

12 March 2019

Dr. Kevin Smith Health Network President & CEO, University kevin.smith@uhn.ca

Dear Dr. Smith,

Thank you for your letter of March 18, 2019, and for your discussions with our colleague Dr. John Dick. We very much support your efforts to clarify the issues that our research has uncovered concerning safe patient care at UHN.

With respect to Mr. Toppings' direction to provide names and MRN numbers of the research subjects in our study, we remain puzzled as to why you, as UHN CEO, would not simply request such details on all relevant patients of Drs. Richard Ward, Kevin Kuo, Erik Yeo and others in the Thalassemia Program, who had overseen the prescribing of unlicensed deferiprone to UHN patients from 2009 to 2015. You suggested in our January 7, 2019 meeting that as UHN CEO, you had no legal impediment to obtain all relevant details within the UHN if/when there is a suspected issue of patient safety.

In his letter to us of February 28, 2019, Mr. Toppings agreed to waive the terms of the Personal Health Information Protection Act (PHIPA), indicating that "Health Institutions like UHN can use PHI about individuals for the purpose of risk management....". The UHN can certainly obtain complete data from Drs. Ward, Kuo and Yeo, who are in the "circle of care" of these patients. We presume they are also PIs of the research study by which the patients were provided deferiprone.

We appreciate your explanation for the statement issued by "UHN officials" (which we expect was approved in advance by the UHN legal team). However, the UHN statement in the Star and sent throughout the UHN, has been broadly interpreted to suggest that the validity of our (peer-reviewed, published) data was being questioned. This had the clear effect of casting public doubt and disparagement upon our concerns for the safety of these patients.

We also note that Mr. Toppings' letter is a reversal of attitude by UHN legal counsel. Former UHN counsel Ms. Bella Martin, although well informed since 2009 about Dr. Olivieri's concerns about the use of unlicensed deferiprone at UHN, firmly rejected any review of patient data.

We understand that the goal of Dr. Baker's Review Team is to determine in which patients such harm had occurred. Are we to understand, as Dr. Dick did, that the UHN legal team is advising that all patients exposed to unlicensed deferiprone be contacted by UHN before Dr. Baker has had the opportunity to review harms to these patients? Surely, then a full list of patients would need to be requested through Drs. Ward, Kuo, Yeo. We expect that so-informing only some but not all of the patients would not be considered fair or reasonable. We are also concerned about what message(s) is intended to be conveyed to patients who have in our view been indisputably harmed, but who remain within the "circle of care" of Dr. Richard Ward and others who have prescribed years of unlicensed deferiprone. To be clear, we are concerned that patients

would be vulnerable to receiving information that may not be completely accurate, does not detail the true history of this matter, and may render the patient with a sense of vulnerability about the security of their ongoing care (for example, would patients who sought their own legal advice against UHN believe that they might be removed from long-term care in the UHN clinic?)

Yours sincerely,

Brenda I Hallie

Brenda L. Gallie, MD, FRCSC, CM, OOnt Head, Retinoblastoma Programs,

Hospital for Sick Children and Alberta Children's Hospital;

Associate Scientist, TECHNA Institute, UHN; Professor, Ophthalmology, Medical Biophysics, Molecular Genetics, University of Toronto. 555 University Ave, Toronto M5G 1X8 brenda@gallie.ca

CC: Dr. Michael Baker

Shawy Cluicic
Nancy F. Olivieri, MD, MA, FRCPC

Professor, Pediatrics, Medicine and Public Health Sciences.

University of Toronto, Canada;

Senior Scientist, Toronto General Hospital, UHN.

200 Elizabeth Street, EN 13-222,

Toronto, Ontario Canada M5G 2C4

nancy@hemoglobal.org