

# **The psychosocial impact of newborn CMV screening: formative research from the Houston Congenital CMV Longitudinal study**

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The findings and conclusions in this report are those of the author and do not necessarily represent the official position of the Centers for Disease Control and Prevention

# CMV: To screen or not to screen?

## Newborn Screening Criteria

Probably satisfied	Jury still out
Magnitude of health problem	Suitable test available
Natural history is adequately understood	Adequate health service provision
Detectable early stage	Costs are worth while in relation to benefit gained
Treatment of an early stage is of more benefit than at a late stage	Test acceptable to the population
	Benefits outweigh risks (physical and psychological)

**The problem**  
Congenital cytomegalovirus (CMV) infection is the most common congenital infection in the United States. It is caused by the cytomegalovirus (CMV), a member of the herpesvirus family. CMV infection is usually asymptomatic, but it can cause serious complications in newborns, including hearing loss, vision impairment, and intellectual disability.

**The study objective**  
To determine the effectiveness of newborn screening for CMV infection in the United States.

## Conclusions

- ### Future steps

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### Newborn Screening Criteria

Magnitude of health problem  
Natural history is adequately understood  
Detectable early stage  
Treatment at an early stage is of more benefit than at a late stage

- Suitable test available
- Adequate health service provision
- Costs are worthwhile in relation to benefits gained
- Test acceptable to the population
- Benefits outweigh risks (physical and psychological)

Test acceptable to the population  
Benefits outweigh risks (physical and psychological)

### The problems

↓

## Population

- Parent group 1: Children born asymptomatic and never developed sequelae (4 focus groups and 2 individual interviews)

- Parent group 2: Children born asymptomatic but developed sequelae (9 individual interviews)

- Parent group 3: Children born asymptomatic, some with significant health problems (9 infants of unknown)

individual interviews)

## Methods

Audio recordings transferred and stored into NVIVO-software package

Content analysis with some pre-identified codes extracted from the literature and emergent codes.

derived from the literature, and some codes derived from the content itself.

Multiple codes

- Felt nervous or panic

- Anger from not knowing why
- Fear for child's future health
- Culture often viewed as fatalistic

### Limitations

Profile journals were also researched and

with very supportive follow-up

Parents of children who screened negative were not interviewed.

[illegible]

Topic	Recommendation	Standardized Intervention	Stratification
Initial response to postoperative course	Standardize analgesic L1-2/3/4/5/6/7/8/9/10/11/12/13/14/15/16/17/18/19/20/21/22/23/24/25/26/27/28/29/30/31/32/33/34/35/36/37/38/39/40/41/42/43/44/45/46/47/48/49/50/51/52/53/54/55/56/57/58/59/60/61/62/63/64/65/66/67/68/69/70/71/72/73/74/75/76/77/78/79/80/81/82/83/84/85/86/87/88/89/90/91/92/93/94/95/96/97/98/99/100/101/102/103/104/105/106/107/108/109/110/111/112/113/114/115/116/117/118/119/120/121/122/123/124/125/126/127/128/129/130/131/132/133/134/135/136/137/138/139/140/141/142/143/144/145/146/147/148/149/150/151/152/153/154/155/156/157/158/159/160/161/162/163/164/165/166/167/168/169/170/171/172/173/174/175/176/177/178/179/180/181/182/183/184/185/186/187/188/189/190/191/192/193/194/195/196/197/198/199/200/201/202/203/204/205/206/207/208/209/210/211/212/213/214/215/216/217/218/219/220/221/222/223/224/225/226/227/228/229/230/231/232/233/234/235/236/237/238/239/240/241/242/243/244/245/246/247/248/249/250/251/252/253/254/255/256/257/258/259/260/261/262/263/264/265/266/267/268/269/270/271/272/273/274/275/276/277/278/279/280/281/282/283/284/285/286/287/288/289/290/291/292/293/294/295/296/297/298/299/300/301/302/303/304/305/306/307/308/309/310/311/312/313/314/315/316/317/318/319/320/321/322/323/324/325/326/327/328/329/330/331/332/333/334/335/336/337/338/339/340/341/342/343/344/345/346/347/348/349/350/351/352/353/354/355/356/357/358/359/360/361/362/363/364/365/366/367/368/369/370/371/372/373/374/375/376/377/378/379/380/381/382/383/384/385/386/387/388/389/390/391/392/393/394/395/396/397/398/399/400/401/402/403/404/405/406/407/408/409/410/411/412/413/414/415/416/417/418/419/420/421/422/423/424/425/426/427/428/429/430/431/432/433/434/435/436/437/438/439/440/441/442/443/444/445/446/447/448/449/450/451/452/453/454/455/456/457/458/459/460/461/462/463/464/465/466/467/468/469/470/471/472/473/474/475/476/477/478/479/480/481/482/483/484/485/486/487/488/489/490/491/492/493/494/495/496/497/498/499/500/501/502/503/504/505/506/507/508/509/510/511/512/513/514/515/516/517/518/519/520/521/522/523/524/525/526/527/528/529/530/531/532/533/534/535/536/537/538/539/540/541/542/543/544/545/546/547/548/549/550/551/552/553/554/555/556/557/558/559/560/561/562/563/564/565/566/567/568/569/570/571/572/573/574/575/576/577/578/579/580/581/582/583/584/585/586/587/588/589/590/591/592/593/594/595/596/597/598/599/600/601/602/603/604/605/606/607/608/609/610/611/612/613/614/615/616/617/618/619/620/621/622/623/624/625/626/627/628/629/630/631/632/633/634/635/636/637/638/639/640/641/642/643/644/645/646/647/648/649/650/651/652/653/654/655/656/657/658/659/660/661/662/663/664/665/666/667/668/669/670/671/672/673/674/675/676/677/678/679/680/681/682/683/684/685/686/687/688/689/690/691/692/693/694/695/696/697/698/699/700/701/702/703/704/705/706/707/708/709/710/711/712/713/714/715/716/717/718/719/720/721/722/723/724/725/726/727/728/729/730/731/732/733/734/735/736/737/738/739/740/741/742/743/744/745/746/747/748/749/750/751/752/753/754/755/756/757/758/759/760/761/762/763/764/765/766/767/768/769/770/771/772/773/774/775/776/777/778/779/780/781/782/783/784/785/786/787/788/789/790/791/792/793/794/795/796/797/798/799/800/801/802/803/804/805/806/807/808/809/810/811/812/813/814/815/816/817/818/819/820/821/822/823/824/825/826/827/828/829/830/831/832/833/834/835/836/837/838/839/840/841/842/843/844/845/846/847/848/849/850/851/852/853/854/855/856/857/858/859/860/861/862/863/864/865/866/867/868/869/870/871/872/873/874/875/876/877/878/879/880/881/882/883/884/885/886/887/888/889/890/891/892/893/894/895/896/897/898/899/900/901/902/903/904/905/906/907/908/909/910/911/912/913/914/915/916/917/918/919/920/921/922/923/924/925/926/927/928/929/930/931/932/933/934/935/936/937/938/939/940/941/942/943/944/945/946/947/948/949/950/951/952/953/954/955/956/957/958/959/960/961/962/963/964/965/966/967/968/969/970/971/972/973/974/975/976/977/978/979/980/981/982/983/984/985/986/987/988/989/990/991/992/993/994/995/996/997/998/999/1000/1001/1002/1003/1004/1005/1006/1007/1008/1009/1010/1011/1012/1013/1014/1015/1016/1017/1018/1019/1020/1021/1022/1023/1024/1025/1026/1027/1028/1029/1030/1031/1032/1033/1034/1035/1036/1037/1038/1039/1040/1041/1042/1043/1044/1045/1046/1047/1048/1049/1050/1051/1052/1053/1054/1055/1056/1057/1058/1059/1060/1061/1062/1063/1064/1065/1066/1067/1068/1069/1070/1071/1072/1073/1074/1075/1076/1077/1078/1079/1080/1081/1082/1083/1084/1085/1086/1087/1088/1089/1090/1091/1092/1093/1094/1095/1096/1097/1098/1099/1100/1101/1102/1103/1104/1105/1106/1107/1108/1109/1110/1111/1112/1113/1114/1115/1116/1117/1118/1119/1120/1121/1122/1123/1124/1125/1126/1127/1128/1129/1130/1131/1132/1133/1134/1135/1136/1137/1138/1139/1140/1141/1142/1143/1144/1145/1146/1147/1148/1149/1150/1151/1152/1153/1154/1155/1156/1157/1158/1159/1160/1161/1162/1163/1164/1165/1166/1167/1168/1169/1170/1171/1172/1173/1174/1175/1176/1177/1178/1179/1180/1181/1182/1183/1184/1185/1186/1187/1188/1189/1190/1191/1192/1193/1194/1195/1196/1197/1198/1199/1200/1201/1202/1203/1204/1205/1206/1207/1208/1209/1210/1211/1212/1213/1214/1215/1216/1217/1218/1219/1220/1221/1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# CMV: To screen or not to screen?

## Newborn Screening Criteria

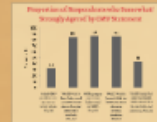
### Probably satisfied

- Magnitude of health problem
- Natural history is adequately understood
- Detectable early stage
- Treatment at an early stage is of more benefit than at a late stage

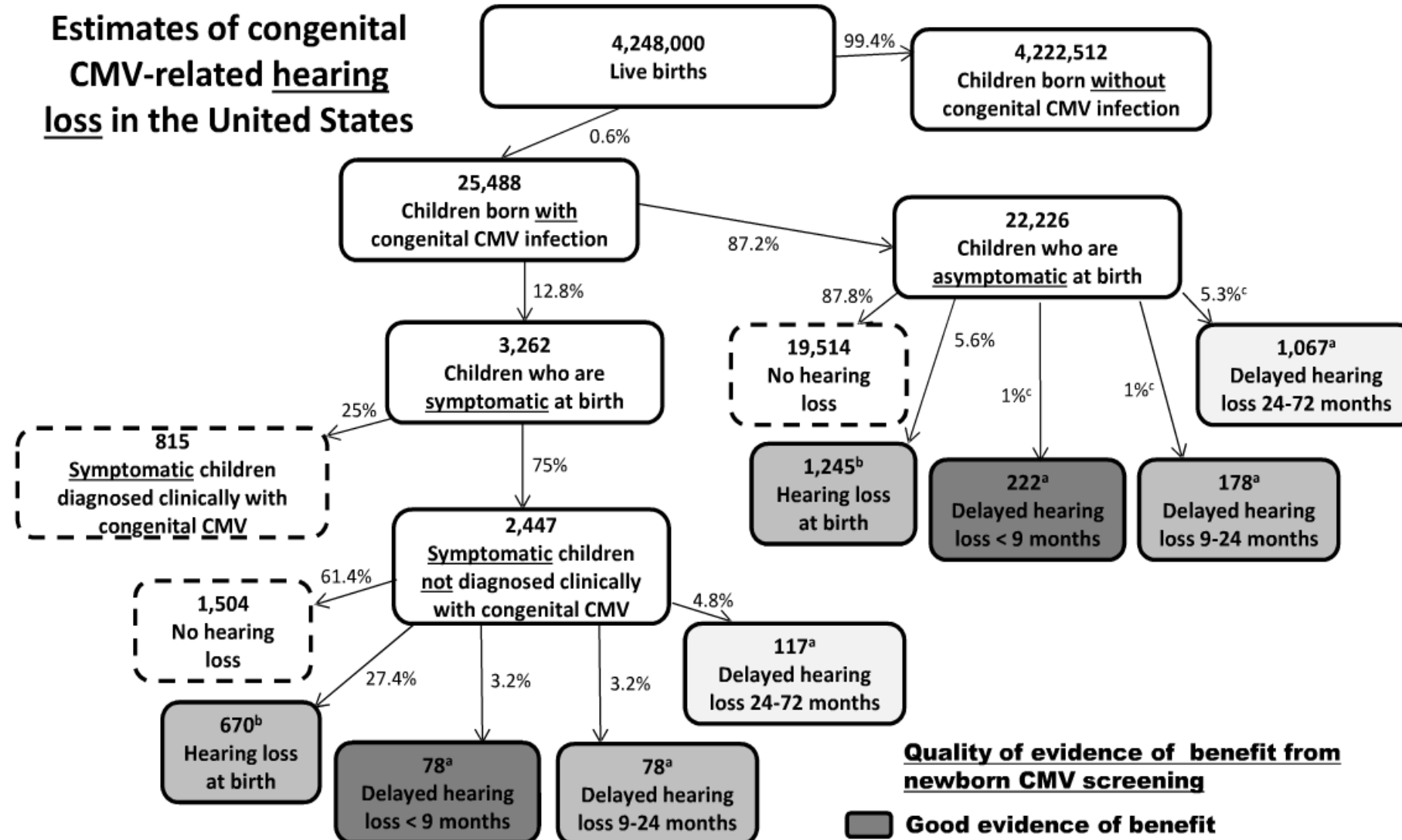


### Jury still out

- Suitable test available
- Adequate health service provision
- Costs are worthwhile in relation to benefits gained
- Test acceptable to the population
- Benefits outweigh risks (physical and psychological)



# Estimates of congenital CMV-related hearing loss in the United States



<sup>a</sup>Benefit would come from non-pharmaceutical treatment

<sup>b</sup>Benefit would come from pharmaceutical treatment



# CMV: To screen or not to screen?

## Newborn Screening Criteria

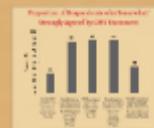
### Probably satisfied

- Magnitude of health problem
- Natural history is adequately understood
- Detectable early stage
- Treatment at an early stage is of more benefit than at a late stage

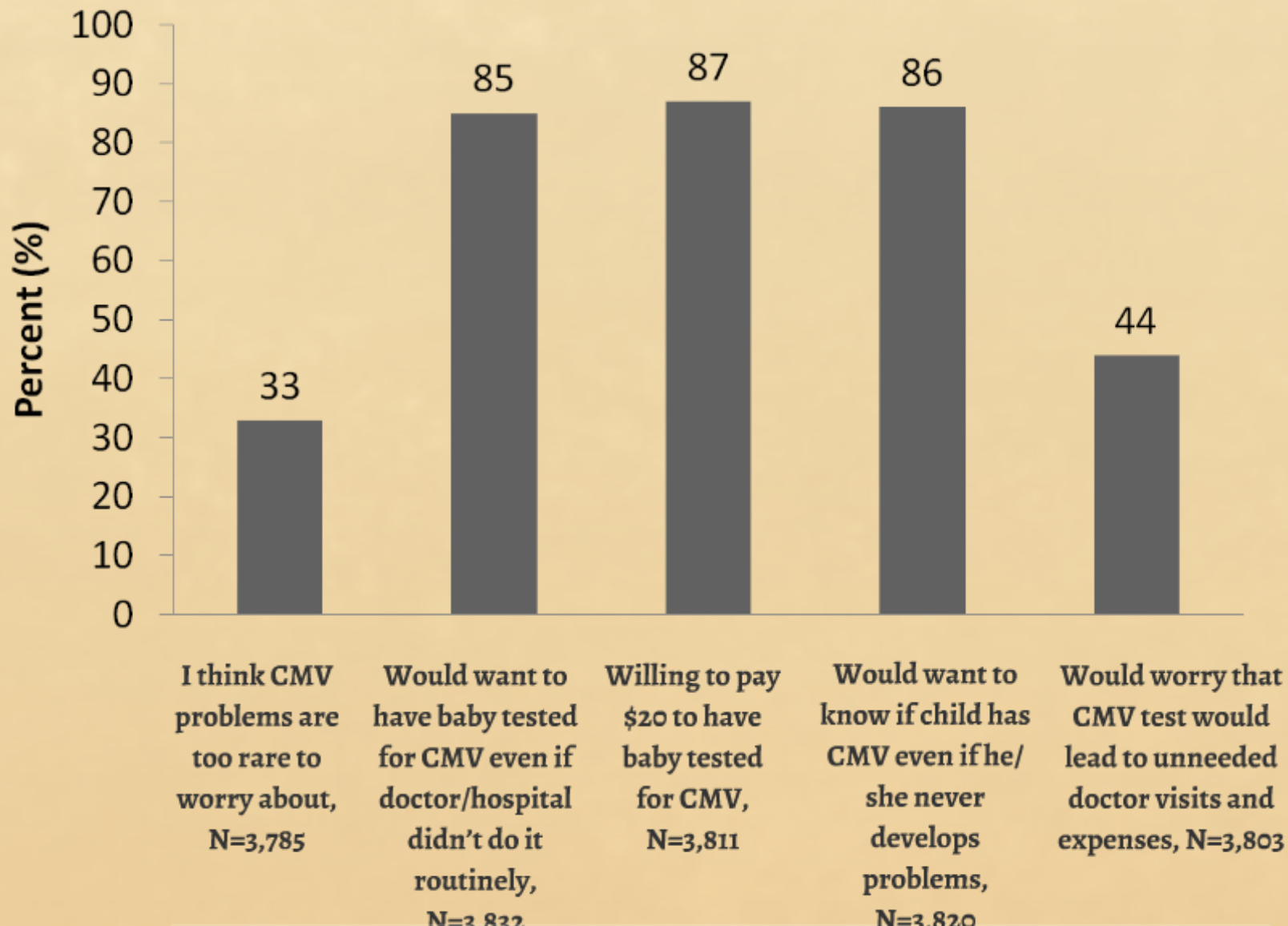


### Jury still out

- Suitable test available
- Adequate health service provision
- Costs are worthwhile in relation to benefits gained
- Test acceptable to the population
- Benefits outweigh risks (physical and psychological)



## Proportion of Respondents who Somewhat/ Strongly Agreed by CMV Statement



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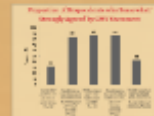
Suitable test available

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# The problem

Approximately 80% of children who screen positive will never develop disease. Knowing the child has congenital CMV infection may be an added psychosocial burden for the family.



# The study objective

Determine the psychosocial impact of newborn CMV screening on the parents of children who screen positive



# Formative research on psychosocial impact of screening

## Population

Parents of children screened for congenital CMV in the last 25 years in Houston, TX

- Parent group 1: Children born asymptomatic and never developed sequelae (4 focus groups and 2 individual interviews)
- Parent group 2: Children born asymptomatic but developed sequelae (9 individual interviews)
- Parent group 3: Children born symptomatic, some with significant health problems (9 individual interviews)

## Methods

Focus groups (120 minutes) and interviews (90 minutes)

Audio recordings transcribed and entered into NVIVO software package

Content analysis with some pre-identified codes derived from the literature and some codes derived from the content itself

Multiple coders

Examples of codes:

- Felt nervous or panicky
- Anger from not knowing risks
- Fear for child's future health
- Calmed by good medical advice

## Limitations

Retrospective assessment of screening

- Old recollections
- Long-term view

Participants were in research study with very supportive follow-up

Parents of children who screened negative were not interviewed



# Results

Topic	Asymptomatic	Asymptomatic late sequelae	Symptomatic
Initial response to positive screen	<ul style="list-style-type: none"> <li>Scared and panicky</li> <li>Unhappy and depressed</li> </ul>	<ul style="list-style-type: none"> <li>Scared and panicky</li> </ul>	<ul style="list-style-type: none"> <li>Feeling under strain</li> </ul>
Impact of knowing child screened positive	<ul style="list-style-type: none"> <li>Child development not a major concern</li> <li>Some fear during infant years</li> <li>Supportive and unsupportive relationships</li> <li>Unconcerned about parent-child bond</li> </ul>	<ul style="list-style-type: none"> <li>Scared and panicky when problems developed</li> <li>Relieved by quality advice and treatment programs</li> <li>Supportive and unsupportive relationships</li> <li>Unconcerned about parent-child bond</li> </ul>	<ul style="list-style-type: none"> <li>Fear for child's future health</li> <li>Appreciated knowledge</li> <li>Nature of symptoms bigger impact on relationships than the diagnosis</li> </ul>
Impact of follow-up care	<ul style="list-style-type: none"> <li>Calmed by good medical advice</li> <li>Angered by poor medical advice</li> <li>Developmental screening led to fewer concerns</li> </ul>	<ul style="list-style-type: none"> <li>Calmed by good medical advice</li> <li>Angered by poor medical advice</li> <li>Developmental screening led to fewer concerns</li> <li>Valued early interventions</li> <li>Glad to avoid diagnostic odyssey</li> </ul>	<ul style="list-style-type: none"> <li>Calmed by good medical advice</li> <li>Angered by poor medical advice</li> <li>Developmental screening led to fewer concerns</li> <li>Valued early interventions</li> <li>Glad to avoid diagnostic odyssey</li> </ul>
Attitudes about their own children's screening	Overwhelmingly valued screening, regardless of child's health status		
	<ul style="list-style-type: none"> <li>Anxiety provoking for some</li> <li>Glad child was tested...in the long run</li> </ul>	<ul style="list-style-type: none"> <li>Initially grieved by "the news no parent wants to hear"</li> <li>No negative views of screening</li> </ul>	<ul style="list-style-type: none"> <li>Highly positive views of screening</li> </ul>
Attitudes about universal screening	Overwhelmingly in favor of universal newborn CMV screening		
	<ul style="list-style-type: none"> <li>Preferred mandatory or opt-out screening rather than opt-in, despite some concerns about government overreach</li> <li>But, emphasized the importance of information and follow-up</li> </ul>		
Communicating about screening	<ul style="list-style-type: none"> <li>Parents are shocked but want the truth</li> <li>Provide prognosis by age so parents can understand likely health outcomes</li> <li>Provide information in writing, especially answers to frequently asked questions</li> <li>Parents prefer in-person notification whenever possible</li> <li>Need for support groups</li> <li>Increase public awareness</li> <li>Helpful messages                             <ul style="list-style-type: none"> <li>Knowledge is power</li> <li>Stay positive for your child</li> <li>You're not alone</li> <li>Participate in follow-up assessments</li> </ul> </li> <li>Less helpful messages                             <ul style="list-style-type: none"> <li>Doom and gloom</li> </ul> </li> </ul>		



# Results

## Topic

## Asymptomatic

## Asymptomatic late sequelae

## Symptomatic

Initial response to positive screen

- Scared and panicky
- Unhappy and depressed

- Scared and panicky Parents of children with autism spectrum disorder (ASD) often experience a range of emotions, including fear, anxiety, and depression, following a diagnosis.

- Feeling under strain

Impact of knowing child screened positive

- Child development not a major concern
- Some fear during infant years Parents of children with ASD often experience a range of emotions, including fear, anxiety, and depression, following a diagnosis.
- Supportive and unsupportive relationships Parents of children with ASD often experience a range of emotions, including fear, anxiety, and depression, following a diagnosis.
- Unconcerned about parent-child bond Parents of children with ASD often experience a range of emotions, including fear, anxiety, and depression, following a diagnosis.

- Scared and panicky when problems developed
- Relieved by quality advice and treatment programs
- Supportive and unsupportive relationships Parents of children with ASD often experience a range of emotions, including fear, anxiety, and depression, following a diagnosis.
- Unconcerned about parent-child bond

- Fear for child's future health
- Appreciated knowledge
- Nature of symptoms bigger impact on relationships than the diagnosis

Impact of follow-up care

- Calmed by good medical Parents of children with ASD often experience a range of emotions, including fear, anxiety, and depression, following a diagnosis.

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"I was like oh my gosh, this could be a lifelong challenge, this could be a game changer for sure, if he is--if these things happen."

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“My dad was actually supportive. He is a retired principal and he, you know he was pretty supportive.”

“For years .. my family wouldn't even let us come to family reunions because there were small children there.”



# Outpace

“I mean she was a normal child and I think we both wanted, wanted to see her as, as a person not as a person with CMV.”

# Results

## Topic

## Asymptomatic

## Asymptomatic late sequelae

## Symptomatic

Initial response to positive screen

- Scared and panicky
- Unhappy and depressed

- Scared and panicky How did you feel when you first found out you had a child with autism?

- Feeling under strain

Impact of knowing child screened positive

- Child development not a major concern
- Some fear during infant years
- Supportive and unsupportive relationships How did you feel about the diagnosis?
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"Just the unknown of what could be possibly wrong, and you know especially like with the brain issues and the learning and things like that. And then along, I thought just what if I do have a deaf child, and how – you know you just you start trying to plan and for all the ‘what ifs.’ "

“The benefits could be that you get to--know if there is progress, regression, what areas should you work on to improve the quality of his life and areas that you wouldn't have to focus on as much by having this information, and also the health or knowledge of how is he doing, what are we expecting.”

“I wonder how many [mothers] out there don't know that their child had congenital CMV, and they just don't know. And they are dealing with all these dilemmas...”



## Impact of follow-up care

- Calmed by good medical advice
- Angered by poor medical advice
- Developmental screening led to fewer concerns

## Attitudes about their own children's screening

- Anxiety provoking for some
- Glad child was tested...in the long run

## Attitudes about universal screening

## Communicating about

## Overwhelmingly valued screening, regardless of child's health status

- Initially grieved by "the news no parent wants to hear"
- No negative views of screening

## Overwhelmingly in favor of universal newborn CMV screening

- Preferred mandatory or opt-out screening rather than opt-in, despite some concerns about government overreach
- But, emphasized the importance of information and follow-up

- Parents are shocked but want the truth

“Once we started to get some more information but I think it took a good year or two before things calmed down because until that child starts to make it through milestones you’re not sure. I wasn’t.”

“I could get my questions answered on what settled my concerns with [the doctor] and even if they weren’t to my liking, they were at least honest answers to build [on].”

## Impact of follow-up care

- Calmed by good medical advice
- Angered by poor medical advice
- Developmental screening led to fewer concerns

Parents who were initially concerned about their child's health status were often reassured by good medical advice.

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## Communicating about

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“It prepared me for what could happen. If I hadn’t known then, it would’ve been even more sad.”

“Just having some knowledge about where he was developmental-wise, was very helpful.”



“I think because for me it's the biggest concern is the learning disability that could happen and if you know you have that (CMV) then you'll know to be attentive and you'll know to seek out intervention because they are struggling.”

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## Communicating about

- Parents are shocked but want the truth

"Knowledge is power"

"Priceless"

"...just where to start when you feel so lost. It was like the beginning of a map."

"Not knowing the truth doesn't make it not true."

## Impact of follow-up care

- Calmed by good medical advice
- Angered by poor medical advice
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Parents who were not screened for CMV were more likely to be concerned about their child's health status than those who were screened.

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## Communicating about

- Parents are shocked but want the truth

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“Number one, it’s noninvasive and number two, there's treatments available for it, and there's options for the family.”

“Yes. It should be mandatory for them to test for the disease because of the fact that if you don’t take the test [and] then something is wrong then... [it] will be too late, will probably be impossible [to help the child].”

“Without a program it would be unconscionable to saddle a new parent with the CMV test news.”

# Communicating about screening

- Parents are shocked but want the truth
- Provide prognosis by age so parents can understand likely health outcomes
- Provide information in writing, especially answers to frequently asked questions
- Parents prefer in-person notification whenever possible
- Need for support groups
- Increase public awareness
- Helpful messages
  - Knowledge is power
  - Stay positive for your child
  - You're not alone
  - Participate in follow-up assessments
- Less helpful messages
  - Doom and gloom

"a kind of plan for my child that I could keep track of."

"Every child is unique, and these problems are unlikely to develop in your child."

"In the first conversation [with Baylor] I got that the statistics on what is the likelihood that he was going to have symptoms and what they might be...that was very positive."

"Reassure them that it is highly likely nothing will happen but to work closely with your pediatrician and do the follow-up testing to catch anything early."

"Here are the percentages, here's the worst case, best case. That would've been a better - better odds, better odds you know for her to think, we got a 90% chance of nothing happening."

doctor and



- But, emphasized the Importance of Information and follow-up

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“Look at this as an opportunity to fall even more deeply in love with your child.”

“One time we came in for a test and she had lost 40% of hearing in on ear. I was so thankful we caught it early.”

## Communicating about screening

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# The Takeaways

## Conclusions

- Screening caused stress and anxiety which diminished over time
  - Parents were calmed by quality advice and treatment
  - Parents valued developmental screening and early interventions
  - Parents of children with sequelae were glad to avoid diagnostic odyssey
- 
- All parent groups were glad their children were screened and supported universal screening
  - **But...**appropriate education, support, and follow-up are crucial

## Future steps

- Formative research on psychosocial impact of a current screening program **not** in a research setting
- Development and testing of educational materials



# Questions?



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