American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
Iowa Chapter

The Heartland Pediatrician

Spring 2018

President's Message

Hello Friends,

I would like to let you know about a new initiative that Iowa AAP will be undertaking in collaboration with National AAP and Georgetown University's Center for Children and Families. Iowa AAP will receive funding to educate stakeholders about EPSDT and to advocate for support of EPSDT if benefits are threatened in our state in the future. We will be reaching out to you in several ways over the next year to offer information about EPSDT and to help you incorporate EPSDT into your practice. Our Iowa partner in this effort is the Child and Family Policy Center based in Des Moines.

EPSDT is the benefits package guaranteed to Medicaid recipients. In Iowa these benefits are continuous from birth until the young person's 22nd birthday. In Iowa we call these benefits "Care for Kids". **EPSDT** is an acronym for **E**arly and **P**eriodic **S**creening, **D**iagnosis and **T**reatment. Medicaid will pay for all the screenings and preventative care approved by EPSDT. In Iowa these benefits are essentially the same as the AAP Bright Futures Guidelines. The 2017-2018 periodicity schedule delineating approved care is available here.

Iowa AAP will be offering a webinar(s) to help you implement EPSDT in your practice. We will also be offering billing and coding information on our website. There will be some opportunities for practices to have an AAP Board member visit you in person to answer questions if you need us.

In addition to educating providers we will be working with the MCOs, DHS, and the state EPSDT program at IDPH to improve the information provided to Medicaid recipients as well as the dissemination process. We

are hoping to develop patient education materials for you to distribute in your offices because many recipients do not understand their benefits.

Lastly, we will be educating legislators about EPSDT and advocating for these services for Medicaid recipients and for all children. We have already started this work by meeting many Senators and Representatives during our Legislative Breakfast held on February 28.

You may learn more about EPSDT **here**.
Please **contact us** with any and all questions.

Marguerite H. Oetting, MD, FAAP
President, Iowa AAP

Open Boards and Commissions

Do you want to get more involved in serving the Governor and Lt. Governor? There are several commissions that will need volunteers to be appointed by the Governor in April 2018.

Don't miss your chance to expand your network, learn new skills, have a voice in decision making, analyze issues, and serve the community by being a part of a board or commission. There are many opening spots to get involved on Boards such as: Child Advocacy Board, Healthy and Well Kids in Iowa Board (HAWK-I), Early Childhood Iowa State Board, and so much more!

Click Here to apply and see all available board and commission positions.

Register Now - IA AAP Annual Meeting and Social

The American Academy of Pediatrics Iowa Chapter will host its Annual Meeting and Social on Wednesday, April 18, 2018. **This is new for 2018!** The social will begin at 6 p.m. and the Annual Meeting at 7 p.m. The event will be hosted at the Iowa Medical Society office at 515 E. Locust Street, Suite 400, Des Moines, IA 50309.

Join fellow IA AAP members for an opportunity to connect and hear updates on the initiatives of the IA AAP.

REGISTER NOW

SAVE THE DATE

Making Effective HPV Vaccine Recommendations

On **Wednesday, April 4 at 6:00 p.m**., plan to attend this event featuring Noel Brewer, Ph.D., a prominent researcher in HPV vaccination and cancer prevention, and Chair of the ACS HPV Vaccination Roundtable. Dr. Brewer will provide an interactive training allowing you the opportunity to learn the latest on HPV vaccine

research and guidelines. Included will be a brief, evidence-based communication strategy to increase vaccine uptake by your adolescent patients. You will also hear stories of Iowans who have been through treatment for HPV associated cancers, and others who want to help us protect adolescents from the six HPV associated cancers. Registration and networking begin at 5:30 p.m. Hors d'oeuvres and beverages will be provided.

The following morning on **Thursday, April 5 at 7 a.m.,** Dr. Brewer will present at grand rounds where the conversation will continue with patient case scenarios. You can attend on-site at Des Moines University or online. Registration is required if you're attending online.

Both activities will be held at Des Moines University. For more information or to register, please visit the **website**, **email**, or call 515-271-1596. This activity has been approved for AMA PRA Category 1 Credit,™ AOA Category 2-A Credit, and nursing contact hours through Des Moines University.

We are looking forward to your attendance! Here are some relevant articles discussing the use of presumptive announcements to recommend HPV vaccine:

- ***Advice For Doctors Talking To Parents About HPV Vaccine: Make It Brief***
- ***Good Talks Needed to Combat HPV Vaccine Myth***

Newborn Screening for Cystic Fibrosis in Iowa:

Accepting the challenge to make timely diagnostic sweat testing a reality

Melody Hobert-Mellecker RN BSN, Carol Johnson, Jenny Marcy CGC, Tim Starner MD, Renae Juska, Lauri Ramsey ARNP, Alladin Abosaida MD, Amy Scar RN BSN, Kathleen Gradoville, ARNP, Tara Eastvold, ARNP

Background

Cystic Fibrosis (CF) is a core condition listed on the Health Resources and Services Administration (HRSA) Recommended Uniform Screening Panel (RUSP) for newborn screening in the United States. Since September 2006, Iowa Newborn Screening Program (INSP) has been reporting newborn screening results for Cystic Fibrosis. Immunoreactive trypsinogen (IRT) is measured and results that are above the established cutoff (currently ≥ 65 ng/mL) reflex to a cystic fibrosis transmembrane conductance regulator *(CFTR)* gene mutation panel for further analysis. Of the over 2000 known mutations that occur in the *CFTR* gene not all are definitively considered to cause cystic fibrosis. Iowa's current panel tests for 23 of the most common CF-causing mutations. Once *CFTR* analysis is completed this result is entered into the lab database. Short term follow-up (STFU) nurses then contact the baby's primary care provider by telephone and provide verbal and written recommendations for referral of the infant to a Cystic Fibrosis Foundation (CFF) accredited CF center for sweat testing, genetic counseling, and CF center care if needed.

In June 2016, the Association of Public Health Laboratory (APHL) through their Newborn Screening Technical Assistance and Evaluation Program (NewSTEPs) in conjunction with the CFF convened an in-

person Cystic Fibrosis Quality Improvement Initiative meeting in Denver, Colorado. By bringing together representatives from laboratory and short-term follow up programs from all fifty state newborn screening programs in the United States, this meeting helped to facilitate a national discussion around the challenges of timeliness in newborn screening specifically related to cystic fibrosis. In addition to defining the challenges, several strategies were identified for implementation of state-based quality improvement initiatives to address these barriers to timeliness. The state of Iowa was represented at this meeting by a leadership team comprised of the program coordinator and the CF medical consultant for the Iowa Newborn Screening Program (INSP). Over the course of the next few months INSP began concrete planning for a process improvement plan aimed at improving timeliness in CF newborn screening in Iowa. Changes were made in the workflow for short term follow up to improve efficiency in case management and to improve communication among our newborn screening (NBS) team.

In February 2017, the Cystic Fibrosis Foundation published a multi-article supplemental issue to the *Journal of Pediatrics* to release the updated Consensus Guidelines for diagnosis of cystic fibrosis. [Farrell, Philip M et al. (February 2017). "Diagnosis of Cystic Fibrosis: Consensus Guidelines from the Cystic Fibrosis Foundation". *The Journal of Pediatrics (Supplement)*, 181S, 1-13.] This article points out that, “at least 64% of the new CF diagnoses in the US now occur in asymptomatic or minimally symptomatic infants following a positive NBS result”. The third statement in the updated consensus guidelines establishes that “newborns greater than 36 wk gestation and >2 kg body weight with a positive CF newborn screen, or positive prenatal genetic test, should have sweat chloride testing performed as soon as possible after 10 d of age, ideally by the end of the neonatal period (4 wks of age). In another of the supplement articles, the authors report that “nearly 24% of US patients with 2 CF-causing mutations do not have associated sweat chloride results. “ [Farrell, Philip M et al. (February 2017). "Diagnosis of Cystic Fibrosis in Screened Populations." *The Journal of Pediatrics (Supplement*), 181S, 33-44.] Additionally they recommend that because “not all infants with CF will have 2 CF-causing mutations detected [through newborn screening} . . . [and] because of the lack of clarity on the disease liability of various CFTR mutations, the sweat test is an especially crucial part of the diagnostic algorithm for this group of infants.” We know from other data presented at national meetings, that in the United States the average time from reporting of abnormal newborn screen results to performance of initial diagnostic sweat testing is 45 days. Farrell and his colleagues have established guidelines for date of confirmation of cystic fibrosis diagnosis subsequent to newborn screening and highlight the fact that “a genotype report from the NBS program is not sufficient” to make a medical diagnosis and that sweat testing “should be performed in all cases of presumptive diagnosis, as soon as possible. . .” and that “prompt diagnosis of CF is vital for optimizing outcomes.”

The Iowa NBS program recommends that diagnostic sweat testing be done only through CFF-accredited centers in order to assure reliable results through compliance with international protocols for testing and for the provision of coordinated medical, genetic counseling, and ancillary services after the results of the diagnostic testing are known. There are two CFF accredited centers in Iowa. INSP recognized early on that it is essential to involve the CF centers so an in-person meeting was conducted in September of 2017 to discuss ways the INSP and the two centers could collaborate more effectively for the benefit of all the children in Iowa who are referred due to positive NBS findings.

During this meeting, Iowa’s process for newborn screening was reviewed. We realized the most impact INSP could make would be in that window of time between when the abnormal result is reported to the primary

care provider (PCP) and when baby shows up for diagnostic testing at a CF center. The goal of this quality-improvement project is to see a substantial, measurable reduction interval between PCP notifications and sweat chloride testing, which in turn reduces the length of time to diagnosis and, more importantly, treatment for these children in order to optimize their health outcomes. We will be collecting pre- and post-implementation data on all CF screen positive infants in Iowa for the period January 1, 2017–December 31, 2018.

The major changes in the recommendations being provided by INSP to PCPs is:

- The incorporation of CFF consensus guideline language urging that sweat testing be completed as soon as possible and before the end of the neonatal period.
- Requesting that PCPs allow STFU to assist them in the referral process by asking the PCP/family to choose a referral center for the infant and then STFU will notify that CF center who will then directly contact parents to schedule the appointment.

If you as a provider have any questions, please do not hesitate to contact us. Our main phone number is 319.384.5097 and our email address is **iowanewbornscreening@uiowa.edu**.

1st Five:

Family Engagement in a Primary Care Setting

Recently, a mother received a diagnosis for her child, and was told that the course of treatment would include a major surgery. The mother was blindsided by this diagnosis and did not even begin to think of questions or concerns, let alone be able to articulate them, until well after she left the provider's office. This mother would have been able to absorb this diagnosis and to move forward if her child's provider had simply said, "This might not look like what you thought it would but we will work on this together. What questions come to mind? If you would like additional information I have resources available about this diagnosis."

"Family engagement" is often used without a clear understanding of what it means and how it impacts the relationships primary care providers build with families. What does this concept look like, from a family's perspective, when it is implemented in a primary care setting?

First of all, what is family engagement? The federal Maternal and Child Health Bureau and the American Academy of Pediatrics have a cooperative agreement that funds the National Center for Medical Home Implementation (NCMHI). NCMHI offers this definition: "Family engagement is a family-centered and

strengths-based approach to making decisions, setting goals, and achieving desired outcomes for children and families."[1]

When parents feel that something is "off" or "not right" with their child, it is important for primary care providers to honor these concerns. Although they may not have a clear medical understanding of what is going on, parents are the experts about their child and honoring the concerns may provide valuable information to you. The AAP Bright Futures Implementation Tip Sheet on Eliciting Parental Strengths and Needs notes that parental confidence will be built by eliciting these concerns and honoring their importance.[2] This will also help empower parents to embrace the needs of their child. Be sure to thank the parent for paying attention to the child's symptoms and responding to those concerns.

When developmental issues are discovered through observation or the use of screening tools, there are many resources and services that providers can refer to. Not all parents are at a point where they want to accept a diagnosis or feel the need for referral for further evaluation. This is an opportunity for family engagement. Yes, the child may need a referral for occupational therapy, physical therapy, speech, Early ACCESS, or school supports but often the parent is frozen in the moment a provider says, "I have some concerns about your child's development."

The best way to lay a foundation for a trusting relationship is to build upon strengths. When a provider acknowledges a family's strengths, it builds confidence in the parents who often feel as if they are not providing adequate care or are worried about making mistakes, especially where there has been a new diagnosis. The National Institute for Children's Health Quality (NICHQ) Family Engagement Guide states that "encouraging each child and family to discover their own strengths, build confidence and make choices and decisions about the child's care even in difficult and challenging situations" is one practice that can be embraced to achieve high quality, family-engaged care.[3]

One simple way to open up a discussion is to ask, "What is one thing that is going well with your family?"

Providers who welcome information about family successes and everyday life build a foundation for allowing parents' comfort in bringing a list of concerns to every visit. Pathways for open communication lines will then be built and parents will report what they are seeing outside of the office. It is also important that a family is supported in learning more about their child's care so that they can effectively participate in care and decision-making to the level that they choose.[4] This may also lead into developing care plans with families; the care plan will reflect family strengths, needs, concerns, and resources.

Family engagement is not a lofty idea or unattainable goal. Taking small steps at each visit with a family to make those stronger connections allows for the child to flourish.

The 1st Five Healthy Mental Development Initiative's Monthly Lunch & Learn Webinar Series will be focusing on family engagement in the months of March and April. For more information on these presentations, contact your local 1st Five Site Coordinator.

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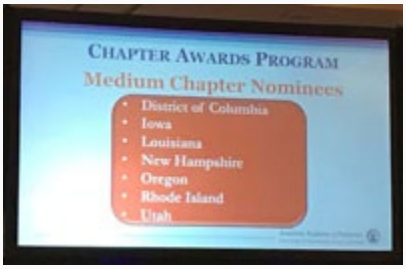
1. AAP Medical Home. (2017, May 16). **Beyond Coexistence: Cultivating successful family partnerships in clinical practice** [Video file].

2. Bright Futures. (2015, April). **Bright Futures** implementation tip sheet.
3. Malouin, R. (2013). *Positioning the Family and Patient at the Center. A Guide to Family and Patient Partnership in the Medical Home.* American Academy of Pediatrics.
4. National Institute For Children's Health Quality. (n.d.). **Family Engagement Guide**.



Iowa Chapter AAP Nominated

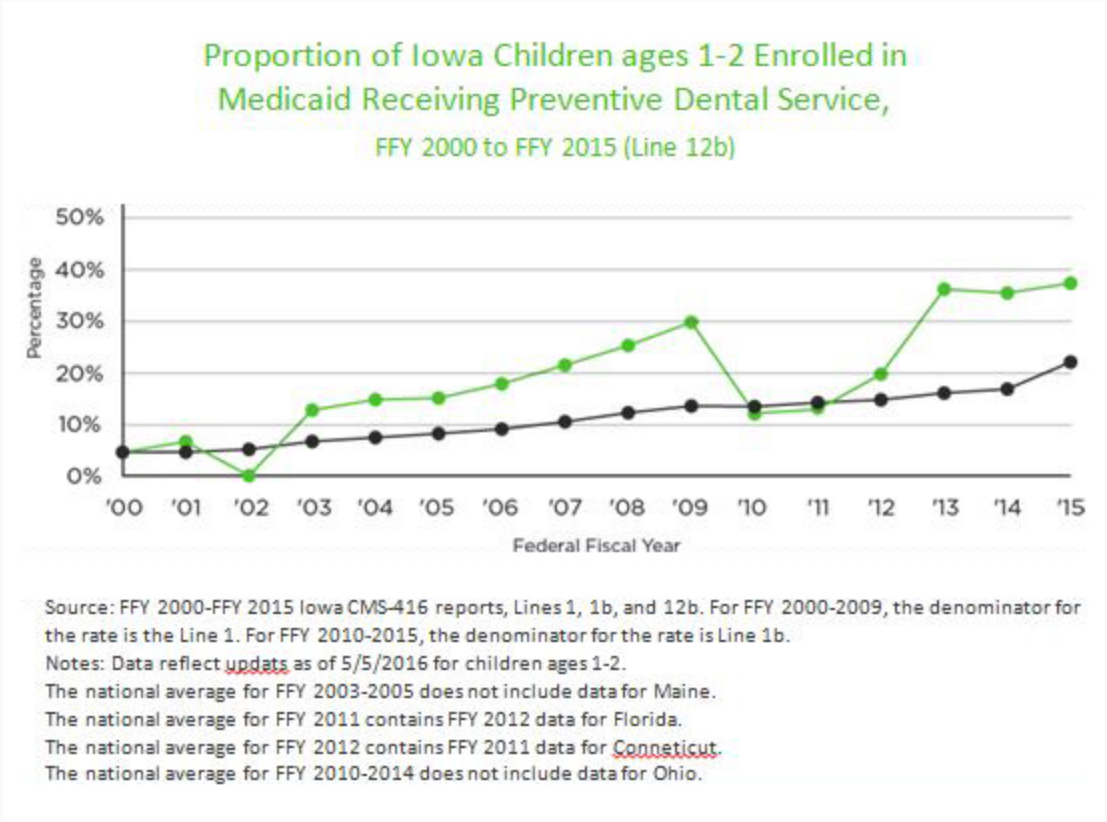
The Iowa Chapter AAP is pleased to announce that it has been nominated for the American Academy of Pediatrics Outstanding Chapter Award, medium-sized chapter category, District VI. In addition, the chapter will receive an Award of Chapter of Excellence at the District Meeting this summer in Itasca, Illinois. Congratulations to the members of the Iowa Chapter AAP and thank you for your continued dedication to the health, safety, and well-being of infants, children, adolescents, and young adults.

Children's Dental Health

Building Momentum for a Cavity-Free Iowa

In 2011, the Delta Dental of Iowa Foundation launched a statewide Dentist By 1™ public education campaign to encourage parents and caregivers to take their children to the dentist by age one. The campaign also targeted specific Iowa communities and was built using a successful grassroots coalition to reach out to medical and dental providers, community partners, families and caregivers.

The Dentist By 1 campaign is working. Since the program began, more Iowa children on Medicaid have seen a dentist for preventive services. The following chart illustrates this increase in comparison to the national average.



CAVITY FREE IOWA

To keep the momentum going, the Delta Dental of Iowa Foundation, in partnership with the Iowa Department of Public Health, I-Smile™ and local providers, has launched an extension of Dentist By 1, now known as Cavity Free Iowa. Cavity Free Iowa seeks to educate, train, and equip primary care and pediatric medical professionals to provide oral health screenings, risk assessments, and fluoride varnish in accordance with Iowa's **Care for Kids program guidelines**.

Through broad partnerships, Cavity Free Iowa links children to oral health education and preventive services by a trusted heath care professional and coordinates dental care through I-Smile to a dentist. In addition, Iowa medical professionals can now bill to provide fluoride varnish for Medicaid children up to age three. Because children see their medical providers at regular intervals during this critical developmental stage, this is a unique opportunity to create a lasting impact on the oral health of Iowa children.

Learn more about the **Smiles for Life curriculum for training** or **contact your local I-Smile Coordinator** for additional information.

New 5-2-1-0 Health Care Program Available

March is National Nutrition Month, a great time to learn more about 5-2-1-0 Health Care to promote healthy eating and active living and incorporate it into your practice! 5-2-1-0 Health Care, sponsored by Iowa Medical Society, offers a series of four educational webinars, tools, materials, and support on prevention of childhood obesity.

Dr. Jennifer Groos, MD, FAAP, Program Lead, discusses various topics such as accurately weighing and measuring pediatric patients, addressing weight stigmas in the clinic, motivational interviewing, and stages one and two best practices. These webinars are available for CME credit. If you are unable to attend or have missed the previous webinars they will be recorded and posted on the **IMS website**.

If your practice is interested in learning more about 5-2-1-0 Health Care or becoming a pilot site please contact **Becca Kritenbrink** at the Iowa Medical Society.

Teaching for a Better Practice

By Jason Kessler, MD, FAAP and Pam Harrison Chambers, MPH, PA-C, DFAAPA

Who among us does not owe who we are and what we do to men and women who gave us their time in teaching the art and science of practicing medicine? Education, like life itself, is a cyclic process where each generation owes its very existence to the one before. But teaching is not just giving back, or carrying on. It is a process of sharing the knowledge we have gained, building on that for the student and improving the depth of our own knowledge in the process.

I recently began working as the program director for the Physician Assistant program at Des Moines University. Early on, I discovered that there is a shortage of good clinical teaching sites available for students to learn the most important aspects of the art they are training to practice. I also learned that this is not just an issue for DMU, nor even just for PA programs. Nearly every clinical training program has this problem. Medical Education is in acute need of clinicians to help in the training of new health care professionals.

Both textbook and clinical information are essential to training practitioners with modern skills to take care of patients according to current standards. Good clinical teaching leads to better health care for our friends and families, quality colleagues, and appropriate use of health care resources.

Our own depth of knowledge is improved through teaching as we strive to explain to another individual what we perhaps reflexively do every day. Teaching students is related to, but a different process, than teaching our patients and their families. Patient-focused teaching calls for giving lay people understanding of their disease process to carry out a treatment plan. Teaching students requires sharing knowledge with enough depth that the student can use that information to enhance clinical decision-making skills. Students ask

questions. They may look at things in a different way. Those questions cause us to think, and to supplement our current knowledge to fully answer these questions. Occasionally, the student's questions or ideas will lead you to consider diagnoses or approaches you may not have otherwise entertained.

Having students in clinic can enhance your relationship with patients. A provider who is involved in teaching others can be perceived as more knowledgeable themselves (which is often true!). Some patients feel a sense of accomplishment from being a part of the education of young providers. Patients with chronic diseases have knowledge of their condition and a desire to be able to help new providers enhance understanding of what it is like to live with the condition.

Perhaps the greatest barrier to taking on students is time. Who has the time to teach? It takes surprisingly little time to provide a quality educational experience. It may take change in workflow to maximize efficiency with teaching. Occasionally, students can even increase efficiency by assisting with literature searches, spending additional time with patients, or assisting in finding or gathering information.

Getting involved in teaching is easy. You can contact me, and I would be happy to talk with you about working with Des Moines University PA students. You can also contact your local medical school, or your own alma mater. Any institution involved in the training of health care professionals would be happy to discuss teaching opportunities. Some may offer perks including adjunct clinical faculty status and access to libraries and resources. Some may even pay for your efforts. But even without these things, teaching students is a rewarding experience that will enhance your own clinical skills and offer a great way to honor and give back to those great teachers who made you the practitioner you are today.

Legislative Update

March 15 marked the end of the Iowa Legislature's second funnel: the deadline for policy bills to pass through one legislative chamber and a committee in the second one. (Tax and appropriation bills are exempt from the funnel, as are leadership bills.) Here is the status of health and/or safety legislation on which the **Iowa AAP** registered a position.

Bills That Advanced

Safe haven: Awaiting the Governor's signature, **SF 360** expands options for parents to legally abandon their newborns without being charged for abandonment. For more, visit this **blog post**.
Abuse of opioid prescription drugs: Awaiting final Senate approval, **HF 2377** curtails prescription shopping in opioids and enhances Iowa's Prescription Monitoring Program. For more, visit this **blog post**.
Pharmacy immunizations and vaccinations: Awaiting final House approval, **SF 2322**, will allow pharmacies to administer several different vaccinations or immunizations for adults and the second and third doses of HPV vaccines for those 12 and older. The Iowa AAP expressed **concerns** over expanding pharmacy immunizations of youth because of the potential adverse impact on youth seeking health care.
Student athlete concussions: Awaiting final Senate action, **HF 2442** calls for several actions to reduce the effects and recurrence of concussions in school sports, including: developing training materials for coaches and guidelines for school personnel and families, establishing rules governing returning to play following a concussion; and providing protective gear to students.

Bills That Failed to Advance

Mandatory reporter training and child welfare reform: Separate bills establishing work groups to improve training for mandatory reporters **SF 2300** and examine Iowa's child welfare **HF 2353** failed to advance.
Recipient work requirements: Also failing to advance were was legislation to impose work requirements on Medicaid recipients (**HF 2428**) and other public assistance recipients **SF 2370**. Iowa AAP expressed its disapproval of both bills to legislators attending its Feb. 28 breakfast.

What's Ahead

In the next week or so, the Legislature will turn most of its attention to the state's budget. Besides crafting a budget for state fiscal year 2019, legislators will consider legislation to de-appropriate some funding for fiscal year 2018 and reduce taxes. Iowa AAP has opposed the magnitude of the reductions in the 2018 budget (SF 2117).

For more information on the session, contact Iowa AAP's lobbyist, **Steve Scott**.

From left to right: Amy Kimball, DO, FAAP; Marguerite Oetting MD, FAAP; and Kathleen Foster Wendel, MD; visited the Secretary of State's Office at the Capitol during Physician Day on the Hill on February 28.

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American Academy of Pediatrics Iowa Chapter
www.iowapeds.org
515 E Locust, Des Moines, Iowa 50309
(515) 421-4778