



children's craniofacial association

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To the Teacher of a Student with a Craniofacial Syndrome

As a teacher you meet many students every single year. With a new year comes a new round of faces. Even then it is possible you may have never met a student with a craniofacial condition. Perhaps this letter is your first introduction. There are many syndromes and conditions that can be categorized as a craniofacial condition. The most commonly known one outside the craniofacial community is a cleft lip and/or palate. Additionally, there are syndromes such as:

- Apert Syndrome
- Craniosynostosis
- Crouzon Syndrome
- Facial Palsy
- Frontonasal Dysplasia
- Hemangioma
- Goldenhar Syndrome
- Microtia/Artesia
- Miller Syndrome
- Moebius Syndrome
- Nager Syndrome
- Pfeiffer Syndrome
- Pierre Robin Sequence
- Treacher Collins Syndrome
- Undiagnosed & more

CCA has educational material on most craniofacial syndromes on our website (ccakids.org) and in print by request.

We are writing this letter to help you prepare for your new student who happens to also have a craniofacial anomaly. In our craniofacial community we try to avoid the verbiage: defect, deformity, disfigurement, and the likelihood. Instead we refer to the conditions as a difference – a craniofacial difference. With many craniofacial syndromes there is no connection between the syndrome and the child's intelligence or development. Often, the child progresses through the growth stages of development on target, as expected. However, if you notice the child having a difficulty learning or a delay, intervention should take place at the earliest possible age and based on your education protocol.

The child's parents know the child more than anyone else. It is always a good idea to have an open dialogue to learn about the child's medical history, concerns, and general behaviors. They will also be able to help guide you on how to best introduce the child's condition to his or her classmates, if agreed upon. Our families often battle multiple surgeries, appointments, equipment and hurdles while balancing a normal family relationships. We appreciate you being patient with us and supporting us to the best of your abilities.

Some challenges to be aware of:

1. Bullying/Teasing
 - a. Unfortunately, this is a common concern in general at schools and is only heightened with a visible difference. We encourage you to intervene as needed. CCA provides a complimentary curriculum to educators that encourages anti-bullying, acceptance, kindness, and being a friend. Your positive steps towards educating students on the importance of acceptance will make strides for your students and our affected families. We strongly encourage you to implement this free curriculum (or parts of it) in your classroom.
2. Hearing Loss
 - a. Some of our craniofacial kids experience hearing loss. They rely on an in-the-ear hearing aid or a BAHA (bone-anchored hearing aid) for support. It may be helpful to have the student closer to the front and near the teacher. It is important to make sure the child keeps the hearing aid dry, has extra batteries in the supply closet, and potentially drying beads or a backup headband (where the aid clips on), if available. Finally, some of our children utilize some sign language. This can be fun to introduce to the class and a very valuable learning module if time permits. Even finger spelling and a few basic signs can make for a fun, inclusive lesson on hearing loss and communication techniques.

3. Feeding Tubes or Modified Diet

- a. Additionally, some of our children also have a feeding tube or modified diet, for at least part of their course of treatment. In such cases, there should be a dialogue with the school nurse and parents in regards to expectations and how these relate to school policy. Please try to communicate any food/cooking projects to parents in advance and understand eating can be an especially difficult time for our kids regarding teasing and bullying.

4. Surgeries/Appointments

- a. Craniofacial kids often have most of their surgeries at a young age and during development phases. It is not unusual for a child to miss school for doctor appointments and procedures. It is important to help the student find a way to keep up with their education. This will also prevent them from falling behind in learning. Other students may wonder why the child is missing class. Get Well cards and care packages are encouraged if a child is out for an extended time, to help them feel connected to their classroom and schoolmates. Additionally, work sent home in advance of absences is especially helpful for parents to prepare. Another great tool we've seen educators use is Skyping the classroom. This is not practical 100% of the time, but can certainly brighten the day while a child is homebound during recovery.

5. Sympathy and Pity vs. Empathy

- a. We want our teachers to know that the most important thing is our kids are like other kids. They desire acceptance and friendship. Sympathy is not needed or desired, rather, a genuine desire to help a child feel included in their classroom. As often as possible, remember the child wants to seem as "normal" as possible, and talking about their differences in a positive or neutral light is the best approach.

You may have ideas and resources that you have used, too. We welcome your suggestions, feedback, and professional opinion! Please continue this conversation with us and help us empower our families around the country. We believe in the work you do as an educator and we value your support.

Sincerely,

CCA Parent

Contact Phone: _____

Contact Email: _____

Additional Info: _____
