

Visit Planner

Provider:	Patient: Interval Galactosemia (GALT)	Gender: Female	Phone:
Visit Provider:	MRN:	DOB: 1/1/2007 (4)	

Conditions: Galactosemia 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
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	
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	

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	
Is there evidence of cataract(s) on ophthalmology exam done since last outpatient visit?	Missing/unknown data, N/A - ophthalmology exam not done since last outpatient visit, yes, no				Per Visit	
Is there evidence of tremor 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, N/A - Non-ambulatory				Per Visit	
Is there evidence of speech-language problems on exam done today?	Missing/unknown data, yes, no				Per Visit	
Tanner Stage of breast development at this time	Missing/unknown data, N/A - patient is male, I, II, III, IV, V				Per Visit	
Tanner Stage of pubic hair development at this time	Missing/unknown data, I, II, III, IV, V				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	

Emergency Management	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date

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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 disorder?	Missing/unknown data, yes, no				888		
Patient/primary caregiver currently has a sick day plan specific to this disorder?	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 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	
Developmental screening occurred at this visit?	Missing/unknown data, yes, no				Per Visit		
Developmental screening tool used at	Missing/unknown data, N/A - no				Per Visit		

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Developmental Assessment		Today's Action		Last Value	Date Last	Pt. Goal	Int. Days	Due Date
this visit (if screening was done)		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					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 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					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 -					Per Visit	

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	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		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 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, Bone specific alkaline phosphatase-WNL, Bone specific alkaline phosphatase-Abn, Estradiol-WNL, Estradiol-Abn, FSH-WNL, FSH-Abn, LH-WNL, LH-Abn, IgF-1 -WNL, IgF-1 -Abn, IgFBP3 - WNL, IgFBP3-Abn, Intact PTH-WNL, Intact PTH-Abn, Osteocalcin-WNL, Osteocalcin-Abn, Total 25-hydroxyvitamin D -WNL, Total 25-hydroxyvitamin D -Abn low, Urinary deoxypyridinoline-WNL, Urinary deoxypyridinoline-Abn high, Urinary pyridinoline-WNL, Urinary pyridinoline-Abn high, urine reducing substances-WNL, urine reducing substances-Abn, other (go to next question and explain)		Per Visit
Explain all abnormal results checked above			Per Visit
Galactose-1-phosphate level (RBC) collected at this visit(enter 99999 if unkonwn or N/A)	(mg % or mg/dL)		Per Visit
Reference range for Galactose-1-phosphate level (RBC) collected at this visit(enter 99999 if unkonwn or N/A)	(mg % or mg/dL)		Per Visit
Galactose-1-phosphate level (RBC) collected at this visit(enter 99999 if unkonwn or N/A)	(umol/g Hb)		Per Visit
Reference range for Galactose-1-phosphate level (RBC) collected at this visit(enter 99999 if unkonwn or N/A)	(umol/g Hb)		Per Visit
Urine galactitol collected at this visit (enter 99999 if unkonwn or N/A)	(mmol/mol Cr)		Per Visit
Reference range for urine galactitol collected at this visit(enter 99999 if	(mmol/mol Cr)		Per Visit

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Laboratory Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
unknown or N/A							
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
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 metabolic visit (z-score >-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 = - 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
Bone age method	Missing/unknown data, N/A – bone age not done, Greulich-Pyle, Other						Per Visit
Date of most recent bone age done since last outpatient metabolic visit (enter 01/01/1901 if N/A)							Per Visit
Results of most recent bone age done since last outpatient metabolic visit (enter N/A if not applicable)	(years, months)						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
Pharmacotherapy	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
Is calcium prescribed	Missing/unknown data, yes, no						Per Visit
If on calcium, dose prescribed (enter 99999 if N/A)?	(mg/day)						Per Visit
If on calcium, route prescribed?	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	
	feeding tube, oral						
If on calcium, frequency prescribed?	Missing/unknown data, N/A – not prescribed, once/day, twice/day, three times/day, other				Per Visit		
Patient/Primary caregiver reports calcium 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 calcium is not taken as prescribed, reason given (enter N/A if not applicable)?					Per Visit		
Method of payment for calcium, 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		
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		
Nutrition	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
Is patient prescribed a galactose restricted diet?	Missing/unknown data, yes, no				Per Visit		
Does patient restrict galactose intake from fruits and/or vegetables?	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		
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		
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		
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		

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Last Visit Comment:

Visit Comment: