Ketogenic Diet Pathway

Lila Worden, MD
Beth Chatfield, RDN
Jamie Cubanski, RN

Connecticut Children's

What is a Clinical Pathway?

An evidence-based guideline that decreases unnecessary variation and helps promote safe, effective, and consistent patient care.

Why is this pathway necessary?

This pathway will help standardize care of patients who are starting a ketogenic diet in the hospital, which is a complex process but infrequently done, making it higher risk for safety concerns.

Objectives of Pathway

- Establish medical and safety standards of care for the initiation of the ketogenic and modified ketogenic diet
- Standardize the diet education for the caregivers
- Promote improved tolerance to the ketogenic diet, with fewer side effects
- Educate medical staff on ketogenic diets as treatment for seizures

About Ketogenic Diet Therapy

- Ketogenic diets are high-fat, low-carbohydrate, evidence-based diets, used to help control drug-resistant seizures.
- They are medically-supervised nutrition treatments for seizures, **not** “diets” for weight loss.

- The goal: alter the body’s fuel source from glucose to fat and mimic the effects of fasting.
  - Ketone bodies: the acidic products formed from breakdown of excessive fat.
  - The brain uses the ketones as fuel.
- Underlying mechanisms remain unclear and are most likely parallel and potentially synergistic, including: changes in neurotransmitter systems, metabolic coupling, glycolytic restriction, enhancement of TCA cycle, inhibitory effects of fatty acids, improved cellular bioenergetics and mitochondrial function along with recent research on inflammatory agents.

Classic Ketogenic diet vs. Modified Keto Diet

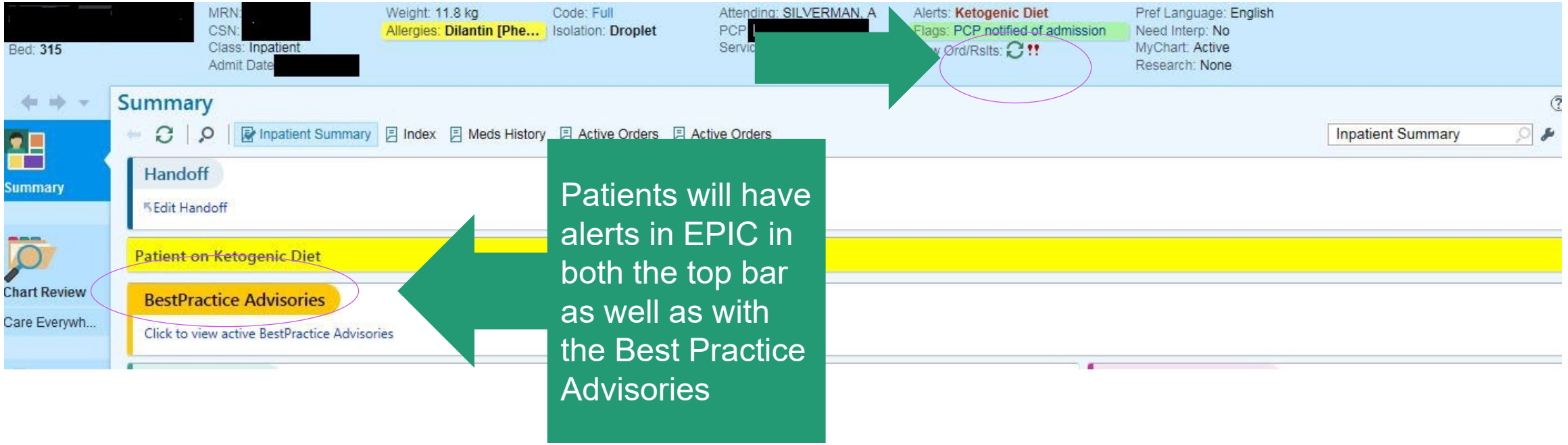
Classic Ketogenic Diet
Calculated “keto ratio” of calories from fat : calories carbs+protein
Every meal is strict ratio, generally 4:1 or 3:1
All food weighed and measured on a gram scale
Calories restricted
Started inpatient for oral eaters

Modified Ketogenic Diet (also called Modified Atkins Diet)
Goal number of net carbs per day, divided up into meals and snacks
Carbohydrates counted by family
Added fat per meal, typically 1-3 Tbs
Calories not restricted
More commercially available products
Usually started as an outpatient

*Inpatient admissions are almost **EXCLUSIVELY** classic ketogenic diet. Modified Ketogenic Diet would have same teaching/monitoring if admitted so there is only 1 pathway now for any ketogenic diet admission.*

Keto Diet alert

- Every child that is actively on the Ketogenic or Modified Ketogenic diet will have a “keto alert” listed in EPIC.



2026 Pathway Updates

- Condensed modified and classic ketogenic diet pathways to one single keto diet pathway
- New guidelines for blood glucose monitoring → now 2x/day
- New monitoring of POC blood ketones 2x/day
  - Since last pathway, we now have ability to check POC ketones
- Addition of blood ketone testing education by RN
  - Nursing documentation to now include blood ketone testing (with how to pull in teaching bullets)
- Update to pre-admission workflow to now include preventative guidelines for acidosis/kidney stones (when appropriate per Neurologist)
- Clinical pathway quality metrics updated

Ketogenic Diet Pathway

This is the Ketogenic Diet Pathway.

We will be reviewing each component in the following slides.

CLINICAL PATHWAY: Ketogenic Diet

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

Inclusion Criteria: Diagnosis of epilepsy, completed pre-admission checklist (Appendix A), approved by ketogenic team
Exclusion Criteria: Fatty acid oxidation defects, porphyria, carnitine deficiency syndromes, pyruvate carboxylase deficiency

Labs

DAY 1:
- POC glucose (glucometer) BID if > 1 year old. If < 1 year old, POC glucose Q4h until glucose > 50 mg/dL for 24 hours, then BID thereafter
- CBC
- Chemistries
- Anti-epileptic medication levels per provider
- POC blood ketone/glucose testing BID and PRN for teaching and/or symptoms
- Urine ketones BID PRN for teaching (as determined by pre-admission keto team)
- I-STAT glucose if signs of hypoglycemia (refer to glucose management)

DAY 2:
- POC glucose (glucometer) BID if > 1 year old. If < 1 year old, POC glucose Q4h until glucose > 50 mg/dL for 24 hours, then BID thereafter
- POC blood ketone/glucose testing BID and PRN for teaching and/or symptoms
- Urine ketones BID PRN for teaching (as determined by pre-admission keto team)
- Review antiepileptic medication levels from day 1

DAY 3-4:
- POC glucose (glucometer) only if poor PO, vomiting, diarrhea *
- Antiepileptic medication levels, PRN

Nutrition*

DAY 1:
- Nutrition assessment with diet history
- Provide 100% maintenance fluids
- Fluid intake per RD schedule: limit fluids to diet decaf drinks, water, or non-herbal decaf tea
- RD calculates keto drink volume:
  - Meal 1: prepared liquid gives 1/3 calories of meal
  - Meal 2: prepared liquid gives 2/3 calories of meal
  - Meal 3: prepared liquid gives 100% calories of meal
  - If <5 yr old or tube feeding: can divide into 5-6 feeds

DAY 2:
Goal: tolerating 75-100% of fluid intake (of allowed fluids)
- Start full ketogenic diet if day 1 diet tolerated
- *If vomiting, lethargic or refusing to eat:*
  - Give 30 mL apple or orange juice (up to 4x/day)
  - Encourage 100% of fruit and vegetables during meals
  - Give fats as tolerated (can cut to ½ the amount)
- *If diarrhea:*
  - Cut the fat in meals to ½ the amount

DAY 3-4:
Goal: tolerating 75-100% of ketogenic diet
- *If vomiting, lethargic or refusing to eat:*
  - Give 30 mL apple or orange juice (up to 4x/day)
  - Encourage 100% of fruit and vegetables during meals
  - Give fats as tolerated (can cut to ½ the amount)
- *If diarrhea:*
  - Cut the fat in meals to ½ the amount

*** Glucose Management:**

If glucose <50 mg/dL and well appearing:
- Give 30 ml apple or orange juice
- Recheck vitals and glucose (glucometer) q1hr until glucose >50 mg/dL

If glucose <50 mg/dL and/or signs/symptoms of hypoglycemia:
- Give 30 mL apple or orange juice immediately
- Recheck vitals and glucose (glucometer) in 30 minutes.
- If glucose remains <50 +/- signs of hypoglycemia: give another 30 mL apple or orange juice
- If glucose still <50 mg/dL after 2nd juice: call MD

Nursing Care

- Insert PIV if needed

Vitals:
- Day 1-2: q4hr, if stable
- Day 3-4: q8hr while awake, if stable

Measurement:
- Day 1: height, weight, head circumference
- Day 2-4: weight daily

Assess and record, throughout admission:
- Mental status
- Seizure activity
- Symptoms of hypoglycemia

Education

DAY 1:
RN education goals/responsibilities:
- Parents taught and demonstrate POC urine ketone testing **OR** POC blood ketone/glucose testing

RD education goals/responsibilities:
Parents demonstrate understanding of:
- Rationale for ketogenic diet
- Potential complications and outcomes of diet
- Maintenance of ketosis
- Fluid schedule and keto drinks in hospital

DAY 2:
RN education goals/responsibilities:
- Reinforce teaching of POC urine ketone testing **OR** POC blood ketone/glucose testing

RD education goals/responsibilities:
Parents are able to:
- Repeat signs and symptoms of dehydration and hypoglycemia
- Describe exchange lists and exchange patterns
- Explain label reading and grocery lists
- Describe prevention and treatment of constipation

DAY 3:
RN education goals/responsibilities:
- Teach/demonstrate administering glycerin suppository PRN
- Reinforce teaching of POC urine ketone testing **OR** POC blood ketone/glucose testing

RD education goals/responsibilities:
- Parents accurately state child's total fluid amount, types of fluid allowed
- Parents verbalize child's calorie levels are set at 75% RDA, adjusted for age/height/BMI/activity
- Parents demonstrate keto diet preparation, including use of scale for foods and fluids, vitamin and mineral supplementation schedule and products
- Give information on OTC meds and hygiene products (i.e. carbohydrate content)
- Review sick day guide and problem solving

DAY 4:
RN education goals/responsibilities:
- Prior to discharge: Parents administer glycerin suppository if no bowel movement since admission

RD education goals/responsibilities:
- Parents verbalize plan to maintain tolerance of the keto diet plan

Other

Safety
(throughout admission):
- Maintain seizure safety sheet
- Net bed as needed
- On day 1: transport equipment (wagon, stroller, wheelchair)

Activity
(throughout admission):
- Developmentally appropriate activities as tolerated

Support
(throughout admission):
- Child and Family Support for diversional activities during procedures

Discharge Criteria:
Parents demonstrate: daily record keeping; meal plans and meal exchanges; appropriate non-carbohydrate meds/supplements/products; problem solving (e.g., ketosis illness, cheating with non-diet foods); phone # for neurology
Appointments: with dietitian at 2 and 4 weeks, then per outpatient pathway; neurology appointment within 4 weeks, at 6 months, then every 4-6 months as needed
Labs/Medications: 1st set of keto profile ordered; prescriptions for medications and supplements provided;
Dietitian approves vitamin and calcium supplement and initiation schedule to parents

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

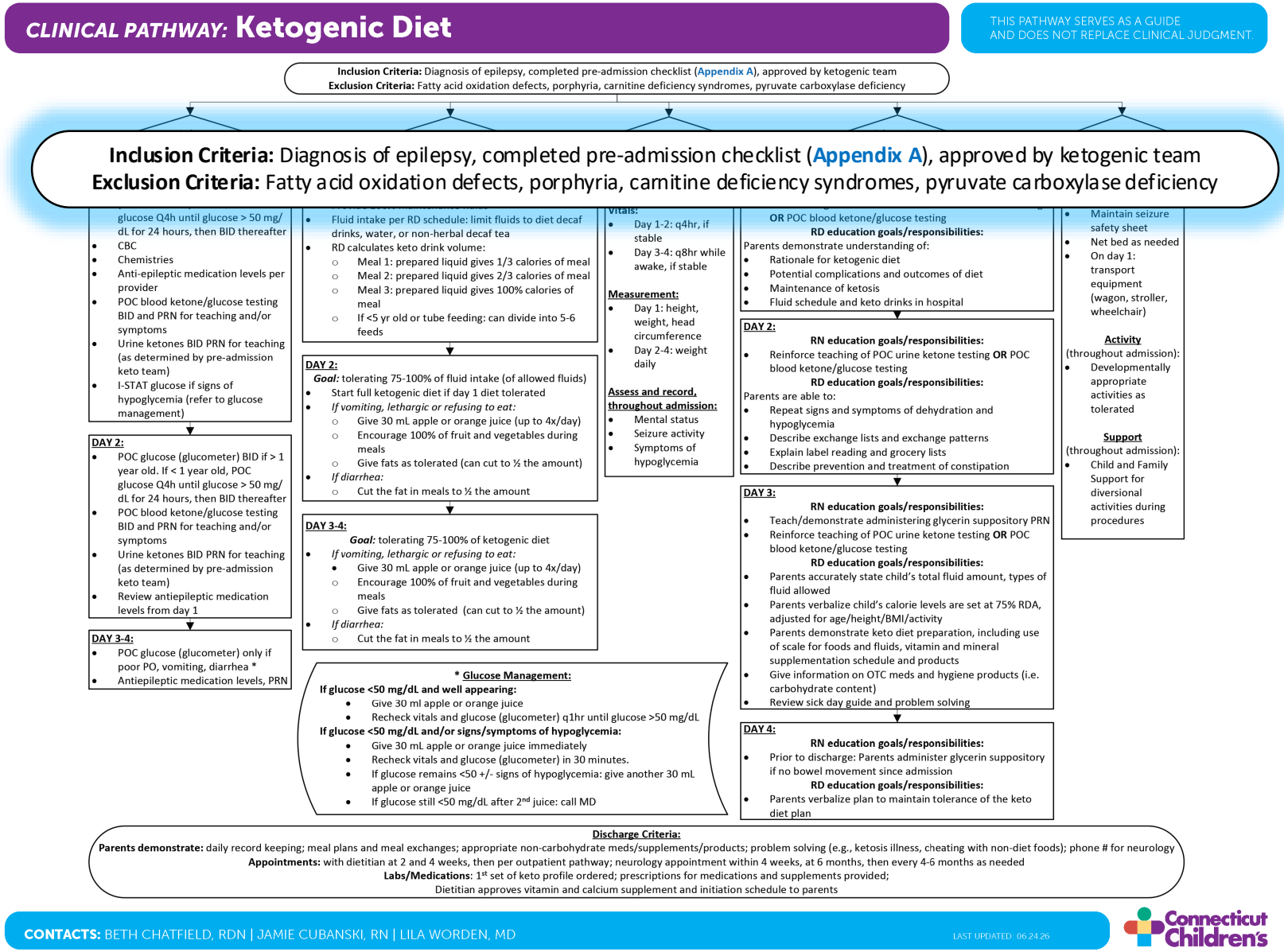
LAST UPDATED: 06.24.26

Connecticut Children's

Inclusion/Exclusion criteria

The pathways is used for patients with a diagnosis of epilepsy that have already completed the pre-admission check list and are approved by the outpatient ketogenic diet team.

Appendix A is the pre-admission checklist. See next slides.



CLINICAL PATHWAY: Ketogenic Diet
Appendix A: Pre-Admission Checklist:

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

One month prior to admission:

MD Responsibilities – Required Work-Up:
- ❑ EEG if >1 year since last study.
- ❑ EKG to be completed prior to admission
- ❑ Serum amino acids, urine organic acids, keto profile, carnitine profile, acylcarnitine profile
- ❑ Height, weight; head circumference for patients ≤3 years old
- ❑ Evaluate need for preventative medication if concurrent zonisamide or topiramate, or if history of kidney stone

Dietitian and Keto RN Responsibilities:
- ❑ Keto screen profile completed by Ketogenic Neurology team in Epic

Registration Responsibilities:
- ❑ Neurology RN to follow CT Children's admission guidelines
- ❑ Schedule date/time for admission to initiate ketogenic diet

One week prior to admission:

MD Responsibilities:
- ❑ Review current anti-convulsant medications
- ❑ Parent(s) verbalize understanding of change to low carbohydrate anti-convulsant regimen for child
- ❑ Convert all medications to low carbohydrate forms
- ❑ Provide weaning schedule for barbiturates and benzodiazepines, if necessary
- ❑ Initiate kidney stone preventative medication if needed: Bicitra (preferred manufacturer Methods or PAI), Effer K or UrocitK. Dosing 1 -2 mEq/kg/day if low risk or 2-3 mEq/kg/day if high risk
- ❑ Parent(s) verbalize understanding of potential need to decrease sedating medications, if necessary

Dietitian and Keto RN Responsibilities:
- ❑ Inform inpatient staff of new ketogenic admission and provide all diet information and menus
- ❑ Parent(s) instructed on low carbohydrate beverages
- ❑ Discuss family support for inpatient stay
- ❑ Parents agree to inpatient ketogenic diet teaching

One day prior to admission:

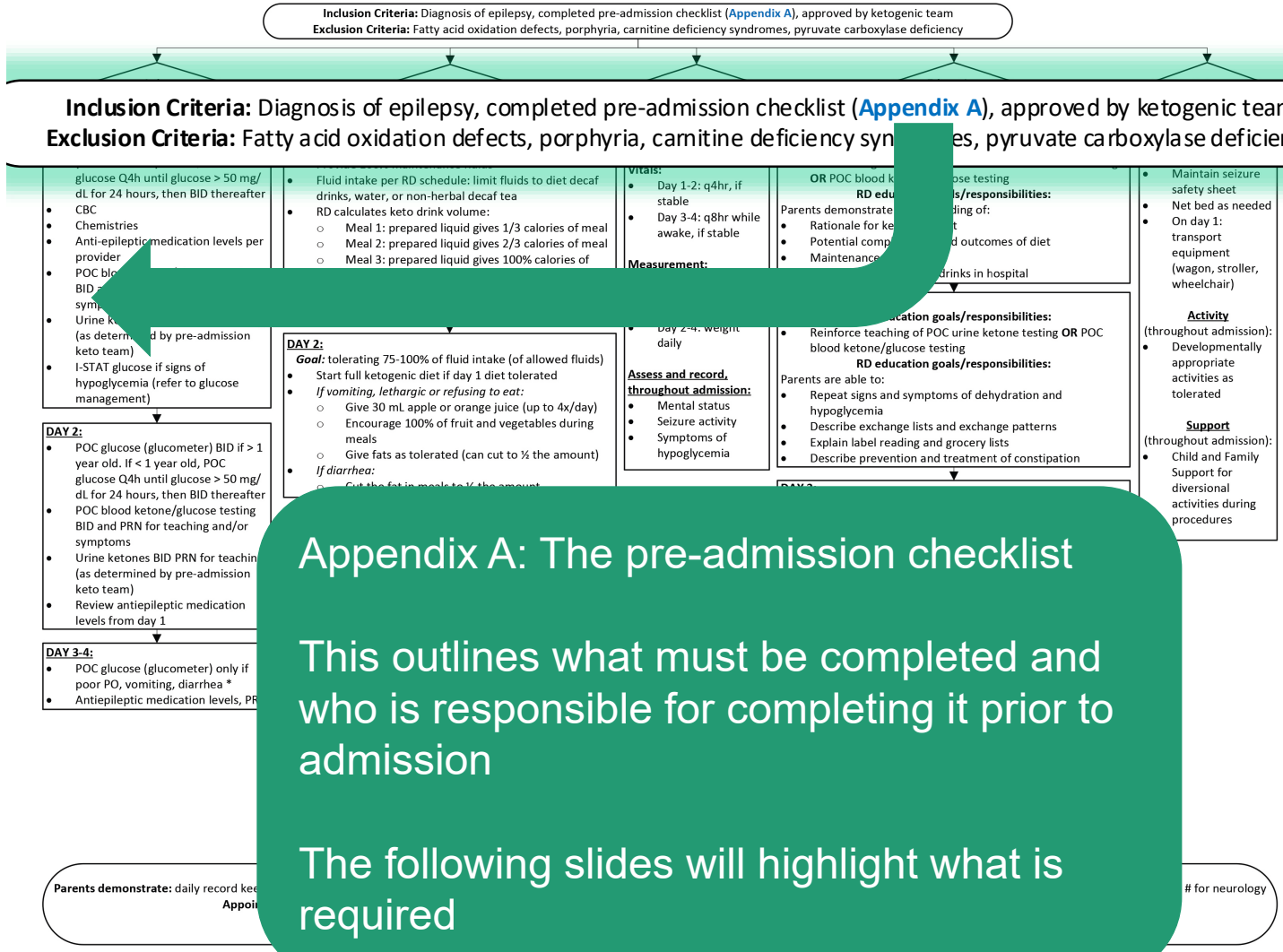
Dietitian and Keto RN Responsibilities:
- ❑ Dietitian/Keto RN to update Epic problem list to include ketogenic diet
- ❑ Parent(s) restrict all solid foods after evening meal
- ❑ Parent(s) limit fluids to ketogenic friendly, zero calorie, decaf soda, water, or non-herbal decaf tea after evening meal
- ❑ If patient is tube fed: parent(s) to follow instructions by dietitian when to stop feeds and give water
- ❑ Parent(s) give first dose of admission day anti-convulsants in unsweetened applesauce at home, sips of water or via G tube
- ❑ Parent(s) bring Ketogenic scale, appropriate beverages and Ketostix for first day of admission
- ❑ Parents verbalize understanding that child must be afebrile and generally healthy prior to admission

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

CLINICAL PATHWAY: Ketogenic Diet

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.



Appendix A: The pre-admission checklist

This outlines what must be completed and who is responsible for completing it prior to admission

The following slides will highlight what is required

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

CLINICAL PATHWAY:
Ketogenic Diet
Appendix A: Pre-Admission Checklist:

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

CLINICAL PATHWAY: Ketogenic Diet

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

Inclusion Criteria: Diagnosis of epilepsy, completed pre-admission checklist (Appendix A), approved by ketogenic team
Exclusion Criteria: Fatty acid oxidation defects, porphyria, carnitine deficiency syndromes, pyruvate carboxylase deficiency

One month prior to admission:

MD Responsibilities – Required Work-Up:
- ❑ EEG if >1 year since last study.
- ❑ EKG to be completed prior to admission
- ❑ Serum amino acids, urine organic acids, keto profile, carnitine profile, acylcarnitine profile
- ❑ Height, weight; head circumference for patients ≤3 years old
- ❑ Evaluate need for preventative medication if concurrent zonisamide or topiramate, or if history of kidney stone

Dietitian and Keto RN Responsibilities:
- ❑ Keto screen profile completed by Ketogenic Neurology team in Epic

Registration Responsibilities:
- ❑ Neurology RN to follow CT Children's admission guidelines
- ❑ Schedule date/time for admission to initiate ketogenic diet

MD
- ❑
- ❑
- ❑
- ❑
- ❑

Diet
- ❑

Reg
- ❑
- ❑

MD
- ❑
- ❑
- ❑
- ❑
- ❑

Initiate kidney stone preventative medication if needed: Bicitra (preferred manufacturer Methods or PAI), Effer K or UrocitK. Dosing 1 -2 mEq/kg/day if low risk or 2-3 mEq/kg/day if high risk
- ❑ Parent(s) verbalize understanding of potential need to decrease sedating medications, if necessary

Dietitian and Keto RN Responsibilities:
- ❑ Inform inpatient staff of new ketogenic admission and provide all diet information and menus
- ❑ Parent(s) instructed on low carbohydrate beverages
- ❑ Discuss family support for inpatient stay
- ❑ Parents agree to inpatient ketogenic diet teaching

One day prior to admission:

Dietitian and Keto RN Responsibilities:
- ❑ Dietitian/Keto RN to update Epic problem list to include ketogenic diet
- ❑ Parent(s) restrict all solid foods after evening meal
- ❑ Parent(s) limit fluids to ketogenic friendly, zero calorie, decaf soda, water, or non-herbal decaf tea after evening meal
- ❑ If patient is tube fed: parent(s) to follow instructions by dietitian when to stop feeds and give water
- ❑ Parent(s) give first dose of admission day anti-convulsants in unsweetened applesauce at home, sips of water or via G tube
- ❑ Parent(s) bring Ketogenic scale, appropriate beverages and Ketostix for first day of admission
- ❑ Parents verbalize understanding that child must be afebrile and generally healthy prior to admission

Nutrition*

…ment with diet history
…aintenance fluids
…RD schedule: limit fluids to diet decaf
…r non-herbal decaf tea
…to drink volume:
…epared liquid gives 1/3 calories of meal
…epared liquid gives 2/3 calories of meal
…epared liquid gives 100% calories of
…l or tube feeding: can divide into 5-6

…100% of fluid intake (of allowed fluids)
…nic diet if day 1 diet tolerated
…argic or refusing to eat:
…L apple or orange juice (up to 4x/day)
…100% of fruit and vegetables during meals
- Give fats as tolerated (can cut to ½ the amount)

If diarrhea:
- …Cut the fat in meals to ¼ the amount

DAY 2:
- POC glucose (glucometer) BID if > 1 year old. If < 1 year old, POC glucose Q4h until glucose > 50 mg/dL for 24 hours, then BID thereafter
- POC blood ketone/glucose testing BID and PRN for teaching and/or symptoms
- Urine ketones BID PRN for teachin… (as determined by pre-admission keto team)
- Review antiepileptic medication levels from day 1

DAY 3-4:
- POC glucose (glucometer) only if poor PO, vomiting, diarrhea *
- Antiepileptic medication levels, PR…

Nursing Care
- Insert PIV if needed

Vitals:
- Day 1-2: q4hr, if stable
- Day 3-4: q8hr while awake, if stable

Measurement:
- Day 1: height, weight, head circumference
- Day 2-4: weight daily

Assess and record, throughout admission:
- Mental status
- Seizure activity
- Symptoms of hypoglycemia

Education

DAY 1:
RN education goals/responsibilities:
- Parents taught and demonstrate POC urine ketone testing **OR** POC blood ketone/glucose testing

RD education goals/responsibilities:
Parents demonstrate understanding of:
- Rationale for ketogenic diet
- Potential complications and outcomes of diet
- Maintenance of ketosis
- Fluid schedule and keto drinks in hospital

DAY 2:
RN education goals/responsibilities:
- Reinforce teaching of POC urine ketone testing **OR** POC blood ketone/glucose testing

RD education goals/responsibilities:
Parents are able to:
- Repeat signs and symptoms of dehydration and hypoglycemia
- Describe exchange lists and exchange patterns
- Explain label reading and grocery lists
- Describe prevention and treatment of constipation

Other

Safety
(throughout admission):
- Maintain seizure safety sheet
- Net bed as needed
- On day 1: transport equipment (wagon, stroller, wheelchair)

Activity
(throughout admission):
- Developmentally appropriate activities as tolerated

Support
(throughout admission):
- Child and Family Support for diversional activities during procedures

Parents demonstrate: daily record kee…
Appoint… …# for neurology

Appendix A: The pre-admission checklist

One month prior to admission:

New MD Responsibilities 2026:
Evaluate need for preventative medication if concurrent zonisamide or topiramate, or if history of kidney stone

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

Connecticut Children's

CLINICAL PATHWAY:
Ketogenic Diet
Appendix A: Pre-Admission Checklist:

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

One month prior to admission:

MD Responsibilities – Required Work-Up:
- ❑ EEG if >1 year since last study.
- ❑ EKG to be completed prior to admission
- ❑ Serum amino acids, urine organic acids, keto profile, carnitine profile, acylcarnitine profile
- ❑ Height, weight; head circumference for patients ≤3 years old
- ❑ Evaluate need for preventative medication if concurrent zonisamide or topiramate, or if history of kidney stone

One week prior to admission:

MD Responsibilities:
- ❑ Review current anti-convulsant medications
- ❑ Parent(s) verbalize understanding of change to low carbohydrate anti-convulsant regimen for child
- ❑ Convert all medications to low carbohydrate forms
- ❑ Provide weaning schedule for barbiturates and benzodiazepines, if necessary
- ❑ Initiate kidney stone preventative medication if needed: Bicitra (preferred manufacturer Methods or PAI), Effer K or UrocitK. Dosing 1 -2 mEq/kg/day if low risk or 2-3 mEq/kg/day if high risk
- ❑ Parent(s) verbalize understanding of potential need to decrease sedating medications, if necessary

Dietitian and Keto RN Responsibilities:
- ❑ Inform inpatient staff of new ketogenic admission and provide all diet information and menus
- ❑ Parent(s) instructed on low carbohydrate beverages
- ❑ Discuss family support for inpatient stay
- ❑ Parents agree to inpatient ketogenic diet teaching

One day prior to admission:

Dietitian and Keto RN Responsibilities:
- ❑ Dietitian/Keto RN to update Epic problem list to include ketogenic diet
- ❑ Parent(s) restrict all solid foods after evening meal
- ❑ Parent(s) limit fluids to ketogenic friendly, zero calorie, decaf soda, water, or non-herbal decaf tea after evening meal
- ❑ If patient is tube fed: parent(s) to follow instructions by dietitian when to stop feeds and give water
- ❑ Parent(s) give first dose of admission day anti-convulsants in unsweetened applesauce at home, sips of water or via G tube
- ❑ Parent(s) bring Ketogenic scale, appropriate beverages and Ketostix for first day of admission
- ❑ Parents verbalize understanding that child must be afebrile and generally healthy prior to admission

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

Connecticut Children's

CLINICAL PATHWAY: **Ketogenic Diet**

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

Inclusion Criteria: Diagnosis of epilepsy, completed pre-admission checklist (Appendix A), approved by ketogenic team
Exclusion Criteria: Fatty acid oxidation defects, porphyria, carnitine deficiency syndromes, pyruvate carboxylase deficiency

Labs

DAY 1:
- POC glucose (glucometer) BID if > 1
- levels from day 1

DAY 3-4:
- POC glucose (glucometer) only if poor PO, vomiting, diarrhea *
- Antiepileptic medication levels, PRN

Nutrition*

DAY 1:
- Nutrition assessment with diet history
- s to diet decaf
- calories
- calorie
- % cal
- vide
- allo
- erat
- up t
- tabl
- ½ the
- unt
- nic c
- up t
- tabl
- Give fats as tolerated (can cut to ½ th
- *If diarrhea:*
  - Cut the fat in meals to ½ the amount

*** Glucose Manag**
If glucose <50 mg/dL and well appearing:
- Give 30 ml apple or orange juice
- Recheck vitals and glucose (glucom

If glucose <50 mg/dL and/or signs/symptoms
- Give 30 mL apple or orange juice im
- Recheck vitals and glucose (glucome
- If glucose remains <50 +/- signs of hyp apple or orange juice
- If glucose still <50 mg/dL after 2nd juice: call

Nursing Care
- Insert PIV if needed

Vitals:
-

Education

DAY 1:

RN education goals/responsibilities:
- Parents taught and demonstrate POC urine ketone testing **OR** POC blood ketone/glucose testing

Other

Safety (throughout admission):
- Maintain seizure

Discharge Criteria:
Parents demonstrate: daily record keeping; meal plans and meal exchanges; appropriate non-carbohydrate meds/supplements/products; problem solving (e.g., ketosis illness, cheating with non-diet foods); phone # for neurology
Appointments: with dietitian at 2 and 4 weeks, then per outpatient pathway; neurology appointment within 4 weeks, at 6 months, then every 4-6 months as needed
Labs/Medications: 1st set of keto profile ordered; prescriptions for medications and supplements provided;
Dietitian approves vitamin and calcium supplement and initiation schedule to parents

Appendix A: The pre-admission checklist

One week prior to admission

New MD Responsibilities:
Initiate kidney stone preventative medication if needed: Bicitra (Preferred manufacturer Methods or PAI), Effer K or UrocitK. Dosing 1 -2 mEq/kg/day if low risk or 2-3 mEq/kg/day if high risk

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

Connecticut Children's

CLINICAL PATHWAY:
Ketogenic Diet
Appendix A: Pre-Admission Checklist:

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

One month prior to admission:

MD Responsibilities – Required Work-Up:
- ❑ EEG if >1 year since last study.
- ❑ EKG to be completed prior to admission
- ❑ Serum amino acids, urine organic acids, keto profile, carnitine profile, acylcarnitine profile
- ❑ Height, weight; head circumference for patients ≤3 years old
- ❑ Evaluate need for preventative medication if concurrent zonisamide or topiramate, or if history of kidney stone

Dietitian and Keto RN Responsibilities:
- ❑ Keto screen profile completed by Ketogenic Neurology team in Epic

Registration Responsibilities:
- ❑ Neurology RN to follow CT Children's admission guidelines
- ❑ Schedule date/time for admission to initiate ketogenic diet

One week prior to admission:

MD Responsibilities:
- ❑ Review current anti-convulsant medications
- ❑ Parent(s) verbalize understanding of change to low carbohydrate anti-convulsant regimen for child
- ❑ Convert all medications to low carbohydrate forms
- ❑ Provide weaning schedule for barbiturates and benzodiazepines, if necessary
- ❑ Initiate kidney stone preventative medication if needed: Bicitra (preferred manufacturer Methods or PAI), Effer K or UrocitK. Dosing 1 -2 mEq/kg/day if low risk or 2-3 mEq/kg/day if high risk
- ❑ Parent(s) verbalize understanding of potential need to decrease sedating medications, if necessary

Dietitian and Keto RN Responsibilities:
- ❑ Inform inpatient staff of new ketogenic admission and provide all diet information and menus
- ❑ Parent(s) instructed on low carbohydrate beverages
- ❑ Discuss family support for inpatient stay
- ❑ Parents agree to inpatient ketogenic diet teaching

One day prior to admission:

Dietitian and Keto RN Responsibilities:
- ❑ Dietitian/Keto RN to update Epic problem list to include ketogenic diet
- ❑ Parent(s) restrict all solid foods after evening meal
- ❑ Parent(s) limit fluids to ketogenic friendly, zero calorie, decaf soda, water, or non-herbal decaf tea after evening meal
- ❑ If patient is tube fed: parent(s) to follow instructions by dietitian when to stop feeds and give water
- ❑ Parent(s) give first dose of admission day anti-convulsants in unsweetened applesauce at home, sips of water or via G tube
- ❑ Parent(s) bring Ketogenic scale, appropriate beverages and Ketostix for first day of admission
- ❑ Parents verbalize understanding that child must be afebrile and generally healthy prior to admission

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

Connecticut Children's

CLINICAL PATHWAY: Ketogenic Diet

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

Inclusion Criteria: Diagnosis of epilepsy, completed pre-admission checklist (Appendix A), approved by ketogenic team

Appendix A: The pre-admission checklist

One day prior to admission

Neurology RN and Ketogenic team maintain Ketogenic alerts in the Epic problem list.

Labs

DAY 1:
- POC glucose (glucometer) BID if > 1 year old. If < 1 year old, POC glucose Q4h until glucose > 50 mg/dL for 24 hours, then BID thereafter
- CBC
- Chemistries
- Anti-epileptic medication levels per provider
- POC blood ketone/glucose testing BID and PRN for teaching and/or symptoms
- Urine ketones BID PRN for teaching (as determined by pre-admission keto team)
- I-STAT glucose if signs of hypoglycemia (refer to glucose management)

DAY 2:
- POC glucose (glucometer) BID if > 1 year old. If < 1 year old, POC glucose Q4h until glucose > 50 mg/dL for 24 hours, then BID thereafter
- POC blood ketone/glucose testing BID and PRN for teaching and/or symptoms
- Urine ketones BID PRN for teaching

- Start full ketogenic diet if day 1 diet tolerated
- *If vomiting, lethargic or refusing to eat:*
  - Give 30 mL apple or orange juice (up to 4x/day)
  - Encourage 100% of fruit and vegetables during meals
  - Give fats as tolerated (can cut to ½ the amount)
- *If diarrhea:*
  - Cut the fat in meals to ½ the amount

DAY 3-4:
Goal: tolerating 75-100% of ketogenic diet
- *If vomiting, lethargic or refusing to eat:*

Assess and record, throughout admission:
- Mental status
- Seizure activity
- Symptoms of hypoglycemia

Parents are able to:
- Repeat signs and symptoms of dehydration and hypoglycemia
- Describe exchange lists and exchange patterns
- Explain label reading and grocery lists
- Describe prevention and treatment of constipation

DAY 3:

RN education goals/responsibilities:
- Teach/demonstrate administering glycerin suppository PRN
- Reinforce teaching of POC urine ketone testing **OR** POC blood ketone/glucose testing

Other

Safety (throughout admission):
- Maintain seizure safety sheet
- Bed as needed
- Day 1:
  - Transport
  - Equipment (carrier, stroller, wheelchair)

Activity (throughout admission):
- Developmentally appropriate activities as tolerated

Support (throughout admission):
- Child and Family Support for diversional activities during procedures

Discharge Criteria:
Parents demonstrate: daily record keeping; meal plans and meal exchanges; appropriate non-carbohydrate meds/supplements/products; pr
Appointments: with dietitian at 2 and 4 weeks, then per outpatient pathway; neurology appointment within 4
Labs/Medications: 1st set of keto profile ordered; prescriptions for medications a
Dietitian approves vitamin and calcium supplement and initiation sche

for neurology

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

©2019 Connecticut Children's Medical Center. All rights reserved.

Connecticut Children's

Once the pre-admission checklist is complete and the patient is approved to begin the ketogenic diet, he/she will be admitted to Connecticut Children's under the Epilepsy Monitor Unit (EMU) service.

When "admit to" order is placed, notification page alerts are sent to the following: Registered Dietitian inpatient consult pager, Neurology RN pager, & Pharmacy pager.

CLINICAL PATHWAY: Ketogenic Diet

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

Inclusion Criteria: Diagnosis of epilepsy, completed pre-admission checklist (Appendix A), approved by ketogenic team
Exclusion Criteria: Fatty acid oxidation defects, porphyria, carnitine deficiency syndromes, pyruvate carboxylase deficiency

Inclusion Criteria: Diagnosis of epilepsy, completed pre-admission checklist (Appendix A), approved by ketogenic team
Exclusion Criteria: Fatty acid oxidation defects, porphyria, carnitine deficiency syndromes, pyruvate carboxylase deficiency

- glucose Q4h until glucose > 50 mg/
for 24 hours, then BID thereafter
istries
epileptic medication levels per
der
lood ketone/glucose testing
nd PRN for teaching and/or
toms
ketones BID PRN for teaching
termined by pre-admission
eam)
T glucose if signs of
glycemia (refer to glucose
gement)

- glucose (glucometer) BID if > 1
old. If < 1 year old, POC
se Q4h until glucose > 50 mg/
or 24 hours, then BID thereafter
- POC blood ketone/glucose testing BID and PRN for teaching and/or symptoms
- Urine ketones BID PRN for teaching (as determined by pre-admission keto team)
- Review antiepileptic medication levels from day 1

DAY 3-4:
- POC glucose (glucometer) only if poor PO, vomiting, diarrhea *
- Antiepileptic medication levels, PRN

- Fluid intake per RD schedule: limit fluids to diet decaf drinks, water, or non-herbal decaf tea
- RD calculates keto drink volume:
  - Meal 1: prepared liquid gives 1/3 calories of meal
  - Meal 2: prepared liquid gives 2/3 calories of meal
  - Meal 3: prepared liquid gives 100% calories of meal
  - If <5 yr old or tube feeding: can divide into 5-6 feeds

DAY 2:
Goal: tolerating 75-100% of fluid intake (of allowed fluids)
- Start full ketogenic diet if day 1 diet tolerated
- *If vomiting, lethargic or refusing to eat:*
  - Give 30 mL apple or orange juice (up to 4x/day)
  - Encourage 100% of fruit and vegetables during meals
  - Give fats as tolerated (can cut to ½ the amount)
- *If diarrhea:*
  - Cut the fat in meals to ½ the amount

DAY 3-4:
Goal: tolerating 75-100% of ketogenic diet
- *If vomiting, lethargic or refusing to eat:*
  - Give 30 mL apple or orange juice (up to 4x/day)
  - Encourage 100% of fruit and vegetables during meals
  - Give fats as tolerated (can cut to ½ the amount)
- *If diarrhea:*
  - Cut the fat in meals to ½ the amount

*** Glucose Management:**
If glucose <50 mg/dL and well appearing:
- Give 30 ml apple or orange juice
- Recheck vitals and glucose (glucometer) q1hr until glucose >50 mg/dL

If glucose <50 mg/dL and/or signs/symptoms of hypoglycemia:
- Give 30 mL apple or orange juice immediately
- Recheck vitals and glucose (glucometer) in 30 minutes.
- If glucose remains <50 +/- signs of hypoglycemia: give another 30 mL apple or orange juice
- If glucose still <50 mg/dL after 2nd juice: call MD

Vitals:
- Day 1-2: q4hr, if stable
- Day 3-4: q8hr while awake, if stable

Measurement:
- Day 1: height, weight, head circumference
- Day 2-4: weight daily

Assess and record, throughout admission:
- Mental status
- Seizure activity
- Symptoms of hypoglycemia

OR POC blood ketone/glucose testing
RD education goals/responsibilities:
Parents demonstrate understanding of:
- Rationale for ketogenic diet
- Potential complications and outcomes of diet
- Maintenance of ketosis
- Fluid schedule and keto drinks in hospital

DAY 2:
RN education goals/responsibilities:
- Reinforce teaching of POC urine ketone testing **OR** POC blood ketone/glucose testing

RD education goals/responsibilities:
Parents are able to:
- Repeat signs and symptoms of dehydration and hypoglycemia
- Describe exchange lists and exchange patterns
- Explain label reading and grocery lists
- Describe prevention and treatment of constipation

DAY 3:
RN education goals/responsibilities:
- Teach/demonstrate administering glycerin suppository PRN
- Reinforce teaching of POC urine ketone testing **OR** POC blood ketone/glucose testing

RD education goals/responsibilities:
- Parents accurately state child's total fluid amount, types of fluid allowed
- Parents verbalize child's calorie levels are set at 75% RDA, adjusted for age/height/BMI/activity
- Parents demonstrate keto diet preparation, including use of scale for foods and fluids, vitamin and mineral supplementation schedule and products
- Give information on OTC meds and hygiene products (i.e. carbohydrate content)
- Review sick day guide and problem solving

DAY 4:
RN education goals/responsibilities:
- Prior to discharge: Parents administer glycerin suppository if no bowel movement since admission

RD education goals/responsibilities:
- Parents verbalize plan to maintain tolerance of the keto diet plan

- Maintain seizure safety sheet
- Net bed as needed
- On day 1: transport equipment (wagon, stroller, wheelchair)

Activity
(throughout admission):
- Developmentally appropriate activities as tolerated

Support
(throughout admission):
- Child and Family Support for diversional activities during procedures

Discharge Criteria:
Parents demonstrate: daily record keeping; meal plans and meal exchanges; appropriate non-carbohydrate meds/supplements/products; problem solving (e.g., ketosis illness, cheating with non-diet foods); phone # for neurology
Appointments: with dietitian at 2 and 4 weeks, then per outpatient pathway; neurology appointment within 4 weeks, at 6 months, then every 4-6 months as needed
Labs/Medications: 1st set of keto profile ordered; prescriptions for medications and supplements provided;
Dietitian approves vitamin and calcium supplement and initiation schedule to parents

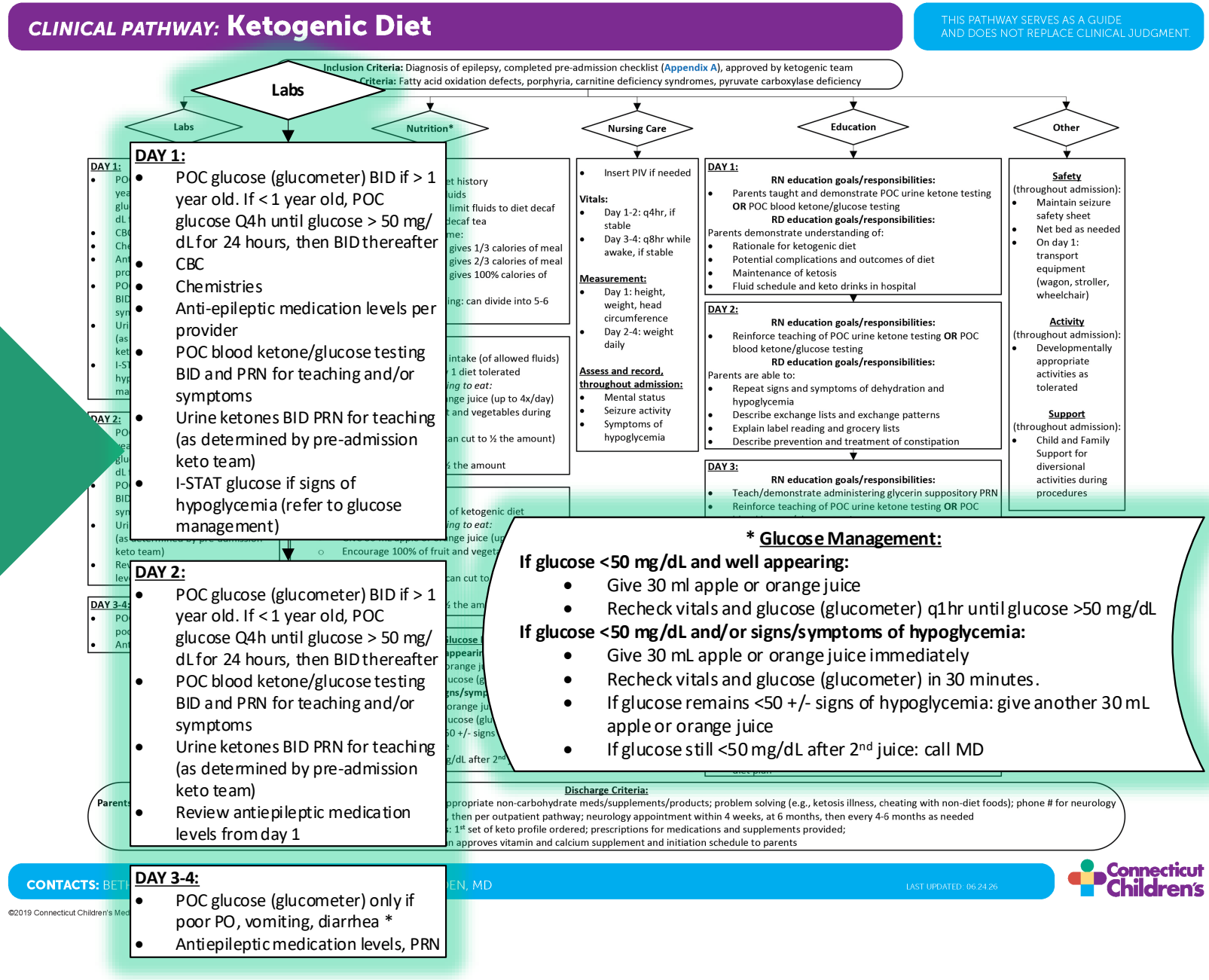
CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

LAST UPDATED: 06.24.26

Labs

Glucose and electrolytes should be monitored closely.

Ketogenic diet risks include hypoglycemia and acidosis.

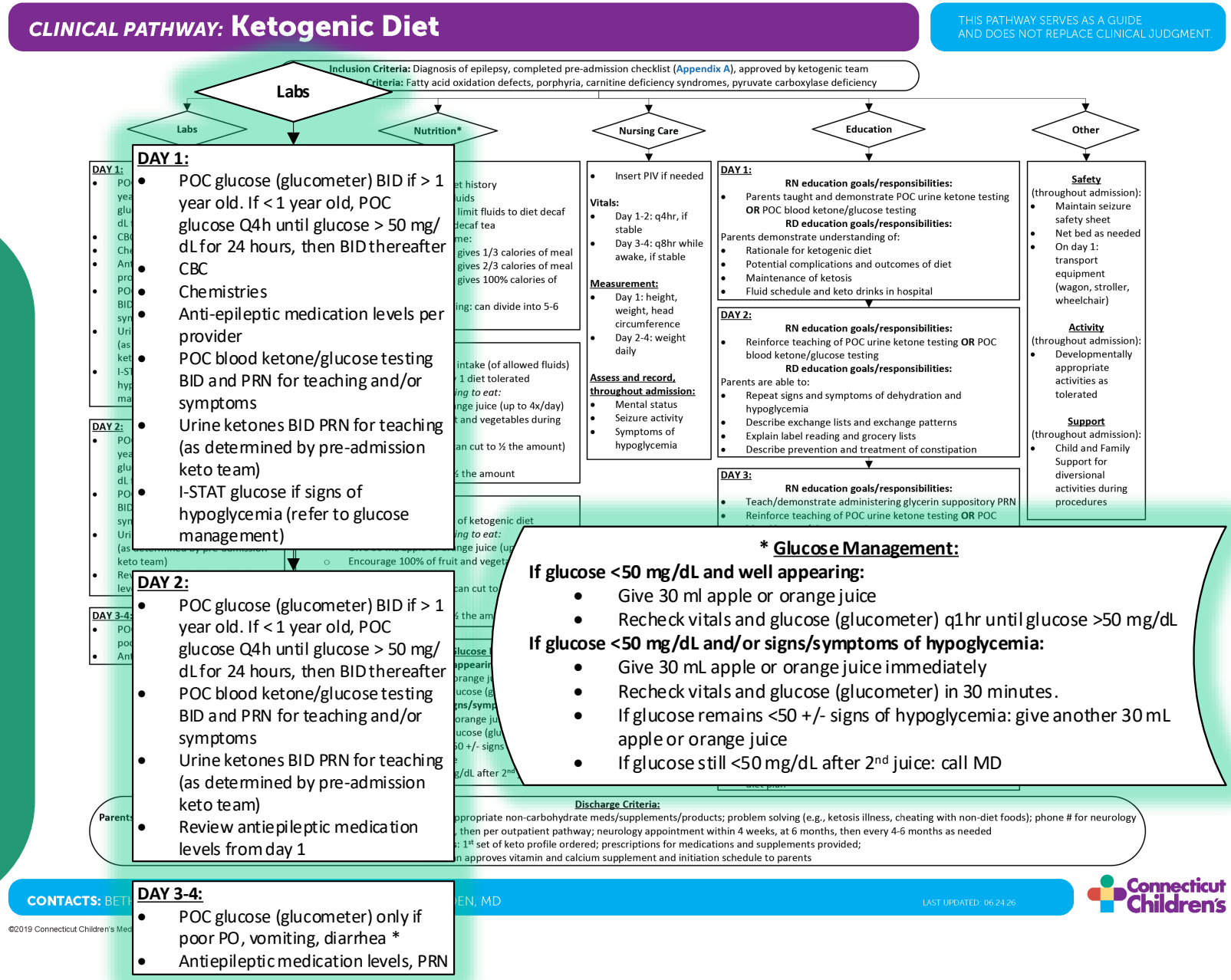


Labs

For patients that are over 1 year of age:

- Check **fingerstick POC blood glucose BID** and **fingerstick POC ketones BID** every day
- Follow protocol for glucose management

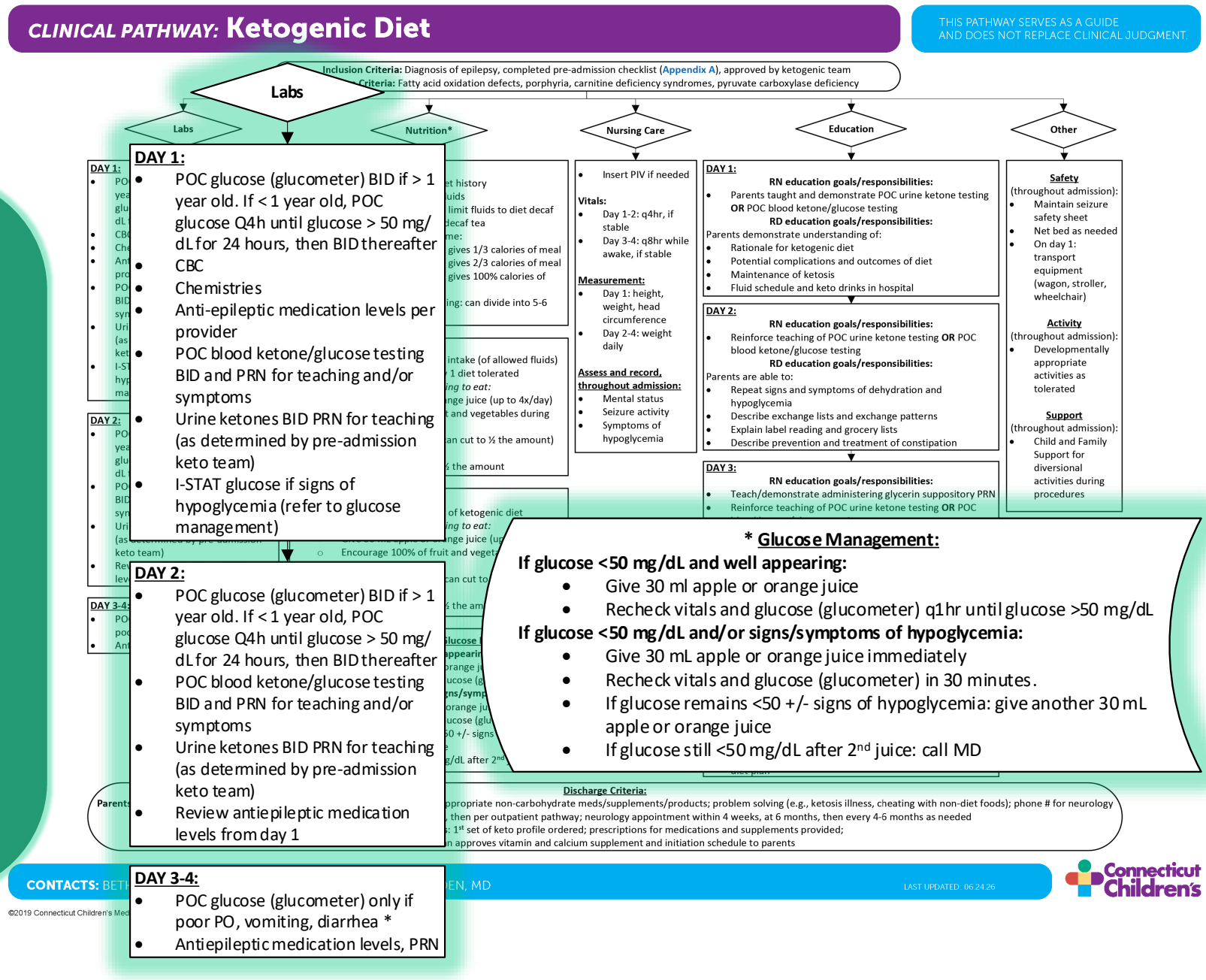
- Urine ketone testing is still performed BID PRN for teaching purposes if family will be using urine ketone monitoring at home (determined by pre-admission keto team)



Labs

There are special blood glucose guidelines for <u>infants</u> (patients 1 year old or younger) as these patients are higher risk for hypoglycemia:

- Check a POC fingerstick glucose every 4 hours until blood sugar is greater than 50 for 24 hours, then change to BID thereafter
- Follow protocol for glucose management (same as for an older child)
- Additionally check POC fingerstick ketones BID

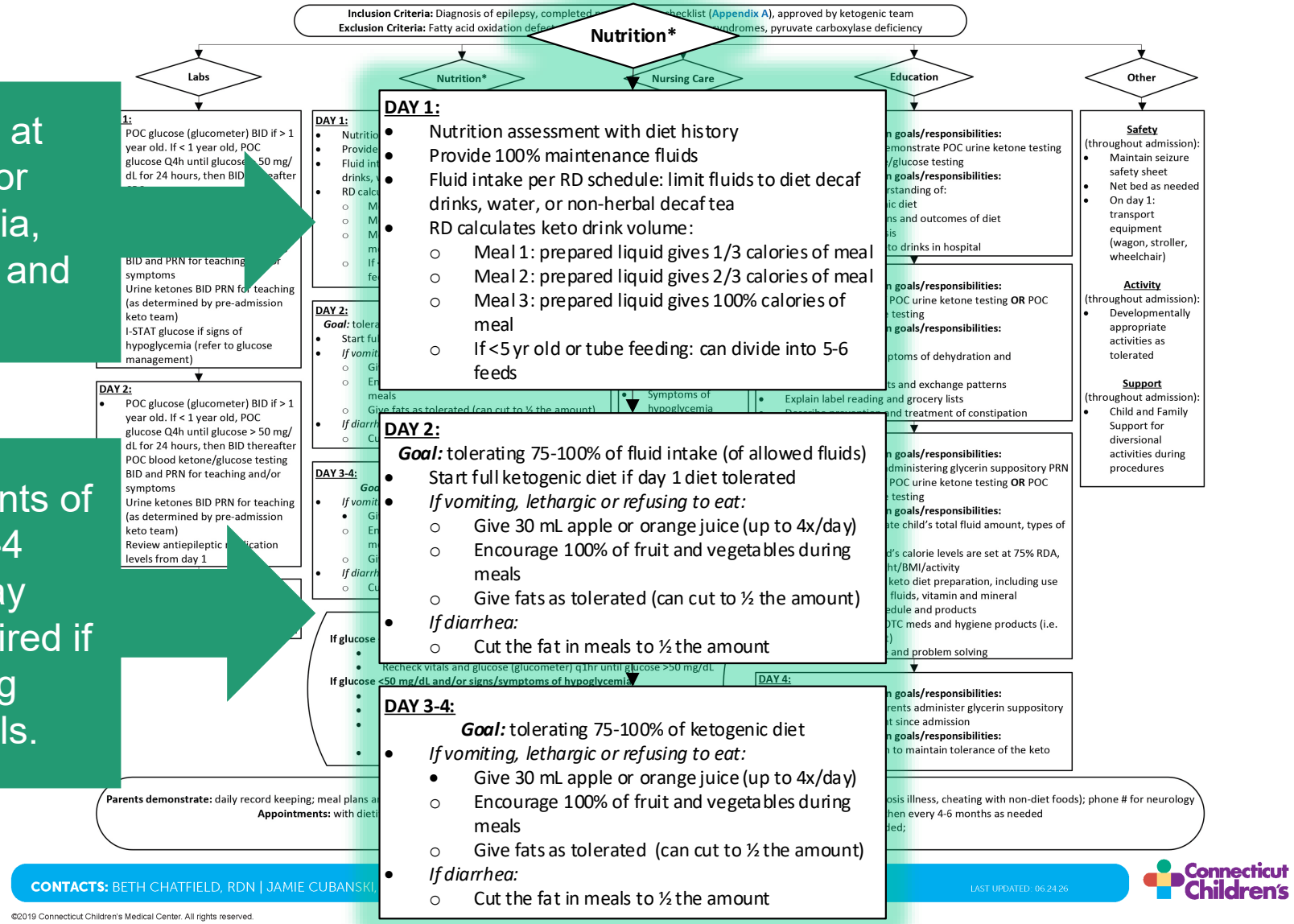


Nutrition

Ketogenic or Modified Ketogenic diets can be chosen from diet orders in EPIC.

Patients are at higher risk for hypoglycemia, dehydration and acidosis.

Small amounts of juice 1 oz 3-4 times per day maybe required if not tolerating regular meals.



Nursing Care

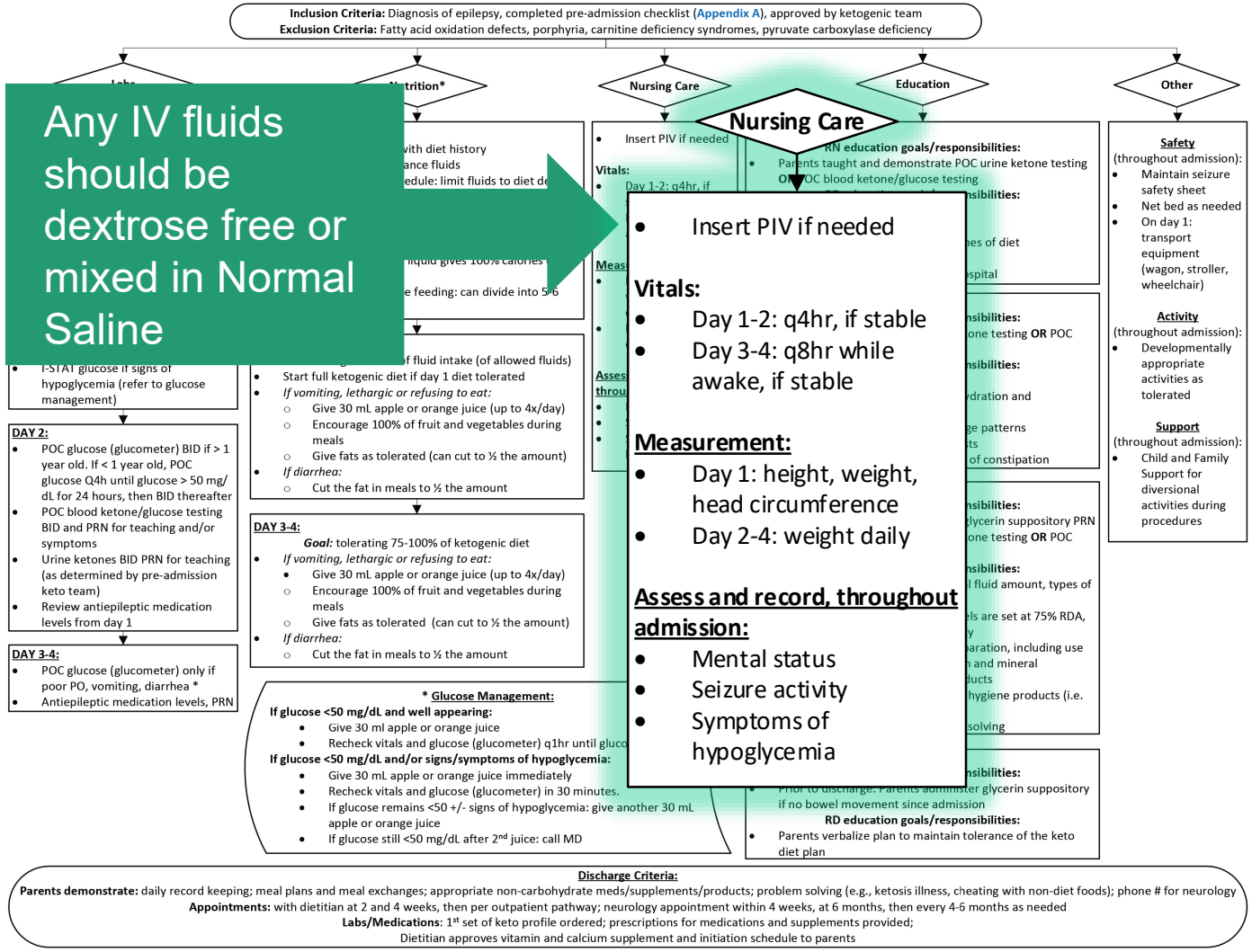
- Nursing should double check all medications given to ensure they are in **keto friendly** sugar free solutions **(less then 1 gram total for the day)**

FYI, There is a new "Best Practice Alert" pop-up when clinician order liquid medications that may have carbohydrates if patient is on a ketogenic diet.

- Neurologic exams should be monitored throughout admission.

CLINICAL PATHWAY: Ketogenic Diet

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.



Any IV fluids should be dextrose free or mixed in Normal Saline

CONTACTS: BETH CHATFIELD, RDN | JAMIE CUBANSKI, RN | LILA WORDEN, MD

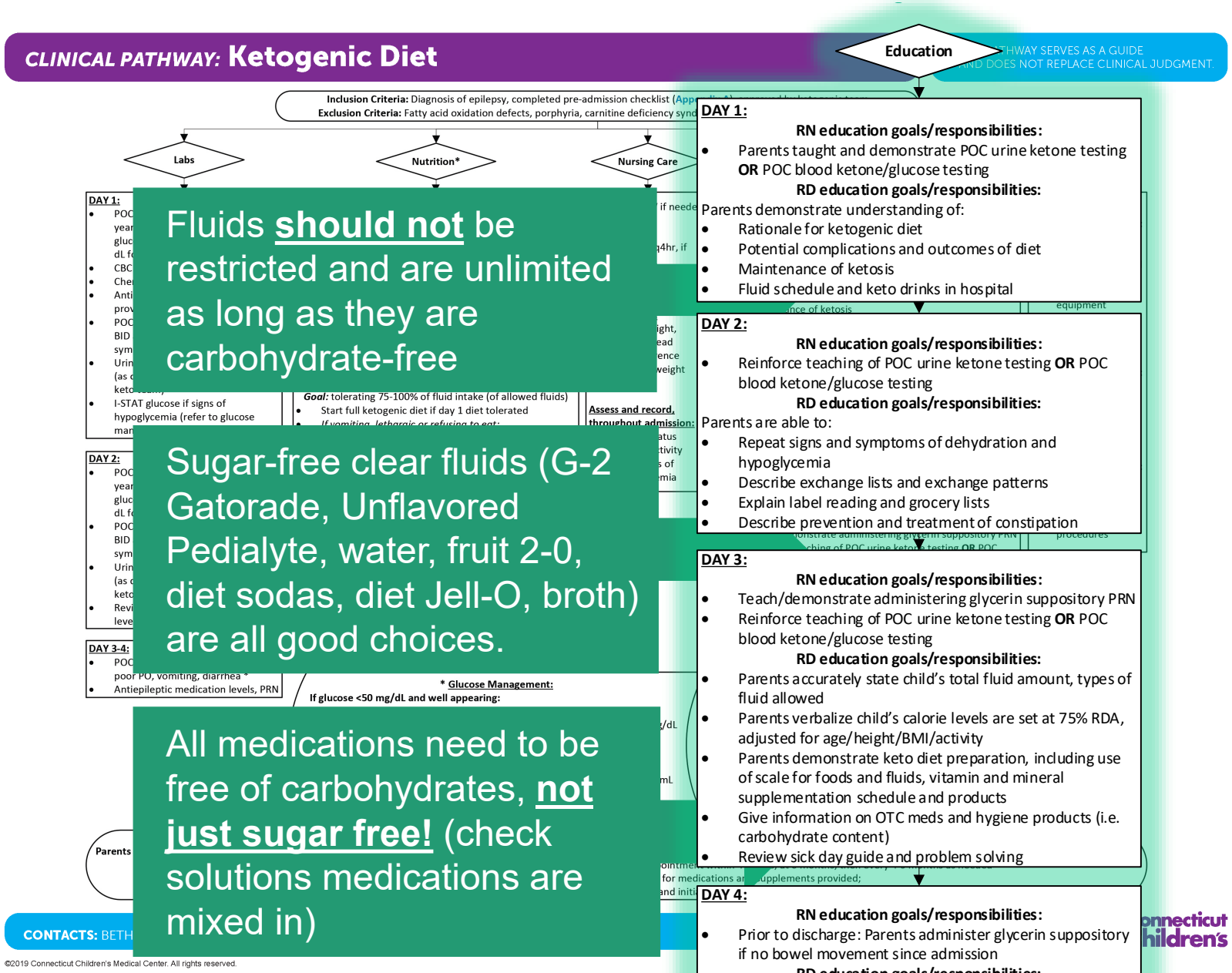
LAST UPDATED: 06.24.26

Education

Caregiver education is a key part of the admission.

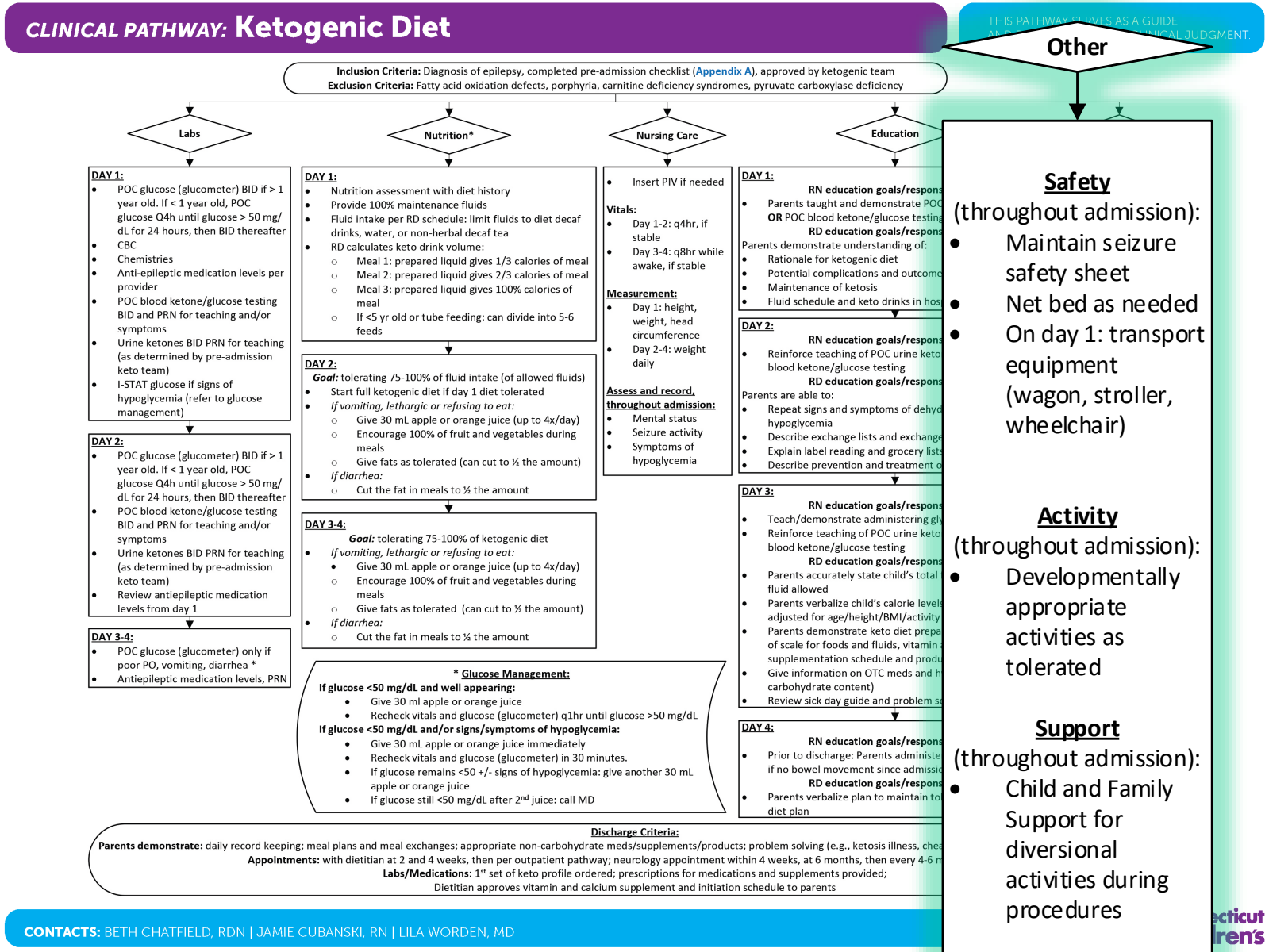
Education occurs incrementally throughout the hospital stay in order to allow time for information to absorb and for caregivers to practice new skills they learn.

Parents should be taught <u>EITHER urine ketones OR blood ketone/blood glucose</u> based on what they will go home with (per outpatient keto team).



Other

All patients should have the appropriate safety, activity and support standards.



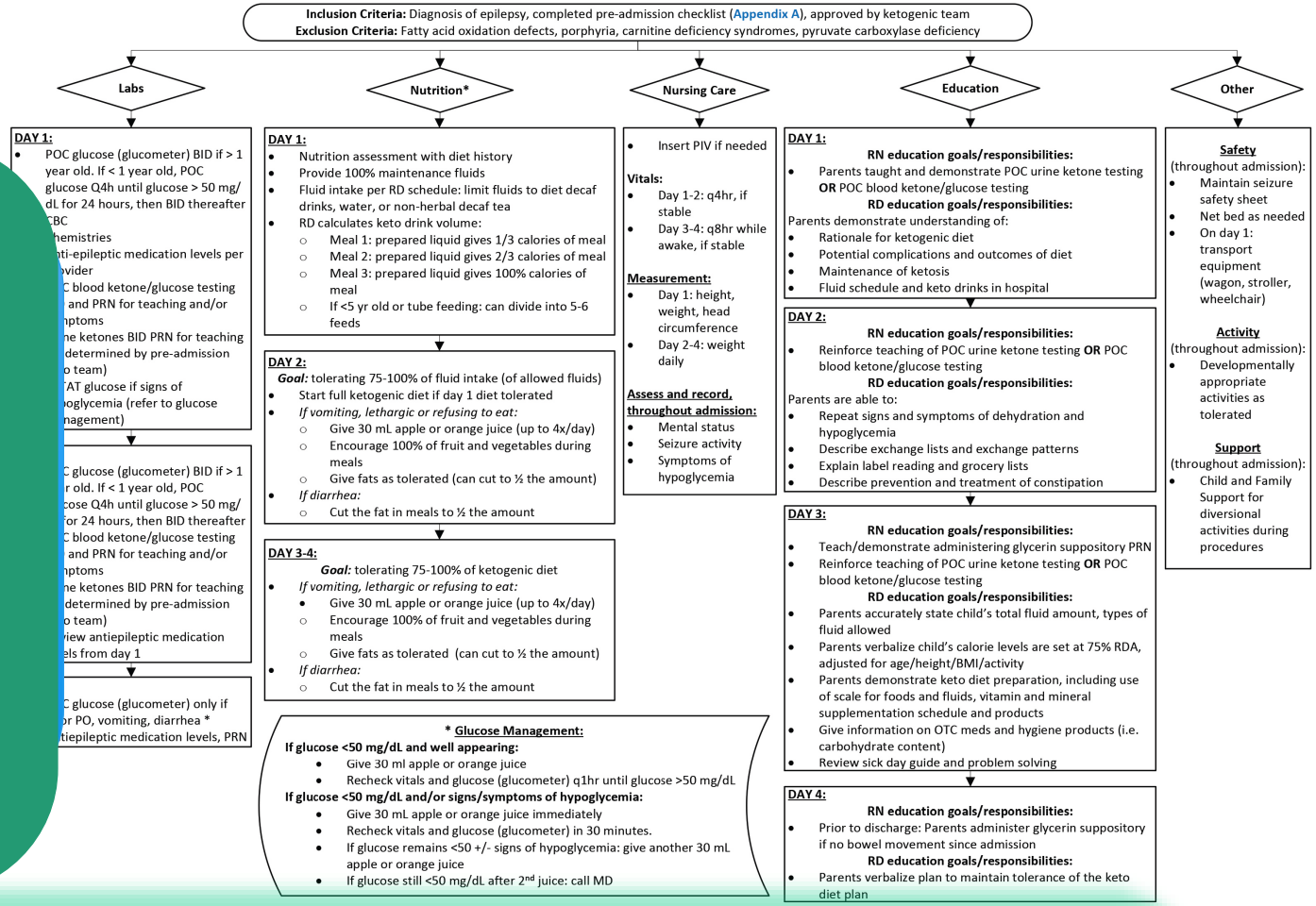
Discharge Criteria

CLINICAL PATHWAY: Ketogenic Diet

THIS PATHWAY SERVES AS A GUIDE AND DOES NOT REPLACE CLINICAL JUDGMENT.

Also need:

- Appointments scheduled with:
  - Dietitian at 2 and 4 weeks AND
  - Neurology at 4 weeks and 6 months
- 1st set of labs ordered (= "limited keto panel at 2 weeks if classic ketogenic diet)
- Prescriptions for meds and supplements
- Dietitian approved vitamin and calcium supplements and initiation schedule



Discharge Criteria:

Parents demonstrate: daily record keeping; meal plans and meal exchanges; appropriate non-carbohydrate meds/supplements/products; problem solving (e.g., ketosis illness, cheating with non-diet foods); phone # for neurology

Appointments: with dietitian at 2 and 4 weeks, then per outpatient pathway; neurology appointment within 4 weeks, at 6 months, then every 4-6 months as needed

Labs/Medications: 1st set of keto profile ordered; prescriptions for medications and supplements provided;
Dietitian approves vitamin and calcium supplement and initiation schedule to parents

Connecticut Children's

Using Medications on a Ketogenic Diet

- Did you know ketogenic patients have a 6th vital sign?? “Medication Carbohydrate Content”
- Carbohydrates are hidden in many medications, typically liquids and chewable tablets.
- Sugar-free does not mean carbohydrate-free.
- Suppositories, caplets, and adult tablets are **less likely** to contain high amounts of carbohydrates.
- Lexicomp contains carbohydrate content of some medications and pharmacy can double check. (Search “carbohydrate content of medication” in Lexicomp to find the list)

Tips and Tricks for Appropriate Medications

- NO liquids
- NO chewable medications
- NO dextrose, glucose, or lactate ringers solutions
- When in doubt, check with pharmacist
- Discharge options: If the tablet form cannot be crushed, some specialty pharmacies can make a carbohydrate-free compounded form of most medications (using ORA PLUS or ALMOND OIL ONLY)
- Suppositories are available for fever and pain relief in infant and pediatric versions

Ketogenic Diet Illness Guideline

The two most important items for families:

(1) recognizing dehydration and hypoglycemia

(2) when to contact pediatrician and Keto team

- If signs and symptoms of hypoglycemia are seen:
  - provide 1 oz of juice 3-4 times a day if child is refusing or not tolerating meals
- Monitor child for signs of dehydration:
  - Three wet diapers in a 24-hour period and pale colored urine (like lemonade) are signs that the child is well hydrated
  - Encourage drinking of small amounts of liquids every hour
- It is common for urine ketones to fluctuate when a child is sick, ranging from their usual level to negative.
  - No treatment to improve ketones is required during illnesses

Ketogenic Diet Illness Guidelines

- **Fever:**
  - Give only sugar-free fever reducing medication. It needs to be in capsule or tablet form, not liquid.
  - All suppositories are also available over the counter.
- Offer plenty of sugar free fluids (G-2 Gatorade, unflavored Pedialyte, water, fruit 2-O, flavored waters, sugar free Jell-O, broth).
  - Unflavored Pedialyte is okay for up to 24 hours, but meals should then be started at ¼ or ½ strength. Tolerance should be evaluated at every meal. No child should stay on Pedialyte alone for more than 24 hrs.
- If vomiting or diarrhea:
  - The fat content of meals can be titrated at every meal to assess tolerance: ¼, ½, ¾ to full-strength fat.

High ketone levels in the hospital

- Ketones can get very high when transitioning into ketosis
- When to notify MD?
  - If POCT ketones > 5 AND if symptomatic (altered mental status, vomiting)
  - If child is asymptomatic and blood glucose is OK, **no** need to notify

Education Key Points for Nursing

- Documentation under education needs to be completed everyday during admission- this includes education on glycerin suppositories and Urine Ketones or Blood Ketones/Glucose
- Ketone monitor will now be added into the education tabs

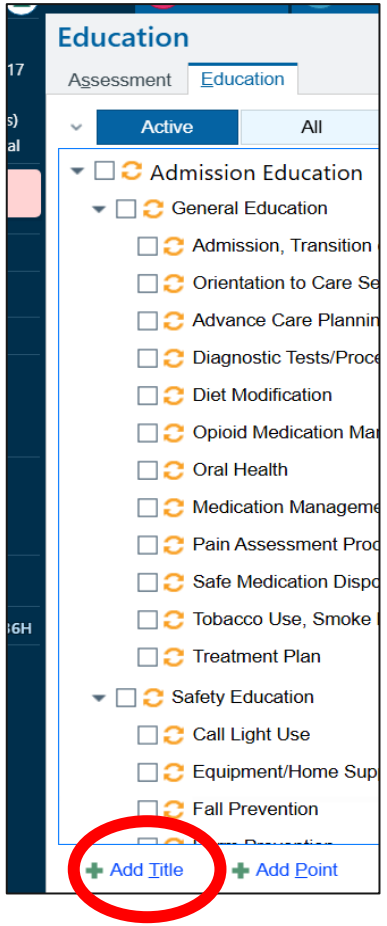
See next slides for how to add the ketogenic diet education to the chart

Please document that education was completed each day in your nursing shift summary so we can track.

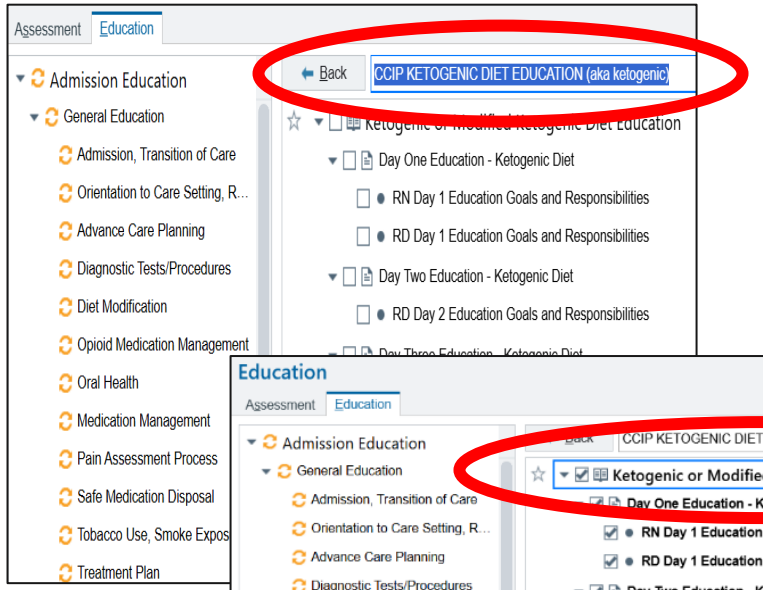
How to Add Ketogenic Education to Chart

1. Go to the ***Education tab***
2. Choose "***Add Title***"
3. Type "***ketogenic***", *and the education title will pop up*
4. ***Check the box*** to select **all** education points, and then ***hit accept***

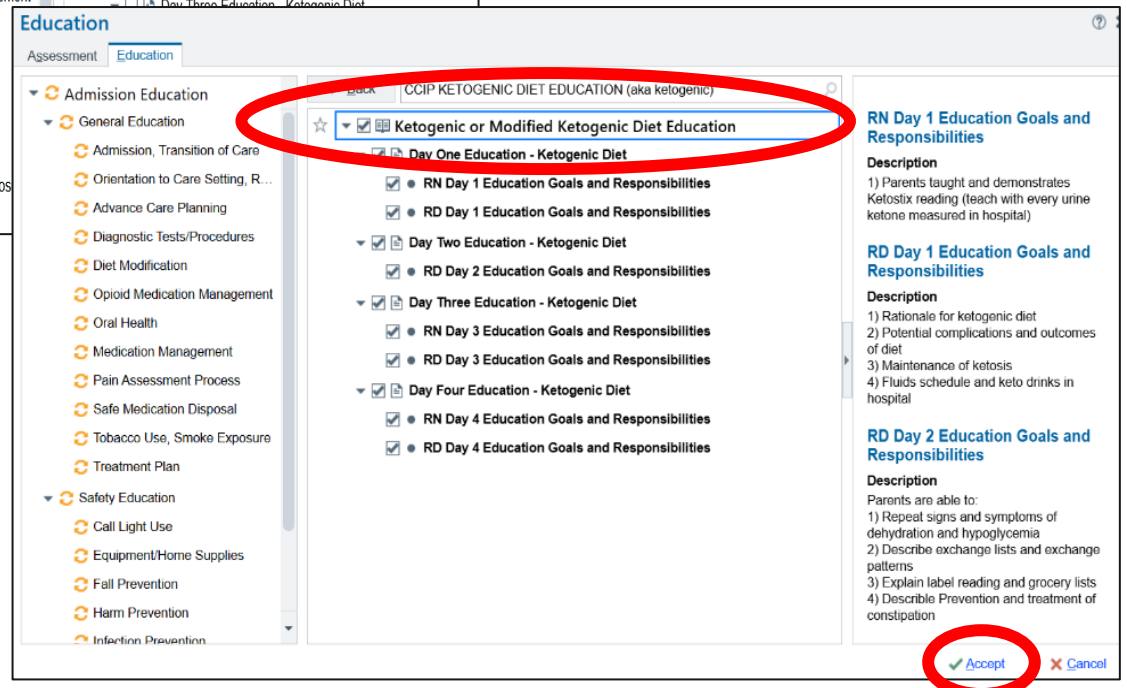
STEPS 1 & 2



STEP 3



STEP 4



Education Binder

- An education binder will be stored in a central location on MS7
- Binder will contain quick reference of nursing education bullet points by day, a printout of the ketogenic diet pathway flowsheet, and a summary of education done pre-admission on the home POC ketone monitor.
- It will also contain an educational PowerPoint for teaching caregivers Ketone/Glucose monitor use (this is also independently available on the pathway internet homepage)
  - Not every patient will use a home POC ketone monitor, some may use urine ketone strips instead

Majority of the ketone monitor education will be completed by Keto RN outpatient for scheduled admissions, but please reinforce caregiver education during the hospitalization

Review of Key Points

- There is now only one single ketogenic diet clinical pathway
- Glucose monitoring should occur BID, but if < 1 yr old, should occur q4h until > 50 for 24 hours, then BID)
- Ketone monitoring occurs BID
- Patients will go home with plan to test EITHER urine ketones OR home POC ketones
- Update to pre-admission workflow to now include preventative guidelines for acidosis/kidney stones when appropriate by MD
- Parental education and medication checks are important to ensure no carbohydrates are given while on the ketogenic diet
- Parents should know:
  - How to recognize and treat dehydration and hypoglycemia
  - When to call the PCP or keto team

Quality Metrics

- Percentage of patients with pathway order set
- Percentage of patients with blood sugar > 50 for all 3 days of admission
- Percentage of patients with education completed AND documented
- ALOS

Pathway Contacts

- Lila Worden, MD
  - Pediatric Neurology
- Jamie Cubanski, RN
  - Pediatric Neurology
- Beth Chatfield, RD
  - Pediatric Neurology

References

- www.CharlieFoundation.org
- Kossoff EH, Zupec-Kania BA, Auvin S, et al. Optimal clinical management of children receiving dietary therapies for epilepsy: Updated recommendations of the International Ketogenic Diet Study Group. *Epilepsia Open*. 2018 May;3(2):175-192.

Thank You!

About Connecticut Children's Clinical Pathways Program

The Clinical Pathways Program at Connecticut Children's aims to improve the quality of care our patients receive, across both ambulatory and acute care settings. We have implemented a standardized process for clinical pathway development and maintenance to ensure meaningful improvements to patient care as well as systematic continual improvement. Development of a clinical pathway includes a multidisciplinary team, which may include doctors, advanced practitioners, nurses, pharmacists, other specialists, and even patients/families. Each clinical pathway has a flow algorithm, an educational module for end-user education, associated order set(s) in the electronic medical record, and quality metrics that are evaluated regularly to measure the pathway's effectiveness. Additionally, clinical pathways are reviewed annually and updated to ensure alignment with the most up to date evidence. These pathways serve as a guide for providers and do not replace clinical judgment.