

Visit Planner

Date of Visit: ____ / ____ / ____

Provider:	Patient: MCAD for Printing	Gender: Male	Phone:
Visit Provider:	MRN:	DOB: 1/1/1901 (110)	
Conditions: MCADD 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
Patient has attended an outpatient metabolic visit during the past 12 months?	Yes, No			Yes	356	
Was patient consented for at age of majority or emancipation	Yes, N/A				Per Visit	
Patient is enrolled in other research studies	Missing/unknown data, no, yes - other Region 4 emergency studies, yes - other Region 4 clinical/medication studies, yes - other Region 4 psychosocial studies, yes - studies related to this IBEM not conducted through Region 4, yes - other research				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	
Metabolic 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	
Primary Care Provider Name (enter "unknown" if missing information, enter "none" if no primary care provider)					Per Visit	
Primary care status	missing/unknown data, on schedule for preventive care, seen for preventive care but not up to date, does not go to primary care provider				Per Visit	
Immunization status	missing/unknown data, up to date, no immunizations to date, immunization lag due to staging, immunization lag due to other reason(s)				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
Body Mass Index	Calculated			< 25	Per Visit	
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	
Has patient had general anesthesia since the last outpatient metabolic visit?	Missing/unknown data, yes, no				Per Visit	

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Past Health History	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
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	
List specific comorbidities (enter N/A if not applicable, enter unknown if missing information)					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 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	
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,				Per Visit	

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Care Coordination	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
	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)					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	
Home Monitoring	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Patient does home monitoring	Missing/unknown data, no, yes-uses glucometer to check glucose, yes-has glucometer but doesn't use it				Per Visit	
Frequency of home monitoring	Missing/unknown data, N/A, only when symptomatic, routinely				Per Visit	
Patient has a prescribed glucometer for this IBEM for home glucose monitoring?	Missing/unknown data, yes, no				Per Visit	
Number of home monitoring glucose samples reported since last outpatient metabolic visit (enter 99999 if N/A)					Per Visit	
Lowest reported glucose on home monitoring samples since last outpatient metabolic visit (if N/A enter 99999)	(mg/dL)				Per Visit	
Laboratory Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Enzyme assay (specific to this IBEM) done at this visit?	Missing/unknown data, no, yes - abnormal, yes - normal, yes - non-diagnostic				Per Visit	
Fatty acid oxidation probe assay done at this visit?	Missing/unknown data, no, yes - abnormal, yes - normal, yes - non-diagnostic				Per Visit	
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				Per Visit	

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	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 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
Western blot (specific to this IBEM) done at this visit?	Missing/unknown data, Not done, <20%, >=20%<50%, >=50%		Per Visit
Documented hypoglycemia (blood glucose <60 mg/dL) since the last outpatient metabolic visit?	Missing/unknown data, glucose not measured, yes (answer next question), no		Per Visit
Lowest blood glucose value since last outpatient metabolic visit (enter 99999 if not measured)	(mg/dL)		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 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, Ammonia-WNL, Ammonia-Abn, Amylase-WNL, Amylase-Abn, Bloodspot acylcarnitines-WNL, bloodspot acylcarnitines-Abn, B-type Natriuretic Peptide (BNP)-WNL, B-type Natriuretic Peptide (BNP)-Abn, CK-WNL, CK-Abn, plasma acylcarnitines-WNL, plasma acylcarnitines-Abn, plasma carnitine levels-WNL, plasma carnitine levels-Abn Low, plasma essential fatty acids -WNL, plasma		Per Visit

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Laboratory Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
	essential fatty acids -Abn, triglycerides-WNL, triglycerides-Abn, urine myoglobin-WNL, urine myoglobin-Abn, urine organic acids-WNL, urine organic acids-Abn, Other (go to next question and explain)					

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	
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Explain all abnormal results checked above					Per Visit	
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Imaging Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
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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	
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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	
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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	
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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	
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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	
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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	
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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	
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Pharmacotherapy	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
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Have glucose paste/gel/tablets been prescribed to this patient for this IBEM?	Missing/unknown data, yes, no				Per Visit	
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If glucose paste/gel/tablets are prescribed for this IBEM, number of times patient has used them since the last outpatient metabolic visit	N/A - not prescribed, 0,1,2,3,4,5,6,7,8,9,10, >10, Missing/unknown data				Per Visit	
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Is L-carnitine prescribed?	Missing/unknown data, yes, no				Per Visit	
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If on L-carnitine, dose prescribed (enter 99999 if N/A)?	(mg/kg/day)				Per Visit	
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If on L-carnitine, route prescribed?	Missing/unknown data, N/A - not prescribed, feeding tube, oral, IV				Per Visit	
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If on L-carnitine, frequency prescribed?	Missing/unknown data, N/A - not prescribed, once/day, twice/day, three times/day, four times/day, only when ill, other				Per Visit	
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Patient/primary caregiver reports L-carnitine 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	
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If L-carnitine is not taken as prescribed.					Per Visit	
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PharmacoTherapy	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
reason given (enter N/A if not)						
Method(s) of payment for L-carnitine, 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
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	
Is cornstarch prescribed?	Missing/unknown data, yes, no				Per Visit	
If on cornstarch, dose prescribed(enter 99999 if N/A or unknown)?	(grams/kg/dose)				Per Visit	
If on cornstarch, route prescribed?	Missing/unknown data, N/A - not prescribed, feeding tube, oral				Per Visit	
If on cornstarch, frequency prescribed?	Missing/unknown data, N/A - not prescribed, once/day, twice/day, three times/day, four times/day, only when ill, other				Per Visit	
Patient/primary caregiver reports cornstarch is taken as prescribed?	Missing/unknown data, N/A - not prescribed, yes - 4-7 days/week, yes - 1 to 3 days/week, yes - only when ill, no (0 days/week)				Per Visit	
If cornstarch is not taken as prescribed, reason given(enter N/A if not applicable)?					Per Visit	
Is patient prescribed a fat restricted diet?	Missing/unknown data, yes, no				Per Visit	
If patient is prescribed a fat restricted diet, prescribed % of total kcal/24 hours from fat (enter 99 if N/A)	(% of total kcal/24 hours from fat)				Per Visit	
If patient is prescribed a fat restricted diet, prescribed fat grams/day (enter 99999 if N/A)	(grams/day)				Per Visit	
If patient is prescribed a fat restricted diet, patient/primary caregiver reports adherence?	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 fat restricted diet is prescribed and followed 0 or 1-3 days/week, reason given for poor adherence (enter N/A if not applicable)					Per Visit	
Specific information given to avoid fasting?	Missing/unknown information, yes, no				Per Visit	
Longest interval permitted between feedings in well state during DAY (in hours)	Missing/unknown information, no fasting restriction given, 1,2,3,4,5,6,7,8,9,10,11,12				Per Visit	
Longest interval permitted between feedings in well state during NIGHT (in hours)	Missing/unknown information, no fasting restriction given, 1,2,3,4,5,6,7,8,9,10,11,12				Per Visit	
Specific information given to avoid	Missing/unknown information, yes, no				Per Visit	

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Nutrition	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
food/formula high in Medium Chain Triglycerides (MCT)?						
Patient uses feeding device (NG tube, G tube, GJ tube)?	Missing/unknown data, yes, no				Per Visit	
If other nutritional supplementation is taken (explain), enter N/A if not applicable.					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	

Last Visit Comment:

Visit Comment: