

Sam's Story

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Nancy and Paul recently adopted a two year-old toddler Sam (Date of Birth: 2017) after dealing with infertility issues (see Nancy's story). Sam is a typical toddler, good-natured and very inquisitive. Typically, before the finalization of an adoption, children are required to undergo a routine examination by a physician. However, the required examination is not meant to be a complete health screening, and many conditions are not even checked. Therefore, Nancy and Paul are bringing Sam to see the Pediatrician at the local medical centre for a standard physical examination and to assess his health status (referral made by family physician).

PATIENT HISTORY

Very little information was known about Sam's biological parents. However, it was known that they died in an automobile accident when Sam's father suffered a massive heart attack behind the wheel, just before Sam turned 2 years of age. In the past two weeks, since Sam was adopted, he has done very well adjusting to his new environment. Moreover, his immunizations for his age were partially completed. Nancy and Paul did their very best to recover as much as they could from Sam's past. Keeping in touch with their pediatrician was an important part of this, so they regularly scheduled visits.

Sam's adoptive parents, Nancy and Paul, have noticed some greasy/oily stools in his diapers 6 months after having adopted him. In addition, they are concerned about his wheezing (e.g., breathing). Nancy calls her family physician and gets a referral for Sam to see a specialist.

Initial visit

The initial visit with the pediatrician consisted of a physical examination, blood work, and a chest x-ray. *(These values are added to the PowerPoint)*

Follow-up visit

The weather is very hot and humid, which makes it almost unbearable to be outside. Sam's parents parked their car and brought Sam into the air-conditioned comfort of the Medical Centre pediatric clinic. Sam appears to be breathing easier once he is in the cool air.

They were immediately seen by the specialist, and Nancy expressed her concern over the colour of Sam's sputum. The sputum Sam has been coughing up was green and viscid.

While talking with Nancy and Paul about Sam's sputum, the specialist looked over at Sam and noticed a white 'frosting' on his face (*the "frosting" is an indication of salty build-up on the drying edge of sweat*). The specialist asked Nancy and Paul if they had noticed this salty-build-up before.

“That must be why his skin tastes a bit salty when I kiss him on the cheek,” Nancy replied.

The specialist then went over the blood count and chest x-ray results with his parents, Nancy and Paul.

After describing the chest x-ray results to them, the specialist had a hypothesis about Sam’s chest x-ray results. To test her hypothesis the pediatrician ordered a sweat chloride test (*the result is listed below*).

Sam was diagnosed with cystic fibrosis. Nancy and Paul would have to make many adjustments to care for Sam.

Sam would require chest physical therapy, exercise, medications, digestive support, and psychosocial care. Nancy and Paul were also informed that Sam would likely experience: frequent hospitalizations, complications such as CF-related diabetes, depression, anxiety, and time-consuming treatment plans that can take 2-3 hours each day.

After hearing about Sam’s diagnosis, Nancy and Paul do their own research and try to learn as much as they can about Sam’s quality of life.

Nancy and Paul consult Sam's Pediatrician and he provides health education to them regarding Sam's growth and development. *Sam cannot understand his health condition*, at this age and he is focused on exploring the world and learning from others. The reactions and interactions he has with his family will shape his future *self-confidence*, it is important for Sam to feel in control of his health as he matures to manage his health needs and live a normal life with accommodations.

Nancy and Paul want Sam to live like a “normal” child and participate in activities regardless of his CF. Nancy and Paul seek advice from Sam’s pediatrician who emphasizes the importance of Sam engaging carefully with other children who have CF.

They enroll him in swimming classes, where he is the only child with CF and Sam was progressing well for his age. He is in a group class with other children and *feels shame swimming* because they do not play with him in the pool.

Some of the children are fearful of Sam's skin which has a mottled and pruritic appearance due to his chloride sweat similar to a dermatitis, as well as his *frequent coughing and wheezing*, they do not understand that Sam has a genetic health condition. Nancy consults her pediatrician and informs them that Sam has been having more *temper tantrums* recently and she cannot understand why as he enjoyed swimming previously.

The pediatrician informs Nancy to continue to bring Sam to his swimming lessons, and eventually his tantrums will resolve as *physical activity* is necessary to support his growth and development and to be patient with him as he is still learning a new routine.

Sam gets older and begins to be more aware that his lifestyle is much different compared to others. He’s been in and out of hospitals for lengthy treatments most of his life. A rule-follower, Sam is careful to take his medications on time and do whatever is needed to maintain his

treatment regimen. Only then can he hope for a lung transplant. Until one day, Sam received a phone call from his physician stating that a new pair of lungs had arrived. Sam is excited but at the same time, he feels uneasy about the procedure and hopes to speak with others to feel reassured that he will get over this sense of fear. Sam is looking forward to a smooth and quick recovery so he can get back to his swimming classes.

Key words: Adoption , Chest Physio , Cystic Fibrosis , Genetics , Immunizations , Lungs Erikson Psychosocial stages of development, Forced Expiratory Volume (FEV1) , Physical Activity, Diet, Lung transplantation, Immunosuppression, Anxiety

Additional Resources:

Cystic Fibrosis: <https://www.youtube.com/watch?v=yd-HmBYpvK4>