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22q Deletion Syndrome Awareness

Emily Cavarretta
Grand Valley State University

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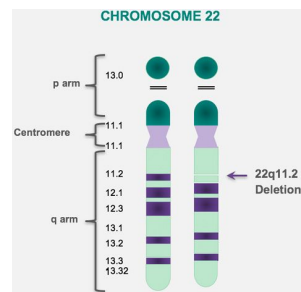
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What is 22Q?

22q was previously known as DiGeorge syndrome and VCFS. Today, this collection of symptoms is known as 22q11.2 Deletion syndrome, a chromosomal error that occurs when a

small part of the 11th branch on the 22nd chromosome is deleted.

Symptoms vary for each person, but the



most common ones include:

- heart abnormalities
- cleft palate
- feeding difficulties
- immune system problems
- low calcium
- facial differences
- developmental delays
- behavioral differences
- dozens of additional characteristics

22q is believed to be the second most common genetic disorder after Down Syndrome! Due to these varying characteristics, 22q is not always diagnosed at birth. Some people are not diagnosed until they are adults.

Resources

- www.22q.org/
 - Facts, videos, support
- 22qfamilyfoundation.org/
 - information, support, awareness
- <https://22qfamilyfoundation.org/what-is-22q/22q-for-teachers>
 - Reference sheet for educators
- Children's Hospital of Philadelphia-22q and You Center
 - Diagnosis management, news articles, information for families and professionals
- State website for Special Education and Parental Rights



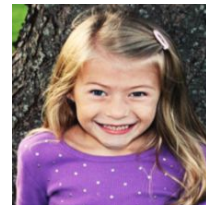
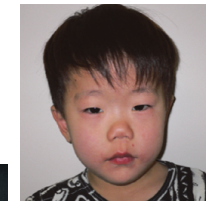
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Picture sources
C22c.org, The Lancet, International Osteoporosis Foundation, News 24 South Africa, No Hands But Ours blog, 22q Family Foundation, Breaking the Silence blog, Fostertest.se, 123rf.com, Clipart-library.com, i.pinimg.com



22q11.2 Deletion syndrome

Previously known as DiGeorge syndrome, velocardiofacial syndrome, conotruncal anomaly face syndrome, and more



What Everyone Should Know

- Every person with 22q has unique strengths and struggles
- 22q may not be obvious at first glance
- You can show support and acceptance to parents and those with 22q
- Be careful not to underestimate or overestimate the abilities of someone with 22q- get to know them

Who works with individuals with 22q?

- **Speech-language pathologists-** feeding, receptive and expressive language
- **Occupational therapists-** age-specific goals of small muscle groups, feeding, handwriting, buttoning, etc.
- **Physical therapists-** large muscle groups: they may begin with head control, rolling, sitting up, and then progress and customize goals for the child



Advice to Parents from Parents

- Your child with 22q needs the same love and attention as any child.
- A child's syndrome does not define who they are
- Join support groups
- Remember to be a family- Don't set your whole life around therapy for your child
- You know your child best, advocate for what you know he or she needs



- Children with 22q can lead fulfilling and successful lives
- The intervention team will include many people such as physical and occupational therapists, speech-language pathologists, teachers, pediatricians, other medical professionals. They want the best outcomes for your child and the whole family!
- Stay hopeful and positive

Tips for Teachers

- Most children with 22q have some degree of developmental disability including delayed speech and language development
- **Strengths:** willingness to learn, simple & focused attention, rote verbal learning and memory, spelling and grammar
- **Challenges:** receptive & expressive language, abstract reasoning, executive functioning, social and emotional functioning, reading comprehension
- Keep the student in the LRE (Least Restrictive Environment)
- Use the child's therapists as resources for classroom applications of strategies
- Don't be afraid to ask questions!

