

CMD Children's Metabolic Disorders Parent  
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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Print Date: 9/13/2008  
Page 2 of 6

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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** **Today's Action**  
Was patient referred for Special Education evaluation at this time? 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	
<b>PharmacoTherapy</b> Is calcium prescribed?	<b>Today's Action</b> 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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Print Date: 9/13/2008  
Page 6 6  
of

**Provider:**  
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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)

