

Back to School for your Child with TSC

Dear Parents, Guardians and Friends,

As the new school year quickly approaches, I thought I would write a short letter to everyone about TSC and your child in school. As an Elementary Educator, and a mom of a 4 year old with TSC, I know this can be a stressful and anxious time for parents and children.

It is important to work with your child's school to try to get the best educational experience possible for your child. As you know, TSC affects every child differently. While some children may be average or even above average, others might be very developmentally affected. However, it is important to realize that TSC's affects can sometimes be subtle, and it is important for educators to be aware of your child's condition and the possible impacts it might have on learning. For example, many children with TSC may have more anxiety than children without TSC, or may have specific learning areas that are affected, making it more difficult or take them longer to learn certain skills or gain knowledge.

Here are some ways you can work with your child's teacher to help ensure a productive and happy school year:

- **Don't** wait until the first day of school to contact your child's teacher and educational team regarding their condition. As a teacher, I know how hectic and busy it is on that first day of school is. Approaching your child's teacher on this day may not be the best way to ensure they get the best help and that your message is heard. It is better to contact the school during the last week of August. The staff is often back at work, but there are no classes running, so the teachers and resource team might have time to focus on your child's needs.
- **Do** approach the school in the last week of August (or better yet in May before the next school year) to discuss your child's condition and potentially how the school will accommodate them. This is particularly important if your child will be attending school for the first time, or if they are starting at a new school.
- **Do** ask if you can meet their new teacher, any EAs that might be involved and the resource teacher, as well it may be a good idea to introduce your child to the principal.
- **Do** be upfront about your child's condition. Some parents worry about "labelling" their child-especially if their child is developmentally typical. However, as a teacher I know it is always best to have more information then less-remember you and the educational team are in a partnership-give them as much information as possible to help them do the best job they can for your child. There is also an important safety consideration. Even if your child has never had a seizure, if they have TSC there is always the possibility that they could develop seizures in the future. By letting the school know that, and what to watch out for, you increase the chances that if a seizure were to occur it would be dealt with appropriately and quickly.
- **Do** carefully read any information that comes home.
- **Do** read over and take an active role in developing the IEP. This is meant to be a working document to help accommodate your child. You have the right to

contribute to its development, and you know your own child best! The goals on the IEP are what the school is working towards with your child-make sure you agree they are the best goals for your child!

- **Do** check to make sure things that are on the IEP are being followed through! The IEP is a legally binding document. If it specifies a certain amount of support for your child-that means they are entitled to receive it! It is up to you to make sure that they do. Unfortunately, with tight budgets and many competing requirements on a teacher's time, it can be a case of the squeaky wheel gets the grease.

There is also a wonderful resource on the TS Alliance website about school issues and TSC, as well as a new document about TSC and behaviour issues. Both of these excellent documents may be helpful to your child's teacher, resource team or school in not only planning how best to meet the needs of your child, but also in helping them to understand this complex disease and its implications for school. You may wish to print this document out and bring it in to your child's teacher:

<http://www.tsalliance.org/documents/Teacher%20Guide%20to%20TSC.pdf>

<http://www.tsalliance.org/pages.aspx?content=567>

Some important terms:

- **IEP** Individual Education Plan. [In Alberta there is a similar process called an IPP (Individual Program Plan).] This document is developed to specify how the school is going to help your child reach his/her educational goals. It may contain modifications to the regular curriculum in cases where the regular grade's goals may be deemed too difficult at this time for your child, or it may contain accommodations that specify how the school will accommodate your child so that they can achieve the goals of the curriculum. This might include things like a seat close to the teacher, extra time to complete seatwork, a special keyboard system to expedite writing tasks etc.
- **IPRC** – Individual Placement and Review Committee [This may be slightly different depending on your province]
- **EA** – Educational Assistant. This person works alongside a teacher as extra support for children who have special needs. In some provinces they may be called TAs or Teacher Assistants, but this title can be a bit misleading as they are not a teacher's assistant but rather a student's assistant. In some circumstances a student may work directly with an EA much of the day, whereas in other cases an EA may be in a classroom during only parts of the day to assist a particular student or group of students.

I hope everyone has a smooth transition to a new school year! It is an exciting time for you and your child. If you have any concerns, please feel free to contact me via email at:

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