



IN FOCUS

MISSOURI DEAFBLIND TECHNICAL ASSISTANCE PROJECT

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What is Cytomegalovirus or CMV?

There are many causes of students having combined vision and hearing losses in children and youth. Due to the complexities of the students' other disabilities, the hearing and vision losses may be overlooked. Cytomegalovirus (CMV) is one of the prenatal causes of deafblindness.

CMV is a common herpes type virus that is transmitted usually through the salivary glands, but also urine and other body fluids. The CMV virus may lie dormant in an individual for years and then become active again. If a woman contracts the CMV virus when pregnant,

she may pass the infection onto her unborn fetus. There is a 10% chance the fetus, when born, will display symptoms of an infection. In addition, other problems may occur including jaundice, spots on the skin, intellectual disabilities, seizures, hearing impairments and possibly severe vision problems. It is important to note that no impairments occur when the CMV virus infects a healthy child and/or adult.

People caring for children with CMV have no increased risk of infection as long as they follow

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universal precautions for hygiene and wash their hands with soap when contacting body fluids. It is recommended to wear disposable gloves when changing diapers. There should be no reason to exclude a child from a school because they possess the CMV virus.

Congenital CMV is the leading cause of a sensorineural hearing loss in children resulting in mild to profound losses. Several issues may occur regarding a child's vision loss. Vision loss is related to the scarring of the choroid, the dark brown vascular coat of the eye between the sclera and retina. Retinitis or inflammation is common. This results in blurred vision and vision loss. Optic atrophy is also associated with CMV causing wasting away of the optic nerve. Vision loss is related to the amount of nerve damage. Other abnormalities may include cataracts, being born with no eyes, and iridocyclitis, inflammation of the iris and ciliary body causing photophobia and light sensitivity.



For more information contact National Congenital CMV Disease Registry, Clinical Care Center, Suite 150, 6632 Fannin Street, Medical Center 3-2371, Houston, Texas 77030.

Resources:

- 1) "Conditions and Syndromes that can Result in Deafblindness: Cytomegalovirus"
www.deafblind.com/deafblind.com/cytomed.html
- 2) "Cytomegalovirus (CMV)"
www.health.state.ny.us/diseases/communicable/cytomegalovirus/fact_sheet.htm
- 3) "Cytomegalovirus Infection"
www.sanfordhealth.org/healthinformation/healthwise/topic./nord189
- 4) **Deaf-Blind Program:** "Common Cause of Deafblindness." Deaf-Blind Program." Sanford School of Medicine. www.usd.edu/cd
- 5) Miles, Barbara & Riggio, Marianne. **Remarkable Conversations.** Perkins School for the Blind. 1999.



Web Links

The Missouri Deafblind Technical Assistance Project has made some additions to their web page. A listing of available resources concerning topics about deafblindness and teaching techniques that are internet accessible to view has been added. It will be updated as new Instructional web links are acquired. For more information contact: Susan Bonner, Project Coordinator, at Susan.Bonner@msb.dese.mo.gov

Deafblindness:

- California Deaf-blind Services: www.cadbs.org
 - Online Introduction to Interveners
- Stickler Syndrome Learning the Facts: <http://vimeo.com/13622948>
- Perkins School for the Blind www.perkins.org/webcasts/
 - CHARGE Syndrome: An Overview
 - CHARGE Syndrome: Impact on Communication and Learning
 - Communication Portfolios
 - Conversations (with students who are deafblind) Personal Reflections about Deafblindness
 - Love: Challenges of Raising a Child with Disabilities
 - Parents, Partners and Ambassadors: A Web-based, Self-guided Tutorial: *for TVIs, O&Ms, VRTYs and teachers to view these three webcasts that demonstrate various issues that parents face.*

Communication:

- [Perkins School for the Blind www.perkins.org/webcasts/](http://www.perkins.org/webcasts/)
 - CHARGE Syndrome: Impact on Communication and Learning
 - Communication Portfolio
 - Teaching Tactile Graphics

- Tangible Symbols
- Washington Sensory Disabilities Services
www.wsdsonline.org/deafblind/videotopics.html
- Actions Speak Louder Than Words
- Hand Under Hand

Hearing Impairment:

- ASLPro.com www.aslpro.com
 - American Sign Language Online Video Dictionary
- California Deaf-blind Services: www.cadbs.org/
 - Teacher of the Deaf/Hard of Hearing

Instructional Strategies:

- IRIS Center for Training Enhancements www.iris.peabody.vanderbilt.edu/resources
 - Accommodations to the Physical Environment: Setting up a Classroom for Students with Visual Disabilities
 - Bookshare: Providing Accessible Materials for Students with Print Disabilities
 - Instructional Accommodations: Making the Learning Environment Accessible to Students with Visual Disabilities
 - Serving Students with Visual Impairments: The Importance of Collaboration
- Perkins School for the Blind www.perkins.org/webcasts/
 - Accessible Science
 - Adaptive Physical Education
 - Early Literacy for Students with Multiple Disabilities or Deafblindness
 - Mealtime Skills
 - Social skills for Children and Youth with Visual Impairments
 - Wheelchair Orientation & Mobility
- Texas School for the Blind and Visually Impaired
www.tsbvi.edu/math/abacusinfo.htm
 - Abacus

- Washington Sensory Disabilities Services
www.wsdsonline.org/deafblind/videotopics.html
 - Little Room Adaptations
 - Materials for Active Learning
 - Literacy and Deafblindness
 - Resonance Board
- Washington State School for the Blind
<http://www.wssb.wa.gov/Content/offcampus/video.asp>
 - Buttoning
 - Cooking Tips
 - Folding Clothes
 - Folding Money
 - Learning to Pour
 - Making a Bed
 - Matching Clothes
 - Room familiarization
 - Shaving Techniques
 - Sighted Guide Technique
 - Strength and Core Training
 - Tying Shoes
 - White Cane Technique
 - Zipping

Transition to Post-School Activities

- American Foundation for the Blind's Teen Video Series-On Your Mark, Get Set...Go to Work www.afb.org/Section.asp?SectionID=7&TopicID=268&DocumentID=3426
 - Finding First Jobs
 - Up Close and Personal
 - Succeeding at your Job
- Perkins School for the Blind www.perkins.org/webcasts/

- Creating Vocational Portfolios for Students with Significant Disabilities
- School to Work: Developing Transition Portfolios for Students with Significant Disabilities

Vision Impairment:

- [American Foundation for the Blind](#)

www.afb.org?Section.asp?SectionID=44&TopicID=108&DocumentID=1573

- 19 Ways To Step Back

[New Resource from NCDB\(National Consortium on Deaf-blindness\)!!!!](#)

Practice Perspectives Article by Katrina Arndt, February 2011

“College Students Who Are Deaf-Blind” Copies (including Spanish) are available

from www.nationaldb.org/NCDBProducts.php?prodID=111

or Susan Bonner at susan.bonner@msb.dese.mo.gov

Job Seeker’s Toolkit

American Foundation for the Blind (AFB) has a new online course that provides virtual career explorations and job-seeking skills training. The **Job Seeker’s Toolkit** is an accessible, self-paced and free on-line course. It helps users develop job related skills and includes topics such as self awareness, career exploration tools, finding employment, interviewing skills and maintaining employment. To access the toolkit go to “what’s New” on AFB CareerConnect at www.afb.org/cc .



The 10th International CHARGE Syndrome Conference, July 28-31, 2011



The Foundation's 10th International CHARGE Syndrome Conference will be held on July 28-31, 2011 in Orlando, Florida at the Rosen Shingle Creek Hotel.

<http://www.chargesyndrome.org/index.asp>

THRIVE: Offers Campus Opportunities for Youth with Disabilities



The University of Central Missouri (UCM) has launched a pioneering, post-secondary program on its Warrensburg campus that serves students in the Kansas City region with developmental and intellectual disabilities. The program, known as THRIVE (Transformation, Health, Responsibility, Independence, Vocation, Education), made its debut in the fall of 2010. Young adults with developmental or intellectual disabilities have the opportunity for a 2-year residential college

experience at University of Central Missouri, transitioning from home to independence.

While seeking a certificate of success, students 18-25 years of age will participate in seminars, classes, and courses for credit, to develop:

- self-reliance
- independence
- new skills
- wellness practices
- job skills

Funded by a grant of nearly \$500,000 from Kansas City-based non-profit organization EXCEL (Expanding College for Exceptional Learners), THRIVE is designed for this population of students who have finished high school and are working toward full inclusion in the workplace and society. The program provides participants with enhanced job skills and new-found independence. Because the curriculum for the two-year, residential certificate program will be tailored to the individual needs of these students, some may go on to earn a degree with the proper supports.

UCM submitted a proposal to EXCEL in November 2009 for the development of the program. Joyce Downing, associate dean of UCM's College of Education, was notified in March 2010 of UCM's successful bid to house the program. UCM is the only campus in Missouri and Kansas to offer such a program.

“Our goal is to provide THRIVE students with an opportunity to succeed beyond high school graduation,” Downing said. “The certificate of completion THRIVE students receive at the end of their two years on campus will be an indication of their ability to adapt to new learning and living situations while expanding their academic successes.”

The transition from high school to independent living often is a challenge for students with developmental and intellectual disabilities. For these students



and their families, obtaining further education to enhance independent living opportunities may require specific skills that are not addressed by the traditional higher education environment. Dozens of similar post-secondary programs like THRIVE already exist across the country, many of which are listed in www.thinkcollege.net.

An initial group of 10-12 students was admitted to the program with the first cohort, followed by a second group for the fall of 2011. While living on campus, THRIVE participants will live with upper level student mentors and community advisors. Each mentor will be assigned three THRIVE students, assisting them in learning the skills of day-to-day living, such as navigating a college campus, maintaining a daily schedule, and living in the residence hall. THRIVE Director Barbara Mayfield and other project staff will work in conjunction with a cross-section of the UCM community to develop the specialized curriculum and provide instruction.

THRIVE students will participate in a learning community with a seminar and courses taught by project personnel each semester. As individual students develop skills that exceed the basic program, individual learning programs will be developed for them in conjunction with UCM faculty and staff, allowing them to participate in selected integrated course offerings and develop their full potential as independent citizens.

“It was the hard work of many components of the UCM campus community that made this possible,” Mayfield said. “We’ve worked closely with personnel from the College of Education, The College of Health and Human Services, the Department of Academic Enrichment, the

Diversity Office, Accessibility Services, University Housing, Student Financial Services, the Counseling Center and Enrollment Management to make this a reality.”

Learn more about THRIVE by contacting [Mike Greife](#) or [Joyce Downing](#) or the UCM College of Education at 660-543-4272. .



Accessible Children’s Gifts

American Foundation for the Blind (AFB) published a listing of “Accessible Toys for the Young and Young at Heart with a Vision Loss” just before the holidays. It is always good to keep on hand ideas for birthdays, holidays and special achievements. The following is a listing of some of their ideas. For more information go to:

<http://www.afb.org/afbpres/pub.asp?DocID=aw110703> .

- Toys for Small Children
 - Toys that play songs, music or funny sounds
 - Toys with large shaped buttons and controls
 - Sing-a-ma-jigs by Mattel
- Toys for Learning
 - Toys with tactile markings
 - Uncle Goose Braille blocks by Lindenwood, Inc.
 - Fridge DFJ by Leapfrog
 - Geosafari Talking Globe by Educational Insights
 - Make sure the keyboard and screen is accessible for the child’s vision
- Electronics
 - Bop It from Hasbro
 - Say What by Radica
 - Geosafari Talking Globe’s new category of [Freeze Up](#)
 - Check web site of BrailleGifts.com
- Games
 - Make them accessible with a Braille writer or Dymo labeler
 - Bananagrams
 - Apples to Apples by Mattel (easy to Braille)
 - Braille playing cards to play War, Old Maid, Fish, etc.

SETS-DB

Supporting Educational Teams of Students with Deafblindness (For Teams Serving Students with Combined Vision and Hearing Losses)



The Missouri Deafblind Technical Assistance Project has developed an in-depth technical assistance option for school districts serving students with combined vision and hearing losses. SETS-DB combines general information about the educational implications of combined vision and hearing losses with direct technical assistance regarding individual student supports to educational teams.

Target audience: SETS-DB is intended for the educational teams of students with deafblindness (including parents/family members).

Format and content: SETS-DB combines lecture and action planning with onsite coaching, over two full days, with staff from the Missouri Deafblind Technical Assistance Project. Participants apply knowledge acquired regarding visual and auditory impairments, communication and movement to the educational programming of the district's student with combined vision and hearing losses. Follow-up consultation and/or onsite coaching may be provided as needed.

Date: SETS-DB is arranged with the local school district with the first day consisting of observation of the student in the educational setting by Missouri Deafblind Technical Assistance Project staff and a two-hour overview presentation on deafblindness.

The second day combines lecture and application of effective practices in the education of students with deafblindness as the information relates to the individual student's educational program. This session will include information on specific instructional strategies and the identification of action items for the educational team to implement in support of the student. An action plan will be developed. Follow up consultation is provided to the school district by phone and/or in person.

Location: The local school district provides space for the SETS-DB class.

Costs: The course is offered free of charge and all training materials are provided by the Missouri Deafblind Technical Assistance Project. Certificates of completion will be provided to educational team members participating in the class. Family members will be provided financial support (mileage).

Contact: Susan Bonner, Project Coordinator at (314) 776-4320 ext. 3255 or susan.bonner@msb.dese.mo.gov



NFDB Changes

The National Family Association for Deaf-Blind is an organization that has been supporting individuals who are deaf-blind and their families for over sixteen years. Yearly membership runs from January 1 through December 31.

NFADB offers support in a variety of ways:

- A toll free number (answered by a real person) that connects families and others to resources and one-to-one support.
- Current information and national updates delivered through a bi-annual newsletter.
- Online resources and support through our website and Facebook page.
- A member listserv that connects you by email to hundreds of other members.

In addition, NFADB connects you to a much larger network of support. They represent families on the National Coalition on Deaf-Blindness by providing a unified voice on national issues related to deaf-blindness. We continue to expand and support a national NFADB Affiliate Network that supports state parent groups as they develop and grow. They can also help families access the services of the state deaf-blind projects, the National Consortium on Deaf-Blindness, the Helen Keller National Center and the American Association of the Deaf-Blind.

Membership Details:

Three membership options are available for families and professionals. Each membership is a household membership and includes all family members living at one address. **One year: \$15 Three years: \$35 Lifetime: \$100**

“Together we can work to make a difference in the lives of individuals who are deaf-blind.”

Visit us them on the web at nfadb.org and on Facebook

For questions, please call Lori at 1-800-255-0411 or NFADB@aol.com



2010-11 NFADB Membership Application

Information about you		
Name(s):		
Address:		
City:	State:	Zip:
Phone:	Email:	

Information about the individual who is deaf-blind	
Name:	Birthdate:
Relationship to you:	
Cause of deaf-blindness:	

Information about your membership <i>(Click on the boxes to select)</i>
Please select your choice of membership. 1-year - \$15 <input type="checkbox"/> 3-year - \$35 <input type="checkbox"/> Lifetime - \$100 <input type="checkbox"/>
I give permission to use my email address to sign me up for the NFADB listserv. Yes <input type="checkbox"/> No <input type="checkbox"/>
I give permission to share my name with other families who have a family member with similar etiologies, disabilities or challenges. Yes <input type="checkbox"/> No <input type="checkbox"/>
How would you like to receive your NFADB newsletter? Email <input type="checkbox"/> Regular mail <input type="checkbox"/>
Would you like materials in: Large print <input type="checkbox"/> Braille <input type="checkbox"/> Spanish <input type="checkbox"/>

Please make checks payable to NFADB and return your membership application and payment to:

NFADB Membership
141 Middle Neck Road
Sands Point, NY 11050-1129

For questions, please call Lori at 1-800-255-0411 or NFADB@aol.com

Missouri Deafblind Families Web Connections
A Family Listserv Network
Development Assisted by
The Missouri Deafblind Technical Assistance Project



Network
Gain Knowledge
Share Knowledge

The Missouri Deafblind Families Web Connections is a closed listserv group initiated by the Missouri Deafblind Technical Assistance Project in response to families' requests and moderated by families who have children on the Missouri Deafblind Census. Membership is by invitation only. A listserv is a means for members of the group to discuss and/or receive information from other members on the list. Content of the listserv messages is moderated by a family moderator. Posting of questions and materials are screened by the moderator prior to posting on the listserv to reduce potential spam. Once the moderator screens the message, it is automatically emailed to all members of the listserv.

The purpose of "*Web Connections*" is to provide a way for families to network with other families who have a child with both visual and auditory losses by:

- Exchanging information about a specific disability
- Exchanging information on raising a child with a dual sensory impairment
- Interacting with other families with similar educational needs for their child
- Provide emotional support to other families with similar needs
- Posting information about special events and conferences relating to deafblindness.

"*Web Connections*" is families with a deafblind child communicating with other families to:

1. Network with other families
2. Gain knowledge of resources
3. Share knowledge of resources

To join the listserv, please send an email to Susan Bonner (susan.bonner@msb.dese.mo.gov) with a request to join "*Web Connections*." Your message will be sent onto the family moderator, who will send you an invitation to join the listserv that includes the instructions for joining.

June 1, 2011 will begin a monthly topic information exchange. June's topic is "**Accessing Community Based Services.**"

Calendar of Events



Fall, 2011

Date: October, 26-28, 2011; January 25-26, 2012 & April 18-19, 2012

Topic: Hand In Hand: Course for Educational teams Supporting Students with Deafblindness

Location: Cape Girardeau, Missouri

Audience: Teachers of students with deafblindness and their educational teams including parents

Contact: Susan Bonner,
Missouri Deafblind Project 314-776-4320, ext. 3255 or
susan.bonner@msb.dese.mo.gov

Missouri Deafblind Technical Assistance Project, Missouri School for the Blind

Project Staff

Jennie Mascheck	Project Director
Susan Bonner	Project Coordinator
Andrea Harrington	Education Specialist
Janus Hinson	Transition Specialist
Virginia Williams	Family Specialist
Michael Grady	Project Evaluator
Linda Van Eck	Project Consultant
Margaret Winston	Project Secretary

3815 Magnolia Avenue, St. Louis, MO 63110
(314) 776-4320 x 3255 www.msb.dese.mo.gov

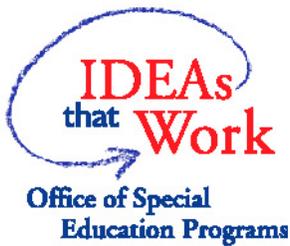


**Missouri Deafblind Technical Assistance Project
Missouri School for the Blind**

In Focus

Susan Bonner Editor

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**Missouri Deafblind Technical Assistance Project
Missouri School for the Blind
3815 Magnolia Ave
St Louis, MO 63110**



In Focus