



# THE BURDEN OF RSV

*A Path to Awareness in Europe*

A Summary of the March 2023  
Stakeholder Meeting



# Introduction

**On 17 March, 2023, the Global Alliance for Patient Access hosted a virtual meeting of stakeholders from across Europe to discuss the burden that respiratory syncytial virus, or RSV, places on infants, young children and their families.**

Participants included:

## **Medical Societies and Health Care Providers**

- Prof. Tobias Tenenbaum, Sana Klinikum Lichtenberg, Academic Teaching Hospital Charité-Universitätsmedizin Berlin
- Prof. Ultan Power, International Respiratory Syncytial Virus Society
- Prof. Peter Openshaw, National Heart and Lung Institute and International Respiratory Syncytial Virus Society
- Catherine Lawlor, Primary Care Respiratory Society

## **Patient Advocacy Organisations**

- Mónica Virchez, Prematura
- Armando Ruiz, Federación Española de Asociaciones de Pacientes Alérgicos y con Enfermedades Respiratorias
- María de Viarce Torres, Asociación de Padres de Niños Prematuros

## **Pan-European Organisations**

- Prof. Maria van den Muijsenbergh, European Forum for Primary Care
- Dr. Daphne Holt, Coalition for Life-Course Immunisation



The meeting launched the European branch of the Global Alliance for Patient Access' RSV Awareness and Advocacy Initiative. RSV can lead to severe illness for infants and young children, and it can also place heavy emotional, financial and social burdens on the families who experience it.

Moving forward, the Global Alliance for Patient Access will partner with local stakeholders throughout Europe to raise awareness of RSV and advocate for policies that ensure equitable and timely access to preventive interventions.



## RSV in Europe

Families throughout Europe will likely encounter RSV at some point during their children's infancy. The virus affects nearly all children before the age of two, and infants and young children face the worst of the disease's burden. Meanwhile, families are left to pick up the pieces, navigating life following a serious illness, including dealing with the emotional and financial impact this can have.

Despite the severity of RSV, many families are unaware of the virus and its impact. Parents need greater awareness of the dangers of respiratory distress and RSV. Meanwhile, policymakers need a deeper understanding of how innovative immunisation strategies may be able to provide protection.

There is only one licensed immunisation potentially available for all infants to minimize the severity of disease, and there are others that will be up for approval in the future. There is another intervention available, but it is only recommended for infants who are born prematurely or have certain underlying medical conditions. Innovative prevention strategies are on the horizon, however. As immunisations become available, policymakers must consider the universal nature of RSV and guarantee equitable access to immunisations for infants and young children, as well as for mothers.



## Discussion & Needs Assessment

The meeting's discussion highlighted several key challenges:

- **A lack of awareness** among the public of both RSV and respiratory distress
- **Barriers to care** as novel immunisations become available
- **Potential harm** caused by misinformation, vaccination fatigue and poor messaging

The meeting identified several needs and proposed solutions as European countries work to combat the many burdens of RSV.



## Needs & Recommendations



### Clear messaging to raise awareness of RSV and respiratory distress

Many parents are not aware of the signs and symptoms of RSV. They need clear, evidence-based messaging that is accessible and easy to understand. Meeting participants identified several strategies that can be used to educate parents, including online platforms, parent networks, social media and more.

During the meeting, participants discussed that the signs and symptoms of respiratory distress also need greater awareness. Parents must be able to recognise when children are suffering from respiratory distress so they can bring their child to a health care provider in a timely fashion. Broader education could be introduced by providers throughout perinatal care.



## Local engagement to improve awareness and vaccination and immunisation uptake

Meeting participants highlighted that one successful strategy stakeholders can implement is engaging with local communities. Local organisations, centres and opinion leaders all play an important role in informing parents about topics like RSV. Meeting participants discussed how the community plays a crucial role in educating new parents and helping them adapt to unexpected challenges like RSV.

Community engagement can generally improve immunisation uptake, meeting participants pointed out. Local voices speaking on the value of preventive interventions can help reduce unease and highlight efficacy. As new preventive interventions become available, community input can encourage parents to make decisions that will protect their babies from the harm of RSV.



## Policies ensuring equitable and timely access

Nearly all children catch RSV before they are two. And all children are at risk of developing severe disease — not just those who are born prematurely or with pre-existing conditions.

Policymakers should recognise the significant burden that RSV places upon the health care system. Without protection from RSV disease, families are more likely to experience long-term consequences, which also places a greater burden upon the system.

Meeting participants discussed ways to pre-emptively address policy barriers and concerns while educating policymakers about RSV and novel immunisations. Depending on the increasing scientific evidence, international committees on vaccination and immunisation may recommend new strategies to prevent RSV disease in the near future. Policymakers should therefore work to ensure that potentially all children have access to these interventions as they become available to reduce the burden on families and the health care system.



# Conclusions

**Families throughout Europe bear the financial, social and emotional burden during and after their child's experience with RSV.** But while the virus levies a heavy burden, there are innovative preventions on the horizon to protect infants — through immunisation and vaccination.

Raising awareness, advocating for equitable policies and engaging with local stakeholders are all avenues that invested parties can take to protect infants, young children and their families from the harm caused by RSV.



## About the European Alliance for Patient Access

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

**GAfPA.org**



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