As you prepare in the upcoming months for your arrival in Phoenix, we hope that you feel like you are about to step into the best family reunion you've ever been to! Your conference chairs have been working hard to plan and secure a variety of different sessions and activities for the week. We are confident that this will be the best conference yet!

Below is a brief summary of what the week will look like with a couple of sneak peeks at some of the sessions that we'll be offering. Please keep in mind that this is a tentative schedule and there may be changes made before July!

We will open the conference Wednesday afternoon with an Orientation hosted by your conference chairs. This is a great time to get a feel for what the week will look like and put some faces to the names that you see all the time! We'll then enjoy a message from a Keynote Speaker and begin introducing partner families! You'll hear more about that as we get closer! We'll have dinner as a group where you'll be addressed and welcomed by the current President of the JSRDF; Eric Swenson.

Join us after dinner for a Pool Party!

Thursday morning we'll get started right after breakfast with a mix of medical talks as well as some great family support talks given by Phoenix Organization, <u>Ability 360</u>. You'll hear from Dr. Meral Gunay with an update on the study being put on by the National Institute of Health as well as, Dr. Theo Heller and Dr. Wadih Zein from the NIH team. Dr. Maida Chen from the University of Washington will discuss respiratory topics and we're excited to be bringing back Dr. John Sayers from the United Kingdom to discuss some exciting information regarding the CEP290 gene and other advancements in research around cystic kidney disease related to Joubert Syndrome.

You can also expect to see small group discussions as well as consultations with the doctors that presented earlier in the day.

Moms – Thursday night is your night get away! We'll gather at Seclusions at the resort for Mom's Night Out!

Friday is another jam packed day of incredible family support sessions. We'll get the opportunity to partake in some really great workshops presented by another local Phoenix organization, Raising Special Kids. We'll start the morning with the Positive Behavior Solutions workshop, then move into another workshop focused on parents of teens called Transitioning to Adulthood, we'll also be looking at IEPs, what your role is as the parent in the special education process, how to prepare, and how to be an effective participant in your child's IEP meeting. We'll end the day with a workshop designed to help couples make and keep a healthy relationship while raising a child with special needs; Resilient Relationships.

You can also look for talks from Dr. Dan Doherty the leader of the University of Washington's Hindbrain Malformation Research team, Dr. Jordan Simmons will discuss kidney involvement and you'll also hear from Dr. Ian Glass and Dana Knutson regarding Prenatal Diagnosis and Family Planning. There will also be consultations scheduled for these doctors on Friday afternoon.

We will close the night with a celebration to honor the memories of our JS angels. Please consider joining us for this very special event.

Dads – your night isn't quite over yet. Watch for details to come on where to gather for Dad's Night! Saturday, the conference will wind down with some great sessions on Building a Voice for your child, Alternative Therapies, Guardianship and Financial Planning as well as yoga for caregivers and affected individuals! Please join us after the sessions for the Volunteer Fair and General Meeting. More information will be provided on both events as the conference gets closer.

Make sure you pack your dancing shoes and dress to impress! Saturday evening, we'll close the conference with dinner, dancing and a silent auction! We'll welcome the new President of the JSRDF, Larry Munger, as well as announce the location for the 2019 conference! You do not want to miss this!