



ANNUAL ACTIVITY REPORT

2019-2020



MUSCO

**“ AT LAST, WE DON’T FEEL
SO ALONE ANYMORE!
IF YOU WANT TO GO FAST,
GO ALONE. IF YOU WANT
TO GO FAR, GO TOGETHER.**

— REACTION OF ONE OF THE PEOPLE
ATTENDING THE CEREBRAL PALSY EVENT
IN DECEMBER 2019 (PROJECT 20)

TABLE OF CONTENTS

2019–2020 ANNUAL ACTIVITY REPORT

04	<u>Messages from MUSCO'S Partner Foundations and Hospitals</u>
06	<u>Foreword</u>
07	<u>2019–2020 Priorities and Highlights</u>
10	<u>Projects Developed in 2019–2020</u>
36	<u>MUSCO : The Bigger Picture</u>
40	<u>Budget</u>
44	<u>Looking Ahead to 2020–2021</u>
47	<u>Conclusion</u>
48	<u>The Teams Behind the Projects</u>

MESSAGE FROM MUSCO'S PARTNER FOUNDATIONS

This past year has been one of unprecedented upheaval, forcing us to go into lockdown and avoid contact with others in an effort to protect the most vulnerable members of society.

High up on the list of these vulnerable groups are seniors, unquestionably the hardest hit by the pandemic, but the families we work with are also at risk. More than ever, we need to protect them and help meet their needs, not only those directly related to COVID-19, but also the challenges and restrictions that have come with it.

While we all comply with social distancing requirements and keep the number of people in our inner circle to a minimum, it is important to remember that we need to stay strong and take care of one another. COVID-19 remains a disease without a cure and one that has also had, and will continue having, major repercussions on the quality of life of our young patients. It is crucial that we continue to mobilize our resources and focus our energy on getting through this, together.

Thank you to the Mirella & Lino Saputo Foundation for lending their support to initiatives like MUSCO that improve the care and services provided to patients and help build a better future for everyone.



Maud Cohen
President and CEO



David Merrett
Chairman of the Board
of Governors



Renée Vézina
President

**CHU Sainte-Justine
Foundation**

**Shriners Hospitals
for Children – Canada**

**Montreal Children's
Hospital Foundation**

MESSAGE FROM MUSCO'S PARTNER HOSPITALS

Since COVID-19 exploded onto the scene in March, professionals across the entire healthcare system, and in particular in our institutions, have pulled out all the stops to provide the very best care and services to patients in need. Both clinical and administrative staff have shown an impressive amount of resilience and adaptability, constantly adjusting to changes as they arise, and always with the utmost compassion.

Although our efforts throughout the crisis have focused on the most urgent pandemic-related considerations, we remain steadfast in our commitment to improving the services provided to patients and their families and optimizing their living conditions.

During the MUSCO Steering Committee's first meeting in April, we decided, together, to take advantage of the opportunities arising from the current circumstances to develop new collaborative tools and seek out solutions to the issues facing our community.



Caroline Barbir
President and CEO



Jacques Boissonneault
Hospital Administrator



Dr Pierre Gfeller
President and Executive
Director

CHU Sainte-Justine /
Marie Enfant
Rehabilitation Centre

**Shriners Hospitals
for Children – Canada**

**McGill University
Health Centre**

FOREWORD

AN ACTIVITY - AND COLLABORATION - FILLED YEAR LEADING UP TO THE PANDEMIC

Although the first half of the Initiative's fiscal year was fairly routine, the second half saw the whole of society upended by the COVID-19 pandemic. Families and patients who are already strained and dealing with one challenge after another were dealt a particularly hard blow with this virus, which further complicated their lives and forced them to adjust to the realities of lockdown. Many of them had to make the tough choice of giving up respite services to avoid coming into contact with the virus, making it difficult to address these critical needs.

In terms of medical staff, the nurses, doctors, administrators, rehabilitation professionals and others who are usually the driving force behind MUSCO's projects were needed on the front lines to protect patient health. They showed tremendous dedication to facing this unprecedented situation, which continues to dominate many of these resources still today. As a result, the Initiative's projects did not move forward at the same pace, given the shortage of key people at the discussion table. Similarly, the lack of field presence resulted in some serious communication issues, with some information inevitably getting lost along the way.

We were reminded that the focus of the MUSCO Initiative is improvement, not emergency response. And we recognized that our member institutions all have their own protocols and procedures in place to enhance safety.

Each institution dealt with this major crisis through internal measures in line with their specific realities.

Although things did not advance as quickly as we would have hoped during the second half of the fiscal year, progress was nevertheless made on the content of various joint projects, and adjustments were made to work around the corresponding limitations. Some of our projects, like Project 7 focusing on patient continuum of care, were reconceptualized, and others substantially reworked, as was the case for Project 16 concerning workshops for onboarding Patient Resources in the Initiative's projects.



Cerebral Palsy Event
Photo: Benoit Desjardins

2019–2020 PRIORITIES AND HIGHLIGHTS¹

GOVERNANCE STRUCTURE NOW SOLIDLY IN PLACE



Linda Moreau, Advisory Pole
Patient Expert
Photo: Ashley MacPhee
Photography

Although the governance structure was mapped out in MUSCO's first year, there were still two bodies to formally set up: the Steering Committee and the Advisory Pole.

The **Steering Committee** is made up of the directors and administrators of our partner institutions and foundations. Its purpose is to monitor the progress and outcomes achieved by the Initiative as well as the impacts on the various departments and teams in place and to formalize decisions and collaborative efforts made at the inter-institutional level. The Steering Committee also discusses political issues related to the efforts undertaken as part of the Initiative and liaises with government representatives if required.

The **Advisory Pole** plays a central role in MUSCO's governance as the body that actively seeks out patients' and families' contributions to the thought process and actions undertaken by the Initiative. The Patient Experts on the Advisory Pole act as "gurus" of sorts, serving in a guidance and brainstorming capacity and ensuring that the quality of the user experience and the involvement of children and their families remain the core focus of MUSCO's actions and innovations.

The Steering Committee and the Advisory Pole both met virtually for the first time on April 24 and May 4, respectively, while lockdown measures were in force. The Steering Committee members emphasized their desire to work as a team, especially amid the pandemic, to explore alternative means of collaboration. Members of the Advisory Pole expressed a strong sense of motivation about getting involved in the process.



120

Contributors to the various working groups



7

Patient Experts recruited to advise on the Initiative's projects



19

Projects advanced during the year



4 Executive Committee meetings

2 Advisory Pole meetings

3 Full Committee meetings

1 Steering Committee meeting

The meeting frequency for the other committees was adjusted. Full Committee meetings were reduced to three times a year in step with the pace of project advancement. The governance structure is now fully operational.

FAMILY AND PATIENT VOICES AT THE HEART OF THE INITIATIVE

With the Advisory Pole as the backbone of the governance structure, the voices of Patient Experts have been put front and center of all discussions, thereby ensuring that the projects undertaken would meet families' needs. **Patient Experts** were approached in a way that helped achieve a certain representativeness in terms of diagnosis, patient journey, socioprofessional category, and involvement of parents (fathers as well as mothers) and the patients themselves.

Not only was the Advisory Pole set up with its own set of operating rules, but efforts were also initiated to recruit Patient Resources.

Unlike Patient Experts, who have a holistic and strategic view of the Initiative and take a “big picture” approach to evaluating projects, **Patient Resources** contribute in an operational way to working groups, bringing a perspective based on their own experience to the table.

Recruiting efforts will be intensified in Year 3 and will be ongoing throughout the Initiative's lifespan.

During the pandemic, in order to make the various discussions as interactive as possible, an **onboarding workshop for patients and families** recruited to join a working group was developed in collaboration with the Planetree consulting firm. The idea was to make it easier for everyone to voice their opinions and to promote partnership and collaboration between patients, families and healthcare professionals within a working group. The content for these workshops is ready to be used, but the onboarding sessions themselves were delayed because of the pandemic. They will therefore be carried over to Year 3.

Lastly, the projects developed during Year 2 have reinforced the importance of ensuring that the concerns of families guide all of our interactions, as was seen during the "Cerebral Palsy: Let's Talk About It!" event in December 2019. The event featured a series of round-table discussions for families and patients and a program that included video testimonials touching on the issues and challenges they face.

EMERGING PARTNERSHIPS AND GOVERNMENT RECOGNITION

Projects like the Cerebral Palsy Event speak volumes about the importance of collaboration for the Initiative. The event was developed through the joint effort of physicians, rehabilitation professionals, administrators, community organizations, patients and patients' families. They all came together for a day to engage in a conversation about medical and social considerations that matter most to families.

This project is symbolic of what MUSCO aims to do : **bring experts together to meet families' needs.**

Another collaboration-centric project came into being with the signature of an agreement by 15 Canadian pediatric centres, spearheaded by the Mirella & Lino Saputo Foundation Chair in Pediatric Surgical Education and Patient and Family-Centered Care. Thus was formed the Canadian Consortium for Research in Pediatric Surgery, the culmination of months of talks between various professionals. A number of national projects will now be possible thanks to these facilitated discussions. This project will help **bring various centres together from around the country to continuously improve practices** in this area.

In addition, various channels of collaboration have been explored to get major projects off the ground. The genome sequencing work being done at the Shriners Hospitals for Children – Canada to advance knowledge of bone diseases led to further discussions with CHU Sainte-Justine, where the first Integrated Centre for Pediatric Clinical Genomics was launched in July 2019. As a result of this dialogue, the two institutions decided to **share resources** by jointly recruiting a genetic counsellor to work with families to explain diagnoses and impacts on them and others. The job is similar in nature to the Inter-establishment Navigator position shared by the Initiative's four partner institutions, which had to be reassigned twice during the year, the first after the position was vacated and the second as a result of maternity leave.

Another joint project that started up during MUSCO's first year (Project 7) captured the attention of the Ministère de l'Économie et de l'Innovation. The project deals with patient continuum of care, with the end goal being to facilitate collaboration and streamline families' contact with the four institutions. The project includes an assessment conducted by a research team linked to the working group. Dubbed "My Way / Mon chemin," this assessment was given the green light for financial assistance from the FSISSS². This grant is the **first sign of ministry recognition** for the ongoing work being conducted by the teams under MUSCO's leadership.

PROJECTS DEVELOPED IN 2019 - 2020

PROGRESS AND DETAILS PER PROJECT

CHU Sainte-Justine Shriners Hospitals for Children – Canada
Montreal Children's Hospital
Marie Enfant Rehabilitation Centre Joint

“

Project 7, the goal of which is to improve communication between the hospitals [is the MUSCO project that matters most to me]. My son is being seen at four different hospitals. (...) we have gone through a whole bunch of situations that took a gazillion calls or emails to make sure everyone was on the same page, only to find out we'd have to start all over again anyway. With this initiative, we hope communication gets better so parents have more time to be parents.

— CAROLINE MARIE, MOTHER OF 5-YEAR-OLD ALEX OLIVIER

PROJECT STATUS REPORT

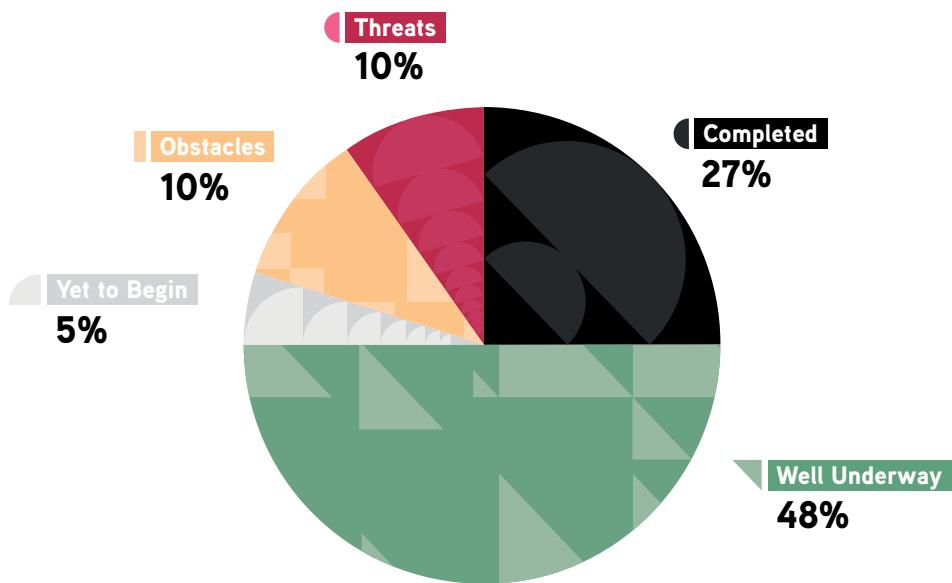
The 2019–2020 action plan **ANNEXE 1**, features some of the projects that were begun during Year 1 of the Initiative. Those that were completed during the first year were removed (e.g., Project 19 — Project Manager Recruitment), as were others that have been put off to a later date (e.g., Project 13 — Spinal Disorder Clinical Research Recruitment, which has been postponed to Year 4).

IN TOTAL, THE INITIATIVE WORKED TOWARDS FURTHERING 19 PROJECTS IN 2019–2020:

- › **7 joint projects,**
- › **12 major projects.**

OF THESE 19 PROJECTS:

- › **5 were completed,**
- › **9 are well underway,**
- › **1 has yet to begin,**
- › **2 are facing obstacles and cannot move forward,**
- › **2 are facing threats that keep them from starting.**



OUTCOME MEASURES

Projects that are being conducted by an in-house team of researchers who are able to assess the corresponding impacts (see Project 7 – Patient Continuum of Care) will be able to identify and document suitable indicators. This competency will have to be developed within other working groups.

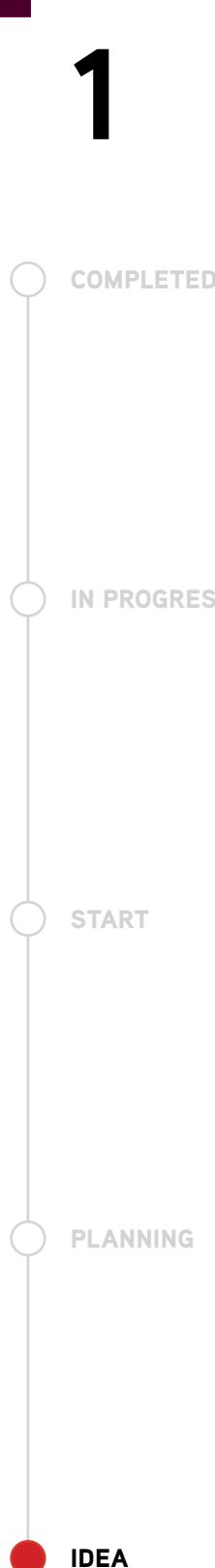
To benefit the Initiative more broadly, an agency was hired to measure the overall impact of these endeavours on families and institutions. This agency is NISKA, which will also be in a position to conduct an impact study in Year 3.

* NOTE

While helping to further these major and joint projects, MUSCO was asked to take part in several other projects being led within the network of organizations set up to help families. Accordingly, the Initiative contributed to the launch of the new version of the L'Accompagnateur website, a platform featuring online resources for parents of people with disabilities: <https://laccompagnateur.org/>.



Families attending
the Cerebral Palsy Event
Photo: Benoit Desjardins



JOINT

CREATE A FUND TO PROVIDE RESPITE AND FINANCIAL AID TO FAMILIES



ACTIONS TAKEN IN 2019–2020

The findings of the study on the respite situation in Quebec commissioned by the organization Solidarité de parents de personnes handicapées (SPPH) and led by the agency Katz Design were presented to the Executive Committee in fall 2019. On the basis of these results, a group committee was identified, made up of hospital, rehabilitation, community and healthcare network professionals. The committee has not yet been able to meet.



IMPACT ON PATIENTS AND FAMILIES

No impact thus far since the project has yet to be launched..



PARTNERSHIPS

During lockdown, MUSCO's teams took part in several discussions with partners in the network about the various issues and challenges involved in responding to and supporting families in need of respite services.



INDICATORS

Indicators not yet identified or documented since the project has yet to be launched.



ACTIONS FOR 2020–2021

The question remains of how to go about developing this project given current hospital realities. Discussions with Patient Experts within the new Advisory Pole have nevertheless led to some new ideas, with a definition of hospital respite that would more closely resemble a childcare or recreational service for children while waiting for an appointment or while parents are attending a seminar. This would help mitigate complications and stress for families in these situations. This approach will have to be described in more detail in Year 3 to confirm the timeliness of this project.



MUSCO'S IMPACT

The integration of the newly created Advisory Pole within the MUSCO governance structure will help outline families' needs in this regard.

2

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

JOINT

DEVELOP EDUCATIONAL TECHNOLOGY

ACTIONS TAKEN IN 2019–2020

 As expected, once the Advisory Pole was set up, it was able to discuss the content of the educational technology project, which had been on hold until the priority needs for potential future users of this tool could be identified. A number of needs and ideas emerged during a brainstorming session with Patient Experts, including the management of appointments and medical visits; the delivery of information on diagnoses, medical specialties and technical aids in non-technical language; the management of consent forms; an app for physiotherapy exercises; pre-exam or pre-op information; and a “cheat sheet” with key information on a child’s condition that can be given to schools, professionals, family members, friends and other people who interact with the child.

IMPACT ON PATIENTS AND FAMILIES

 No impact thus far since the project has yet to be launched.

PARTNERSHIPS

 Hospitals will be consulted to learn more about any applications that are already in development. It will be important to define the project scope in detail so it can be submitted for government approval.

INDICATORS

 Indicators not yet identified or documented since the project has yet to be launched.

ACTIONS FOR 2020–2021

 Further research will be conducted and aimed at establishing an inventory of existing applications that meet the needs brought up by the Patient Experts and to identify which as-yet unmet needs could be addressed by MUSCO’s future application(s). The results will be discussed with the Executive Committee and the administrations of the partner institutions.

MUSCO’S IMPACT

 The existence of the Initiative will make it possible to draft a list of families’ most critical needs and to make families more aware of existing and emerging technologies.

MERC

3

COMPLETED



ACTIONS TAKEN IN 2019–2020

Efforts begun in 2018–2019 to recruit a manager responsible for partnerships were extended to 2019–2020, as a candidate fitting the complex profile had not been found. Governance-related discussions were still underway when COVID-19 struck. The pandemic brought the recruiting process to a halt. Only replacement positions and those for essential workers were allowed to be posted while lockdown restrictions were in place.



IMPACT ON PATIENTS AND FAMILIES

No impact thus far since the project has yet to be launched.



PARTNERSHIPS

Pending the formalization of the governance structure and the recruitment of a partnership manager, a study was undertaken to help advance knowledge and build a list of the various industries and prospective partnerships to be explored in the future.

IN PROGRESS



START



PLANNING



IDEA



INDICATORS

Indicators not yet identified or documented since the project has yet to be launched.



ACTIONS FOR 2020–2021

The challenge will be to find a way to move forward with this project in a meaningful way in 2020–2021 so as not to lose touch with the companies that had expressed their interest when the Technopôle was inaugurated and with the families who had indicated their willingness to take part in the project.



MUSCO'S IMPACT

The project was mentioned during the Cerebral Palsy Event (Project 21), when families were invited to get involved in the future Living Lab. A number of Patient Experts involved in the Advisory Pole have also said they are interested in the project. They could be called upon when the project gets off the ground, depending on the themes explored.

3b

ASSIST COMMUNITY ORGANIZATIONS IN THEIR EFFORTS TO FULFILL THEIR MISSIONS TO HELP PATIENTS AND FAMILIES

 COMPLETED

ACTIONS TAKEN IN 2019–2020

 A formal agreement was drawn up with community organizations interested in using the room set aside in the Marie Enfant Rehabilitation Centre (CRME) to hold occasional information and training sessions for families, in accordance with the terms of the agreement. Their status as recipients of support from the Ministère de la Santé et des Services sociaux through the community organization support program (PSOC) vouched for their reliability. Four organizations had begun to use the space, which was nicknamed “Pied-à-terre,” three of which were aligned with MUSCO’s priorities, namely the Association québécoise des personnes de petite taille (AQPPT), the Centre d’intégration à la vie active (CIVA) and Dysphasie Plus. The room was shut down in response to pandemic-related lockdown measures.

 IN PROGRESS

PARTNERSHIPS

 Ties were established with community organizations interested in developing activities using the specified space.

 START

INDICATORS

- 3 partnerships with community organizations.

 PLANNING

ACTIONS FOR 2020–2021

 Given the current status of COVID-19, it is difficult to know when the room will once again be available for community organizations to use. The issue of whether or not patients can be present will have to be considered once activities of this nature are allowed to resume.

 IDEA

IMPACT ON PATIENTS AND FAMILIES

When this project was brought up in an Advisory Pole meeting, Patient Experts asked about whether parents attending information or training sessions in this room could keep their children with them.

MUSCO’S IMPACT

 The feedback of MUSCO’s Patient Experts shed light on how users could best benefit from these services. This information will help add value to the project and its implementation.

JOINT

4

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

RECRUIT SEVERAL PARENTS TO PARTICIPATE IN THE ADVISORY POLE **ACTIONS TAKEN IN 2019–2020**

The new Inter-establishment Navigator (Project 7) was able to recruit several Patient Experts for the Advisory Pole before the pandemic struck. These individuals were selected based on a pre-defined set of skills and experiential knowledge. A conscious effort was made to ensure the representativeness of the selected candidates in terms of profile (mother, father, patient), types of diagnosis and socioprofessional category. In addition, candidates needed to have experience with at least two of the partner institutions. Seven Patient Experts were ultimately recruited to this Advisory Pole. They have met twice, on May 4 and June 16, when they discussed the Initiative's projects, focusing specifically on the content of Project 2 – Educational Technology. Most Patient Experts are also poised to act as Patient Resources on a number of the working groups in place for the close to 20 projects currently being overseen by MUSCO.

 **IMPACT ON PATIENTS AND FAMILIES**

The existence of a parent and patient committee to address issues of importance to MUSCO and the ties this committee has with other bodies within the governance structure will help ensure that families' needs are taken into account when moving forward with the Initiative's projects.

 **PARTNERSHIPS**

The collaborative ties between the new Advisory Pole and other bodies within the MUSCO governance structure have been outlined in a set of operating procedures. A representative of the Advisory Pole has a permanent seat on the Full Committee.

 **INDICATORS**

- 10 Patient Experts approached
- 7 Patient Experts recruited
- 2 Advisory Pole meetings

 **ACTIONS FOR 2020–2021**

Recruitment will be ongoing to complement the current membership. The Advisory Pole will examine the current report and continue to reflect on specific projects or project components.

 **MUSCO'S IMPACT**

Overall, the presence of Patient Experts will make it possible to obtain feedback on how families see the Initiative and will give a voice to those who will benefit from these projects.

5

INSTALL SURVEY TERMINALS INSIDE THE SAINTE-JUSTINE AGIS! CENTRE OF EXCELLENCE

 COMPLETED

 IN PROGRESS

 START

 PLANNING

 IDEA



ACTIONS TAKEN IN 2019–2020

Some 15 quality-of-life surveys were converted from paper to digital format. The operation was approved by medical archives, and the content of the surveys will be reviewed yearly by the Ethics Committee. During the first phase of the project, a number of families were asked to test the questionnaire. During the second phase, a specific room was set up within the clinic to allow families to complete the survey on-site, along with a series of patient tests to determine their preferences regarding the terminals to be installed in the space. After the closure of the room in light of the pandemic, the third phase, the goal of which was to provide remote access to allow families to complete the surveys at home using a personal appareil, took on another dimension. The AMIKO³ application developed using the Kentico CRM, will be operational in Year 3. The name of the application was even inspired by the name of the Initiative.



IMPACT ON PATIENTS AND FAMILIES

The Patient Experts believe that this project will make it possible to save time, heighten efficiency and ensure various professionals have simultaneous access to the same information in order to provide more personalized treatments to patients. The actual impacts will be observable once the application is online.



PARTNERSHIPS

The project was developed working closely with CHU Sainte-Justine's IT Department.



INDICATORS

The indicators will be populated once the application is uploaded and operational.



ACTIONS FOR 2020–2021

Once the application is available for use and families have been informed of its existence and how it works, a test phase will be carried out to check its functionality and make adjustments as required. The goal will then be to expand the project scope to include other CHU Sainte-Justine clinics.



MUSCO'S IMPACT

The Initiative made it possible to provide operational support, making this a true pilot project that will eventually allow other departments in the hospital to benefit from a similar tool.

JOINT

6

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

OUTLINE A CLEAR AND TRANSPARENT COMMUNICATION PROCESS FOR THE CONTINUUM OF PATIENT CARE BETWEEN PARTNER INSTITUTIONS



ACTIONS TAKEN IN 2019–2020

The project was divided into three phases : (1) diagnosis/pre-assessment, (2) implementation of solutions and (3) results/post-assessment. The purpose of the first phase was to complete the work initiated prior to the beginning of the project to map out existing patient journeys and establish clear figures. Using an integrated approach, including a research team and a design studio, a workshop evaluated three types of diagnoses pre-selected by the working group (spinal surgery, general orthopedic surgery in patients with a motor developmental delay and rhizotomy) to update and refine existing maps. The next step in this phase is to document the experience from the patient's perspective. This phase had to be adapted to the realities of COVID-19, as families could not complete the surveys in a clinical setting. A new retrospective approach will make it possible to ask parents and patients about their entire journey through a telephone interview. In the lead-up to this phase, a multicentre study is being prepared for validation by the ethics committees of each of the institutions, including the protocol and surveys directed at families.

Note that the assessment approach in phases 1 and 3, known as "My Way / Mon chemin," has received the financial support and endorsement of the provincial government through funding from the Fonds de soutien à l'innovation en santé et en services sociaux (FSISSS) in the amount of \$240,000.



IMPACT ON PATIENTS AND FAMILIES

The initial impact of the project will be to give a voice to families during the first phase (diagnosis/pre-assessment), which will help provide a clearer understanding of the issues experienced by patients during their inter-institution journey.



PARTNERSHIPS

To help bring this project to a successful conclusion, a partnership has been developed with a team of researchers and the Meilleur Monde design studio, both of which are members of the working group, composed of representatives of each MUSCO partner institution.



INDICATORS

An analysis chart was developed to assess and compare indicators before and after improvements were made. The chart must also be submitted to the various ethics committees, after which it can be updated as the project advances.



ACTIONS FOR 2020-2021

Once the hospitals' ethics committees give the green light, the diagnosis phase can be initiated with families. A summary will then be prepared to compile the data gathered from professionals and families, which will be used to guide discussions about the second phase and help draft a list of potential solutions that may be beneficial.



MUSCO'S IMPACT

MUSCO brings together the various teams from the participating institutions along with external partners who contribute their expertise to the project.

JOINT

7

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

RECRUIT INTER-ESTABLISHMENT NAVIGATOR TO ASSIST PATIENTS AND THEIR FAMILIES



ACTIONS TAKEN IN 2019–2020

There were many changes made to this new position in Year 2 of the Initiative. First, in an effort to avoid any confusion with the pivot workers already in place in the partner institutions, the title of the position was modified to Inter-establishment Navigator. The position has since been occupied by three people: the first left for an internal position in one of the institutions, and the second left on maternity leave. The third, who currently occupies the position, was hired on a one-year replacement contract and was able to transition smoothly into the position even amid the pandemic. A detailed job description for this position was also developed, focusing on three areas: the clinical component (guiding professionals and patients and keeping them informed by coordinating services and resources between partner institutions), the process component (helping to improve the efficiency of, and access to, services, especially in terms of bridging the gap between partner institutions) and the engagement component (ensuring patients' and families' concerns and priorities are taken into consideration in the Initiative's projects).



IMPACT ON PATIENTS AND FAMILIES

Working with the navigator makes it much easier for referred patients and families to navigate the system (first component). The

navigator brings up points to be considered and sheds light on families' experiences so that longer-term solutions can be established within the scope of Project 7 – Patient Continuum of Care (second component). The navigator also helps amplify patients' and families' voices within the MUSCO Initiative as the moderator of Advisory Pole meetings (third component). Here is an example of what the navigator does in line with the first component: A family living in a rural community outside Montreal has four children, all of whom have the same rare genetic condition. The local social worker already found it difficult to coordinate the various contacts at the different hospitals in Montreal, and that was before one of the children was called in for an urgent operation. The mother could no longer recall everything that had to be done, let alone which interventions were the highest priorities. The family also had to deal with travel arrangements (flights, hotels) and miss time from work. The mother turned to the Shriners Hospital social worker for assistance, who in turn referred her to the Inter-establishment Navigator. Because the navigator had direct access to clinical information and the teams at each of the sites, she was able to keep everyone up to date and guide the caregivers in coming up with a suitable action plan to meet the children's needs and address the challenges facing the family. In the end, the surgery, which almost had to be put off because of the difficulties coor-

dinating pre-op procedures, went smoothly, and the family were not away from their home for more than a few days. What's more, the teams in question now have a mechanism in place to coordinate future appointments.



PARTNERSHIPS

The second navigator and her current maternity leave replacement started gradually meeting with clinical teams at the various institutions. The partnerships developed with these professionals help them have a better understanding of the navigator's role and identify situations where her involvement is required to improve the family experience (first component).



INDICATORS

- 17 interventions to help patients and families
- 64 % of requests handled by professionals
- 47 % of patients from Greater Montreal



ACTIONS FOR 2020-2021

A communication plan will be rolled out in Year 3 to familiarize teams with the Inter-establishment navigator's role and the three focuses of their work. Moreover, given the expected increase in the work to be done with families (first component), the efforts to advance the continuum of care project (second component) and the facilitation of the newly created Advisory Pole and the recruitment of Patient Advisors (third component), the breakdown of tasks will be revisited with the aim of adding a second navigator.



MUSCO'S IMPACT

The Initiative has provided partner institutions with access to a shared resource who will facilitate a clearer mutual understanding of the inner workings of each institution with the goal of better informing and supporting families.

CHUSJ

8

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

CREATE A DATABASE OF PATIENTS RECEIVING ORTHOPEDIC CARE AT CHU SAINTE-JUSTINE

ACTIONS TAKEN IN 2019–2020

A number of discussions took place with the IT teams at CHU Sainte-Justine and the Shriners Hospital for Children – Canada to explore potential collaborative opportunities for this project. It was determined that the goal is not so much to create a shared database as to make it possible for existing databases to talk to one another. A report in this regard will have to be prepared and submitted to the Ethics Committee. The firewalls of the respective institutions will have to be factored into the equation. Other meetings were to be held to advance this project, but they were postponed because of COVID-19.

IMPACT ON PATIENTS AND FAMILIES

No impact thus far since the project has yet to be launched.

PARTNERSHIPS

The project requires the IT departments of both institutions to work together.

INDICATORS

Indicators not yet identified or documented since the project has yet to be launched.

ACTIONS FOR 2020–2021

Meetings will have to resume to get the project moving forward and to prepare the content of the report to be submitted to the Ethics Committee. This last stage will have to be seen to quickly to meet specified deadlines.

MUSCO'S IMPACT

The existence of the Initiative makes it possible for the institutions to explore potential collaborative opportunities and facilitate teamwork.

9

SET UP 3D EOS RADIOLOGY ROOMS IN CHU SAINTE-JUSTINE'S NEW AGIS! CENTRE OF EXCELLENCE

 COMPLETED

ACTIONS TAKEN IN 2019–2020

 Final touches were made to the EOS rooms in the AGIS clinic during the year. There were some cost overruns, due to higher-than-anticipated demolition and construction expenses, although they were still within MUSCO's original budget projections. The EOS rooms are now operational. Other costs that had not been included in the initial program were integrated into the project, namely those associated with setting up audiovisual facilities for Zoom calls between institutions and furnishing the waiting room.

IMPACT ON PATIENTS AND FAMILIES

 Setting up the EOS rooms was aligned with MUSCO's objective to optimize infrastructure for patients and families.

PARTNERSHIPS

 There have not been any partnerships developed as yet. Although this large-scale project is now finalized and has met its initial objectives, additional collaborative opportunities still need to be explored.

 IN PROGRESS

INDICATORS

 More than 20,000 patients were seen in the AGIS clinic in the past year.

ACTIONS FOR 2020–2021

 There are no new actions planned for Year 3.

MUSCO'S IMPACT

 This type of project is more closely aligned with the kind of expenditures donors traditionally tend to get behind. However, MUSCO's involvement may encourage stakeholders to share observations from cases examined in the EOS radiology rooms with other partner institutions.

 START

 PLANNING

 IDEA

MERC

10

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

ACTIONS TAKEN IN 2019–2020

 The first phase of the project, acquiring the equipment for the Technopôle, was completed, albeit with some cost overruns. The financial plan for Phase 2 will therefore have to be revisited, as will the business plan for the musculoskeletal focus of the Research Centre for the coming years. This will involve reassessing expenditures but also seeking out sources of funding. An application was submitted to the Canadian Foundation for Innovation (CFI) for additional funds. Depending on how much is awarded, this may complement or partially replace MUSCO's funding. We will have to wait until fall 2020 to determine whether MUSCO's involvement has had a leverage effect on CFI.

IMPACT ON PATIENTS AND FAMILIES

No outcomes measured for the moment.

PARTNERSHIPS

 Overall within the Technopôle, the equipment that has already been acquired has piqued the interest of researchers working on various rehabilitation issues related to walking and posture.

INDICATORS

 Equipment-related indicators will be documented for items acquired through MUSCO support.

ACTIONS FOR 2020–2021

 Depending on the amount of the CFI funding to acquire equipment in Phase 2 of the Technopôle project, there will be some decisions to make as to the extent of MUSCO's involvement in the project going forward.

MUSCO'S IMPACT

 MUSCO's support may help to leverage CFI funding, as was the case for the FSISSS grant awarded for Project 7 – Patient Continuum of Care.

11

ACQUIRE 3D PRINTERS FOR THE TECHNOPÔLE TO PROVIDE PATIENTS WITH PROTOTYPES OF ORTHOTIC DEVICES AND PERSONALIZED PROSTHETICS

COMPLETED

IN PROGRESS

START

PLANNING

IDEA



ACTIONS TAKEN IN 2019–2020

A request for proposals was issued to acquire the Initiative's first 3D printer. In the end, the actual cost was double what had originally been budgeted. The overruns did not alter MUSCO's overall budget, however, as the difference was applied to other budget lines. A second 3D printer was supposed to have been purchased during the year, but these plans were put on hold awaiting an updated estimate as well as the amount to be granted by CFI (see Project 10).



IMPACT ON PATIENTS AND FAMILIES

The first 3D printer was used to create orthotics and prosthetics for CRME patients. Incidentally, the CRME teams won first prize in the "Modern" category in the Stars du réseau de la santé contest sponsored by Caisse Desjardins du Réseau de la santé for transforming the work of orthotics and prosthetics technicians and mechanics using digital and 3D printing technologies. This honour recognizes endeavours that generate benefits for patients and their families by implementing new procedures.



PARTNERSHIPS

Researchers have indicated a keen interest in the new 3D printer, and this helped in recruiting new research professionals and forging ties within the team during the year. Research teams also received the support of organizations like TransMedTech to fund resources and projects.



INDICATORS

To be developed based on the use of the orthotic devices made using the 3D printer.



ACTIONS FOR 2020–2021

More 3D printers may be procured using MUSCO funds, depending on the amount received from CFI.



MUSCO'S IMPACT

If funds are received from CFI, MUSCO's involvement will have been key in leveraging this second source of funding.

CHUSJ

12

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

SUPPORT THE COORDINATION OF CHU SAINTE-JUSTINE'S URCO CLINICAL RESEARCH



ACTIONS TAKEN IN 2019–2020

The number of projects related to the MUSCO Initiative supported by research assistants with the Clinical Research Unit in Orthopedics (URCO) who work with families in the clinic was reassessed in Year 2, at the same time as efforts were made to revisit other funds used to pay the salaries of these assistants. Other team members were incorporated into the budget to work with families receiving orthopedic care. The teams adapted their practices during the pandemic to continue working with families and made progress in advancing certain protocols.



IMPACT ON PATIENTS AND FAMILIES

The support of research assistants is crucial to providing families with the information they need and to gathering the data required to gain further insight into the condition of each patient as well as to improve protocols to better meet patients' needs.



PARTNERSHIPS

Of the various approaches developed by the teams supported by this project, one of the protocols began to be used by CHU Sainte-Justine and the Shriners Hospitals for Children – Canada for younger patients with spinal cord conditions. The goal is to allow teams from both hospitals to discuss case information to better guide their respective efforts.



INDICATORS

To be documented based on the new protocols.



ACTIONS FOR 2020–2021

The team supported through the Initiative will continue to develop new family protocols and improve existing ones adapted to the new realities of COVID-19. This will have an impact on the use of the clinics and an increase in the number of telemedicine visits.



MUSCO'S IMPACT

The integration of this project into the MUSCO Initiative allows other facilities to access and implement these same protocols and enjoy the corresponding benefits.

14

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

FUND THE SHRINERS HOSPITAL FOR CHILDREN - CANADA GENOME SEQUENCING PROJECT FOR BONE DISEASES

ACTIONS TAKEN IN 2019–2020

Adjustments needed to be made in the calibration of the sequencer, delaying its launch and making it necessary to hire a technician. The device is now calibrated and operational, and additional equipment has been acquired. However, it was impossible to test samples while lockdown restrictions were in place. A collaborative opportunity was explored with the teams at CHU Sainte-Justine to hire a shared resource — a genetic counsellor — to work with families and assist with research projects spearheaded by both hospitals. These plans were put on hold during lockdown as they did not qualify as an essential or replacement service.

IMPACT ON PATIENTS AND FAMILIES

The project is currently on hold, awaiting the sequencing of the first samples and the recruitment of a genetic counsellor to measure impacts on families.

PARTNERSHIPS

The joint recruitment of a genetic counsellor is a collaborative undertaking by the Shriners Hospitals for Children – Canada and CHU Sainte-Justine. Through this shared resource, the two hospitals will be able to pool their strengths and staff a full-time position in a field where part-time postings can be difficult to fill. Discussions with the HR departments of both hospitals

will help clarify some specific concerns about the fact that the job is considered to be a union position at CHU Sainte-Justine but a non-union position at the Shriners.

INDICATORS

Indicators will be developed and populated once the sequencer is operationalized.

ACTIONS FOR 2020–2021

The goal for Year 3 is to sequence the first samples using the newly acquired equipment. The genetic counsellor job will have to be posted and interviews held in collaboration with the HR departments of both institutions.

MUSCO'S IMPAC

The Initiative encouraged the two hospitals to engage in a dialogue about hiring a genetic counsellor and align their recruitment efforts.

MCH

15

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

DEVELOP PROTOCOLS TO PROMOTE ENHANCED RECOVERY



ACTIONS TAKEN IN 2019–2020

A guest lecturer was asked to deliver a presentation on enhanced recovery to the Montreal Children's Hospital and Shriners Hospitals for Children – Canada in June 2019. Contact was established with the nursing department of the Montreal Children's Hospital to discuss plans to hire nurses who have been trained in enhanced recovery. Moreover, the theme for the MCH pediatric surgery team's retreat, scheduled for May 1, 2020, was improving post-op recovery. It would have featured a panel of speakers from the hospital and other institutions who are leading the way in this field. The event would have been directed at surgical, anesthetic, nursing and OR professionals, as well as recovery room nurses and perioperative clinic staff members. The expected turnout was 150 participants, but the event had to be cancelled due to the pandemic.



IMPACT ON PATIENTS AND FAMILIES

The outcomes for families will be measured once the new protocol is in place.



PARTNERSHIPS

The retreat that had been planned for May 2020 was open to the Initiative's partner institutions. A number of these professionals had signed up to attend.



INDICATORS

The indicators will be documented once the project is operational.



ACTIONS FOR 2020–2021

The retreat would not have been easy to convert to a virtual format, so the decision was made to cancel it instead. However, all the materials are ready to go once a replacement date is set. Further efforts will be made to increase awareness within the Montreal Children's Hospital about this new approach in pediatric medicine.



MUSCO'S IMPACT

The Initiative made it easier for professionals in other partner institutions to be apprised of and register for the retreat.

JOINT

16

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

COORDINATE THE INSTITUTIONS' TRAINING PLANS TO SHAPE THE LEADERS OF TOMORROW



ACTIONS TAKEN IN 2019-2020

The content for two types of projects were developed in 2019-2020: (1) a two-day, hands-on, patient-centric post-SPORC (Sainte-Justine Orthopaedic Review Course) course, originally scheduled for March 13 and 14, to round out the training that is usually provided to new orthopedic residents; and (2) an onboarding workshop for Patient Resources sitting on MUSCO's working groups, the content of which was tailored specifically for the Initiative. The post-SPORC course was prepared jointly with the event planning team at CHU Sainte-Justine and was designed to accommodate 24 participants from various institutions. It was cancelled in light of the pandemic. The Patient Resource workshop (2) was developed during lockdown in close collaboration with the consultants at Planetree. The materials (objectives, content, procedures) are ready to be rolled out in either an in-person or virtual setting.



IMPACT ON PATIENTS AND FAMILIES

The impact on families will be measured once the courses and workshops are up and running.



PARTNERSHIPS

The SPORC and post-SPORC courses were developed to be led by professionals from three of the Initiative's partner institutions. The Patient Resource onboarding workshop, designed jointly with the consultants at Planetree, will accommodate multidisciplinary teams from each of the institutions associated with MUSCO.



INDICATORS

The indicators will be documented once the project is operational.



ACTIONS FOR 2020-2021

The post-SPORC project will be revived as soon as in-person events are possible. Participants' physical presence is required to be credited. The Patient Resource onboarding project will be launched in fall 2020.



MUSCO'S IMPACT

MUSCO provides support for planning hands-on courses and workshops that go beyond theory to focus on the patient experience both in a clinical setting and as part of a continuous improvement mindset.

MCH

18

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

PROVIDE BASIC TRAINING IN PEDIATRIC SURGERY **ACTIONS TAKEN IN 2019–2020**

The interactive pediatric surgery manual that was being prepared during Year 1 of the Initiative was finalized in September 2019 and widely distributed. A new boot camp session was held in summer 2019. The 2020 session that was supposed to take place in July 2020 was converted from an in-person to a virtual format to keep up the momentum. The training plan was built around eight pediatric specialties.

 **IMPACT ON PATIENTS AND FAMILIES**

It will be necessary to take a step back to determine whether these tools and sessions are actually changing the practices of these new cohorts of professionals and having an impact on patients and their families.

 **PARTNERSHIPS**

Residents from across Canada and the U.S. have attended the boot camp sessions. The manual on pediatric surgery was distributed to all those who expressed an interest, regardless of their institution of practice. Note that a number of copies of the manual were printed using non-MUSCO funding to be sent to economically disadvantaged countries to help build up their knowledge and improve professional practices.

 **INDICATORS**

- 20 residents who attended the 2019 boot camp, twice as many as the year before
- 25 videos of surgical procedures included in the interactive surgery manual

 **ACTIONS FOR 2020–2021**

The manual will continue to be distributed, and further adjustments will be made to the now-virtual training plan for delivery to residents.

 **MUSCO'S IMPACT**

The tools and materials developed for this project are being sent to participants in MUSCO's partner institutions to help disseminate best practices.

20

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

JOINT

ORGANIZE AN EVENT WITH A UNIFYING THEME

ACTIONS TAKEN IN 2019–2020

An organizing committee made up of representatives from each of the Initiative's partner institutions developed the program for a one-day event on a topic of shared interest: cerebral palsy. The event took place on December 7, 2019, at CHU Sainte-Justine. The idea was for subsequent events to be held at the other partner institutions on a rotating basis. The purpose of the event was to provide patients and families with information and give them an opportunity to discuss various subjects and hear what guest speakers had to say. There were two main thrusts to the program: the first focused on medical/rehabilitation aspects, while the second was more community-oriented. The panels included a variety of speakers and professionals (doctors, rehabilitation professionals, community organization representatives). For some of the topics, video testimonials from patients and parents were produced and shown.

IMPACT ON PATIENTS AND FAMILIES

A post-event survey was sent to participants to determine their level of satisfaction. Of the 160 people in attendance, 48 % answered the survey. 94 % of these respondents said they were happy with the morning lineup (medical/rehabilitation), and 91 % said the same about the afternoon (community). Families described the event as "informative" and "enlightening," and unanimously indicated

their interest in repeating the experience the following year.

PARTNERSHIPS

The event program was developed by representatives of the Initiative's four partner institutions. The organizing committee worked closely with CHU Sainte-Justine's event planning team. The event was promoted not only by MUSCO partner institutions but also by the community organizations that took part in the panel discussion on social issues. The Centre Philou helped provide on-site childcare services so that parents could attend the various activities.



INDICATORS

- 188 registrations, including 27 streaming
- 160 attendees on site: 66 parents, patients or family caregivers; 78 healthcare professionals; 16 representatives of community organizations
- 15 families who used the on-site childcare service
- 18 information booths



ACTIONS FOR 2020–2021

The 2019 event was praised by families and professionals alike. An event of this type will therefore be planned by the Initiative on a yearly basis. The next event was supposed to focus on fibrous dysplasia of bone and was set to take place at the Montreal Children's Hospital. Given the circumstances surrounding the pandemic, it was decided to hold a virtual event instead and to maintain the theme of cerebral palsy, only this time concentrating on the three main themes identified in the first post-event survey.



MUSCO'S IMPACT

The event brought together representatives of MUSCO's four partner institutions and community organizations for a day-long event, where families were given information and the opportunity to share their views.

21

COMPLETED

IN PROGRESS

START

PLANNING

IDEA

CREATE A CANADIAN PEDIATRIC SURGERY RESEARCH CONSORTIUM



ACTIONS TAKEN IN 2019–2020

The members of the consortium committee met twice during the year, in September 2019 and January 2020. After close to a year of discussions and back-and-forth between the parties, the legal agreement binding 15 centres from across Canada was signed in February 2020, making this project a reality and providing it with an official foundation upon which to jointly develop projects within the consortium.

The 15 centres are as follows : the Alberta Children's Hospital, British Columbia Children's Hospital, Children's Hospital of Eastern Ontario, the Children's Hospital at London Health Sciences Centre, CHU de Laval, CHU Sainte-Justine, CHU de Sherbrooke, the Health Sciences Centre/ Children's Hospital of Winnipeg, the IWK Health Centre, the Janeway Children's Health and Rehabilitation Centre, Jim Pattison Children's Hospital, McMaster Children's Hospital, Montreal Children's Hospital, SickKids and Stollery Children's Hospital.



IMPACT ON PATIENTS AND FAMILIES

Bringing 15 research and surgical centres from across Canada together will facilitate the sharing of information and best practices, all for the benefit of patients. The impact on families will be measurable over the long term.



PARTNERSHIPS

The partnership aspect of this project is related to the formal agreement signed by the 15 participating institutions and the projects they will develop together as part of this consortium. The Montreal Children's Hospital and CHU Sainte-Justine are two of these institutions.



INDICATORS

- 15 participating institutions
- 2 committee meetings



ACTIONS FOR 2020–2021

The committee had intended to meet again in July 2020. The consortium's first study, which was launched in Year 2 of the Initiative has a planned completion date of August 2020.



MUSCO'S IMPACT

The creation of the Mirella & Lino Saputo Foundation Chair in Pediatric Surgical Education and Patient and Family-Centered Care, funded by the Mirella & Lino Saputo Foundation, made it possible for the parties to sign this agreement and make the consortium a reality.



MUSCO: THE BIGGER PICTURE

REFLECTIONS AND CONSIDERATIONS

A FORMULA THAT CAN BE EXPORTED TO OTHER INSTITUTIONS WITHIN THE NETWORK AND BEYOND

The MUSCO Initiative, by its very nature, encourages partner institutions to think outside the box. A number of innovative approaches have already emerged as a result. The creation of the role of an Inter-establishment Navigator led the Shriners Hospitals to recruit a “Canadian navigator” to facilitate the patient journey within the Shriners Hospitals network, which apart from its facilities in Montreal and Mexico City is primarily based in the U.S.

The major undertaking that was the quality-of-life survey is being seen as a pilot project by CHU Sainte-Justine, thereby giving an opportunity for the new technology teams to roll out a new application that would then be extended to other clinics within the hospital. CHU Sainte-Justine also foresees the possibility of building on this joint continuum of care project and applying it to patients’ experience with the different units of the hospital.

The CHU Sainte-Justine Foundation is involved in two inter-institution collaboration efforts. The first is with the Marcelle and Jean Coutu Foundation and a number of other hospitals and networks via Q1K, a collaborative initiative involving 1,000 families designed to transform autism care. The second collaboration is being developed in conjunction with SickKids and concerns a precision medicine program. As for the Montreal Children’s Hospital, it is working with the Canada-wide CHILD-BRIGHT Network, the aim of which is to improve outcomes for children and youth with a brain-based developmental disability as well as the national Terry Fox PROFYLE initiative to wage battle against pediatric brain tumours.

PARTNERSHIP WITH INSTITUTIONS OUTSIDE THE MUSCO INITIATIVE

In response to the question of whether to expand beyond the original circle of the four partner institutions, the Steering Committee has decided, for the moment, to maintain the status quo and wait until it has a broader view of the efforts currently in place before pursuing this growth. However, other institutions interested in teaming up with MUSCO are actively encouraged to join the working groups for the various committees.

As it wraps up its second year, the Initiative needs to further strengthen its ties with the four original partner institutions and make more headway with its active projects to confirm the potential opportunities associated with this model and explore the impact that this innovative approach can have on patients and families as well as the teams working in the various departments concerned.

PROJECT OWNERSHIP, INCLUDING PUBLIC-PRIVATE PARTNERSHIPS

In most cases, the individuals involved in the working groups took ownership of their respective projects. More often than not, they simply get down to the task at hand, irrespective of the scope of the commitment or the amount of time required to move things along.

Project ownership is important both for internal teams and external partners. Various agencies have been called upon to contribute their expertise, including the Meilleur Monde design studio, which has been involved in the patient continuum of care project, or the Planetree consulting firm, which has provided invaluable assistance in onboarding Patient Resources into the Initiative's working groups. At issue here is the fact these partners transcend the role of mere service providers to serve as full-fledged members of the team who embrace the same collaborative mindset as the Initiative.

It is important to reinforce and broaden this sense of ownership so that it applies to all the organizations within MUSCO's framework. This will help the Initiative become more transparent and visible. All too often, MUSCO continues to be looked on as a foundation, which is not the case, and its efforts are not sufficiently well known. Bringing in more resources from each institution, communicating regularly with professionals working on the ground, developing new projects and creating a website and other communication tools are all ways this sense of ownership can be enhanced and participants' motivation supported.

MAJOR AND JOINT PROJECTS: TWO APPROACHES, TWO VISIONS

Major projects were the first focus of the MUSCO Initiative. They are much more closely aligned with a traditional vision of philanthropic support. Examples of these projects include the setup of the EOS radiology rooms at CHU Sainte-Justine and the acquisition of the sequencer for the genome sequencing project at the Shriners Hospital for Children – Canada.

In comparison, joint projects are, by their very nature, more in tune with the underlying values that drive MUSCO. Collaboration between teams is a must in the development and implementation of these projects. When innovative new projects are launched, all four partner institutions are called on to contribute their views.

The added value of MUSCO with regard to major projects lies in existing and potential collaborative opportunities as well as in the operational support for project management. The Initiative plays a role of facilitator by bringing key stakeholders together and helping to build bridges between various teams.

DEVELOPING PROJECT MANAGEMENT AND ASSESSMENT TOOLS FOR TEAMS

MUSCO's working groups are made up of world-class professionals and experts in the field of health care. Some lack project management experience or training. These skills would therefore be very useful in helping them move forward with the projects they are in charge of.

Setting up Patient Resource onboarding workshops will help all those involved — physicians, rehabilitation professionals, clinicians, researchers and administrators alike — to have access to the same information and insight into how to integrate families' experience-based knowledge so that their needs are taken into account in project development and implementation efforts.

Likewise, a metrics assessment mindset needs to be implemented. This is more than just determining whether or not a given outcome has been achieved. It is a tool that encourages those involved to take various factors and positions into consideration to move projects forward that will benefit patients and families. The work that will be undertaken in 2020–2021 with the NISKA agency on an impact study involving families and institutions to explore MUSCO's overall impacts should help advance this approach.

Patient continuum
of care project
Workshop





BUDGET DETAILED SUMMARY

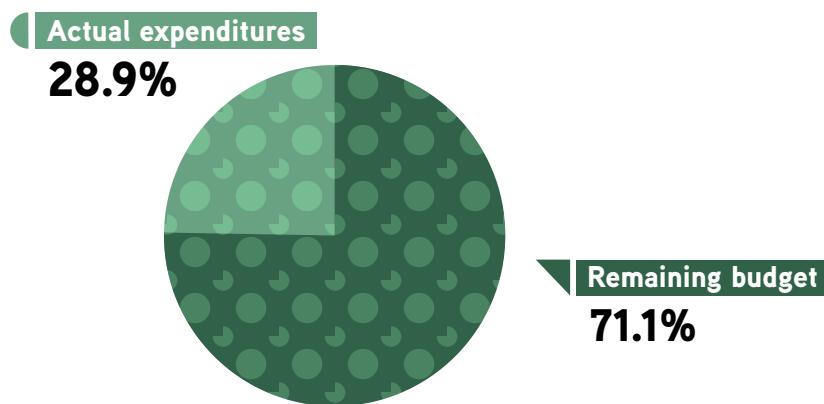
“ [We decided to become Patient Experts for the MUSCO Initiative Advisory Pole because] this is a cause that means a lot to us. We wanted to do our part to help other families who are facing difficulties similar to what we have been through. We want to help patients and their families enjoy a better quality of life.

— DANIEL AND ISABELLE, PARENTS OF 17-YEAR-OLD ANGÉLIQUE

DETAILED FINANCIAL SUMMARY

Close to 29% of the budget had been used by the end of the second year of the Initiative. This is less than had been originally projected but still within realistic limits given the Initiative's five-year timeframe.

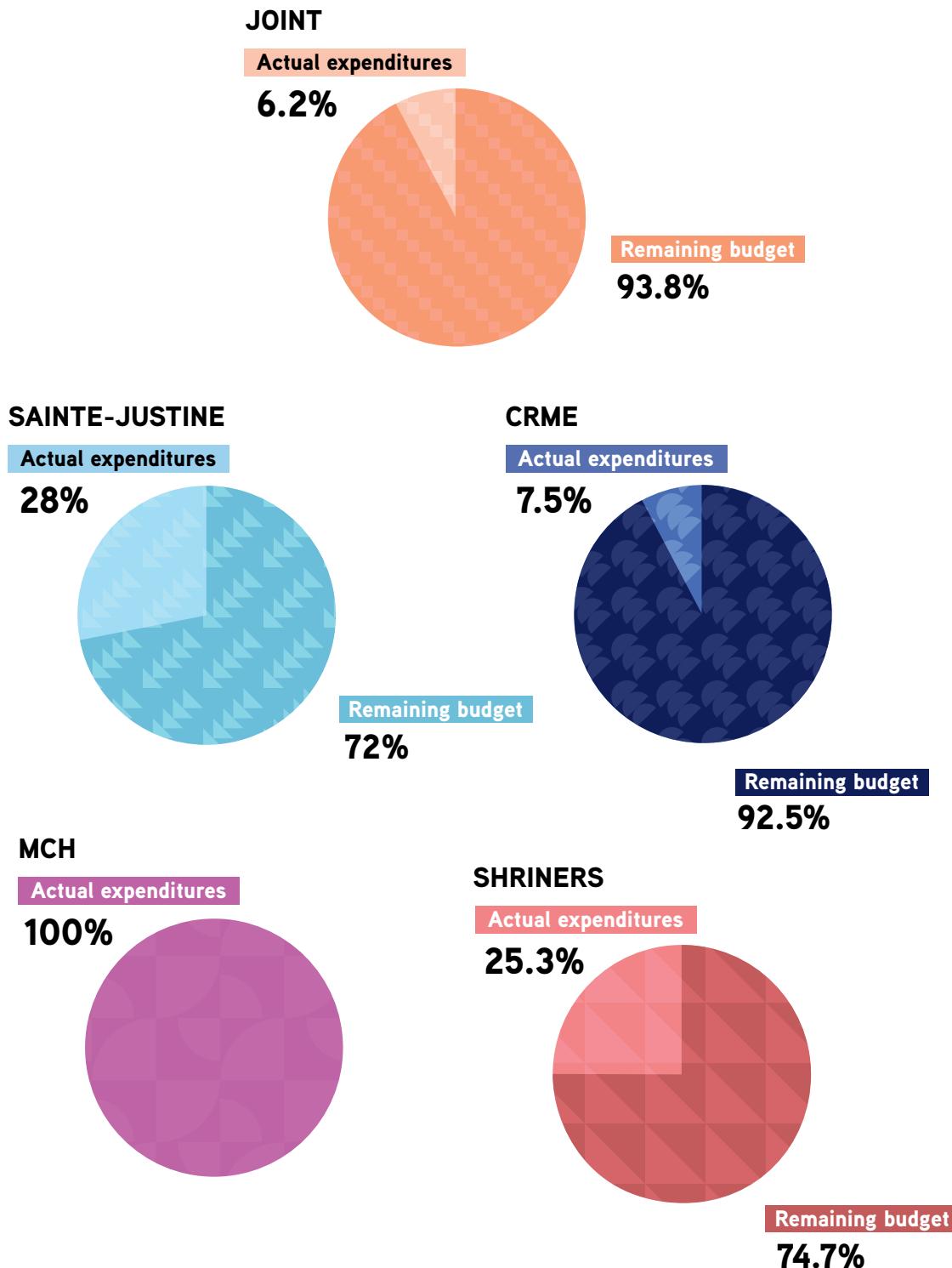
The variation between actual spending and projections can be attributed to the delayed launch of certain projects, which need to progress from idea to project, with clear goals, stages and desired outcomes.



THE BUDGET STATUS FOR EACH OF THE JOINT AND MAJOR COMPONENTS ON AN INSTITUTION-BY-INSTITUTION BASIS IS AS FOLLOWS:

- To date, CHU Sainte-Justine has disbursed nearly 28 % of the funds earmarked for major projects. Expenses doubled from Year 1 to Year 2 due to the increased spending attributable to the URCO clinical research project and the launch of the quality-of-life survey project.
- The CRME has spent 7.5 % of the funds set aside for its major projects. Its first expenditure was made in Year 2 (acquisition of a 3D printer).
- The Montreal Children's Hospital has disbursed the entirety of its major project budget. Note that this was in the form of an endowment fund.
- Shriners Hospitals for Children – Canada has spent 25.3 % of the funds allocated to its major project, 1.5 times less than in Year 1. The time required to calibrate the sequencer led to a delay in the acquisition of other equipment and supplies.
- Only 6.2 % of the funds earmarked for joint projects has been spent, but the amounts disbursed tripled from Year 1 to Year 2.

MAJOR AND JOINT PROJECT SPENDING TO DATE⁴



4

Percentages based on figures reported as at June 30, 2020



LOOKING AHEAD TO 2020-2021

“

I think the MUSCO Initiative will help align the various methods used at each of the centres or hospitals so that, wherever you are referred, you'll get the same care or service. This will have a positive impact on my daughter, who is a patient at several different facilities.

— CRISTINA, MOTHER OF 5-YEAR-OLD NAYLA

THE IMPACT STUDY: A KEY STEP IN MEASURING OUTCOMES, STRENGTHENING ENGAGEMENT AND ADJUSTING OBJECTIVES

Efforts will be undertaken in fall 2020 to review the impact of the Initiative on families and institutions. As we align on the desired outcomes of the different projects, it will be possible to revisit the original objectives to make sure they are still on track to achieve the specified outcomes. In the event that they are not, they will need to be modified and adapted. These efforts will help spark or rekindle a sense of ownership among each of the participants and ensure project indicators are being effectively monitored.

BRANDING PLAN FOR INCREASED TRANSPARENCY AND VISIBILITY

During the course of Year 2, the idea was floated of developing a branding plan for MUSCO to draw attention to the Initiative and the work it does. The tools to be developed will focus on MUSCO's *raison d'être*, what the Initiative represents (and doesn't represent) and the various projects being carried out under the MUSCO umbrella. This plan will be executed in Year 3, with information distributed to families, stakeholders and participants, as well as external partners within the MUSCO community.

STRENGTHENING THE MUSCO TEAM

The Executive Committee confirmed the need to recruit another team member to assist the project manager, bringing the total number of people hired by the Initiative to two. The second person will also help roll out the new brand identity and assist in exploring collaborative opportunities and developing joint projects, including the educational technology project and respite project that have yet to get off the ground.

RECRUITMENT AND ONBOARDING OF PATIENT RESOURCES

The content of the onboarding workshops for Patient Resources selected for the Initiative's working teams was fleshed out during the pandemic. The corresponding workshops will be held in Year 3 so that as many project participants as possible (internal or external) can take part. A list of close to 80 people has been drawn up, and an invitation to take part in these sessions, organized in cooperation with the Planetree consulting firm, will be issued.

CONCLUSION

The MUSCO Initiative has come to the end of its second year of operations. Like any undertaking early in its development, there are still questions: Will the Initiative achieve its goals? In what direction will it evolve? With efforts ongoing and a number of projects underway, there seems to be ample proof that its existence is justified.

This has been further corroborated by the Patient Experts who were recruited this year to serve on the Advisory Pole, a new central body within MUSCO's governance structure. Beyond the issues related to the condition of their children and the difficulties and uncertainties related to COVID-19, all of these Patient Experts were excited to get involved and make a difference in something they saw as necessary and highly relevant.

Many of the activities in our partner institutions were put on hold because of the pandemic, and MUSCO was no exception in that it is not an essential service. Although the usual contributors — the physicians, nurses and administrators who make up the Initiative's working groups — were less available, significant progress was made, projects were developed and the Initiative's governance was finalized, with a new Steering Committee in place to contemplate the overall institutional response in addressing the current and future needs of families.

In the coming year, special attention will be paid to issues related to teleconsultation, telemedicine and telepractice. Although some families are quick to sing the praises of online checkups, which are more convenient and less disruptive to family life, others point out that in-person appointments are critical to avoid overlooking certain diagnoses or post-operative complications that could be harmful to children's health and well-being. The Initiative will have to evolve in step with these changes and re-examine existing practices and the in-hospital care and services offered to patients.



Participant in the
Cerebral Palsy Event
Photo: Benoit Desjardins

THE TEAMS BEHIND THE PROJECTS

THANK YOU FOR EVERYTHING YOU DO!

Steering Committee

Isabelle Demers
Margaret Ruddy
Jacques Boissonneault
Maud Cohen
Renée Vézina
Dave Merrett
Claude Pinard
Ekat Kritikou
Catherine Rowe
Suzanne Korf
Nathalie Kamel
Aurélie Vigné

Advisory Pole

Caroline Marie Fidalgo
Cristina Cando
Linda Moreau
Daniel Bélec
Isabelle Courchesne
Angélique Bélec
Ariane Tremblay
Stéphanie Gould
Aurélie Vigné

Executive Committee

Dr. Stefan Parent
Maryse St-Onge
Dr. Jean-Pierre Farmer
Dr. Reggie Hamdy
Ekat Kritikou
Jacques Boissonneault
Claude Pinard
Aurélie Vigné

Full Committee

Dr. Stefan Parent
Maryse St-Onge
Dr. Jean-Pierre Farmer
Dr. Reggie Hamdy
Ekat Kritikou
Jacques Boissonneault
Claude Pinard
Kelly Thorstad
Dr. René St-Arnaud
Carl-Éric Aubin
Dr. Peter Glavas
Dr. Sherif Emil
Maud Cohen
Catherine Rowe

Adèle Lasne

Suzanne Korf
Nathalie Kamel
Julie Letendre
Stéphanie Gould
Aurélie Vigné

Rehabilitation Equipment Project
Carl-Éric Aubin*
Elizabeth Clark

Technical Aids Project
Carl-Éric Aubin*
Elizabeth Clark

URCO Clinical Research Project

Dr. Stefan Parent*
Marjolaine Roy-Beaudry
Isabelle Turgeon
Nathalie Jourdain
Soraya Barchi
Julie Joncas

DNA Sequencing Project

Dr. René St-Arnaud*
Dr. Frank Rauch
Marie-Josée Giguère
Dr. Jean Ouellet
© Jacques Michaud
© Philippe Campeau
Aurélie Vigné

Enhanced Recovery Project

Dr. Sherif Emil*
Elena Guadagno

Training Plan**Project
(SPORC)**

Dr. Peter Glavas
Dr. Reggie Hamdy
Joelle Fortier
(Patient Resource Workshop)
Marie-Claude Poulin
Julie Letendre
Stéphanie Gould
Aurélie Vigné

**Respite and Financial
Aid Project**

Julie Letendre
Stéphanie Gould
Aurélie Vigné

**Educational Technology
Project**

Julie Letendre
Stéphanie Gould
Aurélie Vigné

Living Lab Project

Maryse St-Onge*
Elizabeth Clark

**Community Organization
Support Project**

Maryse St-Onge*
Josée Laganière

Advisory Pole Project

Julie Letendre
Stéphanie Gould*
Aurélie Vigné
Marie-Claude Poulin

**Quality-of-Life
Survey Project**

Dr. Stefan Parent*
Dr. Marie-Lyne Nault
Sarah Emery
Soraya Barchi
Marjolaine Roy-Beaudry
Julie Joncas
Sylvain Fournier
Sylvain Caron
François Charbonneau
Pierre-François Gautier

Patrick Desmarais

Aurélie Vigné

Surgical Training Project

Dr. Sherif Emil *
Dr. Jean-Pierre Farmer
Elena Guadagno
Dr. Lili Nguyen
Dr. Jean Ouellet

Cerebral Palsy Event Project

Dr. Peter Glavas*
Dr. Marie-Andrée Cantin
Dr. Mathilde Hupin
Maryse St-Onge
Tina del Duca
Dr. Marie Laberge
Josée Laganière
Dr. Reggie Hamdy
Noémie Dahan-Oliel
Dr. Jean-Pierre Farmer
Lise Roche
Lisa Gouin
Joelle Fortier
Aurélie Vigné

**Pediatric Surgery
Consortium Project**

Dr. Sherif Emil*
Elena Guadagno

Branding Group

Maud Cohen
Suzanne Korf
Nathalie Kamel
Claude Pinard
Gabriella Musacchio
Fannie Perron
Aurélie Vigné

Impact Working Group

Céline Rossini
& Krystel de Knibber
Aurélie Vigné

**Patient Continuum
of Care Project**

Kelly Thorstad*
Lucie Thomas
Marie-Annie Lagacé
Androniki Tsoybariotis
Tina del Duca
Maryse St-Onge
Isabelle Dussiaume
Margaret Ruddy
Soo Lin Ng
Sarah Emery
Julie Letendre

Stéphanie Gould
Marie Beauséjour
Martin Sasseville
Sophie Riendeau
& Claire Grillet
Aurélie Vigné

**Inter-establishment
Navigator Project**

Kelly Thorstad
Tina del Duca

**Orthopedic Care
Database Project**

Dr. Stefan Parent*
Sylvain Fournier
Sylvain Caron
François Charbonneau
© (Dr. Jean Ouellet)
© (Dr. Neil Saran)
© (Toufik Baziz)
© (Karina Barco)
© (Dr. René St-Arnaud)
© (Kathryn Fournier)
Aurélie Vigné

3D Radiology Rooms Project

Dr. Stefan Parent*
Mathieu Germain

Support for Administrative Operations

Isabelle Jasmin
Catherine Lowe
Catherine Trépanier
Sylvie Sahyoun
Soraya Barchi
Valérie Caledec
Mélanie Lagacé-Thibault
Sophie Kellie Bergeron
Manuela Maurice
Sylvie Faucher
Amna Marily Gosselin-Martin
Tammy Johnson
Jillian Barnes
Paula Wall
Robert Gordon Scott
Sharon Delisle
Marcella Cicciu
Yarnell Steinberg
Jennifer Dacius
Josée Lamarre
Ines Celeschi
Julia Laletti

**Support for Financial
Operations**

Sylvie Cossette
Marie-Eve Carton
Luisa Stoica
Ralica Marinova Petrova
Laurence Langlois-Parent
Josée Lanteigne
Wedline Rimpel
Shabnam Ahmadzai
Hugo Rivard-Royer
Fayrouz Aouad

**Support for Human
Resources Operations**

Dounia Boussefiane
Cristina Pulciani
Sandra Champagne
Rachel Hawes
Kim Salvetti

KEY

CHU SAINTE-JUSTINE MARIE ENFANT REHABILITATION CENTRE
MONTREAL CHILDREN'S HOSPITAL
SHRINERS HOSPITALS FOR CHILDREN – CANADA MUSCO STAFF
MIRELLA & LINO SAPUTO FOUNDATION EXTERNAL PARTNERS PATIENT EXPERTS

© COLLABORATIVE TIES

CREDITS

WRITTEN BY

Aurélie Vigné
Grammata

DESIGN AND LAYOUT BY

Pilon design

TRANSLATION BY

Shonda Secord

COVER PAGE PHOTOGRAPHY



Cerebral Palsy Event,
December 2019
Photo: Sophie Ouellette



Cerebral Palsy Event,
December 2019
Photo: Sophie Ouellette



MUSCO press conference,
June 2018
Photo: Ashley MacPhee Photography



