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UNH INSTITUTE ON DISABILITY / UCED

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Media Relations

UNH, Partners Launch New Tool For Supporting Students With Genetic Conditions

February 15, 2012

DURHAM, N.H. – Students across the country with genetic conditions like Down syndrome or sickle cell anemia will now be better supported in their educational, medical and physical development, thanks to a new website developed in part by the University of New Hampshire's Institute on Disability. The website, Genetics Education Materials for School Success (GEMSS, www.gemssforschools.org), provides educators, other school personnel, and parents with a "one-stop shop" of useful tools and tips for support of students with genetic conditions throughout the school day. It was developed by the New England Genetics Collaborative (NEGC), a partnership of the Institute on Disability (IOD), the Institute for Health Policy and Practice, Dartmouth Hitchcock Medical Center and the University of Massachusetts Medical School.

Approximately one in every 20 children nationwide has a genetic or metabolic condition like Down syndrome, fragile X syndrome, sickle cell disease, or phenylketonuria (PKU). They most often are taught in general education classrooms, where teams of classroom teachers, paraprofessionals, service providers, and school nurses are charged with meeting their educational and health-related needs. Frequently, however, these school-based teams are ill-equipped to provide the best education or meet other needs of this population in the most meaningful ways, because of a lack of information on the rare conditions affecting these students.

"It was clear that a user-friendly resource on genetic conditions was much needed for those who work in education settings," said Monica McClain, NEGC project manager. "We were fortunate to be able to take advantage of expertise from our broad network to create a tool that will help support student success."

GEMSS provides practical guidance for educational teams in an easily-accessible online format. Each condition and its symptoms is introduced through a brief description in plain language. From there, site visitors can review strategies for addressing dietary and/or medical needs; special education supports; behavior and sensory supports; physical activity, athletics, school field trips, and other events; school absences and fatigue; and emergency planning.

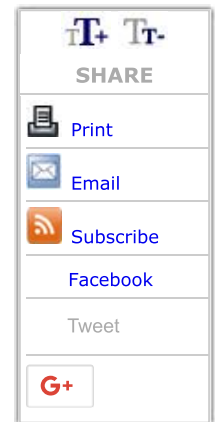
"The GEMSS site is a wealth of information and a valuable asset to teachers and parents in helping them to develop comprehensive educational programs for children who have genetic disorders," said Laurie Lambert, a former New Hampshire general classroom teacher and special educator and inclusion facilitator. "This new tool fills the void of information that was previously available to schools."

New GEMSS content will be added over time and will depend upon readers' input through an online survey.

GEMSS was developed by the New England Genetics Collaborative, which is funded by Cooperative Agreement No. U22MC10980 with the Health Resources and Services Administration/Maternal and Child Health Bureau/Genetic Services Branch. For more information on GEMSS, visit www.gemssforschools.org.

The Institute on Disability at the University of New Hampshire was established in 1987 to provide a coherent university-based focus for the improvement of knowledge, policies, and practices related to the lives of persons with disabilities and their families. Its mission is to strengthen communities to ensure full access, equal opportunities, and participation for all persons. More information is at www.iod.unh.edu.

The University of New Hampshire, founded in 1866, is a world-class public research university with the feel of a New England liberal arts college. A land, sea, and space-grant university, UNH is the state's flagship public institution, enrolling 12,200 undergraduate and 2,300 graduate students.



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