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Finding the GEMSS in Schools.

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finding the GEMSS in your school

BY ANN DONOGHUE DILLON, M.ED., OTR/L • PHOTOS COURTESY THE GEMSS WEBSITE

If you are like me, I always had my eyes and ears open to learn about any information to help my daughter receive a good education! Having a genetic condition that was both rare and new for her school, she made all of us on the team try our best and then hope! I wish GEMSS was available when she was starting out in school! It would have been a great source of information that we could have used as a foundation, and then branched out as needed!

– Ann Donoghue Dillon

Are you the parent of a child who has a genetic condition such as Down syndrome, Fragile X, or Marfan syndrome? Have you searched for a base of knowledge that is comprehensive and reliable? Do you spend energy wondering HOW your child should be included in typical school programs, not questioning IF he/she should be included? You may be surprised to know that there is a new website receiving national and international attention! It is called GEMSS – Genetics Education materials for School Success www.gemssforschools.org

BACKGROUND

Launched in 2012, GEMSS now numbers over 20 conditions on its site. GEMSS has relied on feedback from parents, teachers, and viewers to help shape it. About seven conditions per year are being

added and the site has expanded to include stories of children and adults who have many of the conditions.

Originally, a grant through the New England Genetics Collaborative encouraged workgroups to form within the Collaborative. The



GEMSS was developed by the New England Regional Genetics Collaborative, one of seven HRSA-funded regional genetics collaboratives.

Genetic Alliance is a nonprofit health advocacy organization that works closely with these regional collaboratives on engaging families and individuals and improving access to genetic services. For more information on Genetic Alliance and available resources for individuals and families around genetics and health, visit www.geneticalliance.org.

Education & Outreach Work Group began to dream about using the WEB to educate parents and teachers about the possibilities, cautions, and supports that are necessary to make a child's education more successful! Knowing that education can help alleviate the fears that can block acceptance and inclusion, they aimed to strengthen and reinforce that belief that education for ALL children, including those who happen to have a genetic condition, can occur in the typical classroom alongside their peers if they have the right supports.

The content for each condition is created by a genetics counselor, and then travels to a parent reviewer, a geneticist,



GENETIC ALLIANCE

The world's leading nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities.



PLEASED TO MEET YOU The GEMSS website features “Meet a Child” pages, which introduce school-age children along with their conditions. Brendan and sister Courtney (above) appear in the Down Syndrome section, while Sophia (right) appears on the Tuberous Sclerosis Complex page.



and finally then back to our parent reviewer! Whenever possible, we also try to request input from parents, support groups, and experts in the particular condition. Quite a journey, but we believe the process brings technical and educational information to viewers in a thorough and readable format.

NAVIGATING THE SITE

The landing page for each condition highlights general information and often refers to additional links for more detailed information on the genetics and medical descriptions. Also on the home page are buttons that will lead to predictable broad categories of information for each condition including:

- *Dietary/Medical Needs*
- *Education Supports*
- *Behavioral and Sensory Support*
- *Physical Activity, Trips, and Events*
- *Emergency Planning*
- *Resources*

Within most of those broad categories are two sections: What You Need to Know and What You Can Do. The former gives information and facts for that category, and the later gives ideas and strategies to consider for that category.

The site also includes pages that highlight topics of interest such as transition, resources, or explanations of the difference between early intervention and educational plans. There is also a simple chart that gives parents and teachers a framework for reviewing educational plans. It explains the differences and similarities between an IEP (Individualized Educational Plan) and a 504 Plan.



If your child’s condition is undiagnosed or we do not have your condition listed, this resource (found under FAQs -Education section) is a great place to start. You can also look under similar conditions and get ideas on how to help your child.

An additional feature of most conditions is the story of a child or adult who has that condition. When interviewed, most parents talked about the ways in which the education system had been helpful and how they worked with their school teams. Many parents also offered advice and shared wisdom directed to both teachers and parents. These stories seem to provide a context and help-

Using GEMSS as a School Team

Gretchen is a six-year-old girl who has Down syndrome. Her teacher, excited to welcome Gretchen into her first grade class, was told about GEMSS by the school nurse. Together, the teacher and nurse explored the GEMSS site to prepare for Gretchen's arrival. They made a list of questions to ask Gretchen's parents at an upcoming get-acquainted meeting. Based on reviewing the medical and dietary information, as well as the ideas on communication and supports, some of their questions included:

- Does she have cardiac issues?
- How is her diet? Any restrictions?
- Are there muscle tone issues that impact her eating or swallowing, or her ability to sit in the typical classroom chairs?

Meanwhile, the parents who had originally forwarded the GEMSS site link to the school nurse also did their review of the site. They had learned about it on a national list serve and from

links on a national site. Their questions were concentrated on the educational and academic parts of the site, as well as addressing some fears about emergency planning.

- How can we explore communication strategies and technology that will allow her to fully participate in the regular curriculum?
- What therapies will be useful and effective in helping her fully participate in a typical day at school?
- What supports will help her develop socially and enjoy relationships with peers?
- What can we do to be prepared for any emergency that may arise?

When the team met, they not only worked through these questions but found they had more questions. Using the GEMSS site as a starting point, they felt they 'covered all the bases' but then sought out specific input from others involved in Gretchen's care, such as her pediatrician.



GEMSS – Genetics Education Materials for School Success: Williams Syndrome

The AIM of GEMSS...

- The aim is to assure all children with genetic health conditions succeed in school-life.
- Children who have genetic conditions are members of neighborhood schools across the country.
- In fact, it is estimated that about 1 in 20 children have a genetic condition.



GEMSS is for Teachers, Parents, Doctors and Genetic Counselors

GEMSS will help you provide meaningful educational supports for children who have genetic conditions.

Teachers and parents:

- Use GEMSS to better understand the needs of students who have genetic conditions
- Explore GEMSS to see if there are strategies you can implement
- Share the link with other families and groups

Doctors/Genetic Counselors:

- Refer families and educators to this site
- Provide feedback on new conditions and suggestions to the GEMSS team
- Provide printable handouts and flyers in your office waiting areas for families

GEMSS – A web based resource for families and school personnel that offers "Tools for Schools" to:

- Explain genetic conditions in plain language
- Offer helpful strategies for classrooms, field trips, nursing, diet, communication, instruction, and more
- Offer ideas for Undiagnosed Conditions

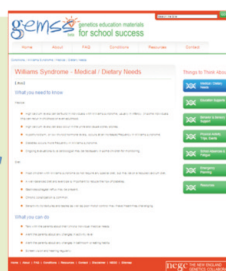


Conditions in GEMSS

- 22q Deletion
- Velocardiofacial
- Down Syndrome
- Fragile X
- MCAD
- Neurofibromatosis
- PKU
- Prader-Willi Syndrome
- Sickle Cell Disease
- VLCAD
- Williams Syndrome
- Undiagnosed / Other conditions
- more to follow



SAMPLE PAGES



Photos courtesy of the Williams Syndrome Association, Inc.

To find the GEMSS website, go to www.gemssforschools.org.

GEMSS was created by geneticists, genetic counselors, teachers and parents as part of the New England Genetics Collaborative (NEGC).



JACK "The Mayor"

Excerpt from GEMSS:Fragile X - "Meet a Child"

"Jack is one of the happiest children I have ever met," says his mother. He has a smile that can light up a room and an endless supply of hugs. He is never too busy to say hello to a friend or to tell a stranger to "have a great day." Being such a friendly little guy has earned him the nickname "The Mayor" at his elementary school.

Jack loves tractors, trains, cows, and music of all types. "He is the only seven year old I know that enjoys listening to jazz while eating his after school snack or singing Tom Petty classics while getting

dressed in the morning," quips his mother. He prefers British cartoons to American and has a whole repertoire of funny little voices and accents that he uses on a regular basis. It is difficult to be around

Jack and not smile! In fact, when the family goes out into the community, it is not unusual for him to leave a trail of smiling strangers behind him.

Ever since Jack was a baby he has loved books. Snuggling and reading a favorite book has always made him feel better when sad or anxious. When he started talking at age four,

When the family goes out into the community, it is not unusual for him to leave a trail of smiling strangers behind him.



his family realized that "he could read really well." They also realized his anxiety was more severe than they imagined. "Over the years he would spontaneously cry when we were outside. It was only after he started talking that he was able to tell us that he was afraid of car horns," his mother remarks.

Jack has made huge gains since his diagnosis of Fragile X Syndrome at sixteen months. "He has most of the symptoms typically found with Fragile X including: dyspraxia, sensory processing disorder, hypotonia, difficulty with communication and anxiety," according to his mother. But with dedicated and experienced school staff, private therapists, and peer supports, he has overcome the challenges that the symptoms cause.

The staff at his school communicates with his family and his private therapists on a daily basis to provide consistency. His classmates include him in school activities and social engagements outside of school. "They are a great group of kids who, despite being very young, are patient and supportive," his mother says. Jack has a nine year old brother named Michael who reminds Jack on a daily basis that he is "the best brother in the world."

His mother feels that "Jack will face many more obstacles as he grows but I am confident that he will continue to conquer them as long as he has the support he needs."

ful ideas to teachers and parents who are beginning on a school journey or want to look ahead into the future.

USING GEMSS IN SCHOOLS

Here are a few ways GEMSS might be used in schools:

- Develop lesson plans and IEPs
- Support children with challenges who are not diagnosed
- Prepare for educational and medical transitions
- Support for field trips
- Planning for meals and snacks
- Posting link to Newsletter/Web
- Staff and parent education
- Develop emergency plan
- Modify physical activity/education
- Promote GEMSS to colleagues/friends/administrators/district

Current Conditions

- 22-q Deletion
- Velocardiofacial
- Achondroplasia
- Angelman Syndrome
- Cornelia de Lange
- Cystic Fibrosis
- Down Syndrome
- Ehlers-Danlos Syndrome
- Fetal Alcohol Spectrum Disorders
- Fragile X
- Marfan Syndrome
- MCAD
- Neurofibromatosis 1
- Noonan Syndrome
- PKU
- Prader-Willi
- Rett/Rett Variant Syndrome
- Sickle Cell Disease
- Tuberous Sclerosis
- Urea Cycle Disorders
- VLCAD
- Williams syndrome
- Undiagnosed (General Strategies & Tips)

FINAL THOUGHTS

As GEMSS expands, more conditions and children's stories will be added. Conditions coming next are Aicardi, Turner /Klinefelter, Kabuki, Smith Magenis, Rubenstein Taybi, and Sotos. Trainees from the NH LEND program* are working with the project to analyze data from a user survey and further inform the project on new directions and identify consumer needs.

GEMSS welcomes viewer input and comments, which can be sent to Karen.smith@unh.edu. Please visit and revisit GEMSS at www.gemssforschools.org and let us know how we can help!•

For more information about the NH LEND Program, please visit <http://www.mchlend.unh.edu/home.aspx>

ABOUT THE AUTHOR:

Ann Donoghue Dillon, M.Ed., OTR/L, is a Clinical Assistant Professor at the Institute on Disability located at the University of New Hampshire. She serves as coordinator of the NH Leadership Series, a faculty member of the NH LEND Program, and helps develop and promote the GEMSS Project. She is currently serving on the NH Governor's Commission on Disabilities. Her daughter Brianna Rose had Aicardi Syndrome and passed away at the age of 25 in 2010.

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