

# 22q Deletion Syndrome

## AKA 22q11.2 Deletion Syndrome

22q11.2 deletion syndrome, or 22q deletion syndrome is a birth anomaly that happens when a small piece of chromosome 22 is missing. The genes of the human body, which are the instruction set of how the body is built, come in 26 pairs of chromosomes. 22q deletion syndrome (“deletion” means “missing”) can affect almost any part of the body and how it works. Many children with 22q deletion syndrome have developmental delays, including slow physical growth, a hard time learning to speak well, and learning disabilities. For more information about 22q deletion, go to the U.S. National Library of Medicine website [tinyurl.com/ya7w5opx](https://tinyurl.com/ya7w5opx).

## Resources for families

### Northwest support resources

- Oregon Family to Family Health Information Center  
[tinyurl.com/ycwhffwc](https://tinyurl.com/ycwhffwc)
- Facebook Oregon22q  
[tinyurl.com/y7opjp5u](https://tinyurl.com/y7opjp5u)

### National/international/online resources

- Chromosome Disorder Outreach  
[tinyurl.com/y96ezo5r](https://tinyurl.com/y96ezo5r)
- Chromosome 22 Central  
[tinyurl.com/y9n59u3o](https://tinyurl.com/y9n59u3o)
- 22q  
[tinyurl.com/yghyxx6](https://tinyurl.com/yghyxx6)

### Information for you and your care team

- Cincinnati Children’s Hospital Velocariofacial/22q deletion syndrome  
[tinyurl.com/y8n6mo2e](https://tinyurl.com/y8n6mo2e)
- Learn More about 22q | gemssforschools.org  
[tinyurl.com/y9uvhm9y](https://tinyurl.com/y9uvhm9y)

### Family stories

- 22q family foundation  
[tinyurl.com/y8mrc8py](https://tinyurl.com/y8mrc8py)
- Meet a child with 22q deletion syndrome  
[tinyurl.com/ybvsea5k](https://tinyurl.com/ybvsea5k)

### Clinical trial information

- Children and Clinical Studies  
[tinyurl.com/y75s4twm](https://tinyurl.com/y75s4twm)
- Find an approved clinical trial  
[tinyurl.com/zp3jesq](https://tinyurl.com/zp3jesq)

### Insurance information and help

- Getting insurance for children (OR)  
[tinyurl.com/ydfaeoy](https://tinyurl.com/ydfaeoy)
- Getting insurance for children (WA)  
[tinyurl.com/yca9lkey](https://tinyurl.com/yca9lkey)
- Understand your health insurance  
[tinyurl.com/y46h8nvx](https://tinyurl.com/y46h8nvx)
- Learn about coverage  
[tinyurl.com/y4639rz6](https://tinyurl.com/y4639rz6)
- Road map to health  
[tinyurl.com/yysc6kv7](https://tinyurl.com/yysc6kv7)
- General/Oregon Health Plan Questions: 855-323-6744

### Other resources

- 22q and You Center-Research and Medical Center  
[tinyurl.com/y72t76f5](https://tinyurl.com/y72t76f5)
- 22q11.2 Deletion Syndrome Clinic  
[tinyurl.com/yb9suvus](https://tinyurl.com/yb9suvus)
- National Organization for Rare Disorders  
[tinyurl.com/ycj6vfso](https://tinyurl.com/ycj6vfso)
- Genetic and Rare Diseases Information Center  
[tinyurl.com/y7hznkyy](https://tinyurl.com/y7hznkyy)
- Camp Resources - Cleft and Craniofacial Community  
[tinyurl.com/ydh3nfze](https://tinyurl.com/ydh3nfze)
- Camp Korey  
[www.campkorey.org](http://www.campkorey.org)

### Books for parents and children

- Bibliography available by calling the Oregon Family to Family Health Information Center at 855-323-6744
- Swindells’ online library search  
[tinyurl.com/y9t2jwcx](https://tinyurl.com/y9t2jwcx)