

## Webinars #5 on Tuesday November 29<sup>th</sup> - 2022 from 17h-18h30 “ERN ITHACA guideline development: From patient to guideline and back again”

Workgroup Clinical guidelines and expert consensus statements,  
Chaired by Dr Agnies van Eeghen

\*\*\*

*Producing expert consensus statements is one of the main goals of ERNs.  
With this new webinar on Guidelines, we want to present you some examples of ERN ITHACA guidelines,  
recommendations on how to develop them and to reflect on how to move forward.*

### *Preliminary program*

#### **Welcome and Introduction**

- Dr Agnies van Eeghen (Amsterdam UMC, NL)  
Update on the ERN ITHACA guideline landscape

#### **Topic 1 Guideline development in rare diseases, challenges and recommendations**

- Mrs Charlotte Gaasterland, Phd (Amsterdam UMC, NL)  
Short overview of methodology
- Dr Mirthe Klein Haneveld (Amsterdam UMC, NL)  
Improving methodology and patient input – getting there better and faster

#### **Topic 2 Patients as guideline experts**

- Lenja Katharina Wiehe, Eurordis  
Vision on patient involvement in guideline development
- José Ramón Fernández-Fructuoso, Phelan-McDermid Syndrome Spanish Association  
The patient representative perspective

#### **Topic 3 Clinical guideline development in progress**

- Prof. Conny van Ravenswaaij (UMC Groningen, NL)  
Experiences in recent guidelines: Phelan-McDermid syndrome (PMS)

### *Discussion time*

#### **Conclusion with speakers and moderator**

\*\*\*

#### **Register and Connect**

We would appreciate if you could fill out the Form if you plan to participate.

<https://forms.office.com/r/tL7nw9Chyk>

#### **Connection details: Microsoft Teams Link**

[Cliquez ici pour participer à la réunion](#)

[https://teams.microsoft.com/l/meetup-join/19%3ameeting\\_ZWQyY2Q0OTgtMjllMC00MThlLTkyMTUtMmRmYzcyZmYzY2E5%40thread.v2/0?context=%7b%22Tid%22%3a%222461c129-d44f-406d-a778-d1a3c4c1527c%22%2c%22Oid%22%3a%223fe3bbab-4860-4b0b-bdc7-6ebc8a2f8f7b%22%7d](https://teams.microsoft.com/l/meetup-join/19%3ameeting_ZWQyY2Q0OTgtMjllMC00MThlLTkyMTUtMmRmYzcyZmYzY2E5%40thread.v2/0?context=%7b%22Tid%22%3a%222461c129-d44f-406d-a778-d1a3c4c1527c%22%2c%22Oid%22%3a%223fe3bbab-4860-4b0b-bdc7-6ebc8a2f8f7b%22%7d)