



Region 4 Priority 2 Workgroup
Telemeeting Agenda - Friday, February 20, 2009
1/866/489-0573; *4545164*

I. Welcome

- II. Introductions and IBEM-IS Participation Updates – by State Roll Call**
Please announce yourself, your state, and, if applicable, the clinic you are representing and provide a brief update of where your center is in the IBEM-IS process (waiting for approval, finalizing IRB application, enrolling, consenting, etc.)

III. IBEM-IS Update

- A. Galactosemia Interval Survey (Handout 1) (N. Leslie)
- B. Update on any new surveys

IV. Engaging Department of Health

- A. Using IBEM-IS Data
- B. Identify Department of Health contacts if state not already represented
- C. Implications for IRB applications

V. Implementation

- A. Enrollment
 - 1. Enrollment Report (Handout 2)
 - 2. IRB Enrollment records needed
- B. Clinical State Lead Activities
 - 1. Updates on involving other sites within state
 - 2. State Site Visit – opportunity for partnering
 - 3. Expectations for Priority 2 Workgroup Members

- C. Research Initiative ~ Family Functioning and Chronic Disease Project

VI. Mountain States “care plans” meeting

VII. IBEM-IS & MEMSCIS “Expansion”

VII. Comments / Announcements

- A. Presentations
- B. Next Meeting – March 20th 1 pm, CT / 2 pm ET
- C. Please enter/update your member information in the member registry
www.region4genetics.org
- D. Rescheduling May meeting
- E. Other

VIII. Adjourn



Region 4 Priority 2 Workgroup
Telemeeting Notes - Friday, January 16, 2008

Participating: Susan Berry Co-Lead, Kristi Bentler, Anne Jurek, MN; Stephanie Gurnon, IN; Jan Askren, KY; Jerry Feldman, Allison Bannick; MI; Nancy, Leslie, Shawn McCandless, Kim Regis, OH; Bill Rhead, Sandy vanCalcar, Abby Donovan, WI; Sally Hiner, Region 4 Genetics Collaborative Coordinator.

I. IBEM-IS Participation Updates:

- Anyone desiring IRB assistance should contact Sally (shiner@mphi.org)

State/Lead	Center	Status
IL/Burton	Children's Memorial Hospital	No Report
	University of IL	No Report
	Rush University Medical Center	No Report
IN/Hainline	Riley Hospital for Children	Consenting (approximately 16 to date)
KY/Gowans	University of KY	No Report
	University of Louisville (Askren)	Meet with financial IRB folks next week.
MI/Feldman	Wayne State	Consenting, none entered to date
	University of MI	Trained
MN/Berry	University of MN	Enrolling all disorders for which data elements are in process - so have consented more than have entered; Done enrollment data for several, starting to add interval surveys
	Mayo	No Report
OH/ Leslie	Cincinnati Children's Hospital	Enrolling, none entered-to-date
	Case Western Reserve	IRB in process
	Nationwide Children's, Columbus	7 Consented, entering data on six of the 7; amended IRB to include phone consent and phone script to be able to contact and enter "in-actives"
	Akron	No Report
	Dayton	No Report
WI/Rhead	Waisman Center	Awaiting IRB approval
	Medical Center of WI	Not yet consenting or enrolling, IRB approval
NE/Skrabel	Nebraska	No Report
IA/Copeland	University of Iowa	No report

Sue will be creating reports monthly to share with the workgroup on IBEM-IS implementation process. To date, 63 patients have been enrolled. Eight centers (all within Region 4) have IRB approval.

Resources on the Region 4 Website

- MN has discovered that using the paper visit planner to collect the data and then add it to the Registry later is quickest. We will continue to post the visit planners in pdf form on the Region 4 website so they can be accessed from the Region 4 Website.

- FIPs numbers will be posted to the Region 4 website so that each center can locate their state FIP. The FIP # is used for the first two digits of the case number.
- Phone script for consenting patients developed by Ohio partners will be posted.

II. IBEM-IS Update - Building the Information System

A. Disorder Pending: DocSite is finalizing building of several surveys. Sally will send out an email when these surveys are live.

- a. Disorders needing finalizing by the group
 - i. Glutaric Acidemia Type 1 – comments to Kristi by end of business Tuesday, January 20. Will be forwarded to DocSite for posting on January 21.
 - ii. Galactosemia- completed enrollment survey. Tabled interval survey until February meeting.
 - iii. Tyrosinemia – Tabled until all of the interval surveys are completed for disorders for which enrollment surveys are already done.

III. IBEM-IS Implementation

A. Issues and concerns

- 1 Consents – permission for re-contact. A large number of individuals have not given consent to be re-contacted. It seems the forms may be from one institution. It may be that individuals really did want the “no” box checked, it may mean that the neither the yes or no box was checked. People are reminded to ask the question. Lack of response cannot be taken as consent, so by default must be assumed to be a “no” response. Being able to re-contact is essential for future cohort studies.

B. SOPs for Implementation

- 1 Reminder – IRB Renewals must be submitted to MPH.
- 2 Data and information required for IRB Renewals – please submit requests for information to Sally. Information of interest to the broader group, such as number enrolled in entire project, will be posted on the Region 4 website so that in the future you will be able to access it without requesting.
- 3 Update on number/case entry for each participating site – reminder that we will be asking each site to report this data at a minimum of every six months. The enrollment reporting form is available on the Region 4 website
- 4 Enrollment invoicing – invoice forms are available on the Region 4 website and are now due for all enrollments occurring up to December 31, 2008.
- 5 Formula for assigning unique patient identifiers. The unique patient identifier is a nine digit number developed as follows:
 1. 1st two digits are the state FIP number (FIP numbers are posted on the Region 4 website for your reference).
 2. Next two digits are the patients birth year
 3. Next digit is the center number. Center numbers are assigned based on the order in which the center was activated in the IBEM-IS by state.

4. The last four digits are the individual patient number which is to be assigned sequentially by case enrollment by the clinic, beginning with 0001.

C. Clinical State Lead Activities

1. Updates on involving other sites within state. Sue reminded state leads that adding additional sites within states is part of the state lead role and activity related to adding additional sites will need to be reported when invoicing for honoraria. Clinical State Leads will be asked to give an activity report during the February meeting.

V. Family Functioning and Chronic Disease Project

Darin and Sally met and have drafted an implementation plan. Focus groups will be scheduled in conjunction with state site visits.

VIII. Presentations: Sue asked members to continue to update the workgroup on where and when the IBEM-IS project is presented. Slides and presentation materials have been developed which can be adapted for use.

- A. NCC PI meeting – Sue Berry presented on the IBEM-IS and MEMSCIS at the NCC PI meeting January 6-8. She was invited as a member of the ACMG National Data group which is moving forward to create unified data sets that are national.
- B. Jurek – Abstract: Anne Jurek, project epidemiologist drafted an abstract she will be submitting in early February. Workgroup members are asked to review and provide feedback by January 27. A discussion about listing authors occurred. Sue generally addresses this issue by including the statement “Priority 2 workgroup members” rather than listing all individuals. Sally offered to post a list of workgroup members that can be easily located on the region 4 website by anyone interested in knowing who those members, or additional authors, are.

IX. MEMSCIS – MEMSCIS was presented to the P2 Workgroup previously.

Implementation met with resistance, primarily because of the need for another IRB approval. University submitted a revision application to their IRB to change the focus from implementation as a research tool to a clinical tool. The revision was approved. Interested clinics may now use MEMSCIS with their patients without IRB review and approval. Anyone interested in MEMSCIS should contact Sally (shiner@mphi.org; 517/381-8247 x14).

Notes by Hiner

**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

CMD Children's Metabolic Disorders Parent Visit Planner

Date of Visit: ____ / ____ / _____

Print Date: 9/13/2008
Page 2 of 6

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:

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

**CMD Children's Metabolic Disorders Parent
Visit Planner**

Date of Visit: ____ / ____ / ____

Provider:
Visit Provider:

Patient: Interval Galactosemia (GALT def)
MRN:

Gender:
DOB:

Phone:

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

**CMD Children's Metabolic Disorders Parent
Visit Planner**

Date of Visit: ____ / ____ / _____

Provider: _____ **Patient:** Interval Galactosemia (GALT def) **Gender:** _____ **Phone:** _____
Visit Provider: _____ **MRN:** _____ **DOB:** _____

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

Visit Planner

CMD Children's Metabolic Disorders Parent
Date of Visit: ____ / ____ / ____

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

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)?

**CMD Children's Metabolic Disorders Parent
Visit Planner**

Date of Visit: ____ / ____ / ____

Print Date: 9/13/2008
Page 6 of 6

Provider:
Visit Provider:

Patient: Interval Galactosemia (GALT def)
MRN:

Gender:
DOB:

Phone:

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)

Age	Unique registry ID	Permission	State	Surveys
2	27061035	No	MN	MCADD Interval,MCADD Enrollment
2	17061035	No	IL	MCADD Enrollment,MCADD Interval
3	17051001	No	IL	MCADD Enrollment,MCADD Interval
2	17071033	No	IL	MCADD Enrollment,MCADD Interval
5	17031034	No	IL	MCADD Enrollment,MCADD Interval
2	17071017	No	IL	MCADD Enrollment,MCADD Interval
8	17001018	No	IL	MCADD Enrollment,MCADD Interval
2	17061036	No	IL	MCADD Enrollment,MCADD Interval
5	17031037	No	IL	MCADD Enrollment,MCADD Interval
4	17041038	No	IL	MCADD Enrollment,MCADD Interval
3	17051039	No	IL	MCADD Enrollment,MCADD Interval
3	17051040	No	IL	MCADD Enrollment,MCADD Interval
3	17051019	No	IL	MCADD Enrollment,MCADD Interval
4	27041001	Yes	MN	MCADD Enrollment,MCADD Interval
2	27061002	Yes	MN	MCADD Enrollment,MCADD Interval
2	27061003	Yes	MN	MCADD Enrollment,MCADD Interval
2	27071004	Yes	MN	MCADD Enrollment,MCADD Interval
2	27061020	Yes	MN	MCADD Enrollment,MCADD Interval
1	27071005	Yes	MN	MCADD Enrollment,MCADD Interval
3	27051055	No	MN	MCADD Enrollment,MCADD Interval
4	27051044	No	MN	MCADD Enrollment,MCADD Interval
2	27061011	No	MN	MCADD Enrollment,MCADD Interval,Neuropsychological Survey
4	27041027	No	WI	MCADD Enrollment,MCADD Interval,Neuropsychological Survey
20	27881012	No	MN	MCADD Enrollment,MCADD Interval
2	27061006	Yes	MN	MCADD Enrollment,MCADD Interval
2	27061010	No	MN	MCADD Enrollment,MCADD Interval
6	27021013	Yes	MN	MCADD Enrollment,MCADD Interval
1	27071067	Yes	MN	MCADD Interval
7	27021064	Yes	MN	MCADD Enrollment,MCADD Interval
11	27971063	Yes	MN	MCADD Enrollment,MCADD Interval
15	27931062	Yes	MN	MCADD Enrollment,MCADD Interval
8	270010021	Yes	MN	MCADD Interval
5	27031014	Yes	MN	MCADD Enrollment,MCADD Interval
14			MN	LCHAD Enrollment,LCHAD Interval
5	270310007	Yes	MN	MSUD Interval
2			Yes	MSUD Enrollment
0	27081089	Yes	MN	MCADD Enrollment,MCADD Interval

0	27081080	Yes	MN	MCADD Enrollment,MCADD Interval
5	17041002	Yes	IL	MCADD Enrollment,MCADD Interval
7	39082001	Yes	OH	
3	39052002	Yes	OH	MCADD Enrollment
1	39072003	Yes	OH	MCADD Enrollment,MCADD Interval
2			MN	VLCAD Enrollment,VLCAD Interval
2			MN	SCAD Enrollment
5	39032004	Yes	OH	MCADD Enrollment,MCADD Interval
4	39042006	Yes	OH	MCADD Enrollment
7	39012005	Yes	OH	MCADD Enrollment
11	17971011	Yes	IL	SCAD Enrollment
0	17081003		IL	MCADD Enrollment,MCADD Interval
4	17051007		IL	
15	17941006		IL	MSUD Enrollment,MSUD Interval
7	17021004		IL	MSUD Enrollment,MSUD Interval
11	17971005		IL	MSUD Enrollment,MSUD Interval
10	17981009	Yes	IL	TFPD Enrollment,TFPD Interval
4	17041010		IL	SCAD Enrollment
24	17841008		IL	VLCAD Enrollment,VLCAD Interval
3	17061012		IL	VLCAD Enrollment,VLCAD Interval
51	275710008	Yes	MN	MSUD Enrollment
21			IL	MSUD Enrollment,MSUD Interval
0		Yes	IL	MCADD Enrollment,MCADD Interval
2	17061014		IL	MCADD Enrollment,MCADD Interval
4	17041015		IL	MCADD Enrollment,MCADD Interval
