

ResQFamily

Survey Recruitment Toolkit



ResQFamily

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EFCUNI european foundation for
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for Paediatric Research



ReSViNET
RESPIRATORY SYNCYTIAL VIRUS FOUNDATION



UENPS Union of European
Neonatal & Perinatal
Societies

Dear Reader,

Thank you very much for your interest in our new scientific research project "**ResQ Family: Impact of Respiratory Syncytial Virus (RSV) hospitalisation on Quality of life of Families** – a multi-country study".

We are very pleased that you have decided to help us reach our target group to improve our understanding of RSV and its impact on affected families. To make it as easy as possible for you, we have prepared this recruitment toolkit. We hope that you will find many valuable elements in it to help you approach potential study participants from your community and motivate them to take part in the survey.

Thank you for reading, participating and sharing!

With best wishes,

Your EFCNI **ResQ Family Project Team**

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1. The ResQ Family survey recruitment toolkit

Respiratory Syncytial Virus (RSV) is a very contagious virus and the most common cause of lower respiratory tract infections such as bronchiolitis and pneumonia in infants. By the age of two years, nearly all infants will be infected with RSV at least once. Globally, it is a leading cause of hospitalisations among young infants with approximately 33 million cases of acute lower respiratory infections causing more than three million hospitalisations each year in children younger than 5 years. While most RSV cases are mild, we can't predict which infants could get seriously ill and end up in hospital. This is because the course of the disease is unpredictable.

When the RSV infection of the child is severe and associated with hospitalisation, it may lead to intensive care unit admissions with use of supportive care such as mechanical ventilation. It may further result in long-term complications such as recurrent wheezing, reduced pulmonary function and asthma. Moreover, RSV-related hospitalisations can be associated with a significant burden on the entire family, causing considerable stress and increased loss of work productivity. Currently, there is a lack of adequate information on how severe RSV infection leading to hospitalisation of infants (< 2 years) impacts the quality of life of affected families.

To close this knowledge gap, EFCNI is conducting the **ResQ Family research project: ResQ Family: Impact of Respiratory Syncytial Virus (RSV) hospitalisation on Quality of life of Families** – a multi-country study. The project runs from December 2021 until June 2024 and covers four European countries: France, Germany, Italy and Sweden. Data will be collected between autumn 2022 and spring 2023, corresponding to a typical RSV season duration in temperate countries in the northern hemisphere.

The aim of the ResQ Family study is to find out how infant RSV hospitalisation impacts the quality of life of affected children and their families. The goal is further to provide scientific evidence on the burden of RSV and raise awareness among all relevant stakeholders including healthcare professionals and patient representatives, decision-makers and the general public.

An online questionnaire will be used to ask parents and caregivers of children experiencing (or having recently experienced) hospitalisation due to RSV infection to share their experiences. Our study focuses on children **up to 24 months** with a **hospital stay due to RSV infection of at least 12 hours in total. The hospital admission should not be longer than 4 weeks ago.**

Experienced researchers and health care professionals renowned in the field of RSV as well as parent/patient representatives support the project as part of an external scientific advisory board and a project expert group. EFCNI received a research grant from Sanofi in support of this independent study. For detailed information about the ResQ Family project, please visit www.resq-family.org.



1.1 Aim of the toolkit

The recruitment toolkit specifically addresses you as parent organisations, healthcare professionals, professional healthcare societies and further related networks to support EFCNI to:

- raise awareness of RSV in all infants and its potential consequences regardless their health conditions,
- spread the survey in your network,
- facilitate data collection, and
- reach the highest possible number of study participants.

This toolkit provides an overview of the project communication and survey recruitment strategies, including ready-to-use elements such as graphics and text templates for social media (Facebook, LinkedIn, Instagram, Twitter), mailings, and newsletter communication, as well as printout materials (postcard, flyer/leaflet).

1.2 How to use the toolkit

To promote the ResQ Family survey, we kindly ask you to

- share the survey link in your network: <https://www.surveymonkey.de/r/K6TVY2B>
- use and/or adapt the provided text templates,
- use the provided (social media) graphics,
- distribute the flyer and postcards in your network/hospital etc.,
- engage in in-person recruitment of possible participants, and
- share and like EFCNI social media posts.

The promotion of the survey will take place between September 2022 and April 2023.

Thank you very much for your support!

If you have any questions, please feel free to contact the responsible research coordinator Dr Christina Tischer, christina.tischer@efcni.org or research@efcni.org.



2. Templates for social media and mailings

2.1. Facebook

Addressed to parents



Just breathe! Was this also your first thought when your child was hospitalised due to **RSV***?

*Respiratory Syncytial Virus

We want to know how you are doing! How you and your family dealt with the **RSV** episode of your child.

- Is your child currently hospitalised or has been hospitalised in the past 4 weeks due to **RSV**?
- Is your child younger than 24 months?
- Are you living in France, Germany, Italy or Sweden?

GET INVOLVED and participate in our **ResQ Family study!**

Complete an online questionnaire (approx. 15 minutes) in your own language providing your personal experience

Much is still unknown about **RSV** and its impact. With your help, we can start to improve the quality of life of affected children and their families.

PARTICIPATE NOW!

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EFCNI received a research grant from Sanofi in support of this independent study.

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ReSViNET RESPIRATORY SYNCYTIAL VIRUS INFECTION

UENPS Union of European Neonatal and Paediatric Societies

ResQFamily

Have you just rushed to hospital because your child has **Respiratory Syncytial Virus (RSV)**? Or have you just emerged from your child's hospitalisation? Then you might have gone through or are still going through a very difficult time. By sharing how you have dealt with your child's RSV episode and its clinical manifestations such as bronchiolitis or pneumonia, you can help to increase our understanding of RSV and its impact and begin to make a change in the quality of life for affected children and their families.

Can you take part in our study? Please join EFCNI's European survey if your child was hospitalised due to RSV (≥ 12 hours) within the last four weeks, if your child is younger than 24 months and if you are living in France, Germany, Italy or Sweden: <https://www.surveymonkey.de/r/K6TVY2B>. The questionnaire is available in the official country languages.

The European study #ResQFamily is unique: it aims at exploring parents' or caregivers' experiences related to the challenges caused by RSV infection and hospitalisation of children – a topic on which there is currently only little information available. Please participate, like and share!

We conduct the study in cooperation with representatives of national parent organisations, #ESPR, #ReSViNET, and @UENPS.Congress.

EFCNI received a research grant from Sanofi in support of this independent study.

For further information, please visit our research project website www.resq-family.org or contact us at research@efcni.org.



#ResQFamily #RSV #RespiratorySyncytialVirus #QoL #QualityOfLife #Research

2.2. LinkedIn

Addressed to parents



Just breathe! Was this also your first thought when your child was hospitalised due to **RSV***?

*Respiratory Syncytial Virus

We want to know how you are doing! How you and your family dealt with the **RSV** episode of your child.

- Is your child currently hospitalised or has been hospitalised in the past 4 weeks due to **RSV**?
- Is your child younger than 24 months?
- Are you living in France, Germany, Italy or Sweden?

GET INVOLVED and participate in our **ResQ Family study!**

Complete an online questionnaire (approx. 15 minutes) in your own language providing your personal experience

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in collaboration with

ESPR European Society for Paediatric Research

ReSViNET RESPIRATORY SYNCYTIAL VIRUS (RSV) FOUNDATION

UENPS Union of European Neonatal and Paediatric Societies

ResQFamily

Have you just rushed to hospital because your child has **Respiratory Syncytial Virus (RSV)**? Or have you just emerged from your child's hospitalisation? Then you might have gone through or are still going through a very difficult time. By sharing how you have dealt with your child's RSV episode and its clinical manifestations such as bronchiolitis or pneumonia, you can help to increase our understanding of RSV and its impact and begin to make a change in the quality of life for affected children and their families.

Can you take part in our study? Please join EFCNI's European survey #ResQFamily if your child was hospitalised due to RSV (≥ 12 hours) within the last four weeks, if your child is younger than 24 months and if you are living in France, Germany, Italy or Sweden: <https://www.surveymonkey.de/r/K6TVY2B>. The questionnaire is available in the official country languages.

In cooperation with representatives of national parent organisations, [European Society for Paediatric Research](#), [ReSViNET | Respiratory Syncytial Virus \(RSV\) Foundation](#), and #UENPS, EFCNI is conducting a European study to explore parents' and caregivers' experiences related to the challenges caused by RSV infection and hospitalisation of children – a topic on which there is currently only little information available.

EFCNI received a research grant from Sanofi in support of this independent study.

For further information, please visit our research project website www.resq-family.org or contact us at research@efcni.org.



#ResQFamily #RSV #RespiratorySyncytialVirus #QoL #QualityOfLife #Research

Addressed to healthcare professionals and parent organisations

Just breathe! Was this also one of the most communicated fears of parents with a child hospitalised due to **RSV**?

We want to discover families' experiences related to the challenges caused by **RSV** infection of their children.

Are you in contact with parents or caregivers of children...

- hospitalised due to **RSV** within the last four weeks,
- younger than 24 months,
- living in France, Germany, Italy or Sweden?

GET INVOLVED and support our **ResQ Family study!**

Promote our online questionnaire by sharing it with affected families!

Much is still unknown about **RSV** and its impact. With your help, we can start to improve the quality of life of affected children and their families. **SUPPORT US NOW!**

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ResQFamily

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European Society for Paediatric Research

ReSViNET
RESPIRATORY SYNCYTIAL VIRUS FOUNDATION

UENPS Union of European Neonatal & Paediatric Societies

Are you in contact with parents or caregivers of children experiencing or having recently experienced hospitalisation due to **Respiratory Syncytial Virus (RSV)** infection? Then we kindly ask you to support our **ResQ Family Project!**

The European Foundation for the Care of Newborn Infants (EFCNI) is looking for voluntary participants to take part in a **study** aiming to understand the impact of **RSV** infection leading to hospitalisation of children on the **quality of life** of affected families – a topic on which there is currently only little information available.

Please share EFCNI's European survey #ResQFamily with parents or caregivers of children (< 2 years) hospitalised due to RSV (≥ 12 hours) within the last four weeks, living in France, Germany, Italy or Sweden: <https://www.surveymonkey.de/r/K6TVY2B> or use ready-to-use elements of our participant recruitment toolkit <https://www.efcni.org/activities/resq-family/recruitment-toolkit/> to promote the study. The questionnaire and the toolkit are available in the official country languages.

We conduct the study in cooperation with representatives of national parent organisations, [European Society for Paediatric Research](#), [ReSViNET | Respiratory Syncytial Virus \(RSV\) Foundation](#), and #UENPS.

EFCNI received a research grant from Sanofi in support of this independent study.

For further information, please visit our research project website www.resq-family.org or contact us at research@efcni.org.

#ResQFamily #RSV #RespiratorySyncytialVirus #QoL #QualityOfLife#Research



2.3. Instagram

Addressed to parents

Just breathe! Was this also your first thought when your child was hospitalised due to **RSV***?
*Respiratory Syncytial Virus

We want to know how you are doing! How you and your family dealt with the **RSV** episode of your child.

- Is your child currently hospitalised or has been hospitalised in the past 4 weeks due to **RSV**?
- Is your child younger than 24 months?
- Are you living in France, Germany, Italy or Sweden?

GET INVOLVED and participate in our **ResQ Family study!**

Complete an online questionnaire (approx. 15 minutes) in your own language providing your personal experience

Much is still unknown about **RSV** and its impact. With your help, we can start to improve the quality of life of affected children and their families.
PARTICIPATE NOW!

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ReSViNET
RESPIRATORY SYNCYTIAL VIRUS FOUNDATION
UENPS Union of European Neonatal and Paediatric Societies

Have you just rushed to hospital because your child has **Respiratory Syncytial Virus (RSV)**? Or have you just emerged from your child's hospitalisation? Then you might have gone through or are still going through a very difficult time. By sharing how you have dealt with your child's RSV episode and its clinical manifestations such as bronchiolitis or pneumonia, you can help to increase our understanding of RSV and its impact and begin to make a change in the quality of life for affected children and their families.

Can you take part in our study? Please join EFCNI's European survey #ResQFamily if your child was hospitalised due to RSV (≥ 12 hours) within the last four weeks, if your child is younger than 24 months and if you are living in France, Germany, Italy or Sweden: <https://www.surveymonkey.de/r/K6TVY2B>. The questionnaire is available in the official country languages.

We conduct the study in cooperation with representatives of national parent organisations, #ESPR, #ReSViNET, and #UENPS.

EFCNI received a research grant from Sanofi in support of this independent study.

For further information, please visit our research project website www.resq-family.org or contact us at research@efcni.org.

#ResQFamily #RSV #RespiratorySyncytialVirus #QoL #QualityOfLife#Research



2.4. Twitter

Addressed to parents

Just breathe! Was this also your first thought when your child was hospitalised due to **RSV***?

*Respiratory Syncytial Virus

We want to know how you are doing! How you and your family dealt with the **RSV** episode of your child.

- Is your child currently hospitalised or has been hospitalised in the past 4 weeks due to **RSV**?
- Is your child younger than 24 months?
- Are you living in France, Germany, Italy or Sweden?

GET INVOLVED and participate in our **ResQ Family study!**

Complete an online questionnaire (approx. 15 minutes) in your own language providing your personal experience

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UENPS Union of European Neonatal & Perinatal Societies

Are you a parent or caregiver of a child (< 2 years) experiencing or having recently experienced hospitalisation due to RSV infection? Then we kindly ask you to participate in our #ResQFamily survey: <https://www.surveymonkey.de/r/K6TVY2B>

#RSV #QualityofLife

Addressed to healthcare professionals and parent organisations

Just breathe! Was this also one of the most communicated fears of parents with a child hospitalised due to **RSV**?

We want to discover families' experiences related to the challenges caused by **RSV** infection of their children.

Are you in contact with parents or caregivers of children...

- hospitalised due to **RSV** within the last four weeks,
- younger than 24 months,
- living in France, Germany, Italy or Sweden?

GET INVOLVED and support our **ResQ Family study!**

Promote our online questionnaire by sharing it with affected families!

Much is still unknown about **RSV** and its impact. With your help, we can start to improve the quality of life of affected children and their families. **SUPPORT US NOW!**

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UENPS Union of European Neonatal & Perinatal Societies

Are you in contact with parents or caregivers of children (< 2 years) experiencing or having recently experienced hospitalisation due to RSV infection? Then we kindly ask you to share our #ResQFamily survey: <https://www.surveymonkey.de/r/K6TVY2B>

#RSV #QualityofLife



2.5. Newsletter

Launch of ResQ Family Online Survey

Call to participate in the European study on RSV infection and hospitalisation

Respiratory Syncytial Virus (RSV) is a leading cause of lower respiratory tract infection in infants, globally accounting for approximately 33 million cases of acute lower respiratory infections causing more than three million hospitalisations each year in children younger than 5 years. The health burden of RSV and its clinical manifestations (bronchiolitis, pneumonia) is high because there are still no approved preventative options, leaving infants vulnerable to infection. By the age of two years, nearly all infants will be infected with RSV at least once.

While most RSV cases are mild, we can't predict which infants could get seriously ill and end up in hospital. This is because the course of the disease is unpredictable. When the RSV infection is severe and associated with hospitalisation, it may lead to intensive care unit admissions with use of supportive care such as mechanical ventilation. It may further result in long-term complications such as recurrent wheezing, reduced pulmonary function and asthma. Moreover, RSV-related hospitalisations can be associated with a significant burden on the entire family, causing considerable stress and increased loss of work productivity. Currently, there is a lack of evidence on how severe RSV infection leading to hospitalisation of children impacts the quality of life of affected families. To close this existing knowledge gap, EFCNI is conducting a study in four European countries: Germany, Sweden, Italy and France.

Can you take part in our study? Please join EFCNI's European survey #ResQFamily if your child was hospitalised due to RSV (≥ 12 hours) within the last four weeks, if your child is younger than 24 months and if you are living in France, Germany, Italy or Sweden: <https://www.surveymonkey.de/r/K6TVY2B>. The questionnaire is available in the official country languages.

The study is conducted in cooperation with representatives of national parent organisations, #ESPR, #ReSViNET, #UENPS and international experts renowned in the field of RSV related research. EFCNI received a research grant from Sanofi in support of this independent study.

For further information have a look at our research project website www.resq-family.org or contact the responsible research coordinator Dr Christina Tischer, christina.tischer@efcni.org or research@efcni.org.

2.6. Mailings

Subject: Your support needed: Survey on the impact of infant RSV infection and hospitalisation on the quality of life of families

Dear XX,

Autumn is almost here! As you all know, this time of year not only stands for colourful leaves and golden light, but it also marks the beginning of the **Respiratory Syncytial Virus (RSV)** season for our little ones.



The health burden of RSV and its clinical manifestations (bronchiolitis, pneumonia) is high because there are still no approved preventative options, leaving infants vulnerable to infection. By the age of two years, nearly all infants will be infected with RSV at least once. While most RSV cases are mild, we can't predict which infants could get seriously ill and end up in hospital. This is because the course of the disease is unpredictable. When the RSV infection is severe and associated with hospitalisation, it may lead to intensive care unit admissions with use of supportive care such as mechanical ventilation. It may further result in long-term complications such as recurrent wheezing, reduced pulmonary function and asthma. Moreover, RSV-related hospitalisations can be associated with a significant burden on the entire family, causing considerable stress and increased loss of work productivity.

Currently, there is a lack of evidence on how severe RSV infection leading to hospitalisation of children impacts the quality of life of affected families. To close this existing knowledge gap, the European Foundation for the Care of Newborn Infants (EFCNI) is looking for voluntary participants to take part in a **study** aiming to explore parents' or caregivers' experiences related to the challenges caused by RSV infection and hospitalisation of their children (< 2 years). Our study focuses on children **up to 24 months** with a **hospital stay due to RSV infection of at least 12 hours in total. The hospital admission should not be longer than 4 weeks ago.**

The project is called: “**ResQ Family: Impact of Respiratory Syncytial Virus (RSV) hospitalisation on Quality of Life of Families** – a multi-country study”. It will be conducted in four European countries: Germany, Sweden, Italy and France. The main aim is to publish the findings in an international scientific journal and raise awareness among healthcare professionals and patient representatives, decision-makers and the general public.

The study is conducted in cooperation with representatives of national parent organisations, #ESPR, #ReSViNET, #UENPS and international experts renowned in the field of RSV related research. EFCNI received a research grant from Sanofi in support of this independent study.

We and EFCNI would highly appreciate if you could support this project by forwarding the survey link to your network and call to participation on social media, either by an individual post or by sharing EFCNI's posts.

In case you have any questions or comments, please feel free have a look at EFCNI's research project website www.resq-family.org or contact the responsible research coordinator Dr Christina Tischer, christina.tischer@efcni.org or research@efcni.org.

Best regards,

XX



2.7. QR code to survey-link

By scanning the QR code, you will be directed to the online questionnaire now available in German, French, Italian and Swedish. Add the QR-Code to your social media postings and/or share it with your network.

German:



French:



Italian:



Swedish:



3. Templates for printout materials

3.1. Postcard

Just breathe!

Was this also your first thought when your child was hospitalised due to **RSV***?

Have you just rushed to hospital because your child has **RSV**? Or have you just emerged from this stressful situation?

We want to know how you are doing! How you and your family dealt with the **RSV** episode of your child.

*Respiratory Syncytial Virus

 ResQFamily

- Is your child currently hospitalised or has been hospitalised in the past 4 weeks due to **RSV**?
- Is your child younger than 24 months?
- Are you living in France, Germany, Italy or Sweden?

GET INVOLVED and participate in our **ResQ Family study!**

Complete an online questionnaire (approx. 15 minutes) in your own language providing your personal experience



Much is still unknown about **RSV** and its impact. With your help, we can start to improve the quality of life of affected children and their families. **PARTICIPATE NOW!**

For more information, please visit www.resq-family.org or contact us: research@efcni.org

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EFCNI received a research grant from Sanofi in support of this independent study.



3.2. Flyer/Leaflet

Just breathe!

Was this also your first thought when your child was hospitalised due to **RSV**?

SURVEY ResQ Family:
Impact of **Respiratory Syncytial Virus** hospitalisation on Quality of life of Families – a multi-country study

PARTICIPANTS NEEDED!

Have you just rushed to hospital because your child has **Respiratory Syncytial Virus (RSV)**? Or have you just emerged from your child's hospitalisation? Then you might have gone through or are still going through a very difficult time. By sharing how you have dealt with your child's RSV episode, you can help to make a change in the quality of life for affected families.

The **ResQ Family Project Team** of the European Foundation for the Care of Newborn Infants (EFCNI) is looking for voluntary participants to explore parents' or caregivers' experiences related to the challenges caused by RSV infection and hospitalisation of children – a topic on which there is currently only little information available. **PARTICIPATE NOW!**

WHO CAN PARTICIPATE

- Is your child currently hospitalised or has been hospitalised in the past 4 weeks due to **RSV**?
- Is your child younger than 24 months?
- Are you living in France, Germany, Italy or Sweden?

GET INVOLVED and participate in our **ResQ Family study!**

Complete an online questionnaire (approx. 15 minutes) in your own language providing your personal experience

This research is carried out by the Scientific Affairs Department of EFCNI (www.efcni.org) in close collaboration with an External Scientific Advisory Board and an international Project Expert Group including parent representatives. EFCNI received a research grant from Sanofi in support of this independent study.

For further information have a look at our project website www.resq-family.org or contact the responsible research coordinator Dr. Christina Tischer, christina.tischer@efcni.org or research@efcni.org.



THANK YOU FOR YOUR PARTICIPATION AND SUPPORT!

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4. Imprint and contact

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EFCNI is represented by Silke Mader, Chairwoman of the Executive Board and Nicole Thiele, Member of the Executive Board.

Visit us on



EU Transparency Register ID Number: 33597655264-22

EFCNI is a non-profit organisation established under German public law | Tax reference number 143/235/22619, certificate dated January 7, 2020.

The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It brings together parents, healthcare experts from different disciplines, and scientists with the common goal of improving long-term health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby.

For more information have a look at our website www.resq-family.org or contact us at research@efcni.org.

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