

■ Help Secure an ICD-10 Code for Koolen-de Vries Syndrome

Why This Matters:

Right now, there is no specific ICD-10 medical code for Koolen-de Vries Syndrome (KdVS). This makes it harder to track the condition, advocate for insurance coverage, and advance research. Together, we can change that.

✉ ■ How You Can Help

We need families to **email their providers** (geneticists, pediatricians, neurologists, therapists, etc.) and ask them to support the creation of an ICD-10 code for KdVS. Every voice counts — your outreach can make a real difference.

1. Download the Draft Letter	■ Include link to letter – This letter explains the request to your provider.
2. Personalize Your Message	Add 1–2 sentences about how the lack of an ICD-10 code has affected your family (insur
3. Send Your Email	Email your provider or care team directly. • Subject line: <i>Support for ICD-10 Code
4. Spread the Word	Share this guide with other KdVS families, post on social media, and ask any healthcare

■ Sample Social Media Caption

Our KdVS community is working to secure an official ICD-10 code — and we need your help! Email your provider using this letter: [Insert link]. Together, we can make it easier for all KdVS families to access care and advance research.

■ Track Our Progress

We'll keep the community updated on how many families have taken action. Together, we are stronger — and every email brings us closer to success.