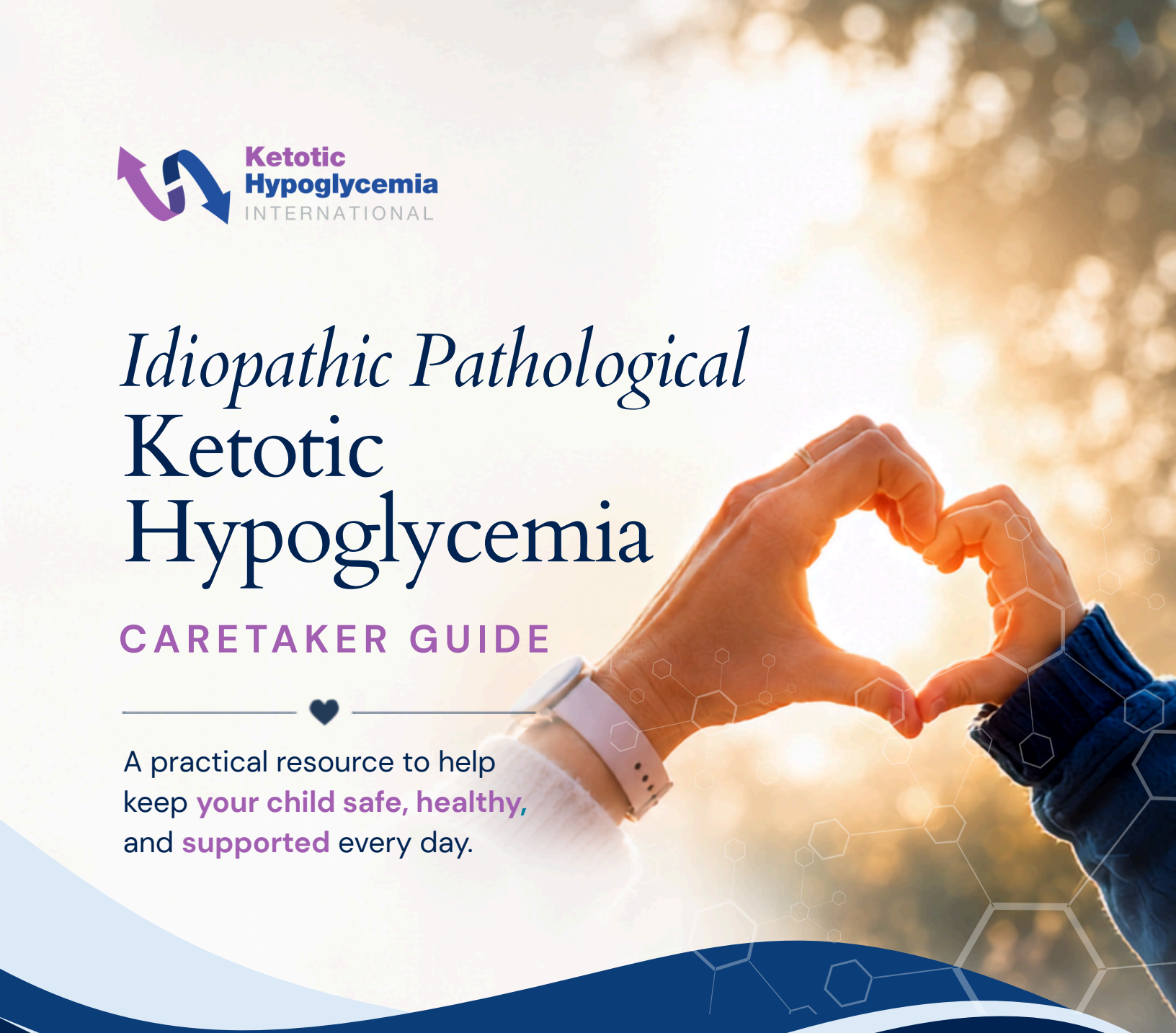
Ketotic Hypoglycemia INTERNATIONAL

Idiopathic Pathological Ketotic Hypoglycemia

CARETAKER GUIDE



A practical resource to help keep **your child safe, healthy,** and **supported** every day.

TOGETHER, WE CAN

prepare, protect, and empower.

This guide is here to give you the tools and confidence you need to help your child live a safe, active, and fulfilling life.

THIS GUIDE BELONGS TO:

Child's Name: _____

Date of Birth: _____

Care Team / Clinic: _____

Emergency Contact: _____

Start Here

How to use this guide

This guide is a practical communication tool for caretakers of a child with idiopathic pathological ketotic hypoglycemia. It should be customized with the child's prescribed care plan, medical emergency letter, medication instructions, and parent or guardian contacts.

For emergencies, follow the child's physician-approved protocol and call 9-1-1 if the child is unresponsive, or seizing.

Primary Contacts

PARENT/ GUARDIAN 1

PHONE

PARENT/ GUARDIAN 2

PHONE

BACKUP EMERGENCY CONTACT

PHONE

Medical Team

ENDOCRINOLOGIST/ METABOLIC SPECIALIST

OFFICE/ AFTER-HOURS PHONE

PREFERRED ER/ HOSPITAL

EMERGENCY LETTER LOCATION

MEDICAL KIT LOCATION

ALLERGIES /RESTRICTIONS

Customize before use:

Replace all placeholder fields, add the child's exact dosing schedule, attach the current emergency protocol letter, and confirm instructions with the medical team.

Understanding Ketotic Hypoglycemia

Physiological KH vs. Idiopathic Pathological KH

Ketotic hypoglycemia means a child's blood glucose drops while ketones rise. Episodes may happen during fasting, illness, vomiting, high activity, heat, poor intake, or disrupted routines. Quick checks, early action, and following the child's care plan are the priority.

Physiological Ketotic Hypoglycemia

COMMON IN YOUNG CHILDREN

Physiological ketotic hypoglycemia can happen when a young child runs out of readily available glucose during a longer fasting window, illness, poor intake, or increased energy demand. The body makes ketones as an alternate fuel source.

This can occur in otherwise healthy children because young children have smaller energy reserves and may not tolerate fasting as well as older children or adults. It is often occasional, tied to a clear trigger, and may improve as the child grows.

Idiopathic Pathological Ketotic Hypoglycemia (IPKH)

MORE CONCERNING OR RECURRENT

Idiopathic pathological ketotic hypoglycemia (IPKH) refers to more concerning or recurrent episodes where the child has abnormally limited fasting tolerance, repeated KH episodes, or symptoms that become difficult to manage even when ketones are elevated.

The term "idiopathic" means that no single underlying cause has been identified after appropriate medical evaluation. However, advances in research and genetic testing continue to show that some individuals previously diagnosed with IKH may later be found to have an underlying metabolic, hormonal, or genetic disorder. For some, symptoms may persist into adolescence and adulthood.

KEY POINTS

- Often related to fasting, illness, poor intake, or high activity
- Can happen in otherwise healthy children
- Often improves with age
- Usually less frequent and easier to manage

KEY POINTS

- Recurrent, severe, or prolonged episodes
- No identifiable cause found after appropriate evaluation
- May persist beyond early childhood for some individuals
- Requires individualized medical plan, monitoring, and escalation steps

CARETAKER TAKEAWAY

Even if an episode is considered physiological, it still needs prompt attention. Check glucose and ketones, offer approved food or drink if the child can safely swallow, hydrate, and contact the parent/guardian.

CARETAKER TAKEAWAY

This child may need a more individualized care plan, closer monitoring, specific nutrition tiring, rescue steps, and clear ER/911 guidance.

IMPORTART TO REMEMBER

Caretakers do not need to diagnose which type of ketotic hypoglycemia is happening during an episode. Your role is to recognize symptoms early, check glucose and ketones, document readings, contact the parent/guardian, and follow the child's individualized care plan. Every child with ketotic hypoglycemia is unique, so triggers, symptoms, and treatment instructions should always be confirmed by the child's medical team.

Physical Symptoms

Common signs of low glucose and/ or rising ketones

Symptoms can vary from child to child. Use this page as a quick scan, then confirm with glucose and ketone testing when symptoms appear or the child seems unwell.

- [ ] **Pale skin**
- [ ] **Rapid/shallow breathing**
- [ ] **Glazed eyes**
- [ ] **Fatigue or lethargy**
- [ ] **Irritability or listlessness**
- [ ] **Hand tremors**
- [ ] **Sweating**
- [ ] **Headache**
- [ ] **Abdominal pain**
- [ ] **Poor appetite**
- [ ] **Fruity or acetone-smelling breath**
- [ ] **Confusion or poor memory**
- [ ] **Vomiting**
- [ ] **Diarrhea**
- [ ] **Seizure**
- [ ] **Other**

Caretaker note

Ask the parent/guardian which symptoms are most typical for this specific child. Check off the box or highlight them on the printed copy so caretakers can recognize the child's pattern faster.

Symptom Response

Action plan for caretakers

What to look for: if the child seems sick, unusually tired, pale, shaky, confused, nauseated, or refuses food, check symptoms against the IKH list and begin the steps below.

1. **Contact parent/guardian immediately**
   Call or text right away. Call 911 if the child is unresponsive, seizing, has trouble breathing, or is not safe to swallow.

2. **Observe and record symptoms**
   Write down what you see and the exact time symptoms began, especially vomiting, diarrhea, fever, or lethargy.

3. **Check glucose and ketones**
   Use the child's meter/ CGM instructions. Confirm CGM lows with a finger stick when the care plan requires it.

4. **Record results**
   Document glucose, ketones, date, time, food/fluid intake, and any treatment given.

5. **Follow the care protocol**
   Use the child's glucose and ketone treatment chart to determine the next step.

7. **Give prescribed rescue carbohydrate only when safe**
   Use the child's approved glucose gel, tabs, juice, or snack only if awake and able to swallow safely.

8. **Escalate if not stabilizing**
   If symptoms worsen, vomiting continues, ketones remain high, or glucose does not improve, follow the emergency plan and go to the ER/911 - not urgent care when the protocol says ER.

9. **Bring the emergency letter**
   Tell ER staff the child has Ketotic Hypoglycemia and provide the physician-approved emergency protocol letter with readings and timeline.

Idiopathic Pathological Ketotic Hypoglycemia Flow Chart

A step-by-step guide to help caregivers recognize symptoms, test glucose and ketones, and respond appropriately.

Child seems unwell or has possible IKH symptoms
Examples: pale skin, fatigue, shakiness, headache, poor appetite, fruity breath, abdominal pain, vomiting, lethargy.

MILD SYMPTOMS

Child is awake, alert, and able to eat/drink. Symptoms are mild or CGM suggests a possible low.

Give approved snack procedure: complex carb + protein, or cornstarch/feeding plan if prescribed. Encourage fluids.

Monitor symptoms.
If symptoms resolve, return to routine and continue observation.

If symptoms worsen, child refuses food, or CGM remains low → move to testing procedure.

MODERATE SYMPTOMS

Symptoms continue, child refuses snack, low CGM alert, or symptoms persist after 15 minutes.

SEVERE SYMPTOMS

Repeated vomiting or diarrhea, lethargy, confusion, child cannot safely swallow, symptoms escalating quickly, seizure, or unresponsive.

EMERGENCY / RESCUE PATHWAY

Call 911 or go to the ER immediately.
Follow the child's emergency plan.

TESTING PROCEDURE: confirm with finger-stick blood glucose and blood ketones.

When in doubt, test both glucose and ketones.

Glucose 70+ mg/dL and Ketones < 0.6

Hydrate, offer snack/meal, monitor closely, and continue normal routine.

Glucose 60–69 mg/dL or Ketones 0.6–1.0

Give fast-acting carb if needed, then carb + protein snack. Encourage fluids/ electrolytes. Recheck in 15 minutes. Contact parent.

Glucose 50–59 mg/dL or Ketones 1.0–2.0

Begin rescue procedure according to care plan (glucose gel, juice, or prescribed treatment). Push fluids if tolerated. Recheck in 15 minutes, contact parent.

Glucose < 50 mg/dL or Ketones > 2.0

High-risk reading. Escalte now.

If child is worsening, unable to drink, vomiting, or not improving, go to the ER / call 911.

Go to the ER / Call 911 now if:

- Child is unresponsive or having a seizure
- Child cannot safely swallow
- Repeated vomiting or diarrhea prevents treatment
- Symptoms worsen rapidly or severe lethargy develops
- Rescue procedure is not working
- The child's individualized medical protocol says to escalate

At the hospital

Tell staff the child has Ketotic Hypoglycemia (and any known metabolic condition, if applicable). Share glucose and ketone readings, symptoms, treatments already given, and provide the emergency medical letter or care plan.

Important: *This chart is a general caregiver resource and should be used alongside the child's individualized medical plan from their parent/guardian and medical team.*

Glucose + Ketone

Monitoring levels

Always use the ranges prescribed for the specific child. The chart below is a template based on common guide categories and should be reviewed by the child's clinician before use.

Glucose, CGM	Glucose, Blood	Ketone, Blood
< 59 mg/dL hypoglycemic (severe)	< 59 mg/dL hypoglycemic (severe)	0.1 - 0.5 (normal)
60 - 70 mg/dL hypoglycemic (moderate)	60 - 70 mg/dL hypoglycemic (moderate)	< 0.6 (small / mild)
70 - 200 mg/dL euglycemic (normal)	70 - 200 mg/dL euglycemic (normal)	0.6 - 1.5 (moderate)
> 200 mg/dL hyperglycemic	> 200 mg/dL hyperglycemic	> 1.6 large / (severe)

Red: Emergency/alarming - act quickly and follow the protocol.

Yellow: Moderate - treat and recheck as directed.

Green: Within target/less alarming - continue nutrition and monitoring.

Quick-Step Caretaker Guide

Print and keep on top of the medical kit

This child has idiopathic pathological ketotic hypoglycemia and may need help keeping blood sugar stable and ketones low. Contact the parent/guardian immediately if the child appears sick or shows symptoms.

At-a-glance

- Check CGM/receiver if child seems unwell.
- Confirm low/uncertain readings with finger stick if instructed.
- Check blood ketones during illness, vomiting, poor intake, or symptoms.
- Keep medical kit with the child or responsible adult at all times.
- Use the emergency medical letter for ER staff.

Emergency triggers

- Unresponsive or seizing.
- Unsafe to swallow
- Vomiting/ fever + lethargy
- Protocol says ER/ 911

Blood sugar response template

70-120 mg/dL
Ideal/target - continue normal routine.

60-69 mg/dL or symptomatic
Callparent/guardian.Giveapprovedcarb + protein snack, recheck in 15 minutes.

50-59 mg/dL or symptomatic
Treatasdirected.Addfluids/electrolytes if instructed. Recheck in 15 minutes.

40-49 mg/dL
Callparent/guardian immediately. Follow rescue protocol and recheck. Escalate if not improving.

Below 40 or LOW
Emergency. Recheck toconfirm only if safe, start emergency protocol, call 911/ER per care plan.

Finger-Prick Testing

Glucose and ketone procedure

Use the child's prescribed glucose and ketone meters. Confirm where supplies are stored and document every reading with the time.

1. Wash hands or wipe finger with alcohol pad and let it air dry.
2. Load lancet into the lancing device and secure the cap.
3. Prick the finger and squeeze gently to form a blood drop.
4. Read the number, write it down, and compare to the protocol.
5. Insert the correct test strip into the meter.
7. Warm the finger and choose a soft area near the fingertip.
8. Touch blood to the strip until the meter beeps or confirms the sample.
9. Dispose of lancet and strip in the designated container.

Medical kit checklist

- [ ] Glucose meter + glucose strips
- [ ] Ketone meter + ketone strips
- [ ] Lancet device + lancets
- [ ] Alcohol swabs + disposal container
- [ ] Glucose gel/tabs/juice or prescribed rescue carbs
- [ ] Emergency medical letter + current schedule

Continuous Glucose Monitor

CGM caretaker basics

How to use it

- Keep receiver/phone within range as directed.
- Check CGM during the day and anytime the child seems tired, pale, shaky, confused, or unwell.
- Do not ignore alarms; follow the care plan.

Important limitations

- Confirm low or questionable readings with finger stick when the protocol requires it.
- CGM readings can lag behind blood glucose during rapid changes.
- Sensor application/syncing should follow manufacturer instructions.

Fill in this child's CGM setup

CGM BRAND/MODEL

RECEIVER/PHONE LOCATION

LOW ALERT SETTING

HIGH ALERT SETTING

WHO RECEIVES ALERTS

WHEN TO CONFIRM BY FINGER STICK

Supportive Food + Drink List

Helpful options during a ketotic hypoglycemia episode

When a child is experiencing symptoms of ketotic hypoglycemia, the goal is to follow the child's care plan, provide quick glucose support when needed, pair carbohydrates with protein when tolerated, and encourage fluids to help rebalance blood sugar and ketones.

Category	*Why it helps*	*Food ideas*	*Drink ideas*
Fast-acting sugar	*Raises blood sugar quickly when numbers are low or symptoms are starting.*	glucose gel or tabs, hard candy/sucker, dried fruit, applesauce pouch, fruit snacks	apple juice, white grape juice, regular sports drink, oral glucose drink
Protein + carb combo	*Helps stabilize blood sugar after the initial rescue step for milder symptoms.*	peanut or seed butter crackers, cheese and crackers, yogurt with granola, turkey sandwich bites, toast with nut butter	milk, lactose-free milk, protein shake, smoothie with yogurt
Complex carbs	*Provides longer-lasting fuel and can help prevent another drop.*	oatmeal, rice, toast, waffles, pancakes, pasta, potatoes, Cheerios, granola bar	meal replacement shake, drinkable yogurt
Hydration + electrolytes	*Supports the body when ketones are elevated, especially during illness, heat, or omitting.*	popsicle, Pedialete freezer pop, broth with crackers	water, Pedialete, electrolyte drink, diluted sports drink, coconut water if approved
Gentle foods if nauseated	*Easier to tolerate when appetite is low or the child feels sick.*	dry toast, crackers, applesauce, banana, plain rice, mashed potatoes	small sips of water, electrolyte solution, diluted juice
Bedtime / sustained support	*May help maintain levels longer when instructed in the child's plan.*	cornstarch mixture if prescribed, yogurt, cheese toast, oatmeal	milk or prescribed formula

If the child refuses food or drink

- Offer small amounts every 5–15 minutes rather than a full snack at once.
- Try easier options: sips of juice, applesauce pouch, smoothie, popsicle, or electrolyte drink.
- If omitting, worsening lethargy, or inability to keep fluids down occurs, follow the emergency plan and contact the parent/guardian immediately.
- If readings remain out of range, symptoms escalate, or the child cannot safely swallow, follow the KH flow chart and emergency protocol.

Helpful reminders

- Simple sugars are for quick response; pair with protein/complex carbs when able.
- Hydration matters because ketones often improve with fluids.
- Follow the child's individualized care plan for exact thresholds and rescue steps.
- When in doubt, contact the parent/guardian and recheck glucose and ketones.

Daily Schedule

Customize for school, home, travel, or babysitting

Time	Care routine / food / dose / notes
Wake	
Breakfast	
Morning snack	
Mid-morning check	
Lunch	
Early afternoon	
Afternoon snack	
After school/activity	
Dinner	
Evening dose/snack	
Bedtime routine	
Overnight instructions	

Activity + heat planning

Add specific hydration/electrolyte instructions for recess, sports, camps, travel days, or hot weather.
Make note when glucose and ketones should be checked during high activity.

Morning + Night Routine

Stability starts with consistency

Use this page to document the child's customized home routine. Doses, products, timing, and formulas should match the current physician-approved plan.

AM

AM Routine

FIRST GLUCOSE/ KETONE CHECK

BREAKFAST INSTRUCTIONS

CORNSTARCH/ FORMULA DOSE

SCHOOL/ CARE HANDOFF NOTES

WHEN TO CALL PARENT

PM

PM Routine

DINNER/EVENING SNACK

BEDTIME STARCH/FEED

OVERNIGHT MONITORING

WATER FLUSH/HYDRATION

WHEN TO WAKE/CHECK

! Never change dosing, fasting windows, feeding pump settings, or rescue instructions without parent/guardian and medical team guidance.

Nutrition + Management Plan

Why the routine matters

1

Scheduled starch or slow-release carbohydrate

Providesaslower,steadiersourceofglucoseduringlongergapsbetween meals or overnight, when prescribed.

2

Formula or tube feeds, if applicable

Supportscalories,protein,hydration,vitamins,minerals, and stable energy when oral intake is not enough.

3

Hydration and electrolytes

Helpreducedehydration-relatedstress during heat, illness, vomiting, diarrhea, or high activity.

4

Frequent balanced intake

Smallmeals/snackswithprotein+complex carbohydrates can reduce fasting stress and support more stable
glucose

Personalization checklist

- ☐ Exact corn starch dose
- ☐ Formula and Feeding tube/pump settings, *if applicable*
- ☐ Hydration/electrolyte plan
- ☐ Illness/vomiting protocol
- ☐ School/camp activity plan
- ☐ Medication/allergy information

G-Button + Pump Guide

Optional page for children with tube feeds

Complete this page only if the child has a gastrostomy button or uses a feeding pump. Confirm all instructions with the parent/guardian and medical team.

G-button parts



External disk / port / internal balloon

Caretaker checklist

- ☐ Identify the child's tube type and size.
- ☐ Wash hands and check the site for redness, leakage, pain, or dislodgement.
- ☐ Align extension set and connect gently; never force.
- ☐ Program pump rate/dose exactly as written.
- ☐ Flush only as instructed.
- ☐ Disconnect, cap the port, and document the feed.
- ☐ Call parent/guardian for leaks, pain, dislodgement, vomiting, or uncertainty.

TUBE TYPE/SIZE

EXTENSION SET LOCATION

PUMP TYPE

RATE/DOSE

FORMULA/PRODUCT

FLUSH INSTRUCTIONS

Emergency Room Handoff

What to say and bring

Use the child's physician-approved emergency letter as the source of truth.

Medication, IV fluids, dextrose concentration, and contraindications can differ by diagnosis.

**Do not rely on a generic guide for hospital orders.*

Suggested handoff script

"This child has idiopathic pathological ketotic hypoglycemia and is experiencing symptoms with abnormal glucose and/or ketone readings. Here are the readings, timeline, food/fluid intake, and treatments already given. Please review the attached emergency protocol letter from the child's specialist."

Bring with you

- Emergency medical letter
- Glucose/ ketone meter readings with times
- Medication and dosing list
- CGM receiver/phone, *if applicable*
- Medical kit, formula/ corn starch, and supplies
- Parent/ guardian contact information

Episode Log

Document, symptoms, readings, and actions

Time	Symptoms	Glucose	Ketones	Food/Fluids/ Treatment	Next Step

Notes

Questions, updates, and caretaker observations

Review this guide after any episode, medication change, school change, camp/travel plan, or updated physician protocol.

Resources & References

A quick-reference page for trusted medical resources, guide sections, and organization contacts.

Start Here 02

What Is Ketotic Hypoglycemia? 03

Physical Symptoms 04

Symptom Response 05

KH Flow Chart 06

Quick-Step Caretaker Guide 08

Glucose + Ketone Monitoring 07

Meal + Snack Response 11

Emergency Room Handoff 16

Episode Log 17

Important: This guide should be used alongside the child's individualized care plan from their parent/guardian and medical team.

Ketotic Hypoglycemia INTERNATIONAL

Family-centered advocacy, education, awareness, and support.

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MEDICAL PRACTICES & PRACTITIONERS

Medical professionals and care centers referenced in and supportive of this guide.

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