

## Managing RSV's Indirect Impact

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*The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.*

On March 28, the coalition released *Managing RSV's Indirect Impact*. This video highlights the emotional, financial, and social burdens that fall on RSV patients and their families, hoping to emphasize the many reasons why policy makers should be encouraged to support innovation in RSV care.

The text from the video follows. Please feel free to share [this video](#) with your networks.

Nearly every child catches RSV by age 2. Respiratory Syncytial Virus affects the lungs and airways and can cause bronchiolitis,

pneumonia, coughing, wheezing, or other cold-like symptoms. But for many families, that's only the beginning. A national survey of parents and health care providers found that the disease also levies an emotional, financial, and social burden.

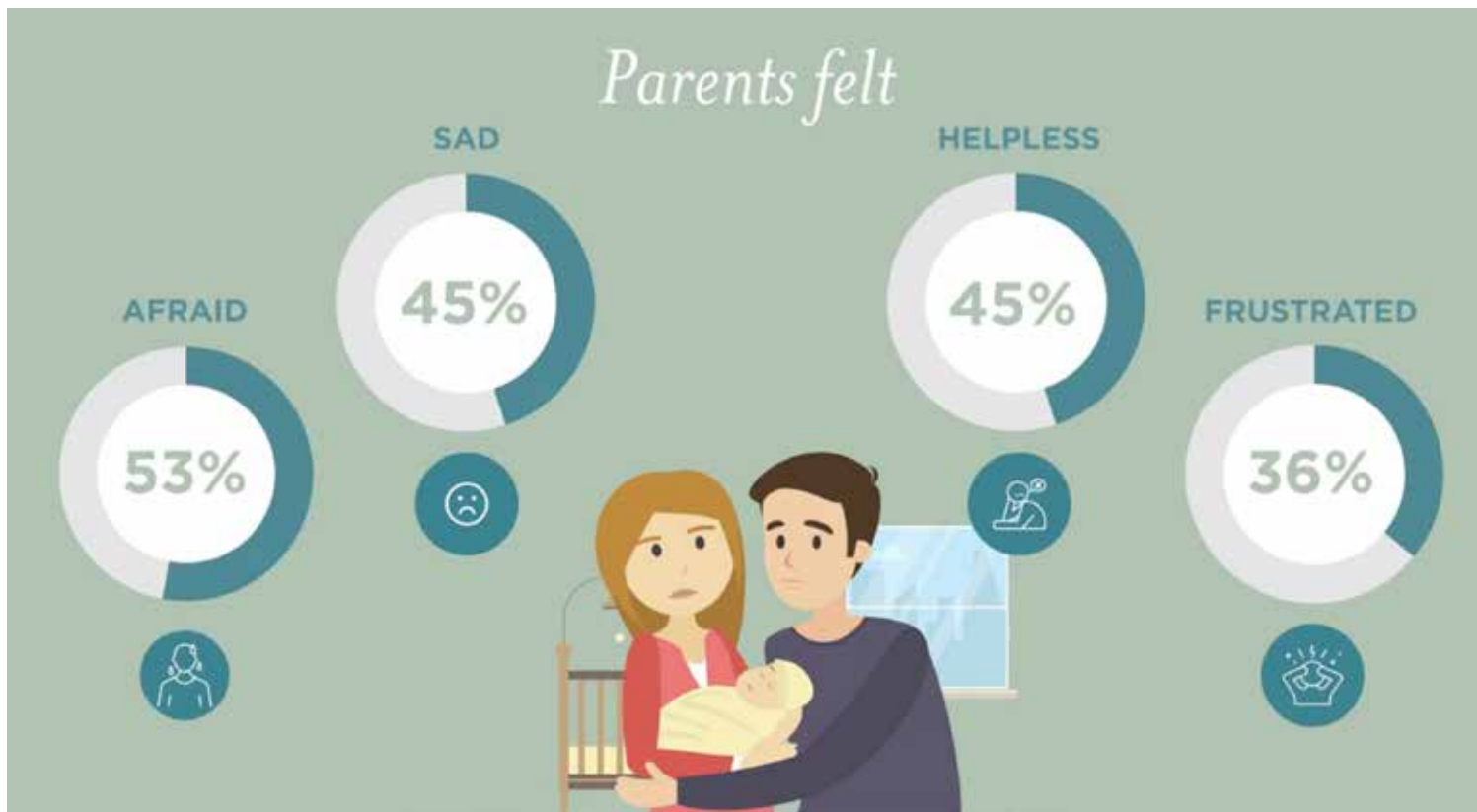
***“Some parents have to request paid time off, take unpaid leave, or cut back on work. And nearly 20% left their job or were fired.”***

Of the 340 parents whose child caught the virus, more than two-thirds said it landed their child in the hospital. 68% of parents reported the experience affected their mental health. While the child was sick, parents felt afraid, sad, helpless, and frustrated. And many felt guilty they couldn't do more to prevent their child's sickness.

***“So, how can policy makers help? By supporting innovation and ensuring timely and equitable access to care and preventive interventions.”***

RSV also dealt a financial blow. Families faced medical bills, loss of potential income, childcare costs for siblings, and transporta-





tion expenses. Meanwhile, some parents have to request paid time off, take unpaid leave, or cut back on work. And nearly 20% left their job or were fired as a result. Perhaps that's why more than two-thirds of surveyed parents described RSV as a financial burden or crisis.

RSV impacted families' social balance, too. More than one-third of parents said the experience strained their relationship with their partner. They had to turn to family members and friends to help with child-care. And, all the while, siblings struggled to understand what was happening.

It's clear that RSV's impact is multifaceted. So, how can policy makers help? By supporting innovation and ensuring timely and equitable access to care and preventive interventions. Surveyed health care providers agree that immunization and vaccine-like interventions could help minimize the burden of RSV. And 82% of parents agreed they'd want their child to receive such an intervention. With good policy and innovation, families and their health care providers can work together to reduce the burden of RSV.

**References:**

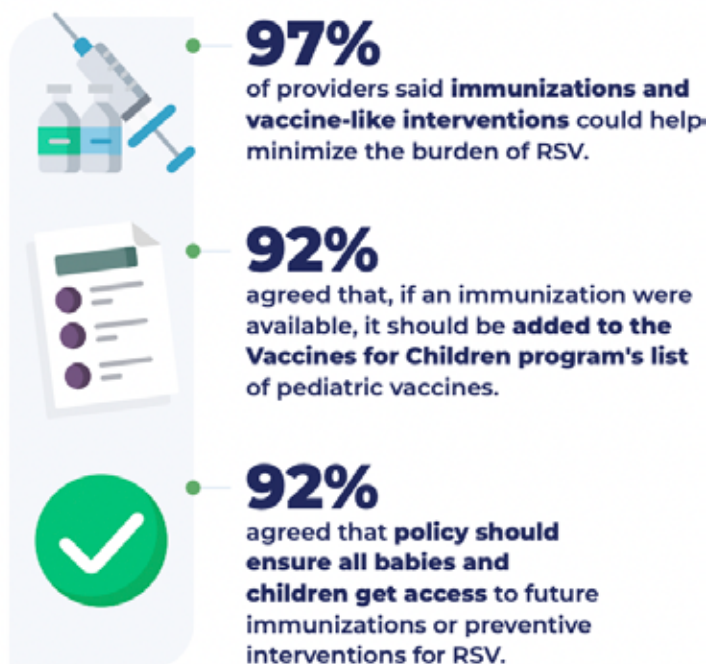
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## Policy Recommendations

Health care providers and parents overwhelmingly support greater awareness and improved options to prevent and treat RSV.





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**National Coalition for Infant Health Values (SANE)**

**Safety.** Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

**Access.** Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

**Nutrition.** Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

**Equality.** Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.

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