NUCDF

LIVE WEBINAR FOR UCD PARENTS

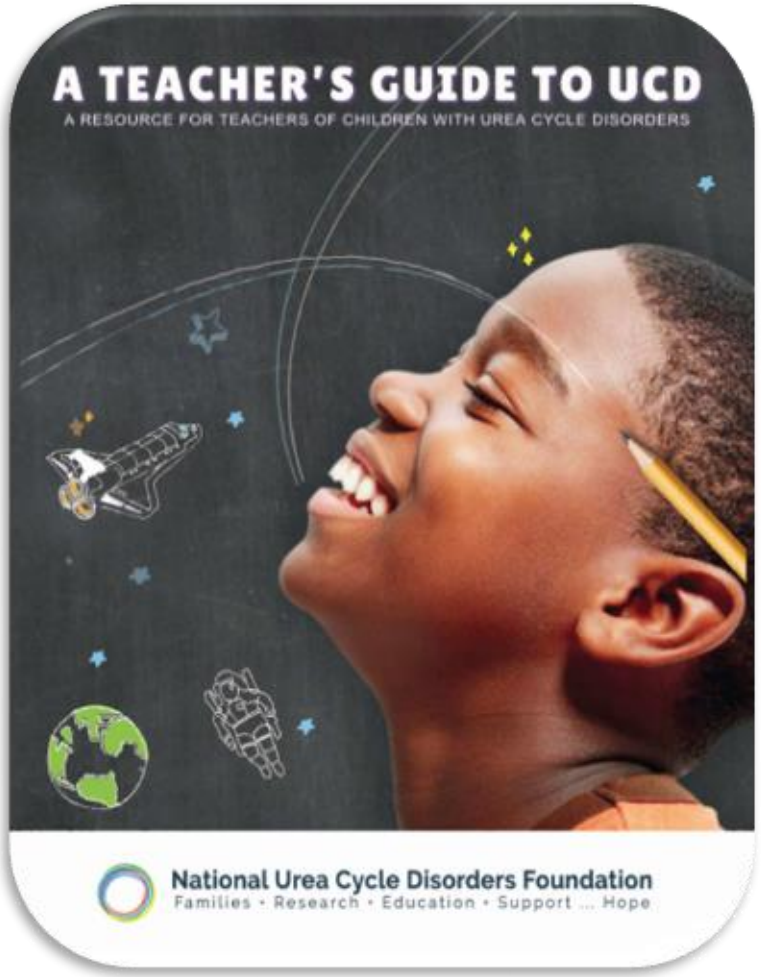
We Have Your Back

Back to School with a UCD

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

Guided by NUCDF's 2026 Teacher's Guide to UCD

Use the guide to prepare every adult who shares the school day



The guide gives school staff a shared starting point for:

- Understanding UCD and why ammonia risk matters
- Following nutrition, hydration, formula, and medication plans
- Recognizing illness and responding to warning signs
- Supporting learning, attendance, privacy, and belonging

Pair the guide with your child's current medical instructions and school plans.

UCD basics in one classroom-friendly explanation

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 the brain.

For school staff, the practical message is simple: prevention, early recognition, and rapid response matter.

A safe school day protects 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.

The plan should be specific enough that a substitute can follow it.

The school must follow your child's plan - not a generic food list

The clinical 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

What school staff need to do

- Serve only foods approved in the written plan
- Know exactly what to do if food or formula is missed
- Notify the family about incomplete meals or unexpected foods

Never change protein, formula, medication, or 'sick day' instructions without the metabolic team.

Prevent prolonged fasting and protect treatment time

A sample school-day rhythm

Arrival	Confirm supplies and morning intake
Morning	Planned snack and hydration
Midday	Low-protein lunch; document intake
Afternoon	Formula, fluids, medication, or snack as ordered
Dismissal	Send relevant intake, symptoms, or changes home

Ask the school

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

G-button and formula needs are part of educational access

TIME

Allow extended breaks

Formula, fluids, and medication may require more time than a typical classroom break.

PLACE

Provide an appropriate space

Offer a comfortable, clean, and private location when privacy is preferred or required.

LEARNING

Do not penalize missed class time

Provide flexible access to instruction and a reasonable way to recover missed work.

Clarify who is trained and authorized, where supplies are stored, and what happens during trips or drills.

Illness or poor intake can become urgent quickly

Potential triggers

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

Possible signs of high ammonia

- Nausea or vomiting
- Lethargy or unusual sleepiness
- Confusion, agitation, or mood change
- Unsteady walking or slurred speech
- Any student-specific early warning sign

Do not wait for a textbook symptom. Follow the student's emergency plan and contact pathway.

Emergency response: recognize, notify, and follow the written plan

1	**Stay with the student**	Keep the student calm, comfortable, and continuously observed.
2	**Notify the nurse**	Move to the designated safe area and request immediate evaluation.
3	**Call the family**	Report the symptoms, intake, timing, and actions already taken.
4	**Use the individual plan**	Only authorized staff should give formula, fluids, or medication as written.
5	**Escalate when directed**	Call 911 if the plan directs it or symptoms persist or worsen; identify UCD and possible hyperammonemia.

Put the emergency plan where people can act on it

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

Confirm that every copy is current - and that the school has a process for replacing outdated versions.

Health and educational plans do different jobs

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 the school for an individualized evaluation. A UCD diagnosis alone does not determine the exact plan or services.

UCD can affect learning, flexibility, and participation

Needs vary widely - observe the individual student rather than assuming a profile.

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

Match classroom support to the observed challenge

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

Protect belonging as carefully as medical safety

NORMALIZE

Treat feeding needs as routine

Avoid comments that make formula, food differences, or nurse visits feel unusual or disruptive.

INCLUDE

Plan for parties and activities

Prepare approved alternatives and preserve participation whenever possible.

INTERVENE

Watch peer interactions

Address teasing or bullying promptly and involve school supports when needed.

Ask the student and family how much information they want shared - privacy preferences are individualized.

A simple daily checklist can close communication gaps

Track only what the team agrees is useful

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 handoff home should answer

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

Before school starts, confirm four things

1. **Current plans** — Medical, nutrition, emergency, and educational documents match the student's needs.
2. **Named people** — Primary staff and backups know their roles across the full school day.
3. **Supplies + access** — Food, formula, medication, equipment, storage, and private space are ready.
4. **Communication** — The school and family know what will be reported, how, and when.

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