

# JDVS FOUNDATION NEWSLETTER



Summer 2024

## Planning for the 2025 Summit

The countdown is on to our next JdVS Family and Medical Professionals Summit! Next year we will be gathering in Chicago, Illinois at the Embassy Suites by Hilton O'Hare/Rosemont. This location was chosen because of the convenient location to the airport and surrounding attractions. It will be an event full of sharing experiences, learning from medical professionals, sibling get-togethers, and so much more! In the next few weeks we will be sending out helpful information on how to begin your own JdVS fundraising campaign.

### Natural History Study

You helped to raise \$50,000 to make this possible! A Natural History Study is a crucial step helping researchers and clinicians understand Jansen de Vries Syndrome over time. Radboud is committed to studying JdVS to better understand the progression of the syndrome and support further inquiry into potential therapeutics or interventions. Stay tuned on how you can get involved and be part of the data collection process!



## JdVS To Attend Global Genes

This September, three JdVS Representatives will fly to Kansas City, Missouri to collaborate with and learn from those leading Rare Disease Initiatives at the Global Genes Rare Disease Advocacy Summit. If you would like to learn more about how JdVS is involved in the greater Rare Disease mission, please email us at [info@jansen-devries.org](mailto:info@jansen-devries.org)!

## JdVS Community At a Glance

Currently the JdVS Foundation is connected with close to 300 diagnosed individuals and their families from all over the world. In 2024 alone we have connected with 24 new families, ranging in age from 9 months to 27 years old. New areas represented include Hong Kong and Israel. Our community continues to grow each week!

