

## The Network of parliamentary advocates for paediatrics to promote new scenarios for a better access to medicines

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# Europe's Lack of Medicine Access

- ❖ Proper access to medicinal products means that medicines, including those for rare illnesses, are readily available for all citizens, easily affordable for all citizens and are safe, effective, and of high quality.
- ❖ Insufficient access to essential medical products poses a serious threat to the wellbeing citizens in the European Union

# Factors that Influence the Availability and Access to Medicines

Supply  
Systems and  
Patient Access

Pricing and  
Transparency

Rigid  
Patenting  
Rules

# Possible Solutions

- ❖ Examine, compare, and take into account the differences in prices of the same medicines in different countries when adjusted to purchasing power parity.
- ❖ Increase transparency from industry when negotiating prices to ensure fair deals for all countries and encourage joint procurement to strengthen negotiating power
- ❖ Increase public funding for research and innovation for the development of new medicines, medical facilities, and medical training in all Member States
- ❖ Call on drug developers to respect transparency in the production costs of medicines
- ❖ Promote measures to stimulate the uptake of generic medicines, which can effectively lower costs and reduce overall expenditure on medicines.



# Possible Solutions

- ❖ Institutionalized European system for rapid information-sharing and real time monitoring of medicinal shortages and stocks
- ❖ Monitoring system to ensure that national stockpiling initiatives are proportionate to their needs and ensure that all countries have fair access to the stockpile
- ❖ Contingency plans and procedures for medicinal shortages must be future-proof and able to withstand all future shocks to the health care system including any future pandemics
- ❖ At the national level, governments and public insurers should find ways to ensure that in a situation of medical shortage, consumers do not end up paying more out-of-pocket

- ❖ Monitor whether patents are granted for genuine innovation and examine the practice of 'evergreening', where pharmaceutical companies get patents for inventions that are not actually new, but are 'old science' with minor modifications to existing products in order to keep their patents indefinitely
- ❖ Examine if patents hinder innovation in the area of diseases where there is no profitable market, such as rare diseases.
- ❖ Evaluate the influence patenting systems have on research and development on new and innovative medicines
- ❖ Stimulate competition between generic medicines and established medicines where the patent has expired to incentivize innovation and reduce costs

# Paediatric research

Today, the majority of the drugs used for children and young patients have not been specifically developed and tested for them.

In Europe and worldwide **only 30% of marketed drugs includes a paediatric authorisation** with serious risks of lack of cure and/or inappropriate 'off-label' medicines' use.

Currently paediatricians often prescribe to children medicines marketed for adults on the basis of clinical practice and medical knowledge.

Children and young patients cannot be compared to adults in their growth path and have a different metabolism.

**For this reason, it is important to lobby for paediatric research to be included in the research agenda at EU level.**





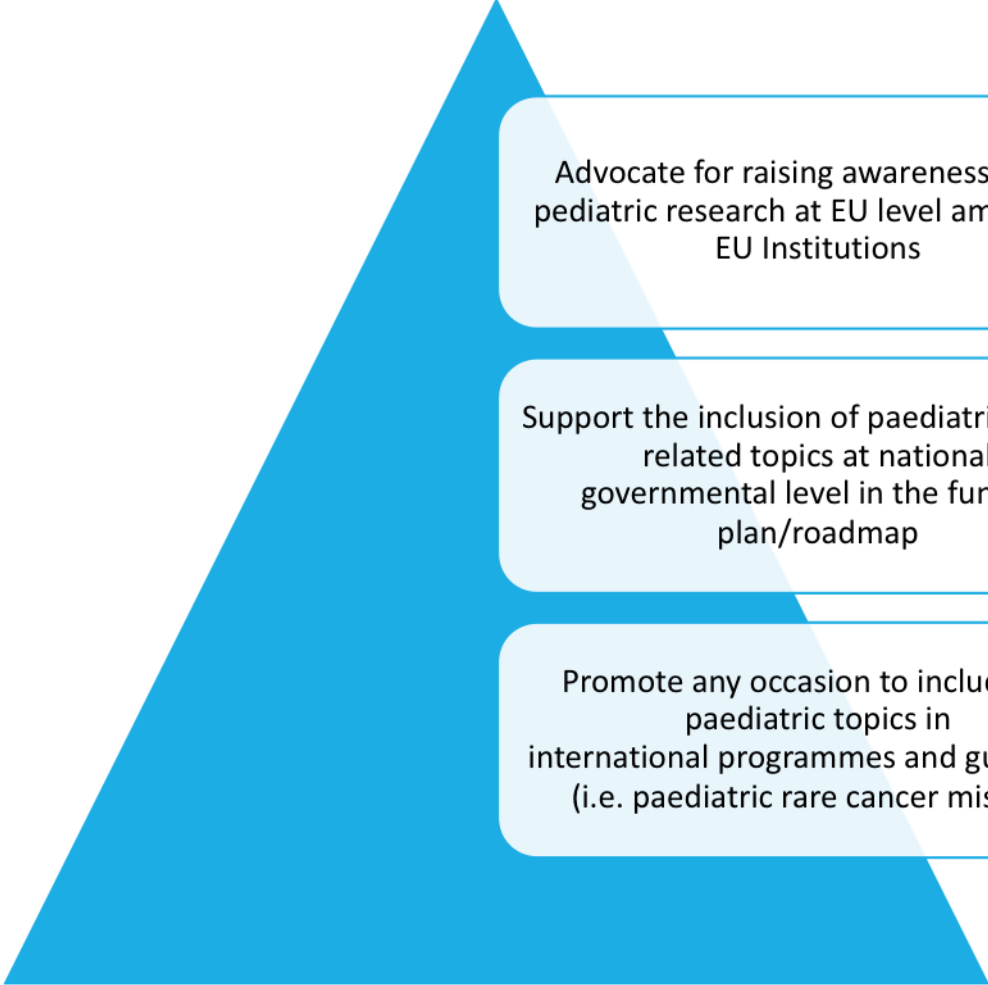
# Network of parliamentary advocates for paediatrics

It will be a group of European and National Parliamentarians who are advocating to improve the lives of children who are often orphans of treatments and to create a new EU political framework focused on children and their health.





# Network aims



Advocate for raising awareness about pediatric research at EU level among the EU Institutions

Support the inclusion of paediatrics/EPTRI related topics at national governmental level in the funding plan/roadmap

Promote any occasion to include the paediatric topics in international programmes and guidelines (i.e. paediatric rare cancer mission)

# EPTRI involvement

 **European Parliament**  
2019-2024

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*Committee on the Environment, Public Health and Food Safety*

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30.04.2020

**2020/0000 (INI)**

**DRAFT REPORT**

on the shortage of medicines - how to deal with an emerging problem  
(2020/0000(INI))

Committee on the Environment, Public Health and Food Safety

Rapporteur: Nathalie Colin-Oesterlé

EPTRI has been invited to provide contribution to a report on how to deal with the emerging problem of the shortage of medicines.

# Proposal of future plans

Liase with  
MEPs

Prepare a  
Position  
Paper

Organise the  
Network of  
MEPs  
advocates for  
paediatrics

Organise a  
Dissemination  
meeting