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ADVANCE YOUR KNOWLEDGE:
**Around the ERN-PaedCan Virtual
Tumor Board 2.0 in 80 Minutes**

24.02.2024

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SPEAKERS

MARTIN SCHALLING

ERN-PaedCan Project Manager St. Anna CCRI, Austria

HARUN ŠABIĆ

CCI Europe DT&C Pillar Member and ERN-PaedCan ePAG, Srce za Djecu Foundation, Bosnia & Herzegovina

BARBARA BRUNMAIR

CCI Europe DT&C Pillar and ERN-PaedCan coordinator, Austria

Structure, for internal use only – to be deleted

- **Welcome and introduction of speakers** →BB
- **Short background info about the CPMS** →Martin
 - What is it, significance for the paediatric cancer community
- **How to upload a case:** →Martin
 - CPMS pathway for HCP, split into several slides and accompanied by screenshots of the tool itself. It should be explained step by step what needs to be done, what the individual steps of a case upload look like – to take away people's inhibitions about trying out the tool in the first place.
- **Concrete examples** →BB + Martin
 - Here you can see which cases have reached the CPMS via CCI Europe (anonymous).
- **The patient pathway – including Non-EU** →Harun + Martin
 - CPMS pathway for HCP, split into several slides, clearly outline the potential role of patient organizations
- **Conclusions and the way forward**→Harun + Martin
 - As discussed: Pat Reps should realize that they need to be more engaged. Harun could emphasize why it is so important that pat advocates need to be involved.
 - Outlook for Non EU countries via the Example of Ukraine

Webinar content

- Short background: what is the CPMS?
- ↳ How to upload a case
- ↳ Specific examples of patient requests
- ↳ The patient pathway
- ↳ What if you are not in an EU-country?
- ↳ Conclusions and the way forward

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CPMS 2.0

- Online platform to discuss patients
 - Commissioned by the EC (DG SANTE)
 - Built by IBM
 - Made for all 24 ERNs and their members
 - Guest access possible
 - Browser-based
 - Secure (2FA)
-
- In February 2025, the CPMS 2.0 has replaced the older CPMS
 - Modernized platform, easier to use

What does CPMS provide

- Access to leading experts in their field
- Available for clinicians in whole EU+Norway
 - Accessible anytime, from anywhere
- Safe way to share sensitive medical information
 - Including documents and images

How to Upload a Case



CPMS Workflow for Clinicians

- **ERN PaedCan website as landing point for clinicians to find necessary information:**
 - **General CPMS Information**
 - **Useful Documents**
 - **List of Expert Groups**

If the clinician does not have prior access to CPMS, they can find the necessary information on the ERN PaedCan website or contact the CPMS Helpdesk

Clinician has a need for consultation

Find the CPMS Experts/Group to approach on PaedCan website

- Non-ERN clinicians primary contact point is CPMS Helpdesk to guide them to the information

Requesting clinician enrolls patient and uploads necessary files to CPMS

- CPMS Groups have specified their needs on ERN PaedCan website

Follow CPMS procedure as defined by each CPMS Group

- E.g. Recurring meeting schedule

Case is being discussed and Outcome/Recommendation produced

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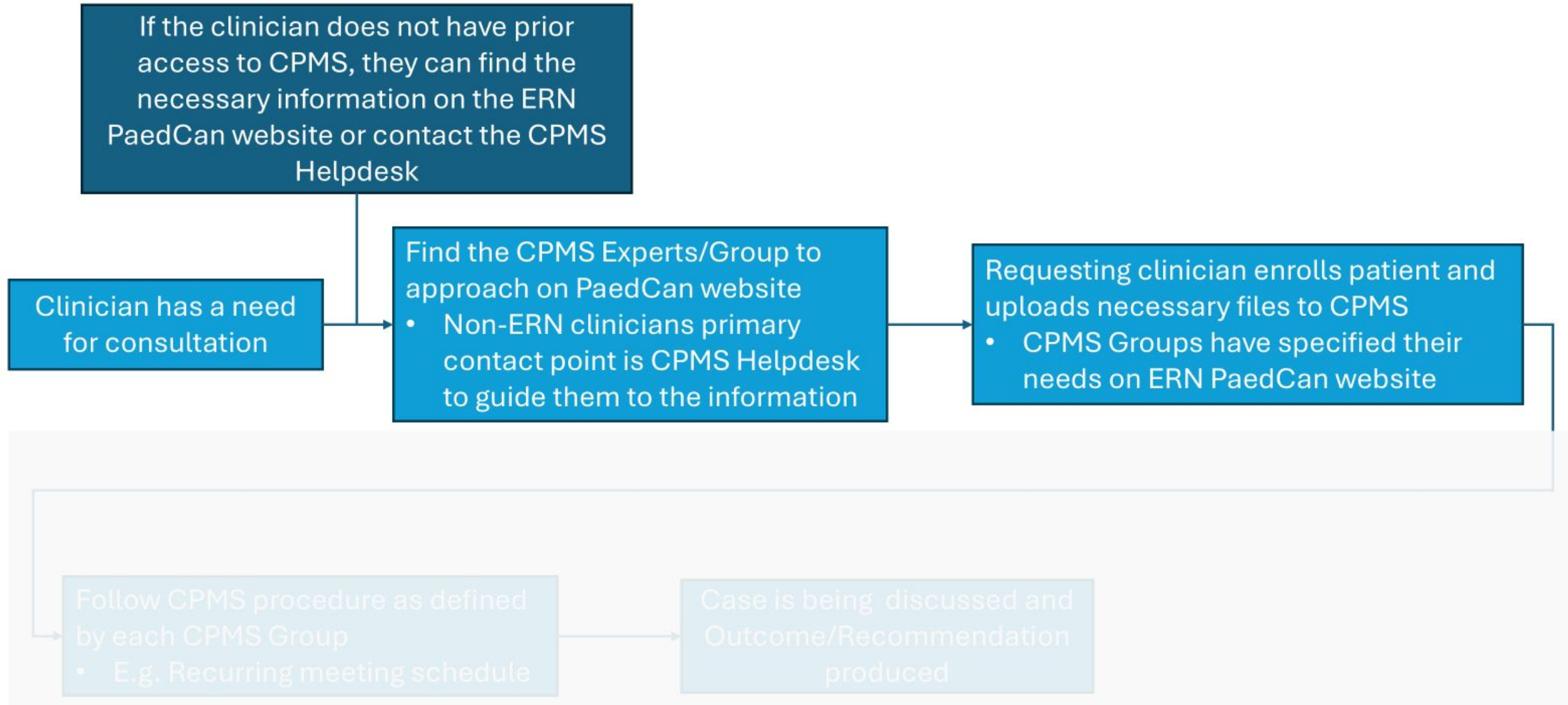
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Live Demo



Patient request examples from the last two years



Request by parent

- **Child, 13 months old, Down syndrome, AML and hearth problems**
 - The cancer treatment was poorly tolerated and had to be discontinued. How to proceed? At this stage, the father concerned contacted CCI Europe

Approach

- CCI Europe notified CPMS Manager
- Collection of all necessary (contact) data
- *Connecting attending physician and CPMS manager*
- *Upload of case on CPMS*
- Treatment advice from Virtual Tumor Board 2 weeks after first contact

← Support by patient advocates

Request by parent

- **Child, 9 years old, brain tumor (high-grade glioma)**
 - In search of a suitable clinical trial

Approach

- CCI Europe notified CPMS Manager
- *Connecting treating physician with CPMS manager*
- *Upload of case on CPMS*
- Advice from ERN-PaedCan Brain Tumor Group

← Support by
patient
advocates

Request by aunt

- **Child, 9 years old, secondary osteosarcoma on the basis of fibrous dysplasia in her head and neck region**
 - In search of head and neck cancer center with most surgical experience

Approach

- CCI Europe notified CPMS Manager
- *Connecting treating physician with CPMS manager*
- *Upload of case on CPMS*
- Advice from ERN-PaedCan Osteosarcoma Group

← Support by patient advocates

Request by parent

- **Child, 4,5 years old, neuroblastoma of the adrenal gland**
 - In search of head and neck cancer center with most surgical experience

Approach

- CCI Europe notified CPMS Manager
- *Connecting treating physician with CPMS manager*
- *Upload of case on CPMS*
- Advice from ERN-PaedCan Neuroblastoma Group

← Support by patient advocates

5

The Patient Pathway



Text

- **Text**
- **Text**
 - Text
- **Text**
 - Text
- **Text**

Non - EU countries

Example Ukraine



Text

- **Text**
- **Text**
 - Text
- **Text**
 - Text
- **Text**

7

Conclusions & the Way Forward



Conclusions & next steps

- **Text**
- **Text**
 - Text
- **Text**
 - Text
- **Text**

Why do patient advocates need to be involved?

- **What is your role as patient advocate, how can you support?**

- **Inform yourself:**

- Find out about the two most important ERN-PaedCan tools: ESCPs (see webinar from Dec. 24) and CPMS.

- **Promote ERN-PAEDCAN:**

- Not only to the national patient community, but also try to make national HCPs and policy makers aware of it (seek direct contact if possible).

- **Overcome barriers together:**

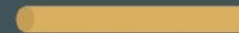
- A CPMS case upload is not as complicated as it seems. → In case of a well established collaboration between hospital and patient advocates, support the treating physician when he/she wants to upload a case in CPMS.



Q & A

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~~Abstracts Deadline: 31/1/2025~~

~~Stipends Deadline: 14/2/2025~~

Early Bird Deadline: **26/2/2025**

Regular Rate Deadline: **23/4/2025**

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