

# Iowa EHDl News

## EHDl

Iowa's Early Hearing  
Detection & Intervention System



Your **Sound Source** for Early Hearing Detection & Intervention Information

Summer 2010

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## Looking for a few good people

Are you a hospital nurse or audiologist working with the EHDl program? We are looking for you.

The Iowa EHDl program is forming a planning group to develop quarterly progress reports as part of a new quality assurance strategy. By next fall, the quarterly progress reports will provide hospitals with information on how they are doing in meeting the state goals for refer and miss rates, as well as their progress in reporting all children into eSP. The reports will provide comparisons with other hospitals with nurseries that are the same level.

Are you one of the few good people we are looking for? Please contact Tammy O'Hollearn at [tohollea@idph.state.ia.us](mailto:tohollea@idph.state.ia.us) or (800) 383-3826. We look forward to working with you to develop a quality assurance tool that is beneficial for the state program, as well as the individual hospital program!

## Advisory Update

The next meeting of the Iowa Early Hearing Detection and Intervention Committee is:

**July 1, 2010**

10 a.m. - 3 p.m., Location: Lucas State Office Bldg., Room 201

July						
S	M	T	W	T	F	S
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4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

Contact Tammy O'Hollearn for special accommodations at least 48 hours in advance of the meeting

Past meeting agendas, minutes and a list of committee members are available online! Visit [www.idph.state.ia.us/iaehdi](http://www.idph.state.ia.us/iaehdi).

# Resource for Providers and Families

[www.signingtime.com](http://www.signingtime.com)

Iowa EHDI staff had the privilege of meeting Rachel Coleman at the National EHDI Conference, held March 2<sup>nd</sup> in Chicago, Ill. Rachel was truly one of the best speakers at the conference! In 1996 Rachel's daughter Leah was born profoundly deaf and four years later, her daughter Lucy was born with spina

bifida. Inspired by her children's needs and challenges, Rachel has been instrumental in putting sign language into the hands of infants and toddlers, both hearing and deaf.



Rachel and her sister, Emilie Brown, founded Two Little Hands Productions, and created the DVD series and television show "Signing Time" which introduces American Sign Language and English vocabulary in a fun and engaging way. The Coleman Family was featured on NBC's Today Show, and their story has been told in many publications such as Ladies Home Journal, Working Mother Magazine and Inc. Magazine. "Signing Time" music videos are currently airing on the cable station Nick Jr. The 26 episode "Signing Time" series aired on public television from 2005-2008 and has received numerous awards. In 2008, Rachel received an Emmy nomination for her role in Signing Time. Rachel is a mentor, advocate and role model for countless families across the country who are raising children with disabilities. Above all recognition, Rachel is thrilled that the Signing Time DVDs are often one of the first resources families seek out when they discover their child has a hearing loss.



## A Sound Beginning for Your Newborn Baby

To order additional hearing screening brochures in English or Spanish, please call the Healthy Families Line at 1-800-369-2229. Ask for publication IDPH 131 (English) or IDPH 131(S) (Spanish). The brochure is available free of charge!

**Healthy Families Line: 1-800-369-2229**

Phones are answered 24 hours a day, seven days a week

# Iowa EHDI News Survey Monkey Results

Thanks to all of you that took the time to respond to our request to participate in a survey about the EHDI newsletter, Iowa *EHDI News*. The majority of our readers (57.4%) who responded to the survey are audiologists, ENT specialists or related specialists; followed by educational staff (27.9%); and nurses, physicians, nurse practitioners or physician's assistants (13.1%). The majority of our readers review the quarterly newsletter (45.9%) through the EHDI website or in hard copy. Over fifty percent of our readers responded that they share the newsletter with others by forwarding the link, posting the newsletter on a bulletin board or news wall and by making copies to give to others.

The image shows a screenshot of a survey form titled "EHDI Newsletter". The form includes a "Default Section" with an introduction: "We need your help! We would like you to participate in the survey below about Iowa EHDI News, which is a quarterly published quarterly to communicate with parents and professionals about newborn hearing screening and follow up in Iowa. We want to ensure we are meeting the needs of our readers! You can help us do this by answering a few questions below that will guide our decision making and content of the newsletter. Thank you for helping to help you!"

The survey questions are:

- 1. Tell us about yourself. I am:** (checkboxes for: parent of a deaf/hard of hearing child, audiologist, ENT specialist or related professional, nurse, physician, nurse practitioner, physician's assistant, school district or educational specialist, early interventionist, family support provider, deaf community member, Other (please specify))
- 2. I read the EHDI newsletter:** (radio buttons for: quarterly, rarely, several times a year, on occasion, throughout the years of publication)
- 3. I prefer reading the EHDI newsletter:** (checkboxes for: online, in hard copy format, does not matter)
- 4. I read the EHDI newsletter:** (checkboxes for: to gain knowledge about evidenced based research and best practices in newborn hearing screening and follow up; locally and nationally)

The following is a list of reasons our readers review the newsletter:

- Gain knowledge about evidence-based research and best practices in newborn hearing screening and follow up; locally and nationally (55.7%)
- Receive updates about statewide implementation of the newborn hearing screening and follow up program (80.3%)
- To share with patients/customers as a resource for support, research or best practices that may have an impact on their child or family (36.1%)
- For advocacy purposes (18.0%)

What do our readers want to see more of in the EHDI quarterly newsletter?

- Evidence-based research articles (23.6%)
- Personal and family stories (10.9%)
- Diversity in the types of articles (10.9%)
- Articles regarding communication options (18.2%)
- Articles on deaf culture (7.3%)
- Articles on advocacy (7.3%)

Best of all, those readers who responded to the survey states they are happy (67.3%) with the content for our newsletter each quarter! Here is an example of the positive responses we received. "Job well done. I enjoy hearing what other hospitals or providers are doing that are successful. I like hearing the patient stories as it reminds me why we do the things we do and that our work does make a difference in the life of a child!"

Thanks again for providing the EHDI program with input! We value your opinions. If you have suggestions for future newsletters, please contact Tammy O'Hollearn at [tohollea@idph.state.ia.us](mailto:tohollea@idph.state.ia.us) or (800) 383-3826.

# Best Wishes

The EHDI program would like to extend our heartfelt thanks and best wishes to Roger Hess, Special Education Director at Northwest Area Education Agency, upon his retirement in June. Many thanks to Mike Jorgensen, parent of a child with a hearing loss. Mike will continue his advocacy efforts through Iowa Hands and Voices. Both Roger and Mike have served on the EHDI Advisory Committee for years. Their service and dedication to the EHDI program has helped move the program beyond initial screening and reporting to building a comprehensive system with many partners.

Thank you both for your dedication and advocacy!

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## New Ear, Nose and Throat Clinic Opens in Council Bluffs

On Tuesday, May 4, 2010, Council Bluffs Mayor, Tom Hanafan and the Council Bluffs Chamber of Commerce held a formal ribbon cutting ceremony at 4:00 p.m. to welcome a new Ear, Nose and Throat Clinic at 320 McKenzie Avenue. The clinic will serve Council Bluffs and the neighboring communities.

The clinic, affiliated with Boys Town National Research Hospital, will offer pediatric and adult medical care for simple to complex ear, nose and throat conditions and will include a center for hearing evaluations and hearing aid technologies. Board Certified physicians at the clinic include Michael Crawford, M.D. and Rodney Lusk, M.D.

The clinic will be opened on Wednesday, May 5, 2010. Clinic hours are Monday-Friday, from 8 a.m. - 5 p.m. To schedule an appointment at the Ear, Nose and Throat Clinic, call (712) 256-5272.

For more information on services available at the clinic, visit Patient Services at [www.boystownhospital.org](http://www.boystownhospital.org).

### Did you know?

Iowa School for the Deaf, in collaboration with the Area Education Agencies and the Lions Foundation of Iowa, will again host sign language classes and mini workshops on deafness during the 2010-2011 school year. The classes are planned to be held via the Iowa Communications Network. Check the Iowa School for the Deaf website at [www.iowaschoolforthe deaf.org](http://www.iowaschoolforthe deaf.org) in late summer/early fall for details.

# Congenital Cytomegalovirus (CMV)

Congenital Cytomegalovirus (CMV) is the leading non-genetic cause of permanent hearing loss in children. This is a widespread infection that affects people of all ages and backgrounds. In adults CMV causes only mild flu-like symptoms. If a mother is infected for the first time during pregnancy, however, her baby can be infected and this can have serious consequences for the baby. In Iowa this congenital infection affects about 1 in 200 newborns (Murph, J. et al, Am J Epidemiol., 147 (10) 940-947). Some characteristics of the infection present challenges to the EHDI system. Only 10% of newborns with congenital CMV display obvious symptoms of the infection at birth. The vast majority of infected babies will have no symptoms related to the CMV, so parents and physicians will not know that the baby is at risk for hearing loss. Studies indicate that 10-15% of these asymptomatic babies will develop permanent hearing loss. Additionally, about half of permanent hearing loss due to congenital CMV will have a delayed onset, so it will not be detected at birth.

Because of these challenges, many people involved in newborn screening have been investigating the possibility of adding a screen for congenital CMV to the panel of conditions detected in the routine newborn bloodspot screen. This possibility has been under extensive investigation at the University of Alabama. Their research results were published recently in the Journal of the American Medical Association (Bopanna, S. et al, JAMA, 303 (14) 1375-1382). Unfortunately, their research indicates that screening tests for congenital CMV infection from the newborn bloodspot screen are not sufficiently sensitive to the presence of the virus to detect even a majority of infected newborns. They indicate that newborn CMV screening may have to rely on other specimen sources, such blood or urine. Until the value of alternate methods is thoroughly investigated, the best way to detect hearing loss due to congenital CMV will be to accurately report this risk factor to the Iowa EHDI team so these babies can be closely monitored. In addition, hand-washing, avoidance of sharing utensils exposed to saliva and other hygienic practices will continue to be important in preventing congenital CMV infection and related hearing loss.

***By Lenore Holte, PhD, EHDI Lead Audiologist, Center for Disabilities and Development, University of Iowa Children's Hospital***

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## Infant Hearing Screening Equipment Loaner Program

**Are you having problems with your hearing screening equipment?** The Iowa EHDI program has a limited number of loaner screening OAE units available for hospitals to use while their screening equipment is being repaired.

There is no charge for borrowing the equipment.

**For information about loaner units, please contact:**

Alitta Boechler – (800) 272-7713

Lenore Holte - (319) 356-1168

Emily Andrews - (319) 384-6894

Nick Salmon - (515) 576-5312

Your single point of contact to assist families in connecting with Early ACCESS and community-based services that address specialized child and family needs

1-888-IAKIDS1 or  
1-888-425-4371

[www.EarlyACCESSIowa.org](http://www.EarlyACCESSIowa.org)

# Listening to Our Youngest Patients

Grinnell Regional Medical Center (GRMC) began offering infant hearing screening in 1998 when the onsite audiologist secured a grant to purchase the equipment. Setting precedence and establishing a culture of education helps GRMC maintain its success with infant hearing screenings.

Advances in technology and staff training now allow certified staff in the Kintzinger Women's Health Center (KWHC) to perform the screening on all infants born at GRMC. Parents appreciate having this service and the advance

education on what to expect. "At birth, our son Kaiden failed the hearing screening. It's a very hard thing to hear," says Ashley Perkins. "The nursing staff at the KWHC discussed the results and the next step. They were very compassionate and reassuring. We returned two weeks later for a follow-up appointment back to the KWHC and were greeted with familiar faces. Kaiden needed to continue on to the next step and the staff were excellent, supporting us through this time. They helped gather contact information and numbers. They even followed up afterwards to see how we were doing. It's difficult wondering if your son will ever hear and the staff was genuine and showed understanding as we worked through this."

"One of the many joys of working with new parents at GRMC is our ability to build the relationships," says Sheryl Baarda. "If the baby does not pass the screen the first time, and sometimes it does happen, we can be that familiar face and comfort to the parents. They can come back in two to four weeks and know where they are going and the people who will be testing their baby. That is a huge benefit."

GRMC begins educating parents about the hearing screening and the importance of testing a child's hearing at pre-natal classes. Parents receive another opportunity to learn about the service and value of hearing screenings at pre-admission. Nursing staff explain the testing process, talk about risk factors, and explain and describe options should their child have a hearing loss.



***"At birth, our son Kaiden failed the hearing screening. It's a very hard thing to hear," says Ashley Perkins. "The nursing staff at the KWHC discussed the results and the next step. They were very compassionate and reassuring."***

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# Listening to Our Youngest Patients

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After admission, the parents are notified when their child is screened. The results are shared with the parents and a written report is provided to the parents and the family physician. Discharge instructions also include information on signs to watch for hearing loss in an infant. If the infant does not pass the initial screen at birth, parents are asked to return in two to four weeks for a rescreen. Area physicians support the GRMC infant hearing process and encourage parents to return for the rescreen during their well-baby exams, if needed.

“With the rescreens available in the OB unit, we have a high return rate. Parents are familiar with the facilities and staff. Plus, most physician offices are located close to the hospital, encouraging easy access and follow-up,” explains Sheryl Baarda, OB nurse manager.

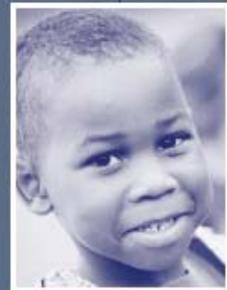
*By Grinnell Regional Medical Center, Kintzinger Women’s Health Center*

## MARK YOUR CALENDAR!

### Iowa Symposium on Hearing Loss: Impact on Children and Their Families

#### Featured Speaker

*Bryan Grubb* - inspiring story of personal achievement while facing significant challenges; a story you will want to hear and will never forget!



#### Topics to include:

- ~ Auditory Dyssynchrony
- ~ EHDI Update
- ~ Outcomes for Children who are Hard of Hearing
- ~ FM Amplification Systemes
- ~ Usher Syndrome
- ~ Recommended Practices in Deaf Education
- ~ Behavior Managment
- ~ What’s New in OB Screening!



September 17 & 18, 2010  
Courtyard by Marriott  
Ankeny, Iowa

#### For more information

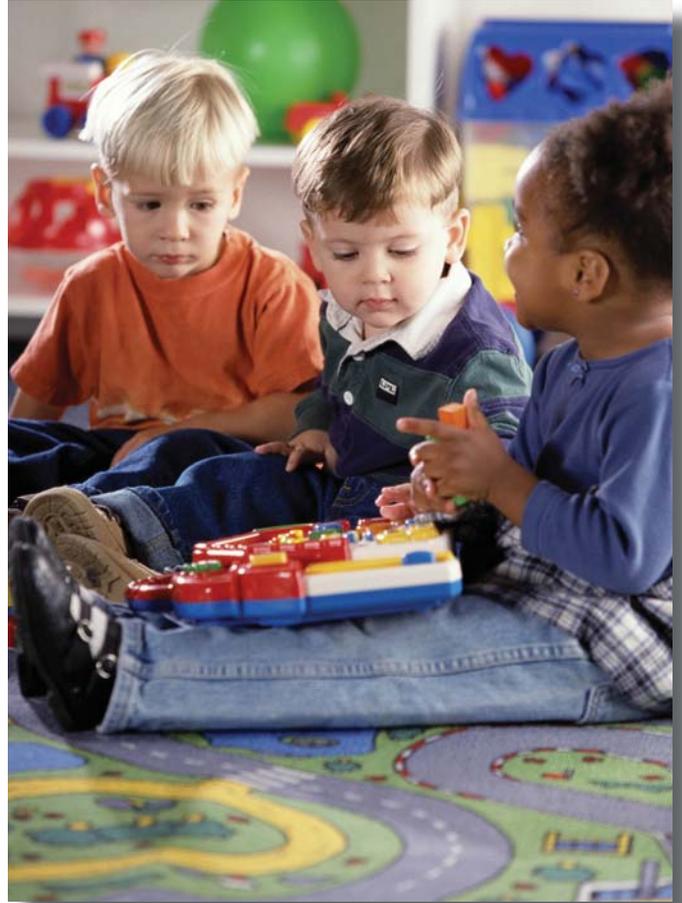
Contact Sara Patkin at  
[m spatkin@yahoo.com](mailto:m spatkin@yahoo.com) or  
(515)963-8664  
CEUs available.

# Summer Social Activities

Providing summer social activities for a child can be a challenge for any parent. The challenge can be even greater for the parent of a deaf or hard of hearing child. Additionally, peer interaction is a key for a deaf or hard of hearing child to grow up happy, with good self-esteem and social confidence. So what options do you have?

There are many options for social interaction. For **younger children**, arranging play dates may be one of the easiest options. Educational professionals from your Area Education Agency (AEA) or school can be a great resource to establish peer interactions. **Iowa Hands and Voices** is an excellent resource to connect with other parents and their children. You can contact Iowa Hands and Voices at (515) 988-8512 or [www.iowahandsandvoices.org](http://www.iowahandsandvoices.org).

Iowa has summer programs for deaf and hard of hearing **toddlers and pre-schoolers**. The Wendell Johnson Speech and Hearing Clinic offers a summer program called "**Listen and Speak Up!**" for children who are 1-5 years of age. The goal of the program is to foster the development of spoken language and listening skills. There is a fee for the program but some scholarships are available. For more information call (319) 335-8736. The Iowa School for the Deaf is hosting a **Summer Camp** for pre-school through 12<sup>th</sup> grade students. The camp is open to deaf and hard of hearing students who are oral or use sign language. For more information call (712) 366-0571 or [www.iowaschoolforthe deaf.org](http://www.iowaschoolforthe deaf.org).



There is also programming for **older children and teens**. In Iowa, the Des Moines Sertoma Club hosts an annual **Fantasy Baseball Camp** for children ages 7-14. For more information contact Pat Taylor at (515) 244-6408. Again, the Iowa School for the Deaf has a **Summer Camp** for students up to 12<sup>th</sup> grade. For information call (712) 366-0571 or check the website at [www.iowaschoolforthe deaf.org](http://www.iowaschoolforthe deaf.org). **Camp Sertoma** in Brainerd, Minnesota offers sessions for 1<sup>st</sup> - 7<sup>th</sup> graders and 8<sup>th</sup> - 10<sup>th</sup> graders in July. The camp is open to students who are deaf or hard of hearing from Minnesota, North Dakota, South Dakota, Iowa and Nebraska.

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# Summer Social Activities

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Sertoma clubs in Iowa provide financial sponsorship for campers to attend. For more information call (218) 828-2344 or [www.campsertoma.com](http://www.campsertoma.com). Camp Lakodia in Madison, South Dakota offers a **National Leadership and Literacy Camp**. There is a session for 5th - 8th graders and another session for 9th - 12th graders. Scholarships are available. For more information call 1-800-642-6410 or [www.nllcamp.com](http://www.nllcamp.com).

Other camps specifically for deaf and hard of hearing children can be found at [www.camps4us.com](http://www.camps4us.com) and selecting "hearing impaired camps" from the list. "**World Around You**" is an e-magazine published by the Clerc Center. The e-magazine focuses on the achievements of young people who are deaf or hard of hearing. Learn more about the e-magazine and how to subscribe at [www.clerccenter2.gallaudet.edu/worldaroundyou](http://www.clerccenter2.gallaudet.edu/worldaroundyou).

Talk with other parents. As mentioned earlier, **Iowa Hands and Voices** is an excellent resource for parents. Find out what other children are doing this summer and seek ways to have your child attend the same activities. Most of all, have fun!

## Summer Camps for Deaf and Hard of Hearing Children and Teens

**Did you know?** The following link ([http://clerccenter.gallaudet.edu/Clerc\\_Center/Information\\_and\\_Resources/Info\\_to\\_Go/Resources/Summer\\_Camps\\_for\\_Deaf\\_and\\_Hard\\_of\\_Hearing\\_Children.html](http://clerccenter.gallaudet.edu/Clerc_Center/Information_and_Resources/Info_to_Go/Resources/Summer_Camps_for_Deaf_and_Hard_of_Hearing_Children.html)) identifies camps, family learning vacations, and remedial clinics for deaf and hard of hearing children. Some programs are designed for the entire family. Most camp programs require a small application fee to accompany the completed application. Contact the camp sponsor directly for more information about their program.

If you are aware of other camp programs for deaf and hard of hearing children that are not on the list, please e-mail [Clerc.Center@gallaudet.edu](mailto:Clerc.Center@gallaudet.edu).

# Welcome New EHDI Staff

## Vicki Hunting

Vicki Hunting was hired in October 2009 and is the Project Coordinator for EHDI. Vicki will provide general oversight to all HRSA-funded elements of EHDI in addition to leading specific quality improvement efforts supported by supplemental funding through March 31, 2011. As a mother of a young adult with profound hearing loss identified in infancy, Vicki Hunting also provides leadership to Iowa's Guide By Your Side (GBYS) network. Vicki lives in Des Moines with her husband, Mark, and two children.

**Contact information:** [vicki-hunting@uiowa.edu](mailto:vicki-hunting@uiowa.edu) or (515) 331-0750.



*Vicki Hunting, EHDl Project Coordinator*

## Peggy Swails

Peggy Swails was hired in February 2010 as the EHDI Follow-Up Coordinator (replacing Erin Kongshaug). Her strengths align perfectly with this role as she provides developmental and administrative support and assists in program evaluation for EHDI. Peggy also shares her time with the Public Health Division at Child Health Specialty Clinics (CHSC). Peggy's vision is to continue Erin's work in advancing Iowa's EHDI System of Care. She earned her Bachelor's and Master's degrees from The University of Iowa School of Social Work and resides in Lone Tree with her husband, John, and their four children.

**Contact information:** [peggy-swails@uiowa.edu](mailto:peggy-swails@uiowa.edu) or (319) 356-3570.



*Peggy Swails, EHDl Follow-Up Coordinator*

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# Welcome New EHDI Staff

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## Susan Hagarty

Susan Hagarty is the coordinator for our Guide By Your Side (GBYS) family support program. Susan, along with trained parent guides around the state, will provide unbiased support to families with children (birth to 3) who are deaf or hard of hearing. Susan hopes to increase the number of referrals into the program so that more families can be served. She and her husband, Brad, are the parents of three daughters, Caitlyn (16), Hannah (15) and Madeline (13). Caitlyn has mild to moderate unilateral hearing loss and Madeline is profoundly deaf with bi-lateral cochlear implants.



Susan Hagarty, Guide by Your Side Coordinator

**Contact information:** [susan-hagarty@uiowa.edu](mailto:susan-hagarty@uiowa.edu).

## Iowa Healthy Families Line

**Health information and referral  
line services 24 hours a day,  
seven days a week.**

The Healthy Families Line can help you find information on topics such as:

- Birth control and pregnancy
- Breast and cervical cancer
- Child care
- Child and infant health
- Domestic abuse
- Maternal and prenatal care
- Sexually transmitted diseases



## Contact Information

### State EHDI Coordinator

Tammy O'Hollearn  
Iowa Department of Public Health  
(515) 242-5639  
tohollea@idph.state.ia.us

### EHDI Follow-Up Coordinator

Peggy Swails  
Child Health Specialty Clinics  
(319) 356-3570  
peggy-swails@uiowa.edu

### Family Support Coordinator

Susan Hagarty  
Child Health Specialty Clinics  
(866) 219-9119  
susan-hagarty@uiowa.edu

### Audiology Technical Assistance

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emily-andrews@uiowa.edu

**Requests?  
Feedback?  
Comments?  
Suggestions?**

We welcome your questions, comments and suggestions about this newsletter. Please forward any feedback about Iowa EHDI News to:

Tammy O'Hollearn, Iowa EHDI Coordinator  
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Des Moines, IA 50319  
Phone: (515) 242-5639  
E-mail: [tohollea@idph.state.ia.us](mailto:tohollea@idph.state.ia.us)

**Additional copies of Iowa EHDI News are available by contacting Tammy O'Hollearn.**