



Patient-oriented Research Project Description

Project Title: EmPOwER: Engaging Persons with cerebral venous thrombosis for meaningful Outcomes and peER support

Project PI: Dr. Thalia Field

Start and End Dates: 2019-08-15 to 2019-12-31

Position Type: Paid \$16/hr Volunteer

Hours per Week: 5-10

Number of Openings: 1

Clinical Research Area: Neurology

Location: [Diamond Health Care Centre](#)

Experience Level: BSc MSc MD PhD MD-PhD PDF

Keywords: cerebral venous thrombosis (CVT), young stroke, patient-centered outcomes

Project Description:

Cerebral venous thrombosis (CVT) is a rare cause of stroke that preferentially affects younger women. Although prognosis is 'excellent' if using outcome metrics from other stroke studies, this does not account for issues such as chronic fatigue, headache, mood issues, and cognitive problems that may significantly affect quality of life. This project is surveying patients with a history of CVT to best assess which symptoms most affect their quality of life with the aim of better elucidating optimal patient-centered outcomes for future trials in CVT. The results from the survey were used to facilitate sessions at a provincial forum on CVT, to share lived experiences of patients and their loved ones/caregivers, and aid in the development of a peer support network. Results from the survey and dialogue from the forum has informed development and design of a CVT website to empower and connect individuals affected by CVT and provide a resource to clinical and research staff.

Candidate's Role & Specific Tasks:

The student will be responsible for activities related to the patient engagement initiative and aid in the knowledge translation process. This will include: (1) design and distribute a CVT newsletter with content targeted towards patients and their loved ones/caregivers, (2) develop and review both lay language and



Patient-oriented Research Project Description

scientific content for the CVT website, (3) create multi-media resources for effective knowledge translation, and (4) assist with the design and execution of a POR qualitative study in patients affected by CVT.

The student will collaborate with and consult with CVT patient advisory committee, comprised of young stroke and CVT survivors, occupational therapist, health economist, patient advocate expert, stroke specialists, and researchers. The student will be exposed to quantitative and qualitative research methods focused on patient engagement and strategies for knowledge translation.

Mentorship Opportunities:

The Vancouver Stroke Program (VSP) is comprised of stroke neurologists and nurses, research coordinators, UBC co-op students, and administrative staff. The student will have the opportunity to collaborate with all VSP members, attend academic and clinical rounds, and be a part of research team meetings. The student will receive support and guidance from the PI, Dr. Thalia Field, and her lab manager, Vanessa Dizonno. After consulting with all parties, the best strategy for meeting frequency and method will be determined.

Application Instructions:

Required documents: Cover Letter Resume Transcript Class Schedule Other

If interested, please direct any further queries or the required documents to the lab manager, Vanessa Dizonno (email: vanessa.dizonno@ubc.ca)