

Cytomegalovirus: Awareness, Perspectives and Policy Actions

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INTRODUCTION

The research study will explore the current Cytomegalovirus (CMV) legislation in the U.S.. More specifically, the research will investigate the impact that CMV legislation has had on CMV awareness. Through the research, the researcher will investigate the need for similar legislation for the state of Louisiana.

Research Questions

1. What is the impact of CMV and early diagnosis?
2. How can legislation increase CMV awareness and prevent future cases of CMV?

LITERATURE REVIEW

1 in 150 children are born with congenital CMV 400 babies die from CMV each year	Pregnant women who get CMV will pass the virus to their unborn child 90% of babies born with CMV will appear healthy at birth
CMV Abbreviation for cyto-megalo-virus	
CMV causes the following in infants: Deafness Vision loss Microcephaly Mental Disability Behavior Issues Cerebral Palsy Seizures	More common than 29 combined metabolic and endocrine disorders in the recommended UD newborn panel Researchers have found a connection between CMV and miscarriage

- ◆ The most common cause for non-genetic deafness, physical disabilities, intellectual disabilities, and death among newborns
- ◆ Few people are of CMV and the impact on women bearing children
- ◆ Many Obstetricians are not aware of CMV
- ◆ Identifying preventative measures
- ◆ Methods to educate new mothers about the dangers of CMV
- ◆ Introduction of bills
- ◆ Policy formation
- ◆ Legislative action



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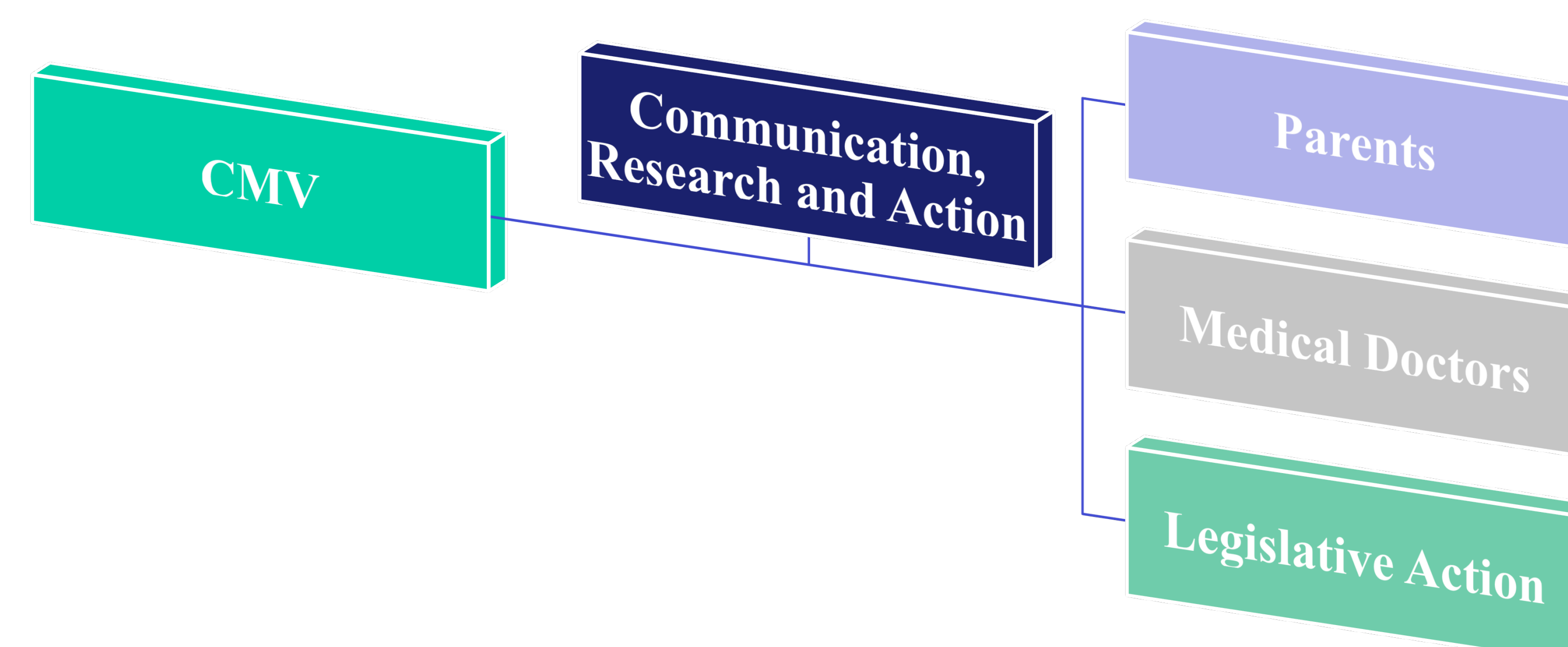
METHODOLOGY

- ◆ Qualitative research
- ◆ Recruitment strategy such as daily digest and Facebook
- ◆ Video recording interviews
 - ◆ Informed consent form
 - ◆ Video release form
 - ◆ Unstructured interview
 - ◆ Up to sixty minutes
 - ◆ Three sets of interview questions
 - ◆ 7 Parents
 - ◆ 4 Doctors
 - ◆ 2 Legislators



FINDINGS

- ◆ Parents' Perspective
 - ◆ Had I known I could have taken precaution
 - ◆ We went big and asked for universal screening
 - ◆ From a monetary standpoint the screening would cost less than caring for a child with CMV. Everything comes down to money
 - ◆ Its accelerating conversation about research and policy
- ◆ Medical Doctors' Perspective
 - ◆ CMV awareness is helping to help move the agenda forward
 - ◆ CMV legislation should offer opportunities for both CMV education and CMV screening for newborns. It also should meet the requirements, and budgets, and cultures of each individual state
- ◆ Legislators' Perspectives
 - ◆ There was no question that it was our responsibility to pass legislation and provided funding for education and screening programs
 - ◆ Legislators are interested in the issues that impact infants and families especially if those families are part of their constituency



DISCUSSION

- ◆ CMV Awareness and Policy development is growing across the U. S.
- ◆ Growing need for education and awareness
 - ◆ Parents want to become more aware and inform other parents of CMV impacts on unborn babies
 - ◆ The education about CMV is important because all the parents interviewed had not known about CMV prior to giving birth
 - ◆ Many OBYN's are not as aware of CMV
 - ◆ Conflict between medical professionals on the perspective of legislations vs a rule change for early detection
 - ◆ All of the doctors were in agreement that a vaccination should be developed
- ◆ CMV Legislation
 - ◆ Parents seem to be very motivated about starting CMV legislation in their state and want more information about how to start that process
 - ◆ The growing advocacy for CMV is encouraging more parents across the country to reach out to the National CMV foundation



CONCLUSION

Parent, Doctors and Legislators see the benefit of CMV legislation and educating the public about CMV, but differ on if the legislation should include targeted or universal screening. Parents have made the biggest impact in CMV legislation since their children have been impacted by CMV. The legislation action has started a dialogue and has created awareness about CMV. More information needs to be learned about how many CMV babies are being impacted by CMV to help make the case for universal screenings. Education needs to start with doctors so they can help to educate their patients about how they can prevent CMV. In closing, everyone needs to work together to bring about positive changes on CMV.

