

# THE BURDEN OF RSV

*A Path to Awareness  
in Latin America*

A Summary of the March 2023  
Stakeholder Meeting



# Introduction

**On 14 March 2023, the Global Alliance for Patient Access hosted a meeting of stakeholders to discuss the unique challenges for infants and young children posed by respiratory syncytial virus, or RSV, in Latin America.**

Participants included:

- Asociación Latinoamericana de Tórax
- Brazilian Society of Pulmonology and Tisiology
- Brazilian Association of Cardiorespiratory Physiotherapy and Physiotherapy in Intensive Care
- Colombian Society of Pediatrics
- Con Amor Vencerás
- Fundación Infant
- Fundación para Padres de Niños Prematuros Costa Rica
- Individual patient advocates
- Researchers and clinicians, including pediatricians and pulmonologists

Participants represented Argentina, Brazil, Colombia, Costa Rica, Mexico, and pan-Latin America.

The meeting marked the launch of the Global Alliance for Patient Access' RSV Awareness and Advocacy Initiative. By partnering with local stakeholders, the Global Alliance for Patient Access seeks to raise awareness of RSV and the impact it has on infants, young children, their families and the health care systems in Latin America.



The Global Alliance for Patient Access and stakeholders will advocate for policies that protect families from the virus' extensive burden and ensure equitable access to preventive interventions as they become available.



## RSV in Latin America

RSV, which nearly all children get by age two, places a heavy burden on families throughout Latin America. In addition to the risk of severe disease, families may face financial, emotional and social burdens.

Few families are aware of RSV, though, and that lack of awareness can limit families' options when a baby becomes sick. According to a presentation from Mauricio Caballero, MD, around 75% of deaths caused by RSV occur at home, instead of at a hospital or other care site, and RSV is the leading cause of post-neonatal infant mortality.

For infants and children in economically vulnerable areas, the disease hits especially hard. The cost burden weighs heavily on families, and Dr. Caballero explained that 99% of deaths caused by RSV occur in economically vulnerable communities.

There aren't any licensed immunizations available for all infants to prevent the virus or to minimize the severity of disease, but there are immunizations that will be up for approval in the future. While there is one intervention available, it is available only for infants who were born prematurely or with certain underlying medical conditions.

# Discussion & Needs Assessment

The group's discussion focused on several issues:

- The **universal experience of RSV**, and the direct and indirect burdens it places on families
- A **lack of awareness** among parents
- **Strategies for educating families** about RSV
- **Differing needs, policies and pathways** among Latin American countries to ensure access to preventive interventions

The discussion revealed several pressing needs as countries work to improve awareness and shape meaningful policy.

## Needs & Recommendations



### Greater awareness and engagement for families

One of the most important tools to prevent serious infection and premature death is awareness. If families are aware of RSV's signs and symptoms, they have a better chance of detecting the virus early, ultimately leading to better health outcomes and a reduced burden.

RSV is a threat for all infants and children. Thus, all parents should have some level of knowledge about the disease. However, many parents are unaware of RSV and its potential impact.

Meeting participants explained that, while a great deal of educational materials are available, reaching parents can be a challenge. Emulating other successful awareness efforts, such as campaigns to raise awareness about COVID-19, may help. Stakeholders emphasized the importance of walking a fine line to avoid misinformation or overwhelming people with information.

Parents also need clarity about what supportive care looks like, as well as information on the future of prevention, including immunizations, for both babies and mothers.



## Better understanding of the burden and severity of RSV

Participants described a clear need for a deeper understanding of the scope and burden of RSV. While research exists on some issues, such as the connection between economic vulnerability and disease severity, differences across populations need further research. Understanding which groups are most impacted by RSV, as well as how severely RSV can impact families, also merits more research.

Meeting participants also noted the need for a clearer understanding of the severity of the virus and its short- and long-term impact on families. Parents must be able not only to recognize a potential case of RSV, but also to know what to do. In many cases, parents are unsure of whether their baby should go to the emergency room.

As stakeholders advocate for policies related to RSV, data that demonstrates the virus' heavy burden will help persuade policymakers to take steps that protect infants and children.

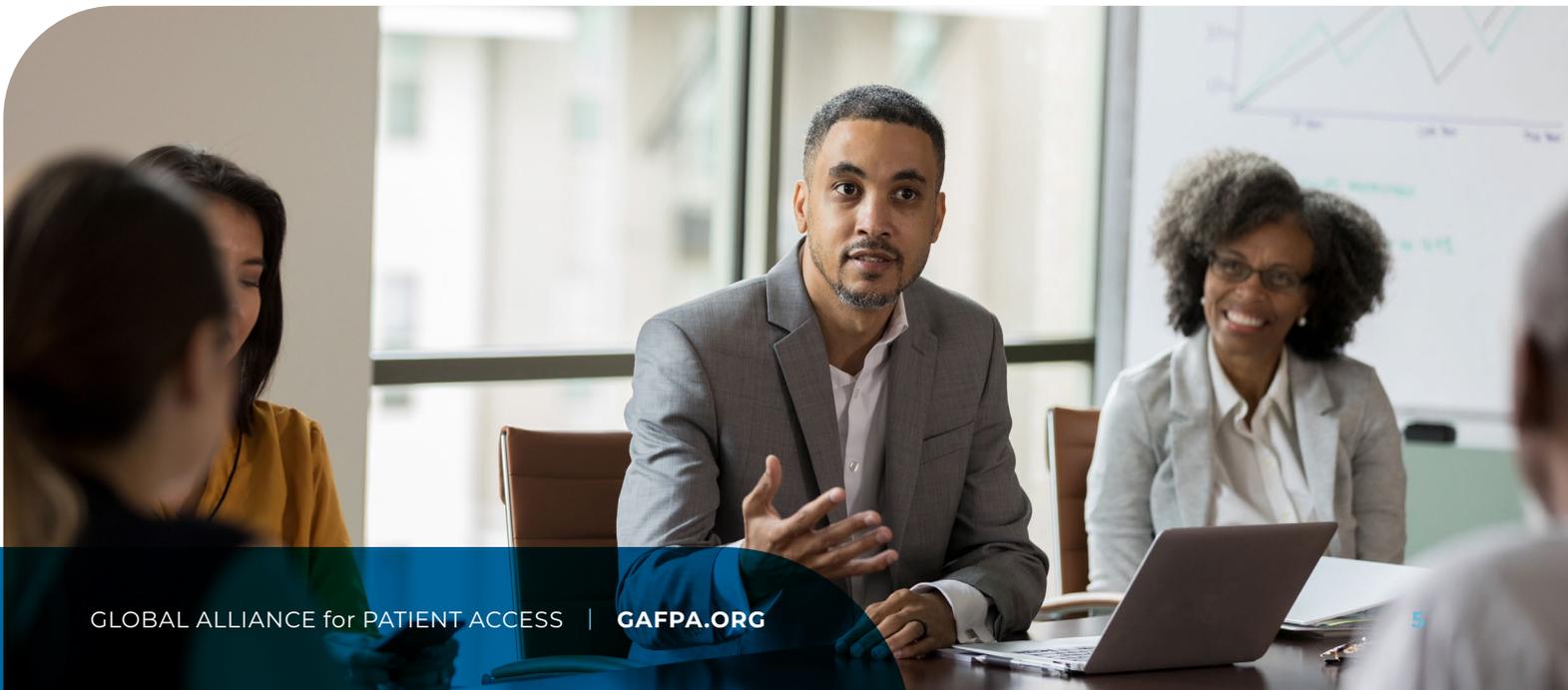


## Policies that ensure equitable access to future treatments

While there is no prevention for RSV currently available for all infants, innovation could soon reduce the burden of RSV. Preventive interventions, including immunizations for mothers and babies, are on the horizon and will soon offer viable ways to address RSV.

Once these interventions do become available, advocacy efforts will need to focus in on individual pathways that ensure broad and equitable access for all infants and mothers. Stakeholders explained some of the differences between their countries when it comes to access pathways. Awareness and advocacy efforts must be tailored to each country's population, policies and access pathway.

Equitable access was also a top priority for meeting participants. RSV impacts nearly all children, and those who are in economically vulnerable communities are most at risk. By the time interventions become available, policies must be in place to provide timely access to them.



# Conclusions

**RSV places a heavy burden on families in Latin America.** Parents must know more about the disease to best protect their children and minimize the disease's burden. And data demonstrating the burden of RSV can help policymakers understand why access to prevention is important.

As preventions to protect babies from RSV become available, advocacy efforts and new policies can help to ensure broad and equitable access. Working together, clinicians, parents and policymakers can further policies that will shield all babies and their families from the harm caused by RSV.



## About the Global Alliance for Patient Access

The Global Alliance for Patient Access is an international platform for health care providers and patient advocates to inform policy dialogue about patient-centered care.

[GAfPA.org](http://GAfPA.org)



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