Follow-up Forms-Pediatric 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 ____________________
● Current Weight _____ kg

● Pediatric Elements Growth Chart Percentiles
  Weight for Height/Length ________%
  BMI ________%
  Head Circumference (for children under 3 years of age) _______cm

● 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
☐ Hirschsprung'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 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:

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**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:

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**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

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**Current PN Formula**
### Daily

**PN Infusion** (check each day that PN infused)

<table>
<thead>
<tr>
<th>Day</th>
<th>Total volume in mL per day</th>
<th>mL/kg/day</th>
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Total Dextrose in g per day or g/kg/day or Dextrose infusion rate in mg/kg/min: __________

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

Cycled over ___ hrs

### Daily

**IV Fat Emulsion** (check each day that fat emulsion infused)

<table>
<thead>
<tr>
<th>Day</th>
<th>IV fat emulsion g per day</th>
<th>g/kg/day</th>
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- 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
- Gastrointestinal Drugs (check all that apply)
- Hormones and Synthetic Substitutes
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
☐ None
☐ Fluids and electrolytes
☐ Hyperglycemia
☐ Hypoglycemia
☐ Other: ____________________________

Organ failure (requiring or not requiring transplantation)
☐ 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)_____________________
(please select)
☐ Family/caregiver
☐ Clinician/healthcare professional
☐ Public Records

Source of Mortality Information:

Causes of Death HPN Related
Cause of Death HPN Related Yes_____ No_____
(check all that apply)
☐ Vascular access (check below all that apply)
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:
  Health and functioning subscale:
  Social and economic subscale:
  Psychological/spiritual subscale:
  Family subscale:
- Short Form - 12 (SF 12) Date administered:
  Physical Functioning (PF):
  Role-Physical (RP):
  Bodily Pain (BP):
  General Health (G):
  Vitality (VT):
  Social Functioning (SF):
  Role-Emotional (RE):
  Mental Health (MH):
  Component Summary Physical Health:
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)

Pediatric Quality of Life Instrument (QOLI) Date administered: Score: 

Age at time of test
Physical domain score:
Emotional domain score:
Social domain score:
School domain score:

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
- PT

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