Follow-up Forms-Pediatric

● = 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

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- **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 ☐ Gastrointestinal Drugs (check all that apply) ☐ Hormones and Synthetic Substitute

- ☐ Antineoplastic Agents
- ☐ Autonomic Drugs
- ☐ Cardiovascular Drugs
- ☐ Central Nervous System Agents
- ☐ Electrolytic and Water Balance (other than PN)
- ☐ Antacids and Adsorbents
- ☐ Antidiarrhea Agents
- ☐ Antiflatulents
- ☐ Cathartics and Laxatives
- ☐ Cholelitholytic Agents
- ☐ Digestants
- ☐ Emetics
- ☐ Antiemetics
- ☐ Lipotropic Agents
- ☐ Antiulcer Agents and Acid Suppressants
- ☐ Prokinetic Agents
- ☐ Anti-inflammatory Agents
- ☐ Pain Medications
- ☐ Vitamins (Other than PN)

_____Ethanol lock

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)

☐ 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