



TOP 12 PARENT TIPS

Welcome to All Things Kabuki and the Kabuki syndrome family! The best advice often comes from those that have traveled a similar journey, so we asked the community to tell us what their top tips for new families were.

1. BUILD A TEAM YOU TRUST. Your child's medical team will grow over time. Here are some things to consider:

- Try to find specialists that have experience treating other patients with Kabuki. Remember that Kabuki is rare and many medical providers and staff may not be familiar with the disorder. Be prepared to spend time educating your child's providers. If they're not interested in taking the time to listen and research, they're probably not the provider for you.
- It's ok to question your medical team and seek a second opinion! ALWAYS listen to your gut!
- Keep as many specialists in one network as possible. This makes it easier for your child's team to access medical information.
- It's ok to fire a doctor! Don't be intimidated by the white coat. You are your child's best advocate. If you feel like you're not being heard, or your child is not receiving the best care possible, it's ok to find a new provider.

2. CREATE A MEDICAL BINDER with your child's most relevant medical information. Do your best to keep your binder relatively light so it's easy to transport to appointments. Some ideas on what you should include:

- List of your child's medical providers and their contact information.
- List of your child's diagnoses and surgical history.
- List of current medications.
- Copies of current labs that may be relevant to diagnoses or treatment.
- Genetic test result showing affected gene and variant.
- Genetic, neurology and developmental reports.
- Reports relevant to diagnoses or current treatments.
- ATK brochures and/or cards!



3. CREATE AN 'ABOUT ME' INFORMATION GUIDE about your child that can be easily shared with child care providers, teachers, therapists and even family members. Include information relevant to your child's underlying diagnoses, likes and dislikes, what may cause them anxiety or trigger negative behaviors, any allergies and unusual special needs (tube fed, medical equipment requirements, etc.)



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4. DON'T GET CAUGHT UP IN DELAYED MILESTONES. Most children with Kabuki syndrome have proven to meet developmental milestones ... in their own time. While a typical child may walk around age 1, Kabuki Kids (according to parent reports on ATK's survey) walk on average at the age of 2. We encourage you to continue working with your child and trust that in their time, they will meet the milestones you'll long to see.

5. WHEN YOU GET DISCOURAGED ... don't forget where you started and how far you and your child have come! You can't pour from an empty cup. Get creative with self-care opportunities and know it's ok to seek clinical help or advice.

6. EARLY INTERVENTION has proven to be invaluable to our children's developmental success. Request a referral to a Pediatric Neuro-developmentalalist to have a full evaluation done on your child. If the waitlist is long, request a referral to have an evaluation done by a Pediatric Neurologist. Additionally, talk to your provider about the benefits (or need) for Speech, Occupational and/or Physical Therapy.

7. RESEARCH LOCAL SERVICES in your area. Does your state offer TEFRA Medicaid? Do you have access to respite care and waiver services? If you're not sure where to start, visit our website (allthingskabuki.org) or contact ATK and one of our team members will help.

8. PARTICIPATE IN RESEARCH. Consider participating in active research opportunities. The first gene known to cause Kabuki syndrome was discovered in 2010. This would not have been possible had families not been willing to participate in research.

9. GET INVOLVED ... ADVOCATE! *Advocate: to publicly support or recommend a particular cause or policy.* We encourage families to join our efforts to advocate for Kabuki syndrome. Together we can reach more, educate more, and raise awareness nationally for a rare syndrome that affects someone we love. ATK will provide you with the resources you need to educate your community.

10. LET YOUR KID BE A KID. Therapy and medical appointments can be all consuming. It's ok to take a break and allow your family time to breathe.

11. LEGAL DOCUMENTS are more important than ever. Things to consider having in place, in the event of an emergency or sudden death:

- Temporary Guardianship – Durable Power of Attorney
- Living Will
- Last Will & Testament
- ABLE Account



12. DON'T GO IT ALONE! Get involved in the Facebook support groups, attend conferences or local gatherings, connect with other families in your area and never be afraid to reach out! The Kabuki syndrome family is here to support you! *Best Wishes, Team ATK*