

Visit Planner

Date of Visit: ____ / ____ / ____

Provider: Patient: Interval Galactosemia (GALT deficiency) Gender: Phone:
Visit Provider: MRN: DOB:

Conditions: Galactosemia (GALT deficiency) Interval Update Preferred Language:
Comorbidities: First Measure Date:

Allergies:

Medications:

Demographics

Follow up status

Today's Action

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

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)

Socioeconomic Status

Current insurance status

Today's Action

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 Today's Action

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)

Today's Action

Is there evidence of cataract(s) 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

Is there evidence of tremor on physical exam done today?

Missing/unknown data, yes, no

Is there evidence of ataxia on physical exam done today?

Missing/unknown data, yes, no

Is there evidence of speech-language problems on exam done today?

Missing/unknown data, yes, no

Tanner Stage of breast development at this time

Missing/unknown data, I, II, III, IV, V

Tanner Stage of pubic hair development at this time

Missing/unknown data, I, II, III, IV, V

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?

(free text)

If not applicable enter N/A.

Complications associated with surgical procedure(s) (free text)
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

Today's Action

Missing/unknown data, yes, no

Patient/primary caregiver currently has a written emergency letter for this IBEM?

Missing/unknown data, yes, no

Patient/primary caregiver currently has a sick day plan specific to this IBEM?

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

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Conditions: Galactosemia (GALT deficiency) Interval Update **Preferred Language:**
Comorbidities: **First Measure Date:**
Allergies:
Medications:

Has patient accessed their web-based emergency plan since the last 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

Emergency Management

Total number of hospital admissions with NO metabolic decompensation since last outpatient metabolic visit

Today's Action

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

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Care Coordination

Other health services received currently

Today's Action

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, 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

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?

Today's Action

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 ones 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

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Education

Was patient referred for Special Education evaluation at this time?

Today's Action

Missing/unknown data, yes, no

Are Special Educational services received by this patient currently?

Missing/unknown data, yes - IEP/IFSP, yes - 504 plan, yes - other, 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

Laboratory Studies

Today's Action

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

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, 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 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

Lab tests chemistry collected at this visit

Missing/unknown data, none, ABG-WNL, ABG-Abn, Ammonia - WNL, Ammonia - Abn, Anion Gap-WNL, 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 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, Other

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)

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, GALT enzyme activity - Abn < ____, GALT enzyme activity - Abn > ____, galactose-1-phosphate level - WNL, galactose-1-phosphate level elevated but within acceptable treatment range for classic galactosemia, galactose-1-phosphate level above acceptable treatment range for classic galactosemia, urine galactitol - WNL, urine galactitol - Abn high, urine reducing substances - WNL, urine reducing substances - Abn, other (go to next question and explain)

?NTX, osteocalcin, IgF-1, IgFBP-3, 25-OH vitamin D total, PTH, LH, FSH, bone specific alk phos

Explain all abnormal results checked above

(free text)

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

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Imaging Studies Today's Action

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
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
Musculoskeletal imaging done since last outpatient metabolic visit?	Missing/unknown data, no, yes-bone age-WNL, yes-bone age-Abn, yes-bone x-rays-WNL, yes-bone x-rays-Abn, yes-dexa scan-WNL, yes-dexa scan-Abn, yes-EMG-WNL, yes-EMG-Abn
Age at time of first abnormal dexa scan (enter 99999 if N/A)	(years)
If abnormal dexa scan since last outpatient metabolic visit (z-score ≤ - 2 to 3), specify site	Missing/unknown, N/A, hip, heel, pelvis, spine, wrist
If abnormal dexa scan since last outpatient metabolic visit (z-score ≤ - 3 to 4), specify site	Missing/unknown, N/A, hip, heel, pelvis, spine, wrist
If abnormal dexa scan since last outpatient metabolic visit (z-score ≤ - 4), specify site	Missing/unknown, N/A, hip, heel, pelvis, spine, wrist
Chronological age at time of most recent bone age done since last outpatient metabolic visit	(years, months)
Results of bone age done since last outpatient metabolic visit	(years, months)
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
Is there evidence of cerebral edema on imaging done since last outpatient metabolic visit?	Missing/unknown data, N/A -imaging not done, no, yes
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
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 calcium prescribed?	Today's Action Missing/unknown data, yes, no
If on calcium, dose prescribed (enter 99999 if N/A)?	(mg/kg/day)
If on calcium, route prescribed?	Missing/unknown data, N/A - not prescribed, feeding tube, oral
If on calcium, frequency prescribed?	Missing/unknown data, N/A – not prescribed, once/day, twice/day, three times/day, other
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)
If calcium is not taken as prescribed, reason given (enter N/A if not applicable)?	

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Pharmacotherapy

Method(s) of payment for calcium,
if prescribed

Today's Action

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

?Vitamin D supplement
Is Estrogen (excluding oral contraceptive) prescribed?
Are Biphosphanates prescribed?

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,
bronchodilators, contraceptives - injection, contraceptives - oral, corticosteroids, diuretics,
hormones, immunosuppressives, insulin, insulin sensitizers, iron, laxatives, mannitol, sleeping
medications, vitamins, other

Nutrition

Is patient prescribed a galactose restricted diet?

Today's Action

Missing/unknown data, yes, no

Other diet questions....

What type(s) of milk/formula is patient taking?

Missing/unknown data, None, Baby formula (regular), Breastmilk, Rice milk, Skim milk, 1%
milk, 2% milk, Soy milk, Special metabolic formula, Whole milk, Other

If on special metabolic formula, name(s) of
formula(s), enter N/A if not applicable

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)

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), Other

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)

