

# The importance of awareness raising and European Antibiotic Awareness Day 2024

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## Promoting awareness and amplifying patient advocacy on antimicrobial resistance (AMR)

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AMR One Health Network

24.10.2024

“ A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE ”



# About the European Patients' Forum



- Independent, non-governmental umbrella
- Founded in 2003
- 80 national coalitions & EU disease-specific organisations

## Our vision

A Europe where patient organisations are *valued partners* in creating equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise

## Our mission

To advance the interests of patients and patients' communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment and *partnership*



# Impact of AMR on patients' health & safety

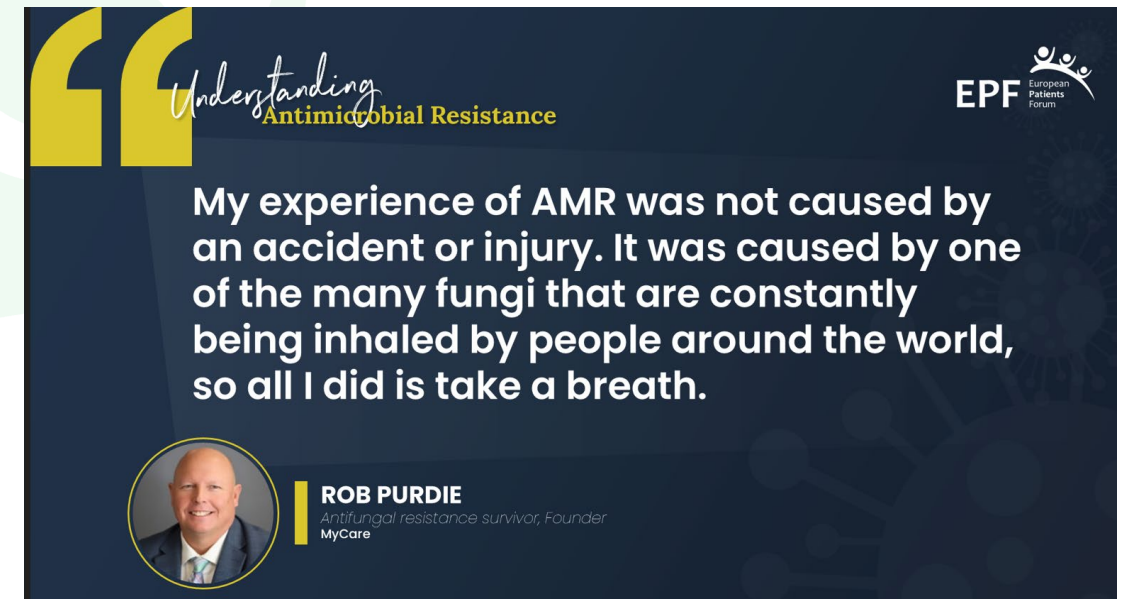
## Patients are particularly vulnerable to AMR

- They spend more time in HC settings
- They may need antibiotics as part of HC procedures to prevent or treat infections

## AMR can have detrimental impacts

- More invasive and lengthy treatments
- Long-term health impacts and increased mortality
- Impacts on mental health
- Increased costs and societal impacts


→ **AMR affects patients' trust in HC systems and access to safe care**



*Understanding*  
**Antimicrobial Resistance**

EPF European Patients Forum

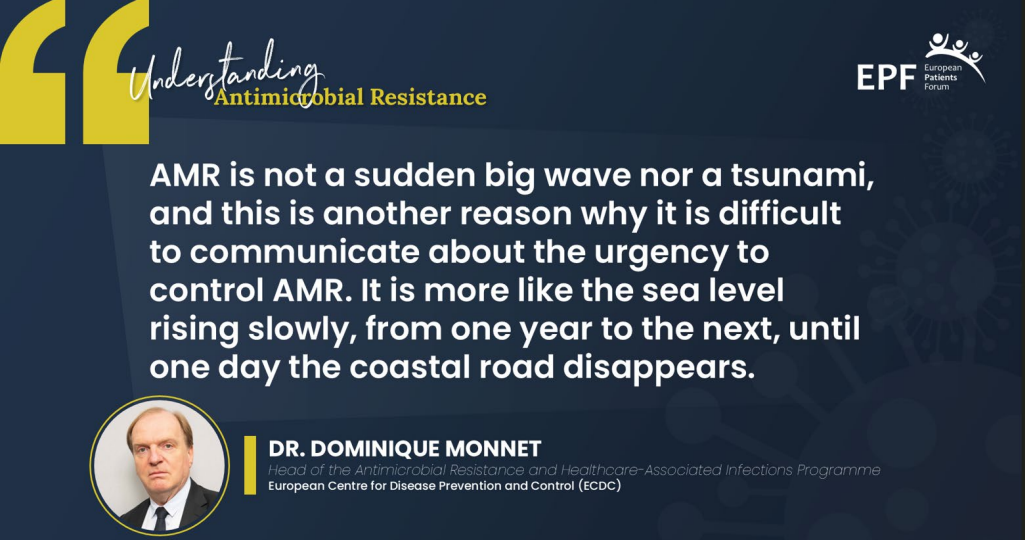
**My experience of AMR was not caused by an accident or injury. It was caused by one of the many fungi that are constantly being inhaled by people around the world, so all I did is take a breath.**



**ROB PURDIE**  
Antifungal resistance survivor, Founder MyCare

# The challenges of AMR communication


- A complex scientific issue and term!
- AMR causes 35,000 deaths/year (EU/EEA) but is rarely identified as a cause of death.
- To encourage behaviour changes, both **positive messaging** and **awareness of the burden** are key.
- **Balanced messaging** is needed, e.g. promoting prudent use of antibiotics while ensuring that patients finish their full course.
- Communication must be adapted to the **diversity of patients** affected by AMR.



*Understanding*  
Antimicrobial Resistance

EPF European Patients Forum

AMR is not a sudden big wave nor a tsunami, and this is another reason why it is difficult to communicate about the urgency to control AMR. It is more like the sea level rising slowly, from one year to the next, until one day the coastal road disappears.



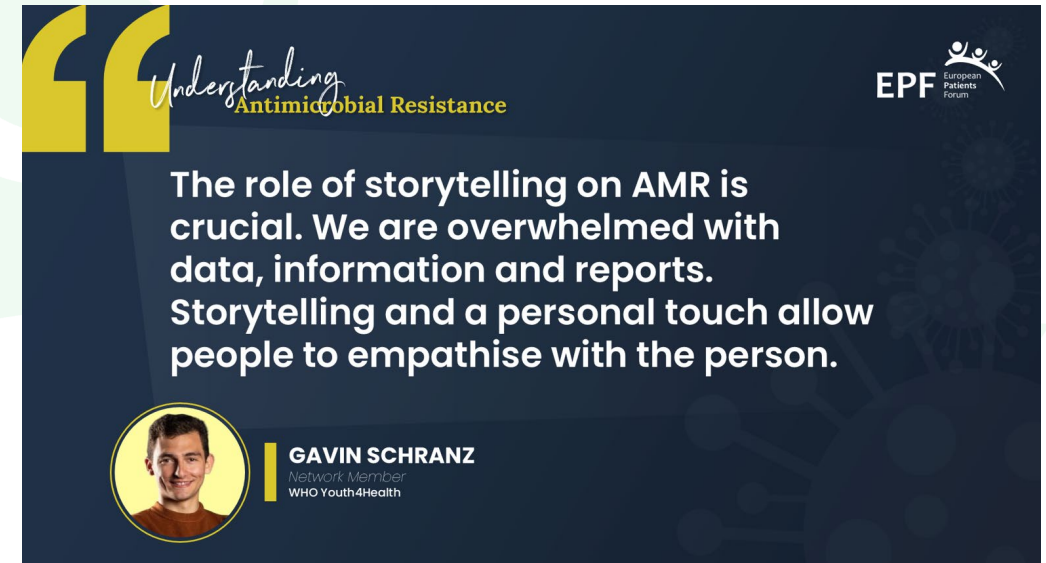
**DR. DOMINIQUE MONNET**  
Head of the Antimicrobial Resistance and Healthcare-Associated Infections Programme  
European Centre for Disease Prevention and Control (ECDC)

# Empowering patients on AMR

**Lack of awareness of AMR and how to counter it remains an issue!**

**Importance of:**


- **Raising awareness**, including through patient stories that highlight the reality of AMR
- Developing **capacity-building programmes** for POs
- **Promoting mentorship programmes** as an effective tool to promote knowledge sharing and empowerment



*Understanding*  
**Antimicrobial Resistance**

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The role of storytelling on AMR is crucial. We are overwhelmed with data, information and reports. Storytelling and a personal touch allow people to empathise with the person.



**GAVIN SCHRANZ**  
Network Member  
WHO Youth4Health

# Patient organisations' role on AMR

- **Raising awareness** of AMR, including by developing and adapting communications campaigns
- **Collaborating** with HCPs and others to implement best practices in HC settings
- **Improving patients' health literacy** to achieve antibiotic use reduction targets and improve prevention
- **Advocating** for enhanced policy action and equitable access to life-saving products

→ AMR requires a **multi-stakeholder and inclusive approach**



# EPF's initiatives on AMR

## EPF and The AMR Narrative webinar series on amplifying patient advocacy on AMR (June-Sept 2024)

### Objectives to:

- Highlight the impacts of AMR on various patient groups
- Emphasise the importance of patients' and community engagement
- Provide a platform for dialogue and connection

Recordings are available on [our website](#).



**WEBINAR SERIES**

### Amplifying patient advocacy on Antimicrobial Resistance (AMR)

Register

1 Patient Advocacy on AMR in the EU: Where do we begin?

Date & Time: 20 June 2024, 3 - 4pm CEST  
Platform: Zoom  
Language: English

EPF The AMR Narrative



**WEBINAR**

### How do we use our voices to reach a wider community for AMR?

29 August 2024, 3pm CEST

With:

Perrella Skonheim, Founder of Prematurforeningen Mirabel, Patient survivor story

Panel discussion featuring:

Ana Tamayo, Communications Specialist at ADAPC, EU JAMA 2  
Andrea Cavata, Global Health Advisor at REACT Europe  
Dr. Debba Lo Fo Wong, Regional Adviser, Control of AMR at WHO Europe  
James Miller, Rights and Gender Advisor at Stop TB Partnership  
Laura Alonso, Communications Specialist at ADAPC, EU JAMA 2

EPF The AMR Narrative



**WEBINAR**

### How can we take AMR advocacy to the next level, including policymaking?

12 September 2024, 3pm CEST

With:

Rob Purdie, Founder of MACARE, Antifungal resistance survivor  
John Karulis, WHO, Survivor of AMR, sepsis, bloodstream infection survivor

Panel discussion featuring:

Antonella Carlone, CEO of Cancer Patients Europe  
Diane Shuler Smith, Communications Professional and AMR Advocate  
Hana Bartakova, Interim Director, Health First Europe & AMR Patient Group  
Dr. Malin Grape, Secretary, AMR Ambassador, Ministry of Health and Social Affairs

EPF The AMR Narrative

# 2024 Skills Training Course for Young Patient Advocates (STYPA)

STYPA is offering a tailored high-quality training to young (18-30) patient advocates who want to learn more about advocacy and maximise their leadership potential.



Participants are guided by EPF and trainers to set up their own AMR advocacy campaign.



# European Antibiotic Awareness Day

- A 1-week communications campaign on AMR including dissemination of ECDC materials
- Collecting patient stories across our membership
- An AMR Communications toolkit for our members
- A podcast with an ECDC expert to share the latest data and information on AMR

 For the European Antibiotic Awareness Day, EPF is looking for **patient stories on the impacts of Antimicrobial Resistance (AMR)**.

Share your patient story with us!

Have you or someone you know faced a situation where **antibiotics** didn't work?

## EPISODE 8

European Antibiotic Awareness Day with ECDC

Special Guest:

**Vivian Leung, ECDC**  
Antimicrobial Consumption Expert



# THANK YOU FOR YOUR ATTENTION

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