UNIVERSITY OF TORONTO
FACULTY OF MEDICINE

Medical Alumni Association
University of Toronto

Comprehensive Research
Experience for Medical Students

MEDICAL ALUMNI ASSOCIATION AND CREMS-SPONSORED
DR. ELVA MAY ROWE FUND

INTERNATIONAL HEALTH SUMMER RESEARCH PROGRAM
2017 SUPERVISOR PROJECT INFORMATION FORM

If you wish to act as a Supervisor for a first or second year University of Toronto medical student wishing to conduct a research project abroad between June and August 2017, please complete the below form with as much detail as possible.

PLEASE PROVIDE A COPY OF THE ON-SITE SUPERVISOR'S CV. THIS IS REQUIRED FOR THE ADJUDICATION PROCESS.

****Submit this form to crems.programs@utoronto.ca by the deadline of Thursday January 5, 2017.****

PART A: Supervisor and On-Site Supervisor Contact Information

UofT Researcher:	**Dr. Nancy Olivieri**
Email Address:	**nancy@hemoglobal.org**
Telephone:	**647-299-6935**
Mailing Address:	**Toronto General Hospital** **200 Elizabeth Street, EN 13-222,** **Toronto, Ontario Canada M5G 2C4**
Department:	**Medical Oncology and Hematology**
Degree (MD, PhD, MD/PhD):	**MD, MA, FRCPC**
SGS Appointment/where?:	**Dr. Nancy Olivieri**
Selected Publications (3 most recent and relevant to the project the student will be working on):	**Chakrabarti P, Bohara VK, Ray S, Ray SS, Nath UK, Chaudhuri U. Can the availability of unrestricted financial support improve the quality of care of thalassemics in a center with limited resources? – a single center study from India. Thalassemia Reports 2013; 3; 1 DOI: 10.4081/thal.2013.e2** **Olivieri NF, Thayalasuthan V, O'Donnell A, Premawardhena A, Rigobon C, Muraca G, Fisher C, Weatherall DJ. Emerging insights in the management of hemoglobin E beta thalassemia. Ann NY Acad Sci 2010; 1202: 155-7.** **Premawardhena A, Fisher CA, Olivieri NF, de Silva S, Arambepola M, Perera W, O'Donnell A, Peto TE, Viprakasit V, Merson L, Muraca G, Weatherall DJ. Haemoglobin E beta thalassaemia in Sri Lanka. Lancet. 2005; 366: 467-70.**

UNIVERSITY OF TORONTO
FACULTY OF MEDICINE

Medical Alumni Association
University of Toronto

Comprehensive Research
Experience for Medical Students

Name of On-site Supervisor:	
Location of placement (Name of Institution/hospital; City; Country):	Department of Haematology, Nil Ratan Sircar Medical College, Kolkata (Calcutta) West Bengal, India www.nrsmc.edu.in
Email Address:	haematology@nrsmc.edu.in, prantar@gmail.com
Telephone:	+91 33 24 327 429 (M); +91 94 33 018 899; +91 85 85 816 824
Degree (MD, PhD, MD/PhD):	D.M. (Clinical Haematology) Diplomate of National Board Medicine M.D. (General Medicine) M.B.B.S.
Area of Medicine of the Research Project (2 keywords):	Thalassemia, Global Health

PART B: PROJECT INFORMATION

Project Title (this can be modified later, but we would like to have working title from the start):

Evaluation of the impact of "Patient Ambassadors" in a large thalassemia program in Kolkata, India

Provide background information on the project and program/institution; max 500 words:

We plan to evaluate the impact of "Patient Ambassadors" on the treatment of children with two blood disorders, childhood acute lymphoblastic leukemia and thalassemia major at The Nil Ratan Sircar Medical College and Hospital, Kolkata, India. Leukemia is the most common childhood cancer worldwide including in India, where approximately 9,000 children are diagnosed every year. Five-year overall survival for the most common form, acute lymphoblastic leukemia (ALL), approaches 90% in higher-income countries. In India, overall survival is approximately 40%. Thalassemia is an inherited disorder of hemoglobin synthesis and one of the most common single-gene disorders worldwide. Approximately 7-9,000 children with the most serious form, thalassemia major, are born in India each year. In higher-resource countries thalassemia has been transformed to a chronic condition with survivals into the sixth decade; at NRS Hospital > 30% of children die before their eighteenth

birthday. The main reason for these poorer survivals is *refusal (non-initiation) and abandonment (non-completion) of treatment.* Rates of refusal or abandonment of treatment for childhood ALL in India vary from 17 to 62%; similarly, at NRS Hospital, treatment is abandoned in ≈ 30% of children with thalassemia. This is not primarily related to unavailability or high costs of therapy chemotherapy, blood transfusions and chelating therapy are provided free to all children at NRS. Multiple other factors, as well as lack of finances, influence refusal or abandonment of therapy, and include inadequate communication between health-care providers and families and the pre-determined health beliefs of parents. A multi-pronged approach, involving improvements in supportive care, can result in reductions in treatment abandonment. We have raised funds to improve the poor survivals in these children through a program of educational, social and moral support through the appointment of *Patient Ambassadors* -- individuals who are patients themselves, selected by Dr. Chakrabarti. A Patient Ambassador who is successfully coping with long-term treatment for thalassemia will work with families judged at risk of abandoning treatment. The CREMS-supported student(s) will accompany the Patient Ambassador on regular (daily) interactions with families with newly-diagnosed children, to explain to parents and children complicated and detailed information vital to the understanding of this disease. The information will include education on disease processes and complications, treatment practices, scheduling, travel required for effective therapy, the expectations of treatment, and the adverse effects of treatment. The Patient Ambassador (and student) will also assist local nurses and doctors by providing weekly assessments of the family's adjustment and encourage compliance with life-saving medication. We hope ultimately to prevent treatment refusal or abandonment in 50% of the vulnerable families of children newly diagnosed with ALL and thalassemia at the NRS Hospital.

What, if any, second language is required for the student to successfully complete this project?

Some facility in Bengali and Hindi would be useful.

Is this project for 1 or 2 students to complete?

☐ 1 ☐ 2

Because of the volume of patients at NRS Medical College and the scope of the project, it would be useful to have two students sharing the work on this project.

How long have you worked with the on-site supervisor and briefly describe your working partnership:

Since 2009, we have consulted on local patients with physicians in Kolkata (Calcutta), West Bengal, India, working with Dr. Chakrabarti, advising and consulting on clinical management and screening in this thalassemia patient population, and providing support for focused research projects. We have together conducted field trips to examine practices of care for thalassemia patients in other parts of India (from 2009 to 2017), and in Bangladesh (in 2012). We have hosted Dr. Chakrabarti in small group sessions and conferences in Sri Lanka, Toronto and Oxford.

UNIVERSITY OF TORONTO
FACULTY OF MEDICINE

Medical Alumni Association
University of Toronto

CREMS
Comprehensive Research Experience for Medical Students

Have you visited the city/town where the medical student will be placed? If yes, when was your last visit? **Yes. Our last visit with Dr. Chakrabarti was in 2017 to help establish a CREMS student's work there and to plan clinical and research projects.**
Student's roles/responsibilities in bullet form (Please be as specific as possible): • **Each student will: meet daily with a family with thalassemia to establish relationships with the affected child and his/her family;** • **Each student will on a regular basis collect and collate data (demographic, medical and laboratory) data on approximately 50 children and begin to construct a data base for these families;** • **Each student will assist the Patient Ambassador in monitoring of compliance, follow up visits, prescriptions and other details of management in each family;** • **Students will accompany Dr. Chakrabarti on regular teaching and clinical rounds and participate in clinics with daily interactions with patients aged approximately 5-35 years;** • **Each student will "shadow" Dr. Chakrabarti's staff including nursing and social work to assist in and gain knowledge in the comprehensive management of thalassemia including the psychosocial adjustments to this chronic disease;** • **Students should develop a deep and broad understanding of the clinical and laboratory aspects of thalassemia, a common single gene disorder worldwide, including disease complications and approaches to treatment;** • **Students may, outside of this project also conduct chart reviews to document common primary complications of thalassemia in other patients at NRS.**

Is this project for a specific student, or will you interview and select an interested student who would contact you directly for this opportunity? *Note: All supervisor/student applications will be adjudicated by a panel of faculty, given a score, and ranked based on the score given. Funding will be based on ranking.*	☐ For a specific student. Name of student: ☐ For whichever student is chosen after interview **We would welcome any student for this project. We hope that two can be funded to facilitate the work.**
If human subjects are involved, has Ethics been obtained? *(Note: Written proof or an email indicating protocol approval may be requested prior to the student's arrival at on-site location)*	☐ Yes ☐ No ☐ N/A **Yes**

PLEASE PROVIDE A COPY OF THE ON-SITE SUPERVISOR'S CV. THIS IS REQUIRED FOR THE ADJUDICATION PROCESS.

Attached.