

## INTERVAL SURVEY: MALONIC ACIDEMIA.DRAFT3

### Demographics

Is patient followed by >1 metabolic center?  
Missing/unknown data, yes, no

If patient is followed by >1 metabolic center note which Metabolic Centers in which States (enter N/A if not applicable)

If patient is followed by >1 metabolic center, did patient grant permission to share data via IBEM-IS between treating metabolic centers?  
Missing/unknown data, N/A, Yes, No

If deceased, date of death (if N/A enter 01/01/1901)

Follow up status  
Active, Inactive - Deceased, Inactive - Lost to follow up, Inactive - Moved to another State participating in IBEM-IS, Inactive - Moved to another State not participating in IBEM-IS, Inactive -Refused follow up, Inactive - Treatment deemed not necessary

### Socioeconomic Status

Current insurance status  
Missing/unknown data, commercial/private insurance, military insurance, none (self-pay), State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), Other

### Measurements

Weight at this visit (enter 99999 if not measured)  
(kg)

Height at this visit (enter 99999 if not measured)  
(cm)

Head circumference (OFC) at this visit (enter 99999 if not measured)  
(cm)

### Past Health History

Date of last outpatient metabolic visit (if unknown enter 01/01/1901)

Has patient had general anesthesia since the last outpatient metabolic visit?  
Missing/unknown data, yes, no

Has patient had surgical procedure(s) since the last outpatient metabolic visit?  
Missing/unknown data, yes, no

What type of surgical procedure(s) were done since the last outpatient metabolic visit? If not applicable enter N/A

Complications associated with surgical procedure(s) done since the last outpatient metabolic visit? If not applicable enter N/A

### Emergency Management

Patient/primary caregiver knows how to reach the 24 hour on-call contact information for a metabolic provider  
Missing/unknown data, yes, no

Patient/primary caregiver currently has a written emergency letter for this disorder?  
Missing/unknown data, yes, no

Patient/primary caregiver currently has a sick day plan specific to this disorder?  
Missing/unknown data, yes, no

Patient was enrolled in a web-based emergency alert program?  
Missing/unknown data, yes - MEMSCIS, yes - other web-based program, no

**Emergency Management**

Has patient accessed their web-based emergency plan since the last outpatient metabolic visit? Missing/unknown data, N/A - patient does not have a web-based emergency plan, yes - MEMSCIS, yes - other web-based emergency plan, no

Number of ER visits since last metabolic visit Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10,>10

Number of ER visits METABOLIC RELATED since last outpatient metabolic visit Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10,>10

Total number of ER visits with NO metabolic decompensation since last outpatient metabolic visit Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10,>10

Number of hospital admissions (total) since last metabolic visit Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10,>10

Total number of hospital (inpatient) days METABOLIC RELATED since last outpatient metabolic visit Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10,11-20,21-30,31-40,41-50, 51-60,>60

**Care Coordination**

Other health services received currently Missing/unknown data, None, Audiology, Behavioral/developmental Pediatrics, Cardiology, Dermatology, Endocrinology, Hematology/oncology, Home health care, Nephrology, Neurology, Neuropsychology, Occupational therapy, Ophthalmology, Orthopedics, Otolaryngology, Physical therapy, Psychiatry, Psychology, Public health nursing, Pulmonology, Respiratory therapy, Speech-language therapy, Transplant evaluation - kidney, Transplant evaluation-heart, Transplant evaluation - liver, Transplant received - kidney(complete Transplant survey now if not previously done), Transplant received - heart(complete Transplant survey now if not previously done), Transplant received-liver(complete Transplant survey now if not previously done), Other

Community resources received currently Missing/unknown data, none, daycare, family support group related to this IBEM, family support - other, Medical Home, nutritional services (WIC/MAC), personal care attendant (PCA), preschool, Head Start, respite care, social services - county, social services - medical, social services - developmental disability, waived services (CAC/CADI waiver /other waivers), other

Providers seen at this metabolic visit Dietitian, genetic counselor, neuropsychologist, nurse, nurse practitioner, physician, physician assistant, psychologist, social worker, other (go to next question and explain)

Other providers seen at this metabolic visit(enter N/A if not applicable)

**Developmental Assessment**

Developmental screening occurred at this visit? Missing/unknown data, yes, no

Developmental screening tool used at this visit (if screening was done) Missing/unknown data, N/A - no developmental screening occurred at this visit, Ages and Stages Questionnaire, Ages and Stages - Social/Emotional Questionnaire, Denver (DDST-II), PEDS Questionnaire, provider history, other standardized screening tool

Developmental milestones achieved at this time? Missing/unknown data, N/A - no developmental screening occurred at this visit, yes, no

If developmental milestone(s) not achieved, which one(s) were not achieved? Missing/unknown data, N/A - developmental screening occurred at this visit and all developmental milestones were achieved, N/A - no developmental screening occurred at this visit, Cognitive, Fine motor, Gross motor, Social-emotional, Speech-language

If developmental milestones were not achieved, was patient referred for further developmental evaluation? Missing/unknown data, N/A - all milestones achieved, N/A - no developmental screening occurred at this visit, yes, no

Was neuropsychological evaluation done since last outpatient metabolic visit? (If yes, complete Neuropsych Survey) Missing/unknown data, Yes, No

Overall neuropsychological testing impression (from most recent neuropsych evaluation) Missing/unknown data, N/A - no neuropsych evaluation has been done on this patient, above average, average, below average

Are behavioral concerns suspected at this time? Missing/unknown data, Yes (go to next question and explain), No

If behavioral concerns are suspected at this time, explain (enter N/A if no behavioral concerns suspected)

If behavioral concerns are suspected at this time, was patient referred for further evaluation? Missing/unknown data, N/A - no behavioral concerns suspected, Yes - to behavioral pediatrics, Yes - to neuropsychologist, Yes - to psychiatrist, Yes - to psychologist, Yes - to therapist/counselor, Yes - to other, No

**Education**

Was patient referred for Special Education evaluation at this time? Missing/unknown data, yes, no

Special Educational services are received currently: age (in years) child qualified for services? Missing/unknown data, N/A - no Special Ed services are currently received, N/A - patient is >21 years old, <1, >1-2, >2-3, >3-4, >4-5, 6-10, 11-17, 18+

Reason Special Educational services are received currently? Missing/unknown data, N/A (no Special Ed services are currently received), cognitive disability, fine motor disability, gross motor disability, learning disability, social-emotional disability, speech-language disability, other health impaired (OHI), other

**Home Monitoring**

Patient does home monitoring? Missing/unknown data, no, yes - urine ketones

Frequency of home monitoring. Missing/unknown data, N/A, only when symptomatic, weekly, every 2 weeks, monthly, other frequency

Number of home monitoring samples reported since last outpatient metabolic visit (enter 99999 if N/A)

**Laboratory Studies**

Molecular testing: Common or targeted mutation panel done at this visit(enter specific mutation(s) on Intake Survey)? Missing/unknown data, no, yes - abnormal: compound heterozygote, yes - abnormal: homozygote, yes - abnormal: simple heterozygote, yes - alteration(s) of unknown significance detected, yes but no mutations were detected

Molecular testing: Full sequencing done at this visit(enter specific mutation (s) on Intake Survey)? Missing/unknown data, no, yes - abnormal: compound heterozygote, yes - Presumed compound heterozygote – 2nd mutation not identified, yes - abnormal: homozygote, yes - abnormal: simple heterozygote, yes - alteration (s) of unknown significance detected, yes but no mutations were detected

Lab tests chemistry collected at this visit Missing/unknown data, none, ABG-WNL, ABG-Abn, Anion Gap-WNL, Ammonia – WNL, Ammonia – Abn, Anion Gap-Abn, Ca+++WNL, Ca+++Abn, Cl-WNL, Cl-Abn, CO2-WNL, CO2-Abn, Gluc-WNL, Gluc-Abn, K+WNL, K+Abn, LDH - WNL, LDH - Abn, Magnesium - WNL, Magnesium - Abn, Na+WNL, Na+Abn,

Phosphorus - WNL, Phosphorus - Abn, Total Cholesterol(fasting) - WNL, Total Cholesterol (fasting) - Abn, Total Cholesterol(random) - WNL, Total Cholesterol(random) - Abn, Uric Acid - WNL, Uric Acid - Abn, Other

Lab tests hematology collected at this visit Missing/unknown data, none, Fibrinogen - WNL, Fibrinogen - Abn, Hct-WNL, Hct-Abn, Hgb-WNL, Hgb-Abn, INR-PTT - WNL, INR-PTT - Abn, Peripheral blood smear - WNL, Peripheral blood smear - Abn, Plat-WNL, Plt-Abn, RBC-WNL, RBC-Abn, WBC-WNL, WBC-Abn, Other

Lab tests liver function collected at this visit Missing/unknown data, none, Albumin-WNL, Albumin-Abn, AlkPhos-WNL, AlkPhos-Abn, ALT-WNL, ALT-Abn, AST-WNL, AST-Abn, direct bili-WNL, direct bili-Abn, GGT - WNL, GGT - Abn, Globulin - WNL, Globulin - Abn, prealbumin-WNL, prealbumin-Abn, total bili-WNL, total bili-Abn, Total Protein - WNL, Total Protein - Abn, Other

Lab tests renal function collected at this visit Missing/unknown data, none, BUN-WNL, BUN-Abn, Cr-WNL, Cr-Abn, 24-hour creatinine clearance-WNL, 24-hour creatinine clearance-Abn, Nuclear Medicine GFR-WNL, Nuclear Medicine GFR-Abn, Other

Lab tests miscellaneous collected at this visit Missing/unknown data, none, BNP-WNL, BNP-Abn, CK-WNL, CK-Abn, CRP-WNL, CRP-Abn, ESR-WNL, ESR-Abn, ferritin-WNL, ferritin-Abn, transferrin-WNL, transferrin-Abn, TSH-WNL, TSH-Abn, T4 (free)-WNL, T4 (free)-Abn, T4(total)-WNL, T4(total)-Abn, UA-WNL, UA-Abn, Zinc-WNL, Zinc-Abn, Other (go to next question and explain)

Lab tests other general (indicate type and if WNL or Abn) collected at this visit, enter N/A if not applicable

Biochemical testing specific to this IBEM collected at this visit Missing/unknown data, not done, amylase-WNL, amylase-Abn, lipase-WNL, lipase-Abn, plasma acylcarnitines-WNL, plasma acylcarnitines-Abn, plasma amino acids-WNL, plasma amino acids-Abn, plasma carnitine levels-WNL, plasma carnitine levels-Abn, plasma total hcy-WNL, plasma total hcy-Abn, serum B12-WNL, serum B12-Abn, serum MMA-WNL, serum MMA-Abn, urine ketones-WNL, urine ketones-Abn, urine organic acids-WNL, urine organic acids-Abn, Other (go to next question and explain)

Biochemical testing specific to this IBEM collected at this visit. Missing/unknown data, not done, Ammonia-WNL, Ammonia-Abn, Amylase-WNL, Amylase-Abn, Bloodspot acylcarnitines-WNL, bloodspot acylcarnitines-Abn, B-type Natriuretic Peptide (BNP)-WNL, B-type Natriuretic Peptide (BNP)-Abn, CK-WNL, CK-Abn, plasma acylcarnitines-WNL, plasma acylcarnitines-Abn, plasma carnitine levels-WNL, plasma carnitine levels-Abn Low, plasma essential fatty acids -WNL, plasma essential fatty acids -Abn, triglycerides-WNL, triglycerides-Abn, urine myoglobin-WNL, urine myoglobin-Abn, urine organic acids-WNL, urine organic acids-Abn, Other (go to next question and explain)

Other biochemical testing specific to

this IBEM (indicate type and if WNL or Abn) collected at this visit, enter N/A if not applicable

Enzyme assay from fibroblasts done at this visit? Missing/unknown data, no, yes - abnormal, yes - normal, yes - non-diagnostic

**Imaging Studies**

Cardiac imaging done since last outpatient metabolic visit? Missing/unknown data, no, yes-chest x-ray-WNL, yes-chest x-ray-Abn, yes-echocardiogram-WNL, yes-echocardiogram-Abn, yes-EKG-WNL, yes-EKG-Abn, yes-stress test-WNL, yes-stress test-Abn

History of Cardiomyopathy Missing/unknown data, yes - dilated, yes - hypertrophic, no,

Has cardiomyopathy worsened/progressed since the last outpatient metabolic appointment? Missing/unknown data, N/A – no known cardiomyopathy, yes, no

Current treatment of cardiomyopathy (free text, - discuss answer options other than free text) (enter N/A if not applicable, unknown if missing/unknown data)

Abdominal imaging done since last outpatient metabolic visit? Missing/unknown data, no, yes-abdominal CT-WNL, yes-abdominal CT-Abn, yes-abdominal MRI-WNL, yes-abdominal MRI-Abn, yes-abdominal ultrasound-WNL, yes-abdominal ultrasound-Abn, Yes-Abdominal x-ray-WNL, Yes-Abdominal x-ray-abn

Musculoskeletal imaging done since last outpatient metabolic visit? Missing/unknown data, No, Yes-bone x-rays-WNL, Yes-bone x-rays-Abn, Yes-EMG-WNL, Yes-EMG-Abn

Dexa scan since last outpatient metabolic visit (z-score >-2), specify site Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other

If abnormal dexa scan since last outpatient metabolic visit (z-score = -3 to -2), specify site Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other

If abnormal dexa scan since last outpatient metabolic visit (z-score <= -4), specify site Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other

Neurological imaging done since last outpatient metabolic visit? Missing/unknown data, no, yes-cranial ultrasound-WNL, yes-cranial ultrasound-Abn, yes-EEG-WNL, yes-EEG-Abn, yes-head CT-WNL, yes-head CT-Abn, yes-head MRI-WNL, yes-head MRI-Abn

Evidence of periventricular heterotopias Yes, No, missing, unknown-imaging not done

Evidence of pachygyria Yes, No, missing, unknown-imaging not done

Is there evidence of abnormal myelination on CNS imaging since last outpatient visit? Missing/unknown data, no, yes, N/A - imaging not done

Is there evidence of thin corpus callosum on CNS imaging since last outpatient visit? Missing/unknown data, no, yes, N/A - imaging not done

Is there evidence of reduced brain volume due to increased ventricular size on central nervous system imaging? Missing/unknown data, N/A – imaging not done, no, yes

Is there evidence of reduced brain volume due to generalized increased extra-axial fluid on central nervous system imaging? Missing/unknown data, N/A – imaging not done, no, yes

Is there evidence of basal ganglia injury on imaging done since last outpatient metabolic visit? Missing/unknown data, N/A -imaging not done, no, yes

Renal/pelvic/genital imaging done since Missing/unknown data, no,

Comment [R01]: Specific brain abnormalities in past reports

last outpatient metabolic visit? yes-genitogram-WNL, yes-genitogram-Abn, yes-nuclear medicine DMSA renogram-WNL, yes-nuclear medicine DMSA renogram-Abn, yes-pelvic ultrasound-WNL, yes-pelvic ultrasound-Abn, yes-renal ultrasound-WNL, yes-renal ultrasound-Abn, yes-testicular ultrasound-WNL, yes-testicular ultrasound-Abn, yes-VCUG-WNL, yes-VCUG-Abn

Other imaging (indicate type of imaging and if WNL or Abn) done since last outpatient metabolic visit?, enter N/A if not applicable

**Pharmacotherapy**

Is L-carnitine prescribed? Missing/unknown data, yes, no

If on L-carnitine, dose prescribed(enter 99999 if N/A)? (mg/kg/day)

If on L-carnitine, route prescribed? Missing/unknown data, N/A - not prescribed, feeding tube, oral, IV

If on L-carnitine, frequency prescribed? Missing/unknown data, N/A – not prescribed, once/day, twice/day, three times/day, four times/day, only when ill, other

Patient/primary caregiver reports L-carnitine is taken as prescribed? Missing/unknown data, N/A – not prescribed, yes - 4-7 days/week, yes - 1 to 3 days/week, no (0 days/week)

If L-carnitine is not taken as prescribed, reason given (enter N/A if not applicable)?

Method of payment for L-carnitine, if prescribed Missing/unknown data, N/A - Not prescribed, commercial/private insurance, military insurance, none - can't afford to fill medication prescription, self-pay, State program (newborn screening funds, special needs program, MCH block grant), State/Federal insurance (Medicaid/Medicare), Other

If on metronidazole (Flagyl), dose prescribed(enter 99999 if N/A)? (mg/kg/day)

If on metronidazole (Flagyl), route prescribed? Missing/unknown data, N/A - not prescribed, feeding tube, oral

If on metronidazole (Flagyl), frequency prescribed? Missing/unknown data, N/A - not prescribed, once/day, twice/day, three times/day, four times/day, only when ill, other

Patient/primary caregiver reports metronidazole (Flagyl) is taken as prescribed? Missing/unknown data, N/A - not prescribed, yes - 4-7 days/week, yes - 1-3 days/week, no (0 days/week)

If metronidazole (Flagyl), is not taken as prescribed, reason given(enter N/A if not applicable)?

Method of payment for metronidazole (Flagyl), if prescribed Missing/unknown data, N/A - not prescribed, commercial/private insurance, military insurance, none - can't afford to fill medication prescription, self-pay, State program (newborn screening funds, special needs program, MCH block grant), State/Federal insurance (Medicaid/Medicare), Other

Other medications (see optional DocSite detailed medication survey also) Missing/unknown data, none, Ammonul, analgesics, antacids, antianxiety, antibiotics, anticoagulants/thrombolytics, anticonvulsants, antidepressants, antiemetics, antifungals, antivirals, antihistamines, antihypertensives, antiinflammatories, antipsychotics, antipyretics, aromatase inhibitor, biophosphonates, bronchodilators, contraceptives - oral, contraceptives - injections, corticosteroids, diuretics, estrogen, GnRH analog, growth hormone, immunosuppressives, insulin, insulin sensitizers, iron, laxatives, manitol,

progesterone, sleeping medications,  
testosterone, vitamins, other

**Nutrition**  
 What type(s) of milk/formula is patient taking? Missing/unknown data, None, Baby formula (regular), Baby formula (soy), Breastmilk, Rice milk, Skim milk, 1% milk, 2% milk, Soy milk, Special metabolic formula, Toddler formula (regular), Toddler formula (soy), Whole milk, Other: Pregestimil, Lipistart  
 Is patient prescribed a high MCT diet? Missing/unknown data, yes, no  
 If other nutritional supplementation is taken (explain), enter N/A if not applicable.  
 Patient uses feeding device (NG tube, G tube, GJ tube)? Missing/unknown data, yes, no  
 Additional nutritional comments? (enter N/A if not applicable)

Other Comments

| <b>Laboratory Studies</b>  | <b>Today's Action</b>  | <b>Last Value</b> | <b>Date Last</b> | <b>Pt. Goal</b> | <b>Int. Days</b> |
|--|--|-------------------|------------------|-----------------|------------------|
| Enzyme assay (specific to this IBEM) done at this visit?   | Missing/unknown data, no, yes - abnormal, yes - normal, yes - non-diagnostic   |                   |                  |                 | Per Visit        |
| Fatty acid oxidation probe assay done at this visit?   | Missing/unknown data, no, yes - abnormal, yes - normal, yes - non-diagnostic   |                   |                  |                 | Per Visit        |
| Western blot (specific to this IBEM) done at this visit?   | Missing/unknown data, Not done, <20%, >=20%<50%, >=50%   |                   |                  |                 | Per Visit        |
| Documented hypoglycemia (blood glucose <60 mg/dL) since the last outpatient metabolic visit?   | Missing/unknown data, glucose not measured, yes (answer next question), no   |                   |                  |                 | Per Visit        |
| Lowest blood glucose value since last outpatient metabolic visit (enter 99999 if not measured)   | (mg/dL)  |                   |                  |                 | Per Visit        |
| Highest CK since last outpatient metabolic visit (if N/A enter 99999)  |  |                   |                  |                 | Per Visit        |
| Documented hyperammonemia since last outpatient metabolic visit?   | Missing/unknown data, ammonia not measured, yes (answer next question), no   |                   |                  |                 | Per Visit        |
| If hyperammonemic since last outpatient metabolic visit, highest value (if N/A enter 99999)  |  |                   |                  |                 | Per Visit        |
| <b>Pharmacotherapy</b>   | <b>Today's Action</b>  | <b>Last Value</b> | <b>Date Last</b> | <b>Pt. Goal</b> | <b>Int. Days</b> |
| Have glucose paste/gel/tablets been prescribed to this patient for this IBEM?  | Missing/unknown data, yes, no  |                   |                  |                 | Per Visit        |
| If glucose paste/gel/tablets are prescribed for this IBEM, number of times patient has used them since the last outpatient metabolic visit | N/A - not prescribed, 0,1,2,3,4,5,6,7,8,9,10, >10, Missing/unknown data  |                   |                  |                 | Per Visit        |
| <b>Nutrition</b>   | <b>Today's Action</b>  | <b>Last Value</b> | <b>Date Last</b> | <b>Pt. Goal</b> | <b>Int. Days</b> |
| What type(s) of milk/formula is patient taking?  | Missing/unknown data, None, Baby formula (regular), Baby formula (soy), Breastmilk, Rice milk, Skim milk, 1% milk, 2% milk, Soy milk, Special metabolic formula, Toddler formula (regular), Toddler formula (soy), Whole milk, Other |                   |                  |                 | Per Visit        |
| Is cornstarch prescribed?  | Missing/unknown data, yes, no  |                   |                  |                 | Per Visit        |
| If on cornstarch, dose prescribed(enter 99999 if N/A or unknown)?  | (grams/kg/dose)  |                   |                  |                 | Per Visit        |
| If on cornstarch, route prescribed?  | Missing/unknown data, N/A - not prescribed, feeding tube, oral   |                   |                  |                 | Per Visit        |
| If on cornstarch, frequency prescribed?  | Missing/unknown data, N/A - not prescribed, once/day, twice/day, three times/day, four times/day, only when ill, other   |                   |                  |                 | Per Visit        |

|   |   |          |
|---|---|----------|
| Patient/primary caregiver reports cornstarch is taken as prescribed?  | Missing/unknown data, N/A - not prescribed, yes - 4-7 days/week, yes - 1 to 3 days/week, yes - only when ill, no (0 days/week)  | Per Visi |
| If cornstarch is not taken as prescribed, reason given(enter N/A if not applicable)?                            |   | Per Visi |
| Is patient prescribed a fat restricted diet?  | Missing/unknown data, yes, no   | Per Visi |
| If patient is prescribed a fat restricted diet, prescribed % of total kcal/24 hours from fat (enter 99 if N/A)  | (% of total kcal/24 hours as fat)   | Per Visi |
| If patient is prescribed a fat restricted diet, prescribed fat grams/day from FOODS per day(enter 99999 if N/A) | (grams/day)   | Per Visi |
| If patient is prescribed a fat restricted diet, patient/primary caregiver reports adherence?                    | Missing/unknown data, N/A - not prescribed, yes - 4-7 days/week, yes - 1 to 3 days/week, no (0 days/week)   | Per Visi |
| Specific information given to avoid fasting?  | Missing/unknown information, yes, no  | Per Visi |
| Longest interval permitted between feedings in well state during DAY (in hours)                                 | Missing/unknown information, no fasting restriction given, 1,2,3,4,5,6,7,8,9,10,11,12   | Per Visi |
| Longest interval permitted between feedings in well state during NIGHT (in hours)                               | Missing/unknown information, no fasting restriction given, 1,2,3,4,5,6,7,8,9,10,11,12   | Per Vi   |
| Is MCT oil prescribed?  | Missing/unknown data, yes, no   | Per Visi |
| If on MCT oil, dose prescribed? (enter 99999 if N/A)  | (mL/24 hours in diet)   | Per Visi |
| If on MCT oil, frequency prescribed?  | Missing/unknown data, once/day, twice/day, three times/day, four times/day, other, N/A - MCT oil not prescribed   | Per Visi |
| If on MCT oil, route prescribed?  | Missing/unknown data, feeding tube, oral, N/A - MCT oil not prescribed  | Per Visi |
| Patient/primary caregiver reports MCT oil is taken as prescribed?   | Missing/unknown data, N/A - not prescribed, yes - 4-7 days/week, yes - 1-3 days/week, no (0 days/week)  | Per Visi |
| If MCT oil is not taken as prescribed, reason given?  |   | Per Visi |
| Method of payment for MCT oil, if prescribed  | Missing/unknown data, commercial/private insurance, military insurance, none - can't afford to fill prescription, self-pay, State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), Other, N/A - MCT oil not prescribed               | Per Visi |
| Are essential fatty acids prescribed (i.e. safflower, walnut, canola)?  | Missing/unknown data, yes, no   | Per Visi |
| If prescribed essential fatty acids, frequency prescribed?  | Missing/unknown data, N/A-essential fatty acids not prescribed, once/day, twice/day, three times/day, four times/day, other   | Per Visi |
| If prescribed essential fatty acids, route prescribed?  | Missing/unknown data, feeding tube, oral, N/A - essential fatty acids not prescribed  | Per Visi |
| Patient/primary caregiver reports essential fatty acids are taken as prescribed?                                | Missing/unknown data, N/A - not prescribed, yes - 4-7 days/week, yes - 1-3 days/week, no (0 days/week)  | Per Visi |
| If essential fatty acids are not taken as prescribed, reason given?   |   | Per Visi |
| Method of payment for essential fatty acids, if prescribed  | Missing/unknown data, commercial/private insurance, military insurance, none - can't afford to fill prescription, self-pay, State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), Other, N/A - essential fatty acids not prescribed | Per Visi |
| If prescribed metabolic formula – prescribed fat grams from FORMULA per day (enter 99999 if N/A)                | (grams/day)   | Per Visi |

Patient/primary caregiver reports metabolic formula is taken as prescribed? - 4-7 days/week, yes - 1-3 days/week, no (0 days/week)

If metabolic formula is prescribed and not taken as prescribed, reason given? (enter N/A if not applicable)

Method of payment for metabolic formula, if prescribed

Missing/unknown data, N/A - not prescribed, commercial/private insurance, military insurance, none - can't afford to fill prescription, self-pay, State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), WIC, Other

Per Visi

Per Visi

Per Visi

Per Visit