

# JDVS FOUNDATION NEWSLETTER



Fall 2024

## 2025 Summit Planning and GiveLively

Thank you to the community members that joined our First Summit Planning Meeting last month. It is not too late to get involved. Rooms are ready to [book now](#). Family participation is very important to ensuring the success of the event for everyone involved. A few teams have been created on our GiveLively platform (QR Code below) and we would love to see more for the Giving Season!

### NEW PUBLICATION!!

#### Cyclic Vomiting Syndrome in Patients Affected by Jansen-de Vries Syndrome: Results From an International Survey

This publication clearly puts the Cyclic Vomiting Syndrome in the spotlight as part of JdVS which will be important for professionals as well as caregivers to know.

This is a great example of how the families and doctors can work together to increase insight into this relatively novel syndrome.

### Other activities:

- Hosted quarterly Medical Advisory Board meeting in October.
- Accepted into CombinedBrain and attended first PAG meeting
- JdVS and Special Education presentation at Lasell University highlighting how educators can support unique learners
- Dr. Lachman has a publication pending peer review titled: **Proteomics and phosphoproteomics profiling in glutamatergic neurons and microglia in an iPSC model of Jansen de Vries Syndrome**
- Collaboration between JdVS and Boston University School of Graduate Medical Sciences Genetics Counseling program
- **Dr. Curry** will present on JdVS at the ACMG Meeting in March 2025
- Awarded grants from Horizon Therapeutics/Amgen and Ultragenyx

### Mighty Networks

In August the Mighty Networks platform was launched to better connect JdVS Community Members. Mighty Networks is a virtual meeting place for us to share experiences and offer support to each other as we navigate this rare journey. Mighty Networks offers the ability to sort by discussion topics and join channels based on your areas of interest related to JdVS. If you are a JdVS Community member and want to join, please email [kara@jansen-devries.org](mailto:kara@jansen-devries.org)

**JDVS FAMILY AND MEDICAL  
PROFESSIONALS SUMMIT  
CHICAGO, ILLINOIS  
JULY 11TH-13TH, 2025**

### JdVS Community At a Glance

8 new JdVS Champions and their families have connected with the community since August 2024, ranging in age from 19 months-32 years old.



 give lively

