

children's craniofacial association

General Tips for Media Representation

What does the craniofacial community want you to know?

- We want to be accepted for who we are, not how we look.
- We want to be treated like everyone else, but unfortunately our community experiences isolation, teasing, and bullying.
- We want you to know that we are more alike than different—kids with a facial difference like the same things that kids without a facial difference like (video games, sports, dolls, music).
- We do want you to respectfully ask questions – get to know us and we might both make a new friend.
- We don't want you to make assumptions about our intelligence or abilities from your initial reaction to our facial difference.
- We desire both acceptance and inclusion. It's not enough *just to be nice*. Many of our kids are never invited to play or join in and this passive exclusion leads to social isolation, depression, and anxiety.
- Kindness is a universal desire. It is available to anyone, anywhere, at any time. Kindness overcomes social differences and leads to acceptance and inclusion.

General Respect

Use **Person First Language** (i.e., "I met Peter, who has Goldenhar syndrome," or "In the book, Auggie is the main character and he has a craniofacial condition," and "The kids I met have facial differences...").

Words to Use

- Difference
- Facial Difference, Physical Difference
- Craniofacial
- Craniofacial community
- Craniofacial anomaly
- Craniofacial condition
- Craniofacial syndrome
- Facial difference community
- Rare condition, rare syndrome
- Specific syndrome names (Apert, Crouzon, Goldenhar, Pfeiffer, Treacher Collins, etc.)

Words to Avoid

- Deformity
- Disfigurement
- Disability (okay if the person identifies as disabled, but do not assume)
- Disease or disorder (sometimes okay, but try *syndrome* or *condition*)
- "Look normal" or "they want to be treated like normal kids"
- Suffer – avoid saying kids "suffer from" facial differences