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Dear Family,

Welcome to the Joubert Syndrome and Related Disorders Foundation! The foundation is comprised of individuals living with Joubert Syndrome (JS) and their family members, as well as medical professionals and scholars who have an interest in advancing the research related to JS. As a group, we are here to support you as you navigate the recent diagnosis of Joubert Syndrome. It is likely that the news of the diagnosis has left you with more questions than answers. Please know that during this time you can find support and access resources through the Joubert Syndrome and Related Disorders Foundation website (www.jsrdf.org). On the site, you will find the following information:

- [An overview of Joubert Syndrome \(JS\)](#)
- [Healthcare recommendations](#)
- [Personal stories and testimonials from JS families](#)
- [Informational videos from researchers/professionals in the field](#)
- [Information about the biennial family conference](#)
- [Grants to defray significant costs](#)
- [A way to connect with other families through private social media groups](#)
- [Tips and resources for navigating life with JS](#)

In addition to accessing the website, please email us through the general email address for the foundation: info@jsrdf.org. If you choose to share contact information, we will be in touch to get you connected with our beautiful community of individuals with JS, family members of individuals with JS, medical professionals, scientists, and researchers who are dedicated to raising awareness and supporting one another.

We realize that receiving a Joubert Syndrome diagnosis may be the beginning of an unexpected journey for you. Our hope is that we, as fellow members of the JS family, can offer guidance along the way. As our website states, "Wherever you are in your journey, we can help." We look forward to connecting with you!

With love,
The Joubert Syndrome and Related Disorders Foundation
Family Support Committee

Joubert Syndrome and Related Disorders Foundation (JSRDF)
is a non-profit 501(c)(3) organization [Tax Exempt #52-1871536]

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