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Rebecca's Story

Rebecca at the age of five years old is considered a legend in her medical community. We received word in December 2007 of her unique diagnosis. She has a partial duplication of Chromosome 17p (13.2-13.1) du novo. At the time she was the only documented case in the world with this chromosome abnormality.

Rebecca sees nine different specialists on a very regular basis. Her Neurosurgeon monitors her Hydrocephalus (water on the brain) and Arnold Chiari Malformation (her cerebellum is growing into her spinal cord 9 cm) and to look for tumors due to the TP53 gene factor (cancer suppressor gene). Her Neurologist monitors her medications for her seizures. Her GI doctor monitors her reflux, her g-tube and her weight and diet. Rebecca's ENT monitors her reflux, her nodules on her vocal cords, her ear tubes and her higher range hearing loss. Her Geneticist documents her growth and development. Rebecca's Endocrinologist monitors her limited height growth and hormone levels. Her Ophthalmologist monitors her eyesight. Her Dentist manages her teeth from her prolonged reflux and retarded tooth growth. Her allergist monitors her triggers. And most importantly her pediatrician looks at the whole child. We just added her newest specialist, her orthopedist who now monitors her Legg Calve Perthes Disease – A vascular necrosis of the hip (the blood supply going into the head of her femur has been compromised and her bone in the process of dying). It has been discussed the need for reconstructive surgery on her hip once she goes into the re-calcification stage of her disease. In total Rebecca has been hospitalized 17 different times sixteen of those hospital stays happened within a twenty two month period of time and our house burned down on her third hospital stay. This child has lived through more trauma than people live through in a lifetime. All of these specialists do not include her outpatient and school Occupational Therapists, Physical Therapists and Speech Pathologists who see her on a weekly basis to help her achieve whatever milestones are possible. My time off is spent in those waiting rooms and diagnostic and therapy centers.

Her medical costs have been staggering. When she was on Neocate – that formula costed \$1100.00 a month which we were able to get her insurance company to pay for through the help of our Congressman. Now her formula costs which are out of pocket now are around \$500.00 a month due to the fact that she is able to eat table food by mouth limiting the use of her G-tube. Her G-tube supplies can run \$400.00 a month which again not covered because she is only using the G-tube for medications at this point. This does not include the \$7700 we paid just last year in co pays and pharmaceuticals only. That was with an HMO plan. UPS, my husband's employer has switched to a PPO plan which we are responsible for 15% of all costs now. My husband and I work a total of five jobs and do not qualify for any state or federal monies. The only program Rebecca would be eligible is the Katie Beckett Waiver. This waiver would pay for medical costs incurred above and beyond her private insurance plan. The problem is she was placed on that waiting list three years ago at 198 on that list. She is currently 92 on that list. So we have another 3 years of waiting. The only way we are managing is the fact we are paying an interest only credit line. There are no extra's in our life. We do not have cable, we are not able to put money away for my other two children's college education, and forget putting money away

for retirement. There is no money in savings so if our car were to break down – or her hospital bill was outrageous – we have no extra money to be able to provide. How nervous do you think I am with the instability of this economy?

These medical costs are only one part of the equation. Navigating the Special Educational system in the Connecticut public school has been rude awakening. These educators are not working in the best interest of our children. They are working through the financial constraints of their system and thus not adequately providing for these special needs children so these children have the potential of success however big or small. Especially now with budget crisis' in many of our cities and towns – it is the special education department which is being affected most often. In the city of Shelton Rebecca would have been impacted by this years budget deficit for her 1:1 paraprofessional and her media specialist who is helping her paraprofessional program her \$10000.00 communication device positions were in jeopardy. That was with a \$700,000.00 budget crisis. With a \$4,000,000.00 budget crisis for the next fiscal year the schools superintendent is talking of removing all para professionals from the classroom. When Connecticut is the third worst state in the country when it comes to funding for special needs – to have a school system that targets those most vulnerable kids on the school district is downright appalling given the gross capita of this state. If I were you the legislature, I would be embarrassed to stand before me to say you are helping my child. The challenge is only you can change the language in the law and the funding to the schools to protect those most vulnerable. When I have to incur legal expenses just to protect those services in place for my daughter currently – it further angers me. The fact that healthcare has been stalled in the senate is further irritation that you the legislature on both the federal and state level are more interested in your own political agenda's then listening to your constituents and looking and helping the real need in the community. We need help. I ask that you help us.



