

Visit Planner

Date of Visit: ____ / ____ / ____

| | | | |
|---------------------------------------|------------------------------|----------------------------|---------------|
| Provider: | Patient: Adda Patient | Gender: Female | Phone: |
| Visit Provider: | MRN: | DOB: 10/13/2011 (0) | |
| Conditions: Bioplerin Interval | Preferred Language: | | |
| Comorbidities: | First Measure Date: | | |
| Other Allergies: | | | |
| Drug Allergies: | | | |
| Medications: | | | |

| Demographics | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
|---|---|------------|-----------|----------|-----------|----------|
| Patient has attended an outpatient metabolic visit during the past 12 months? | Yes, No | | | Yes | 356 | |
| Was patient re consented for at age of majority or emancipation | Yes, N/A | | | | Per Visit | |
| Is patient followed by >1 metabolic center? | Missing/unknown data, yes, no | | | | Per Visit | |
| If patient is followed by >1 metabolic center note which Metabolic Centers in which States (enter N/A if not applicable) | | | | | Per Visit | |
| 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 | | | | Per Visit | |
| If deceased, date of death (if N/A enter 01/01/1901) | | | | | Per Visit | |
| Metabolic 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 | | | | Per Visit | |
| Primary Care Provider Name (enter "unknown" if missing information, enter "none" if no primary care provider) | | | | | Per Visit | |
| Primary care status | missing/unknown data, on schedule for preventive care, seen for preventive care but not up to date, does not go to primary care provider | | | | Per Visit | |
| Immunization status | missing/unknown data, up to date, no immunizations to date, immunization lag due to staging, immunization lag due to other reason (s) | | | | Per Visit | |
| Socioeconomic Status | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| 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 | | | | Per Visit | |
| Measurements | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Weight at this visit (enter 99999 if not measured) | (kg) | | | | Per Visit | |
| Height at this visit (enter 99999 if not measured) | (cm) | | | | Per Visit | |
| Head circumference (OFC) at this visit (enter 99999 if not measured) | (cm) | | | | Per Visit | |
| Past Health History | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Date of last outpatient metabolic visit (if unknown enter 01/01/1901) | | | | | Per Visit | |
| Has patient had general anesthesia since the last outpatient metabolic visit? | Missing/unknown data, yes, no | | | | Per Visit | |
| Has patient had surgical procedure(s) since the last outpatient metabolic visit? | Missing/unknown data, yes, no | | | | Per Visit | |
| What type of surgical procedure(s) were done since the last outpatient metabolic visit? If not applicable enter N/A | | | | | Per Visit | |

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| Past Health History | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Complications associated with surgical procedure(s) done since the last outpatient metabolic visit? If not applicable enter N/A | | | | | Per Visit | |
| List specific comorbidities (enter N/A if not applicable, enter unknown if missing information) | | | | | Per Visit | |
| Have new symptoms of this condition developed since the last outpatient metabolic visit? | Missing/unknown data, no new symptoms, abnormal EEG, athetosis, chorea, dystonia, eczema, hypersalivation, hypertonia, hypotonia, extremity tremor, lethargy, opisthotonus, orofacial dyskinesia, pneumonia, seizures – myoclonic, seizures – tonic clonic, seizures – other type | | | | Per Visit | |
| Emergency Management | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Patient/primary caregiver currently has a sick day plan specific to this disorder? | Missing/unknown data, yes, no | | | | Per Visit | |
| Number of ER visits since last metabolic visit | Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Number of hospital admissions (total) since last metabolic visit | Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10 | | | | Per Visit | |
| Total number of hospital admissions with NO metabolic decompensation since last outpatient metabolic visit | Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Care Coordination | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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) | | | | Per Visit | |
| Other providers seen at this metabolic visit(enter N/A if not applicable) | | | | | Per Visit | |
| Developmental Assessment | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |

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| Visit Provider: | MRN: | DOB: 10/13/2011 (0) | | | | |
| Developmental Assessment | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Developmental screening occurred at this visit? | Missing/unknown data, yes, no | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Developmental milestones achieved at this time? | Missing/unknown data, N/A - no developmental screening occurred at this visit, yes, no | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Was neuropsychological evaluation done since last outpatient metabolic visit? (If yes, complete Neuropsych Survey) | Missing/unknown data, Yes, No | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Are behavioral concerns suspected at this time? | Missing/unknown data, Yes (go to next question and explain), No | | | | Per Visit | |
| If behavioral concerns are suspected at this time, explain (enter N/A if no behavioral concerns suspected) | | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Has there been a progressive loss of developmental milestones since the last outpatient metabolic visit? | Missing/unknown data, yes, no | | | | Per Visit | |
| Education | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Was patient referred for Special Education evaluation at this time? | Missing/unknown data, yes, no | | | | Per Visit | |
| Are Special Educational services received by this patient currently? | Missing/unknown data, yes - IEP/IFSP, yes - 504 plan, yes - other, no | | | | Per Visit | |
| 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+ | | | | Per Visit | |
| Reason Special Educational services are received currently? | Missing/unknown data, N/A (no Special Ed services are currently received), cognitive disability, developmental delay, fine motor disability, gross motor disability, learning disability, social-emotional disability, speech-language disability, other health impaired (OHI), other | | | | Per Visit | |
| Home Monitoring | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Patient submits blood samples obtained at home for monitoring? | Missing/unknown data, no, blood phenylalanine and tyrosine levels, blood phenylalanine levels only | | | | Per Visit | |
| Recommended frequency of blood samples obtained at home for monitoring | Missing/unknown data, N/A, more than once/week, weekly, every other week, every other month, less often than every other month | | | | Per Visit | |
| Number of blood phenylalanine levels obtained since the last outpatient metabolic visit (enter 99999 if missing/unknown data) | | | | | Per Visit | |
| Average phenylalanine level obtained | (mg/dL) | | | | Per Visit | |

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| Home Monitoring | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| by home or other lab monitoring since the last outpatient metabolic visit (enter | | | | | | |
| Number of blood tyrosine levels obtained since the last outpatient metabolic visit (enter 99999 if missing/unknown data) | | | | | Per Visit | |
| Average tyrosine level obtained by home or other lab monitoring since the last outpatient metabolic visit (enter 99999 if missing/unknown data) | (mg/dL) | | | | Per Visit | |
| Recommended therapeutic phenylalanine goal (enter 99999 if | (mg/dL) | | | | Per Visit | |
| Recommended therapeutic tyrosine goal (enter 999 | (mg/dL) | | | | Per Visit | |
| Highest phenylalanine value obtained since the last outpatient metabolic visit (enter 99999 if missing/unknown data) | (mg/dL) | | | | Per Visit | |
| Lowest tyrosine level obtained since the last outpatient metabolic visit (enter 99999 if missing/unknown data) | (mg/dL) | | | | Per Visit | |
| Phenylalanine levels: average percent above recommended therapeutic phenylalanine goal since last outpatient metabolic visit (enter 99 if missing/unknown data) | (%) | | | | Per Visit | |
| Phenylalanine levels: average percent below recommended therapeutic phenylalanine goal since last outpatient metabolic visit (enter 99 if missing/unknown data) | (%) | | | | Per Visit | |
| Tyrosine levels: average percent below recommended therapeutic tyrosine goal since last outpatient metabolic visit (enter 99 if missing/unknown data) | (%) | | | | Per Visit | |
| Laboratory Studies | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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, | | | | Per Visit | |

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| Laboratory Studies | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| | 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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) | | | | Per Visit | |
| Lab tests other general (indicate type and if WNL or Abn) collected at this visit, enter N/A if not applicable | | | | | Per Visit | |
| Biochemical Testing Specific to this IBEM collected at this visit | Missing/unknown data, not done, total 25-OH vitamin D-WNL, total 25-OH vitamin D-Abn low, plasma amino acids-within therapeutic range, plasma amino acids-above therapeutic range, DHPR-WNL, DHPR-Abn, plasma essential fatty acids-WNL, plasma essential fatty acids-Abn, folic acid-WNL, folic acid-Abn, selenium-WNL, selenium-Abn, serum B12-WNL, serum B12-Abn, urine MMA-WNL, urine bipterin-WNL, urine bipterin-Abn, urine MMA-Abn high, urine organic acids-WNL, urine organic acids-Abn, Other (go to next question and explain) | | | | Per Visit | |
| Other biochemical testing specific to this IBEM (indicate type and if WNL or Abn) collected at this visit, enter N/A if not applicable | | | | | Per Visit | |
| Prolactin level at this visit (enter 99999 if N/A) | (ng/mL) | | | | Per Visit | |
| Blood phenylalanine level at this visit (enter 99999 if N/A) | (mg/dL) | | | | Per Visit | |
| Blood tyrosine level at this visit (enter 99999 if N/A) | (mg/dL) | | | | Per Visit | |
| Imaging Studies | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Dexa scan since last outpatient | Missing/unknown data, N/A, hip, heel, pelvis, | | | | Per Visit | |

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| Imaging Studies | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| metabolic visit (z-score >-2), specify site | 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 | | | | Per Visit | |
| If abnormal dexa scan since last outpatient metabolic visit (z-score = -4 to -3), specify site | Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other | | | | Per Visit | |
| 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 | | | | Per Visit | |
| 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 | | | | Per Visit | |
| Is there evidence of abnormal myelination on CNS imaging since last outpatient visit? | Missing/unknown data, no, yes, N/A - imaging not done | | | | Per Visit | |
| Renal/pelvic/genital imaging done since last outpatient metabolic visit? | Missing/unknown data, no, 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 | | | | Per Visit | |
| Other imaging (indicate type of imaging and if WNL or Abn) done since last outpatient metabolic visit?, enter N/A if not applicable | | | | | Per Visit | |
| Brain MRI abnormalities noted since last outpatient visit? | Missing/unknown data, no, N/A - imaging not done, abnormal vascular proliferation in cortex, brain atrophy, calcification, basal ganglia abnormality, thalamus abnormality, white matter abnormality, other | | | | Per Visit | |
| Pharmacotherapy | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| Is folinic acid prescribed? | Missing/unknown data, yes, no | | | | Per Visit | |
| If on folinic acid, dose prescribed(enter 99999 if N/A)? | (mcg/day) | | | | Per Visit | |
| If on folinic acid, route prescribed? | Missing/unknown data, N/A - not prescribed feeding tube, oral | | | | Per Visit | |
| If on folinic acid, 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 Folinic acid 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 Visit | |
| If folinic acid, is not taken as prescribed, reason given(enter N/A not applicable) | | | | | Per Visit | |
| Method of payment for folinic acid 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, MC block grant), State/Federal insurance (Medicaid/Medicare), Other | | | | Per Visit | |
| Is L-dopa prescribed? | Missing/unknown data, yes, no | | | | Per Visit | |
| If on L-dopa, dose prescribed(enter 99999 if N/A) | (mg/kg/day) | | | | Per Visit | |
| If on L-dopa, formulation prescribed | Missing/unknown data, N/A - not prescribed, | | | | Per Visit | |

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| | 10% carbidopa, 25% carbidopa, slow-release | | |
| If on L-dopa, route prescribed? | Missing/unknown data, N/A - not prescribed, FeedingTube, Oral | | Per Visit |
| If on L-dopa, frequency prescribed? | Missing/unknown data, N/A - not prescribed, Once/day, Twice/day, Three times/day, Four times/day, Other | | Per Visit |
| Patient/primary caregiver reports L-dopa 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 Visit |
| If L-dopa is not taken as prescribed, reason given(enter N/A if not applicable) | | | Per Visit |
| Method of payment for L-dopa, if prescribed? | Missing/unknown data, N/A - not prescribed, Commercial/private insurance, State/Federal insurance (Medicaid/Medicare), Military insurance, self-pay, None - can't afford to fill medication prescription, State program (newborn screening funds, special needs program, MCH block grant), Other | | Per Visit |
| Is 5-hydroxy tryptophan (5-HTP) prescribed? | Missing/unknown data, yes, no | | Per Visit |
| If on 5-hydroxy tryptophan (5-HTP), dose prescribed (enter 99999 if N/A)? | (mg/kg/day) | | Per Visit |
| If on 5-hydroxy tryptophan (5-HTP), route prescribed? | Missing/unknown data, N/A - not prescribed, feeding tube, oral | | Per Visit |
| If on 5-hydroxy tryptophan (5-HTP), 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 5-hydroxy tryptophan (5-HTP) 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 Visit |
| If 5-hydroxy tryptophan (5-HTP) is not taken as prescribed, (enter N/A if not applicable) | | | Per Visit |
| Method of payment for 5-hydroxy tryptophan (5-HTP), 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 | | Per Visit |
| Is L-deprenyl prescribed? | Missing/unknown data, yes, no | | Per Visit |
| If on L-deprenyl, dose prescribed(enter 99999 if N/A)? | (mg/day) | | Per Visit |
| If on L-deprenyl, formulation prescribed? | Missing/unknown data, N/A - not prescribed, 10% carbidopa, 25% carbidopa, slow-release | | Per Visit |
| If on L-deprenyl, route prescribed? | Missing/unknown data, N/A - not prescribed, FeedingTube, Oral | | Per Visit |
| If on L-deprenyl, frequency prescribed? | Missing/unknown data, N/A - not prescribed, Once/day, Twice/day, Three times/day, Four times/day, Other | | Per Visit |
| Patient/primary caregiver reports L-deprenyl 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 Visit |

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|--|--|--|--|--|-----------|
| If L-deprenyl is not taken as prescribed, reason given(enter applicable) | | | | | Per Visit |
| Method of payment for L-deprenyl, if prescribed | Missing/unknown data, N/A - not prescribed Commercial/private insurance, State/Federal insurance (Medicaid/Medicare), Military insurance, self-pay, None - can't afford to fill medication prescription, State program (newborn screening funds, special needs program, MCH block grant), Other | | | | Per Visit |
| Is sapropterin dihydrochloride (Kuvan) prescribed? | Missing/unknown data, yes, no | | | | Per Visit |
| If sapropterin dihydrochloride (Kuvan) is prescribed, was neuropsychologic evaluation performed pre- prescription (if yes complete Neuropsych survey now)? | Missing/unknown data, yes, no | | | | Per Visit |
| If sapropterin dihydrochloride (Kuvan) is prescribed, was neuropsychological eval performed while being treated with this medication(if yes complete Neuropsych survey now)? | Missing/unknown data, yes, no | | | | Per Visit |
| If on sapropterin dihydrochloride (Kuvan), dose prescribed(enter 99999 if N/A) | (mg/kg/day) | | | | Per Visit |
| If on sapropterin dihydrochloride (Kuvan), route prescribed? | Missing/unknown data, N/A - not prescribed, feeding tube, oral – dissolved, oral – tablet form | | | | Per Visit |
| If on sapropterin dihydrochloride (Kuvan), frequency prescribed? | Missing/unknown data, N/A – not prescribed, once/day, other | | | | Per Visit |
| Patient/primary caregiver reports sapropterin dihydrochloride (Kuvan) 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) | | | | Per Visit |
| If sapropterin dihydrochloride (Kuvan), is not taken as prescribed, reason given (enter N/A if not applicable)? | | | | | Per Visit |
| Method(s) of payment for sapropterin dihydrochloride (Kuvan), if prescribed | Missing/unknown data, N/A - not prescribed Commercial/private insurance, Military insurance, None - can't afford to fill medication prescription, NORD, patient assistance program, Self-pay, State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), Other | | | | Per Visit |
| Does metabolic specialist consider patient responsive to sapropterin dihydrochloride (Kuvan)? | Missing/unknown data, N/A-not prescribed, yes, no | | | | Per Visit |
| Criterion metabolic specialist used to determine sapropterin dihydrochloride (Kuvan) responsiveness | Missing/unknown data, >20% decrease in phenylalanine level post-medication, >30% decrease in phenylalanine level post-medication, improved behavior, improved mood stability, improved attention, improved academic performance, increased dietary phenylalanine tolerance, other | | | | Per Visit |
| If patient was reported to have experienced potential side effects/adverse reaction to sapropterin dihydrochloride (Kuvan), explain (enter N/A if not applicable) | | | | | Per Visit |
| 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, | | | | Per Visit |

Visit Planner

Date of Visit: ____ / ____ / ____

| Provider: | Patient: Adda Patient | Gender: Female | Phone: | | | |
|--|---|----------------------------|---------------|----------|-----------|----------|
| Visit Provider: | MRN: | DOB: 10/13/2011 (0) | | | | |
| Pharmacotherapy | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| | 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 | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date |
| 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 patient prescribed a protein restricted diet? | Missing/unknown data, yes, no | | | | Per Visit | |
| If patient is prescribed a protein restricted diet, prescribed protein grams/day from foods - not including metabolic formula (enter 99999 if N/A) | (grams/day) | | | | Per Visit | |
| If protein restricted diet (from foods, not including metabolic formula) is prescribed and followed 0 or 1-3 days/week, reason given (enter N/A if not applicable) | | | | | Per Visit | |
| Is patient prescribed low protein foods? | Missing/unknown data, yes, no | | | | Per Visit | |
| Method of payment for low protein foods, 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 | | | | Per Visit | |
| If prescribed metabolic formula, amount of protein prescribed from metabolic formula per day (enter 99999 if N/A): | (grams/day) | | | | Per Visit | |
| If on special metabolic formula, name(s) of formula(s), enter N/A if not applicable | | | | | Per Visit | |
| Patient/primary caregiver reports metabolic formula 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 Visit | |
| If metabolic formula is prescribed and not taken as prescribed, reason given? (enter N/A if not applicable) | | | | | Per Visit | |
| 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 Visit | |
| Average protein intake/day reported since last outpatient metabolic visit (enter 99999 if N/A) | (grams/day) | | | | Per Visit | |
| If patient is prescribed a phenylalanine restricted diet, prescribed phenylalanine intake/day (enter 99999 if N/A) | (mg phenylalanine/day) | | | | Per Visit | |
| Average phenylalanine intake/day reported since last outpatient metabolic visit (enter 99999 if N/A) | (mg phenylalanine/day) | | | | Per Visit | |
| Name(s) of other amino acid supplement(s) if prescribed (enter N/A not applicable) | | | | | Per Visit | |
| Formulation of other amino acid supplement(s) if prescribed | Missing/unknown data, N/A-not prescribed, bar, capsules, tablets, powder/mix-ins, other | | | | Per Visit | |
| Patient/primary caregiver reports other | Missing/unknown data, N/A-not prescribed, y | | | | Per Visit | |

Visit Planner

Date of Visit: ____ / ____ / ____

| Provider: | | Patient: Adda Patient | | Gender: Female | | Phone: | |
|---|--|------------------------------|-----------|----------------------------|-----------|---------------|--|
| Visit Provider: | | MRN: | | DOB: 10/13/2011 (0) | | | |
| Nutrition | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date | |
| amino acid supplement(s) are taken as prescribed | - 4-7 days/week, yes - 1-3 days/week, no (0 days/week) | | | | | | |
| If other amino acid supplement(s) are prescribed and not taken as prescribed, reason given? (enter N/A if not applicable) | | | | | Per Visit | | |
| Method of payment for other amino acid supplement(s), 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/MC block grant), State/Federal insurance (Medicaid/Medicare), WIC, Other | | | | Per Visit | | |
| Patient uses feeding device (NG tube, G tube, GJ tube)? | Missing/unknown data, yes, no | | | | Per Visit | | |
| If other nutritional supplementation is taken (explain), enter N/A if not applicable. | | | | | Per Visit | | |
| Additional nutritional comments? (enter N/A if not applicable) | | | | | Per Visit | | |
| Other | Today's Action | Last Value | Date Last | Pt. Goal | Int. Days | Due Date | |
| Other Comments | | | | | Per Visit | | |

Last Visit Comment:

Visit Comment: