



Guidelines and Criteria for the Research Program

Hydrocephalus Canada Mission

Connecting the spina bifida and hydrocephalus communities across Canada through services, support, education, awareness and research.

1. Research Priorities

Hydrocephalus Canada chooses to play a role in facilitating research through a stronger presence in the research community and by influencing the creation of a research agenda (international and national) through increased collaboration with various stakeholders.

The following areas have been identified as important research priorities:

- better shunts
- better alternatives to shunts
- better/faster diagnosis of normal pressure hydrocephalus
- better hydrocephalus management – better testing of shunt function/malfunction •
- causes of congenital hydrocephalus
- long term effects of hydrocephalus on social skills in adults
- the management of bladder and bowel incontinence
- the social isolation of young persons with spina bifida
- better infection management
- the genetics of mothers with spina bifida

2. Research Support

Hydrocephalus Canada responds to requests to support research that will improve the quality of life for all individuals with hydrocephalus and spina bifida and their families. We work in partnership with hospitals, rehabilitation centres, universities and other research facilities by:

- participating in focus groups,
- distributing information about research projects through our newsletters,
- including information about research projects on the Hydrocephalus Canada website and social media channels,

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- endorsing research projects to possible research participants,
- advocating for more government funding for research,
- providing letters of support to other funders, or
- offering financial support to small research projects, including support for the Hydrocephalus Canada Award in the Comprehensive Research Experience for Medical Students (CREMS) Program at the University of Toronto.

3. Research Funding

On a year-to-year basis, Hydrocephalus Canada will consider awarding individual research grants. The funds available annually to support research will be allocated in the approved Hydrocephalus Canada budget.

The number and amount of grants awarded annually will vary.

Funds are sent to the institution where the research will be carried out.

4. Responsibilities of the Grantee

Hydrocephalus Canada encourages researchers to present at professional conferences and at Hydrocephalus Canada's Annual General Meeting, if called upon.

The researcher must provide a concise summary of the final report of the research in layman terms. The purpose and results must be clearly described. This can be in the form of an abstract. It will be used for public and/or professional education. This report is to be forwarded within 90 days following the completion of the study.

Hydrocephalus Canada is to be acknowledged and thanked for its financial support and assistance in all publications and presentations relating to the research that has been funded.

No printed material or publications bearing Hydrocephalus Canada's name and/or logo may be produced without the knowledge and written consent of Hydrocephalus Canada.



Guidelines and Criteria for the Research Program

5. Confidentiality Issues

All volunteers of Hydrocephalus Canada's Research Committee must be made aware of the issue of confidentiality. All information is confidential and will not be shared with anyone other than members of Hydrocephalus Canada staff or Board of Directors who are bound by the confidentiality agreement.

6. Conflict of Interest Statement

It is the policy of Hydrocephalus Canada that individuals on the Research Committee or those who review applications must disclose any financial, professional or personal gains that may influence the position or review process of a research grant application.

Approved by the Hydrocephalus Canada Board of Directors November 28, 2024