

WILLIAMS SYNDROME A PARENT PERSPECTIVE



Children's
HOSPITAL • ST. LOUIS
BJC HealthCare

 **Washington**
University in St. Louis
Physicians



*Sarah Moonier,
contributing writer
of this brochure,
is pictured here with
her daughter Katie.*

AS A PARENT OF A YOUNG CHILD with Williams syndrome (also known as Williams Beuren syndrome or WS), I understand that the beginning of a diagnosis can feel very overwhelming and frightening. The good news is that you are about to embark on your greatest journey. It is filled with triumph, joy and love. There will be low points, but as you navigate through this syndrome you will find that it will change you for the better. You are not only a parent...

YOU ARE THEIR TEACHER

- Your child is full of potential. Learning will take longer, but many of their goals will be reached, one benchmark at a time. There will be times in their journey where learning will be difficult, transitions stressful and frustration will mount, but with support from educators, medical professionals and therapists, you will learn ways to help your child achieve a level of independence that will make their lives meaningful and well adjusted.
- Don't give up on your hopes and dreams for your child. Victories are greater and the milestones sweeter. As their first teacher, you have a large hand in their success.
- As soon as possible, seek out programs that will help your child. I started with Parents as Teachers and then moved to the Early Childhood Intervention program in my county. Since then, we have participated in music therapy through her school, horse therapy and recreational programs for children with special needs.
- These programs are not only for your child, but you, too. Professionals can help you become a better teacher.
- Find the value of music. Children with WS may be highly receptive to music. Music may help your child absorb more information, reduce anxiety and increase on-task behaviors.

YOU ARE THEIR ADVOCATE

- Along your journey, you will encounter people who do not understand. Whether it's a lack of education about WS or fear of the unknown, some people will not recognize the potential in your child.
- Ask those people, whether they are friends, family or health-care providers, to learn about WS. Share resources with them such as the Williams Syndrome Association website (williams-syndrome.org). If they won't learn, find others who will. It is important that you surround yourself with people who help you meet your family's needs. The result is that your child will be surrounded by caring, encouraging people.
- Find people who focus on what your child can do instead of what they cannot. Look for practitioners who are mindful of research and open to learning new things.



- Don't be afraid to ask for what you feel your child needs: ask for more time, more therapists, more support. You will find that the more educated you become about WS and what works for your child, the better advocate you can be. You never know what opportunities will arise unless you ask for them.

YOU ARE THEIR ROCK AND CHEERLEADER

- Individuals with WS are very emotional and empathetic. This characteristic can be very endearing and at times challenging.
- Embrace the emotions of your child and learn ways to soothe them. Celebrate with them and use their desire to please as rewards for their achievements.
- In your child's times of fear and anxiety, you can use emotion to help them find comfort.
- There are many strategies that educators and doctors can share with you about helping your child overcome their fears.

YOU ARE AN HONORARY MEMBER OF AN AMAZING COMMUNITY

- The world of WS can be lonely at times, but it doesn't have to be. Although the syndrome is relatively rare, there are amazing support groups to help you. Seek them out.

- Start with the Williams Syndrome Association. They offer support groups on social media, local events and national opportunities to meet others.
- Go to conventions and area events. By getting involved, you will find the journey more manageable and you will meet amazing people who will understand you every step of the way.

YOU ARE HUMAN

- Accept that you'll go through stages of grief. Let yourself be mad, sad and in denial. It all leads to acceptance and eventually advocacy.
- Learn to be understanding of others in your family, as each person copes with the diagnosis differently.
- You'll find some family members and friends lose tact and don't know what to say. Forgive them. You'll find that over time, many of those same people will fall in love with your child and become important parts of their life.
- Care for yourself. Your life will change and you may feel at times like you are immersed in the world of WS, but you, your marriage, and your other relationships still matter.
- Seek out family and friends to watch your child so you can go on a date, see your friends or spend time alone. If you don't have support within your family and friends, ask your doctors and therapists about respite support. There are programs designed to give families who have children with special needs time to recharge. It's important for your mental health.

YOU ARE ABOUT TO CHANGE FOR THE BETTER

Finally and most importantly, approach this journey with humor and a positive outlook. You will sleep again, you will feel at peace, you will find normalcy. It takes time and those first years are the hardest, but it will come. Live your life in the moment and don't focus on the fear of the future. You will come to discover the blessing you have been given. You will find that along this journey you will grow great friendships and learn amazing things. You will come to know love, pride and laughter like you have never experienced before. As a parent who has walked in your shoes, I welcome you to the amazing world of Williams syndrome.

ST. LOUIS CHILDREN'S HOSPITAL

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For more information about the Williams Syndrome Center
or to make an appointment, call
314.454.KIDS (5437) or 800.678.KIDS (5437)

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