Lundbeck's Commitment to the DEE Community

Partnering to drive meaningful change for those impacted by DEE

Lundbeck is committed to advancing care for people living with developmental and epileptic encephalopathy (DEE)—by listening to the community, partnering with advocacy organizations, and driving innovation where need is greatest.



Understanding the Need

DEE includes a multitude of rare, severe epilepsies that begin in infancy or childhood, and are often characterized by treatment-resistant seizures and developmental challenges. Many families face significant daily burdens, and treatment options remain limited—underscoring the urgent need for continued progress.



Examples

- Angelman Syndrome
- CACNA1A
- CDKL5
- CHD2
- Dravet Syndrome
- Dup15q
- GABA-A
- GLUT-1
- GRIN
- Infantile Spasms
- KCNT1
- Koolen-de Vries
- Lennox-Gastaut Syndrome
- PCDH19
- Rett Syndrome
- SLC6A1
- SNC8A
- SCN2A
- STXBP1
- SNYGAP1
- Tuberous Sclerosis Complex

This list is **NOT exhaustive.** There are **hundreds of rare epilepsies**, and new underlying causes continue to be identified.

Lundbeck's Commitment in Action

LISTENING TO AND PARTNERING WITH THE ADVOCACY COMMUNITY

We actively engage with advocacy groups and families to understand their **experiences, priorities, and unmet needs**. By working directly with communities affected by DEE, we:

- Listen to those most impacted, including families and caregivers
- Use real-world community insights to guide education, support, and research efforts

CLINICAL STUDIES DESIGNED WITH PEOPLE LIVING WITH DEE AND THEIR FAMILIES IN MIND

We include **a wide range of rare epilepsies in our clinical studies to reach more individuals**, and we integrate community input to:

- Inform the clinical study experience for individuals, families, and caregivers impacted by DEE
- Shape study-related support and practical tools for families and caregivers

SHARING KNOWLEDGE

We **center the voices of people living with DEE** to support the community. Recent initiatives include the **D.E.E.P. D.I.V.E. educational series**, designed in part to:

- Share **Progress** updates
- Translate DEE research **Data** (eg, community surveys)
- Provide meaningful, accessible **Insights** to support understanding of DEE
- Reinforce our **Vision** to help people impacted by DEE navigate their journey
- Increase awareness and **Education** (eg, clinical trial recruitment)

> **"Easy to follow and incredibly informative.** This webinar made a real difference in my understanding of DEE and its potential impact on my child."
>
> ***—Parent of a child living with Dravet syndrome***

D.E.E.P. D.I.V.E.

Developmental and Epileptic Encephalopathy **(DEE)**

- **D**EE **P**rogress
- **D**ata
- **I**nsights
- **V**ision
- **E**ducation

Advocacy at Our Core

At Lundbeck, advocacy is embedded in how we work, and we will remain committed to listening, learning, and partnering with the DEE community—to advance care, elevate voices, and help improve outcomes for those impacted by DEE.

Want to Learn More About DEE?

Visit our website

Scan to receive updates from Lundbeck

For more information on Lundbeck's US Patient Advocacy activities contact:
uspatientadvocacy@lundbeck.com

This educational document is intended for US distribution only and is not a substitute for medical advice. Always talk to your healthcare provider.

References: Child Neurology Foundation. Child Neurology Foundation.org. Accessed July 8, 2026. Lundbeck. Dup15q Alliance. www.dup15q.org. Accessed August 20, 2026. Freibauer AE, et al. *Seizure*. 2023;110:119-125. Scheffer IE, et al. *Nat Rev Dis Primers*. 2024;10(1):61.

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