



UNIVERSITY OF TORONTO
FACULTY OF MEDICINE



Medical Alumni Association
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Medical Alumni Association & CREMS Programs
Dr. Elva May Rowe Fund

PLEASE PROVIDE A COPY OF THE ON-SITE SUPERVISOR'S CV. THIS IS
REQUIRED IN ORDER TO PROCESS YOUR APPLICATION

PLEASE SUBMIT THIS COMPLETED FORM TO
CREMS.PROGRAMS@UTORONTO.CA BY **FEBRUARY 25, 2019**

PART A: SUPERVISOR AND ON-SITE SUPERVISOR CONTACT INFORMATION

U OF T RESEARCHER	
NAME:	Dr. Nancy Olivieri
EMAIL:	nancy@hemoglobal.org
DEPARTMENT:	Professor, Pediatrics, Medicine and Public Health Sciences, University of Toronto, Canada; Senior Scientist, Toronto General Hospital
SGS (please indicate where)	Institute of Medical Science, University of Toronto, Canada
Selected Publications (3 most recent and relevant to the project)	<p>Premawardhena A, Ranawaka U, Pilapitiya T, Weerasinghe G, Hapangama A, Hettiarachchi S, Salvin K, Silva I, Hameed N, Weatherall M, Olivieri N, Weatherall DJ. Headache: an important symptom possibly linked to white matter lesions in thalassemia. In press, Br J Haematol 2019</p> <p>Olivieri NF, Jayawardena S, Shakory S, Chandrakumaran P, Khan S, Kirubarajan A, Premawardhena A, Mettananda S, Sabouhanian S, Allen A, Cader R, Bandara D, Rees D, Weatherall DJ. Recurrent leg ulceration in patients with Hemoglobin E beta thalassemia. Abstract submitted, Amer Soc Ped Hem Onc, 2019</p> <p>Olivieri NF, Jayawardena S, Shakory S, Chandrakumaran P, Khan S, Kirubarajan A, Premawardhena A, Mettananda S, Sabouhanian S,</p>



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	Allen A, Cader R, Bandara D, Rees D, Weatherall DJ. Linear growth in patients with thalassemia in Sri Lanka. Abstract submitted to Amer Soc Ped Hem Onc, 2019
	Allen A, Allen S, Olivieri, NF. Improving Laboratory and Clinical Hematology Services in Resource Limited Settings. Hematology-Oncology Clinics of North America 2016; 30 (2) 497.
ON SITE SUPERVISOR	
NAME:	Dr. Anuja P Premawardhena
LOCATION OF PLACEMENT:	Professor in Medicine, Department of Medicine, University of Kelaniya, Sri Lanka; Consultant in charge: Adolescent & Adult Thalassaemia Care Unit, North Colombo (Teaching) Hospital. Ragama, Sri Lanka
EMAIL:	premawa@hotmail.com
AREA OF RESEARCH:	Thalassaemia, Global Health

PART B: PROJECT INFORMATION

PROJECT TITLE: Long-term Analysis of the Clinical and Laboratory Features of Hemoglobin E Thalassemia in Sri Lanka

PROJECT/PROGRAM/INSTITUTION BACKGROUND INFORMATION

(MAX 500 WORDS):

Thalassemia is an inherited blood disorder characterized by decreased production of hemoglobin, and (with sickle cell disease) one of the two most common monogenic disorders worldwide. Although imposing a huge disease burden throughout Asia, thalassemia, until recently, was rarely included in the priorities of governments or international health agencies. In 2000, The World Health Organization acknowledged thalassemia as a major global health problem. Worldwide, Hemoglobin E (HbE) thalassemia is the commonest form of severe beta thalassemia, accounting for approximately one-half of cases worldwide, and is an increasingly severe public health problem throughout the Indian subcontinent and Southeast Asia. Its phenotypic variability makes management particularly challenging. Since 1996, our research and clinical programs have worked in Sri Lanka, where thalassemia is the most common inherited disease, with patients in Colombo (the capital) and Kurunegala (about three hours north) providing consultations in management,



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screening, and conducting basic and applied research in thalassemia. We helped to support The National Thalassemia Center (in 2001), and in 2004 established a charity (Hemoglobin®) directed at raising funds to improve care for thalassemia. We have established strong collaborations with clinicians and researchers throughout the island. We have followed, for 23 years, a cohort of 250 patients with HbE thalassemia, the most extended follow-up of any cohort worldwide.

While Sri Lanka has a high standard of public health care with respect to many infectious diseases, a number of problems complicate the care for thalassemia, its most common genetic disease. No national thalassemia registry is available, and while some clinics are models of care, management in many others is marginal. This is why our vision is to create an island-wide clinical database for thalassemia both to provide safer, systematized, evidence-based care, and to generate clinical data to permit research to evaluate new therapies. We have developed a disease-specific web-based tool to facilitate communication within the circle of care, of each patient, a tool termed “Depict Health”. Depict Health runs on high-performance cloud computing allowing input of health data where there is cell phone coverage or Internet. Briefly, at each clinical encounter, clinicians at the treatment center upload, securely and at point of care, relevant data on a timeline that is immediately accessible to care providers and clinicians working at other treatment centers. We will be testing this in the summer of 2019 in Colombo and Kurunegala, and hope eventually to extend this system island wide.

STUDENT ROLES/RESPONSIBILITIES (PLEASE BE AS SPECIFIC AS POSSIBLE):

The 2019 CREMS student project is two-pronged. The student will review, alongside one of two expert hematologists, approximately 200 patients whose relevant data (including transfusion requirements, cardiac, liver and endocrine complications, causes of deaths, quality of life) will then be recorded in an extensive, existing data base. As an ancillary research project this summer, the recording of HbE thalassemia data using a disease-specific web-based tool, Depict Health (outlined below) will also be explored. Once all data are entered, the student will assist statisticians in Colombo in the analysis of these data and will assist Drs Olivieri and Premawardhena in the preparation of a publication which follows upon their previous observations [*Premawardhena A, Fisher C, Olivieri NF et al. Lancet 2005; 366: 1467–70*]. Student duties will therefore include working, with two expert supervisors, to conduct: clinical and laboratory review of patients, review of relevant medical records; data entry; assistance with statistical analysis; “shadow” expert physicians to gain an appreciation and understanding of thalassemia, and other hematologic and tropical diseases. There will also be opportunities to explore the frequency of complications in other forms of thalassemia. For example, last year one CREMS U of T-supported student evaluated the prevalence and risk factors associated with leg ulcers in HbE thalassemia. There are other similar chart reviews to be reviewed and assembled.



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

Fluency in Tamil or Sinhalese is always helpful but is NOT required for the success of this work.

- Is this project for 1 or 2 students to complete?

Two students would be ideal since they can assist each other but the work can be conducted with one student. We hope that two students can be funded in parallel on this project.

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

My clinical and research teams have worked in Sri Lanka for 23 years, with our (recently deceased and greatly mourned) colleague Professor Sir David Weatherall. Dr Premawardhena trained in basic and clinic research at the institution founded by Professor Weatherall (Weatherall Institute of Molecular Medicine, University of Oxford, UK), and received his D. Phil with a thesis focusing on studies of HbE thalassemia. I have worked with Dr. Premawardhena for the past 15 years in a very strong and productive collaboration. We meet and discuss our work on each field trip to Sri Lanka, two to three times annually.

- Have you visited the city/town where the student will be placed? If yes, when was your last visit?

Yes. My last visit in July 2018 completed a month-long visit during which our U of T students completed several projects. I will be conducting my next field trip next month (March 9 to 19) 2019.

- 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 the on-site location)?

Yes there is Research Ethics Board approval for these studies.



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