

The Special Friends Foundation Pamphlet

Welcome to the Special Friends Foundation (SFF). SFF primary assists individuals with Rubinstein Taybi Syndrome (RTS) and their families. It is important that every child and their family have access to the resources they need in order to provide an enriching and loving environment. It is in this supportive home, that each child will reach his greatest potential.

What is the Special Friends Foundation?

The Special Friends Foundation (SFF) is a nonprofit organization established in 1997 by Chris Garavente, who's fourth child, Louis, was diagnosed with Rubinstein-Taybi syndrome (RTS).

The primary mission of the Special Friends Foundation is to provide information and resources to individuals with RTS and their families.

What is Rubinstein Taybi Syndrome (RTS)?

RTS is a rare syndrome. It refers to a specific pattern of physical features and developmental disabilities, which occur together in a consistent fashion. Individuals with RTS have short stature, developmental delay, similar facial features, and broad thumbs and first toes. (Stevens & Carey, 1991)

What causes RTS?

The cause of RTS is unknown and there is no reason to believe that anything the parents did or did not do during pregnancy caused the child to have RTS. (Stevens & Carey, 1991)

If I have another child, will that child have RTS?

It is highly UNlikely. There is less than 1% chance of having another child with RTS.

Are there medical tests to specifically diagnosis RTS?

No, RTS is diagnosed by specific physical characteristics. A genetist or other medical professional will make the diagnosis.

Is there a cure?

There is not a cure at this time. Currently, research is being conducted to identify the chromosome involved with RTS.

What medical issues can I expect?

It is important to understand that all children are individuals and thus have different characteristics. And just as any child will have varying degrees of medical issues, so will each child with RTS. It is very important to note that your child will NOT have all these issues, and in fact can have very few of the medical issues. The medical issues include feeding difficulties, such as reflux, respiratory infections, kidney issues, ear and eye infections, cardiac issues, tear duct obstruction, sometimes diarrhea but usually chronic constipation, undescended testicles in males, and skeletal issues. (Baxter, 2000)

“Travis is an absolute joy in our lives. When he was born, the devastation that I felt kept me from understanding what a wonderful part he and yes, even his small delays and handicaps would be in our lives. He is very loved by us all –including everyone at his school and everyone at our church. I still have moments when I wish he were ‘normal’ and could have more of a ‘normal’ life. I am sure that this will never completely subside, but I have come to love and appreciate Travis for what he is instead of dwelling on what he isn’t. With the acceptance of these problems comes such an overwhelming appreciation and desire for him to simply reach his potential. He has become an important part of our family. He is happy and so are we.” Excerpt taken from A Book for Families.

What developmental issues can I expect?

Each child with RTS will develop at his or her own rate. Even though children with RTS share many similarities, parents must remember that their child is an individual who will develop to his own potential. Most children with RTS are described as happy, loving children that enjoy music and swimming. (Baxter, 2000)

Speech is one of the slowest developmental areas of a child with RTS, therefore special emphasis should be placed on speech therapy using a total communication approach and should start as early as possible. Physical therapy and occupational therapy may help the child with his progress in reaching developmental milestones. The extent of cognitive disability varies in each individual. Typically, children with RTS will be involved with special education. (Baxter, 2000)

Where can I find emotional support?

The RTS community is a very loving community that offers a large basis of support. There are many RTS groups organized by parents in different countries. Most can be found on Facebook.

Where can I find financial assistance?

The Special Friends Foundation offers financial assistance to cover expenses incurred due to RTS that are not covered by medical insurance or Medicaid. SFF reviews each case individually and pays the providers directly.

How can I help SFF to help others?

SFF is a nonprofit organization. We greatly appreciate both time and financial donations. All donations to the foundation are tax deductible to the full extent of the law.

Reference:

Baxter, Lorrie (2000): The RTS Brochure First Printing.

Stevens, CA and Carey, JC (1991): Rubinstein-Taybi Syndrome: A Book for Families.