

Enriching lives
through education,
awareness and
research.

PARTNERS



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Koolen-de Vries Syndrome
Foundation

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KDVS

Koolen-de Vries
Syndrome Foundation

Our Aims

● To act as an international group, supporting, informing and networking with anyone affected by KdVS and with any interested professionals.

● To promote awareness of KdVS.

● To bring KdVS families and individuals together to support one another.

● To support and promote relevant research projects and encourage participation from KdVS individuals.

● Collaborate with our Medical Advisory Board to provide up-to-date information regarding new KdVS research, surveys, findings and medical advances.

● To help facilitate social gatherings and educational events for individuals and families affected by KdVS and medical professionals and/or support staff.

● To ensure hospitals, doctors, health authorities, genetic clinics and other professionals are aware of the KdVS Foundation so patients can access available resources.

● To give presentations about KdVS to parent groups, professionals and the public.

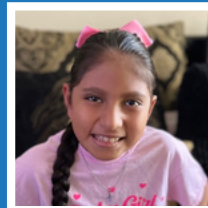
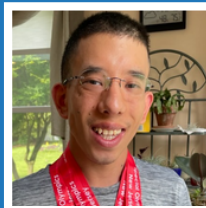
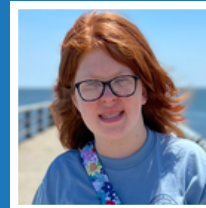
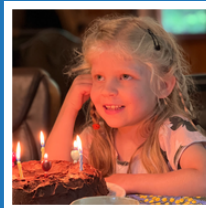
● To represent the voice and perspectives of KdVS families and individuals by participating in professional working groups, advisory boards, committees and conferences worldwide.

● To raise funds to support the group's activities and produce literature for increased KdVS awareness.

Koolen-de Vries Syndrome (KdVS) is a rare genetic condition caused by partial loss of part of chromosome 17 [17q21.31 microdeletion], including the gene called KANSL1. It can also be caused by a change in the KANSL1 gene.

While these genetic changes can cause developmental delays, learning difficulties, and create possible health concerns, individuals vary in the degree to which they are affected.

Every Kool Individual is Unique!



Ways We Serve

KdVSF Scientific Meeting and Patient Advocacy Summit

KdVS researchers meet to review findings and plan future partnerships, while the Patient Advocacy Summit unites individuals, families, caregivers and professionals to learn, connect and share resources.

Annual Kool Kampaign Fundraiser

Each year, the KdVS Foundation asks our community to reach out to their friends and families to solicit donations that will go directly toward funding research and our new multidisciplinary clinic, the Kool Klinik.

KdVS Foundation's Kool Klinik

Opening in April 2026, the multidisciplinary Kool Klinik, housed at Children's Hospital Colorado in Aurora, CO, provides KdVS-specific, coordinated care from a team of expert specialists all in one place.

KdVSF Connect Virtual Series

These virtual events occur monthly and focus on bringing the KdVS community together to receive new support, share resources and simply connect.

Contact Database

The KdVS Foundation keeps a confidential global database of families, helping connect them locally, map our community, and share KdVS numbers with our Medical Advisory Board.

www.kdvsfoundation.org