




AZIENDA
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PISANA



European
Reference
Network

for rare or low prevalence
complex diseases

 **Network**
Connective Tissue
and Musculoskeletal
Diseases (ERN ReCONNET)

ERN SHOWCASES

ERN ReCONNET

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Conflict of interest


- *“I have no actual or potential conflict of interest in relation to this program/presentation”.*

ReCONNET



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8 Nations

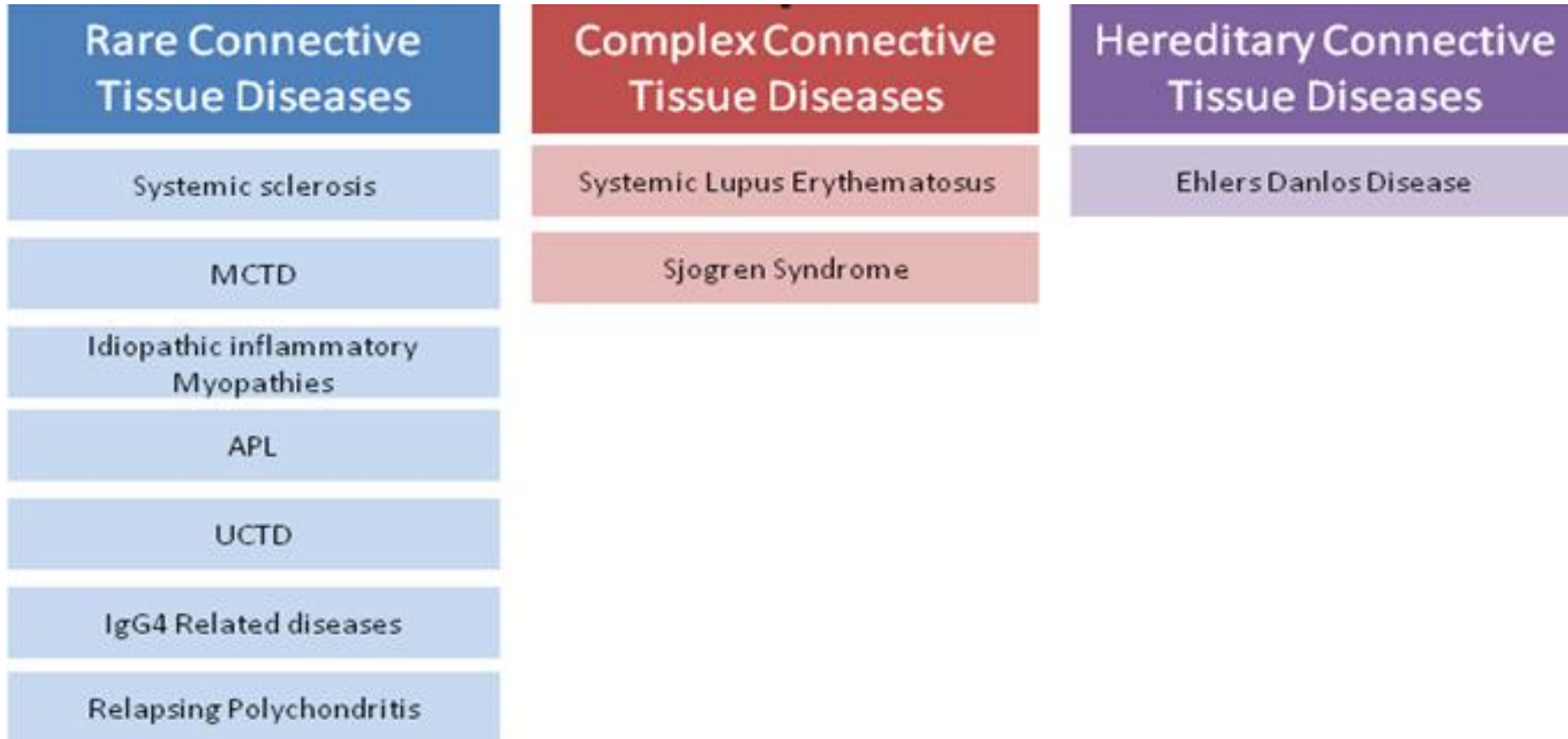


26 HCPs



10 rCTDs

Thematic areas of ReCONNET



The story of M...

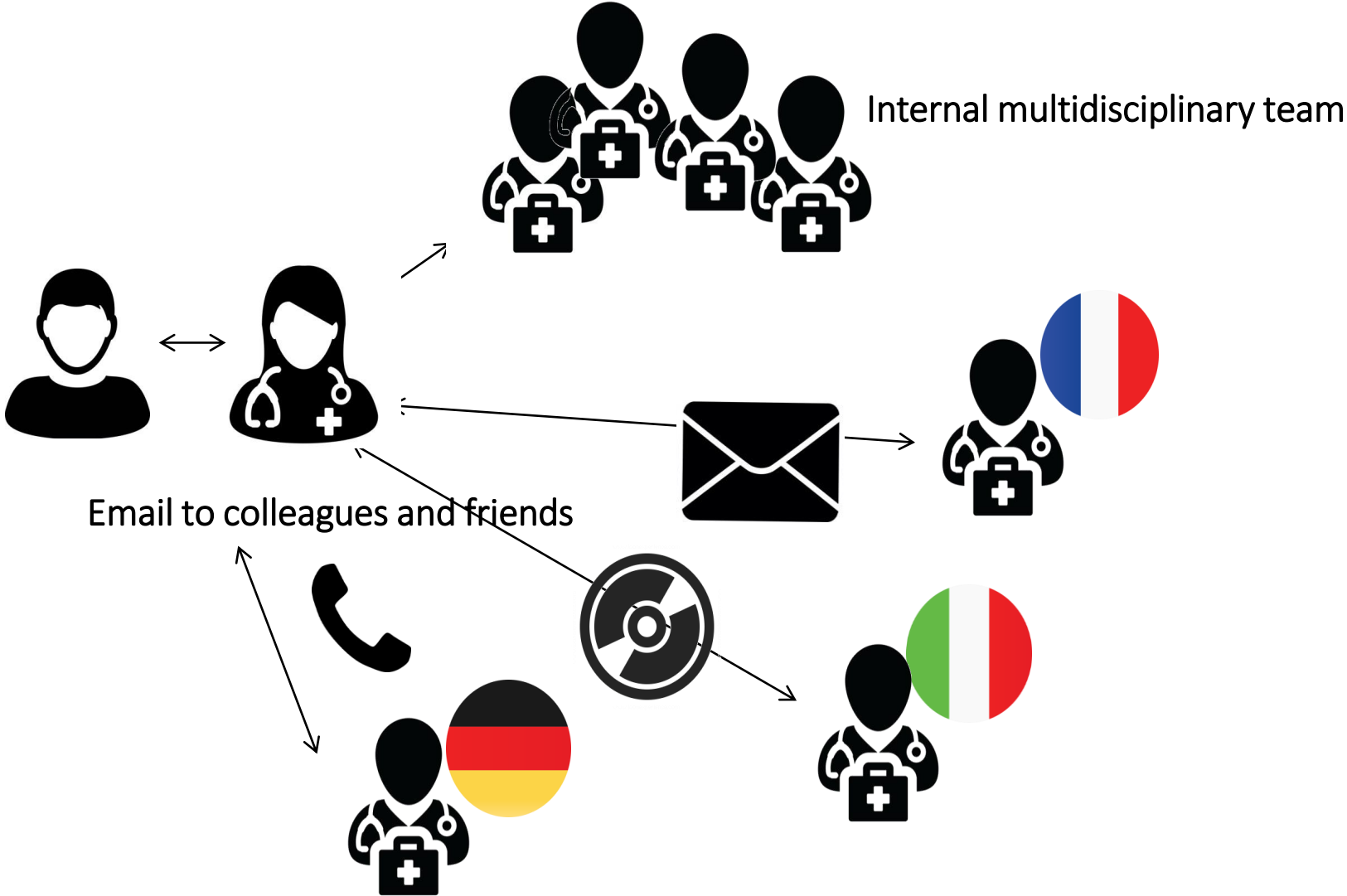
Many questions and doubts arise

- Is the reaction associated with SLE?
What is the role of her autoimmune disease?
- How to treat her?
Should we treat her skin manifestations?
- Should we worry about future and more severe adverse events?

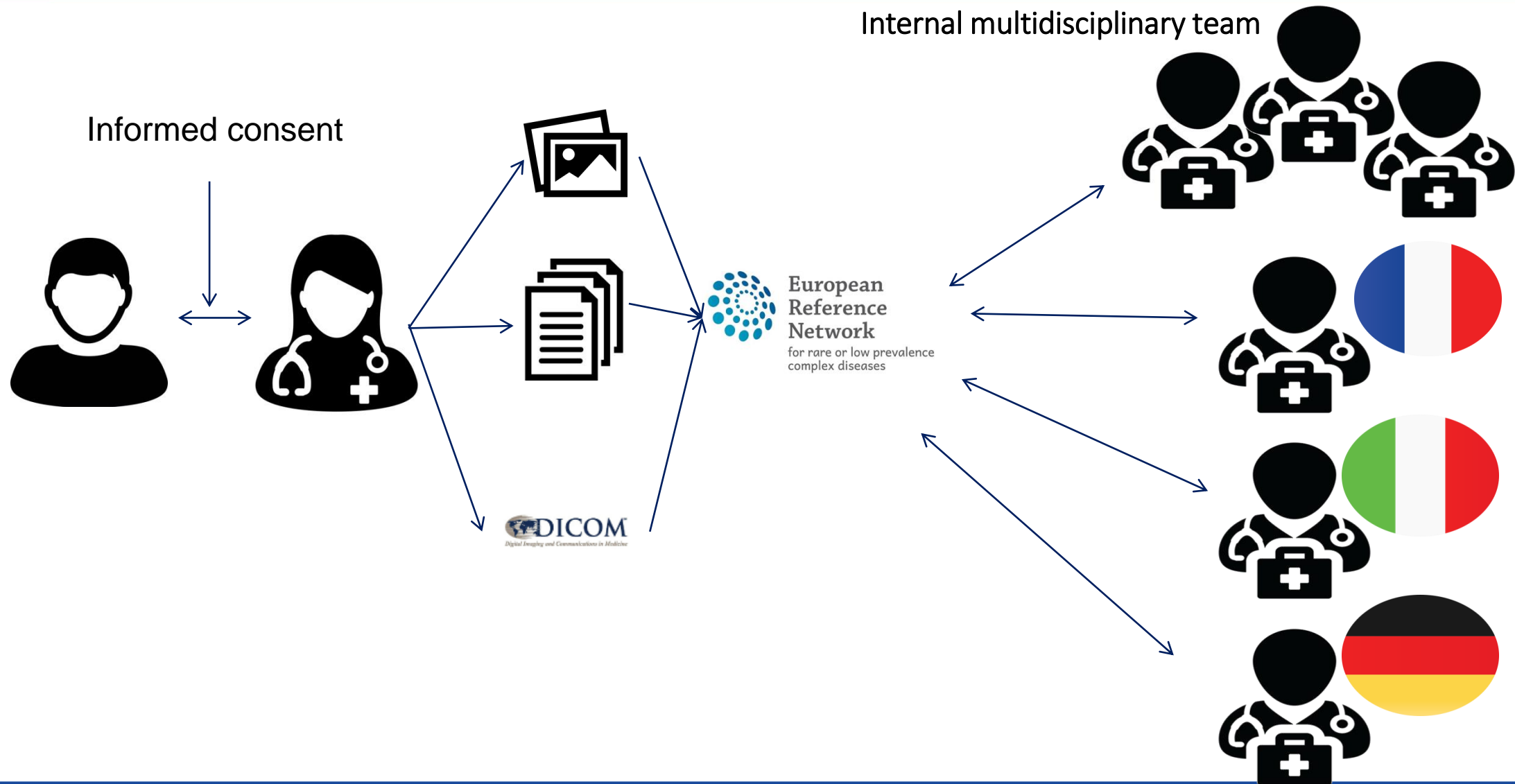
The current situation

- Multidisciplinary discussion at our hospital involving: the rheumatologist, the oncologist, the allergologist
- No previous similar experience

Before the CPMS



After the CPMS



Timeline

3 Oct 2018 A new panel was started

4 Oct 2018 Panel is in state “panel selection”

| | | |
|-------------------------------|----|--------------------|
| 12 panel members were invited | 11 | from ERN ReCONNECT |
| | 1 | from ERN SKIN |

No invitation emails were sent by the CPMS system

9 Oct 2018 The panel lead sent invitation emails to all the invited panelists

Acceptance

- Panelists
 - 9 October 1 panelist
 - 10 October 2 panelists
 - 14 October 2 panelists
 - 16 October 1 panelist
- Answers into the CPMS:
 - 9 October 1 panelist
 - 15 October 1 panelist
 - 17 October 1 panelist
 - 11 November 1 panelist
- “Unconventional answers”
 - 14 October 1 panelist answered by Whatsapp to the panel lead
 - 17 October 1 panelist answered by email to the panel lead

Outcome

- 3 panelists asked for further investigations
- 1 proposed a treatment for the patient
- 1 member asked also to his oncologist to revise the images (outside the CPMS)
- No panelist suggested to stop chemotherapy

The added value of the CPMS discussion

- The multidisciplinary discussion at our clinic concluded for continuation of therapy, treatment based on skin manifestations
- No activity of the disease, no issue related with SLE
- CPMS HAS SUPPORTED AND REINFORCED OUR APPROACH

Problems with CPMS

- The procedure of registration is not considered “user friendly”, and many people didn’t request the access
- Many HCPs have difficulties during the authorization process
- Out of 49 requests for the access to the CPMS 23 were rejected. Among them 6 physician still don’t have access to the platform because they did not request access again.
- Some physicians are “shy” to reply directly into the platform and sent private contact to the panel leader
- Time consuming
- Patients reported that the “informed consent” form is unfriendly and difficult to read
- For this case: no invitation emails were sent by the system (issue solved by the central IT helpdesk)

PROS of CPMS

- Easy way to share knowledge and expertise across the Europe
- Possibility to share documents, images, directly from the platform
- Immediate visualization by all the panel members of the answers
- May allow immediate actions to improve the clinical course of the patient
- Possibility to involve experts from other ERNs
- Possibility to invite guests from non-ERN HCPs
- Ensure protection of the patient's personal data (according to EU-GDPR)
- Production of an outcome document

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- Possibi

- Immed

- May all

- Possibi

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CPMS could become an
unprecedented opportunity for
physicians and patients

patient

CPMS: for who?

- We believe that the CPMS is useful for discussing difficult cases at referral centres, but mostly should be used by centres outside the ERN.
- In the same period I have received three emails from colleagues met at conferences/courses asking for advice on clinical cases.
- The contact with our center was not due to the ERN, but to personal contacts.

How to move on?


- Little is known about the CPMS outside ERNS
- As ERN ReCONNECT we have devoted part of our dissemination activities to this aspect
- Hospitals should be informed via local health care systems
- Dissemination of CMPS and strategies to implement its use in clinical practice within the hospitals and health care systems should be identified

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Thank you for your attention