

Visit Planner

Date of Visit: ___ / ___ / _____

Provider:	Patient: Interval Biotinidase	Gender: Male	Phone:
Visit Provider:	MRN:	DOB: 1/1/2009 (0)	

Conditions: Biotinidase 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
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	
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	
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	
Family History	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Age at time of first abnormal dexta scan (enter 99999 if N/A or unknown)	(years)				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	
Diagnostic Testing	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Mutation description: Allele 1 (format example 985A>G)					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	
Complications associated with surgical procedure(s) done since the last outpatient metabolic visit? If not applicable enter N/A					Per Visit	
Is there evidence of optic nerve atrophy on ophthalmology exam done since last outpatient metabolic visit?	Missing/unknown data, N/A – ophthalmology exam not done since last outpatient metabolic visit, yes, no				Per Visit	
Is there evidence of hearing impairment on audiology testing done since last outpatient metabolic visit?	Missing/unknown data, N/A – audiology testing not done since last outpatient metabolic visit, yes – yes – sensorineural, yes – conductive, yes- mixed sensorineural and conductive, no				Per Visit	

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Date of audiology testing done since last outpatient metabolic visit (enter 01/01/1901 if N/A)					Per Visit		
Type of audiology testing performed since last outpatient metabolic visit	Missing/unknown data, N/A – audiology testing not done since last outpatient metabolic visit, ABR-Automated, ABR-Frequency Specific, OAE-Automated, TOAE/DPOAE, Sound Field, Tympanogram				Per Visit		
If hearing impaired, laterality of impairment	Missing/unknown data, N/A- hearing not tested, N/A -no hearing impairment, right, left, both right and left				Per Visit		
If hearing impaired, severity of impairment	Missing/unknown data, N/A – hearing not tested, N/A – no hearing impairment, 20-40 dB (mild), 40-60 dB (moderate), 60- 80 dB (severe), >80 dB (profound)				Per Visit		
If hearing impaired, progression of hearing loss	Missing/unknown data, N/A – hearing not tested, N/A – no hearing impairment, >15 dB loss in 1 year, no progression of hearing loss since previous audiology testing				Per Visit		
Current habilitation for hearing impairment	Missing/unknown data, N/A – hearing not tested, N/A – no hearing impairment, hearing aid(s), cochlear implant				Per Visit		
Is there evidence of dermatitis on physical exam done today?	Missing/unknown data, yes, no				Per Visit		
Is there evidence of ataxia on physical exam done today?	Missing/unknown data, yes, no				Per Visit		
Emergency Management	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
Patient/primary caregiver knows how to reach the 24 hour on-call contact information for a metabolic provider	Missing/unknown data, yes, no				Per Visit		
Patient/primary caregiver currently has a written emergency letter for this IBEM?	Missing/unknown data, yes, no				888		
Patient/primary caregiver currently has a sick day plan specific to this IBEM?	Missing/unknown data, yes, no				Per Visit		
Patient was enrolled in a web-based emergency alert program?	Missing/unknown data, yes - MEMSCIS, yes - other web-based program, no				Per Visit		
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				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				Per Visit		

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Care Coordination	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
	evaluation-heart, Transplant evaluation - liver, Transplant received - kidney, Transplant received - heart, Transplant received-liver, 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					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	
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	
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	Missing/unknown data, N/A (no Special Ed					Per Visit	

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Education	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
are received currently?	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						
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 Enrollment 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 Enrollment 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 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 miscellaneous collected at this visit	Missing/unknown data, none, CK-WNL, CK-Abn, CRP-WNL, CRP-Abn, ESR-WNL, ESR-Abn, ferritin-WNL, ferritin-Abn, transferrin-WNL, transferrin-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		
Explain all abnormal results checked above					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		
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, Plat-WNL, Plt-Abn, RBC-WNL, RBC-Abn, WBC-WNL, WBC-Abn, Other				Per Visit		
Serum biotinidase enzyme activity(enter 99999 if N/A)	(nmol/min/mL)				Per Visit		
Serum biotinidase enzyme assay from unrelated control specimen (enter 99999 if N/A)	(nmol/min/mL)				Per Visit		
Reference range for serum biotinidase enzyme activity (enter 99999 if N/A)	(nmol/min/mL)				Per Visit		
Biochemical testing specific to this IBEM collected at this visit;	Missing/unknown data, not done, biotin level – WNL, biotin level – Abn, lactic acid –WNL, lactic acid –Abn, IBEM collected at this visit plasma acylcarnitines – WNL, plasma				Per Visit		

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Laboratory Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
	acylcarnitines –Abn, urine acylcarnitines – WNL, urine acylcarnitines – Abn, urine organic acids –WNL, urine organic acids – Abn, other (go to next question and explain)						
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	
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	
Renal/pelvic/genital imaging done since last outpatient metabolic visit?	Missing/unknown data, no, yes-genitogram-WNL, yes-genitogram-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	
PharmacoTherapy	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
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					Per Visit	
Is biotin prescribed?	Missing/unknown data, yes, no					Per Visit	
If on biotin, formulation prescribed (enter N/A if not applicable)	Missing/unknown data, capsule, suspension, tablet					Per Visit	
If on biotin, dose prescribed (enter 99999 if N/A)?	(mg/day)					Per Visit	
If on biotin, route prescribed?	Missing/unknown data, N/A - not prescribed, feeding tube, oral					Per Visit	
Patient/primary caregiver reports biotin	Missing/unknown data, N/A – not prescribed,					Per Visit	

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PharmacoTherapy	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
is taken as prescribed?	yes - 4-7 days/week, yes - 1 to 3 days/week, no (0 days/week)						
If biotin is not taken as prescribed, reason given (enter N/A if not applicable)?					Per Visit		
Method(s) of payment for biotin, 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		
Nutrition	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
If other nutritional supplementation is taken (explain), enter N/A if not applicable.					Per Visit		
Patient uses feeding device (NG tube, G tube, GJ tube)?	Missing/unknown data, yes, no				Per Visit		
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		

Last Visit Comment:

Visit Comment: