



Tenth meeting of the CIOMS Working Group on Severe Cutaneous Adverse Reactions of Drugs (SCAR)

20 June 2023

Meeting Minutes

Participants

Priya Bahri (EMA), David Brott (Takeda), Siew Eng Choon (), Chia-Yu Chu (National Taiwan University Hospital), Roni P. Dodiuk-Gad (Emek Medical Center), Leslie Dondey-Nouvel (Sanofi), Koji Hashimoto (Ehime University), Alexandre Kiazand (AstraZeneca), Filippa Nyberg (Karolinska University Hospital), Ariel Porcalla (AbbVie), Melissa Reyes (FDA), Sarah Schlieff (Bayer), Neil Shear (University of Toronto), Takahiro Ueda (PMDA)

Secretariat: Lembit Rago, Catherine Bates

Regrets: Haur Yueh Lee (Singapore General Hospital), Hevé le Louet (CIOMS), Violeta Regnier Galvao (Eli Lilly)

Introduction

Lembit welcomed the group and updated members on CIOMS activities.

Key actions/decisions

- CIOMS to obtain rights from patients to publish photos. These authorizations should be kept at the CIOMS Secretariat.
- Add a note as an appendix to explain how the photos were obtained and include acknowledgements.
The WG decided to reorder the Foreword and the Executive Summary: the Foreword comes before the Executive Summary, not after.
 - The Foreword should come first (after abbreviations) and should provide the rationale for the WG to produce the report.
 - The Executive Summary should come after the Foreword and should describe the work performed by the WG to deliver this report
 - The Introduction provides the context for the topic.
- The chapter summaries that are currently in the Introduction will be moved to the Executive Summary.
- A statement should be provided in the Foreword and Introduction to highlight the patient's perspective and the burden of life-long worry about medicines. Patients fear that if they have been affected by a SCAR disease e.g. SJS, they could get it again. Patients refer to themselves as "survivors".
- Chapter leads to complete summaries/recommendations which will be placed at the beginning of each chapter. These summaries should be more detailed than the synopses that are currently in the Introduction, (these synopses will be moved to the Executive Summary).
- Catherine to obtain permission to reproduce targeted follow up form from NIH (see link in chat)
- Leslie to inquire about possibility of including targeted follow up forms as examples for the report.
- Insert SCAR vs Non-SCAR graphic from Priya. Catherine to amend.
- Choon to share additional photos of SJS/TEN
- Catherine to send Chapter 5 only to Priya then Chapters 6,7,8 at a later stage.
- Discussion about race/ethnic background. Editorial Committee to review. (Chapters 1 and 6)