HTPN PATIENT REGISTRY FORM 2013

Informed consent signed? □ Yes □ No

HTPN Registry Patient code: _____
(3 code letters for the center followed by any 5 numbers, e.g. TGH00001)

HTPN CENTER (Full name): _____

Code: _____ Province: _____

Date of data extraction: _____ (mm/dd/yyyy)
(Enter this value for all forms on the website)
NOTE: *If patient expired or is weaned off TPN, use the day of death or the last visit to the TPN clinic, respectively, as date of data extraction!*

Type of record (please check)**:**
□ Baseline Follow up: □ 2 year □ 4 yr □ 6 yr □ 8 yr □ 10 yr □___ yr

PATIENT BASIC

This is □ an adult record □ a pediatric record
Has this patient been seen previously in your clinic? □ Yes □ No
Gender: □ F □ M Date of birth: _____ (mmm/yyyy)
Age: _____
Occupation: _____
Highest level of education attained (if known): _____

Please note:

- *Suggested document source: clinic or hospital charts over the past 12 months*
- *If patient expired or is weaned off TPN, use the day of death or the last visit to the TPN clinic, respectively, as date of data extraction! When previous 12 months are asked in the form, use the 12 months before death/weaning.*
- *Pages 1-2 are permanent patient information. If there are changes from one year to the next, only write the change, e.g. change in anatomy due to additional surgery).*
- *For the entire form, write "NA" if data is not available.*

ANATOMY *(Website: click ANATOMY)*

What type of record is this? □ Baseline □ Follow-Up _____years

Is the anatomy known? □ Yes □ No

If baseline, enter information below.
If follow-up, has there been any change in GI anatomy since last entry? □ Yes □ No
If yes, enter information below. **If no**, go to the last question on this page: Other medical diagnosis

Does the entire small bowel remain? □ Yes □ No

If no, is the length of the small bowel known? □ Yes □ No

If yes, what is the total length of small bowel? cm: _____
If known, describe the small bowel remaining:
_____

Does the full colon remain? □ Yes □ No

Only part of the colon remains? □ Yes □ No

If yes, describe: _____

Only rectum remains? □ Yes □ No

Remaining colon? □ Yes □ No

Is the gastrointestinal tract in continuity (re-anastomosed)? □ Yes □ No

Is there an ostomy bag? □ Yes □ No

If yes, what type (Gastromy Venting Tube, Duodenostomy, Jejunostomy, Ileostomy, Colostomy, Other:Specify)? _____

Describe other GI surgery (e.g. whipple, cholecystectomy, etc.):
_____

Other medical diagnosis:
_____
_____
_____
_____
_____

NUTRITION ASSESSMENT *(Website: click NUTRITION)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

Anthropometry

Actual Body Weight (ABW): _____ kg Height_____ cm BMI: _____kg/m^2

Weight at start of TPN: _____kg BMI at start of TPN: _____ kg/m^2
*(If patient had an interruption in TPN, please enter here weight at **re-start** of TPN)*

Estimated Nutrient Requirement

Current Total Estimated Energy Requirement (TEER)(kcal/day) calculated by Harris-Benedict (HB)
HB Male: [66.5 + 13.7 W (kg) + 5.0 H (cm) – 6.7 A (y)]: _____ kcal/d

HB Female: [655 + 9.5 W (kg) + 1.8 H (cm) – 4.7 A (y)]: _____ kcal/d

Multiply HB by Stress factor (1.0 if sedentary – 2.5 if physically active)
Stress factor used: _____

TEER = HB x Stress factor: _____ kcal/day (Enter this value in website)

Protein Requirements (g/kg): _____

Nutrient Intake
TPN:
Energy (kcal/day): _____ (If TPN < 7 days/week, indicate average per day)
Protein (g/day): _____ (If TPN < 7 days/week, indicate average per day)

Oral (Estimate only. If applicable, include nutritional supplements):
Energy (kcal/d)_____Protein (g/d): _____

Specify Oral Diet Type (low oxalate, short gut, post-gastrectomy, lactose restricted, modified fibre, DAT, anti-dumping, other) _____

Enteral Diet (if applicable):
Energy (kcal/day): _____ (If < 7 days/week, indicate average per day)
Protein (g/day): _____ (If < 7 days/week, what is average per day)

Name of enteral product: _____
Specify tube site: □ Gastrostomy □ Gastrojejunostomy □ Jejunostomy
□ Other (specify): _____

Alcohol (g/week): _____ (e.g. 1 glass wine; 1 beer; or 2 oz. liquor = 10 g)
or: □ Alcohol intake unknown

Smoking (# cigarette/day): _____ or: □ unknown

BONE MINERAL DENSITY *(Website: click BONE MINERAL DENSITY)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

If baseline, enter information below.

If follow-up, did this patient have a bone mineral density performed since last data entry?
□ Yes □ No
If yes, enter information below. **If no,** go to Bone Fractures

Date of BMD: _____ (mm/dd/yyyy)

Spine: BMD (g/cm^2): _____ T-score: _____ Z-score: _____

Femoral neck: BMD (g/cm^2): _____ T-score: _____ Z-score: _____

Total hip: BMD (g/cm^2): _____ T-score: _____ Z-score: _____

Bone Fractures

Risk of fracture:
Average_____ Minimal Increase: _____ Moderate Increase: _____ High Risk: _____

Has the patient had bone fractures? □ Yes □ No

If yes, number of fractures over past 12 months or since last record: _____

Type of fracture: _____

- See medication section to record bone medications

QUALITY OF LIFE *(Website: click QUALITY OF LIFE)*

Date of home TPN start? _____ (mm/dd/yyyy)

What type of record is this? □ Baseline □ Follow-Up: _____ years

Is patient alive? □ Yes □ No

If no, date of death? _____ (mm/dd/yyyy)

Is patient still on Home TPN? □ Yes □ No

If no, when was TPN stopped? _____ (mm/dd/yyyy)

Determine the Karnofsky Performance Scale at:

- Present time:_____
- Start of Home TPN (if available or estimated retrospectively): _____

Karnofsky Performance Scale:

100 - Normal, no complaints, no evidence of disease
90 - Able to carry normal activity, minor signs/symptoms
80 - Normal activity with effort, some signs/symptoms
70 - Cares for self, unable to carry normal activity/active work
60 - Requires occasional assistance, able to care for most needs
50 - Requires considerable assistance, frequent medical care
40 - Disabled, requires special care and assistance
30 - Severely disabled, hospitalization indicated, death not imminent
20 - Hospitalization necessary, very sick, active supportive treatment
10 - Moribund, fatal processes progressing rapidly
0 - Dead

HOSPITALIZATION *(Website: click HOSPITALIZATION)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

Is the number of hospitalizations available over past 12 months? □ Yes □ No

If yes, number of hospitalizations over past 12 months: _____

Total number of days in hospital over past 12 months: _____

How many of those hospitalizations are due to TPN-related complications? _____

How many of those total days in hospital are due to TPN-related complications? _____

HTPN REGIMEN *(Website: click HTPN REGIMEN)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

Is this patient still on Home TPN? □ Yes □ No

When did Home TPN regimen start? _____ (mm/dd/yyyy)

When did Home TPN regimen end? (if applicable)_____ (mm/dd/yyyy)

Has there been an interruption in HTPN since last entry? □ Yes □ No

If yes, how many months? _____

Has there been any change (macronutrients, micronutrients, volume, calories, days per week) in HTPN regimen since the last entry? □ Yes □ No

Reasons HTPN regimen ended:

□ Weaned

□ Deceased

If death:

- Is it TPN-related? □ Yes □ No

If yes, cause(s) of TPN-related death:

□ Sepsis □ Thrombosis/embolus □ Liver failure

□ Other (specify)_____

- Is it non-TPN related death? □ Yes □ No

If yes, cause(s) of non-TPN related death:

□ Underlying disease □ Cardiovascular □ Cancer □ Other (specify): _____

□ Intestinal transplantation

□ TPN-related complications Specify_____

□ Non-TPN related complications Specify_____

□ Other Specify_____

Current HTPN Regimen Details

Please note: If patient expired or off TPN, record the last available TPN prescription

Is the TPN bags/month known? □ Yes □ No

Number of bags per month: _____

TPN regimen cycled? □ Yes □ No

Is the TPN hours of infusion/day known? □ Yes □ No
Number of hours of infusion/day: _____
Number of days/week on TPN: _____
□ 3-in-1 system □ 2-in-1 system □ Hydration only

NOTE: *For the following please describe the quantity of the following macro and micronutrients as daily averages over a one-week period. For example: multiply nutrient infused per day, by the number of days per week the patient receives HTPN, then divide that value per 7, to obtain the daily average.*

TPN daily average:
Amino acid content (g/day): _____ Dextrose (g/day): _____
Lipids (mL/day): _____
Name of lipid: _____ Concentration □ 10% □ 20% □ 30%

Total calories from TPN (amino acid + dextrose + lipids) (kcal/day): _____*
(*Note: dextrose - 3.4 kcal/g; protein - 4 kcal/g, lipid 20% - 2 kcal/mL)
Total volume (mL/day): _____

Additional IV fluids (average over 7 days) (mL):
Describe additional IV fluids _____

Additives:
Multi-12 - □ Yes □ No Vitamin K - □ Yes □ No
Other TPN vitamins: _____
Heparin (units): _____
Other medication(s) added to TPN bag: _____□ None

Trace elements/electrolytes converted to umol/day and mmol/day, respectively?
□ Yes □ No

Trace elements contents (umol/day) *daily average*:
Zinc: _____ Manganese: _____
Selenium: _____ Chromium: _____
Copper: _____ Iodide: _____
Iron: _____

Electrolytes contents (mmol/day) *daily average*:
Na: _____ Cl: _____
K: _____ Ca: _____
Phosphate: _____ Acetate: _____
Mg: _____ Other (specify): _____

INDICATIONS FOR HTPN *(Website: click INDICATIONS FOR HTPN)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

If baseline, enter information below.

If follow-up, has the indications for HTPN changed since last entry? □ Yes □ No
If yes, enter information below. **If no**, proceed to the next page.

1. Short bowel syndrome: - □ Yes □ No **If yes, choose the cause(s):**
   - □ Volvulus
   - □ Crohn's disease
   - □ Mesenteric infarction due to
     - □ venous thrombosis or
     - □ arterial thrombosis/embolus
   - □ Surgical complication
   - □ Other(specify): _____
   - □ Trauma
   - □ Necrotizing Enterocolitis
   - □ Intestinal atresia
   - □ Gastrochesis

2. Mucosal defects: □ Yes □ No **If yes, choose the cause(s):**
   - □ Secretory diarrhoea due to (diagnosis): _____
   - □ Celiac disease
   - □ Autoimmune enteritis
   - □ Microvillus inclusion
   - □ Radiation Enteritis
   - □ Other(specify): _____

3. Motility disorder: □ Yes □ No **If yes, choose the cause(s):**
   - □ Pseudo-obstruction (□ Primary □ Secondary)
   - □ Aganglionosis / Hirschprung's Disease
   - □ Visceral neuropathy
   - □ Other(specify): _____
   - Cause of pseudo-obstruction: _____
   - □ Visceral myopathy
   - □ Neuronal Intestinal Dysplasia

4. Tumour/cancer: □ Yes □ No **If yes, choose diagnosis:**
   - □ Desmoids
   - □ Gardner's syndrome
   - □ Familial Polyposis
   - □ Other cancer(specify location): _____
   - □ Carcinoid
   - □ Ovarian
   - □ GI tract (specify location):_____

5. Surgical complications: □ Yes □ No **If yes, define:**
   - □ Enterocutaneous fistula
   - □ Other (specify)_____
   - □ Obstruction
   - □

6. Pancreatic Disorders: □ Yes □ No Cause: _____

7. Other (specify): _____

VASCULAR ACCESS *(Website: click VASCULAR ACCESS)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

If baseline, enter information below.

If follow-up, has there been any change in vascular access since last entry?
□ Yes □ No **If yes,** enter information below**. If no,** proceed to LINE SEPSIS section below**.**

Type of catheter:

□ PICC
□ Tunnelled Catheter (e.g. Hickman): _____
□ Implanted Catheter (e.g. PortaCath): _____
□ Other (specify): _____

Number of lumens: _____

Inserted □ surgically □ radiologically □ Other (specify): _____ □ unknown

Date of insertion: _____ (mm/dd/yyyy)

Line Sepsis

NOTE: *If patient expired or off TPN, look at the 12 months prior to death/weaning, i.e. 12 months from the extraction date, which might not be the actual day you are filling out this form (see also first page).*

Is the number of line sepsis over last 12 months available: □ Yes □ No

If yes, number of documented line sepsis over past 12 months (positive line blood culture + fever): _____

Number of changes in vascular access over past 12 months: _____ unknown: _____

Reason for line change:

How many times has the line been changed for each of the following reasons over the past 12 months?

- Sepsis: _____
- Break: _____
- Occlusion: _____

LABORATORY RESULTS (W*ebsite: click LABORATORY RESULTS)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

NOTE: *Record recent blood work while patient has been stable over 2 months and not hospitalized. The lab results should be from the same period of time every year unless unstable clinically. Write "NA" if not available. Please enter in specified units.*

Date of Lab Results: _____ (mm/dd/yyyy)

Hb (g/L): _____
WBC (x 10^9/L): _____
Platelets (x 10^9/L): _____
MCV (fL): _____
Neutrophils (x 10^9/L): _____

Na (mmol/L): _____
K (mmol/L): _____
Mg (mmol/L): _____
Phosphate (mmol/L): _____
Creatinine (umol/L): _____
ALP(U/L): _____
AST(U/L): _____
Total protein (g/L): _____
INR: _____
PT(s):_____
PTT(s):_____
Cl (mmol/L): _____
Bicarbonate (carbon dioxide)(mmol/L): __
Ca (mmol/L): _____
BUN (urea) (mmol/L): _____
Random Glucose(mmol/L): _____
TBILI(umol/L): _____
ALT(U/L): _____
Albumin (g/L): _____
Pre-albumin (if available)(g/L): _____

Cholesterol (mmol/L): _____
Ferritin (ug/L): _____
Iron Sat: _____
RBC Folate (nmol/L): _____
PTH (pmol/L): _____
Triglycerides (mmol/L): _____
Iron (umol/L): _____
Transferrin (g/L): _____
Vit B12 (pmol/L): _____
25-OH vit D (nmol/L): _____

Plasma trace elements:
Zinc (umol/L): _____
Chromium (umol/L): _____
Copper (umol/L): _____
Selenium (umol/L): _____
Manganese (nmol/L): _____

24-H Urine:
Total Oxalates(umol/d): _____
Total Calcium(umol/d): _____
Total urine volume(mL): _____
Total Citrate(mmol/d): _____
Total Creatinine(mmol/d): _____

LIVER COMPLICATIONS (W*ebsite: click LIVER COMPLICATION)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

If baseline, enter information below.

If follow-up, has there been any change in liver condition since last entry?
□ Yes □ No **If yes,** enter information below. **If no,** proceed to CURRENT THERAPY FOR LIVER DISEASE

Liver disease? □ Yes □ No

In the physicians judgement, is the liver disease TPN-related? □ Yes □ No

- If TPN-related, diagnosis of liver disease (specify): _____
- If non-TPN related, diagnosis of liver disease:
  □ Viral Hepatitis: □ Hepatitis A □ Hepatitis B □ Hepatitis C
  □ Autoimmune □ Hemachromatosis □ Alcohol-induced □ Metastasis

Liver biopsy? □ Yes □ No
If yes, date of biopsy: _____ (mm/dd/yyyy)
Results: □ TPN cholestasis □ Steatosis □ Fibrosis □ Cirrhosis

Other diagnosis (specify): _____

Abdominal Ultrasound/Computed Tomography? □ Yes □ No □ US □ CT
If yes, date of ultrasound/CT: _____ (mm/dd/yyyy)
Results: □ steatosis □ cirrhosis □ gallstones □ common bile duct stones
□ cholecystectomy □ fibrosis □ other (specify): _____

Other causes of liver disease excluded? □ Yes □ No

CURRENT THERAPY FOR LIVER DISEASE

Has there been change in TPN Regimen for liver disease? □ Yes □ No
If yes, what was the action taken:
Reduce dextrose in TPN? □ Yes □ No
Reduce lipids in TPN? □ Yes □ No
Reduce TPN days/week? □ Yes □ No
Discontinue TPN? □ Yes □ No

Changes to Enteral: □ Yes □ No
Changes to Oral: □ Yes □ No
Define changes: _____

See medication section to record liver medications.

MEDICATIONS (*Website: click MEDICATIONS)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

Type/name of current oral and IV medications:
Immuno suppressors (specify):_____
Motility agents (specify):_____
Antidepressors (specify): _____
Narcotics (specify): _____
Antidiarrheal medication (specify): _____
Sedatives (specify): _____
Anticoagulation medication (specify): _____
Reason (specify):_____
Insulin medication (specify): _____
□ Subcutaneous □ in TPN □ subcutaneous + TPN
Inhibitor of acid secretion: H2 Antagonist □ Oral □ IV
PPI □ Oral □ IV
Other (specify) _____

Liver Medications:
URSO: □ Yes □ No Dosage: _____
Antibiotics: □ Yes □ No Specify antibiotic: _____
Carnitine: □ Yes □ No
Choline: □ Yes □ No
Other (specify):_____

Bone Medications:
Oral calcium: □ Yes □ No Dosage (g/day): _____
Oral vitamin D: □ Yes □ No Dosage (IU/day): _____
Oral bisphosphonate: □ Yes □ No Name of oral bisphosphonate: _____
IV bisphosphonate: □ Yes □ No Name of IV bisphosphonate:_____
Frequency of infusion: _____

Other medications:
_____
_____
_____

ADDITIONAL DIAGNOSIS (*Website: click Additional Diagnosis)*

What type of record is this? □ Baseline □ Follow-Up: _____ years

Date of last assessment: _____ (mm/dd/yyyy)

Other medical diagnosis

Seizures: □ Yes □ No

Stroke: □ Yes □ No

Heart disease: □ Yes □ No

Artificial heart valve: □ Yes □ No

Organ transplant: □ Yes □ No

High blood pressure: □ Yes □ No

Blood disorder: □ Yes □ No

Liver disease: □ Yes □ No

Diabetes: □ Yes □ No

Pacemaker: □ Yes □ No

Kidney disease: □ Yes □ No

Arthritis/Joint: □ Yes □ No

Other: □ Yes □ No