# **Norman Saunders Complex Care Initiative - Grant Competition**

## Background

An endowment fund was established by friends and family of the late Dr. Norman Saunders to recognize his contributions to the care of children and their families in his primary care paediatric office as well as at SickKids throughout his distinguished career. The purpose of this endowment, known as the Norman Saunders Complex Care Initiative (NSCCI) is to stimulate and support research and academic discovery related to the clinical care of children with multiple and complex health challenges.

As part of this initiative, beginning in 2007 a sum of \$50,000 per year was made available to support research addressing important questions relating to the clinical care of the growing population of complex care patients. This grant competition was open to all faculty affiliated with the University of Toronto and was administered through the Division of Paediatric Medicine in the Department of Paediatrics and the Research Institute at SickKids. See below for a list of research projects funded over the last six years.

In 2018 the annual research grant competition became a national competition to provide a new opportunity for clinicians in the field of paediatric complex care across Canada. Dr. Saunders was a visionary who knew that the care of children with medical complexity and their families could be improved. A pdf summary of the impact of the NSCCI (published in the journal *Children*) can be found <u>here</u>.

#### **Purpose**

To promote innovative, interdisciplinary research related to the broad area of complex care in child health. The Norman Saunders Complex Care Initiative has designated approximately \$100,000 annually to provide clinicians and researchers in the field of paediatric complex care in Canada with grant funding to pursue innovative research ideas. Funding may be used for a stand-alone project or may be used as seed funds to gather pilot data that would support a larger application to a federal granting agency.

## **General information**

- Subject to a competitive peer-review process.
- Approximately \$100,000 is available per year for all grants. Maximum budget is \$50,000.00 for each application.
- Grants will typically have a timeline of one year, with consideration for a two-year timeline (without additional funding) with appropriate justification in the grant application.
- The budget must be thoroughly justified, and preference will be given to excellent projects with an efficient but feasible budget that would allow for more than 2 projects/year to be funded.
- Grant applications must detail the importance of the study to the lives of CMC and their families. Applications
  should reflect the lived experience of study participants when determining data collection methods, outcomes
  measured and the sharing of study results. Applicants are encouraged to detail how insights from patients and
  families have been considered in the design of the study and execution of the proposed study.

## Criteria

Grant applications should be focused on children with medical complexity, defined as children who share the following four characteristics:

- presence of one or more complex chronic conditions that are often multisystem and severe,
- have a functional limitation that is often significant and impacts their daily lives, often causing the child to be reliant on technology such as feeding tubes and tracheostomies,
- high healthcare utilization, requiring specialized care and services from different providers in multiple sectors

 high healthcare service needs e.g., care provision in the home and care coordination which can have significant social and financial impacts on the family

Applications that relate to specific patient populations that have a primary underlying diagnosis with firmly established advocacy and support groups and access to other funding sources (e.g. childhood cancer, cystic fibrosis, transplant patients) will not be considered eligible for this competition.

# **Targeted issues**

Funding is to increase knowledge/awareness/tools to improve the care of CMC through projects which relate to a range of relevant domains/activities including:

- Developing/testing/piloting novel models of care e.g., medical home
- Enhancing care coordination
- Defining/measuring/improving outcomes
- Addressing health systems issues
- Quality of life
- Designing/evaluating therapeutic interventions

# **Eligibility**

- Physicians, nurses, allied health professionals, researchers and trainees who are affiliated with an academic health science centre or university in Canada. New and early career investigators are encouraged to apply.
- Research partnership with patients and families, community groups, policymakers and/or family advisors is strongly recommended, and applications should clearly describe how patients and family will be engaged through the research and knowledge translation process (including in the budget).

# **Application Guidelines**

Applicants should submit their applications as follows:

- Submission is **electronic only** and must be sent as a single PDF file
  - The submission should be presented in one PDF file containing (in this order):
  - <u>Completed Norman Saunders Complex Care Initiative Grant Application form</u>
  - Proposal and Appendices (see details below)
  - CVs of all applicants/co-applicants (abbreviated version, maximum 5 pages)
  - Internal scientific review which may include hospital RI or university review. Please upload reviewers' comments. (if unable to obtain this then will need to contact us directly to discuss at grantcomp.paedmed@sickkids.ca)

## Proposal:

- Three single-spaced pages to be submitted electronically. Please do not exceed the page limit only 3 pages will be evaluated. Use 8.5" x 11" paper, one side only, single space type, no smaller than 12 points, a margin of one inch around the page.
- Must include:
  - Background, Rationale and Objective(s), highlighting what is currently known and what the gaps in knowledge are,
  - Research Question and Research Methods (design, measures, analysis),
  - Budget, Timeline and Feasibility,
  - Roles and Expertise of Research Team Members
  - Potential Impact of project and relevance to the Norman Saunders Complex Care Initiative (see Background, Purpose, Criteria above)

Knowledge Translation and Dissemination plan

## Please ensure that patient and/or family engagement is addressed in at least one section of your proposal.

## Appendices:

- Maximum two pages of references
- Maximum two figures
- Maximum two reprints, manuscripts (only if pertinent)
- One page budget justification (NB ineligible expenses include conference travel, standard office equipment, computer hardware, furniture, and salary support for investigators.) Patient-partner compensation is allowable (see <u>Guidelines for Patient-Partner Compensation by Child-Bright Network and Strategy for Patient-Oriented Research (SPOR)</u>)
- Letters of support (if appropriate)

# Submit your application:

Applications are to be emailed to: grantcomp.paedmed@sickkids.ca

# Submission Deadline:

Applications for the 2022 grant are due August 31st, 2022.

## Contact:

Mariam Elsawy Administrative Assistant Paediatric Medicine <u>mariam.elsawy@sickkids.ca</u> 613.276.1657

# **Review Process, Responsibility & Accountability**

# **Composition or Review Committee:**

Committee of at least seven members which may include:

- Committee Chair (to be decided from amongst the committee members)
- A representative member from the Division of Paediatric Medicine, SickKids
- A senior scientist from the Research Institute, SickKids
- A representative from Holland Bloorview Kids Rehab
- An Allied Health Professional
- A member of Dr. Norman Saunders' family
- A family/parent representative
- A complex care clinician from outside Toronto
- Ad hoc reviewers may be invited depending on topics submitted for review

# Peer-review Process and Evaluative Criteria:

- Each application will be assigned to two to three reviewers for independent assessment
- Each application will be evaluated on:
  - a) clinical relevance to complex care in child health,

- b) scientific merit,
- c) feasibility,
- d) relevance to the Norman Saunders Complex Care Initiative
- The scores given by the reviewers will be discussed at the reviewer committee meeting
- A consensus of scores and ranks will be reached; committee members with a conflict of interest with the applicants will be recused from the decision making regarding that grant
- The budget must be thoroughly justified as preference will be given to excellent projects with an economical but feasible budget that would allow for more than 2 projects/year to be funded
- Results including reviewers' suggestions/feedback will be provided to applicants

# **Responsibility & Accountability**

The following is required of all funded applications:

- REB approval from relevant institution(s)
- Begin project within twelve months of receipt of funds
- Submit annual progress report
- Submit final report with a financial statement within six months of project completion
- Return unused or remaining funds
- Be prepared to present findings at a symposium to showcase projects funded by the NSCCI

# **Funded Projects**

## 2021:

- Understanding Changes in Hospitalization and Mortality Patterns Among Children and Youth with Medical Complexity (CMC) during the COVID-19 pandemic - Eyal Cohen (PI), Kate Nelson (PI), Paula Robson (KU). [Hospital for Sick Children]
- SWIFT: Studying the Wider Impact of Faster Genetic Testing in Critical Care Linh Ly (PI), Lauren Chad (PI). [Hospital for Sick Children]
- Development of Physician-Caregiver Trust During Inpatient Care of Children with Medical Complexity -Tammie Dewan (PI), Chantelle Barnard (PI). [University of Calgary]

## 2020:

- Understanding Approaches to Decision-Making among Caregivers of Children with Medical Complexity: A Qualitative Study - Kate Nelson (PI). [Hospital for Sick Children]
- The Role of Family Adaptation in the Transition to Adulthood for Youth With Medical Complexity: A Qualitative Case Study - Lin Li (PI), Patricia Strachan (PI). [McMaster University]
- Application of polygenic risk score for predicting bone fragility in children with medical complexity Fiscaletti M (PI), Manousaki D (PI) [Sainte Justine University Hospital Center]
- An Essential Subset Of Good Outcome For Complex Care Nora Fayed (PI) [HSPRI/Queens]

## 2019:

 A Mixed-Methods Evaluation of the Unique Experiences of Stakeholders from a Satellite Clinic in Northern Ontario for Children with Medical Complexity – Nathalie Major(PI), Eyal Cohen (PI), Julia Orkin (PI) and Nora Fayed (PI). [Children's Hospital of Eastern Ontario / Hospital for Sick Children / Queen's University]

- Digital Health for Complex Care Kids (DigiComp Kids) A Co-Design and Usability Testing Study Nancy Carter (PI), Marissa Bird (PI) [McMaster University School of Nursing]
- Patient-reported experiences and outcomes for the care of children with medical complexity and palliative care needs in the ED – Nathalie Orr Gaucher(PI), Anne-Josée Côté (PI). [CHU Sainte-Justine, Université de Montréal and Alberta Children's Hospital, University of Calgary]

# 2018:

- High Flow Nasal Cannula Therapy for the Management of Obstructive Sleep Apnea in Children with Complex Medical Conditions – Indra Narang (PI). [Hospital for Sick Children]
- Understanding the Relationship between Pain Trajectories and Well-being in Children and Youth with Cerebral Palsy – Darcy Fehlings (PI) [Holland Bloorview Kids Rehabilitation Hospital]
- Patterns of care in children with CNS static encephalopathy according to location of death: A mixed methods study of parents' experiences – Nathalie Orr Gaucher (PI), Nina Kleiber (PI). [Université de Montréal]

## 2017:

- Development of a Conceptual Framework for Quality of Life in Children with Medical Complexity Nearing the End of Life – Kim Widger (PI). [Hospital for Sick Children]
- Housing and Health: An Exploration of Housing need in Children with Medical Complexity (CMC) Julia Orkin (PI). [Hospital for Sick Children]
- Paediatric Tracheostomy Care: An evaluation of an innovative competency-based education program for community health care providers – Reshma Amin (PI), Julia Orkin (PI). [Hospital for Sick Children]

# 2016:

- Competence in Complex Care: A Multicenter Randomized Trial of Curricular Modules in the Care of Children with Medial Complexity for Paediatric Residents - Julia Orkin (PI).\*(Co-funded with a Paediatric Consultants Educational Scholarship Grant) [Hospital for Sick Children]
- Exploring families and Health Care Providers (HCPs) Experiences Using a Cloud-based Care Plan for Children with Medical Complexity (CMC) - Sherri Adams (PI) [Hospital for Sick Children]
- The Experiences of Bereaved Family Caregivers with Advance Care Planning for Children with Medical Complexity - Julia Orkin (PI). [Hospital for Sick Children]

For details on funded projects from 2015 and earlier, please email Mariam Elsawy.