



THE JOURNEY TO IOWA CMV LEGISLATION

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Objectives

- Leave with concrete ideas on how to be successful in the legislative process
- Gain confidence in ability to engage in legislation and talk with legislators



Why?

- Daughter Pippa, born in 2015 with a preventable birth defect.
- Angry, heartbroken
- Decided to turn those feelings into action and positive change



Our Legislative Journey

- Legislation introduced 2016 session, bill did not get a vote.
- Modified legislation introduced 2017 session.
- Bill received bipartisan support.
- Bill passed Senate and House unanimously.
- Bill was signed into law 4/20/17.
- CMV Public Health Initiative, or “Pippa’s Law” went into effect 7/1/17.
- Iowa is the 8th state with some form of CMV legislation.



Legislation details- prevention

- ❖ The center for congenital and inherited disorders shall develop and publish or approve and publish informational materials to educate and raise awareness of cytomegalovirus and congenital cytomegalovirus among women who may become pregnant, expectant parents, parents of infants, attending health care providers, and others, as appropriate. The materials shall include information regarding all of the following:
 - ❖ Incidence, transmission, birth defects, diagnosis, prevention, early interventions/treatment/services available



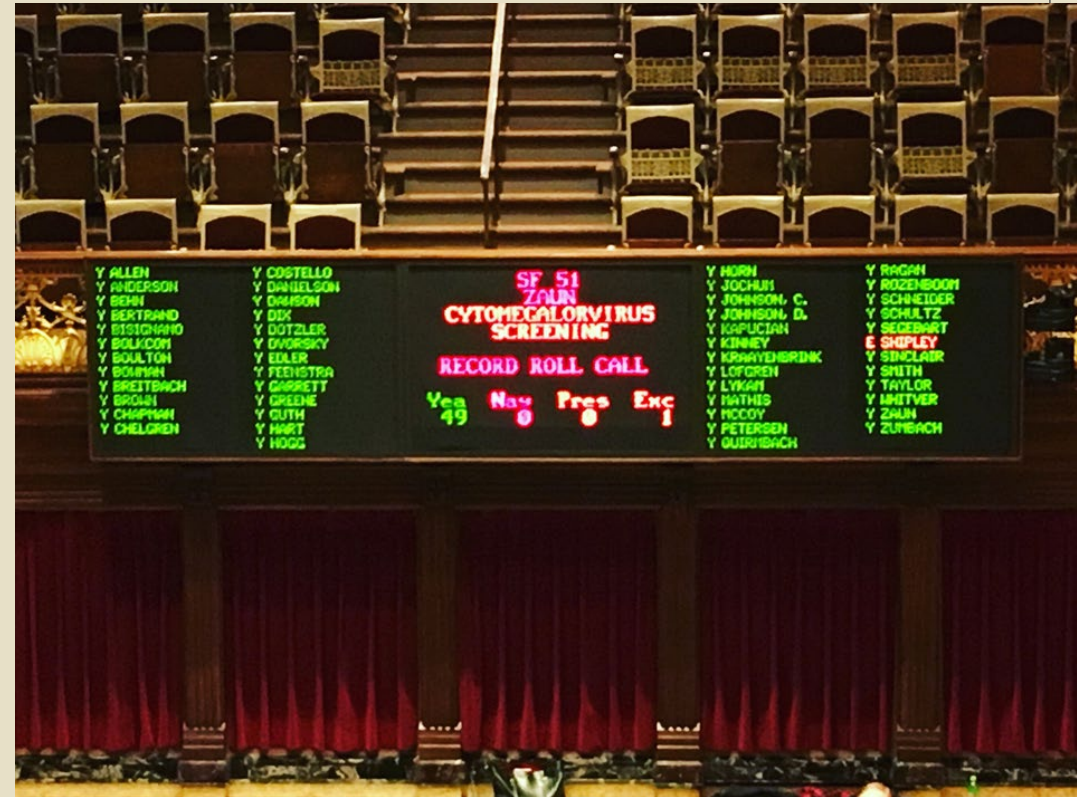
Prevention continued

- ❖ An attending health care provider shall provide to a pregnant woman during the first trimester of the pregnancy the informational materials published under this subsection.
- ❖ The department shall publish the informational materials on its internet site and shall specifically make the informational materials available electronically to child care facilities and child care homes, school nurses, hospitals, attending health care providers, and other health care providers offering care to pregnant women and infants.



Legislation details- screening

- ❖ If the results of the newborn hearing screening performed under this section demonstrate that the newborn has hearing loss, the birthing hospital, birth center, physician, or other health care professional required to ensure that the hearing screening is performed on the newborn under this section, shall do all of the following:
 - ❖ Test the newborn or ensure that the newborn is tested for congenital cytomegalovirus before the newborn is twenty-one days of age.
 - ❖ Provide information to the parent of the newborn including information regarding the birth defects caused by congenital cytomegalovirus and early intervention and treatment resources and services available for children diagnosed with congenital cytomegalovirus.
 - ❖ Parents can refuse testing.



Educational material

Cytomegalovirus (CMV)

What Women Need to Know



About CMV

CMV is most commonly transmitted by young children at home or work. Those infected with CMV often show no signs or symptoms, others may have mild flu-like symptoms such as fever, sore throat or fatigue.

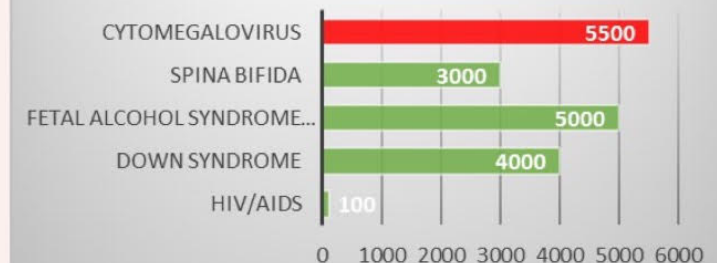
When CMV occurs during pregnancy the baby can become infected before birth (congenital CMV) and this may cause damage to the brain, eyes and or inner ears. Children born with congenital CMV may develop permanent medical conditions and disabilities such as deafness, blindness, cerebral palsy, other mental and physical disabilities, seizures and in some cases it may result in death.

Incidence

- According to the National CMV Foundation 1 in 150 children in the United States are born with congenital CMV and 1 in 5 of those children will develop permanent problems such as hearing loss or developmental disabilities.
- Congenital CMV is the most common cause of non-hereditary hearing loss in children.



US Children Born With or Developing Long-Term Medical Conditions Each Year



Educational material

Women who are pregnant or planning to become pregnant, and who have close contact with young children, should discuss their risk for CMV infection with their medical provider.

Iowa Department of Public Health
Newborn Screening Programs
1-800-383-3826
<http://idph.iowa.gov/genetics/CMV>



Transmission

- The virus is generally passed from infected people to others through direct contact with bodily fluids such as:
 - ♦ Urine
 - ♦ Saliva
 - ♦ Blood
 - ♦ Tears
 - ♦ Mucus
 - ♦ Other bodily fluids

Prevention

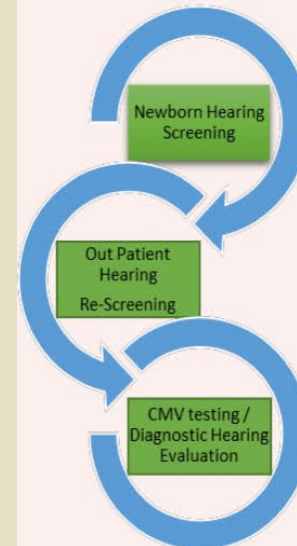


Always wash your hands with soap and water after changing diapers, feeding a young child, wiping a young child's nose/mouth, and handling toys.

Don't share food, drinks, eating utensils, and toothbrushes. Try to avoid contact with saliva when kissing or snuggling.

Make sure to clean toys, countertops and other surfaces that may have come in contact with children's saliva or urine.

Diagnosis



• If the baby doesn't pass the newborn hearing screening in the hospital it is important to have an outpatient hearing screening before 10 days of age.

• If the baby doesn't pass the outpatient hearing screening your provider should talk to you about testing for congenital CMV and schedule a diagnostic hearing evaluation immediately.

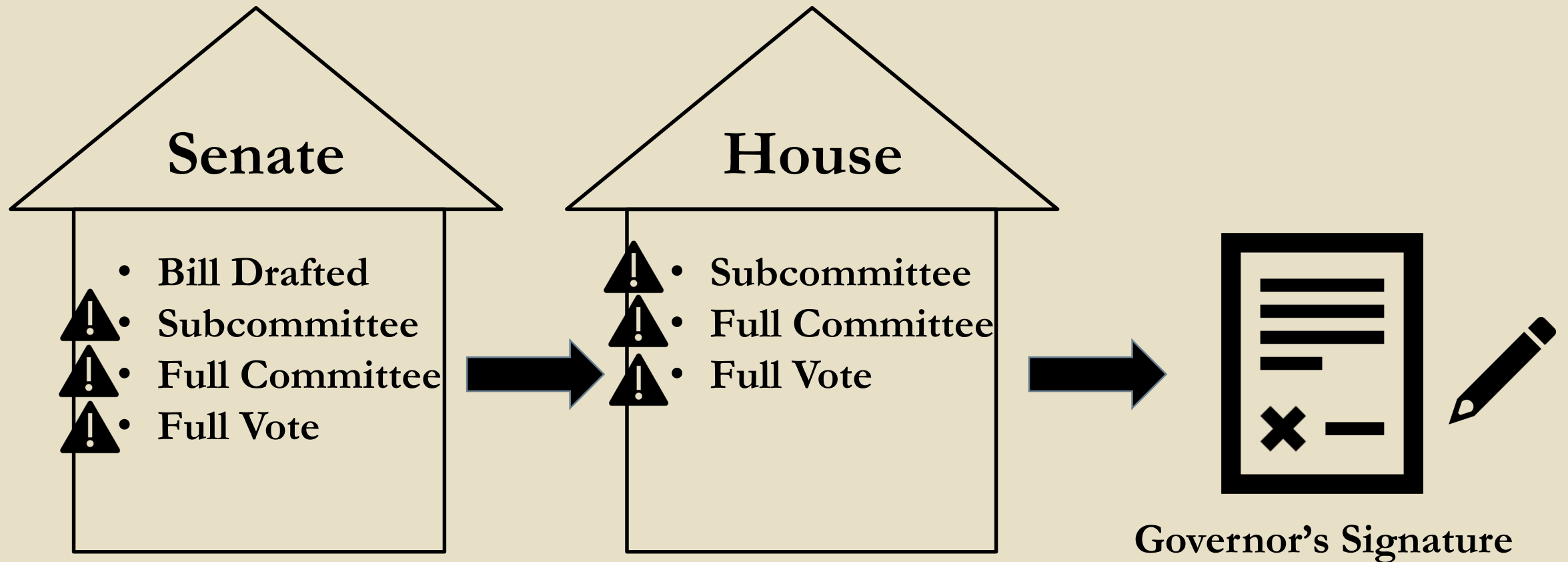
• CMV testing is a simple and painless process using a urine or saliva sample.

• In order to detect congenital CMV, testing must be done immediately or before the child is 21 days old.



TIPS FOR SUCCESS

Know the Process



Have a Clear Goal

- Be clear with what you are asking for.
- Do other states have a law/policy that you can work from?
- Make it as easy as possible for legislators:
 - “I am asking you to consider drafting legislation to help me reach this goal”
 - “I would like you to support SF 51”
 - “I would like you to bring SF 51 to the floor for a vote”



Engage YOUR Representative/Senator

- Legislators may be more likely to respond if they represent you!
- Ask them to recommend a different legislator if they are not able to help!



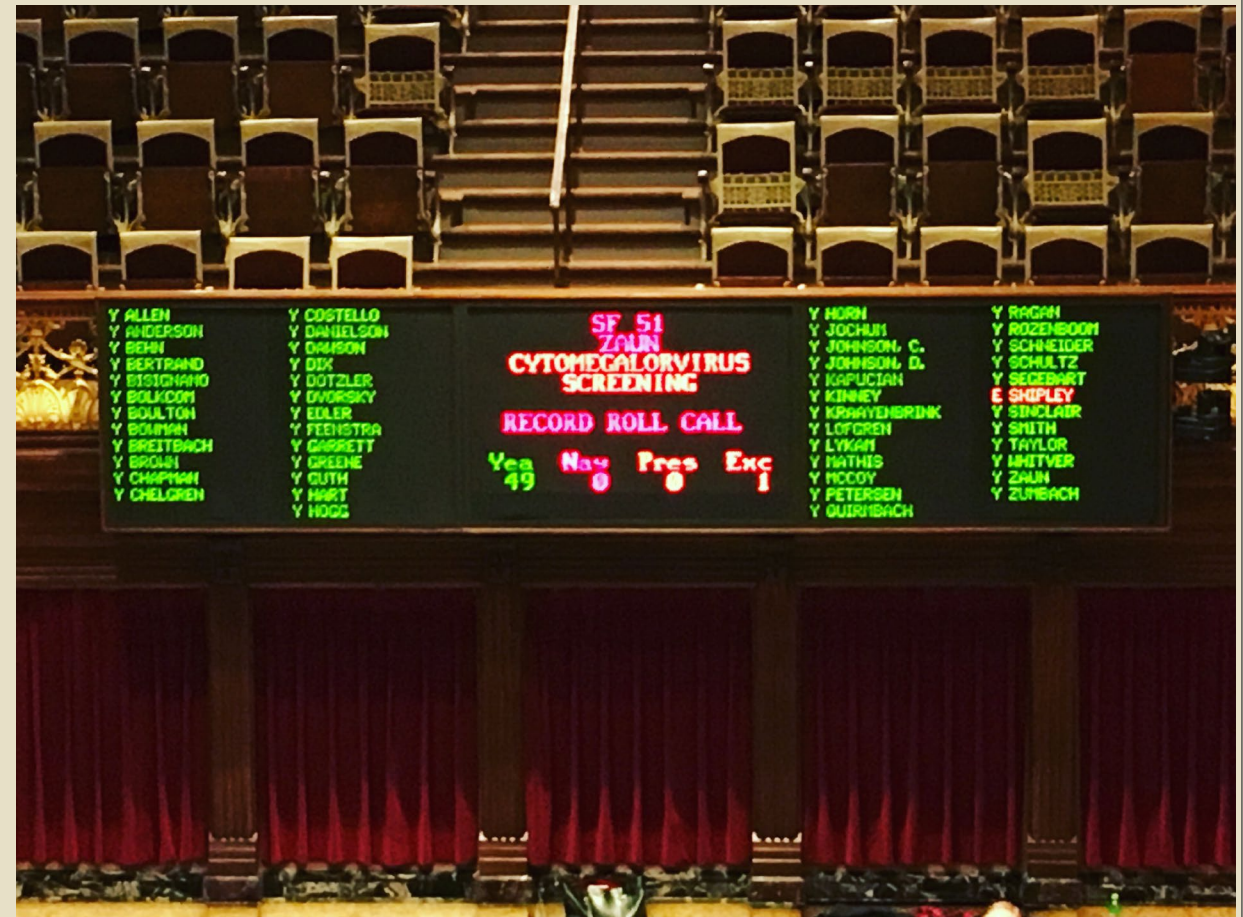
Gather Your Troops

- Create Facebook group of families with similar goals.
- Ask friends, family, and professionals to call and email.
- Have clear leaders who can communicate EXACTLY what you need from the group.
- Make it as easy as possible, have a sample email for people to use.



Use Your Connections!

- Ask old friends, family, acquaintances if they know anyone in the government who may be able to help
- People are usually willing to help!



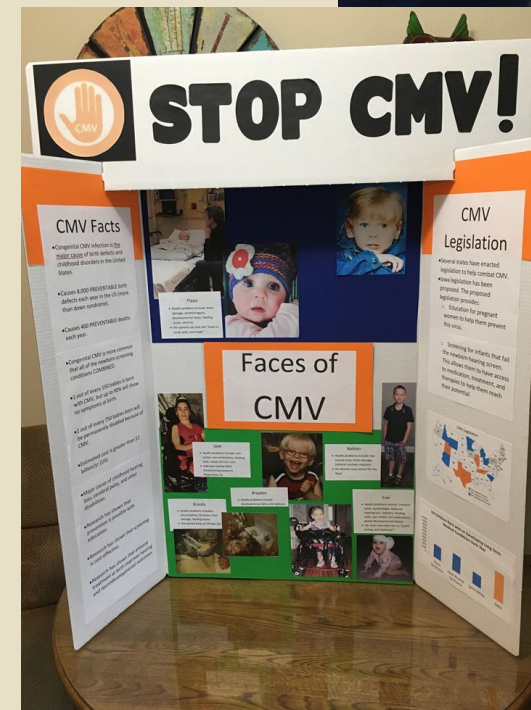
Be Flexible!

- Make concessions in order to get bill passed
- Be willing to work with different legislators, depending on the legislative climate.



Host a “Day on the Hill”

- Call to reserve room and date— early in the session
- Put it on the legislative calendar
- Send emails to remind legislators
- Tell your story
- Know your “stump speech”
- Bring your child
- Bring fact sheets
- Call legislators out to meet you
- Invite media



Have Standard Fact Sheet, Email, “Stump Speech”

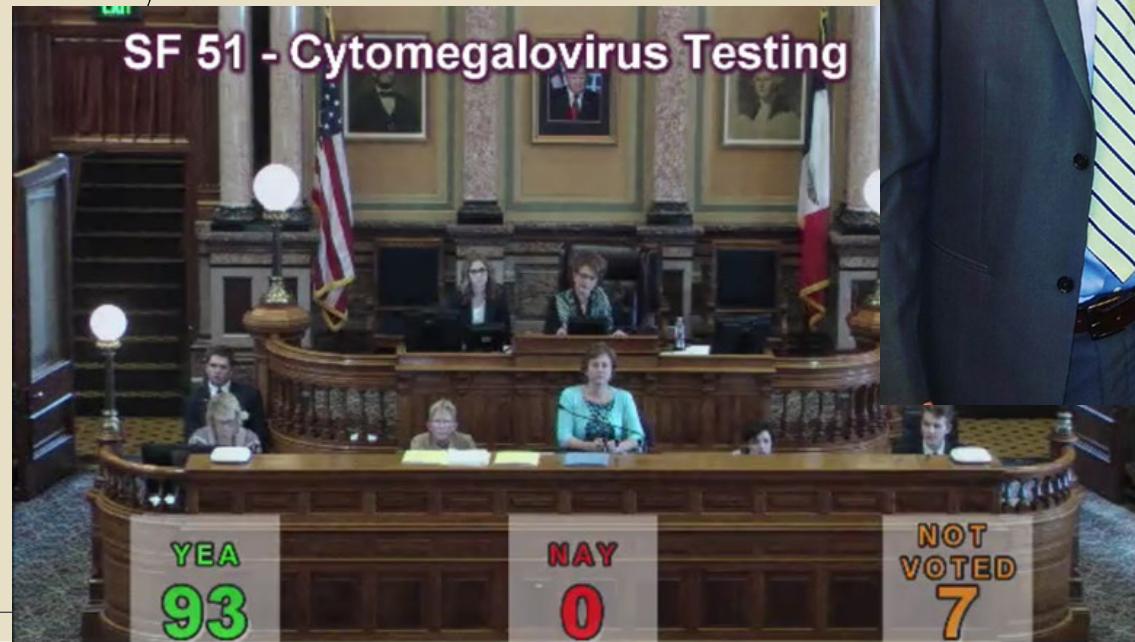
- Fact Sheet- hand out at Capitol, include in email
 - Keep it simple
 - Keep it short
 - Make it easy to read
- Email- send to legislators
 - Tell personal story
 - Include photographs
 - State what you want them to do
- Stump Speech- use when meeting in person
 - Give basic facts
 - Tell personal story
 - Ask for their help

Cytomegalovirus (CMV) Fact Sheet

- Causes 8,000 PREVENTABLE birth defects and disabilities each year in the US (more than down syndrome).
 - Causes 400 PREVENTABLE deaths each year in the US.
 - Congenital CMV is more common than all of the newborn screening conditions COMBINED.
 - Estimated cost is \$2 billion/year (US 1990s).
 - 1 out of every 150 babies is born with CMV, but up to 90% will show no symptoms at birth.
 - 1 out of every 750 babies born will be permanently disabled because of CMV.
 - Major cause of childhood hearing loss, cerebral palsy, and other disabilities.
 - Research has shown that prevention is possible with education.
 - Research has shown that screening infants is cost-effective.
 - Research has shown that antiviral treatment at birth improves hearing and neurodevelopmental outcomes.
- Source: National CMV Foundation

Be Persistent, Don't Stop—Ever!

- It's ok to encounter resistance
- Keep emailing, keep calling
- There are plenty of places where a bill can stall— don't let it!
- Ask lobbying groups to call for you



Get to the Capitol

- Target key legislators
- Be confident- legislators are just people
- Ask them to step out to talk with you
- Bring your child/children
- Email to ask for meetings– be flexible if possible



Target Key Legislators

- Majority Leader- House AND Senate
- Minority Leader- House AND Senate
- Subcommittee Chair
- Full Committee Chair



Know the Political Climate

- Which party is in control?
- How will your bill align with the party's platform?
- Which legislator should sponsor your bill, in the Senate? In the House?
- How much will your bill cost?
- What will the drawbacks to your bill be? Know how to respond.



Use the Legislative Website

- Find bills
- Find bill assignments
- View committee members
- View lobbyist declarations
- Find out when meetings will be

The screenshot displays the Iowa Legislature website at <https://www.legis.iowa.gov>. The page features a navigation bar with links to Senate/House, Legislators, Legislation, Committees, Iowa Law & Rules, Legislative Agencies, Publications, Resources & Civic Education, Lobbyist Information, and Archives. A search bar is located in the top right corner.

On the left side, there are three search sections:

- BILLS**: A search box with fields for "Number" and "Keyword", a "Go" button, and an example "(e.g. SF123, S3001)".
- IOWA CODE**: A "Quick Search" box with a "Go" button and an example "(e.g., 7E, 7E.1)".
- IOWA ACTS**: A "Quick Search" box with dropdown menus for "GA" (86 (20)), "Session" (2), and "Chapter" (1001), along with a "Go" button.

The main content area is divided into two columns:

- Popular Links**: A list of links including Audio/Video Presentations, BillBook, Code & Acts Sections Amended, Daily Receipts, Enrolled Bills, Factbook & Map of the Week, Find Your Legislator, Legislative Document Research, Bills & Rules Watch, Schedule Capitol Tour | Information, Public Input: Improving State Government, Submit Response, and View Moderated Responses.
- Popular Publications**: A list of publications including Annual State Budget Analysis, Email Subscription to Legislative Documents, Fiscal Notes, Iowa Acts, Iowa Administrative Code (updated biweekly), Iowa Code, Iowa Economic Trends, Iowa Official Register (Redbook), Interim Calendar & Briefings, LSA Factbook, Order Legal Publications, and Reports Required to be Filed with General Assembly.

On the right side, there is an **Interim Schedule** section listing upcoming meetings:

- Health Policy Oversight Committee (J)**: 11/08/2017 10:00 AM, RM 103, Sup. Ct. Chamber
- Administrative Rules Review Committee (J)**: 11/14/2017 9:00 AM, RM 116
- Tax Expenditure Committee (J)**: 11/27/2017 9:00 AM, RM 103, Sup. Ct. Chamber

Use the Website Cont'd

Iowa Legislature

Iowa Legislature - BillBook

Secure | https://www.legis.iowa.gov/legislation/BillBook?ga=%24selectedGa.generalAssemblyID&ba=SF51

Apps | Suggested Sites | Imported From IE | CDC Data and Statistics | Lung Sounds | Over 5 | Heart Sounds Lesson

The IOWA LEGISLATURE

SENATE/HOUSE | LEGISLATORS | LEGISLATION | COMMITTEES | IOWA LAW & RULES | LEGISLATIVE AGENCIES | PUBLICATIONS | RESOURCES & CIVIC EDUCATION | LOBBYIST INFORMATION | ARCHIVES

The Iowa Legislature > Legislation > BillBook

Print | Permanent Link

Bill Information

GA: 87 (01/09/2017 - 01/13/2019)

Name: Go

Keyword: Go

Senate: SF 51

House: Pick one

Versions: Enrolled

No Amendments for the selected bill

Bill History

04/20/2017 Signed by Governor. S.J. 1112.

04/18/2017 Sent to Governor. S.J. 1061.

04/18/2017 Reported correctly enrolled, signed by President and Speaker. S.J. 1061.

NOBA Information

Senate Full Approps (SF 516) Panel View

Senate Floor (SF 516) Panel View

Final (SF 516) Panel View

Graybook (SF 516) Panel View

Related Information

Track Versions

LSB 1667XS SF51

Floor Managers

Senate: Chapman

Senate File 51 - Enrolled

Senate File 51

AN ACT
RELATING TO A CYTOMEGALOVIRUS PUBLIC HEALTH INITIATIVE AND THE
TESTING OF NEWBORNS FOR CONGENITAL CYTOMEGALOVIRUS.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

Section 1. NEW SECTION. **136A.5B Cytomegalovirus public health initiative.**
1. In accordance with the duties prescribed in section 136A.3, the center for congenital and inherited disorders shall collaborate with state and local health agencies and other public and private organizations to develop and publish or approve and publish informational materials to educate and raise awareness of cytomegalovirus and congenital cytomegalovirus among women who may become pregnant, expectant parents, parents of infants, attending health care providers.

Declare a “Day” in Your State

- Designate “Awareness Day” in Iowa, with public signing
 - ie 1/17/17 was “CMV Awareness Day in Iowa”
- Online form available to request proclamation
- Can generate interest and awareness
- Invite legislators to attend
- Invite media to attend



The Work Continues...

- Lack of funding
- Lack of awareness
- How to spread word about law?
- Other funding opportunities?

Questions?

- Email
 - iowacmv@gmail.com
- Facebook
 - Iowa CMV Network

