



A.S.P.E.N.'s National Patient
Registry for Nutrition Care

Sustain Follow-up Data Collection Form (Revised 2/4/2014) (both pediatric and adult elements)

Patient Information

Visit Date (Please select)

Patient Birth Date (Please select)

Gender (please select)

What is the nature of this follow-up?

(check all that apply)

- Routine or uncomplicated outpatient visit
(including telephone contact, update, or other demographic updates)
- Outpatient visit with morbidity
- Patient hospitalized
- Patient expired
- Patient discontinued therapy not due to morbidity or mortality

Discontinuation of Home PN

Was Home PN Discontinued for this patient since last recorded visit? Yes No

Date PN Discontinued (Please select)

- Reason PN Discontinued
- 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 wishes to discontinue
 - Loss of vascular access
 - Patient Expired
 - Patient hospitalized

- Lost to followup
- Other

Restart Home PN

Was Home PN Restarted for this patient since last recorded visit? Yes No

Restart Home PN Date (Please select)

Morbidity

In what setting was the patient treated? (check all that apply)

- Treated as outpatient
- Treated in Emergency department or short stay unit
- Hospitalized

Date of Admission to Hospital (Please select)

Has patient been discharged on Home PN? Yes No

Date of discharge on Home PN (Please select)

What was the main cause of morbidity? (check one primary reason)

HPN Related Issue (check all that apply)

Catheter related

Central Line Bloodstream Infection

Was catheter removed? Yes No

Was patient given antibiotics for this infection? Yes No

Type of organism (please select)

Did patient have skin or pocket infection? Yes No

Thrombosis/Occlusion

Was catheter removed? Yes No

Anticoagulation regimen? Yes No Please describe:

Other treatment for occlusion? Yes No - Please describe:

Incorrect position (ex. Outgrown)

Damage (leak, crack, broken)

Other

If catheter was removed, was another central line placed for PN? Yes No

Type of catheter placed:

- PICC
- Port
- Tunneled
- Other

Lumen:

- Single Lumen
- Double Lumen
- Triple Lumen

Date new catheter placed:

<input type="text"/>	<input type="text"/>	(Please select)
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- Metabolic Issues (check all that apply)
 - Dehydration
 - Electrolyte imbalance
 - Hyperglycemia
 - Liver failure
 - CHF
 - Renal insufficiency
 - Other

Non-HPN Related but Related to Indication for HPN (check 1 primary reason)

Bowel Rest

- Enteritis/Colitis
 - Chemotherapy
 - Infectious
 - C. diff
 - Diverticulitis, non-obstructing
 - Giardia
 - Viral
 - Other - Please specify:
- Inflammatory
 - Crohns
 - Graft vs. Host
 - Ischemia bowel/Intestinal angina
 - Necrotizing Enterocolitis (NEC)
 - Non-specific enteritis/colitis

- Radiation
- Ulcerative Colitis
- Eosinophilic esophagitis
- Other - Please specify:

- Idiopathic
- Pancreatitis
 - Acute
 - Chronic

- Dysmotility
 - Hirschsprung's- pediatric
 - Hirschsprung's adult
 - Ileus, prolonged
 - Autonomic (i.e. 2o to Diabetes)
 - Idiopathic
 - Post-op
 - Scleroderma
 - Intestinal pseudoobstruction
 - Other Please specify:

- Failure to Thrive/Malnutrition
 - Pediatric
 - Feeding intolerance
 - Socio-economic
 - Neglect/Munchausen
 - Other
 - Adult
 - Cancer Cachexia
 - Cardiac Cachexia
 - Hepatic failure
 - Pulmonary Cachexia
 - Renal Cachexia
 - General Malnutrition
 - Pre-op nutrition support

- GI Fistula
 - Benign
 - Malignant

- Malabsorption

- Celiac disease
- Congenital Malabsorption
- Cystic fibrosis
- Idiopathic
- Pancreatic insufficiency
- Scleroderma
- Other Please specify:

Obstruction

- Malignant
 - GYN
 - GI
 - Other Please specify:

- Benign
 - Adhesive
 - Stricture
 - Crohn's disease
 - Radiation
 - Diverticulitis
 - Other

Short Bowel Syndrome - Non fistulous in origin

- Bowel resection
- Crohn's disease
- Radiation
- Other: Please specify:

Small bowel stoma Yes No

Where is stoma?

- Jejunum
- Ileum
- Duodenum
- Don't know

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 (current or last known measurement)

Measurement date 2003

Length of remaining **large** bowel in continuity Less than 50% Greater than 50%

Bowel measurement technique (before any lengthening procedure):

At time of surgery Radiographically Estimated

History of bowel lengthening surgical procedure Yes No

Operative procedure used:

- STEP
- Non-STEP lengthening procedure
- Don't know

Length prior to lengthening surgery: cm

Length after lengthening surgery: cm

Enteral Nutrition Failure

- Inability to place EN tube
- Refusal of EN tube
- Inability to tolerate EN

Post-operative Surgical Complications

- Chyle Leak
- Anastomotic Leak
- Bowel perforation
- Abdominal abscess

Not Related to HPN or Indication for HPN

Mortality

Check here if patient expired

Is date of death known? Yes No

Date of Death: (Please select)

Approximate Date of Death: (Please select)

Approximate Date of Death is 6/15/YYYY if only the year is known.

Source of Mortality Information Family/caregiver
 Clinician/Healthcare Professional
 Public Records

Primary Cause of Death (select primary reason)

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:

Related to Indication for HPN

Death related to underlying diagnosis? Yes No

(check all that apply)

- post operative bleeding, explain:
- bleeding
- sepsis
- other

Not Related to HPN or HPN Indications

(check all that apply)

- Myocardial Infarction
- Congestive Heart Failure
- Cerebral Vascular Accident
- Pulmonary Embolus
- Other Cancer
- New Trauma (i.e., accident, fall, gsw, etc.)

- Other
- Unknown

Unknown

Please carefully review the information in the remaining section, and update the patient's information. (Information auto-populated from previous record.)

Follow-up Demographics

Patient Number (As designated by study) Enrolled in registry

Attending Physician's Name

Discharging Institution Name

PN Home Infusion Care Provider Name

1. Gestational age at birth (weeks gestation)

2. All age children: Birthweight: grams

Date began Home PN

Mobility status: Ambulatory Bedrest

Who does patient live with?

Alone

Someone else (check all that apply)

- Parent
- Spouse
- Significant Other
- Child
- Hired professional assistance
- Other: Please specify:

Don't know

Insurance Coverage (check all that apply)

- Private Insurance
- Medicare
- Medicaid
- Personal Payment
- Medicare Supplement
- Unknown
- Other: Please specify:

Current Nutritional Status

Current Height/Length cm

Current Weight Kg

Pediatric Elements

Weight for Height/Length: % (percentile)

BMI: % (percentile)

Head Circumference (for children under 3 years of age) cm

Labs at Follow-up

(complete as many as you have)

Date Labs Collected (Please select) (date closest to most labs drawn)

Serum Albumin g/dL

Platelet Count /uL (per microliter)

Total Bilirubin mg/dL

Direct Bilirubin mg/dL

AST U/L

ALT U/L

BUN mg/dL

Creatinine mg/dL

Primary Indication for Home PN

(Please be as specific as possible)

Bowel Rest

Enteritis/Colitis

Chemotherapy

Infectious

C. diff

Diverticulitis, non-obstructing

Giardia

Viral

Other: Please specify:

Inflammatory

Crohns

- Graft vs. Host
- Ischemia bowel/Intestinal angina
- Necrotizing Enterocolitis (NEC)
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Idiopathic

Pancreatitis

Acute

Chronic

Dysmotility

Hirschsprung's pediatric

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GI Fistula

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Other: Please specify:

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GYN

GI

Other: Please specify:

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Adhesive

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Crohn's disease

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Refusal of EN tube

Inability to tolerate EN

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Chyle Leak

Anastomotic Leak

Bowel perforation

Abdominal abscess

Significant Comorbid Conditions

(check all that apply)

Alcohol or drug addiction (past or current)

Active Oncologic Process

Active non-PN related infection

Cirrhosis

Chronic Kidney Disease

Congestive Heart Failure

COPD

- Diabetes
- Thyroid dysfunction
- Immunosuppression
- Neurologic disorder

Goals of PN therapy

Weight related goals (check all that apply):

- Weight gain for adults
- Growth for children
- Weight maintenance
- Weight loss (ex. obesity)

Non-weight related goals (check all that apply):

- Future surgery and re-establishment of GI anatomy
- Indefinite (permanent) HPN
- Resolution of GI issue and stopping HPN

Current PN Formula

PN Infusion days per week

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

Total Dextrose in g per day or g/kg/day

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

Cycled over hrs

IV Fat Emulsion days per week

IV fat emulsion dose g per day or g/kg/day of fat infusion

Type of Fat Emulsion: select all that apply

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

Medications

(Check all that apply)

- | | | |
|--|---|--|
| <input type="checkbox"/> Anti-depressants | <input type="checkbox"/> Growth Hormone | <input type="checkbox"/> Prokinetic Agents |
| <input type="checkbox"/> Anti-infectives | <input type="checkbox"/> Glucagon- like peptide 2 (GLP-2) | <input type="checkbox"/> Steroids |
| <input type="checkbox"/> Anti-inflammatory - NSAIDS | <input type="checkbox"/> Insulin | <input type="checkbox"/> Thyroid hormone replacement |
| <input type="checkbox"/> Anti ulcer and acid supplements | <input type="checkbox"/> Glutamine | <input type="checkbox"/> Other Nutritional supplements |
| <input type="checkbox"/> Biologic Response Modifiers | <input type="checkbox"/> Narcotics | |
| | <input type="checkbox"/> Octreotide | |
| | <input type="checkbox"/> Pre-Pro biotics | |

Food and Diet

(Check all that apply)

- NPO
- On concurrent enteral nutrition or breast milk via tube
- What % calories come from enteral or breast milk via tube:

What type of enteral formula is the patient on?

Name of product:

- Breast Milk
- Calcilol
- Compleat Pediatric
- Elecare
- Fibersource
- Neocate
- Necate Infant
- Vivonex RTF
- Pediasure
- Pregestimil
- Pulmocare
- Other
- Liquids or oral rehydration only
- Breast fed
- Food and/or beverages for comfort only
- Restricted/therapeutic diet
- Unrestricted diet/Ad lib
- Unknown
- If on oral nutrition or breast feeding, what % calories come from oral?

Current Catheter

Type of Central Venous Catheter PICC
 Port
 Tunneled
 Other: Please specify:

Lumen

Single Lumen
 Double Lumen
 Triple Lumen

Date of Insertion (Please select)

Type of Catheter Flush or Lock(check all that apply)

Heparin
 Ethanol
 Antibiotic
 Saline only
 Taurolidine

Catheter Used for Blood Draw Never
 Occasionally
 Often or Always
 Don't Know

Signature: