For Educational Staff

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Thank you for visiting the International 22q11.2 Foundation website to learn more about the learning and cognitive issues associated with this syndrome. The 22q11.2 deletion syndrome is very complex and the learning needs of this population can vary substantially from one student to the next. It is therefore extremely important to thoroughly assess these students and plan comprehensive programs to take *all* of their learning challenges into account.

When should school staff consider 22q11.2?

The 22q11.2 deletion syndrome is highly under recognized and often students go many years before a correct diagnosis is made. The incidence level for this syndrome is high (1 in 1000), however, due to the wide range of problems associated with it, many physicians fail to make a timely and accurate diagnosis. School staff is in a unique position to assist in this area.

Students with this syndrome often enter the educational system as preschoolers with delayed language acquisition (due to anatomical differences), hypernasal or articulation difficulties, and developmental delay. Others, however, may not have delayed speech or significant learning differences early, but surface later in elementary school with significant challenges in math application and reading comprehension.

Staff may reasonably suspect that this syndrome may be the underlying cause for a student's learning problems in the following situations:

- Multiple anomalies (examples. heart defect, speech delay, hypotonia, learning challenges, immune issues, ADD, social skills deficits)
- Heart defect plus any one other major criterion (heart defects are present in over 60% of students with 22q11)
- Three major issues (ex. learning, hypernasal speech, ADD) and no heart disease
- Two major plus two minor issues

If the school staff believes that there is an underlying medical issue that has not been recognized, it is important to refer the family to a geneticist or physician for further study where a definitive diagnosis can be made.

Why is it important to identify?

- Specialized medical treatments are available
- Early intervention is often needed
- There is a high incidence of potentially series issues that need monitoring and early treatment
- Students are likely to need a very specialized school program to make adequate yearly progress
- Transition to adulthood can be difficult. Many adults will need continued support through community agencies.
- There is a 50% chance a child of an affected parent will be born with the deletion
- Many support groups (local to international) are available

Although some may argue that schools may not ***need*** to know a diagnosis to educate a given student, research into the cognitive learning profile of students with this syndrome has led to a deeper understanding of the possible causes of school difficulties. More effective approaches to learning have been

identified, and better outcomes have been achieved. It is vitally important that school staff understand the learning issues associated with 22q11.2 to adequately identify the unique issues facing these students and plan accordingly.

Learning Issues Frequently Associated with 22q11.2

The following is a list of common learning challenges associated with the syndrome:

- Cognitive Impairment (30% with IQs below 70, 70% with IQs in the low average range)
- Verbal scores often significantly higher than perceptual
- Learning Challenges--primarily reading comprehension (not decoding), math applications, higher level thinking, making inferences etc.
- Speech/Language Impairments (articulation, expressive, receptive, pragmatic, problem solving)
- Executive Function Deficits
- Working Memory Difficulties
- Low Muscle Tone (trouble with fine and gross motor tasks)
- Slow Processing Speed
- Attention Difficulties
- Behavioral Challenges (depression, anxiety)
- Social Skill Deficits
- Visual Processing Issues (form constancy, visual sequential memory, visual discrimination)
- Delay in Achieving Independent/Adaptive Skills

In addition to the materials on this website, there are a wide variety of other education related resources available to assist

your school in programming effectively for students with 22q11.2. They are listed below:

Websites, Webinars and Consulting:

Dempster Family Foundation—Education Station. Free webinars for staff under the tab "22q University".

www.dempsterfamilyfoundation.org

Cutler-Landsman Consulting—Resources and information on education topics related to the 22q11.2 deletion. Staff training is available.

www.cutlerlandsman.com

Books and Articles

Book:

Educating Children with Velo Cardio Facial Syndrome (also known as 22q11.2 Deletion and DiGeorge) by Cutler-Landsman
www.pluralpublishing.com

Scholarly Articles:

Antshel, B. Hier, W. Fremont, S. V. Faraone & W. Kates Predicting reading comprehension academic achievement in late adolescents with velo-cardio-facial (22q11.2 deletion) syndrome (VCFS): a longitudinal study, Journal of Intellectual Disabilities, Vol. 58, Oct. 2014, p. 926-939

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