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 The Hospital for Sick Children (SickKids) throughout his distinguished career. The purpose of this endowment, known as the Norman Saunders Complex Care Initiative (NSCCI) was 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 10 years.

In 2018 it was felt that the annual research grant competition should become a national resource to provide a new opportunity for the growing number of clinicians in the field of paediatric complex care across Canada, to apply for funds to support their research and academic projects. Dr. Saunders was a visionary who knew that we could do better in caring for these children with medical complexity and their families. It is in keeping with his wishes that we hope to broaden the impact of funding through his philanthropic NSCCI endowment.

Purpose

To promote innovative, interdisciplinary research related to the broad area of complex care in children's health. The Norman Saunders Complex Care Initiative fund has designated approximately \$100,000 to be used annually to provide clinicians in the field of paediatric complex care in Canada with grant funding to pursue research ideas that are currently not the targeted areas of conventional funding agencies. This money would be used to fund a stand-alone project or may be used as seed money to pursue a pilot project that would then be funded by a larger granting agency. Projects eligible for funding from a disease specific granting agency or industry will not be considered.

General information

- Subject to a competitive review process
- Approximately \$100,000 is available per year. Maximum annual budget is \$50,000.00.
- Projects requiring more than one year of funding may be considered; however evidence of an application for other external funding will be a requirement if a second year of funding is required.
- 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

Criteria for award

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

 caregivers identify high healthcare service needs e.g. care provision in the home and care coordination which can have significant social and financial impacts of 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 for this competition.

Targeted issues

Funding aims to provide more knowledge/awareness/tools to improve care to CC population 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 junior early career investigators are encouraged to apply.

 Research partnership with patients and families, community groups, and/or family advisors is strongly recommended and applications should include a patient and family engagement plan (including a budget where appropriate).

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):
 - Completed Norman Saunders Complex Care Initiative Grant Application form
 - 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. Here is an example of a
 template for internal scientific review [insert link to form]. 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 only 8.5" by 11" paper, one side only, single space type no smaller than 12 points, a margin of one inch around the page is needed
- Must include:
 - Rationale and objectives, including what is currently known and what the gaps in knowledge are
 - Expertise/qualifications of applicants essential for this study
 - Research question and research methods (design, measures, analysis)
 - Time-line and feasibility
 - Impact of study and relevance to the Norman Saunders Complex Care Initiative (see Background, Purpose, Criteria above)
 - Potential outcome and plan for knowledge translation and dissemination

APPENDICES:

- Maximum two pages of references with full titles
- Maximum two figures
- Maximum two reprints, manuscripts, etc. only if absolutely pertinent
- One page budget justification (ineligible expenses: conference travel, standard office equipment, computer hardware, furniture) and personnel involved
- Appropriate ethics protocols (these may follow application)
- Letters of support (if appropriate)

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

Submission Deadline: Congratulations to the winners of the 2020 grant. Applications for the 2021 grant are due August 31st, 2021.

For further information please contact:

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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 of Toronto
- Ad hoc reviewers may be invited depending on topics submitted for review

Peer-review Process and Evaluative Criteria:

In general, the CIHR peer review process and ranking scales will be followed.

- Each application will be assigned to two-three reviewers for independent assessment
- Each application will be evaluated on:
 - a) clinical relevance to complex care in children's health,
 - b) scientific merit,
 - c) feasibility,
 - d) relevance to the intent of 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:

- Obtain REB approval from institutions involved
- Begin funding 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

2020:

- Understanding Approaches to Decision-Making among Caregivers of Chidlren with Meidcal Complexity: A
 Qualitative Study Kate Nelson (PI), Francine Buchanan, Sanjay Mahant, Tammie
 Dewan, Sherri Adams, Kimberley Widger, David Nicholas. [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), Nancy Carter, Jan Willem Gorter, Jenny Ploeg, Linda Till, Marcy White. [McMaster University]
- Application of polygenic risk score for predicting bone fragility in children with medical complexity Fiscaletti M
 (PI), Manousaki D (PI), Marano M, Bonneau V, Doré-Bergeron MJ. [Sainte Justine University Hospital Center]
- An Essential Subset Of Good Outcome For Complex Care Nora Fayed (PI), Eyal Cohen, Joan Tranmer, Myla
 Moretti, Michael Sidra, Esther Lee, Francine Buchanan, Samatha Noyek [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 – Dr. Nathalie Major, <u>Dr. Eyal Cohen, Dr. Julia Orkin</u> and Nora Fayed (PIs) / S Sutherland, D Newhook, J Kenney, N Dussah, H Guerra (Co-Investigators) [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 Dr. Nancy Carter, Dr. Marissa Bird (Pls) / A Polanski, A Lim, C Grennan, C Fajardo, E Chambers, R Yates, S Mierdel, S Reaume, M McGillon (Co-Investigators) [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 Dr. Nathalie Orr Gaucher, Dr. Anne-Josée Côté (Pls) / S Ali, G Thompson, N Kleiber, MF Langlet, A Descoteaux, MA Marquis, A Payot, CJ Bourque, MJ Doré-Bergeron (Co-Investigators) [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 – Dr. Indra Narang (PI)/ Dr. Reshma Amin/ Dr. Eyal Cohen/ Adele Baker [Hospital for Sick Children]
- Understanding the Relationship between Pain Trajectories and Well-being in Children and Youth with Cerebral Palsy – Dr. Darcy Fehlings (PI)/ Dr. Heather Shearer/ Dr. Pierre Côté/ Dr. Sheilah Hogg-Johnson/ Dr. Patricia McKeever [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 – Dr. Nathalie Orr Gaucher (PI)/ Dr. Niina 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)/ Dr. Adam Rapoport/ Sherri Adams / Dr. Jurg Streuli / Rose Steele.
- Housing and Health: An Exploration of Housing need in Children with Medical Complexity (CMC) Dr. Julia
 Orkin (PI)/ Dr. Eyal Cohen / Joanna Soscia / Kathy Netten / Kara Hounsell
- Paediatric Tracheostomy Care: An evaluation of an innovative competency-based education program for community health care providers – Dr. Reshma Amin (PI)/ Dr. Julia Orkin (PI) / Stephanie Chu / Catharine Walsh / Krista Keilty / Sandra McKay.

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)/ Kathleen Huth/ Sara Long-Gagne.*(Cofunded with a Paediatric Consultants Educational Scholarship Grant)
- Exploring families and Health Care Providers (HCPs) Experiences Using a Cloud-based Care Plan for Children with Medical Complexity (CMC) - Sherri Adams (PI)/ Arti Desai.
- The Experiences of Bereaved Family Caregivers with Advance Care Planning for Children with Medical Complexity - Julia Orkin (PI)/ Sarah Lord/ Reshma Amin.

For details on funded projects from 2015 and earlier, please email **Shannon Brass**.