

Creative ways to help kids understand rare diseases

Parents and doctors can help children understand rare diseases like TSC and SJIA with the help of cartoon dogs and comic book superheroes.

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Any diagnosis of a disease can be overwhelming, but even more so for parents who have been told their child has a rare disease. Helping children understand something that seems confusing and scary can almost seem to be a bigger challenge than dealing with the disease itself, but several resources are available to help parents better communicate this information with their children.



Comic stories can help young patients understand and better tolerate their symptoms.

Understanding the complexities of disease can be challenging for young children who live with tuberous sclerosis complex (TSC), a condition that appears as noncancerous tumors that can occur in major parts of the body like the brain, skin and kidneys and can also result in epilepsy or developmental delays. Enduring repeated visits to the doctor's office and undergoing the needed screening processes, while dealing with behavioral symptoms, is often difficult for a child to handle. Siblings who witness their brother or sister with TSC suffer a seizure can find the experience downright frightening or confusing. Although TSC is a rare disease, its effects are more widely felt than many realize. "It's the leading genetic cause of epilepsy and a leading genetic cause of autism," said Kari Luther Rosbeck, president and CEO of the Tuberous Sclerosis Alliance, on the Rare Disease Report. "In the United States, two children are born each day with tuberous sclerosis complex."

While most physicians try to explain the condition as best they can, children often respond better to visuals, such as animated videos. Now kids can get a better understanding of TSC by watching the cartoon storybook "Turbo & Scott," or reading the eBook with their families. Designed by Novartis and narrated by Rosbeck, the story follows the story of a young boy who has TSC named Scott and his best friend Turbo, a stuffed dog. The tale takes the two friends through some of the ups and downs of dealing with TSC, taking the approach of tackling a difficult subject through the voice of a children's book character. From medical visits to show and tell at school, Turbo is alongside Scott every step of the way, highlighting the fun times that they share despite some of the challenges they face.

Families of children who have systemic juvenile idiopathic arthritis (SJIA), a rare, serious and distinct form of childhood arthritis that can cause spiking fevers, rash and joint pain, must manage unpredictable symptoms. Because inflammatory symptoms may precede joint symptoms in SJIA, a child may see many different doctors before being diagnosed correctly. In many cases, the diagnosis is made by a pediatric rheumatologist. Even

after diagnosis, understanding the ins and outs of what is considered an “autoinflammatory disease” can be baffling for children, who just want to understand why they are feeling sick.

So Novartis and MediKidz Limited co-created, "What's Up With David? MediKidz Explain Systemic Juvenile Idiopathic Arthritis", a superhero adventure, to explain SJIA in comic book format. MediKidz Limited is a medical information and publishing company that specializes in explaining health conditions to kids and teens. In the United States, copies of the comic book are available to families free of charge through many doctors who treat SJIA. In the story, a boy named David is frustrated by his symptoms that cause fever, visible rashes on his body and pain that makes it hard for him to move quickly. The superheroes that reside in Mediland, a planet shaped like the human body, are determined to help David understand why he feels this way, and take David on a trip through Mediland so he can better comprehend how the immune system works, why he experiences certain symptoms and how medicines can make him feel better.

The comic book, which is peer-reviewed by two pediatric rheumatologists, explains how rare SJIA is and illustrates how autoinflammatory diseases are different from other forms of autoimmune diseases, such as rheumatoid arthritis.

“Systemic Juvenile Idiopathic Arthritis or SJIA is a rare, disabling and distinct form of Juvenile Arthritis for which few educational resources exist,” said Norman Ilowite, MD, Chief, Division of Rheumatology, The Children’s Hospital at Montefiore, in Bronx, New York. “This full-length comic book explains SJIA specifically, and not only may help the diagnosed child understand their SJIA, but may also be helpful for siblings, classmates and even teachers who are not familiar with SJIA and its symptoms.”

Sometimes it takes colorful characters – like stuffed dogs and superheroes – to help kids really understand their rare diseases.

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