

Minutes of ALLOCATE Thematic Group Meeting (ERN-Skin)

12 December 2025

Participants

- Veronique del Marmol (Belgium) – VDM
- Kristian Gaspar (Hungary) – KG
- Dagmar Presser (Germany) – DP
- Peter Arenberger (Czech Republic) – PA
- Vesta Kucimskiene (Lithuania) – VK
- Irina Sawanes (Hungary) – IS
- Teresa Oranges (Italy) – TO

VDM represented the **ALLOCATE Board** during this meeting.

1. Syndromic and Paediatric Hidradenitis Suppurativa (HS)

VDM recalled that **syndromic forms of HS** are most likely those considered under **rare diseases with an OrphaCode**, and that these forms are currently included in **ERRAS** at the Brussels level.

VDM proposed to specifically **study paediatric HS**, with the perspective of potentially including these cases within ERN activities. A dedicated study will be proposed within the **ALLOCATE group**.

Teresa Oranges, as a paediatric dermatologist, noted that in her clinical experience, **paediatric HS does not appear to be rare**. VDM therefore highlighted the importance of studying this population as a whole, in order to better define:

- the **phenotype**,
- **disease severity**,
- **age at onset**,
- and the distinction between **pre-pubertal and post-pubertal HS**.

It was agreed that an **adaptation of the current HS registry** would likely be required to adequately capture paediatric cases.

A discussion will be initiated between **Teresa Oranges (TO)**, **Anne-Sophie Sarkis**, and potentially **Heleen de Koning** (Erasmus MC Rotterdam). Once cases are collected, a **population-based analysis** will be performed.

2. Roadmap and Obligations for the Coming Year

The meeting mainly focused on the **roadmap**, ongoing projects, and ERN obligations for the upcoming year.

VDM reviewed the different tasks for the group, including:

- **ERRAS**
- **Webinars**
- **CPMS activities**
- **Future meetings**

3. CPMS

A minimum of **three CPMS per year** is required.

Two dates were proposed for 2026:

12 January 2026 at 15h30 : Teresa Oranges on « **SAPHO SYNDROME IN MONOZYGOTIC TWINS – an UPDATE** »

- **16 March 2026 at 16h00** : subject and speaker **to be confirmed**

The initially proposed time was **15:00**, but VK expressed a preference for **16:00** due to time zone differences. For 12th January 15h30 is proposed for convenience.

In future CPMS **Dr Heleen de Koning** (Erasmus MC Rotterdam) will propose to present **paediatric cases**.

Dr de Koning, who works as a paediatric dermatologist at Erasmus MC, also expressed interest in **joining the ALLOCATE group**.

4. Webinars

Proposed webinar topics:

- **HS surgery**
- **Paediatric HS**

PA suggested **Monika Arenbergerová** as a potential speaker.

KG suggested focusing the surgical webinar on **specific and complex situations**, such as:

- emergency surgery,
- surgery in adolescents,
- special clinical scenarios.

No date has yet been fixed for the next webinar.

5. ERRAS

VDM emphasized the importance of **collecting syndromic HS cases** at a **multicentric European level** in order to strengthen data collection within ERRAS.

Anne-Sophie Sarkis will send an email to centres interested in sharing cases.

She will also provide the **necessary inclusion criteria and items** required for registration in ERRAS.

Valérie may support this process.

6. Actions and Next Steps

- **Anne-Sophie Sarkis** to contact **TO** and **Heleen de Koning** to assess the need for an **amendment to the HS registry** (additional items for first visit and follow-up, especially for paediatric cases).
- **Hanae Jaali Chabor** can assist in scheduling a **webinar date**.
- **CPMS on 12 January 2026**: organisation to be finalised (contact **Julia Neveu?**).
- **Anne-Sophie Sarkis** to coordinate the **collection of syndromic HS cases** from European centres, including **Rotterdam**.