATIENTS’ COMMITTEE
(MUHC UC)*

2018-2019
ACTIVITY REPORT

*ALSO KNOWN AS THE ‘CUC’ (ACRONYM USED FOR BOTH ‘CENTRAL USERS’ COMMITTEE’ AND ‘COMITÉ DES USAGERS DU CUSM’)*
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>INFORMATION ABOUT THE INSTITUTION</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>MESSAGE FROM THE CO-CHAIRS</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>PRIORITIES AND ACHIEVEMENTS OF THE PAST YEAR</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>THE COMMITTEE AND ITS MEMBERS</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>CONTACT INFORMATION</td>
<td>7</td>
</tr>
<tr>
<td>6</td>
<td>ACTIVITIES OF THE MUHC UC</td>
<td>7</td>
</tr>
<tr>
<td>7</td>
<td>MUHC UC MEETINGS</td>
<td>11</td>
</tr>
<tr>
<td>8</td>
<td>COLLABORATION WITH THE OTHER ACTORS IN COMPLAINT EXAMINATION SYSTEM</td>
<td>12</td>
</tr>
<tr>
<td>9</td>
<td>GOALS ESTABLISHED FOR NEXT YEAR</td>
<td>14</td>
</tr>
<tr>
<td>10</td>
<td>CONCLUSION (ISSUES, RECOMMENDATIONS AND PROJECTS)</td>
<td>14</td>
</tr>
<tr>
<td>11</td>
<td>FINANCIAL REPORT</td>
<td>14</td>
</tr>
<tr>
<td>12</td>
<td>ACTIVITIES OF THE USERS’ AND RESIDENTS’ COMMITTEE OF LACHINE HOSPITAL &amp; CAMILLE-LEFEBVRE PAVILION</td>
<td>14</td>
</tr>
</tbody>
</table>
1. INFORMATION ABOUT THE INSTITUTION

The McGill University Health Centre (MUHC) is a non-merged institution.

The MUHC is comprised of the:

- Lachine Hospital and Camille Lefebvre Pavilion - Lachine
- Montreal General Hospital - MGH
- Montreal Neurological Institute and Hospital - Neuro

Glen Site:

- Cedars Cancer Centre - CCC
- McGill Academic Eye Centre – MAEC
- Montreal Chest Institute - MCI
- Montreal Children’s Hospital - MCH
- Research Institute – RI
- Royal Victoria Hospital - RVH

2. MESSAGE FROM THE CO-CHAIRS

The McGill University Health Centre Users’ Committee (MUHC UC) has again been pro-active this year in our mandate to advocate in patients' best interests and to monitor the quality of health care at this designated bilingual institution.

We recognize the uniqueness of our socio-culturally diverse and marginalized patient population, and advocate passionately for their inclusion to ensure that their care is therapeutic and respectful of their cultural needs and dignity.

A new hospital CEO was appointed in spring 2018, and the new leadership was unable to meet our request to save the Patient Education Office, the My Toolbox Chronic Disease Self-Management Program, and the Cancer Survivorship Program.

In anticipation of provincial elections that were held last fall, the MUHC UC, in collaboration with our colleagues at the CHUM UC, organized an information session with the health ministry candidates from various political parties to have a clearer idea of their respective healthcare visions.

We continue to monitor the lack of effective security measures at the Montreal General Hospital, a Level 1 trauma centre, which often treats victims of gang violence and experiences violent disturbances by psychiatric patients and visitors.

The Family Advisory Forum (FAF) of the Montreal Children’s Hospital (MCH) played a strategic role during the derogation processes related to Law 130, and we added our efforts and support to help preserve the MCH’s departments of Paediatric Surgery and Psychiatry.

The CUC was invited to be a part of a working group to address access to services in English at the MUHC. The staff member heading this group has since expanded her mandate to include the wider issue of accessibility for those with a disability, and the CUC continues to collaborate with her on this working group.

A highlight of this past year was the inclusion of four adults with a physical disability in the citywide Code Orange simulation. The MCH was one of two sites accepting mock patients for the Code Orange simulation. We had a patient...
who uses an electric wheelchair, a patient with a visual impairment who uses a white cane, and a Deaf couple who rely on American Sign Language (ASL) for communication to pose as parents of injured children in the simulation exercise. All staff found their inclusion to be a valuable learning experience, and our four volunteers were proud to pave the way to improving emergency measures for people with a disability at the hospital.

We fielded many complaints and requests for assistance, with patients and families having difficulty reaching specialists through the central call centre. Notably, there was a surge in complaints over poor communication and billing. Siobhan Ua'Siaghail, our administrative assistant, worked tirelessly to make sure patients and families were able to get the help they needed.

Our Committee was able to make financial contributions in support of a number of worthy projects including improving access to health services for members of the Deaf community. An assessment was made of current accessibility and accommodation policies for the Deaf at the MUHC, with an exploration of the possibility of Remote Video Interpretation, and a final report with recommendations was submitted. As well, a contribution was made to the French section of the McConnell Patient Resource Centre’s Accessibility Collection, a special collection of titles for patients in accessible formats, such as CDs, DVDs and large print books.

We turned to the media in supporting the right of Indigenous children to have a parent or family member accompany them on emergency medical evacuation flights to the MCH for care. We are currently championing the reestablishment of the Wachiya lounge at the MCH for Indigenous families and we continue to pursue the creation of a smudging room.

We organized and participated in numerous community awareness events throughout the year, including the Salon Visez Droit, Patients’ Rights Week, and National Aboriginal Day. Of note, Dr. Lionel Carmant, the new Deputy Health Minister for Youth, accepted our invitation to be a guest speaker for Black Heritage Month at the MCH.

In March 2019, the Centre for Applied Ethics, a division of the Quality Department, asked our committee to provide input on an Ethics Framework Consultation. We felt this meeting was given on too short notice, and that we should have been included in a more long-standing capacity in this initiative.

The CUC elections will be held in May 2019, and we will work diligently to ensure a smooth transition to the new executive team. Regardless of the make-up of the CUC after these elections, we are confident that those gathered around the table will be well equipped to make sure the voices of patients and families are heard during these challenging times.

Amy Ma, Co-Chair
MUHC Users’ Committee

Seeta Ramdass, Co-Chair
MUHC Users’ Committee
3. PRIORITIES AND ACHIEVEMENTS OF THE PAST FISCAL YEAR

Priorities identified:

- Follow-up to the consultation that was held on a new MUHC Ethics Framework
- Accessibility at all MUHC sites
- Installation of a smudging room for Indigenous and Métis spiritual care
- Overcrowding and oversaturation in ERs
- Accessibility issues for mobility-challenged patients
- Long surgery wait-times
- Long clinic wait-times
- Negative impact of MUHC budget cuts on nursing, patient needs, services, and rights
- Vendôme Metro Station accessibility project
- Need for a pharmacy at the Glen Site
- Greater patient participation at public MUHC Board of Directors meetings
- Cancellation of the Cancer Survivorship Program
- Cancellation of the My Toolbox chronic disease and chronic pain self-management patient program
- Cancellation of the Patient Education Office program
- Concerns about security
- Timely replacement of nurses necessary to meet the needs of patients
- Temporary seasonal closures of operating rooms
- Optilab and its impact
- Patient Engagement across all levels of the MUHC
- Delays in access to specialists
- Delays in access to diagnostic testing
- Diversity and inclusion: patients from socio-culturally diverse and marginalized groups to get access to equitable healthcare

Achievements:

- Supported second phase of pilot program to improve healthcare access for the Deaf (Glen-RVH UC initiative)
- Assisted in the development, implementation, and beta-testing of the OPAL app. (CCM UC)
- Increased presence of patients’ voices through various media interviews and public relations efforts
- Completed surveys of in-patients and stroke patients (MNI UC)
- Prepared and distributed hygiene kits to MGH patients (MGH UC)
- Revised the CUC Bylaws and Roles & Responsibilities of members
- Revised the CUC Election Bylaws
- Acquired 5 iPads for sub-committees and 4 laptop computers for the CUC executive to conduct their business
- Developed a formal Complaint Form for factual intake and quality control follow-up (Glen-RVH UC initiative)
- Members attended numerous conferences and shared what they learned with the user committee

4. THE COMMITTEE AND ITS MEMBERS

About the McGill University Health Centre Users’ Committee *
(* Frequently referred to as the ‘CUC’, acronym for both ‘Central Users’ Committee’ and ‘comité des usagers du CUSM’)

The CUC is composed of a socio-culturally diverse group of MUHC patients who are dedicated to helping other patients and to collaborating with the hospital to achieve the highest standards of patient-centered care in a comprehensive academic health institution that has an international reputation for excellence in clinical programs, research and teaching.
The CUC has a maximum of 14 members. Each site and mission-related user subcommittee has two (2) representatives on the CUC, and there are seven (7) site- or mission-related subcommittees in total. The members, unless otherwise indicated, were elected in May 2016 for a term of three (3) years. They will remain in office until the next elections take place in May 2019, unless they resign, are dismissed, re-appointed, re-elected or replaced.

**The site-related subcommittees are:**
- Lachine Hospital and Camille-Lefebvre Pavilion - Lachine UC & Residents’ Committee (RC)
- Montreal General Hospital - MGH UC
- Montreal Neurological Hospital - Neuro UC
- Montreal Children’s Hospital (Glen Site) Family Advisory Forum (FAF) - MCH UC
- Royal Victoria Hospital (Glen Site) - RVH UC

**The mission-related subcommittees are:**
- Cancer Care Mission - CCM UC
- Medical Mission - MM UC

<table>
<thead>
<tr>
<th>No</th>
<th>First Name</th>
<th>Surname</th>
<th>TYPE OF MEMBER</th>
<th>ROLE</th>
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<tbody>
<tr>
<td>1</td>
<td>Amy</td>
<td>Ma</td>
<td>FAF User</td>
<td>Co-Chair - Elected</td>
</tr>
<tr>
<td>2</td>
<td>Seeta</td>
<td>Ramdass</td>
<td>FAF User</td>
<td>Co-Chair - Elected &amp; Board Representative</td>
</tr>
<tr>
<td>3</td>
<td>Hafeez</td>
<td>Subhan</td>
<td>MGH User</td>
<td>Treasurer - Elected</td>
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<tr>
<td>4</td>
<td>*Falk</td>
<td>Kyser</td>
<td>NEURO</td>
<td>Secretary - Elected</td>
</tr>
<tr>
<td>5</td>
<td>Douglas</td>
<td>Burns</td>
<td>RVH User</td>
<td>Member - Appointed</td>
</tr>
<tr>
<td>6</td>
<td>Pierre</td>
<td>Hurteau</td>
<td>CCM User</td>
<td>Member - Elected</td>
</tr>
<tr>
<td>7</td>
<td>*Tomy-Richard</td>
<td>Leboeuf-McGregor</td>
<td>MM User</td>
<td>Member - Elected</td>
</tr>
<tr>
<td>8</td>
<td>Pierrette</td>
<td>Leroux</td>
<td>LACHINE User</td>
<td>Member - Elected</td>
</tr>
<tr>
<td>9</td>
<td>Elizabeth</td>
<td>Markakis</td>
<td>RVH User</td>
<td>Member - Elected</td>
</tr>
<tr>
<td>10</td>
<td>Tom</td>
<td>McCutcheon</td>
<td>MGH User</td>
<td>Member - Elected</td>
</tr>
<tr>
<td>11</td>
<td>*Kevin</td>
<td>McKie</td>
<td>CCM User</td>
<td>Member - Elected</td>
</tr>
<tr>
<td>12</td>
<td>Mari Jo</td>
<td>Pires</td>
<td>NEURO User</td>
<td>Member - Appointed</td>
</tr>
<tr>
<td>13</td>
<td>*Evelyn</td>
<td>Seligman</td>
<td>MM User</td>
<td>Member - Elected</td>
</tr>
<tr>
<td>14</td>
<td>Vacant</td>
<td></td>
<td>Resident</td>
<td>Lachine Camille-Lefebvre Pavilion</td>
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* Falk Kyser - Leave of absence from September 2018 and resigned as CUC Secretary January 2019
  - Replaced by Elizabeth Markakis (Interim CUC Secretary) from September 2018 to February 2019 & from February to May 2019 (Appointed CUC Secretary)
  - Replaced by Nicole Savoie (NEURO representative) from November 2018 to February 2019

* Tomy-Richard Leboeuf-McGregor - Deceased Nov. 2018

* Kevin McKie - Resigned November 2018
  - Replaced by Jeanette Sharma April & May 2018
  - Replaced by Brenda MacGibbon from November 2018 to May 2019

* Evelyn Seligman - Leave of absence from September 2018 to February 2019
  - Replaced by Silvana Di Lollo from November 2018 to February 2019
5. CONTACT INFORMATION

<table>
<thead>
<tr>
<th>FUNCTION</th>
<th>NAME</th>
<th>CONTACT INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Co-Chair</td>
<td>Amy Ma</td>
<td>(514) 934-1934 ext. 31968</td>
</tr>
<tr>
<td>Co-Chair</td>
<td>Seeta Ramdass</td>
<td>(514) 934-1934 ext. 31968</td>
</tr>
<tr>
<td>Person in the institution responsible for the CUC</td>
<td>Patricia Lefebvre</td>
<td>(514) 934-1934 ext. 43943</td>
</tr>
<tr>
<td>Administrative assistant of the CUC</td>
<td>Siobhan Ua’Siaghail</td>
<td>(514) 934-1934 ext. 31968</td>
</tr>
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6. ACTIVITIES OF THE MUHC UC

1. Inform users about their rights and obligations

- Dissemination of the MUHC Users’ Committee pamphlet informing users of their rights and responsibilities - ONGOING
- During Users’ Rights Week, awareness activities were organized by the CUC and its different site and mission sub-committees and included two talks: 1) On Tuesday, September 26, Léa Pelletier-Marcotte, lawyer and coordinator of the Coalition des organismes communautaires québécois de lutte contre le SIDA (COCQ-SIDA), and Stéphane Richard, coordinator of GAP-VIE, spoke in French on the topic of Confidentiality. 2) On Wednesday, September 27, Clinical Ethicist Zita Kuszewski of the CIUSSS Centre Ouest gave a talk in English entitled: How The Healthcare Reforms Have Impacted Patient Rights - September 2018
- Awareness tables were set up at the different sites and during different events – ONGOING
- During the Annual General Meeting, the 2017-2018 Activities Report was presented, site and mission sub-committees presented their reports, modifications to the By-Laws were ratified and a question and answer period followed - November 5, 2018
- Advocate training was given by Benoit Racette of the Conseil pour la protection des malades talk entitled Comment militer au sein d’un comité d’usagers ou de résidents - May 8, 2018
- A meeting to discuss the state of healthcare in Quebec was jointly organized by the CHUM UC and CUC. The speakers were Quebec Solidaire’s Amir Khadir and the Parti Québécois’ Health Critic Diane Lamarre. Representatives from several UCs were in attendance, some coming from as far as Lanaudière – April 30, 2018
- The CUC had a kiosk at the Salon Visez Droit at Complexe Desjardins. It was staffed by various CUC and sub-committee members - April 9-12, 2018
- The RVH UC annual dinner invited speaker was Dr. Arvind Joshi. Members across all sites were invited – June 13, 2018
- Patricia Lefèbvre, Director of Quality, Evaluation, Performance and Ethics, presentation was on Participation des patients / usagers dans la vie organisationelle - June 11, 2018
During the Black Heritage Month event, Coalition Avenir Québec (CAQ) Deputy Health Minister for Youth Dr. Lionel Carmant addressed his own mission and mandate with respect to Health Services as well as the contributions of other people of colour to the health sciences. He also talked about his connection to the MCH, as he did his residency there - March 2019

2. (a) Promote quality improvement of the users’ living conditions

- Accessibility and functional accommodation issues are addressed at the Glen Site during a monthly meeting. This project is spearheaded by the Glen-RVH UC in collaboration with the MUHC - ONGOING
- UC member participation on a Code Orange focus group. People with physical disabilities were invited to share their observations of barriers they faced in hospitals - September 2018
- Neuro UC negotiated actively for solutions regarding the road in front of the MNH’s main entrance, as access was challenging due to roadwork.
- Neuro UC coordinated with the administration to ensure that patients and family were aware of the new family room and healing garden.
- The OPAL project generated a lot interest from both MUHC Senior Management and the Ministry
- Funded the Glen-RVH UC project to render the French collection accessible to a wider public by buying health titles for patients in accessible formats such as audio books, DVDs, and large print books
- Funded the MGH UC project to buy more much-appreciated ‘survival’ kits that are distributed to patients

Participation on Legislated MUHC Committees

- Board of Directors of the MUHC
- Quality and Risk Management (COQAR)
- Vigilance Committee

Participation on Other MUHC Committees

Users’ subcommittees representing the various sites and missions
- Building the future of excellence in academic childcare - Complex Care
- Bureau de la qualité et de l’amélioration de l’Hopital de Montréal pour les Enfants
- Code White Steering Committee
- Communications: video on Patient Engagement
- Council of Nurses (CIICE)
- CSISS Committee (Controlling Specific Infections – Successful strategies
- Infection Control Committee
- MUHC Parking Services Committee
- MCH - Council for Services to Children and Adolescents (CSCA) non-legislated
- MGH Steering Committee (Modernization of the MGH)
- Medical Mission Quality Improvement Committee
- Quality Improvement Table de concertation (committee focused on patient-partnership questions)
- Technology Assessment Unit (TAU)
- Telephone Access Committee
Participation on or Collaboration with other (non-MUHC) committees

- Comité pour l’intégralité psycho-sociale des personnes handicapées
- Concertation Inter-Quartier (CIQ)
- Conseil pour la protection des malades (CPM)
- Comité des Usagers du Centre hospitalier de l’université de Montréal (CU du CHUM)
- McGill Faculty of Medicine Equity Task Force

2. (b) Assess the degree of users’ satisfaction regarding services obtained

- Telephone access survey
- Survey of stroke patients regarding care and discharge (Neuro UC)
- Survey of patients to evaluate accessibility to the MNH (Neuro UC)
- Suggestion boxes placed in various locations that belong to the Cancer Care Mission (CCM UC)
- MGH UC phone line and office hours

3. Defend the collective or individual rights and interests of users

Media activities - Below are links to some of the media interviews in which we participated in the last fiscal year:

- May 25, 2018: CJAD. News item about lack of pharmacy at Glen Site.


January 14, 2019: La Presse. Article by Ariane Lacoursière entitled Infiltration d’eau dans le stationnement du CUSM. Le consortium qui a construit l’hôpital payeral la facture des travaux. [http://plus.lapresse.ca/screens/877003f5-cc3c-4ac6-8f8e-ef95db736f42_7C_0.html](http://plus.lapresse.ca/screens/877003f5-cc3c-4ac6-8f8e-ef95db736f42_7C_0.html)


4. Accompany and assist, on request, a user in any step he/she undertakes including when he/she wishes to file a complaint

The office of the CUC receives requests regularly for assistance or accompaniment from users as well as complaints. When possible, requests for assistance are dealt with immediately. All complaints are forwarded to the office of the Complaints Commissioner / Ombudsman and to the co-presidents or representatives of the various UCs that represent the specific sites and missions.

Members of the MGH UC continue to keep regular office hours (Monday to Thursday, from 10:30 to 12:00). Users are able to call and reach someone or drop in to request assistance.

5. Ensure, as appropriate, the proper functioning of the Residents' Committee and ensure that they have the necessary resources to perform their duties

There are two representatives from the Users'/Residents’ Committee of the Lachine Hospital and Camille-Lefebvre Pavilion (‘Lachine’) that sit on the CUC. They regularly attend the meetings of both the CUC and
Lachine and are in regular communication with both the CUC and Lachine Hospital and Camille-Lefèbvre’s staff and administration. The administrative assistant of the CUC is also at their disposal, when needed. In addition, the Committee receives an allocation.

6. Evaluate, where applicable, the effectiveness of the measure put in place pursuant to the provisions of section 209.0.1 of the "Act respecting health services and social services"

Does not apply

7. Representation / Coordination / Harmonization

Special one-day CUC meeting with subcommittee Co-Chairs to draft amendments to Bylaws and Roles and Responsibilities governing all CUC as well as site- and mission- subcommittee members - March 2018
Carole Dupéré, Commissioner for a Respectful and Non-violent Workplace, was invited to the October CUC meeting to present the MUHC Civility and Respect policy. The policy is based on the Quebec Charter of Human Rights and Freedoms and the Act Respecting Labor Standards - October 2018
A one-day CUC and subcommittee Co-Chair retreat was planned to brainstorm and identify priorities - January 2019

7. MUHC UC MEETINGS

| Frequency: | 10 full meetings, once a month, except for July and August |
| Length:    | 3 hours |
| Annual General Meeting: | November 5, 2018 |
| In Camera: | 3 In Camera (or partially In Camera) meetings |

In addition, approximately 15 CUC executive meetings were held during the course of the year.

8. COLLABORATION WITH THE OTHER ACTORS IN COMPLAINT EXAMINATION SYSTEM

The CUC collaborated with the office of the Complaints Commissioner / Ombudsman by informing patients and their families of their rights, and what to do when they felt their rights were not being respected or their healthcare was being compromised. In addition, the UC assisted patients and their families in lodging formal complaints to the office of the Complaints Commissioner / Ombudsman, when requested.

Most of the CUC’s monthly meetings were attended by an Ombudsman, Associate Ombudsman, or Delegate. The Associate and Delegates also regularly attended the monthly meetings of some of the sub-committees during the year. At these meetings, they presented their reports, and an open discussion would ensue about the trends noted among the complaints and requests for assistance received from users and their families.
COMPLAINTS AND REQUESTS FOR ASSISTANCE RECEIVED BY THE CUC:

Complaint Categories:

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<thead>
<tr>
<th>Category</th>
<th>%</th>
<th>Number</th>
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<tr>
<td>Accessibility</td>
<td>29%</td>
<td>55</td>
</tr>
<tr>
<td>Care and services provided</td>
<td>18%</td>
<td>34</td>
</tr>
<tr>
<td>Interpersonal relationships</td>
<td>16%</td>
<td>30</td>
</tr>
<tr>
<td>Organization and material resources</td>
<td>17%</td>
<td>32</td>
</tr>
<tr>
<td>Financial assistance</td>
<td>9%</td>
<td>17</td>
</tr>
<tr>
<td>Rights</td>
<td>6%</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>9</td>
</tr>
<tr>
<td>TOTAL COMPLAINTS:</td>
<td>100%</td>
<td>188</td>
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1 Of these, 93 were forwarded to the office of the Complaints Commissioner / Ombudsman.
9. GOALS ESTABLISHED FOR NEXT YEAR

Our main goals for 2019-2020:

Our top priorities are to play an active role during the 2020 Accreditation Canada visits, ensure the reinstatement of the Wachiya lounge, follow up on the status of the Cancer Survivorship Program, the My Tool Box program and the Patient Education Office, and increase patient inclusion in hospital activities through working with the Table de Concertation.

We will continue to:

- work in collaboration with the administration and the CEO to improve the quality of care for patients
- monitor the quality of healthcare for patients
- exercise vigilance with regards to policies addressing patient safety and security
- work towards ensuring that culturally safe and sensitive healthcare is provided to all MUHC patients with respect for their sociocultural background
- pay particular attention to ensuring that culturally safe and sensitive healthcare is provided to our most vulnerable and marginalized patients

10. CONCLUSION (ISSUES, RECOMMENDATIONS AND PROJECTS)

Our UCs will continue to be actively involved in events, subcommittees and task forces addressing sensitive patient rights issues such as improved access for patients with limited mobility and medical assistance in dying. We will also continue to advocate for culturally sensitive and equitable healthcare for sociocultural diverse and marginalized communities.

We will also continue to support a number of projects including:

- ongoing development and implementation of OPAL: an app for mobile phones that provides MUHC cancer patients with personalized information about their appointments, test results, medical consults documents, educational material and much more;
- consultation with the Canadian Deafness Research Training Institute (CDRTI) to develop an understanding of the needs of the deaf community in accessing health services

11. FINANCIAL REPORT

See attached: Annex 3A, 3B and 4

12. ACTIVITIES OF THE USERS’ AND RESIDENTS’ COMMITTEE OF THE LACHINE HOSPITAL & CAMILLE-LEFEBVRE PAVILION

- Promotion of the rights of users and residents, viewed documentary about Claude Brunet - September 2018
- Distribution of Emergency kits - items for patients in the Emergency Room - ONGOING
- Raising awareness of the Users’ and Residents’ Committee and its role - by visiting each resident and distributing kits and pamphlet