



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

Baseline Forms- Pediatric

Data Collection Tools © A.S. P. E. N.

● = critical elements

Patient Information Form

● Today's date (mm/dd/year) _____

● ___ New PN Patient ___ Existing PN Patient

Patient Number (As designated by study) _____ (will be assigned once the record is in)

● Attending Physician's Name _____

● Discharging Institution Name _____

● PN Home Infusion Care Provider Name _____

● Patient Birth Date (mm/dd/yr) _____

● (If less than 18 years of age- pediatric elements pop up)

Gestational age at birth (___ weeks gestation)

All age children: Birthweight ___ lbs. ___ oz. or ___ kg ___ grams

● Gender: Male ___ Female ___

Patient home location: Urban ___ Suburban ___ Rural ___

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

● Ethnic Category: Hispanic or Latino ___ Not Hispanic or Latino ___

● Racial Categories (select all that apply)

American Indian/Alaska Native ___

Asian ___

Native Hawaiian or Other Pacific Islander ___

Black or African American ___

White ___

Is English the patient's primary language? Yes ___ No ___

If NO, please specify primary language: _____

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) _____

What is the highest level of education attained for the patient?

Finished High School Yes____ No____
Finished College Yes____ No____
If in school, what grade?____

Does the patient/parent-caregiver have internet access?

Yes____ No____ Don't know____ Unable to answer____

Baseline Nutritional Status

Baseline Nutrition Information

● 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

● Current Labs

Date Labs Collected: mm/dd/yr (date closest to most lab draws)

Serum Albumin g/dL

Platelet Count /uL (per microliter)

Direct Bilirubin mg/dL

AST U/L

ALT U/L

INR

BUN mg/dL

Creatinine mg/dL

● **Underlying 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-Crohn's 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:

● **Reason for Parenteral Nutrition** (check all that apply)

- Active Inflammatory Bowel Disease
- Bowel dysmotility
- Chemotherapy Associated GI Dysfunction
- Congenital Bowel Defect (Intestinal Atresia)

- Gastroschisis Associated Dysmotility
- Intractable Diarrhea
- Intractable Vomiting
- Mesenteric Ischemia

- Non-Short Bowel Diarrhea/Malabsorption
- Pancreatitis
- Radiation Enteritis
- Short Bowel Syndrome

- Gastrointestinal Fistula
 - Gastrointestinal Obstruction
 - Necrotizing Enterocolitis
 - Neurological Swallowing Disorder
 - 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
-

- Physical Disabilities** (check all that apply):
 - Visual Impairment
 - Hearing Deficit
 - Dexterity Impairment
 - Mobility Impairment
 - Other Please specify:
-

● **Pediatric Elements Measurement of Developmental Delay**

Bayley Scales of Infant Development

Age at time of test:

Mean scaled score

Cognitive Composite score

Language Composite Score

Motor Composite Score

Fine motor score

Gross motor score

WIPPSI

Age at time of test:

Full Scale IQ

Verbal score

Performance score

Baseline PN Formula/Medication/Nutrient Intake

___ 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 _____ hours

___ 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:

● **Check Medications** (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
- Anti-inflammatory Agents

- Hormones and Synthetic Substitutes
- Pain Medications
- Vitamins (Other than PN)
- ____ Ethanol lock

● **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?

● **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____

Baseline 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:

Baseline Functional Status

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

Productivity

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

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

Primary caregiver (please select)

- Self
- Parent
- Spouse
- Significant Other
- Child
- Hired professional assistance
- Other: _____

Who will be **primarily** responsible for administration of **PN** at home?

- Patient
- Parent
- Spouse
- Significant Other
- Child
- Hired professional assistance
- Other: _____

Who received HOME PN teaching? (Check all that apply)

- Patient
- Parent
- Spouse
- Significant Other
- Child
- Hired help
- Other: _____

Community Resources/Support Group

Patient made aware of or have referral to specific community resources, Oley Foundation, or early childhood intervention services, OT or PT.

- Yes
- No