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**485<sup>th</sup> REPORT OF THE ACADEMIC POLICY COMMITTEE TO SENATE – Part B  
on the APC meeting held on February 8<sup>th</sup>, 2018****I. TO BE APPROVED BY SENATE****(A) NEW TEACHING PROGRAMS REQUIRING SENATE APPROVAL- *none*****(B) ACADEMIC PERFORMANCE ISSUES / POLICIES / GOVERNANCE/AWARDS - *none*****(C) CREATION OF NEW UNITS / NAME CHANGES / REPORTING CHANGES****Faculty of Medicine****Azrieli Centre for Autism Research (ACAR) – Centre Azrieli pour la Recherche en Autisme (CARA) *appendix A***

At a meeting on February 8<sup>th</sup>, 2018, APC reviewed and endorsed a proposal to approve the Azrieli Centre for Autism Research (ACAR). The research focus of ACAR is Autism Spectrum Disorders, which globally affect 1 to 2% of children globally, and associated neurodevelopmental conditions. Leaning on the MNI's expertise and reputation in neuroscience, this research centre will act as a central hub for collaborative research, training and knowledge translation at McGill University and across the province of Quebec, through the Transforming Autism Care Consortium (TACC) network, which gathers over 40 researchers and 200 associate members. Established thanks to a generous donation from the Azrieli Foundation, the ACAR will create a framework for scientific progress, which will have a meaningful impact on people living with autism disorders and their families.

APC therefore recommends that Senate approve the following resolution:

*Be it resolved that Senate approve and recommend to the Board of Governors for approval the official creation of the Azrieli Centre for Autism Research (ACAR).*

**(D) CHANGES IN DEGREE DESIGNATION – *none*****(E) INTER-UNIVERSITY PARTNERSHIPS – *none*****(F) OTHER – *none*****II. TO BE ENDORSED BY SENATE / PRESENTED TO SENATE FOR DISCUSSION – *none*****III. APPROVED BY APC IN THE NAME OF SENATE****(A) DEFINITIONS – *none*****(B) STUDENT EXCHANGE PARTNERSHIPS / CONTRACTS / INTERUNIVERSITY PARTNERSHIPS - *none*****(C) OTHER - *none*****IV. FOR THE INFORMATION OF SENATE**

**A) ACADEMIC UNIT REVIEWS – *none***

**B) APPROVAL OF COURSES AND TEACHING PROGRAMS**

**1. Programs**

- a) APC Approvals (new options/concentrations and major revisions to existing programs)

- i. New Programs

**Graduate and Postdoctoral Studies**

Faculty of Science

Ph.D.in Psychology; Behavioural Neuroscience (0 cr.)

APC approved this new concentration on February 8<sup>th</sup>, 2018.

- ii. Major Revisions of Existing Programs - *none*

- b) APC Subcommittee on Courses and Teaching Programs (SCTP) Approvals

(Summary Reports: <http://www.mcgill.ca/sctp/documents/>)

- i. Moderate and Minor Program Revisions

*Approved by SCTP on January 10<sup>th</sup>, 2018 and reported to APC on February 8<sup>th</sup>, 2018*

**Faculty of Education**

B.Ed. in Secondary Science and Technology (120 cr.)

B.Ed. in Physical and Health Education (120 cr.)

**Faculty of Engineering**

B.Eng.; Major in Mining Engineering (150-151 cr.)

B.Eng.; Minor in Technological Entrepreneurship (18 cr.)

B.Eng.; Major in Bioengineering (141-151 cr.)

B.Eng. in Chemical Engineering (143-146 cr.)

B.Eng. in Civil Engineering (139 cr.)

B.Eng. in Computer Engineering (133-140 cr.)

B.Eng. in Electrical Engineering (134-139 cr.)

B.Eng.; Honours in Electrical Engineering (134-139 cr.)

B.Eng.; Co-op in Software Engineering (141-147 cr.)

B.Eng. in Mechanical Engineering (142-148 cr.)

B.Eng.; Honours in Mechanical Engineering (142-148 cr.)

B.Eng.; Major in Materials Engineering (148 cr.)

B.Eng.; Co-op in Materials Engineering (148 cr.)

B.Eng.; Major in Mining Engineering (144-145 cr.)

B.Eng.; Co-op in Mining Engineering (150-151 cr.)

**Desautels Faculty of Management**

B.Com.; Major in General Management; Concentration in Finance (15 cr.)

B.Com.; Major in Finance (30 cr.)

B.Com.; Minor in Finance (for Non-Management Students) (18 cr.)

**Faculty of Science**

B.Sc.; Minor in Computer Science (24 cr.)

B.Sc.; Interfaculty Program in Cognitive Science (54 cr.)

B.A. and B.Sc.; Honours in Cognitive Science (60 cr.)

ii. Program Retirements

*Approved by SCTP on January 10th, 2018 and reported to APC on February 8<sup>th</sup>, 2018*

**Faculty of Education**

Concurrent B.Sc./B.Ed.; Major Concentration in Biology – Cell/Molecular with Minor in Chemistry for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Biology – Organismal with Minor in Chemistry for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Biology – Cell/Molecular with Minor in Physics for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Biology – Organismal with Minor in Physics for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Chemistry with Minor in Biology for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Chemistry with Minor in Physics for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Mathematics for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Physics with Minor in Biology for Teachers (135 cr.)

Concurrent B.Sc./B.Ed.; Major Concentration in Physics with Minor in Chemistry for Teachers (135 cr.)

**2. Courses**

a) New Courses

*Reported as having been approved by SCTP on January 10<sup>th</sup>, 2018: 14*

Faculty of Education: 3

Faculty of Medicine: 2

Schulich School of Music: 4

Faculty of Science: 5

b) Course Revisions

*Reported as having been approved by SCTP on January 10<sup>th</sup>, 2018: 11*

Faculty of Education: 3

Faculty of Medicine: 3

Faculty of Science: 5

c) Course Retirements

*Reported as having been approved by SCTP on January 10<sup>th</sup>, 2018: 1*

Faculty of Science: 1

**3. Other - none**



Montreal, November 30, 2017

Research Advisory Council (RAC)  
Professor Martha Crago  
RAC Chair  
Vice-Principal, Research and Innovation

**Re: Azrieli Centre for Autism Research (ACAR), response to reviewers from the RAC**

Dear Professor Martha Crago and members of the Research Advisory Council,

We wish to thank the reviewers for their enthusiasm and positive feedback regarding our proposal. We have added further details as requested.

***RAC 1. More information was requested on the strategic positioning of the Centre, especially with respect to other Centres outside McGill.***

Autism impacts over 50M children worldwide; major investments are being directed to research and practice in this area. McGill and the Neuro has several pockets of strength and many unique advantages in neuroscience, reflected in the university wide priority on Health Brains Health Lives. As such, ACAR addresses this university wide priority in the area of autism and related conditions. Our approach will remain collaborative, harnessing the intersection of multidisciplinary expertise of ACAR members, spanning genomics, brain sciences, and cognitive research.

Compared to other autism centers and initiatives, ACAR is internationally unique in its (1) multidisciplinary, (2) the focus on translational research and community engagement (3) the support and anticipated involvement from the Faculty of Medicine and McGill's teaching hospitals, and (4) the exceptional level of support we have received from donors and the wider community – these are features rarely found in autism centers anywhere in the world. This positioning was recently reaffirmed by Principal Fortier as well as the Minister Barrette, at the ACAR gift announcement which took place earlier this month: <http://www.mcgill.ca/neuro/node/2800>

***RAC2. Please include additional information on the justification for the creation of ACAR, given the presence of TACC.***

ACAR is a physical center at the Neuro that consolidates strengths of all McGill's researchers, other McGill centers, and teaching hospitals, in translational autism research. ACAR is also the main hub for TACC, a de-centralized province-wide research network, that includes over 40 researchers and 200 members in 7 universities (including McGill) and 5 hospitals. TACC has been designated as an FRQ-S Thematic Network, alongside other provincial strategic groupings enhancing Quebec's competitiveness in autism research and structuring its development. Although ACAR and TACC have the same Directors, TACC's Scientific Steering Group has province-wide representation and guides all its activity. The two entities are complementary and are needed to balance depth of research programming which ACAR will accomplish with breadth/connectivity through the network architecture of TACC.

**RAC3. Please include more details about the ACAR Clinic.**

The “ACAR Clinic” is short-hand for a new clinical research platform that develops and evaluates translational (diagnostic and therapeutic) programs currently not available in routine care. It will be the focal point of interaction with families who would be invited to participate in ongoing research studies. The platform will also support McGill researchers in advancing their programs as a central point for recruitment, specialized behavioral assessment, and engagement of families in research.

Dr. Elsabbagh’s current research database includes over 600 families who will be readily integrated into the new ACAR platform. Further scaling up of activities will focus on under-represented populations, e.g., programs for autistic adults and high impact programs as well as clinical trials (all areas of strengths and substantial capacity at the Neuro). We anticipate direct involvement and interactions with health and social services, including over 15 clinicians across different hospitals/departments who are involved in referring new families and individuals.



Mayada Elsabbagh  
Co-Director, ACAR

## **Research Centre Proposal**

**April 19 2017**

### **I. Identification**

- Name of the research centre

Azrieli Center for Autism Research

- Proposed co-directors

Guy Rouleau, Montreal Neurological Institute

Mayada Elsabbagh, McGill University Health Centre and Douglas University Mental Health Institute

- Lead Faculty

Faculty of Medicine

- Other Faculties involved in supportive capacity

Faculty of Arts

Faculty of Education

- Physical location of the research centre

Montreal Neurological Institute

### **II. Rationale**

- Context and background for creating a research centre

ACAR is a state of the art research centre that advances knowledge in autism and supports its translation into societal benefits. The focus of research are Autism Spectrum Disorders, which affect 1–2% of children globally as well as associated neurodevelopmental conditions. Estimated lifetime economic costs for every affected individual reach \$2.4M, and there is often a dramatic impact on the entire family. Autism interferes with the person's ability to relate to and communicate with others. The condition affects people differently with some suffering serious consequences and social exclusion, while others can lead independent and fulfilling lives. Recent discoveries are illuminating the underlying neurobiology of altered development in autism and identifying periods of greatest responsiveness to treatment. Rapid development of several technologies including genomics, cellular modelling, neuroimaging and electrophysiology offer a unique opportunity to understand genetic and molecular factors and associated downstream intermediate phenotypes, thus delineating mechanisms at multiple levels. To achieve these goals, autism research increasingly relies on multidisciplinary research and large cohorts of participants to overcome challenges in the biological and behavioral heterogeneity of the condition, and in turn to improve quality of life of people affected. ACAR will leverage McGill/MNI's strengths and international reputation in neuroscience to advance translational research, training, and knowledge translation in autism.

- Overall purpose of the research centre

ACAR will act as the central hub for collaborative research, training, and knowledge translation within McGill university, and province-wide through an emerging research network<sup>1</sup> "Transforming Autism Care Consortium; TACC". This network currently groups over 40 researchers and 200 associate

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<sup>1</sup> As defined by FRQ-S program for Thematic Networks. A formal application to recognize and fund the network is currently under review in the 2016-17 competition.

members. Appendix F includes a more detailed description of synergy between ACAR as a research center and TACC as a provincial network.

- Past history

ACAR is the result of a collaborative proposal to form a new autism center recently approved by the Azrieli Foundation. Further collaborative links among ACAR members are evident through multiple competitive grants recently obtained (>6M from Brain Canada) or submitted (>5.5M from FRSQ, Birks Family Foundation, Couture Foundation, Bourgeois Foundation).

- Recommendations – reference attached letters of support

David Eidelman, Dean, Faculty of Medicine

Marc Weinstein, VP, University Advancement

### **III. Program**

ACAR is a center for translational research focused on autism and related neurodevelopmental conditions, with following goals:

- Short-term

1. Research: Recruit ACAR core members with complementary expertise in translational autism research, and support development and sustainability of their programs
2. Platforms & Common resources: Enable highly competitive integrated research through
  - a. A new clinical research platform (ACAR Clinic) to advance clinical registries, behavioral assessment, and interface with clinical services for families enrolled in center's research
  - b. Customization of MNI experimental platforms for participants on the spectrum/their family members across the lifespan
  - c. Develop a new animal research platform with marmosets
  - d. Development of a Family Registry and a Data Repository
3. Capacity building: Build capacity through institutional and province-wide programs Training, seed funding, and event programs

- Long term goals

4. New knowledge: Advance knowledge in the biological mechanisms underlying autism.
5. Clinical Trials: Develop large scale clinical trials
6. Partnerships: Develop action-oriented knowledge translation partnerships towards improving quality of life for people with autism or a related condition through:
  - a. Enhanced excellence in patient care
  - b. Improved family centeredness and coordination of care across the life span
  - c. An autism friendly society e.g., NGOs, education, policy, industry.

- Value added

1. Attract and/or retain world-class research talent
2. Integrate and facilitate a host of high-impact research strategies, providing insights into the biological origins of the heterogeneous clinical phenotype in autism
3. Advance high impact research on autism biomarkers across the lifespan
4. Provide a unique training and mentoring environment at the cross-roads of basic and translational research, complementing existing degree programs.
5. Increase accessibility and impact of new knowledge and innovations, benefitting children and families

- Description of the research program – axes of research

Autism Spectrum Disorder (ASD) describes a range of neurodevelopmental disorders characterized by deficits in social communication and social interaction, combined with restricted, repetitive patterns of behavior, interests or activities. ASD affects 1–2% of children globally, with a higher prevalence in boys.

Although there is a large body of internationally recognized research on ASD currently being produced by Quebec researchers, these efforts will be substantially enhanced by integrating them into a common province-wide network with shared resources. There is also an unprecedented interest to fund such efforts from private organisations, who recognize a large unmet need to translate research findings into meaningful and effective interventions for autistic individuals and their families.

ACAR is an ambitious trans-disciplinary center to understand spectrum of autism disorders from the behaviour of patients to the genes responsible and the consequences of those genetic aberrations for brain connectivity. The **Genomics Axis** will identify and characterize genetic factors underlying ASD using current and next generation sequencing and related technologies and their applications for risk stratification. The **Advanced Animal Models Axis** will produce and study cell and animal models of gene mutations associated with ASD with a special focus on those which affect brain connectivity. The **Brain Development Axis** will identify very early neural risk markers and their impact on human brain development using powerful imaging and neuro-informatics tools. Imaging (MRI, EEG) methods will be used to understand origins of the atypical connectivity and its change over development. The **Behavior Axis** will focus on perceptual and cognitive profiles in autism, and how they can feed intervention programs. Advanced assessment (standardized measures, eye tracking, behavioral experiments) will be used to map dimensions of variability in the autism phenotype. Finally, the knowledge translation axis will strengthen community based research and research utilization by community organizations by forming formal links between researchers, clinicians, funding organizations, and ASD patient groups. It will also help disseminate results of the TACC to the general public and other stakeholders. We will move neuroscience research along the translational pathway toward clinical trials, care pathways, and social impact.

- Contribution to training

#### ACAR Trainees

Through members and their labs, ACAR will provide a unique multidisciplinary environment and supportive resources for trainees at all levels.

#### TACC Quebec Autism Research Training Program

Through TACC, the center will establish a province-wide competitive program. The program will offer additional benefits and training opportunities to students enrolled or newly accepted into degree programs. The program will annually accept 6-10 new graduate trainees at any Quebec university for a period of 3 years, offering:

- 1-year scholarships
- Annual summer school
- Cross-disciplinary mentorship
- Annual funding to present at an international conference

#### Specialist autism training at McGill and its teaching hospitals

We will conduct an environmental scan to assess needs and capacity for specialist training, e.g., diagnostic, mental health, medical comorbidities. This information will be used to develop sustainable training objectives through ACAR, working with all relevant faculties, e.g., Medicine (all programs), Science (clinical psychology program), Education (educational psychology program).

- Funding for research activities

ACAR activities will be funded through the following sources:

1. The center has been funded by a gift from the Azrieli Foundation (16.1 M over five years)

2. ACAR members have their own operating budgets
3. ACAR will leverage infrastructure and funding through synergy and alignment with other groups/centers (detailed in the next section)
4. Funding for activities of the broader provincial network TACC is currently requested (detailed above)

#### **IV. Strategic positioning**

- Positioning, added value, and importance

Currently several strengths in autism research exist across various departments and institutes but are not coherently connected. ACAR's focus on translational autism research builds on the MNI's reputation as a leader in neuroscience. The center, along with the research network TACC, will provide an organizing framework for a wide range of collaborative activities and partnerships to advance research, training, and societal impact.

ACAR will ensure that existing capacity and excellence are fully leveraged through collaboration with various centers and initiatives with shared goals:

1. McGill Healthy Brains Healthy Lives Initiative (Alan Evans)
2. Brain Imaging Centre (Rick Hoge)
3. MNI Neurodevelopment group (Edward Ruthazer)
4. MNI Open Science (SGC; Guy Rouleau)
5. Ludmer centre (Alan Evans)
6. Faculty of Medicine and (Dean, Associate Dean-Education)
7. MNI Clinical Trials Unit
8. New McGill School for Public Policy (Antonia Maoni, Dean of Arts)
9. ACCESS- SPOR (Srividya Iyer, Scientific and Clinical Director)
10. CHILD-BRIGHT- SPOR (Keiko Shikako-Thomas, Knowledge Translation Lead)

Beyond the local context, ACAR provides a focal point to showcase McGill's international competitiveness in autism research.

#### **V. Governance**

- Description of the governance structure

ACAR in an MNI Center, with two co-Directors who will oversee its development and sustainability. An ACAR Board will monitor progress and offer recommendations.

- Organizational chart

See Centre chart and MNI global organizational chart (Appendix G)

- Proposed inaugural membership of the board and other key committees

The ACAR Board will meet 3 times per year and will include the following:

1. Co-directors of the research center
2. Dean, Faculty of Medicine (or delegate)
3. Vice-Principal, Advancement (or delegate)
4. Vice-Principal, Research and Innovation (or delegate)
5. Provost (or delegate)
6. Azrieli Foundation representative(s)
7. Two parent representatives
8. A trainee representative
9. Two TACC Steering Group Members from institutions other than McGill

As the leading hub for TACC, ACAR will also manage TACC workgroups/committees that are now in the

process of developing their own milestones/timelines. These include the following groups (detailed in the TACC Charter):

1. Steering Group
2. Advisory Committee
3. Friends of TACC

ACAR AND TACC will host a joint annual general meeting and conference in October, as part of an annual events plan based on their common objectives. See Appendix F for details.

## **VI. Membership**

ACAR will have *Core* and *Associate Members*. A larger number of researchers and their team members will interact with ACAR members through the network structure of TACC. Membership categories are detailed below; a full list of affiliated McGill members is included in Appendix D.

### ACAR Core Members

ACAR's core members are MNI researchers with dedicated translational research programs in autism or related conditions. In addition to the co-director (Elsabbagh), ACAR will recruit 3 MNI faculty members with complementary expertise in translational autism research.

### ACAR Associate Members

Associate Members are established researchers based at any McGill Institution and with whose programs include a significant focus and funded projects on autism or related conditions. Most are also members of the TACC steering group:

1. Salvatore Carbonetto
2. Carl Ernst
3. Alan Evans
4. Nahum Sonenberg
5. Edward Ruthazer

### TACC's Members

ACAR members are also by default members of TACC. As a research network, TACC membership structure follows FRQ-S guidelines for Thematic Networks (Regular Members, Associate Members, Honorary Members). These categories are described in the TACC Charter. McGill researchers who have joined TACC as regular members are listed in Appendix D.

- Process for accepting new members

Nominations for new core and associate members of ACAR will include full CVs and letters of support. They are then submitted to the board for approval. Terms of membership are renewable, and each term will be up to six years for core and associate members.

## **VII. Facilities and other resources**

- Research platforms and additional platform staff

Through collaboration with existing MNI platforms/centers, ACAR will customize existing experimental infrastructure and create new platforms to support a wide range of research activities. This includes platforms for animal models, cellular models, genomic sequencing, MRI, EEG, eye tracking, drug screening, and neuroinformatics. ACAR will also create a new autism clinical research platform (ACAR Clinic). New staff supporting platforms are a Medical Director, Senior Clinical Psychologist, Clinical research coordinator, and a Nurse.

Facilities will be available to all ACAR member and to TACC Steering Group members.

- Support staff

As an MNI Centre, ACAR will rely for the most part on senior administrative personnel who will work with the co-directors to ensure seamless administration, financial management, development, and external communications. ACAR will add two positions for an Administrative Coordinator and a Technician.

- TACC staff

As the coordinating center for TACC, a provincial core team for the network will also be based at ACAR among other Quebec research centers. These are Senior Program Manager, Programs Coordinator, Data Scientist, and a Knowledge Broker.

- Future expansion

ACAR will move to a purpose designed facility in approximately three years.

## **VIII. Budget**

Operational expenditures over five years and sources of funding is included in Appendix E, consistent with the budget approved by the Azrieli Foundation. Sustainability of the centre will be ensured through the following:

- The ACAR gift includes an endowment
- New philanthropic investments are being actively pursued
- Harmonization with TACC attracts a broader group of funders and ensures flexible allocation of funds according to strategic priorities and emerging opportunities, e.g., FRSQ thematic network application under review
- New proposals can be made to the Azrieli Foundation for new directions that build on accomplishments in the next 5 years.

## **Appendices:**

- A. ACAR Bylaws
- B. TACC Charter
- C. Letters of support
- D. McGill Members
- E. Budget
- F. About ACAR vs. TACC
- G. Centre chart and MNI global organizational chart

## **APPENDIX I: Azrieli Centre for Autism Research Bylaws**

### **1. Name and Location**

The name of the research centre, in the form “Azrieli Centre for Autism Research”, based at the Montreal Neurological Institute.

### **2. Purpose**

ACAR will advance neuroscience research, training, and knowledge translation in autism.

### **3. Management**

The co-director of the research centre are responsible for the management and reports to the dean of the Faculty of Medicine, who will act as chair of the board.

### **4. Membership of the Board**

The membership of the board will include the following:

1. Co-directors of the research center
2. Dean, Faculty of Medicine (or delegate)
3. Vice-Principal, Advancement (or delegate)
4. Vice-Principal, Research and International Relation (or delegate)
5. Provost (or delegate)
6. Azrieli Foundation representative(s)
7. Two parent representatives
8. A trainee representative
9. Two TACC Steering Group Members from institutions other than McGill

The board members who are also members of the research centre, and who do not serve *ex officio*, will be elected by their appropriate constituencies. The terms of appointment of the board members, other than the dean(s), Vice-Principal (Research and International Relations), or their delegates, will normally be three years for faculty and one or two years for students and postdoctoral fellows.

### **5. Appointment of the Director**

Recommendations for nomination of the director and, if necessary, the associate director of the research centre will be made to the board by a subcommittee consisting of at least the dean, two active full members of the research centre, and one other member of the board. If necessary, the board may decide to conduct an open search for a director. The recommendation of the board for the appointment of a director and, if necessary, an associate director, will be conveyed to the Provost by the dean of the Lead Faculty. The Provost has the responsibility of approval of the appointments. In the case of appointments across multiple Faculties, the deans of all Faculties affected must be consulted. The appointment of the director and, if necessary, associate director, will normally be for a term of up to six years.

### **6. Annual Report**

The co-directors of the research centre will prepare the annual report, which will include all financial details of the operation of the research centre, along with the centre's measurable goals for the coming year. This will be presented to the board for approval. Following its approval, the annual report will be submitted to the Provost, the Vice-Principal (Research and International Relations), and the deans of all contributing Faculties.

## **7. Membership of the Centre**

### **ACAR Core Members**

ACAR's full members are MNI researchers with dedicated translational research programs in autism or related conditions.

### **ACAR Associate Members**

Associate Members are established researchers based at any McGill Institution and with whose programs include a significant focus and funded projects on autism or related conditions.

Nominations for new full and associate members of the research centre must include full *curricula vitae* and letters of support. They must be submitted to the board for approval. Terms of membership are renewable, and each term will be up to six years for full and associate members, up to two years for student members and postdoctoral scholar/research associate members, and up to one year for visiting members.

## **8. Research Resource Allocations and Budget**

The research centre's budget will be prepared by the director for approval by the board.

Recommendations for the allocation of research centre resources to members will also be made by the director to the board. Full and associate members can bring appeals concerning resource allocation to the board, whose decision will be final.

## **9. Annual General Meeting**

There will be an annual general meeting of all members of the research centre, during which the annual report will be presented and approved by core members of the center.

## **10. Meetings of Board**

The board will meet at least once a year to receive the annual report, review activities and membership, approve the budget, and help resolve any difficulties that may have arisen during the past year. It may meet more often if necessary.

An extraordinary meeting of the board will be convened if a written request to do so, signed by at least two-thirds of the full and associate members of the research centre, is submitted to the chair of the board.

## **11. Research Agreements, Contracts, Grants, and Gifts**

The research centre does not have the right to sign and enter into research agreements, grants, or contracts that require McGill institutional approval from authorized University signing officers. Similarly, gifts to the centre must be managed through the appropriate University channels.

# CHARTE

**RÉSEAU POUR TRANSFORMER LES SOINS EN AUTISME (RTSA)**

Dernière modification : 7 décembre 2016

Approuvée par les membres du réseau le : *27 mars 2017*

Approuvée par le Fonds de recherche du Québec – Santé le : *TBD*

## 1. DESCRIPTION DU RÉSEAU

### 1.1. NOM DU RÉSEAU

L'organisme porte le nom officiel de « RÉSEAU POUR TRANSFORMER LES SOINS EN AUTISME » et il utilise l'acronyme « RTSA ». En anglais, le Réseau se désigne sous le nom de « TRANSFORMING AUTISM CARE CONSORTIUM » et il utilise l'acronyme « TACC ».

### 1.2. OBJECTIFS DU RÉSEAU

Les objectifs du réseau sont les suivants:

- 1.2.1. Relier et mobiliser les forces du Québec dans la recherche sur le trouble du spectre autistique (TSA, ou autisme);
- 1.2.2. Améliorer l'accès et la disponibilité de l'expertise et des ressources de la recherche;
- 1.2.3. Améliorer la collaboration et la coordination entre les institutions, les secteurs et les disciplines;
- 1.2.4. Améliorer l'intégration des connaissances dans la pratique et la politique; et
- 1.2.5. Maximiser les investissements dans la recherche. Cela sera réalisé par la création, la gestion et la promotion d'infrastructures scientifiques et d'initiatives stratégiques, de bases de données cliniques et de transfert de connaissances vers les cliniques, les patients et les soignants.

### 1.3. DESCRIPTION DE LA THÉMATIQUE

Le réseau est composé de membres et d'organismes universitaires et communautaires qui ont un intérêt commun à comprendre, gérer et traiter les troubles du spectre autistique.

## 2. DIRECTION DU RÉSEAU

### 2.1. RÔLES ET RESPONSABILITÉS DU DIRECTEUR DU RÉSEAU

Le mandat du directeur se définit comme suit :

- 2.1.1. Assure le leadership nécessaire à la vitalité du Réseau, à la participation active de ses membres, à la pertinence et à la qualité scientifique de ses activités;
- 2.1.2. Voit à l'élaboration, à la mise à jour et au respect d'une charte ou de règles de fonctionnement;
- 2.1.3. Voit à l'établissement d'un processus de sélection et de révision des objectifs et priorités du Réseau;

- 2.1.4. Assure la transparence, l'efficacité et l'équité dans l'allocation et l'utilisation des fonds consentis au Réseau et est responsable de ses décisions auprès du Conseil d'administration du FRQS;
- 2.1.5. Voit au rayonnement scientifique du Réseau sur la scène nationale et internationale.

## 2.2. PROCESSUS DE NOMINATION, DURÉE DU MANDAT ET RENOUVELLEMENT

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- 2.2.1. Nomination : Le Directeur du Réseau est nommé par les membres réguliers du Réseau. Le choix du directeur doit être approuvé par le Conseil d'administration du FRQS.
- 2.2.2. Durée du mandat : La durée du mandat du directeur du Réseau correspond au cycle de renouvellement de la subvention émise par le FRQS, celle-ci est en générale d'une durée de quatre ans. Le mandat du directeur est renouvelable.
- 2.2.3. Démission : En cas de démission, le Bureau de direction est responsable de nommer un directeur qui restera en poste pour la partie non écoulée du mandat.
- 2.2.4. Directeur adjoint : Le Directeur peut choisir un Directeur adjoint parmi les membres réguliers du Réseau. Le rôle du Directeur adjoint est de représenter le Directeur lors des activités du Réseau.

## 3. STRUCTURE DE GOUVERNANCE

### 3.1. ASSEMBLÉE DES MEMBRES

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- 3.1.1. Composition : L'Assemblée des membres est composé de tous les membres du Réseau. L'Assemblée des membres est représenté par le bureau de direction du Réseau.
- 3.1.2. Mandat : Chaque membre de l'Assemblée des membres a pour mandat de:
  - 3.1.2.1. Partager son avis sur les axes de recherche, ressources communes, et programmes du Réseau pour améliorer leur accès et utilisation par tous les membres;
  - 3.1.2.2. Participer aux rencontres du Réseau;
  - 3.1.2.3. Bénéficier des priviléges et respecter les responsabilités des membres tels que décrits à la section 4.3.
- 3.1.3. Fonctionnement : L'Assemblée des membres se réunit au moins une fois par année.

### 3.2. BUREAU DE DIRECTION

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- 3.2.1. Composition : Le Bureau de direction comprend le directeur du Réseau, ainsi que le Directeur adjoint, et les responsables des Axes de recherche. La durée du mandat de chacun des membres correspond au cycle de renouvellement de la subvention octroyée par le FRQS, soit en général, quatre ans.
- 3.2.2. Mandat : Le Bureau de direction a pour mandat de :

- 3.2.2.1. Assurer l'atteinte des objectifs du Réseau;
  - 3.2.2.2. Choisir et définir les Axes de recherche, les Ressources communes, et les Programmes du Réseau;
  - 3.2.2.3. Créer les comités ou instances jugés nécessaires, définir leur mandat et désigner leurs membres et leurs présidents;
  - 3.2.2.4. Recevoir des rapports de tous les comités ou instances;
  - 3.2.2.5. Assurer le renouvellement de la subvention générale du Réseau auprès du FRQS.
- 3.2.3. Fonctionnement :
- 3.2.3.1. Le Bureau de direction se réunit au minimum quatre fois par année. Il détermine le lieu et la date de ses réunions;
  - 3.2.3.2. Le quorum des réunions est de la moitié des membres plus un;
  - 3.2.3.3. Les membres du Bureau de direction peuvent se faire remplacer aux réunions;
  - 3.2.3.4. Le vote se prend à la majorité simple et le Directeur vote.
- 3.2.4. Coordination :
- 3.2.4.1. La Coordination est en charge du secrétariat académique du Réseau;
  - 3.2.4.2. Le Coordonnateur est choisi par le Directeur du Réseau;
  - 3.2.4.3. Le Coordonnateur est responsable de toute la documentation associée à la gestion du Réseau (transfert de fonds, procès-verbaux, etc.);
  - 3.2.4.4. Il reçoit les demandes de subventions et de bourses et les transmet au Bureau de direction;
  - 3.2.4.5. Il agit comme secrétaire et président d'élection aux réunions de l'Assemblée des membres, du Bureau de direction, du Comité scientifique, et autres comités du réseau.

### **3.3. COMITÉ SCIENTIFIQUE**

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- 3.3.1. Composition : À l'exception du directeur, le Comité scientifique est composé au minimum de trois individus externes au Réseau, choisis en fonction de leur domaine d'activité et de leur qualité d'expertise scientifique;
- 3.3.2. Mandat : Le Comité scientifique a pour mandat de:
- 3.3.2.1. Donner un avis sur les infrastructures, plateformes, activités courantes et projets soumis au Réseau;
  - 3.3.2.2. Évaluer tous les deux ans les activités des membres réguliers du Réseau;
  - 3.3.2.3. Conseiller le Réseau sur ses orientations.

- 3.3.3. Fonctionnement : Le Comité scientifique se réunit au moins une fois par année ainsi qu'à la demande du Directeur et/ou du Bureau de direction. Les rapports du Comité scientifique sont remis au Bureau de direction qui peut les transmettre au FRQS.

### **3.4. COMITÉ « AMIS DU RTSA »**

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- 3.4.1. Composition : le Comité est composé au minimum de trois représentants de groupes de patients, d'organismes de financement privés ou autres groupes liés aux activités du RTSA;
- 3.4.2. Mandat : Le Comité a pour mandat de:
- 3.4.2.1. Donner un avis sur les orientations du Réseau vis-à-vis ses activités communautaires et l'utilisation des fonds privés;
  - 3.4.2.2. Aider à la levée de fonds pour les activités du RTSA;
  - 3.4.2.3. Aider à la liaison entre le RTSA et les groupes communautaires.
- 3.4.3. Fonctionnement : Le Comité se réunit au moins une fois par année ainsi qu'à la demande du Directeur et/ou du Bureau de direction. Les rapports du Comité sont remis au Bureau de direction qui peut les transmettre au FRQS.

## **4. MEMBRES**

### **4.1. ADHÉSION ET RENOUVELLEMENT**

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- 4.1.1. Admissibilité : Toute personne active en recherche au Québec dans le domaine des troubles du spectre autistique ou dans tout autre domaine qui y est relié peut devenir membre du Réseau.
- 4.1.2. Adhésion : Les nouveaux membres font application au Comité des membres. Ce comité approuve l'adhésion au Réseau des nouveaux membres selon leurs qualifications, et selon les directives du Bureau de direction.
- 4.1.3. Renouvellement : Le statut des membres est révisé tous les deux ans par l'intermédiaire du Comité de membres. L'absence de toute activité scientifique ou contribution au sein du Réseau pour une période de deux ans peut entraîner un changement de statut ou une fin d'adhésion.

### **4.2. CATÉGORIES DE MEMBRES**

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- 4.2.1. Membre régulier : chercheur autonome (selon la définition du FRQS) participant à un secteur de recherche dans la programmation scientifique du Réseau. Tout membre du Bureau de direction est considéré comme membre régulier.
- 4.2.2. Membre associé : membre qui fait partie du Réseau et reçoit les informations le concernant, mais n'est pas membre du Bureau de direction et ne participe pas nécessairement à un secteur de recherche faisant partie de la programmation scientifique du Réseau. Cette

catégorie comprend des intervenants tels que cliniciens, étudiants, stagiaires postdoctoraux et chercheurs invités.

- 4.2.3. Membre honoraire : personne (chercheur ou autre) dont le Réseau tient à souligner le mérite exceptionnel ou à qui il veut exprimer sa reconnaissance pour services rendus dans le domaine des troubles du spectre autistique. Ce statut ne comporte aucun droit ni obligation.

#### **4.3. PRIVILÈGES ET RESPONSABILITÉS DES MEMBRES**

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- 4.3.1. Privilèges : Les membres réguliers font partie de l'Assemblée des membres. Ils ont (selon les disponibilités) accès aux subventions du Réseau. Les membres associés peuvent participer à l'Assemblée des membres, mais ils n'y ont pas droit de vote.
- 4.3.2. Responsabilités : Le membre régulier doit :
- 4.3.2.1. Participer aux réunions scientifiques;
  - 4.3.2.2. Apporter son concours aux différents comités et au développement du Réseau;
  - 4.3.2.3. Contribuer à la préparation des demandes de renouvellement de subvention du Réseau.
- 4.3.3. Droit de vote : Seuls les membres réguliers détiennent un droit de vote.
- 4.3.4. Réunion : L'Assemblée des membres doit se réunir au moins une fois par an.
- 4.3.5. Éthique : Dans toutes leurs activités de recherche (au sein ou à l'extérieur du Réseau), les membres du Réseau doivent respecter les règles, normes et lignes directrices en vigueur au Canada, en matière d'éthique sur la recherche auprès des sujets humains ou des animaux.

### **5. STRUCTURE SCIENTIFIQUE**

Le Réseau est structuré en deux thèmes stratégiques, qui comportent des Axes de recherche, des Ressources Communes, et des Programmes.

#### **5.1. AXES DE RECHERCHE**

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Le Réseau comporte 4 Axes de recherche :

- 5.1.1. Génomique : Cet axe identifiera et caractérisera les facteurs génétiques qui sous-tendent l'autisme en utilisant les approches génomiques telles que le séquençage de prochaine génération et les technologies connexes.
- 5.1.2. Modèles cellulaires et animaux : Cet axe produira et étudiera des modèles cellulaires et animaux de mutations génétiques associées à l'autisme, en mettant l'accent sur ceux qui affectent la connectivité du cerveau.
- 5.1.3. Développement du cerveau : Cet axe identifiera les marqueurs de risque neural très précoces de l'autisme et leur impact sur le développement du cerveau humain en utilisant des outils tels que l'imagerie par résonance magnétique et l'électroencéphalogramme;

- 5.1.4. Profiles cognitifs et interventions: Cet axe se concentrera sur les profils perceptifs et cognitifs de l'autisme et sur la façon dont ils peuvent alimenter les programmes d'intervention.

## 5.2. RESSOURCES COMMUNES

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Le Réseau comporte 3 Ressources communes.

- 5.2.1. Registre provincial harmonisé : Cette ressource coordonnera le recrutement des patients atteints de TSA et de leurs familles;
- 5.2.2. Biobanque : Cette ressource recueillera, stockera et maintiendra des échantillons de patients atteints de TSA et de leurs familles;
- 5.2.3. Base de données : La base de données LORIS existante sera adaptée pour intégrer des données issues de multiples modalités (imagerie, génétique, comportementales et cliniques) générées par les chercheurs du RTSA.

## 5.3. PROGRAMMES

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Le Réseau comporte 3 Programmes.

- 5.3.1. Projets pilotes : Ce programme offrira des fonds ouverts à tous les chercheurs québécois pour des projets de recherche novateurs à court terme dans le domaine des TSA.
- 5.3.2. Formation : Ce programme offrira des bourses de formation aux stagiaires afin d'encourager la recherche dans le domaine des TSA et de fournir du mentorat aux membres du réseau. Le programme appuiera également les réunions des membres du RTSA et les ateliers spécialisés et fournira des bourses de voyage aux stagiaires pour participer à des conférences nationales et internationales.
- 5.3.3. Spectre des soins : Ce programme renforcera la recherche communautaire et l'utilisation de la recherche par les organismes communautaires en établissant des liens formels entre les chercheurs, les cliniciens, les organismes de financement et les groupes de patients atteints de TSA. Il aidera également à diffuser les résultats du RTSA auprès du grand public et d'autres intervenants.

## 6. RÈGLES DE FINANCEMENT

### 6.1. SOUTIEN DE PROGRAMMES ET PROCÉDURES DE GESTION

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Le Réseau soutient, gère et finance diverses activités telles que : colloques, projets pilote, développement de plateformes, achat, entretien ou développement d'outils, activités de formation, etc. La nature et les objectifs de ces activités de même que les modes de gestion sont consignés dans un règlement édicté par le Bureau de direction.

### 6.2. CRITÈRES DE FINANCEMENT

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Toute demande de subvention est à envoyer à la Coordination du Réseau. La demande sera évaluée par le Comité consultatif et la décision sera donnée par le directeur après approbation du Bureau de direction. Les demandes seront évaluées selon les critères scientifiques en vigueur au FRQS.

### **6.3. MODALITÉS D'OCTROI DE LA SUBVENTION**

Les subventions et les bourses octroyées par le Réseau sont fonction des disponibilités financières et de l'évolution de la réglementation du FRQS et/ou les IRSC.

## **7. RÉSOLUTION DES CONFLITS**

Le seul mécanisme d'appel d'une décision prise par une instance du Réseau consiste dans le dépôt d'une plainte écrite auprès du Directeur. Les décisions du Bureau de direction sont toutefois sans appel.



## David Eidelman, M.D., C.M.

Vice-Principal, Health Affairs  
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Faculty of Medicine  
McGill University  
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July 4, 2016

Dr. Guy Rouleau,  
Professor and Chair, Department of Neurology and Neurosurgery  
Director, Montreal Neurological Institute

Dear Guy,

I am pleased to approve provisional status for the Azrieli Centre for Autism Research (ACAR). This is a wonderful initiative that promises to enhance McGill's efforts in this important research field. As you are aware, according to university regulations, final approval of this Centre must be completed within 24 months.

For your information, I am attaching a copy of the McGill Policy on Research Centres.

Congratulations on this important initiative and good luck with the Senate approval process.

Warm regards,

A handwritten signature in black ink that reads "D. Eidelman".

*David Eidelman, M.D., C.M.*

cc.

Rose Goldstein, Vice Principal (Research and Innovation)  
Shari Baum, Associate Dean (Research)





## TERM SHEET FOR

a new research and clinical enterprise in the field of  
autism spectrum disorders (“ASD”)

to be used by the Montreal Neurological Institute, of McGill University (the “MNI”).

**Between:**

- Montreal Neurological Institute (the “MNI”); and
- The Provost’s Office (the “Provost’s Office”); and
- University Advancement (“UA”); and
- The Office of the Vice-Principal, Administration and Finance (“A&F”)
- The office of the Vice-Principal, Health Affairs, Dean of Medicine

The above units of McGill University (the “**Units**”) have agreed as follows concerning a new research and clinical enterprise in the field of ASD to be used by the MNI.

1. The project “*Transforming how we understand and treat ASD, from lab bench to the community*” (see description in Appendix 1), is a priority for the MNI and will be key component in the newly established Neurodevelopmental research unit at the MNI. The primary funder to this initiative is the Azrieli Foundation, having made a philanthropic gift of \$16,100,000, to be paid over a 5-year period (see Appendix 2 for the gift agreement).
2. The Units agree that the space assigned to carry out this project shall be allotted from space currently assigned to either the MNI or the Faculty of Medicine and the MNI will be responsible for any expenses incurred in the development/renovation and furnishing of this space.
3. The Units agree that the MNI will be accountable to establish an appropriate governance structure to manage the project to ensure its proposed outcomes are met (see Appendix 3 for proposed governance). In particular, the Director of the MNI shall co-direct the project, and ensure the establishment of a project steering committee. More generally, the Units will work together to build an overall governance structure within the University that creates accountability and decision making lines among the various neurosciences initiatives, including the Ludmer centre, and the new Open science initiative.
4. The Units agree the Director of the MNI shall be responsible for the project and the administration and stewardship of the Azrieli Foundation gift. As per the gift agreement (Appendix 2) a detailed report of the activities of the project, including, without limitation,

expenditures made in connection therewith, in form and substance satisfactory to the Azrieli Foundation, will be prepared by the MNI and send annually to the Azrieli Foundation.

5. In recognition of the Azrieli Foundation gift, the Units agree, as per the gift agreement, that the University will name the proposed ASD research centre, *The Azrieli Centre for Autism Research* (“ACAR”), the whole subject to the requisite approvals. Provisional status for ACAR has been obtained (see letter of confirmation from the Dean of Medicine, in Appendix 4). The Units agree it is the responsibility of the MNI to obtain final approval of this Centre within 24 months, as per the McGill Policy on Research Centres.
6. The Budget for the project is set out in Appendix 5: Budget. The Units agree that the MNI is solely responsible for ensuring funding for this project, from the Azrieli Foundation gift, and other potential sources, during the gift payout timeline and thereafter.
7. It is understood that clinical activities within the project will be undertaken by the MNI in partnership with the Montreal Children’s Hospital and the MUHC, and McGill will not assume any costs within the context of this partnership, beyond funding to be provided by the Azrieli Foundation gift. For further clarity, funding linked to the clinic is entirely for research personnel, and to support and accelerate the collection of cases for research. Alternative clinical sites will be considered by the MNI should it be decided not to partner with the MUHC.
8. Additional sources of funding for the project have been identified by the MNI and are set forth in Appendix 6: Prospective and secured funding for autism at the MNI. The MNI undertakes to apply funding from the sources listed in Appendix 6, when possible, to the project; in particular, the MNI will apply these funds to the direct spend budget items, so as to have the Azrieli Foundation funding increase its endowment portion commitment, currently at \$4,000,000 (see clause 3 in gift agreement, Appendix 2), so as to ensure the long term sustainability of the project.
9. In addition, as a means to further increase the endowment portion of the project, the MNI undertakes to maximize funding from the recent Canada First Research Excellence Fund award; and apply said funding to the direct spend budget line items so as to increase the Azrieli Foundation funding to the endowment, as per above.

Neurodevelopmental disorders are a stated priority of CFREF, and there are links within CFREF to topics across the study of autism. Within the CFREF envelope is also the opportunity to apply for matching grants for funding received from partners - including private philanthropy. These fall into four program categories:

- International collaboration platform
- Neuro-Innovation Fund

- Knowledge Mobilization
- Technology development

These four programs will have approximately \$17M in CFREF funding attached to them. Of the specific activities of ACAR, 1) drug development, 2) education and public outreach, and the 3) innovation awards, are immediately evident as qualifying for matching opportunities under these program categories, specifically Neuro-Innovation Fund and Knowledge Mobilization.

10. It is anticipated by the MNI that the endowment portion of the project will double to \$8,000,000 during the course of the gift period, through additional philanthropic fundraising, and significant reallocation of Azrieli Foundation funding to the project endowment, pursuant to CFREF and external grant funding being applied to project.

11. In particular, as regards the budget contained in Appendix 5, the MNI undertakes to ensure the management and sustainability of the project in the following manner:

- 1) **For Faculty and trainee support:** after the 5-year gift period, salaries will be provided through grant monies or faculty positions must be absorbed into existing complement as departures occur. Specifically, one of the hires is clinical, so will not be a Tenure Track position. The other two positions are Tenure Track and will be assumed by the department of Neurology and Neurosurgery. For example, the animal model recruit fits the description of the ongoing search for a tenure track position at the Centre for Research into Neurosciences. In addition, one of the hires could be linked to CFREF (pathway person).  
Alternatively, the project endowment will supplement or cover the entirely these costs anticipated at the \$200,000 level.
- **For platform development and operation:** the Azrieli Foundation gift will cover initial costs for these platforms. Users fees such as currently employed with the Brain Imaging center at the MNI will be used to sustain these platforms, long term. As for the genomics research, it is anticipated that clinically useful diagnostic tests will be established, and that these tests will become part of standard medical care.
- **Clinic:** The clinical care budget is focused on supporting quality improvements and coordination among services, which would then be sustained past the grant period though Ministry funding for routine services.
- **Training program and research awards:** for the training program and research awards, these will be only for the 5-year project duration, as agreed upon with the Azrieli Foundation.
- **Public education and outreach:** it is projected the project endowment will be increased, as per above, at a rate to sustain these activities; alternatively, these activities will be significantly decrease after the gift period.

12. The Units will review this Term Sheet on an annual basis, on or around the anniversary date, and make any adjustments or corrections deemed necessary in order to respect the initial terms of this agreement.
13. This Term Sheet is binding on each Unit and on the signatories' successors who represent each Unit.
14. The following Appendices (attached) form an integral part of this Term Sheet:

**Appendix 1:** project description of “*Transforming how we understand and treat ASD, from lab bench to the community*”

**Appendix 2:** Azrieli Foundation gift agreement

**Appendix 3 :** project governance structure

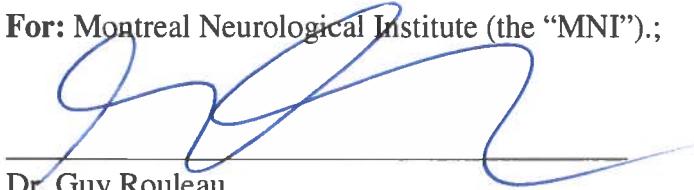
**Appendix 4:** letter confirming provisional status for ACAR

**Appendix 5:** project budget

**Appendix 6:** prospective and secured funding for autism at the MNI

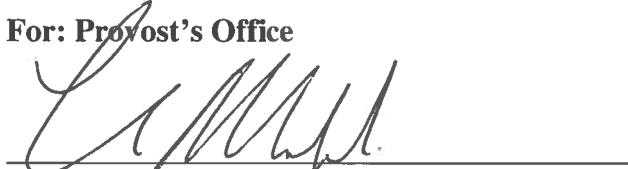
**AGREED AS ABOVE ON November 24, 2016**

**For:** Montreal Neurological Institute (the “MNI”).;

  
Dr. Guy Rouleau Date

Director, Montreal Neurological Institute (the “MNI”).;

**For:** Provost’s Office

  
Chris Manfredi Date

Provost and Vice-Principal, Academic

**For:** Vice-Principal, Health Affairs, Dean of Medicine

  
Dr. David Eidelman, VP, Health Affairs, Dean of Med  Date

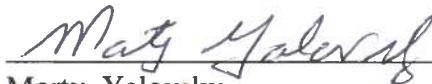
**For:** University Advancement



Marc Weinstein  
Vice-Principal, University Advancement

Date 22 Nov 2016

**For: Administration and Finance**



Morty Yalovsky,  
Interim Vice-Principal, Administration and Finance

Date Nov 23, 2016



## APPENDIX D. McGill Members

ACAR Full member (and co-directors of TACC)		
Rouleau, Guy	McGill University	Dr Rouleau investigates human neurological/brain disorders. He has identified and characterized several genetic risk factors and causative genes for such disorders. For this purpose he uses both high-throughput sequencing (targeted regions, exomes, whole-genomes) and high-density SNP genotyping. His team also develops various cellular models to conduct complementary functional studies.
Elsabbagh, Mayada	McGill University	Understanding the root causes of autism and tracing its developmental pathways using an approach integrating innovative research with the mission of accelerating translation of scientific discoveries into community impact. Mayada Elsabbagh also contributes to collaborative research and translational networks aimed at accelerating the pace of discovery in early autism. Working with partners from around the globe, she contributed to mapping knowledge translation priorities in under-resourced communities including low- and middle-income countries.
ACAR Associate Members and TACC Steering Committee members at McGill		
Evans, Alan	McGill University	Dr. Alan Evans uses three-dimensional computer techniques to study functional neuroanatomy. He collaborates with cognitive neuroscientists to examine memory, language, mood and sensory processing.
Sonenberg, Nahum	McGill University	My laboratory studies the molecular basis of the control of protein synthesis in eukaryotic cells and its importance in diseases such as cancer, obesity, diabetes and neurological diseases.
Carbonetto, Salvatore	McGill University	Function of cell adhesion molecules in synaptic plasticity and their dysfunction in disorders in intellectual deficiency and autism.
TACC Regular Members at McGill		
Bertone, Armando	McGill University	Lab-Based: neural underpinnings of sensory / cognitive differences in ASD during development, multimodal sensory processing in ASD and how they relate to social cognition, learning and behaviour. School-Based : developing and validating (RCT) a computer-based, attention training program geared at improving attentional abilities of children with ASD and other neurodevelopmental conditions

Buhas, Daniela	McGill University	My research is involving mainly clinical studies. My interests are the genetic and especially the biochemical genetic disorders/dysfunctions in patients with neurodevelopmental conditions, including autism spectrum disorder. Another theme where I am involved is the evaluation of impact of genetic testing on families with children having ASD.
Burack, Jacob	McGill University	My students and I study the development of attention and other cognitive processes among persons with ASD. Our emphasis is on the ways that unique styles and biases can affect attentional performance. In doing so, we argue against traditional deficit models. This research is based in developmental theory and methodology.
Chen, Brian	McGill University	Neural development, neurodevelopmental disorders, synapse formation, neural circuit formation, animal models, human induced pluripotent stem cells, drug discovery
Ernst, Carl	McGill University	STEM CELLS, GENOMICS, RNASEQ, CRISPR/CAS9, NEURODEVELOPMENT
Flanagan, Tara	McGill University	Transition from school to community; Quality of Life; Self-Determination; Universal Design for Learning; Inclusive Education; Social Inclusion; Inclusive Workplaces
Iyer, Srividya	McGill University	Youth mental health and early intervention in Canada and beyond, including: Development, implementation, and evaluation of models to increase youth access to timely, appropriate and engaging care; Early intervention for serious mental illnesses, particularly psychosis; Influence of sociocultural context on services, outcomes and stakeholder roles; Collaborative research capacity within communities.
Khoutorsky, Arkady	McGill University	I am interested in investigating the mechanisms by which dysregulated mRNA translation in the brain leads to neuropsychiatric disorders such as autism. My research involves identification of dysregulated translational control mechanisms, aberrantly translated mRNAs and altered neuronal circuits in animal models of autism.
Kieffer, Brigitte		Animal models

Knoppers, Bartha Maria	McGill University	Developing ethics frameworks; integrating ethics in biotechnology (industry); analysing ethical and legal obstacles to the utilisation of electronic and research files (health); proposing ethical and legal policies; creation of databases; build international consortia; harmonisation of principles and proceedings governing privacy of medical data.
Majnemer, Annette	McGill University	My research interests focus primarily on the child, family and environmental factors that influence activity limitations and participation restrictions in children and youth with brain-based developmental disabilities. I am also interested in rehabilitation service utilization patterns in pediatric settings, and knowledge translation initiatives that promote best practices.
Murai, Keith	McGill University	Synaptic development, plasticity, learning/memory, protein synthesis, homeostasis, neurodevelopmental disorders, autism-spectrum disorders, Fragile X syndrome, human iPSCs, mouse models, cortex, hippocampus, mouse genetics
Nadig, Aparna	McGill University	Social cognition, conversation/pragmatics, development of language and communication in ASD, support services and interventions for individuals with ASD, self-determination and employment in adulthood
Oskoui, Maryam	McGill University	I am a pediatric neuro-epidemiologist with interest in neurodevelopmental disorders. I Co-Direct the Canadian Cerebral Palsy Registry and am site lead for the Canadian Neuromuscular Disease Registry. I co-lead the Brain Development Behaviour integrated network (MUHC), and a member of the AAN Guideline Development Subcommittee (working on autism treatment guidelines).

Quintin, Eve-Marie	McGill University	<p>My research examines the trajectory of cognitive, socioemotional, and brain development throughout childhood and adolescence with a focus on music perception and cognition. I investigate autism spectrum disorders, fragile X syndrome, and typical development with a combination of cognitive-behavioral and neuroimaging methods and cross-sectional and longitudinal research designs. I aim to produce results that can improve education programs, community and family services, diagnostic procedures, and mental health care for individuals with neurodevelopmental disorders.</p>
Ristic, Jelena	McGill University	<p>social cognition, attention, electroencephalography, eye tracking, development, interactive cognition</p>
Shikako-Thomas, Keiko	McGill University	<p>Knowledge translation, stakeholder engagement, patient-oriented research, participation in leisure, evidence-informed policymaking, social determinants of health</p>
Sjöström, Jesper	McGill University	<p>Dr Jesper Sjöström's research is focused on the mechanisms, phenomenology, and functional consequences of Spike-Timing-Dependent Plasticity (STDP) in neocortical circuits, in health as well as in diseases such as epilepsy and autism. His team employs two-photon laser scanning microscopy, quadruple whole-cell recordings, optogenetics, and computational modelling.</p>
Sladeczek, Ingrid E.	McGill University	<p>Early intervention for children and youth with developmental disabilities (DD) (e.g., ASD, intellectual disabilities), families, and key stakeholders; Canadian policy as is relates to DD; consultation, and both group and single-n methodology.</p>
Snider, Laurie	McGill University	<p>Empowering Parents; Knowledge translation</p>
Stellwagen, David	McGill University	<p>Synaptic plasticity, inflammation, TNF, homeostasis of neuronal activity, excitatory-inhibitory balance, Neurodevelopmental disorders, autism-spectrum disorders, Rett's syndrome, human iPSCs, mouse models, cortex, hippocampus, striatum, electrophysiology, imaging.</p>
Dendukuri, Nandini	McGill University	<p>Developing Bayesian statistical methods for health technology assessment diagnostic studies</p>

ACAR BUDGET							
Expendable items	Year 1	Year 2	Year 3	Year 4	Year 5	TOTAL	Justification
FACULTY AND TRAINEE SUPPORT	\$500,000	\$900,000	\$560,000	\$460,000	\$200,000	\$ 2,620,000	New investigators will be recruited on a competitive basis and funded through ACAR for their first three years. After this period, salaries will be absorbed through the University's operating budget or provided through grant monies. Competitive 1-year fellowships will also be offered for graduate students and fellows to undertake multidisciplinary training at ACAR.
PLATFORM DEVELOPMENT AND OPERATION	\$1,020,000	\$1,520,000	\$1,520,000	\$620,000	\$350,000	\$5,030,000	Platforms will flexibly allocate the proposed budget to development and/or operating costs towards ACAR goals, i.e., equipment purchase/upgrades, technical staff contracts, and other operating costs. Initial costs are higher for the new platform (marmosets, faculty). Similar to existing MNI platforms, sustainability will be ensured after the grant period through new funding and/or user fees.
ACAR CLINIC (Clinical research platform)	\$250,000	\$250,000	\$250,000	\$250,000	\$250,000	\$1,250,000	While all participating medical personnel are funded through the ministry of health, ACAR will build a unifying collaborative and administrative framework to harmonize and connect operations among relevant clinics and with research. This includes supporting family participation in studies and research integration activities.
AUTISM TRAINING PROGRAM	\$240,000	\$240,000	\$240,000	\$240,000	\$240,000	\$1,200,000	ACAR's Autism Training Program will initiate a research and professional training program set in the ACAR clinic. Costs will cover salary of the coordinator, stipends for trainees to support graduate and post graduate training, and travel/meeting costs for them to interact with each other and with mentors. The medical and allied health internship program requires no additional costs as it will be set in the ACAR clinic, where interns are supervised by ACAR members.

PUBLIC EDUCATION AND OUTREACH	\$200,000	\$200,000	\$200,000	\$200,000	\$200,000	\$1,000,000	ACAR's education and community engagement program will support broader outreach, providing opportunities for partnership and collaboration, including education, professional development, consultation, and other capacity building activities.
ACAR RESEARCH AWARDS	\$200,000	\$200,000	\$200,000	\$200,000	\$200,000	\$ 1,000,000	Seed funding will be awarded to researchers undertaking innovative, high-risk/high-reward, interdisciplinary projects on a competitive basis through an annual competition.
<b>TOTAL: EXPENDABLE BUDGET</b>	<b>\$2,410,000</b>	<b>\$3,310,000</b>	<b>\$2,970,000</b>	<b>\$ 1,970,000</b>	<b>\$1,440,000</b>	<b>\$12,100,000</b>	
ENDOWMENT	<b>\$4,000,000*</b>					<b>\$ 4,000,000</b>	To provide a stable and sustainable base of support for foundational activities (including post-funding period), and to support emerging opportunities.
<b>Grand Total</b>						<b>\$16,100,000</b>	

\* Assuming an annual payout of 4.25%, revenues will be \$170,000 annually

## **The Transforming Autism Care Consortium (TACC) and the Azrieli Centre for Autism Research (ACAR): working in synergy to enhance ASD research and care in Quebec**

ACAR and TACC are two newly formed entities with a synergistic, mutually supportive relationship and a common goal: to generate breakthroughs in autism research, and to translate discoveries into better care for patients and families across Quebec and around the world. ACAR and TACC will jointly launch in the fall of 2017, at an event shared with their key philanthropic investors [to name all confirmed funders by the launch date].

### **About ACAR**

**ACAR** is a new research centre at the Montreal Neurological Institute (MNI) funded through a \$16.1M gift from the Azrieli Foundation. ACAR leverages McGill's exceptional neuroscience strengths to advance research, training and translation into improved care. Within ACAR, genomic research will identify new pathways for ASD; new cell and animal models will illuminate the mechanisms for how neural circuits are wired and how synapses are formed, maintained and changed; and brain imaging will allow us to discover how neural connectivity is affected in ASD patients.

ACAR will capitalize on the MNI's powerful research platforms, including those at the *McConnell Brain Imaging Centre* and the *Ludmer Centre for Neuroinformatics and Mental Health*, to accelerate the pace of discovery in autism and related conditions. As ACAR's research avenues produce promising therapies, they can be tested through the Montreal Neurological Institute's unique *open science drug discovery platform*, speeding time to clinic.

Research innovation will be directly offered to families in a world-class "ACAR Clinic", a new clinical research platform at the MNI where families will be partners in advancing discovery, translation, and training the next generation of ASD clinical specialists.

ACAR will also benefit from the extraordinary \$84M investment received by McGill through the Canada First Research Excellence Fund (CFREF) to launch the Healthy Brains for Healthy Lives project. This seven-year initiative aims to produce breakthroughs in neurodegenerative, neurodevelopmental and psychiatric disorders by funding innovative, multidisciplinary projects led by McGill researchers. ACAR is ideally positioned to receive funding through Healthy Brains for Healthy Lives, and is already preparing funding applications.

### **Catalyzing Quebec's strengths through a new network**

ACAR is the coordinating node in **TACC**: a new research network that has brought together over 40 researchers and 200 professionals across Quebec's universities, hospital and community partners with a focus on ASD. Building on the expertise and reach of its members, TACC will advance three key objectives:

- **Modeling the future of care** through research engaging 1,000 families. Cutting-edge scientific research has offered new models for personalized care. We will implement these new models and evaluate their value in improving diagnostics and medical management for 1,000 Quebec families. TACC will advance complementary scientific goals and harmonize their efforts around the same families, ensuring maximal benefits.

- **Augmenting autism capacity** through innovative training and partnerships. We will offer unique training and partnership opportunities, increasing the number of qualified professionals and expanding use of evidence in the wider community.
- **Integrating autism research and training in Quebec** within a unified framework. TACC will hire a provincial core team to increase interactions among researchers, support for innovative new projects and trainees through transparent and flexible mechanisms, and to develop an active communications and events program reaching to stakeholders and the wider public.

TACC was the result of a two year, grassroots process led by researchers representing Montreal's largest hospital- and university-based research institutions. Following extensive consultation, and expansion of membership to encompass many of Quebec's leading research and ASD care organizations, TACC has submitted a proposal to become Quebec's officially recognized autism research network, supported by the *Fonds de recherche du Québec – Santé (FRQS)*.

TACC has been kick-started through a combination of research funding provided by its members and philanthropic contributions, and is actively pursuing additional public and private resources to achieve its goals.

**ACAR and TACC will mutually support one another's objectives** in the following ways:

- ACAR will be a core member of TACC and will play a coordinating role among its members, ensuring collaboration, mutual training opportunities and knowledge transfer.
- ACAR and TACC have the same co-Directors and will overlap in their research leadership through the TACC's Steering Committee and Scientific Advisory Board.
- ACAR will add significant research strength to TACC, and will benefit from and support the 1,000 Families initiative. ACAR will enhance TACC's genetic, imaging, animal and cell model capacity, while TACC will, in turn, scales up these activities through harmonized clinical registries across Quebec's University Health Centers.
- ACAR will leverage \$1.9M provided from the Azrieli Foundation's founding investment to support TACC's capacity-building objectives, providing training opportunities and helping to coordinate partnerships and exchange among members.
- TACC will enrich ACAR's family-focused research and ensure it direct benefits by providing a framework to link with researchers, caregivers, decision-makers, and community partners across the province.

**Together, ACAR and TACC represent significant steps forward** in cementing Quebec's place as one of the world's ASD leaders, and in supporting enhanced care for patients and families in our community and beyond.



# ACAR Centre Governance

## Co-Directors

G. Rouleau  
M. Elsabbagh

## Steering Committee

### *Genomics*

G. Rouleau

### *ASD Models*

N. Sonnenberg  
S. Carbonetto

### *Brain Imaging*

A. Evans  
S. Baillet

### *Drug Discovery*

G. Rouleau

### *ACAR Clinic*

M. Elsabbagh

## External Advisory Board (proposed)

**Simon Baron Cohen** (Director, Autism Research Centre, University of Cambridge)

**Nissim Benvenisty** (Principal Researcher, Azrieli Centre, Hebrew University)

**Thomas Bourgeron** (Director, Human Genetics and Cognitive Functions Unit, Pasteur Institute)

**Louis R. Reichardt** (Scientific Director, The Simons Foundation)





# The Neuro moving forward

