

Policy, Advocacy, and Legislation Related to Congenital Cytomegalovirus

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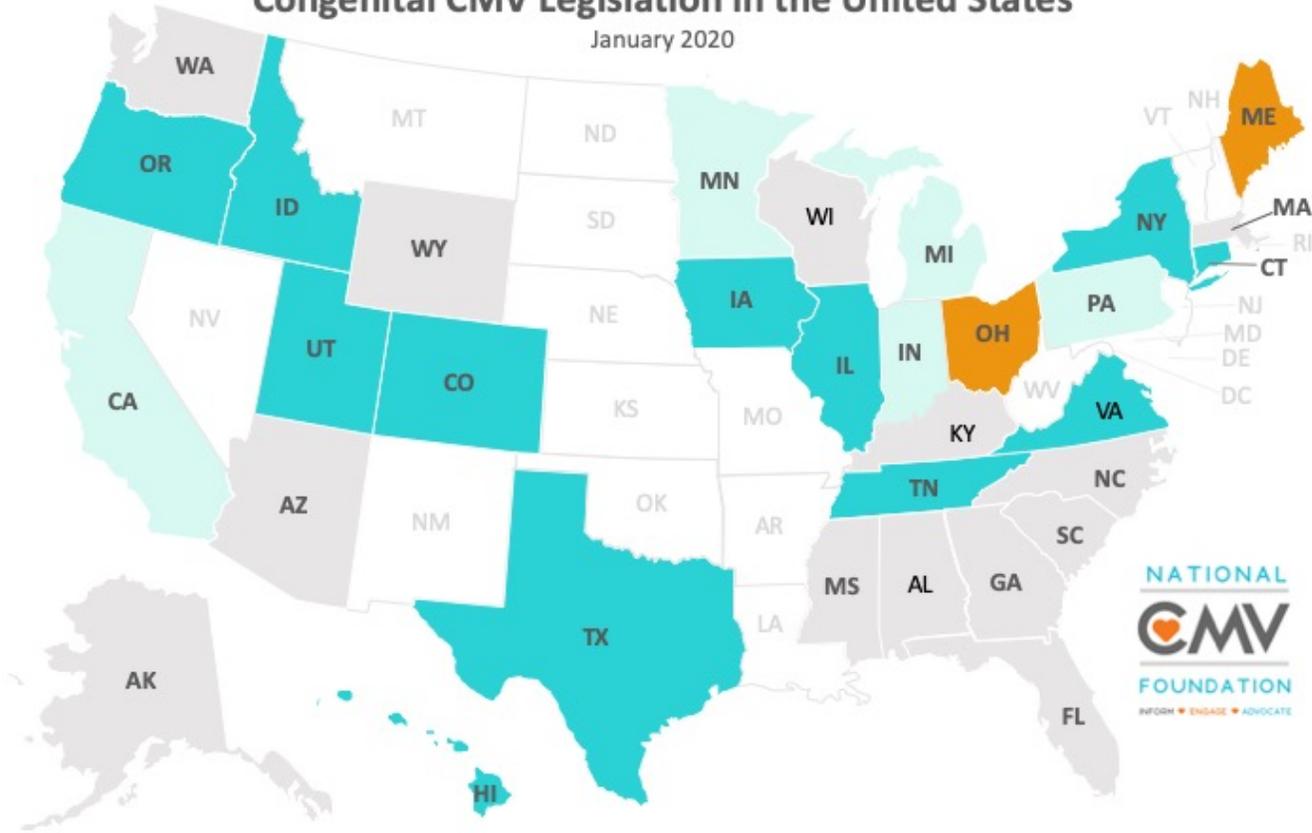


Objectives

- Participant will be able to describe CMV laws in the US.
- Participant will be able to describe 3 ideas for success when working on a CMV law.
- Participant will be able to describe current status of Recommended Uniform Screening Panel (RUSP) nomination for cCMV (Congenital Cytomegalovirus).
- Participant will be able to describe appropriate referrals for children born with cCMV.

Congenital CMV Legislation in the United States

January 2020



Other Law Enacted Screening or Education Law Enacted Law Proposed Stakeholder Interest in Legislation

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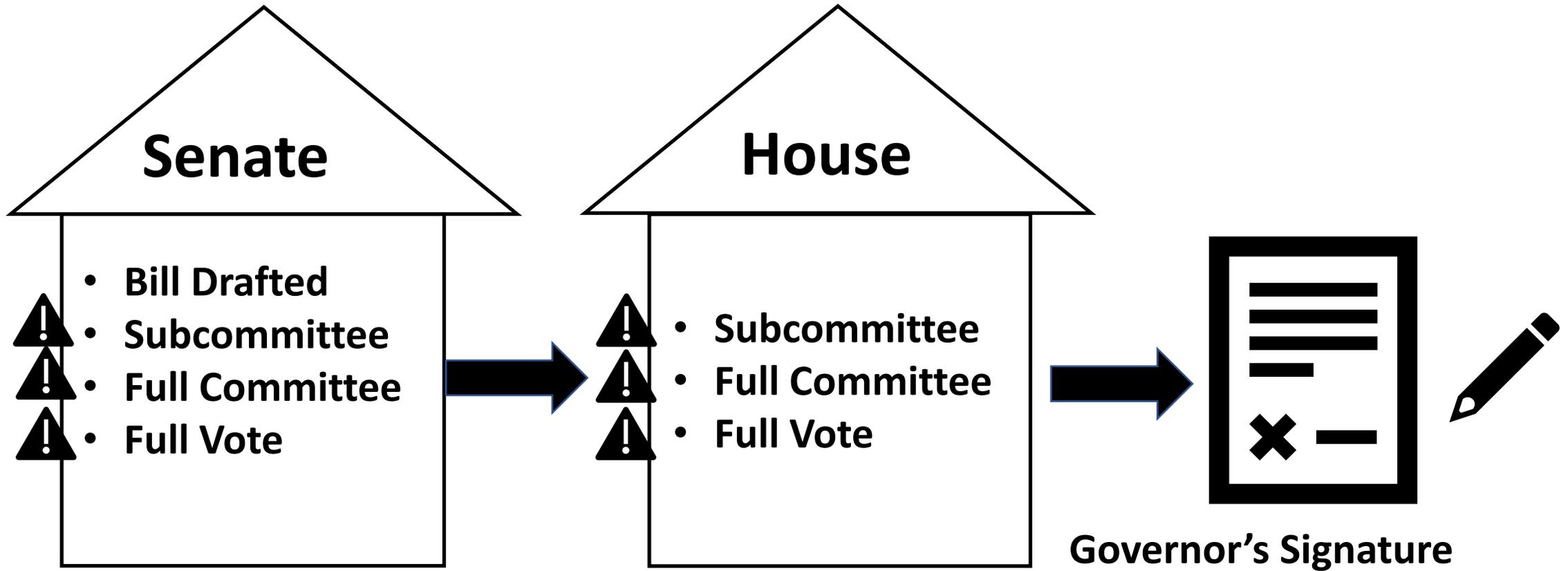
Current CMV Law

Summary of Current Legislative Mandates

- Four states, Illinois, Iowa, New York, and Utah require both education of pregnant women and targeted newborn screening.
- Nine states require the state to educate the public and professionals about congenital CMV: Colorado, Hawaii, Idaho, Illinois, Iowa, New York, Oregon, Texas, Utah.
- Tennessee requires health care providers to educate women of childbearing age.
- Only Utah has legislation that is accompanied by ongoing funding (\$70,000 per year). Idaho has proposed \$15,000 per year.
- Connecticut, Iowa, New York, Utah, and Virginia require each newborn that fails the newborn hearing screening to be tested for congenital CMV.
- Illinois requires that a CMV test be offered to the parents of every child who fails the newborn hearing screening

Ideas for Legislative Success

Learn 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”



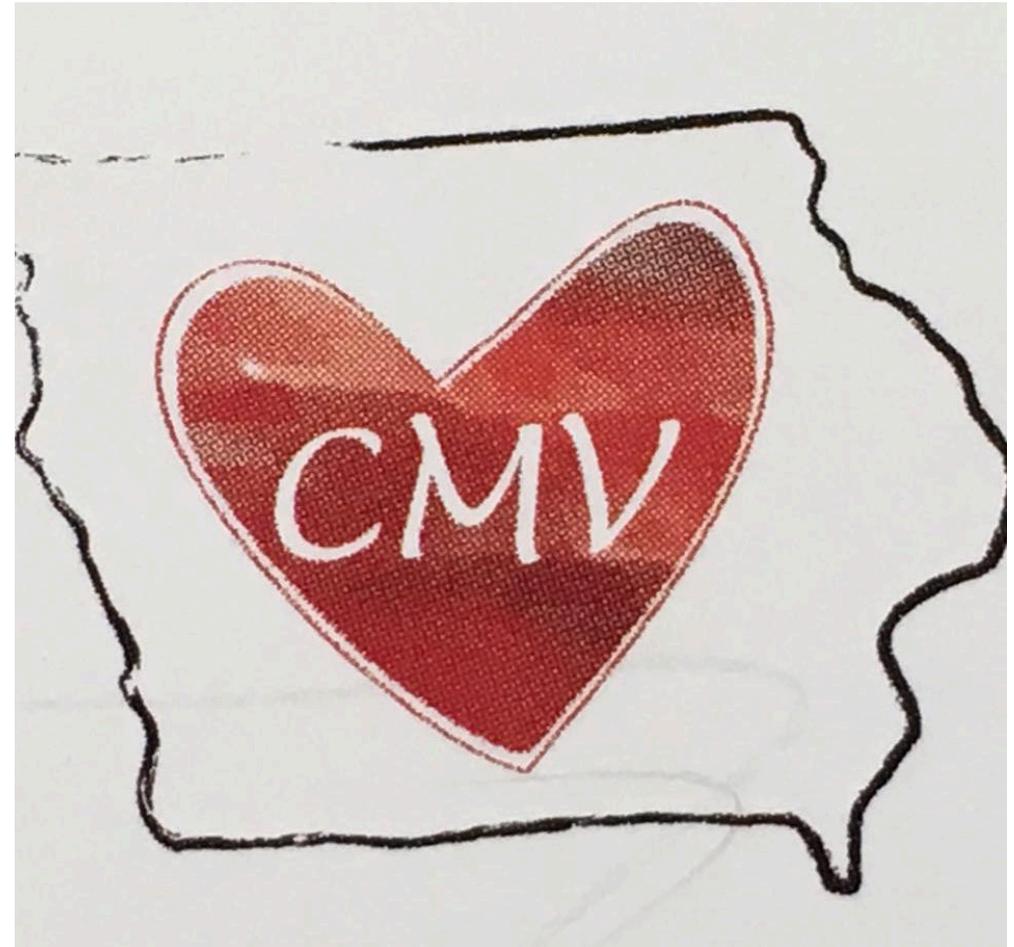
Engage YOUR Representative/Senator

- 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!
- There are many ways to engage legislators:
 - Email
 - Phone
 - Town Hall
 - Call out at Capitol



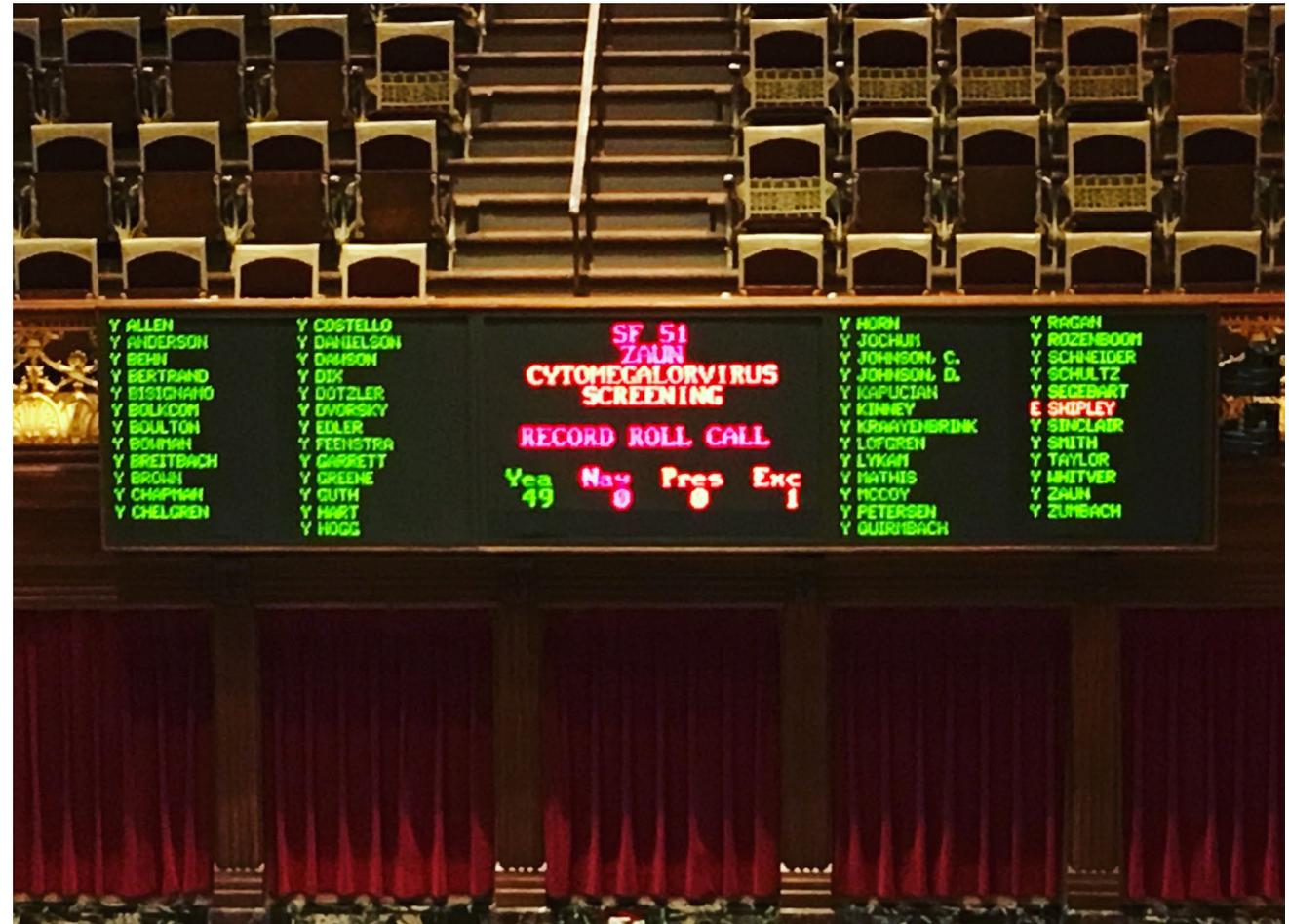
Gather Your Troops

- 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!



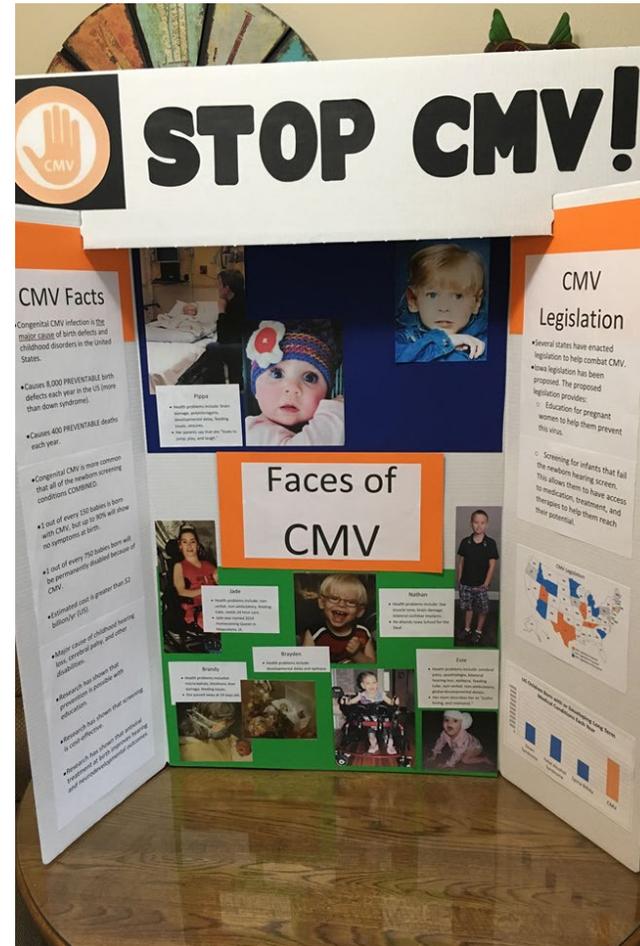
Be Flexible!

- You may have to make concessions in order to get a 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, and “Stump Speech”

- Fact Sheet- hand out at Capitol, include in email
 - Keep it simple, short, and easy to read
- Email- send to legislators
 - Tell personal story, include photographs, state clearly what you want from them
- Stump Speech- use when meeting in person
 - Give basic facts, tell personal story, ask for their help

Be Persistent, Don't Stop—Ever!

- It's ok to encounter resistance
- There are plenty of places where a bill can stall— don't let it!
 - Call
 - Email
 - Go to Capitol
 - Ask other stakeholders to get involved



Get to the Capitol

- Target key legislators
- Be confident
- Ask them to step out to talk with you
- Bring your child/children
- Email to ask for meetings
- Learn when legislators are at the Capitol



Target Key Legislators

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



Use Your Legislative Website

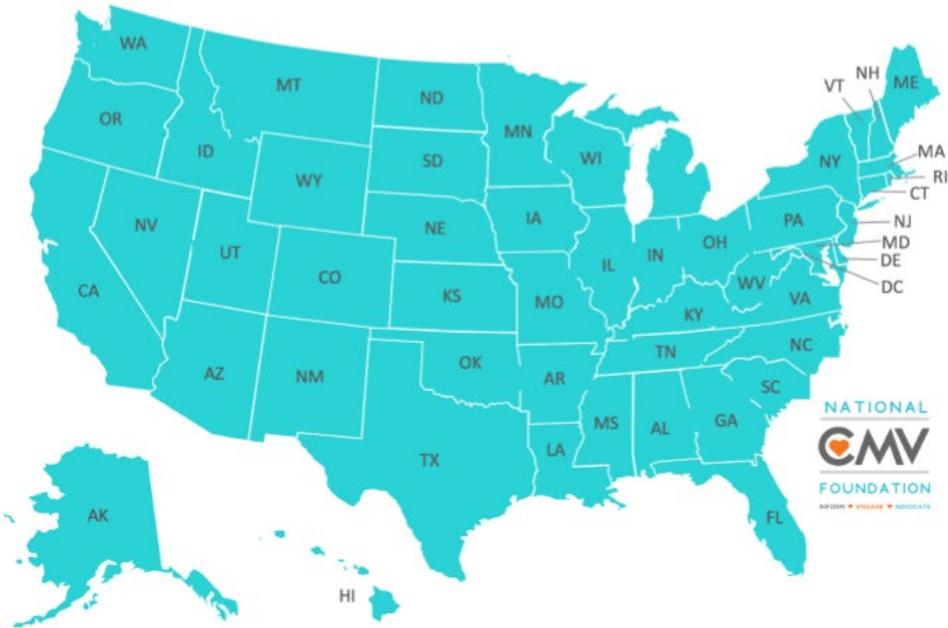
- Find bills
- Find bill assignments
- View committee members
- View lobbyist declarations
- Find out when meetings will be

The screenshot displays the Iowa Legislature website interface. At the top, there is a navigation bar with links for 'FAQ', 'Home', and 'Publications'. Below this is a main header with the text 'The IOWA LEGISLATURE' and a search bar. A secondary navigation bar includes links for 'SENATE/HOUSE', 'LEGISLATORS', 'LEGISLATION', 'COMMITTEES', 'IOWA LAW & RULES', 'LEGISLATIVE AGENCIES', 'PUBLICATIONS', 'RESOURCES & CIVIC EDUCATION', 'LOBBYIST INFORMATION', and 'ARCHIVES'. The main content area is divided into several sections: 'BILLS' with a search box for 'Number' and 'Keyword'; 'IOWA CODE' with a 'Quick Search' box; 'IOWA ACTS' with a 'Quick Search' box and dropdown menus for 'GA' (86) and 'Session' (2); 'Popular Links' listing various resources like 'Audio/Video Presentations' and 'BillBook'; and 'Interim Schedule' showing upcoming committee meetings such as the 'Health Policy Oversight Committee' and 'Administrative Rules Review Committee'.

Declare a “CMV Day” in Your State

- Designate “Awareness Day” with a 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





Nomination
to the
Recommended
Universal
Screening
Panel (RUSP)

RUSP Nomination



RUSP Nomination Status

- The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) is charged with reviewing disorders submitted for RUSP consideration.
- At the end of September, the activities of the ACHDNC were put on an indefinite hold because Congress has not reauthorized the Newborn Screening Saves Lives Act.

Advisory Committee on Heritable Disorders in Newborns and Children



The statutory authority for the Congressionally established Advisory Committee on Heritable Disorders in Newborns and Children (Committee) expired on September 30, 2019. All official business related to the Congressionally established Committee, including workgroup activities, is halted at this time. Options for continuing the work of the Committee are being considered. Further information will be provided on the Committee's website when available.

Update: There will not be a meeting on February 13 and 14, 2020.

Referrals for cCMV Positive Children

- Infectious Disease
 - Manage antiviral therapy if indicated
- Therapies: physical, occupational, speech, feeding
- Early Intervention Services
 - cCMV is often automatic qualifier
- Audiology
- Ophthalmology

Other Opportunities for CMV Advocacy



DONATE



CREATE A
FUNDRAISER



ATTEND A
FUNDRAISER



POST ON
SOCIAL MEDIA



SIGN OUR
RUSP PETITION

References

National CMF Foundation: www.nationalcmv.org

Health Resources & Services Administration:
<https://www.hrsa.gov/advisory-committees/heritable-disorders/index.html>



THANK YOU!

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