THE CK2 BUTTERFLY COLLECTIVE

Uniting *CSNK2A1* (OCNDS) and *CSNK2B* (POBINDS) Neurodevelopmental Communities

"WHEN WE CONNECT, WE GROW. WHEN WE COLLABORATE, WE FLY."

Overview - Shared biology, Shared mission

CSNK2A1 and *CSNK2B* are two genes that encode the alpha and beta subunits of Casein Kinase II (CK2), a critical enzyme involved in many cellular processes including brain development. Mutations in each gene cause distinct neurodevelopmental conditions, Okur-Chung Neurodevelopmental Syndrome (OCNDS) and Poirier–Bienvenu Neurodevelopmental Disorder (POBINDS), respectively. While the CK2α subunit encoded by *CSNK2A1* retains catalytic activity on its own, its biological function is most fully realized when paired with the CK2β subunit encoded by *CSNK2B*. Together, these subunits assemble into the complete CK2 enzyme, a structure that visually resembles a butterfly. This imagery inspired the creation of the CK2 Butterfly Collective, a joint initiative to advance science, awareness, and support for both communities.

What is CK2?

CK2 is a critical enzyme made of two subunits: **01: CK2α = Alpha subunit** **02: CK2β = Beta subunit**

Together, they regulate essential processes in the developing brain. When mutations occur in either gene, neurodevelopment is affected, each resulting in a distinct disorder. However, biologically, the two genes are part of the same system.

Why We've Joined Forces

Just as the full power of the CK2 enzyme emerges when its alpha and beta subunits work together, our communities are strongest when we come together in partnership. By forming the CK2 Butterfly Collective, we share research, amplify awareness, and build a united support system for all families affected by CK2-related disorders.

CK2 Butterfly COLLECTIVE

Why the Butterfly?

CK2's 3D protein structure looks like a butterfly[1] in flight: a symbol of resilience, transformation, and unity. Our collective reflects this beauty in biology and in our connected missions.

[1]*Niefind K, Guerra B, Ermakowa I, Issinger OG. Crystal structure of human protein kinase CK2: insights into basic properties of the CK2 holoenzyme. EMBO J. 2001 Oct 1;20(19):5320-31. doi: 10.1093/emboj/20.19.5320. PMID: 11574463; PMCID: PMC125641.*

CSNK2A1 (CK2α) → OCNDS

Okur-Chung Neurodevelopmental Syndrome/*CSNK2A1*-Related Syndrome

- **First described: 2016**
- **Inheritance: *de novo*, autosomal dominant**
- **Gene: *CSNK2A1* (Alpha subunit)**

Symptoms:

- Speech delay/disorder or absence of speech (~95%)
- Global developmental delay (~95%)
- Motor delays, gait abnormalities, hypotonia (~81%)
- GI symptoms (e.g., constipation, ~71%)
- Intellectual disability (~57%), autism (~38%), learning challenges
- Sleep disruption (~85%)
- Feeding issues (39%)
- Epilepsy (~33%)
- Vision (~63%) and dental anomalies
- Short stature (~48%), hypermobility, skeletal differences

Treatment Focus:

- Speech therapy, including assistive communication, starting at 12 months of age
- Intellectual and behavioral assessments with appropriate educational support
- Physical and occupational therapy for motor delays
- Monitor and evaluate for epilepsy and gait difficulties
- Monitoring growth and use of G-tubes if there are persistent feeding issues
- Evaluate vision, teeth, and immune system function

CSNK2B (CK2β) → POBINDS

Poirier–Bienvenu Neurodevelopmental Disorder/*CSNK2B*-Related Syndrome

- **First described: 2017**
- **Inheritance: *de novo*, autosomal dominant**
- **Gene: *CSNK2B* (Beta subunit)**

Symptoms:

- Epilepsy (~90% of individuals, often early-onset & drug-resistant)
- Developmental delay, speech and motor impairments (~89%)
- Intellectual disability (~80%)
- Neurobehavioral/Psychiatric manifestations (~31%)
- Low muscle tone (~46%), ataxia/impaired coordination (~12%)
- Physical traits: short stature (~20%), facial & skeletal anomalies (~50%)
- Dental issues (missing/atypical teeth, ~17%)

Treatment Focus:

- Anti-seizure medications
- Early intervention therapies
- Growth hormone therapy (in select cases)
- Support for learning and behavioral needs
- Speech, physical, and occupational therapies as needed

STAY CONNECTED

CSNK2A1 FOUNDATION

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