

Enriching lives
through education,
awareness and
research.

PARTNERSHIPS



CONTACT US

Koolen-de Vries Syndrome
Foundation

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KDVS

Koolen-de Vries
Syndrome Foundation

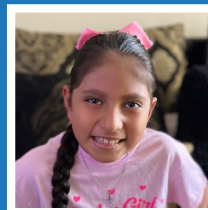
Our Aims

- 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!**



www.kdvsfoundation.org

Ways We Serve

KdVSF Scientific Meeting and Patient Advocacy Summit

KdVS researchers gather at a scientific meeting to review recent findings and strategize for future partnerships. We hold the Patient Advocacy Summit as a way to bring KdVS individuals, caregivers and families together, while also connecting them with researchers and other medical professionals. Families can learn, connect and share resources at this summit.

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. This two month event kicks off every July 17th when we celebrate KdVS Awareness Day.

KdVSF Connect Virtual Series

Our KdVSF Connect virtual events occur monthly and focus primarily on bringing the KdVS community together to share topics of interest, receive new support, and share resources.

Contact Database

The KdVS Foundation maintains a confidential database of KdVS families from around the world. This database allows us to help families make connections in their geographic areas, understand where the KdVS community resides and share with our Medical Advisory Board the number of individuals registered.