Telomere Biology Disorders and Your Child at School



Your child's complex medical needs might make it difficult to get the right school plan in place, but it can be done! Federal Education law makes it possible to individualize your child's school plan based on their specific needs. Everyone's school plan looks different. There is a lot of information out there, and each school and district operate a little differently. Here are some ideas for school services that your child may benefit from and qualify for. Ask for a team meeting to discuss the right resources for your child.

Resource 1: School Healthcare Plan

It is possible that all you need to do to support your student is great communication with the school nurse. The school nurse will walk you through whatever forms you will need to make sure that all emergency plans are documented and easy-to-follow. If there is not a nurse at your child's school, each school district has a manager of the nursing team, who can help you make decisions about next best options.

Resource 2: A 504 Plan

504 plans are also known as "accommodation plans," which help to provide support and eliminate barriers for your child's unique circumstances. Before you ask for a meeting, spend some time googling accommodation plans to get some ideas of what might work best for your child. Is all they need an elevator pass, free bathroom pass, and trips to the school counselor for periodic support? Perhaps your child needs more time on tests, a quiet place to take them, or the ability to have someone else take notes for them. All of these accommodations (and more) are possible under a 504 plan, and are individualized to your child's unique needs.

Resource 3: An Individualized Education Plan (IEP)

Does your child have a qualifying disability? Does the disability affect their educational performance? Are they unable to make progress in the general classroom without specially designed instruction? Based on the answers to these questions, your child may qualify for an IEP. This plan will decide which specialists may work with your child at school (for example, Physical Therapy, Occupational Therapy, Speech Therapy), and determine if they need special education for math, reading, and writing instruction. An IEP gives your child a limited number of "minutes" for each of these services, per week. Sometimes the IEP services are provided in the classroom, and sometimes the children are pulled out to a special classroom, otherwise known as a "resource room."

Resource 4: Homebound or Home/Hospital Instruction

If your child has extensive medical needs (such as in the case of a bone marrow transplant) and is not allowed to go to school, districts often provide a teacher to come to your child, either at your home or at the hospital. Some schools write Homebound or Home/Hospital Services into an IEP or 504 plan as a necessity that your child needs to keep up during a long absence. Some major children's hospitals have a Hospital School program, which provides the instruction at the hospital. Check with your care team to discuss the options.

Resource 5: A combination of each of these resources!

Some kids have a School Healthcare Plan and a 504 plan. Others have an IEP and a 504. Some have just a 504 and Homebound instruction when needed. You do not need *all* the plans, but talk to your school about what is *most appropriate* for your child.