Follow-up Forms-Adult Data Collection Tools © A.S.P.E.N.

● = critical elements

Follow-up Demographics

● Follow-up Date (mm/dd/year): ____________________

Patient Number (As designated by study)___________________

● Attending Physician' s Name___________________________

● Discharging Institution Name________________________

● PN Home Infusion Care Provider Name_________________

● Patient Birth Date (mm/dd/yr) _________________

● Gender: Male___ Female____

● Date began Home PN (mm/dd/year)_____________________

Who does patient live with? (please select)

- Alone____
- Parent____
- Spouse____
- Significant Other____
- Child____
- Hired professional assistance____
- Other____

● Insurance Coverage (check all that apply)

- Private Insurance___
- Medicare___
- Medicaid___
- Personal Payment___
- Medicare Supplement___
- Other (Specify) ___________________________

Current Nutritional Status

● Height ____ cm Length for Infants or bedbound children ______cm

If extrapolated, please explain and indicate method used ____________________

- Usual Weight _____ kg (prior to illness)
- Current Weight _____ kg

- **Labs at Followup**

Date Labs collected: (mm/dd/yr)______________

Serum Albumin_____ g/dL

Platelet Count _____/µL (per microliter)

Direct Bilirubin_____ mg/dL

AST_______U/L

ALT______U/L

INR______

BUN_____mg/dl

Creatinine_____mg/dl

- **Any New Diagnoses** (check all that apply)

☐ AIDS

☐ Esophageal Atresia

☐ Intestinal Atresia

☐ Gastroschisis

☐ Crohn's Disease

☐ Cystic Fibrosis

☐ Gastrointestinal Cancer

☐ Gastromotility/Pseudo-obstruction disorder

☐ Gynecological tumor

☐ Hirchsprung's Disease

☐ Hyperemesis Gravidarum

☐ Gastrointestinal Bypass for Obesity

☐ Mesenteric Ischemia

☐ Mitochondrial Disorder

☐ Necrotizing Enterocolitis

☐ Neurological Swallowing Disorder

☐ Non-Crohns Inflammatory Bowel Disease

☐ Pancreatitis/Pancreatic Insufficiency

☐ Radiation Enteritis

☐ Short Bowel Syndrome

Small bowel stoma ◯ Yes ◯ No

Colonic Stoma ◯ Yes ◯ No

Large bowel in continuity with small bowel ◯ Yes ◯ No

Ileo-cecal valve present ◯ Yes ◯ No

Length of remaining **small** bowel in continuity ☐ cm

Length of remaining **large** bowel in continuity ☐ cm

Bowel measurement technique (before any lengthening procedure:

◯ At time of surgery

◯ Radiographically

◯ Estimated

History of bowel lengthening surgical procedure Yes____ No____

If yes, operative procedure used:

Length after lengthening surgery:
cm

☐ Other Diagnosis Please specify:

Ongoing Reason for Parenteral Nutrition (check all that apply)

- ☐ Active Inflammatory Bowel Disease
- ☐ Bowel dysmotility
- ☐ Chemotherapy Associated GI Dysfunction
- ☐ Congenital Bowel Defect (Intestinal Atresia)
- ☐ Gastrointestinal Fistula
- ☐ Gastrointestinal Obstruction
- ☐ Gastroschisis Associated Dysmotility
- ☐ Intractable Diarrhea
- ☐ Intractable Vomiting
- ☐ Mesenteric Ischemia
- ☐ Necrotizing Enterocolitis
- ☐ Neurological Swallowing Disorder
- ☐ Non-Short Bowel Diarrhea/Malabsorption
- ☐ Pancreatitis
- ☐ Radiation Enteritis
- ☐ Short Bowel Syndrome
- ☐ Other Please specify:

Goals of PN therapy (check all that apply):

- ☐ Weight gain
- ☐ Weight maintenance
- ☐ Weight loss (for the Gastric Bypass patient with a fistula for instance)
- ☐ Future surgery and re-establishment of GI anatomy
- ☐ Indefinite (permanent) HPN
- ☐ Resolution of GI issue and stopping HPN

Current PN Formula

_____Daily

PN Infusion (check each day that PN infused)

- ☐ Sunday
- ☐ Monday
- ☐ Tuesday
- ☐ Wednesday
- ☐ Thursday
- ☐ Friday
- ☐ Saturday

Total volume in ml ____ per day or ____ mL/kg/day

Total Dextrose in g ☐ per day or ☐ g/kg/day or Dextrose infusion rate in mg/kg/min: ☐

Total Protein as Amino Acids in in g ☐ per day or ☐ g/kg/day

Cycled over ☐ hrs

_____Daily

- **IV Fat Emulsion** (check each day that fat emulsion infused)
  - ☐ Sunday
  - ☐ Monday
  - ☐ Tuesday
  - ☐ Wednesday
  - ☐ Thursday
  - ☐ Friday
  - ☐ Saturday

IV fat emulsion ☐ g per day or ☐ g/kg/day

- ☐ Soybean/Safflower
- ☐ Soybean only
- ☐ Emulsion containing Omega-3 fatty acids
- ☐ Other: ☐

- **Food/Diet** (Check all that apply)
  - ☐ NPO
  - ☐ On concurrent enteral nutrition
    - What % calories come from enteral: ☐
    - What type of enteral formula is the patient on? Name of product: ☐
  - ☐ Liquids or oral rehydration only
  - ☐ Food and/or beverages for comfort only
  - ☐ Restricted/therapeutic diet
  - ☐ Ad lib

If on oral nutrition, what % calories come from oral? ☐

- **Date PN Discontinued** (mm/dd/yr) _________________

● Reason PN Discontinued_(check all that apply)

___Patient transitioned to oral diet___
___Patient transitioned to enteral nutrition___
___Patient had small bowel transplant ____
___Patient had surgery to restore intestinal continuity____
___Patient converted to IV fluids____
___Patient completed PN therapy course____
___Patient placed on hospice care____
___Patient Expired____
___Patient hospitalized for some other reason ____
Please explain_________
___Other ____ Please explain________________________________

____

● **Type of central venous catheter**

- ☐ PICC
- ☐ Port
- ☐ Tunneled catheter
- ☐ Other

Lumen: Single Lumen ____ Double Lumen______ Triple Lumen____

Date of Insertion:(mm/dd/yr)________________________

How often is dressing changed?(please select) Daily____, QOD____, 3 x week, Weekly

Who is changing dressings? (please select) Patient____ Caregiver_____ Both_____ Visiting Nurse_____

● **Check Medications on Discharge** (Check all that apply)

- ☐ Anti-infective Agents
- ☐ Antineoplastic Agents
- ☐ Autonomic Drugs
- ☐ Cardiovascular Drugs
- ☐ Central Nervous System Agents
- ☐ Electrolytic and Water Balance (other than PN)

- ☐ Gastrointestinal Drugs (check all that apply)
  - ☐ Antacids and Adsorbents
  - ☐ Antidiarrhea Agents
  - ☐ Antiflatulents
  - ☐ Cathartics and Laxatives
  - ☐ Cholelitholytic Agents
  - ☐ Digestants
  - ☐ Emetics
  - ☐ Antiemetics
  - ☐ Lipotropic Agents
  - ☐ Antiulcer Agents and Acid Suppressants
  - ☐ Prokinetic Agents

- ☐ Hormones and Synthetic Substitute
- ☐ Pain Medications
- ☐ Vitamins (Other than PN)

_____ Ethanol lock

☐ Anti-inflammatory Agents

Morbidity

- **Re-hospitalization Information**

Patient admitted directly to: ICU________ general med-surg unit________

- **Reason for this rehospitalization** (CHECK ALL THAT APPLY)

☐ Surgery

☐ Bleeding

☐ Sepsis not related to catheter

☐ New Medication

☐ Chemotherapy regimen

☐ Catheter related

☐ Catheter related to bloodstream infection

Was catheter removed during this hospitalization? Yes___ No____

Was patient given antibiotics for catheter related bloodstream infection? Yes___ No___

Type of organism: [ ]

Did patient have skin/tunnel/pocket infection? ○ Yes ○ No

☐ Thrombosis/Occlusion

Was catheter removed during this hospitalization? Yes____ No____

Anticoagulation regimen? ○ Yes ○ No If yes, describe: [ ]

Other treatment for occlusion? ○ Yes ○ No If yes, describe: [ ]

☐ Incorrect position (Outgrown)

☐ Damage (leak, crack)

☐ Other: [ ]

☐ Fluid and electrolyte imbalance

☐ Psychological/substance abuse

☐ Other

☐ Myocardial infarction

☐ Congestive heart failure

- [ ] Cerebral vascular accident
- [ ] Pulmonary embolus
- [ ] Trauma
- [ ] Obstruction
- [ ] Other: [ ]

- [ ] Unknown (This category is for patients who were re-hospitalized but for unknown reasons-for example, patient may have been re-hospitalized elsewhere)

Describe: [ ]

● **If catheter removed during this hospitalization, was another central venous access placed for PN?**

Yes____ No____

Type of central venous catheter:

- [ ] PICC
- [ ] Port
- [ ] Hickman/Broviac
- [ ] Other

Lumen: Single___ Double____ Triple_____

Date of Insertion(mm/dd/yr): [ ]

Place of Insertion:

- [ ] Surgical OR_____
- [ ] Radiological Suite_____
- [ ] Bedside_____

How often is dressing changed? (please select)

- [ ] Daily
- [ ] Every Other Day
- [ ] 3 x week
- [ ] Weekly

Who is changing dressings? (please select)

- [ ] Patient
- [ ] Caregiver
- [ ] Both
- [ ] Visiting Nurse

● **Metabolic Issues** (check all that apply)

- [ ] None
- [ ] Fluids and electrolytes
- [ ] Hyperglycemia
- [ ] Hypoglycemia

☐ Other: ☐

- **Organ failure (requiring or not requiring transplantation)** (check all that apply)
  - ☐ Liver failure
  - ☐ Renal (requiring dialysis or not)
  - ☐ Heart
  - ☐ Pulmonary (requiring ventilatory support or not)
  - ☐ Other: ☐

Metabolic Bone Disease: Yes____ No____

First diagnosed by

- ☐ DEXA
- ☐ Bone Fracture

Mortality

- Date of Death (mm/dd/yr)______________________
- Date Unknown? ☐ Approximate Date: (mm/yr)______________________
- Source of Mortality Information: (please select)
  - ☐ Family/caregiver
  - ☐ Clinician/healthcare professional
  - ☐ Public Records
  - ☐

● Causes of Death HPN Related

Cause of Death HPN Related Yes_____ No_____

(check all that apply)

- ☐ Vascular access (check below all that apply)
  - ☐ sepsis
  - ☐ thrombosis
  - ☐ other: ☐
- ☐ Metabolic (check below all that apply)
  - ☐ fluids and electrolytes
  - ☐ hyperglycemia
  - ☐ hypoglycemia
  - ☐ other: ☐
- ☐ Organ Failure (check below all that apply)
  - ☐ liver
  - ☐ renal

- ☐ heart
- ☐ pulmonary
- ☐ other: ____

☐ Other: ____

- **Other Causes of Death**
  - Death Related to Underlying Diagnosis ☐ (check below all that apply)
    - ☐ post operative bleeding, explain: ____
    - ☐ bleeding
    - ☐ sepsis
    - ☐ other: ____
  - Death Related to Reason for HPN ☐ (check below all that apply)
    - ☐ post-operative
    - ☐ bleeding
    - ☐ sepsis
    - ☐ other: ____

Myocardial Infarction ☐

Congestive Heart Failure ☐

Cerebral Vascular Accident ☐

Pulmonary Embolus ☐

Other Cancer ☐

New Trauma (i.e., accident, fall, gsw, etc.) ☐

Other ☐ : ____

Unknown ☐ Describe circumstances: ____

Current Psychosocial

Neuropsychological problems

- ☐ Depression____ (If yes, complete depression/anxiety))
- ☐ Dementia____
- ☐ Personality disorder ____
- ☐ No psychological problems____
- ☐ Other____

Depression/Anxiety (check all that apply)

- ☐ Pre-existing (pre-HPN) diagnosis of major depression (APA, DSM-IV, 1994)
- ☐ Pre-existing (pre-HPN) diagnosis of anxiety disorder

- New diagnosis of depression requiring treatment (behavioral or pharmacological)
- New diagnosis of anxiety requiring treatment (behavioral or pharmacological)
- New treatment for situational depression

Quality of Life:

Has Quality of Life Instrument Been Administered? Yes___ No_____

- Quality of Life Instrument (QOLI) Date administered: ____ Score: ____
- Quality of Life Index (QLI) Date administered: ____

Overall Score: ____ (0-30)

Health and functioning subscale: ____ (0-30)

Social and economic subscale: ____ (0-30)

Psychological/spiritual subscale: ____ (0-30)

Family subscale: ____ (0-30)

- Short Form - 12 (SF 12) Date administered: ____

Physical Functioning (PF): ____ (0-100)

Role-Physical (RP): ____ (0-100)

Bodily Pain (BP): ____ (0-100)

General Health (G): ____ (0-100)

Vitality (VT): ____ (0-100)

Social Functioning (SF): ____ (0-100)

Role-Emotional (RE): ____ (0-100)

Mental Health (MH): ____ (0-100)

Component Summary Physical Health: ____ (0-100)

Component Summary Mental Health: ____ (0-100)

- Short Form - 36 (SF 36) Date administered: ____

Physical Functioning (PF): ____ (0-100)

Role-Physical (RP): ____ (0-100)

Bodily Pain (BP): ____ (0-100)

General Health (G): ____ (0-100)

Vitality (VT): ____ (0-100)

Social Functioning (SF): ____ (0-100)

Role-Emotional (RE): ____ (0-100)

Mental Health (MH): ____ (0-100)

Component Summary Physical Health: ____ (0-100)

Component Summary Mental Health: ☐ (0-100)

☐ HPN QOL (Baxter) Date administered: ☐ Score: ☐

Inflammatory Bowel Disease Questionnaire (IBDQ) Date administered: ☐ Score: ☐ (32-224)

☐ Other: ☐ Date administered: ☐ Score: ☐

Current Functional Status

Mobility (please select)

- ☐ Independent
- ☐ Requires minimal assistance (25% assistance from caregiver)
- ☐ Requires moderate assistance (50% assistance from caregiver)
- ☐ Requires maximum assistance (75% assistance from caregiver)
- ☐ Completely dependent on caregiver for mobility

Activities of Daily Living (ADL) (please select)

- ☐ Independent
- ☐ Needs partial assistance
- ☐ Totally dependent
- ☐ Requires skilled home nursing care
- ☐ Pediatrics: Age appropriate dependence

Care of Catheter and HPN related procedures (please select)

- ☐ Independent
- ☐ Needs partial assistance
- ☐ Totally dependent
- ☐ Requires skilled home nursing care

Able to return to work or school Yes_____ No_____

Employment Status (please select)

- ☐ Working full time
- ☐ Working part time
- ☐ Not working
- ☐ Student

If not currently working, please check all that apply:

- ☐ Retired
- ☐ Medical disability
- ☐ Health related leave of absence
- ☐ Not working because of health
- ☐ Not working because of insurance coverage

Who is the primary caregiver at home? (please select)

- ☐ Self
- ☐ Parent
- ☐ Spouse
- ☐ Significant Other
- ☐ Child

- ☐ Hired Professional Assistance
- ☐ Other:_______________________

Who is **primarily** responsible for administration of PN at home?

- ☐ Patient
- ☐ Parent
- ☐ Spouse
- ☐ Significant Other
- ☐ Child
- ☐ Hired Professional Assistance
- ☐ Other:__________________________

Community Resources/Support Group

Confirmed that patient has information on HPN specific community resources and/or Oley Foundation: (please select)

- ☐ Yes
- ☐ No
- ☐ N/A

Participates in local support group for HPN and/or Oley Foundation (please select)

- ☐ Yes
- ☐ No

Pediatric Element: Participates in (check all that apply)

- ☐ Infant/toddler services
- ☐ Early childhood intervention
- ☐ WIC
- ☐ OT
- ☐ PT