

It is estimated that somewhere between 30-40% of cases of deafness in children are related to congenital CMV infection.

Virus causes more than a third of cases of hearing loss in infants

By Mark R. Schleiss, M.D.

American Legion Professor of Pediatrics,
Director of Pediatric Infectious Diseases,
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About 1% of all babies in the U.S. are born with congenital CMV infection—that's about 40,000 a year. Nearly 15% of those babies will have some element of hearing loss caused by CMV. Which means that 4,000-6,000 American newborns have neurodevelopmental injury, including hearing loss, caused by congenital CMV. For a majority of these babies, the only symptom of infection will be hearing loss. Hearing loss caused by CMV is often delayed in onset, becoming evident in later childhood.

With the advent of newborn screening programs, there have recently been exciting developments in research to identify not only newborns who are deaf or hard of hearing, but also to ascertain the causes of hearing loss in newborns. Recently, my colleague at the University of Minnesota Children's Hospital, Dr. Lisa Schimmenti, reviewed the genetic causes of hearing loss in newborns (*FOCUS*, June 2005). In this month's article, I want to review the role that infections play in causing hearing loss in newborn infants. Of the infections that cause hearing loss in infants, the most common and important is an infection caused by a virus called **cytomegalovirus (CMV)**.

A variety of infectious germs, or "pathogens," can be the cause of hearing loss in infants and children. An infection can cause hearing loss either by infecting the baby before birth while still in the womb, or by infecting the baby or young child after birth.

A number of infectious pathogens, including syphilis, rubella ("German Measles"), and CMV, can cross from mother to baby before birth. When this happens, the inner ear (the cochlea) can be injured, leading to hearing loss. At one time, rubella (German Measles) was the most common infection causing deafness in newborn infants. Congenital infection (infection acquired by the baby before birth) from rubella occurred in over 25,000 newborn infants in the United States in the early 1960s, and the majority of these babies had a hearing loss.

Among those infections which cause deafness in infants after birth, the most common are two kinds of bacteria, known as Hemophilus influenzae type B (HIB), and Streptococcus pneumoniae. These bacteria, usually acquired by person-to-person transmission in early childhood, cause bacterial meningitis ("spinal meningitis") in early childhood, which results in 10-15% of cases in hearing loss.

Fortunately, these diseases are all very rare today. Rubella was controlled by the development of a vaccine in the 1960s which has essentially eliminated this infection in the developed world. HIB and streptococcus pneumoniae vaccines became available in the 1990s. All of these vaccines are given as a part of a child's routine immunization series. It is almost unheard of today for any of these infections to be associated with deafness in infants or children.

In the United States today, CMV is the most common infection which causes deafness in childhood. For CMV to cause deafness, the infection must be transmitted to the baby prior to birth. CMV is a virus which is a member of a family of viruses known as Herpesviruses. Thus, it is similar at the genetic (DNA) level to the same viruses which cause chicken pox (Varicella-Zoster virus), cold sores (Herpes Simplex virus), and infectious mononucleosis (Epstein-Barr virus). CMV virus is transmitted very easily from person-to-person. About 50% of all adults have had CMV infection.

Virus...continued on Page 4

Here's What's Happening

**Friday,
Sept. 9**

Community of Hope hosts a DeafTeen Quest parent information meeting and rally for teens from 6:30-9:30 p.m. at Cedar Valley Church gym, 8600 Bloomington Ave. S. in Bloomington. For more information e-mail COHDeafOutreach@aol.com.

**Friday,
Sept. 9**

CSD and St. Paul Parks and Rec sponsor Swim Night for the Deaf and Hard of Hearing Community from 7:30 to 9:30 p.m. at Oxford Pool, 1079 Iglehart, St. Paul. \$3 kids/\$4 adults. For more information, contact Mary Livingston at St. Paul Parks and Recreation, 651-266-6366 (v), 651-266-6378 (tty), or mary.livingston@ci.stpaul.mn.us.

**Saturday,
Sept. 10**

Shows at the Minnesota Renaissance Festival are ASL-interpreted. The festival goes from 9 a.m. to 7 p.m. in Shakopee. For information, see www.renaissancefest.com.

**Sunday,
Sept. 11**

AG Bell's Kids (for girls ages 8-12) heads to the Tropics Waterpark in Shoreview from 1 to 4 p.m. RSVP by Thursday to Lynne at 763-780-8270 or tav58@sprynet.com.

**Wednesday,
Sept. 14**

An ASL Poetry Reading with Metro Deaf School's Cara Barnett and The Tactile Mind's John Lee Clark begins at 6 p.m. at the College of St. Catherine in St. Paul. For free tickets call 612-822-2500 or see www.saseonline.org.

**Tuesday,
Sept. 20**

The Cued Speech Association of Minnesota holds "Cue Clutches" at Java Jacks, 46th & Bryant Ave. in Minneapolis from 6:30 to 8 p.m. for cueing practice.

**Tuesday,
Sept. 27**

The founder of the planned ASL community in South Dakota, Marvin Miller, leads the discussion in ASL at the **Deaf Culture Salon at St. Paul College Auditorium**, 235 Marshall Ave. Registration begins at 6:30. The Salon runs from 7 to 9 p.m. Cost is \$5. See www.LaurentSD.com for details about the proposed town.

**Friday,
Sept. 30**

MinneCODA presents "Abababa Road Tour," a Deaf Culture storyteller and comedian. from 7 to 9 p.m. at the University of Minnesota's St. Paul Student Center. The performance will be repeated Oct. 1 at Faribault High School. Tickets are \$15 for adults and \$10 for students. .2 RID CEUs will be provided. For more information, contact aamundsen@comcast.net or visit www.abababatour.com.

**Friday,
Sept. 30**

The Moog Center for Deaf Education in St. Louis, Mo., presents **a workshop for Teachers of Mainstreamed Deaf/ Hard of Hearing Students.** See www.oraldeafed.org/schools/moog/ for details.

**Sunday,
Oct. 2**

"Impressionism: Breaking the Rules," an ASL-interpreted tour at the Minneapolis Institute of Arts, begins at 2 p.m. For details, call 612-870-3131(v) or 612-870-3132(tty).

**Saturday,
Nov. 5**

The Family Support Connection offers a workshop on behavior issues in deaf and hard of hearing kids. 10 a.m. to noon at Lifetrack Resources, 709 University Ave., in St. Paul. More details will be included in the next FOCUS.



ASL-Interpreted Performances

Joseph and the Amazing Technicolor Dreamcoat

Sunday, Sept. 18, 2 p.m.
Request ASL: accessible@orpheum.com.
Orpheum Theatre, 910 Hennepin Ave. S., Mpls.; 612-373-5639, -5655(tty); www.hennepintheatredistrict.com/servicesd.asp.

Triple Espresso -- A Highly Caffeinated Comedy

Thursday, Sept. 22, 7:30 p.m.
Tickets reduced to \$25.
Music Box Theatre, 1407 Nicollet Ave. S., Mpls; 612-874-9000; www.tripleespresso.com.

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Friday, Sept. 30, 10:30 a.m. & 7:30 p.m.
Reduced tickets: 612-874-0400
Children's Theatre Co., 2400 3rd Ave. S., Mpls.; www.childrenstheatre.org.
Amsterdam's hottest young troupe shows off with inline skating, acrobatics and martial arts.

The Who's Tommy

Sunday, Oct. 16, 7:30 p.m.
Describer: Rick Jacobson
Interpreter: Susan Masters
Tickets reduced to \$17 from \$24.
Hennepin Stages, 824 Hennepin Ave., Mpls.; 612-673-0404; www.aboutmmt.org.

The Cat's Journey (ages 2-5)

Wednesday, Oct. 19, 11 a.m.; Oct. 22, 11 a.m.
Sleeping Beauty (all ages)
Oct. 26, 10:30 a.m.; Oct. 28, 7:30 p.m.
Reduced tickets: 612-874-0400
Children's Theatre Co., 2400 3rd Ave. S., Mpls.; www.childrenstheatre.org.

The Madwoman of Chailot

Saturday, Oct. 22, 8 p.m.
\$8-14, 612-624-2345 or utheatre@umn.edu.
Rang Center, University of Minnesota's West Bank, 330 21st Ave. S.; theatre.umn.edu.

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Our mission is to build better lives for children who are deaf or hard of hearing by providing parent-to-parent support.

Newsletter Editor: Audrey Alwell

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In Your Corner

By Candace Lindow-Davies,
Family Support Coordinator

September is here and the kids are back in school. This time of year always feels like a chance for a fresh start—or, at the very least, a time of change. The new school year always brings changes for our kids as well as the rest of the family. And, change can be stressful. So, we hope your school year is off to a good start.

We're experiencing changes of our own here at the Family Support Connection. We are looking to join forces with the national, like-minded organization "Hands & Voices." (See the story to the right here for more on that group.) I was lucky enough to attend their national conference in Colorado this past July. This is an exciting new step for our program. We feel that this association will bring additional strength to our program, and further our mission of providing families support for all the decisions they make. Stay tuned for updates about this and other changes for our organization.

In this month's *FOCUS*, we feature an article about cytomegalovirus or CMV. We are so honored to have Dr. Mark Schleiss from the University of MN author this piece for us. This is another fascinating topic. The potential for research in this area is enormous. We only hope that researchers like Dr. Schleiss and others can push for more information about the origin of hearing loss and therefore, provide parents with more answers.

Next month, we plan to address the behavioral health of our children who are deaf and hard of hearing—and we need your help. Over the summer, we have received numerous calls from parents who have concerns about their children's behavior. We often hear, "Is this due to the hearing loss or is this just my child's personality?" Or, "What do I do when he shuts his eyes, takes off his cochlear implant and refuses to cooperate?" Topping the list is, "They [medical doctor, teacher, day care provider] are suggesting that my daughter has attention deficit disorder. I have heard that children with hearing loss are often misdiagnosed with this. What do I do?" So, next month, we would like to have an expanded "Ask a Professional: Question and Answer" section as our feature. This is your chance to ask a professional about your child's behavior issues. Please submit your questions to fsc@lifetrackresources.org, or call toll-free 866-346-4543(v), or 866-857-2379(tty) by Sept. 19.

Thank you to all of you who responded to Linda Werness-Jaroszewski's request for funny little stories for her "Little Grin" column. So many of you had such adorable stories that we have material for many issues to come. Thanks for sharing with us.

Take care, and have a great September!

The Family Support Connection is looking for a volunteer to help in our office with the library, mailings or other office support. If you can spare a few hours a week—any day or time—please contact us: 651-265-2435 (v), -2379 (tty).

Hands,Voices offers services like Family Support Connection

The Family Support Connection is considering becoming a chapter of Hands & Voices, a nationwide, non-profit organization that offers support to families with children who are deaf or hard of hearing.

Hands & Voices, which is based in Colorado, has chapters in 11 states, including one in Wisconsin. The organization celebrates its 10th anniversary this Fall. The group provides services that are similar to those of The Family Support Connection (FSC). They offer parents and professionals a variety of support activities such as outreach events, educational seminars, advocacy, lobbying efforts, parent-to-parent networking, and a quarterly newsletter. Like the FSC, Hands & Voices welcomes all methods of communication.

"As Hands & Voices brings more chapters on board, we will be a stronger lobbying group for all parents, and therefore, can push for better outcomes for our children," explained Candace Lindow-Davies, Family Support Coordinator. "We'd provide better services to Minnesota families through shared resources across state lines."

To learn more about Hands & Voices, see www.handsandvoices.org.

Fundraising walk Sept. 18

A fundraising walk to support organizations that serve deaf and hard of hearing people runs from 1 to 5 p.m. Sunday, Sept. 18 around Lake Phalen.

The 5k walk will begin at Lake Phalen's Park Shelter. The event serves as a kick-off to the National Deaf Awareness Week, a week-long celebration of the culture, heritage, and language unique to Deaf people around the world. Walkers are invited to a light lunch afterwards.

The walk is organized by Global Deaf Connection. Last year in St. Paul the Deaf Awareness Walk attracted 80 participants and raised a total of \$8,000 for five Deaf-related organizations. Contact Emily at travel@deafconnection.org for more information.

Virus...continued from Page 1

Usually a CMV infection causes few if any symptoms when you initially “catch” it. However, if a woman is pregnant when she first gets a CMV infection, the virus can cross the placenta to the infant, producing what is called “congenital CMV infection.” Once a CMV infection is acquired in this fashion, there is a risk to the baby for a number of symptoms. These are noted below. In severe cases, infants with congenital CMV infection can have enlarged abdominal organs (caused by liver and spleen enlargement), growth problems, blood count abnormalities requiring transfusions, and brain injury. If there is brain injury, developmental delay and mental retardation can occur. There can be a wide range of severity of symptoms, but not all babies have symptoms. In fact, the majority of babies born with congenital CMV infection look and act entirely normally as newborns. However, even these completely “asymptomatic” babies are at risk for deafness in up to 15% of cases. Thus, even in the “mildest” of cases, there is a significant risk that congenital CMV infection can cause hearing loss.

Symptoms of Congenital Cytomegalovirus Infection

- **Hearing loss**
- **Small for gestational age**
- **Growth failure**
- **Skin rashes**
- **Enlarged abdominal organs**
- **Blood count abnormalities**
- **Reduced head growth**
- **Developmental Delay**

Currently, there is no licensed vaccine for CMV. Thus, efforts to decrease the likelihood of acquiring CMV infection during pregnancy should be focused on prevention. CMV is often transmitted from child-to-parent (just as rubella was in the 1960s). Children in group day care centers often acquire CMV infections from other children,

which in turn, if transmitted to a pregnant parent, can lead to congenital CMV when the baby is born. Thus, women can decrease their risk of catching CMV by minimizing their exposure to infectious secretions of young children, such as urine and saliva. Women of childbearing age can discuss their risk of CMV with their obstetrician, and be tested for CMV antibodies to assess their risk.

If a baby is born with congenital CMV infection, it is important for families to be aware that there is an antiviral drug available which appears to be useful in preventing CMV-induced deafness in some babies. The drug is called Ganciclovir, and it is highly active against CMV. It should be used only following consultation with an expert on antiviral treatment in children.

In cases of CMV-induced deafness in which antiviral therapy does not provide any improvement, hearing aids can be utilized. In cases of severe, bilateral deafness caused by congenital CMV, cochlear implantation has been used and is highly effective. The University of Minnesota Children’s Hospital in the Division of Infectious Diseases is one of a number of participating sites in the Collaborative Antiviral Study Group (CASG) and can, in collaboration with the Lion’s Hearing Center at the University of Minnesota, provide families with up-to-date information regarding treatment options for hearing-impaired infants with congenital CMV infection (612-624-1112).

Ultimately, the control of CMV in newborn infants and the prevention of CMV-induced deafness will likely depend upon the development of an effective vaccine. Until a vaccine is available, increased knowledge of CMV in the lay and medical communities, will be necessary.

One aspect of the natural history of CMV in congenitally infected newborns that complicates recognition of this disease is the fact that hearing loss caused by congenital CMV may be progressive. Thus, a newborn with congenital CMV infection may “pass”

the newborn hearing screen, only to go on to develop CMV-induced deafness months or, in some cases, years later. Newborn hearing screening programs may therefore miss a large number of cases of congenital CMV-induced deafness, since the deafness is not yet present in the immediate newborn period when hearing screening occurs.

A solution to this problem would be not only to perform universal newborn hearing screening, but also to perform universal newborn screening for CMV infection. Those babies found to test positive could then be monitored carefully for hearing loss, and possibly treated with antiviral medications. Current research at the University of Minnesota is examining the feasibility of doing this kind of testing on newborns using blood spots obtained as a part of the newborn metabolic screen. Future research will focus on integrating newborn hearing screening programs with newborn CMV screening programs. When CMV testing is combined with genetic testing, it should be feasible in the not-too-distant-future to quickly identify not only the presence of hearing loss, but also the cause of that hearing loss, in order to offer specific interventions to families in a more timely, efficient fashion.

For More Information:

**University of Minnesota
Department of Pediatrics,
Division of Pediatric Infectious
Diseases and Immunology:
[www.med.umn.edu/peds/id/
home.html](http://www.med.umn.edu/peds/id/home.html)**

**“Cytomegalovirus” Chapter
available at Emedicine.com
([www.emedicine.com/PED/
topic544.htm](http://www.emedicine.com/PED/topic544.htm))**

**National Congenital
Cytomegalovirus Registry:
www.bcm.edu/pedi/infect/cmvl**

The Family Support Connection needs your help to support the services we provide to families with children who have recently been diagnosed with hearing loss. Along with monetary donations, we could use phone cards in \$10 increments so experienced parents can contact these families to provide support and practical suggestions for raising a child who is deaf or hard of hearing. Please contact us if you can help. See contact information on Page 2.

Raptor release interpreted

The Fall Raptor Release Sept. 24 at Lake Rebecca Park Reserve in Rockford will be ASL-interpreted.

Sponsored by Three Rivers Park District and The Raptor Center at the University of Minnesota, the free event runs from 10 a.m. to 3 p.m.

Participants can observe and photograph at close range the Raptor Center's resident eagles, falcons, hawks and owls. Activities include face-painting and making raptor masks and gliders. Visitors also can hike the park's scenic trails and see the trumpeter swan refuge.

Lake Rebecca Park Reserve is about 30 miles west of Minneapolis on County Road 50. For more information, see www.ThreeRiversParkDistrict.org.



A Little Grin

By Linda Werness-Jaroszewski

A child asked his father why the birds on a telephone line were kind of jumpy while other birds on a different line were sitting quietly. After a moment of thinking, his father replied that that particular line was a TTY line, causing the birds to jump.

Fitness classes offered

St. Paul Parks and Recreation and CSD have teamed up to offer several fitness classes for people who use ASL.

Water Aerobics taught in ASL runs on Tuesdays from Sept. 20 to Oct. 25 and from Nov. 8 to Dec. 13 from 6 to 6:55 p.m. at Como Elementary School in St. Paul. Cost is \$20 each session.

Yoga in ASL follows Water Aerobics from 7 to 8 p.m. also at Como. Cost is \$15 per 6-week session.

Two sessions of kickboxing, a high energy workout, will be offered Mondays, Sept. 19 to Oct. 31 and Nov. 7 to Dec. 19 from 5:30 to 6:30 at Martin Luther King Recreation Center, 271 Mackubin Street, in St. Paul.

The cost is \$18 per session.

The instructor for these classes is Jessica Lynn Frank (better know in the community as Jessalyn). She is a graduate of Gallaudet University and has taught a variety of fitness classes.

Registration is due by Sept. 15 (Sept. 14 for kickboxing). For a registration form, contact Mary Livingston at St. Paul Parks and Recreation, 651-266-6366 (v), 651-266-6378 (tty), or e-mail mary.livingston@ci.stpaul.mn.us.



The Campfire Cue & S'mores party last month drew more than 40 people to Lebanon Hills Park—one family came all the way from Iowa. Kids' ages ranged from 2 to 16. Next year's event will be Aug. 12-14 with room for group camping (and cueing).

Trip to Space Camp fulfills girl's dreams

By Brienna Herold, 13

Last May I went to Space Camp in Huntsville, Alabama during the week for kids who are deaf.

I wanted to go because I love space and Science. I also wanted to try it because I had heard of it in a *Highlights* magazine long, long ago.

There were about 200 kids at the camp, and about 60 of them were deaf. We were divided into "mission teams." My team, "Atlas," had 9 deaf kids and 6 hearing. I was the youngest in my group.

The dorms where we slept were called "Habitat" and looked like rooms in the Space Station. Each room had 4 or 5 boys or girls sleeping in bunk beds. There were separate dorms for girls and boys.

Each day we had a different "mission" where we did jobs like Mission Control or like the astronauts at the International Space Station. When we pretended to have a space walk, we put on ice-packed vests and pulled white space suits over them. We wore helmets like real astronauts. They were heavy. I sat in a moon walk chair and was lifted up in the air. I had to keep hold of the wall so I wouldn't "float out in space" while I worked. It was fun.

We made rockets that we launched. My rocket shot off the launch pad, and the bottom part came right off, and the parachute didn't work. So, the rocket landed like an arrow sticking out of the ground.

We also had the chance to go on rides. My favorite was doing the Space Shot. You go way up in the air on a tall structure built for the ride, then you drop. It makes you feel weightless.

Other things we did included watching IMAX movies, doing experiments, making things, and playing volleyball.

Space Camp for the Deaf and Hard of Hearing is sponsored by Western Pennsylvania School for the Deaf and is offered annually. To learn more about it, see www.spacecamp.com/deaf.

If you have a camp story to share, please send it to us at fsc@lifetrackresources.org.



Off The Shelf

By Robin Coninx, FSC Specialist

We will be taking inventory of our library Nov. 7-12. All library resources that are checked out will be due back by Nov. 4. Materials still may be checked out in September and October. For a list of library materials, visit our web site: www.familysupportconnection.org.

The Midwest Auditory Oral Education Conference for parents and professionals who support spoken language skills for children who are deaf or hard of hearing is Oct. 20 at Four Points Sheraton in St. Paul. For details, see www.northernvoices.org.

Colleges reach out to students affected by Hurricane Katrina

Two colleges that serve students who are deaf or hard of hearing have opened their doors to students displaced by Hurricane Katrina.

The National Technical Institute for the Deaf at Rochester Institute of Technology in New York is accepting student enrollments for Fall quarter or the entire school year. Contact the NTID Office of Admissions at 585-475-6700 (v/TTY) or at NTIDAdmissions@rit.edu.

Gallaudet University in Washington, D.C., is accepting graduate, undergraduate, secondary and elementary students who are deaf, hard of hearing or hearing. For details, see www.gallaudet.edu.

Group honors Cued Speech creator with memorial scholarship, library

The National Cued Speech Association (NCSA) is working on several projects honoring the developer of Cued Speech, Dr. R. Orin Cornett, who passed away in 2002.

NCSA has created the Dr. R. Orin Cornett Scholarship Fund for deaf college students who use Cued Speech. Donations can be sent to NCSA's office, 23970 Hermitage Drive, Cleveland, Ohio, 44122. The first scholarship will be awarded in July 2006 at the first national NCSA Conference Celebrating Literacy, Excellence and Diversity July 20-23, 2006 in Towson, MD.

NCSA also has established an agreement with Gallaudet University to set up a virtual research library featuring Dr. Cornett's research papers as well as serving as a central address for Cued Speech research.

To learn more about NCSA's mission and projects, see www.cuedspeech.org.

Captioned movie shown



The family movie "Charlie and the Chocolate Factory" (rated PG) shows with open captions at the Kerasotes Showplace/Coon Rapids Sept. 19 and 20 and in Inver Grove Heights Sept. 21 and 22.