CSNK2A1 FOUNDATION

Okur-Chung Neurodevelopmental Syndrome (OCNDS) and Educational Support

A Guide for Educators

Prepared by the CSNK2A1 Foundation Parent Advisory Board with collaboration from Deanna Heuring, Ed.S.

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Legal Disclaimer:

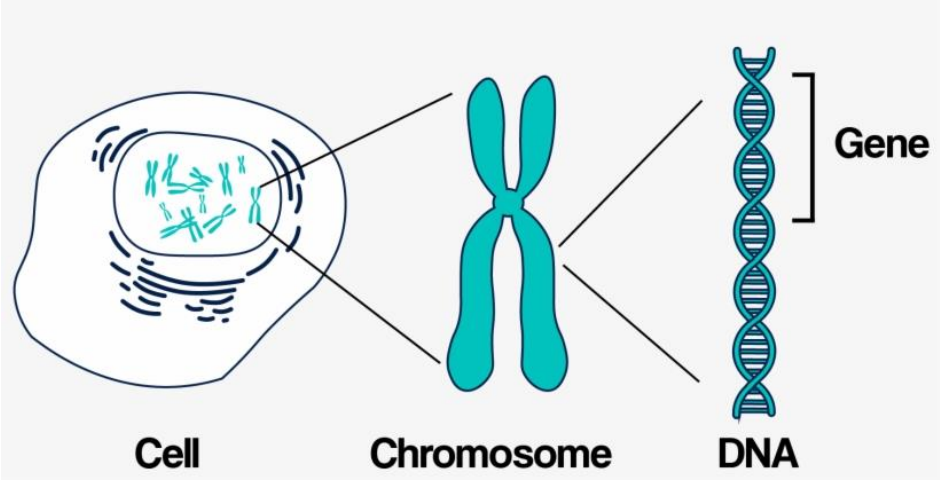
The information provided in these slides is for **informational purposes only** and is not intended as legal advice. Every child's educational needs and Individualized Education Program (IEP) process are unique, and laws and regulations may vary by state and school district.

We encourage parents and caregivers to consult with a qualified **special education attorney or advocate** to better understand their rights and options under the Individuals with Disabilities Education Act (IDEA) and other applicable laws.

The CSNK2A1 Foundation does not provide legal representation or advice but is committed to empowering families with knowledge and resources to advocate for their children effectively.

Okur-Chung Neurodevelopmental Syndrome (OCNDS)

An ultra-rare genetic syndrome first identified in **2016**.



Caused by mutations in the **CSNK2A1** gene on chromosome 20.

The gene **CSNK2A1** produces a protein called **CK2**.
The CK2 Protein is found in **every cell of the body** and plays a crucial role in development.

Individuals with a mutation in this gene have Okur-Chung Neurodevelopmental Syndrome.

- Currently there are about 392* individuals diagnosed with **OCNDS** in the world.

- **Not everyone with OCNDS will present in the same way or to the same degree, from *mild to severe*.**

*updated Q1 2026

BRAIN

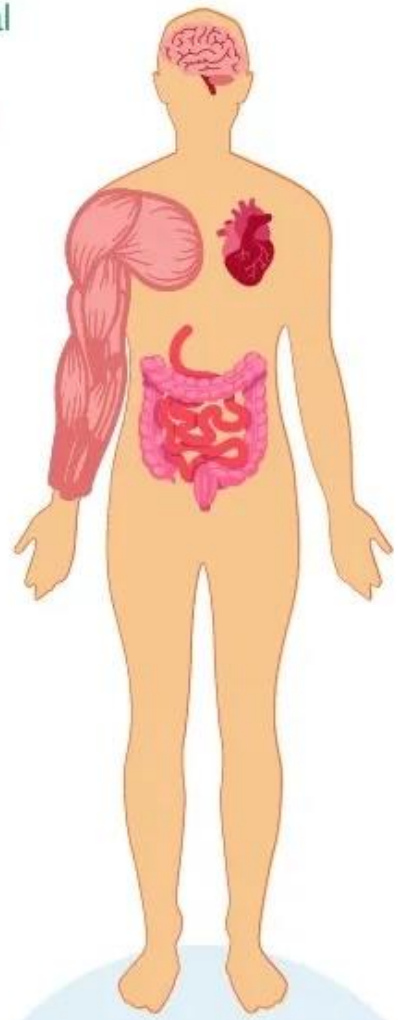
- Developmental delay/intellectual disability
- Speech delay/inability to speak
- Brain MRI abnormalities
- Sleep issues
- Microcephaly (smaller head)
- Seizures (~25% of individuals)
- Learning disabilities
- Sensory challenges

MUSCLE

- Hypotonia (decreased muscle tone, mobility issues)
- Musculoskeletal findings (loose/hyperextensible joints, scoliosis, kyphosis)
- Ataxia / gait difficulties / poor coordination

GI

- Difficulty feeding
- Difficulty gaining weight
- Constipation



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FACE

- Dysmorphic facial features

EYE

- Vision difficulties (strabismus, refractive error)

ORAL

- Misaligned teeth
- Cavities

HEART

- Congenital heart defects

OTHER

- Behavioral issues (autism, stereotypic movements, aggression, ADHD)
- Postnatal short stature

Clinical Features

Gene Reviews

Children with OCNDS benefit from:

Speech/Language Therapy

Early Intervention

Vision Therapy

Occupational Therapy

THERAPIES

Physical Therapy

Assistive Communication Technology

Behavior Therapy

Equine Therapy

Music Therapy

***Please note this is not an exhaustive list. Each individual will have their own therapeutic needs.**

Overarching Goals the Family has for the Team:

- **MINDSET**. Maintain the mindset everyone is working in the best interest of the student
- **MEETING BEFORE SCHOOL:** A team meeting before the school year to set student up for success.
- **COMMON METHODS:** Having common methods between home and school (i.e. phrases, behavior expectations, independence)
- **COMMUNICATION BETWEEN HOME & SCHOOL**: Ways to communicate regularly such as a notebook or daily chart that can go between home and school to maintain expectation consistency
- **DATA SHARING**: Sharing data between home and school therapists
- Big picture goals and the path to them. (i.e. use Charting the Life Course Trajectory)

Background information about OCNDS Caregivers:

- At any given time, Caregivers are juggling therapies, medical appointments, and phone calls for insurance coverage.
- Caregivers are valuable resources about their child and may know reasons for behaviors that don't seem obvious.
- If Caregivers get short or upset, it's not personal. Caring for a child with complex needs can be mentally, physically, and emotionally exhausting. Every day often comes with its own set of challenges.
- In new settings, certain behaviors may seem new to educators but are actually familiar patterns for the child. Caregivers can share context from past experiences to help address and reduce these behaviors effectively.
- Caregivers often feel unheard and misunderstood. As noted, there are only 319 individuals currently diagnosed with this condition. The closest support in a similar situation is hundreds of miles away.
- Many children with OCNDS have severe sleep disruption, meaning difficulty falling asleep or staying asleep, or they wake 4-5 times per night interrupting Caregiver sleep, leading Caregivers to be short on restful sleep.

Categories for IEP Teams to Consider

Language/ Communication

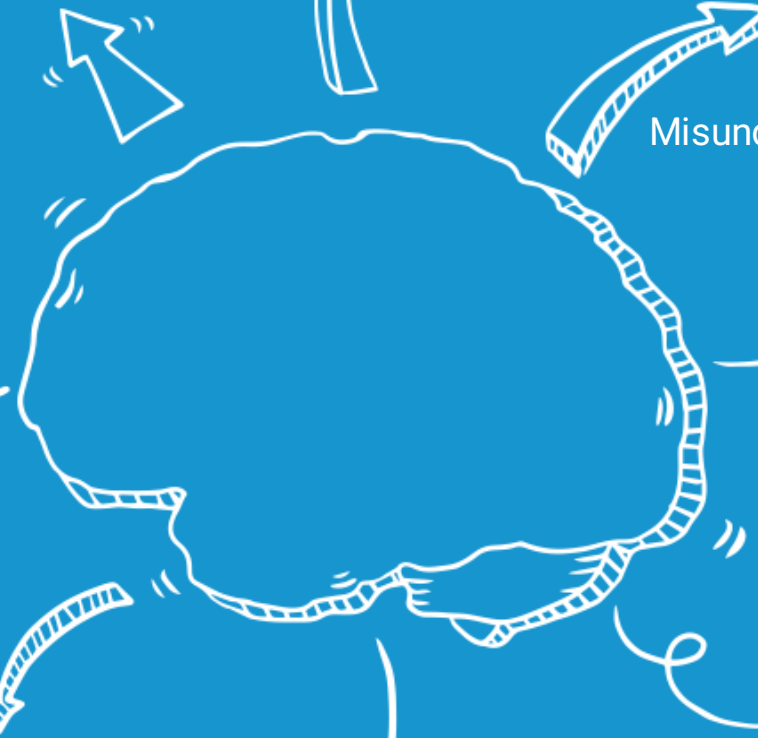
Slower receptive and expressive skills
May sign
May use device or assistance

Motor Skills

Gross motor/fine motor delays/disorders

Social/Emotional

Vulnerable to bullying
Misunderstanding of social cues/body language



Cognitive Abilities

Delayed processing
Impaired processing
Low IQ

Adaptive/Self Help

Executive Dysfunction
Delayed or missing adaptive skills

Sensory

Body doesn't take in stimuli normally
Sensory overwhelm
Fluorescent light issues
Sound Sensitivity

Speech

Delays
Disorders

Behavioral

Demonstrates behaviors unexpected for setting
Repetitions-words or routines
Schedule oriented

CSNK2A1 Foundation as a Resource

- Website www.csnk2a1foundation.org
- What is Okur-Chung Neurodevelopmental Syndrome - CSNK2A1 Foundation information page
- General Session Day 2 | Developing Social and Pragmatic Skills in School Age Children & Discussion

THANK YOU

for all you do educating children of all abilities!