LETTERS TO NEW SCHOOL / STUDENTS OR NEW SCHOOL YEAR

children's craniofacial association
www.ccakids.org

To the Teacher and Classroom 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 like. 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.

<u>Some challenges to be aware of:</u>

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 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 Zoom-ing with 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

For more resources or to request books, curriculum, and educational materials, please visit: https://ccakids.org/choosekind-initiative-new/

For direct assistance and/or to request a speaker for your school or classroom, please contact:
Khadija Moten, kmoten@ccakids.com

August 2021

Dear Edison Intermediate School Community,

We are truly excited to be joining the Edison family this year as our oldest son, Kiran, is entering the 6th grade. Our fellow Jefferson Elementary families were able to extend a warm welcome to us when we moved to Westfield in July 2020, virtually at first and then in person during the last part of the school year. Now that school is officially back to "normal" (well, at least pandemic normal), we wanted to introduce the McKinley and Tamaques families to Kiran, who has a rare craniofacial condition called Goldenhar Syndrome. Kiran spent his first 8 months of life in two different NICUs (St. Barnabas and NYU) and has had a complicated medical trajectory since then, which includes 16 surgeries and over 60 hospitalizations. He will need additional surgeries as he continues to grow.

Due to his unique appearance, we anticipate that kids may have lots of questions for you. So below is a compilation of our own top "Frequently Asked Questions" from young inquiring minds:

1) Question: What's that thing on his head?
   Answer: Since Kiran's ears do not have openings (like our ears do), he needs a device to help him hear sound. The hearing device is called a BAHA – it stands for Bone Anchored Hearing Aid.

COOL FACT ABOUT THE BAHA

This device can be placed anywhere on your head (even your forehead!) and you can hear everything around you. But for best hearing, the device should be worn by the mastoid bone (a bone located behind your ear).

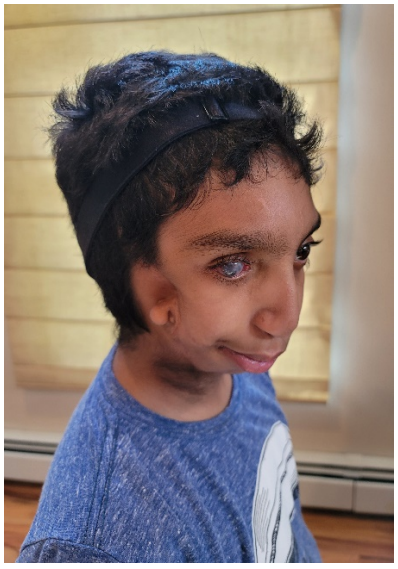
2) Question: One eye looks different than the other eye. Can he see out of both eyes?
Answer: Kiran is blind in his right eye, but he can see perfectly well out of his left eye. You may find him wearing a contact lens which has been painted to match the color and look of his left eye.

FUN FACT ABOUT KIRAN'S BLIND EYE

When Kiran was born, his right eye was very small, like the size of a pea. He wore different size contact lenses to help his eye socket widen until he was 2 years old.

We often joke that Kiran sees better with one eye than most people see with two! (It's true!)

3) Question: Why does his face look like this?
Answer: Kiran grew a little differently while in his mom's belly, and some parts of his face did not develop completely. The right side of his face is noticeably different since his eye, jaw, chin, and tongue are smaller than typical. Kiran's had 5 surgeries on his face so far and will have more as he continues to grow. All of the surgeries were to help him breathe and grow stronger.



INTERESTING FACT ABOUT KIRAN'S JAW

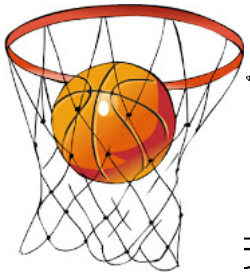
Kiran's craniofacial surgeon performed a novel jaw surgery on him when he was only 7 months old. He was one of the first kids to have artificial bone put into his jaw line.

4) Question: What is that backpack that Kiran wears with the tube hanging out of it?
Answer: Because it's hard for Kiran to eat by mouth, he gets his nutrients through a tube that connects directly to his stomach. This is called a gastrostomy tube, or G-tube for short. The backpack holds the pump that controls how much liquid food he gets and how fast it goes into his tummy.

FUN FACT ABOUT THE GTUBE

Kiran can "eat" when he's sleeping. The pump will run even when he's gone to bed for the night. And when he is sick, medicine is given through the tube instead of his mouth. That's right – he doesn't have to taste yucky medicine!

5) Question: Does Kiran like to play video games?
Answer: Oh yes!!! Fortnite is his favorite game right now, and he's excited to join the video game club this year. Kiran also loves to watch his iPad (especially YouTube) and tv/movies, travel, swim, play basketball, ride his bike, go on roller coasters, and spend time with friends and family. You may find it hard to understand his speech at first, but he is great about repeating himself or rephrasing his sentences so you know what he is trying to say. He is a whiz at electronics, so chatting over Messenger Kids or Hangouts is another great way to chat.



We can't encourage you enough to ASK AWAY! Feel free to reach out with any questions you or your children may have as they interact with Kiran. We are happy to help answer any questions, and no question is off limits (honestly!).

Dana (Mom):
dgunthorpe@yahoo.com,

Sharontha (Dad):

sharontha1621@gmail.com

You can also find us on

Facebook and LinkedIn

It's only a matter of time before you see first-hand the beauty and kindness of our own Wonder.

We look forward to seeing you this school year and around the neighborhood!

Sincerely,
Dana, Sharontha, Kiran and Caleb Fernando

April 17, 2008

Dear Parents,

At school today we talked about differences. We read a book called It's Okay to Be Different by Todd Parr, and we discussed all the things that make each of us unique and special.

I brought in a feeding tube and showed the class how it works. We also discussed what a trach is and how it helps people who aren't able to breathe through their mouth and nose. I showed the kids a trach and photos of kids with trachs and facial differences.

We talked about Peter's prosthetic ear and how we take it off every night at bedtime and put it back on in the morning. Peter's routine is get dressed, brush teeth, put band-aid on neck, put on ear, and put on glasses. Feeding tubes and taking ears on and off are such a typical part of our house that even my three-year old wants his ear taken off at bedtime! Obviously, normal for one household can be quite unusual for another.

Because Peter's ear has come off during class recently, the teachers and I thought it might be a good opportunity to open the issue for discussion and questions. No question is too silly or unimportant, and I am happy to answer as best I can.

Enclosed is a letter from Peter that I hope is written in a way for your child to understand. The other essays and "Meet Peter Dankelson" page is meant for your reading if you have any interest in more details about his condition. I have also enclosed information about Children's Hospital of Michigan who so kindly donated the folders. Peter sees about eight different specialists there, and we are very pleased with the medical care he receives. There is also a newsletter from the Children's Craniofacial Association, which is our family's favorite charity. This particular issue highlights our annual "Pete's Scramble" golf outing that raises money and awareness for CCA and kids like Peter.

Please feel free to email or call me with any questions about the enclosed information or presentation that was given to the class today.

Happy Spring!

Dede Dankelson
(248) 219-6544
dede@perceptiondesigns.com

"Beyond the Face is a Heart"

Hi,

My name is Peter Dankelson, and I would like to talk about a few things that make me different from you. Even though we've been in school for almost a whole year now, I know you were probably surprised when my ear fell off in class! I suppose that was pretty freaky, but for me it's just a typical day.

You see, I was born with a "small ear." It didn't grow with the rest of my body, so when I was five years old my entire family went to Washington D.C. to have a special big ear made my Mr. Robert Barron. He used to make disguises for people in the CIA to protect them during undercover work. Isn't that cool? You should see his office; it's full of ears, fingers, eyes, and noses. Sometimes he makes big ears for kids like me and other times he helps people who have been burned in a fire or had to have surgery from cancer. He is an amazing artist, and a very special friend to have. Mr. Barron is going to make me another big ear this summer since I've grown quite a bit over the last three years.

I have to take my ear off every day at bedtime. My Mom puts it back on in the morning before school. We use a special glue to make it stick to my head. I ran into another kid in the hallway the other day and that's why my ear came off. Actually, it's a pretty funny trick to play on people that don't know about it. One of my favorite things is to try and trick my doctors into examining my pretend ear because sometimes they forget that it's not real!

Sometimes when people first get to know me, they wonder about how I look a little bit different than they do. I run and play and like to be silly just like all other first graders. You may see some scars on my face and notice that I wear a band-aid on my neck. The bones in my face do not grow the same as yours, and in order to breathe and eat I have to have surgeries to make them bigger. I had a lot of trouble breathing when I was born, so my doctors gave me a trach. A trach is a breathing tube that goes in your neck. I had the trach for four years before I was able to breathe normally through my mouth and nose. In fact, I had to have several surgeries on my face to help place and lengthen bones. I wear the band-aid because there is still an open hole in my neck. It helps protect me from icky germs.

When I was born I was not able to learn to take a bottle because I was so tiny and weak. The doctors put a special "button" in my belly called a feeding tube that helped me eat. I still use my feeding tube because I don't eat enough on my own to grow big and strong. I'm still learning to chew and swallow food, so don't be surprised if I don't eat the same way you do. I'm sure you have all noticed my special shakes that I drink for lunch. We call them "brain shakes" because Mom says they will make me smart.

Thanks for letting me share some of my differences with you. Just remember that the next time you see someone who looks different, don't be afraid to say hi and maybe even make a new friend.

Love, Peter - April 2008

UPCOMING SURGERY LETTER

children's craniofacial association
www.ccakids.org

Ms. Reynolds

April 9, 2009

IE: Olivia Sanborn's Upcoming Surgery

Dear Kindergarten Friends,

As some of you know, Olivia is having surgery in Dallas, Texas, on April 16th. We will be leaving for Dallas Monday the 13th of April and will return on the 23rd. We wanted to take the chance to share some info, as we know that her friends will be curious as to what's going on.

Today we had a little discussion in Olivia's class (guided by her). We tried to keep it positive and simple. Olivia told her classmates that she is going on an airplane, will be staying in the hotel and then the hospital and how nice she is treated at both places. Olivia is very well aware that she has a surgery coming up and we are very honest with her. Before the surgery we are trying to focus on the positive and helping her feel loved and supported by her friends and family. We know that when she comes back to school, there will be many more questions. Olivia will have a halo device attached to her head/face when she returns to school. We are not sure of the exact date of this and some of her interaction for the first few weeks will likely be via webcam, home schooling/tutoring and short visits to the classroom. Ms. Agner (and the other kindergarten teachers) will discuss all of this before Olivia comes back to school and the children will see a picture of her before she's on the webcam or back to school in person.

The difference between this surgery and ones that Olivia has had before is she will wear the halo device for 9 weeks. We will return to Dallas the Monday after school gets out to have the device removed. We are planning a gathering at the park for some time in July so that all of her friends can see her after the device is removed. Another difference in this surgery is that this one will dramatically change Olivia's looks. It will improve her breathing and her speech, but she will look much different (and the surgery will overcorrect for a time). Our goal, of course, is to support her medically but also emotionally during this time.

We haven't specifically showed the children a picture of the device, but Olivia has explained it to them a little bit. If you are interested in seeing a picture of another child with the device on, please email us and we can forward that to you.

While we are gone, we know that Olivia would love to know that her are friends thinking of her. We have setup a "care page" for her online that allows us the capability to give a "report" (as often as we want) on how things are going to a whole group of folks at one time. It also allows a place for pictures and folks to comment with well-wishes. You can go to carepages.com and create an account and then add OliviaMSanborn to your dashboard. If you have any questions or can't sign in, please email us at Laurelsanborn@gmavt.net. It's a great way for us to get information out there, and it's also a GREAT source of support for us as we are away from home.

Also, our address at the hotel is:
Marriott Residence Inn, 7642 LBJ Freeway, Dallas, Texas 75251 USA, Phone: 1-972-503-1333 ,
Fax: 1-972-503-8333 and Olivia loves getting cards and mail.

Because we feel so much love and support in general from the RES community, we are confident that Olivia will have much support during this time. Thank you, and feel free to email or call us if you have questions, etc. at 802-434-5989 or 802-338-0200.

Sincerely, Mark, Laurel, Amelia and Olivia Sanborn

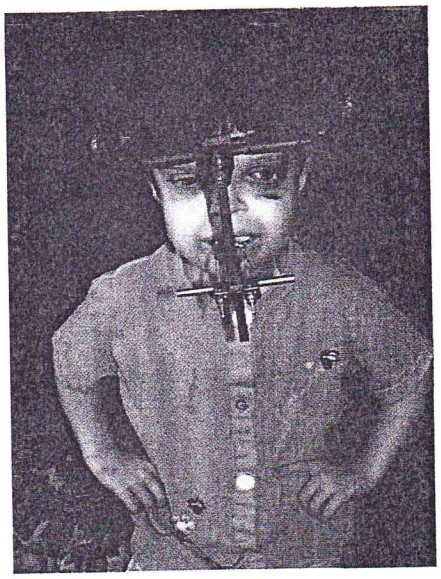
Reynolds

To share with all students at Morning/Class Meeting

One of our kindergarten students, Olivia Sanborn, recently had surgery on her head and face.
You may know Olivia or her sister Amelia, who is in second grade.

After her surgery, Olivia will be returning to school wearing a halo device on her head and face.
This purple halo helps to keep her bones in place while she is healing; it will also help her to breathe better.

This is a picture of Olivia after her surgery wearing the halo device.



When Olivia returns to school with this device, it is important to remember 2 things:

1. Safe space
2. What do we say when someone is using a medical device, like a wheelchair, a cast, or a halo device?

1 - When a person returns to school after surgery or an operation, their body is healing.
It is important that they are not bumped into or pushed in any way.
They need a large safe space around them so that accidents don't happen.
Teachers will be reminding students not to run or push ANYONE in the hallway.

2 – Olivia will look different wearing a device on her face.
She will be happy to return to school and will want to talk with her friends.
It is important to use kind words and talk to Olivia when she returns to school.

Here are some of the things you could talk to her about or that you could ask her:
-Are you glad to be back?
-How do you feel?
-Can I walk down the hall with you?

If you have questions about Olivia's halo device, you can ask Mrs. Crenshaw, Ms. Kane or your mom or dad.

Thank you for keeping our school a kind and caring community!