NUCDF

LIVE WEBINAR FOR UCD PARENTS

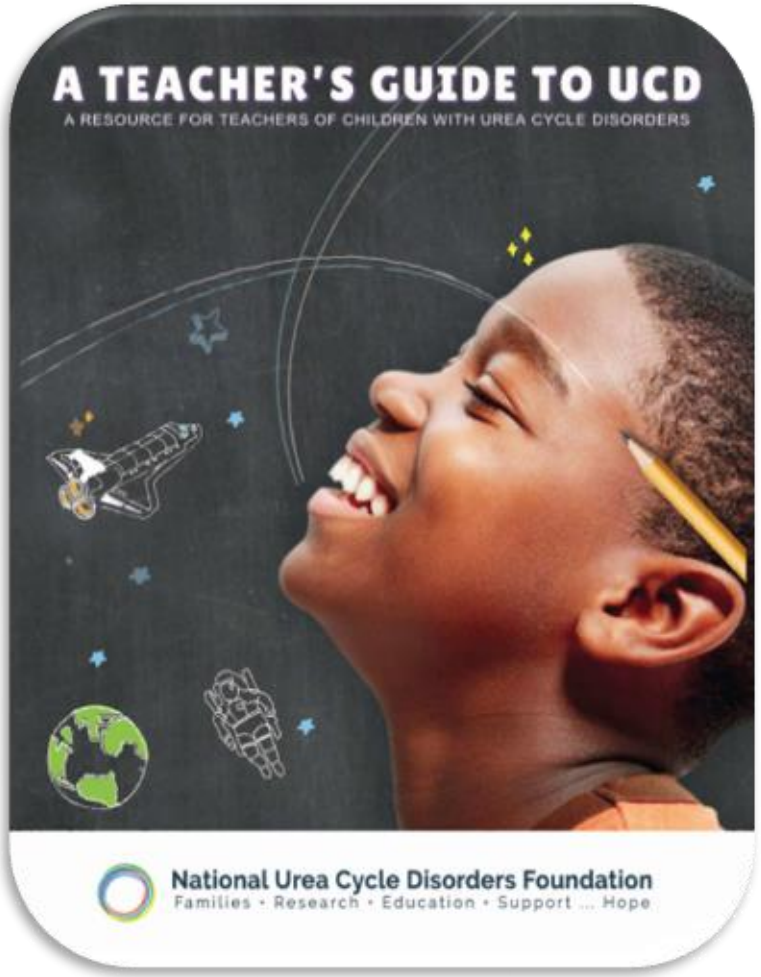
We Have Your Back

Back to School with a UCD

Tuesday, August 4, 2026,
7:00 PM ET

A parent's guide to preparing the school team

Turn the Teacher's Guide into your child's school plan



Tonight, we'll focus on what parents can share, ask, and confirm:

- Explain UCD and ammonia risk in clear, practical language
- Translate care instructions into your child's daily school routine
- Prepare staff to recognize changes and respond without delay
- Request learning supports while protecting privacy and belonging

Leave with documents to share, questions to ask, and people to confirm.

A simple UCD explanation you can share with school staff

1

Protein is broken down

The body uses amino acids for growth and repair.

2

Ammonia is produced

Nitrogen from that process forms ammonia, which is toxic.

3

The liver detoxifies it

Urea-cycle enzymes normally convert ammonia to urea.

4

The body excretes urea

The kidneys remove urea from the bloodstream.

With a UCD, a missing or poorly working enzyme can allow ammonia to build up and affect your child's brain.

The message to share: prevention, early recognition, and rapid response matter.

Your child's plan should protect nutrition, treatment time, and dignity

NUTRITION

Follow the prescribed plan

Protein allowance, low-protein foods, calories, formula, snacks, and hydration are individualized.

ACCESS

Protect needed time

Meals, snacks, formula, medication, fluids, and nurse visits cannot depend on classroom convenience.

BELONGING

Normalize differences

Provide privacy when wanted, avoid stigma, and keep the student included in ordinary school experiences.

Ask: Could a substitute follow this plan without guessing?

Bring your child's written nutrition plan - not a generic food list

Your child's plan may include

- A specific daily protein allowance
- Prescribed medical formula and low-protein foods
- Carbohydrate and fat intake at planned intervals
- Individual hydration and medication instructions

Ask school staff to confirm

- Which foods are approved and where is the written plan?
- What happens if food or formula is missed?
- How will incomplete meals or unexpected foods be reported?

When the plan changes, share new written instructions with every location.

Map your child's school day to prevent long gaps without food

Use your child's actual schedule

Arrival	Confirm the morning handoff and supplies
Morning	Protect planned snack and hydration
Midday	Follow the prescribed lunch plan; record intake
Afternoon	Protect formula, fluids, medication, or snack time
Dismissal	Send relevant intake, symptoms, and changes home

Questions to ask

- How are meal and snack times protected?
- Who covers formula, fluids, medication, and nurse visits?
- What is the backup when staff or schedules change?

Plan G-button and formula access before school begins

TIME

Allow extended breaks

Ask how much time your child needs for formula, fluids, and medication.

PLACE

Provide an appropriate space

Choose with the team a comfortable, clean space that respects your child's privacy.

LEARNING

Do not penalize missed class time

Confirm how your child will access missed instruction and make up work.

Who is trained and authorized? Where are supplies stored? What is the backup for trips and drills?

Teach staff your child's triggers and early warning signs

Triggers to discuss

- Viral illness or infection
- Missed diet, formula, or medication
- Inadequate hydration
- Injury, stress, or excessive exercise
- Growth spurts, puberty, or menses

Signs to personalize

- Nausea or vomiting
- Lethargy or unusual sleepiness
- Confusion, agitation, or mood change
- Unsteady walking or slurred speech
- Your child's earliest or most reliable warning sign

Write your child's early signs into the emergency plan - do not rely on a generic list.

Walk the school team through the emergency response

1	**Stay with the student**	Agree where your child will wait and who stays with them.
2	**Notify the nurse**	Confirm how the nurse is reached and who provides immediate evaluation.
3	**Call the family**	Decide who calls you and what details you need to hear.
4	**Use the individual plan**	Review exactly what authorized staff may give under the written plan.
5	**Escalate when directed**	Write when to call 911 and how staff will identify UCD and possible hyperammonemia.

Ask where every copy of the emergency plan will live

Student file

Current plan and contacts

Nurse's office

Supplies, orders, and response

Classroom

Immediate access for daily staff

Substitute materials

Essential, privacy-protected instructions

Trips + activities

Portable plan, supplies, and trained adult

Ask who updates every copy - and how outdated versions are removed.

Know which school plan addresses each need

HEALTH

IHP + Emergency Plan

Daily health procedures, student-specific symptoms, immediate actions, contacts, and authorized care.

ACCESS

Section 504 Plan

Individualized aids and services that provide equal access when the student meets Section 504 eligibility criteria.

SPECIAL EDUCATION

IEP

Special education, related services, goals, and supports when the student meets IDEA eligibility requirements.

Ask for an evaluation when UCD affects access, attendance, concentration, behavior, or learning.

Tell the school how UCD affects your child

Share patterns you see at home and ask teachers to document what they observe.

Executive function	Focus, working memory, organization, starting tasks, or self-monitoring
Information processing	Understanding information or keeping pace with the class
Mental flexibility	Adapting to changes, shifting tasks, or considering alternatives
Sensory integration	Sensitivity to sounds, movement, touch, or visual input
Emotional + social wellbeing	Stress, anxiety, frustration, food differences, or feeling isolated

Request supports that match your child's needs

Starting tasks	Step-by-step directions, visual checklist, brief prompt
Rigidity or transitions	Predictable routine, gradual change, one-on-one preview
Processing pace	Additional time, visual or auditory supports, hands-on reinforcement
Attention	Smaller chunks, movement breaks, attention-focusing tools
Problem solving	Teach a repeatable framework and provide guided practice
Frequent absences	Flexible attendance and a realistic plan to recover missed work

Protect your child's belonging as carefully as medical safety

NORMALIZE

Treat feeding needs as routine

Ask staff to treat formula, food differences, and nurse visits as routine.

INCLUDE

Plan for parties and activities

Plan approved alternatives so your child can join parties and activities.

INTERVENE

Watch peer interactions

Ask staff to address teasing or bullying promptly and involve school supports.

Ask your child what they want shared - privacy preferences are individualized.

Agree on a simple daily handoff with the school

Track only what your family and school team will use

Food + formula	What was offered and what was consumed
Hydration	Scheduled checks or intake concerns
Nurse visits	Time, purpose, and care provided
Symptoms	What changed, when it began, and who was notified
Learning impact	Missed instruction, fatigue, behavior, or needed recovery

The school-home handoff should answer

- Did the routine go as planned?
- Was anything missed or changed?
- Does the family need to follow up tonight?

Before school starts, leave with four confirmations

1	**Current plans**	You have shared current medical, nutrition, emergency, and educational documents.
2	**Named people**	You know the primary staff and backups for the full school day.
3	**Supplies + access**	You confirmed food, formula, medication, equipment, storage, and private space.
4	**Communication**	You and the school agree what will be reported, how, and when.

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