



HTPN REGISTRY

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Welcome!

The Canadian Home Total Parenteral Nutrition Registry aims to collect pertinent demographic and clinical data on the HTPN population in Canada and to determine the factors affecting survival, complications, and TPN-dependency. This aids us in establishing standards of practice, improving quality of care, and highlighting areas of further research.

If you have any comments or questions regarding the HTPN registry, please contact **Katherine Schwenger** at katherine.schwenger@uhnresearch.ca



How does the HTPN Registry Work?

- All clients in the participating programs are asked, whether they want to be part of the Home TPN registry. Participation is completely voluntary.
- Home TPN staff from participating programs follows the participants and records their data into the registry. The first data entry (baseline) is done at the time the client agrees to participate and after that every 2 years. However, follow-up data will be collected every 6 months for patients on Teduglutide.
- The data collected remains completely confidential and can only be accessed as a whole by the individual programs for database comparisons. The programs are able to compare their own program to all the other programs as a whole, but they cannot compare between specific Home TPN programs.

Highlights from 2019



DDW 2019—San Diego

This year at DDW, Ennaliza Salazar presented on patients with dysmotility receiving home parenteral nutrition using the data from the HTPN registry



Annual CNS Conference

This year's annual CNS conference was held in Niagara Falls, Ontario where Drs Allard, Schwenger, Salazar and Clermont-Dejean presented data from the registry.



ESPEN 2019—Poland

Nayima Clermont-Dejean's presented an abstract titled "HPN patients with severe gastrointestinal dysmotility have similar clinical outcomes to patients with short bowel syndrome."

FAQ



What data do we collect?

Data Collection for all patients on HTPN registry:

All patients on HTPN registry have data collection follow ups every **2 years**

• **Pages Required:**

- ✓ Anatomy
- ✓ Nutrition
- ✓ Bone Mineral Density
- ✓ Quality of Life
- ✓ Hospitalization
- ✓ HTPN Regimen
- ✓ Indications for HTPN
- ✓ Vascular Access
- ✓ Laboratory Results
- ✓ Liver Complications
- ✓ Medications
- ✓ Additional Diagnosis

If the patient is **ALSO** on Teduglutide:

Additional data collection follow ups occur every **6 months**

- Only last 3 “Teduglutide Follow-up” pages are required:
 - ✓ Medications
 - ✓ HTPN Regimen
 - ✓ Laboratory Results

Publication Highlights

- Raman M, Gramlich L, Whittaker S, Allard JP. Canadian Home Total Parenteral Nutrition Registry: Preliminary Data on the patient population. Can J Gastroenterol 2007; 21(10): 643-648
- Aljarallah B, Fernandes G, Aljarallah B, Fernandes G, Jeejeebhoy KN, Gramlich LM, Whittaker JS, Armstrong D, Duerksen DR, Allard JP. The Canadian Home Total Parenteral Nutrition (HTPN) Registry: Vitamin K supplementation and bone mineral density. JPEN 2012; 36(4): 415-20.
- Fernandes G, Kaila B, Jeejeebhoy K, Gramlich LM, Armstrong D, Allard JP. Canadian home parenteral nutrition (HPN) registry: validation and patient outcomes. JPEN 2012; 36(4):407-14.
- Abdalian R, Fernandes G, Duerksen D, Jeejeebhoy KN, Witthaker S, Gramlich L, Allard JP. Prescription of Trace Elements in Adults on Home Parenteral Nutrition: Current Practice Based on the Canadian Home Parenteral Nutrition Registry. JPEN J Parenter Enteral Nutr. May 2013; 37(3):410-415.
- Hortencio TDR, Arendt BM, Teterina A, Jeejeebhoy KN, Gramlich LM, Whittaker JS, Armstrong D, Raman M, Nogueira RJN, Allard JP. Changes in home parenteral nutrition practice based on the Canadian home parenteral nutrition patient registry. JPEN J Parenter Enteral Nutr. 2015 Sep 25.
- Tran V, Bielawska B, Jeejeebhoy KN, Gramlich LM, Raman M, Whittaker JS, Armstrong D, Marliss EB, Allard JP. Variations in practice pattern related to cancer patients received home parenteral nutrition. Nutrition. 65: 27-32. Published, 2019.

Upcoming Projects



Using HTPN registry data, Ennaliza and Nayima are working on a manuscript examining patients with severe gastrointestinal dysmotility compared to patients with short bowel syndrome. The results showed that those with gastrointestinal dysmotility have similar clinical outcomes to those with short bowel syndrome.

Jessica Noelting’s manuscript titled “Survival of patients with short bowel syndrome on home parenteral nutrition: results from the Canadian national registry” has been submitted to Clinical Nutrition .

Katherine Schwenger is currently using the HTPN registry data to examine the clinical outcomes of younger versus older patients. This manuscript will be submitted to an academic journal in 2020.

Other ongoing projects: 1) the effect of Teduglutide on PN weaning; 2) 2-year outcomes comparing soy-bean based versus low soy-bean lipid emulsion.

We invite all centers to share their ideas and collaborate for data analysis. Please remember, should you need the whole registry data, please contact the National Coordinator.

Our 12 Centres



Toronto General Hospital, Toronto, ON; Capital Health/University of Alberta, Edmonton, AB; Hamilton Health Sciences HPN Program; B.C. HTPN Program, Vancouver; . Boniface Hospital, Winnipeg, Manitoba; St. Michael’s Hospital, Toronto, ON; Foothills Medical Center HTPN Program, Calgary, AB; McGill University Health Centre, Montreal, QC; L’Hôtel-Dieu de Québec , Quebec, QC; Saskatchewan Adult HTPN Program, Regina, SK ; Hôpital Saint-Luc , Montreal, QC. The Ottawa Hospital/L’Hôpital d’Ottawa, Ottawa, ON

Thank you!

Thank you all for your dedication to the HTPN Registry. We would also like to thank our sponsors for their ongoing support with the Canadian HTPN Registry.



Canadian Nutrition Society
Société canadienne de nutrition