



The International  
22q11.2 Foundation Inc.

# The Same Name Campaign

The International 22q11.2 Foundation, Inc.  
[www.22q.org](http://www.22q.org)

# 22q11.2 Deletion Syndrome

## also known as:

- Velo-cardio-facial syndrome  
Characteristic facial features, cardiac, and palatal defects, learning differences
- DiGeorge Syndrome  
Absent thymus, hypocalcemia, cardiac defects  
Conotruncal Anomaly Face Syndrome plus others...

# 22q11.2 Deletion Syndrome

- **VCFS, DGS, etc.**- older terms described specific clinical phenotypes prior to discovery of the 22q11.2 microdeletion
- Genetically, no detectable difference in microdeletions found in people with VCFS versus those with DGS or other related syndromes
- Technically, the terms are not synonymous: people with VCFS do not have DGS, even though both have the same underlying 22q11.2 deletion!

# The Issue

- Several different names used for the same condition
- Creates confusion among families and professionals
- Families, professionals may not access all available information and resources
- Further divides our community, hampering a unified effort toward research and support

# The Campaign

- Foundation recognized need to address name issue in order to move forward with our mission
- Same Name Campaign: educational effort aimed at professionals and families, with the goal of establishing consistent terminology for the 22q11.2 deletion syndrome
- Intent is to increase collaboration among groups, with all on the same page, moving in the same direction, supporting the worldwide 22q community

# The Campaign

- Foundation is sensitive to concerns of families and other groups who may find it difficult to switch to a different name
- Primary focus on professionals who make initial diagnosis: over time, fewer children newly diagnosed with VCFS, DGS, or other outdated terminology

# The Campaign

- Presentations about campaign at professional meetings
- Mailings /publications to professionals and families encouraging consistent use of the 22q11.2 deletion nomenclature instead of older names
- Working toward consensus among professionals and support organizations throughout the world
- Encouraging publishers of professional journals to adopt consistent standards for naming the syndrome in all published articles



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# Think 22q!

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