



The 2021 Koolen-de Vries Syndrome Foundation Patient Advocacy *Virtual* Summit will take place from July 14-16, 2021. Alicia Holcombe is the chair of the Summit and is available to answer any questions, concerns or comments. [Alicia@kdvsfoundation.org](mailto:Alicia@kdvsfoundation.org). Summit Committee Members: Jess Collier, Angela de Jong, Kaci Fisher, Alayna Haynam, Ashley Point, Shelley Stagner.

#### **Whom should attend?**

We have invited many KdVS experts to speak at the summit. As always, any family members or friends who want to learn more about KdVS are welcome to register and attend--moms, dads, grandparents, siblings, neighbors, doctors, therapists, and friends.

#### **When can I register?**

June 2021 we will open registration for the virtual summit.

#### **What is the schedule?**

We will have a mix of recorded and live events. Recorded presentations will be available July 1, 2021 before the live sessions taking place July 14-16. We ask that you prepare by watching the recorded session before July 14<sup>th</sup>.

#### **How much will registration be?**

TBD. Please understand it takes resources from the Koolen- DeVries Syndrome Foundation to host an event such as this and to bring you experts to help advocate for your KdVS individual.

#### **What technology will I need to participate?**

We will be using Zoom for live sessions; we ask that you have a working camera and microphone. Below is a tutorial about how to use Zoom as a participant:

[Zoom Tutorial](#)

#### **What if I miss a session, will it be recorded?**

Yes, all the live Q&A sessions with the experts will be recorded and available for replay. Group parenting & grandparent sessions will not be recorded. You can access all recordings following the event for 60 days after 7/1/21.

**I would like to sponsor part of the summit or I have a friend, company or foundation that might be interested. Whom should I contact?**

We welcome all sponsorship ideas. Please email [kdvspas@kdvsfoundation.org](mailto:kdvspas@kdvsfoundation.org) with any contacts or interested persons.

**I have additional questions, whom should I contact?** [kdvspas@kdvsfoundation.org](mailto:kdvspas@kdvsfoundation.org).