

We sometimes find that the wisest words come from those living with CF just like you. The following pieces were written by parents in our CF center based on their experiences managing CF in school. We and they hope you find this information helpful. As always, the CF team is here to answer any questions you have.

## Educating Schools and Advocating for Your Children

*It is important that people that will be interacting with your child on a regular basis have an understanding of Cystic Fibrosis and how it affects your child. Since my daughter began pre-school I have gone in to talk to her teachers. I also send home a letter each year to the parents of her classmates. When she began elementary school I knew it was important to have a 504 Plan in place. This ensures that my daughter's needs are met and accommodations are made which guarantee her an equal educational opportunity. Everyone, from my daughter's classroom teacher to the school secretary, is aware of her CF and that understanding makes everything easier. For example, when I am signing my daughter in late, I know that the secretary understands why my daughter is coming into school late. I don't have to go into a big explanation or feel uncomfortable. With understanding comes acceptance.*

*In addition, I visit my daughter's classroom at the start of each school year and speak to her classmates about CF. I read a short story about CF, explaining things as they relate to my daughter. I give the students an opportunity to ask questions or share things in their own lives that may be similar (ex. some kids have asthma and can relate to the use of a nebulizer or an inhaler, or some have been hospitalized for various reasons). The more children understand, the less strange things seem. In turn, many of her classmates have become advocates for CF. I often have other parents tell me that their children explain CF to other people. It goes a step further when these children come out and support her at the Great Strides walk. Children genuinely like to help one another and like to feel a part of things. My daughter loves the supports she gets from her peers!*



## The Importance of a 504 Plan

*A 504 plan is important because it ensures that your child's educational and medical needs are met. Having a 504 plan will guarantee that your child will receive the accommodations that will help her be successful in the classroom as well as keep her safe. We knew we wanted our daughter to begin school with a 504 plan in place. We approached her elementary school the spring before she was to begin kindergarten. To our surprise, we were met with some opposition from the school nurse and guidance counselor. Since our daughter would only be there for a half day, they tried to tell us she didn't need one. We knew that it was important for this plan to be in place and felt all her teachers needed the information it contained. It is the child's right to have a 504 plan and we did not waiver.*

*Our daughter's plan includes accommodations such as private and unlimited bathroom privileges, unlimited access to water and what to do in case there is a problem with her g-tube. Absences and latenesses are addressed as well as getting make-up work in a timely manner. No modification is too insignificant to include in the plan. Putting it in writing ensures that it must be adhered to. Every teacher that comes in contact with our daughter throughout the school day has a copy of her plan. A child may only see the physical education teacher once a week, but that may be the time an issue arises so that teacher needs to understand what is going on and how to help the child. The more the school staff knows about CF, the better they will be able to offer support and understanding. This plan will follow our daughter throughout her school years and changes can be made as needed. It is much easier to get a plan in place when your child is relatively healthy than to try to put one together when something is going wrong.*

## Help! There are other CF students at my child's school!

*When my daughter entered high school, there were 3 students with CF attending the same high school. My daughter was a freshman, there was a junior boy and an unknown senior, all with CF. The boy was well known to us, since he & my daughter had attended the same nursery and middle school. However, we were never totally certain of the senior girl's identity.*

*How does a parent handle this with the issues of common infections, and HIPAA? Firstly, it is important to have a 504 plan in place, and specify that your child should be separated from others that may have conditions that are infectious to your child. This includes keeping children with CF separate from one another. Most commonly this also means having your child's or the other child's seat moved away from someone who has returned to school following a respiratory illness, such as pneumonia.*

*It is important to have a discussion about your child's situation with the school nurse, the guidance counselor, the child study team (who sign the 504 plans) and the principal if necessary. In our case, a discussion with the nurse and guidance counselor was sufficient.*

*The school should make the best effort to separate students with CF in both time and space. Due to HIPAA laws, the administration should not reveal names of other CF students to you, however they should honor the concerns of all CF students by separating CF students in time and space. This means not scheduling them together for common classes, and if that must happen that they be separated by the maximum possible distance (at least 6 feet). Additionally they should not be assigned to work together on group projects. It is important to have a discussion with your student about the risks of hanging around other students with CF, and reinforce hand hygiene, covering your mouth, etc. If my child was in the same class as another CF student, I would ask for a classroom reassignment.*

*The CF community is small; other CF patients are known within the same community. If possible, I have found it helpful to discuss common health concerns with the other CF student's parents. The other CF parents are usually very supportive and will work together to protect the health of our CF students.*

