

## Infants Aren't the Only Ones Hurt by Respiratory Syncytial Virus (RSV)

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*The National Coalition for Infant Health is a collaborative of more than 180 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.*

A seasonal respiratory virus that threatens the lives of infants also can have a ripple effect on caregivers, families and workplaces, a new data analysis demonstrates.

Respiratory syncytial virus, or RSV, typically strikes between October and March with cold-like symptoms that can turn deadly for

infants, especially those born prematurely. In fact, RSV bronchiolitis is the leading cause of infant hospitalization in the United States. But a new analysis of data from the SENTINEL 1 study shows the disease also has secondary effects on infants' caregivers.

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In addition to the agony of watching their infant struggle, caregivers of infants with RSV reported:

**Stress.** Caregivers reported a stress level of 5.8 on a scale of one to seven, with seven being “very stressful.” A month after their infant’s hospital discharge, caregivers still reported stress.



**Reduced productivity.** Mothers (91%) and fathers (81%) both reported reduced productivity as a result of having their child hospitalized for RSV. And 73% of mothers and 58% of fathers reported absenteeism from work, while 64% of both mothers and fathers reported "presenteeism" – being at work but being unable to fulfill work responsibilities.

**Emotional impact.** In open-ended questions, caregivers of hospitalized infants with RSV reported emotional impact as one of the major experiences related to their child's disease. Fear, worry and stress were recurrent themes.

As one of the paper's researchers, Pia Pannaraj, MD, MPH, explained, "This study provides insight into the burdens these families face, from the terror of watching a baby struggle to breathe to the devastation of being fired from a job because of the time off needed to be by their baby's side in the hospital. As physicians, we need to be cognizant of the impact of a disease like this not only on the patient but across the family unit."

Published in [Clinical Pediatrics](#), the analysis considered data from 43 hospitals across the United States for infants who were born prematurely between 29 and 35 weeks gestation. (1) The infants, who were younger than 12 months old, had not received preventive treatment for RSV before they contracted, and were hospitalized with, the virus.

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Though research reveals RSV's impact to be far reaching, access to preventive medicine, palivizumab, continues to be a challenge for the families of premature infants. [Policy](#) from the American Academy of Pediatrics Committee on Infectious Diseases suggested in 2014 that the treatment was not needed for infants born after 29 weeks gestation. (2) Although the Food and Drug Administration indication is significantly broader than the AAP policy, many health plans and state Medicaid systems subsequently adjusted their coverage policies, limiting access for [most preterm infants](#). (3) The National Perinatal Association 2018 Respiratory Syncytial Virus (RSV) Prevention Clinical Practice Guidelines are more in line with the FDA indication and provide recommendations that cover those who are most at risk. (4)

As this latest research demonstrates, RSV's impact is broader than many realized. If policymakers hope to narrow the virus' effect on both infants and their caregivers, they might start by expanding access to preventive treatment.

**References:**

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4. [Goldstein, M., Philips, R., DeVincenzo, J., Krilov, L., Merritt, T.A., Yogev, R., Staebler, S., Kadri, M., Fergie, J.E., Schechter, M.S., Gorham M., Cherry, J.D. National Perinatal Association 2018 Respiratory Syncytial Virus \(RSV\) Prevention Clinical Practice Guideline: An Evidence-Based Interdisciplinary Collaboration. Neonatology Today. Volume 12, Issue 10, October 2017, 1-14.](#)

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