



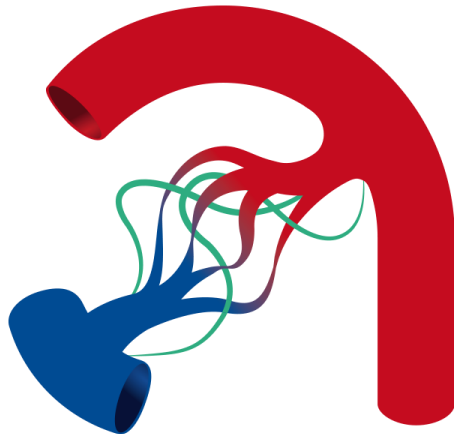
European Reference Network

for rare or low prevalence
complex diseases



Network

Vascular Diseases
(VASCERN)



11.45-12.05

Clinical Patient Management System (CPMS)

- Latest progress, improvements & developments for the simplified CPMS workflow and user-friendly mobile CPMS (Bart Verlinden, European Commission)
- Referral of guest cases: process & examples: Serbia and Portugal (Ibrahim Donmez)

<https://vascern.eu/what-we-do/cpms-discussion-of-complex-clinical-cases/>



#VASCERNdays2020



VASCERN Online Board Meeting
22nd June 2020



European
Reference
Networks

Share.Care.Cure.

The Clinical Patient Management System

Bart Verlinden

ERN Project Manager Information Systems Unit- External Consultant
Directorate General Health and Food Safety
(DG SANTE)

CPMS Latest Development

- Notifications updated – September 2020
 - Easily access Notification Preferences
 - Better visibility of Notification types
 - Ability to choose which Notifications are received
 - Set frequency of Notifications
- Learn : link to latest Webinar 6th October
 - [Notification Improvements & Updated DICOM Viewer - Oct 2020](#)

⚙ User Settings



Notifications

Mandatory Events

- Request to participate in a panel
- New meeting time proposal
- Invitation to a meeting
- Request for additional information on a Panel
- All contributions on a Panel recorded **Appears for a Panel Lead ONLY**
- Request to transfer a patient records **Appears for a Transfer Coordinator ONLY**

Optional Events

- A Panel contribution has been recorded
- A Panel outcome is ready to be reviewed
- A direct comment has been left on a Panel
- Any comment has been left on a panel

Notifications

When I have a task in my task-list, remind me

- Daily

Help & Support

If you have any queries, ideas, suggestions, or need help with an issue please contact ERN-CPMS via email at Sante-ERN-CPMS-itsupport@ec.europa.eu.



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[CPMS Release Notes](#)

⚙️ User Settings



Notifications

Task Notifications

When I have a task in my task-list, remind me:

- Daily
- Once Weekly
- Once Monthly First day of each month

Immediate notification emails will be sent to you for all mandatory and any optional events you choose as soon as they occur.

Reminder mails will be sent to you at your chosen frequency.

You will not be mailed if you have no outstanding tasks in your task list.

Meeting Reminders

Meetings: Remind me before a meeting

- 24 hours
- 4 hours
- 1 hour

Cancel

Save

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CPMS Planning

- **Current CPMS System:**
 - Simplified Workflow (development)
 - Phase 1: Flexible Workflow – Q1 2021
 - Phase 2 : Timeline improvements – Q2 2021
 - Expert Groups (analysis) – Timeline TBD
- **CPMS Lite Mobile App (analysis) – 2022?**
 - ITAG 27/10
 - November 2020: Launch Task Force with input from expert users

New Panel Workflow

- Quicker Panel creation
- Easier navigation between different Panel elements
- Data Gathering ↔ Panel Selection ↔ Meeting Scheduling
- Easier creation of Panel outcome
- Cleaner presentation of Panel Timeline

Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

#1645 Patient One

PANEL IN PROGRESS

Centre DE03 - Klinikum der Universität München_eUROGEN

Panel Manager Brian Murphy

ERN eUROGEN - Urogenital Diseases

Panel Lead Dr. A Comer

Thematic Area WS3 Rare urogenital tumors

Consultation Form

Attachments

Panel Members

Meetings

Contributions & Outcome

CONSULTATION FORM Recorded: 22/Jul/2019 16:16 (Europe/Berlin) by: Doctor One Edited: 22/Jul/2019 17:16 (Europe/Berlin) by: Doctor One

- Consultation Request
- Patient Information
- Episode Description
- Rare Disease Diagnosis
- Comorbidities
- Phenotype/Genetic Features and Biobanks
- Family History
- Health Behaviours
- Allergies and Other Adverse Reactions
- History of Past Illness and Disorders
- Special Treatment Intervention
- Surgical Procedures
- Transplantation History
- Medication

CONSULTATION REQUEST

Do not use any nicknames liable to identify the patient, including his/her first name or last name.

* Nickname:

Eric

Is urgency required for this panel?

* Is this a repeat of a previous panel for the same patient but a different episode?

 Yes No Don't know

* Consultation request description:

AFWFHWA

* Consultation request reason:

Treatment

* Healthcare provider:

AT01 - EB-Haus

* Point of care specialist:

poc

* ERN:

 ERN-SKIN

* Panel lead:

Doctor One

Panel Manager:

Save

Help & Support

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[Browser Information](#)

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

#1645 Patient One

PANEL IN PROGRESS

Centre DE03 - Klinikum der Universität München_eUROGEN
 ERN eUROGEN - Urogenital Diseases
 Thematic Area WS3 Rare urogenital tumors

Panel Manager Brian Murphy
 Panel Lead Dr. A Comer

Consultation Form Attachments Panel Members Meetings Contributions & Outcome

Request Additional Data

PDF

Edit

Consultation Form Recorded: 03/Feb/2020 10:45 (Europe/Berlin) by: Doctor One

CONSULTATION REQUEST

Nickname: Super Man

Is urgency required for this panel? Yes

Is this a repeat of a previous panel for the same patient but a different episode? Yes

Consultation request description short: Cras neque diam, cursus eu sem ac, molestie consequat massa. Ut volutpat sit amet elit tempus fermentum

Consultation request reason: Diagnosis

Consultation request reason description: Cras neque diam, cursus eu sem ac, molestie consequat massa. Ut volutpat sit amet elit tempus fermentum. Ut eget interdum purus. Pellentesque vestibulum enim nunc, ut feugiat augue pretium quis. Vivamus nisl arcu, facilisis vel pulvinar vitae, fermentum a sapien. Sed molestie interdum neque non consectetur. Etiam a mauris massa.

Healthcare provider: AT01 - EB-Haus

Point of care specialist: Dr. Zero

ERN: ERN-SKIN

Panel lead: Doctor One

Panel Manager: Centre Panel Manager

Primary thematic area: ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO,

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020



Pansels



Enrollment



Record Attachments



Transfer

#1645 Patient One

PANEL IN PROGRESS

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Panel Manager Brian Murphy

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Thematic Area WS3 Rare urogenital tumors

Consultation Form

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Panel Members

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Contributions & Outcome

Medical Documents

Use this feature to share Files and DICOM images with this Panel. The server can remove identifying data from DICOM images and CDA standard documents. You must remove all identifying data from all other file types before uploading.

The sharing rules for these Files and DICOM images are the same as for this form. When you share this form with a Panel all attached files and DICOM images are also visible to the Panel.

Attach file / image

Attach Using FTP

Viewer	Document	Upload	Date	Size	
DICOM	Tissue sample	Doctor One	04/June/2020	391.3 MB	
pdf	patiend Details	Doctor One	04/June/2020	79.5 KB	

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#1645 Patient One

PANEL IN PROGRESS

Centre DE03 - Klinikum der Universität München_eUROGEN
 ERN eUROGEN - Urogenital Diseases
 Thematic Area WS3 Rare urogenital tumors

Panel Manager Brian Murphy
 Panel Lead Dr. A Comer

Consultation Form Attachments Panel Members Meetings Contributions & Outcome

Available Invited Invite Guest Members Accept / Refuse Co-ordinator Assistance

Thematic Area: --- Entire ERN ---

Available Healthcare Professionals	HCPs	Specialisation	Invite All
WELL, Diana	DE16 - Universitätsklinikum Magd...	Doctor	Invite
BOURNE, Jason	DE03 - Klinikum der Universität Mun...	Professor	Invite

Help & Support

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#1645 patient One

PANEL IN PROGRESS

Centre DE03 - Klinikum der Universität München_eUROGEN
 ERN eUROGEN - Urogenital Diseases
 Thematic Area WS3 Rare urogenital tumors

Panel Manager Brian Murphy
 Panel Lead Dr. A Comer

Consultation Form Attachments Panel Members Meetings Contributions & Outcome

Available Invited Invite Guest Members Accept / Refuse Co-Ordinator Assistance

Invited panel Members

Name	Specialisation	Status	When
Comer, A	Doctor	Lead	Invited: 07/Jun/2020
BOURNE, Jason	Professor	Invited	Invited: 07/Jun/2020
TWAIN, Mark	Professor	Accepted	Invited: 07/Jun/2020

Accept All

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020



Panels



Enrollment



Record Attachments



Transfer

#1645 Patient One

PANEL IN PROGRESS

Centre	DE03 - Klinikum der Universität München_eUROGEN	Panel Manager	Brian Murphy
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Thematic Area	WS3 Rare urogenital tumors	Panel Members	BOURNE, Jason

[Consultation Form](#)[Attachments](#)[Panel Members](#)[Meetings](#)[Contributions & Outcome](#)

Upcoming Meetings

[Schedule a new meeting](#)**Description:** Preliminary discussions about patient**Scheduled:** 11/June/2020 14:45 (Europe/Berlin) for 30 minutes**Invited:** Participant 1 (Host)
Participant 2
Participant 3[View meeting details](#)

test video

[Join Meeting](#)**Description:** Follow up discussions**Scheduled:** 20/jun/2020 12:00 (Europe/Berlin) for 30 minutes**Invited:** Participant 1 (Host)
Participant 2
Participant 3[View meeting details](#)

test video

[Starts in: X days](#)

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

Panels

Enrollment

Record Attachments

Transfer

#1645 Patient One

PANEL IN PROGRESS

Centre	DE03 - Klinikum der Universität München_eUROGEN	Panel Manager	Brian Murphy
ERN	eUROGEN - Urogenital Diseases	Panel Lead	Dr. A Comer
Thematic Area	WS3 Rare urogenital tumors	Panel Members	BOURNE, Jason

[Consultation Form](#)
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Schedule a Meeting

Type of meeting: Part of ERN Recurring Meetings
 Individual Meeting
 Proposed Meeting

Meeting Title:

Description Prism lo-fi thundercats, ennui literally activated charcoal hoodie subway tile helvetica. Gentrify tattooed small batch, vexillologist succulents cliché you probably haven't heard of them roof party microdosing yr. Man bun celiac affogato messenger bag.

ERN Meetings:

Monday	Tuesday	Wednesday	Thursday	Friday
10:00 CET	10:00 CET	10:00 CET	10:00 CET	10:00 CET
11:00 CET	11:00 CET	11:00 CET	11:00 CET	11:00 CET
12:00 CET	12:00 CET	12:00 CET	12:00 CET	12:00 CET
13:00 CET	13:00 CET	13:00 CET	13:00 CET	13:00 CET

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020



Panels



Enrollment



Record Attachments



Transfer

#1645 Patient One

PANEL IN PROGRESS

Centre	DE03 - Klinikum der Universität München_eUROGEN	Panel Manager	Brian Murphy
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Thematic Area	WS3 Rare urogenital tumors	Panel Members	BOURNE, Jason

[Consultation Form](#)[Attachments](#)[Panel Members](#)[Meetings](#)[Contributions & Outcome](#)

Meeting: Patient Discussion

[Date & Time](#)[Participants](#)[Summary](#)

test video

[Join Meeting](#)**Title:** Patient Discussion [Edit](#)**Description:** Preliminary discussions about patient**Meeting Status:** Upcoming**Type of Meeting:** Individual Meeting**Duration:** 30 Minutes**When:** 10/jun/2020 12:00 (Europe/Berlin)

10/jun/2020 10:00 (UTC)

Meeting Panel: Participant 1 (Host)

Participant 2

Participant 3

Meeting Comments

panel member 1 06/jun/2020 17:52
Kogi stumpdown blue bottle blog forage deep

Complete:
panel member 2 06/jun/2020 18:21
Quinoa shabby chic vice roof party food truck narwhal glutenfree cronut PBR&B.

panel member 1 06/jun/2020 18:21
Quinoa shabby chic vice roof party food truck narwhal glutenfree cronut PBR&B.

Task marked as Complete

[Cancel](#)[Save as...](#) ▾[Close](#)

Help & Support

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020



Pans



Enrollment



Record Attachments



Transfer

#1645 Patient One

PANEL IN PROGRESS

Centre DE03 - Klinikum der Universität München_eUROGEN
 ERN eUROGEN - Urogenital Diseases
 Thematic Area WS3 Rare urogenital tumors

Panel Manager Brian Murphy
 Panel Lead Dr. A Comer
 Panel Members BOURNE, Jason

Consultation Form

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Meetings

Contributions & Outcome

Meeting: Patient Discussion

Date & Time

Participants

Summary

test video

Join Meeting

Meeting participants

Name	Invited	Status
Comer, A	07/Jun/2020 11:30 (Europe/Berlin)	Host

Invite the members of the Panel

Name	Invite
BOURNE, Jason	<input type="button" value="Invite"/>
TWAIN, Mark	<input type="button" value="Invite"/>

Invite the members of your ERN

Thematic Area: --- Entire ERN --- ▾

Available Healthcare Professionals

HCPs

Specialisation

Compose message...

Meeting Comments

panel member 1 06/Jun/2020 17:52
 Kogi stumptown blue bottle blog forage deep

Complete:
panel member 2 06/Jun/2020 18:21
 Quinoa shabby chic vice roof party food truck narwhal glutenfree cronut PBR&B.

panel member 1 06/Jun/2020 18:21
 Quinoa shabby chic vice roof party food truck narwhal glutenfree cronut PBR&B.

Task marked as Complete

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

#1645 Patient One

PANEL IN PROGRESS

Centre	DE03 - Klinikum der Universität München_eUROGEN	Panel Manager	Brian Murphy
ERN	eUROGEN - Urogenital Diseases	Panel Lead	Dr. A Comer
Thematic Area	WS3 Rare urogenital tumors	Panel Members	BOURNE, Jason

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[Contributions & Outcome](#)

Meeting: Patient Discussion

[Date & Time](#)
[Participants](#)
[Summary](#)
[test video](#)
[Join Meeting](#)

Meeting Summary

[Edit](#)

No meeting summary has been recorded yet

Meeting Comments

panel member 1 06/Jun/2020 17:52
Kogi stumptown blue bottle blog forage deep

Complete:
panel member 2 06/Jun/2020 18:21
Quinoa shabby chic vice roof party food truck narwhal glutenfree cronut PBR&B.

panel member 1 06/Jun/2020 18:21
Quinoa shabby chic vice roof party food truck narwhal glutenfree cronut PBR&B.
Task marked as Complete

Compose message...

Cancel

Save as... ▾

Comment

Task

Close

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

#1645 Patient One

PANEL IN PROGRESS

Centre	DE03 - Klinikum der Universität München_eUROGEN	Panel Manager	Brian Murphy
ERN	eUROGEN - Urogenital Diseases	Panel Lead	Dr. A Comer
Thematic Area	WS3 Rare urogenital tumors	Panel Members	BOURNE, Jason

[Consultation Form](#)
[Attachments](#)
[Panel Members](#)
[Meetings](#)
[Contributions & Outcome](#)

My Contribution

Attach a file: ...

How much time did you spend on this assesment?

Panel Member Contributions

TWAIN, Mark

Hella gluten-free schlitz cronut. +1 pitchfork master cleanse man braid viral, farm-to-table subway tile trust fund pug disrupt. Hashtag vegan tattooed freegan wayfarers swag hot chicken literally edison bulb lo-fi offal

Help & Support

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020



Pans



Enrollment



Record Attachments



Transfer

#1645 Patient One

PANEL IN PROGRESS

Centre	DE03 - Klinikum der Universität München_eUROGEN	Panel Manager	Brian Murphy
ERN	eUROGEN - Urogenital Diseases	Panel Lead	Dr. A Comer
Thematic Area	WS3 Rare urogenital tumors	Panel Members	BOURNE, Jason

[Consultation Form](#)[Attachments](#)[Panel Members](#)[Meetings](#)[Contributions & Outcome](#)

Panel Outcome

Are you the point of care specialist, the panel lead or a panel participant?

Did you find this virtual panel useful?

(Please rate the usefulness of the panel on a scale from 1 to 10 where 1 is "not useful" and 10 is "extremely useful".)

How satisfied are you with the outcome of this panel?

(Please rate your satisfaction on a scale from 1 to 10 where 1 is "completely unsatisfied" and 10 is "completely satisfied".)

[Save Panel Outcome \(Draft\)](#)

My Contribution

Hella gluten-free schlitz cronut. +1 pitchfork master cleanse man braid viral, farm-to-table subway tile trust fund pug disrupt. Hashtag vegan tattooed freegan wayfarers swag hot chicken literally edison bulb lo-fi offal

Panel Member Contributions

TWIN, Mark

Help & Support

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Panels



Enrollment



Record Attachments



Transfer

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Thematic Area	WS3 Rare urogenital tumors	Panel Members	BOURNE, Jason

[Consultation Form](#)[Attachments](#)[Panel Members](#)[Meetings](#)[Contributions & Outcome](#)

Panel Outcome

Viral butcher gluten-free raw denim air plant waistcoat. Pug locavore tote bag sartorial. Slow-carb food truck four loko sriracha, 8-bit prism neutra fingerstache pork belly skateboard ethical typewriter polaroid. Helvetica intelligentsia jean shorts hammock tumblr pinterest portland lyft locavore yuccie offal jianbing viral brooklyn poutine. Flexitarian art party kombucha, semiotics fixie vice green juice.

[Signoff Panel Outcome](#)

My Contribution

Hella gluten-free schlitz cronut. +1 pitchfork master cleanse man braid viral, farm-to-table subway tile trust fund pug disrupt. Hashtag vegan tattooed freegan wayfarers swag hot chicken literally edison bulb lo-fi offal

Panel Member Contributions

TWIN, Mark

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Pannels



Enrollment



Record Attachments



Transfer

#1645 Patient One

PANEL IN PROGRESS

Centre DE03 - Klinikum der Universität München_eUROGEN

Panel Manager Brian Murphy

Themat **Signoff and Close Panel**

You are signing off and closing this panel.

This is an irrevocable action! When you close this panel it is still visible within the ERN but a closed panel cannot be restarted.

Panel C

Viral b
locav
srirac
ethica
hamm
jianbir
semio

Questionnaire

How much time did you spend on this Panel?

hh:mm

HH:MM

Was the Panel a success?

- Yes
 No
 Not Determined

What was the Outcome?

- Diagnosis Un-diagnosed
 Treatment other
 Clinical Trial

Patient Status

- Alive
 Dead
 Lost to follow up
 Opted out

Cancel

Close Panel

My Con

Hella g
man b
disrup
chicker

Panel Member Contributions

TWIN, Mark

Help & Support

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020



Panels



Enrollment



Record Attachments



Transfer

#1645 Patient One

PANEL CLOSED

Centre DE03 - Klinikum der Universität München_eUROGEN

Panel Manager Brian Murphy

ERN eUROGEN - Urogenital Diseases

Panel Lead Dr. A Comer

Thematic Area WS3 Rare urogenital tumors

Archive

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Outcome Document

PDF

Consultation Form Recorded: 11/June/2020 18:45 (Europe/Berlin) by: Doctor Comer

CONSULTATION REQUEST

- Nickname: Super Man
- Is urgency required for this panel? Yes
- Is this a repeat of a previous panel for the same patient but a different episode? Yes
- Consultation request description short: Cras neque diam, cursus eu sem ac, molestie consequat massa. Ut volutpat sit amet elit tempus fermentum
- Consultation request reason: Diagnosis
- Consultation request reason description: Cras neque diam, cursus eu sem ac, molestie consequat massa. Ut volutpat sit amet elit tempus fermentum. Ut eget interdum purus. Pellentesque vestibulum enim nunc, ut feugiat augue pretium quis. Vivamus nisl arcu, facilisis vel pulvinar vitae, fermentum a sapien. Sed molestie interdum neque non consectetur. Etiam a mauris massa.
- Healthcare provider: AT01 - EB-Haus
- Point of care specialist: Dr. Zero
- ERN: ERN-SKIN
- Panel lead: Doctor One
- Panel Manager: Centre Panel Manager
- Primary thematic area: ALLOCATE hidradenitis suppurativa PAPA, PAPASH, PASH, PASS, SAPHO,

Help & Support

If you have any queries, ideas, suggestions, or need help with an issue please contact ERN-CPMS via email at Sante-ERN-CPMS-itsupport@ec.europa.eu.



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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

#1645 Patient One

PANEL IN PROGRESS

Centre DE03 - Klinikum der Universität München_eUROGEN

Panel Manager Brian Murphy

ERN eUROGEN - Urogenital Diseases

Panel Lead Dr. A Comer

Thematic Area WS3 Rare urogenital tumors

Consultation Form

Attachments

Panel Members

Meetings

Contributions & Outcome

Request Additional Data

PDF

Edit

Consultation Form Recorded: 03/Feb/2020 10:45 (Europe/Berlin) by: Doctor One

CONSULTATION REQUEST

- * Nickname: Super Man
- Is urgency required for this panel? Yes
- * Is this a repeat of a previous panel for the same patient but a different episode? Yes
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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

-  Panels
-  Enrollment
-  Record Attachments
-  Transfer

#1645 Patient One

Centre DE03 - Klinikum der Universität München_eUROGEN
ERN eUROGEN - Urogenital Diseases
Thematic Area WS3 Rare urogenital tumors

- Consultation Form
- Attachments
- Panel Members
- Meetings
- Contributions

[Request Additional Data](#)

Consultation Form Recorded: 03/Feb/2020 10:45 (Europe/Berlin) by: Doctor One

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- * ERN: ERN-SKIN
- * Panel lead: Doctor One
- Panel Manager: Centre Panel Manager
- * Primary thematic area: ALLOCATE hidradenitis suppurativa PAPA, PA

Timeline

- Meetings
- Members
- Documents
- Contributions

Contributions

Member	Status
gusty gusty	No contribution
Diana Well	No contribution
alan.comer	Contributed: 08/jun/2020

Meeting: sdf

Description: sdf
 Invited: alan.comer (Host)
 Scheduled: 27/jun/2020 13:00 (Europe/Berlin) for 30 minutes

Test video **Starts in: 16 day(s)**

- alan.comer very importnat 08/jun/2020 17:52
- Complete: alan.comer** comment as a task 08/jun/2020 17:53
- alan.comer "comment as a task" 09/jun/2020 09:16
- Task marked as Complete

Panel Members

Member	Status	Actions
alan.comer	Lead	Invited: 07/jun/2020
gusty gusty	Accepted	Invited: 07/jun/2020 Accepted: 08/jun/2020
Diana Well	Accepted	Invited: 08/jun/2020 Accepted: 08/jun/2020

- alan.comer gusty gusty was invited to join the panel 07/jun/2020 16:22
- alan.comer alan.comer accepted on behalf of gusty gusty 08/jun/2020 13:35

Help & Support

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Patient ID: ERN-DE03-eUROGEN-001 Sanchez, Rick DOB: 05/02/1981 (M) Enrolled: 07/Jun/2020

#1645 Patient One

Centre DE03 - Klinikum der Universität München_eUROGEN

ERN eUROGEN - Urogenital Diseases

Thematic Area WS3 Rare urogenital tumors

Consultation Form

Attachments

Panel Members

Meetings

Contributions

Request Additional Data

Consultation Form Recorded: 03/Feb/2020 10:45 (Europe/Berlin) by: Doctor One

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- Point of care specialist: Dr. Zero
- * ERN: ERN-SKIN
- * Panel lead: Doctor One
- Panel Manager: Centre Panel Manager
- * Primary thematic area: ALLOCATE hidradenitis suppurativa PAPA, PAP

Timeline

Meetings Members Documents Contributions

Meeting: sdf

Description: sdf
Invited: alan.comer (Host)
Scheduled: 27/Jun/2020 13:00 (Europe/Berlin) for 30 minutes

Test video **Starts in: 16 day(s)**

alan.comer
very importnat

08/Jun/2020 17:52

Complete: alan.comer
comment as a task

08/Jun/2020 17:53

alan.comer
"comment as a task"

09/Jun/2020 09:16

Task marked as Complete

Meeting: Patient Discussion

Description: Stuff to talk about
Invited: alan.comer (Host), guesty guesty (Invited)
Scheduled: 08/Jun/2020 13:00 (Europe/Berlin) for 5 minutes

Test video **Join Meeting**

Help & Support

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[CPMS Release](#)



CPMS Useful Links

Learn! CPMS Training (see videos after log in):
<https://cpms-training.ern-net.eu>

Use! CPMS Production:
<https://cpms.ern-net.eu/login/>

Inform! CPMS Overview Video:
<https://webgate.ec.europa.eu/ern/imgs/cpms%20overview.mp4>

Ask! CPMS Support:
SANTE-ERN-CPMS-ITSupport@ec.europa.eu



QUESTIONS ?



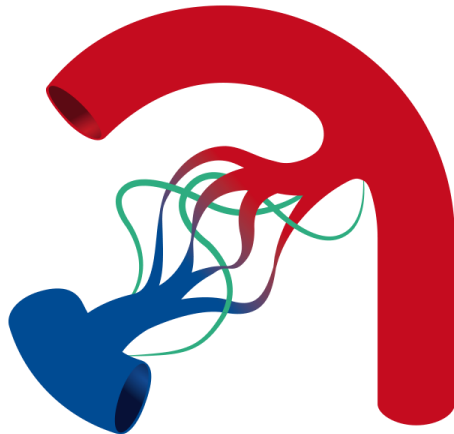
European Reference Network

for rare or low prevalence
complex diseases



Network

Vascular Diseases
(VASCERN)



Clinical Patient Management System (CPMS)

- Referral of guest cases: process & examples:
Serbia and Portugal (*Ibrahim Donmez*)

<https://vascern.eu/what-we-do/cpms-discussion-of-complex-clinical-cases/>

 #VASCERNdays2020



Referral of Patients to VASCERN CPMS: ERN Mission on External Cases



ERN COLLABORATIVE PLATFORM [MEMBERS AREA] CLINICAL PATIENT MANAGE



European
Reference
Network

VASCERN

Gathering the best expertise in Europe to provide accessible cross-border health care to patients with rare vascular diseases

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ePAG (Patient Advocacy)

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Clinical Patient Management System (CPMS)



CPMS - <https://cpms.ern-net.eu/login/>

CPMS Training - <https://cpms-training.ern-net.eu/login/>



Clinical Patient Management System (CPMS)

For Healthcare Professionals, Members of VASCERN

If you would like to join the CPMS and you belong to one of VASCERN's Healthcare Providers (HCPs) then please contact the lead HCP representative at your HCP for authorization, and then contact the VASCERN [helpdesk](#). Once authorized, you will have to register to be able to login

For Healthcare Professionals, NOT Members of VASCERN

If you are a medical doctor who is not a VASCERN member, and wish to discuss a complex case with VASCERN experts using the **Clinical Patient Management System (CPMS)**, please follow the steps below:

1. You will to send a mail to VASCERN Helpdesk at cpms.vascern@aphp.fr

- In your email, **please answer the following questions:**

- What is the rare disease (if diagnosed) for which you would like to consult VASCERN's experts?

VASCERN External Cases Process



1. You will to send a mail to VASCERN Helpdesk at cpms.vascern@aphp.fr

In your email, please answer the following questions:

- What is the rare disease (if diagnosed) for which you would like to consult VASCERN's experts?
- If undiagnosed, could you please describe the problem?
- What is the issue with this specific case and what are the problems identified?
- What is your specialty?
- Is the patient already followed in your center?
- Country
- Is it an urgent case?

2. Once we receive your request, we will assess whether we are the right ERN for the case. If so, you will receive a **secure link** to provide any supporting documents such as case overview, files and images relevant to the case.

3. If you want to participate in the panel discussions, you will receive technical instructions to how to gain CPMS access. Please note that, this is only a temporary access that is valid for 90 days.

4. During the process the VASCERN Helpdesk will be in touch with any assistance and requirements.

*****Please note that if a national center from your country is already member of VASCERN, they are the first line of referral and should be contacted first.**

VASCA-WG External Cases from Serbia and Portugal on CPMS



- 2 Discussions via CPMS
- Duration for the Serbian case 1 year: first external case for VASCERN, no process in place.
 - The healthcare professionals sent in their individual requests, via our CPMS contact e-mail (August 2019 for Serbian and May 2020 for Portugal).
- For Portugal: about 1 month to send the outcome report: process in place
 - Prof Leo Schultze Kool, panel lead for both cases and each patient's case was discussed with other VASCA WG members: Prof Miikka Vikkula & Prof Laurence Boon from Belgium and Prof Päivi Salminen from Finland
- An outcome report was produced and sent to each treating physicians in July 2020



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