

EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING

31 OCTOBER 2023

PRESENTATION

MCAS Treatment:
Addressing Unmet Needs

SPEAKER

Scarlett Eagle (she/her)

Community Content Coordinator, The Ehlers-Danlos Society



Mast Cell Diseases in Practice and Research: Issues and Perspectives Raised by Patients and their Recommendations to the Scientific Community




OBJECTIVES

- Better understand the needs of people with mast cell diseases
- Align patient needs with the goals of physicians and researchers
- Encourage global communication among patient advocacy groups, physicians, researchers, industry, and government

METHODS

- **WHO:** Patient advocacy groups and physician advisors
- **WHERE:** 12 countries and regions
- **WHAT:** Developed top 10 lists for MCAS and mastocytosis
- **WHEN:** 2020 — 2022
- **WHY:** To propose possible actions to address unmet needs

Jennings, et al. (2022). Mast Cell Diseases in Practice and Research: Issues and Perspectives Raised by Patients and Their Recommendations to the Scientific Community and Beyond. *The journal of allergy and clinical immunology. In practice*, 10(8), 2039–2051.



Special Article
Mast Cell Diseases in Practice and Research: Issues and Perspectives Raised by Patients and Their Recommendations to the Scientific Community and Beyond

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DIAGNOSTIC DELAYS



Average time from symptom onset to diagnosis varies greatly (4-12 years) due to:

- 1 Symptom variation
- 2 Lack of awareness
- 3 Lack of reliable tests

Special Article

Mast Cell Diseases in Practice and Research: Issues and Perspectives Raised by Patients and Their Recommendations to the Scientific Community and Beyond

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BACKGROUND: Since 2010, patients and physicians have collaborated to understand unmet needs of patients with mast cell diseases, incorporating recommendations and mast cell activation disorders, which include mast cell activation syndromes.

OBJECTIVE: The Open Innovation in Science project aims to report understanding of the needs of patients affected by mast cell diseases, and encourage global communication among patient advocacy groups, physicians, researchers, industry and governments. A major aim is to support the scientific community's efforts to improve diagnosis, management, therapy, and patients' quality of life by addressing unmet needs.

METHODS: An collaboration with mast cell disease specialists, 13 patient advocacy groups from 12 countries and regions developed lists of unmet needs. A core team of leaders from patient advocacy groups collected and analyzed the data and prepared possible actions to address patient needs.

RESULTS: Findings identified similarities and differences among participating countries in unmet needs between patients

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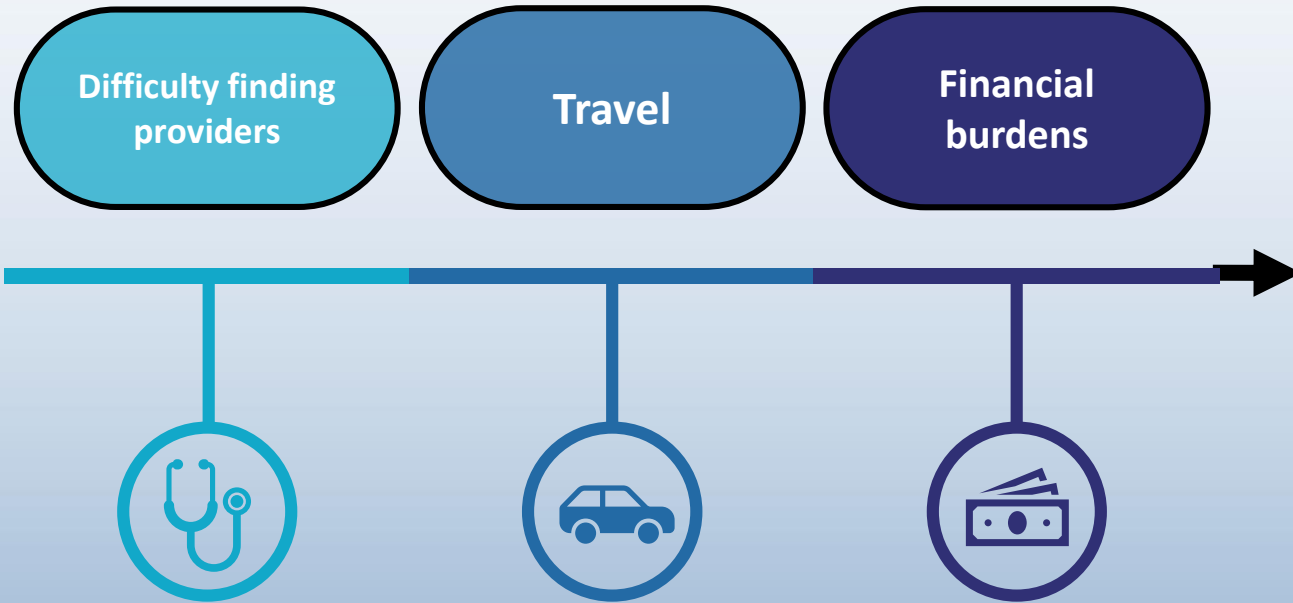
2039

BARRIERS TO CARE



Shortage of healthcare professionals who are knowledgeable about:

- Symptom recognition
- Diagnosis
- Trigger identification
- Management



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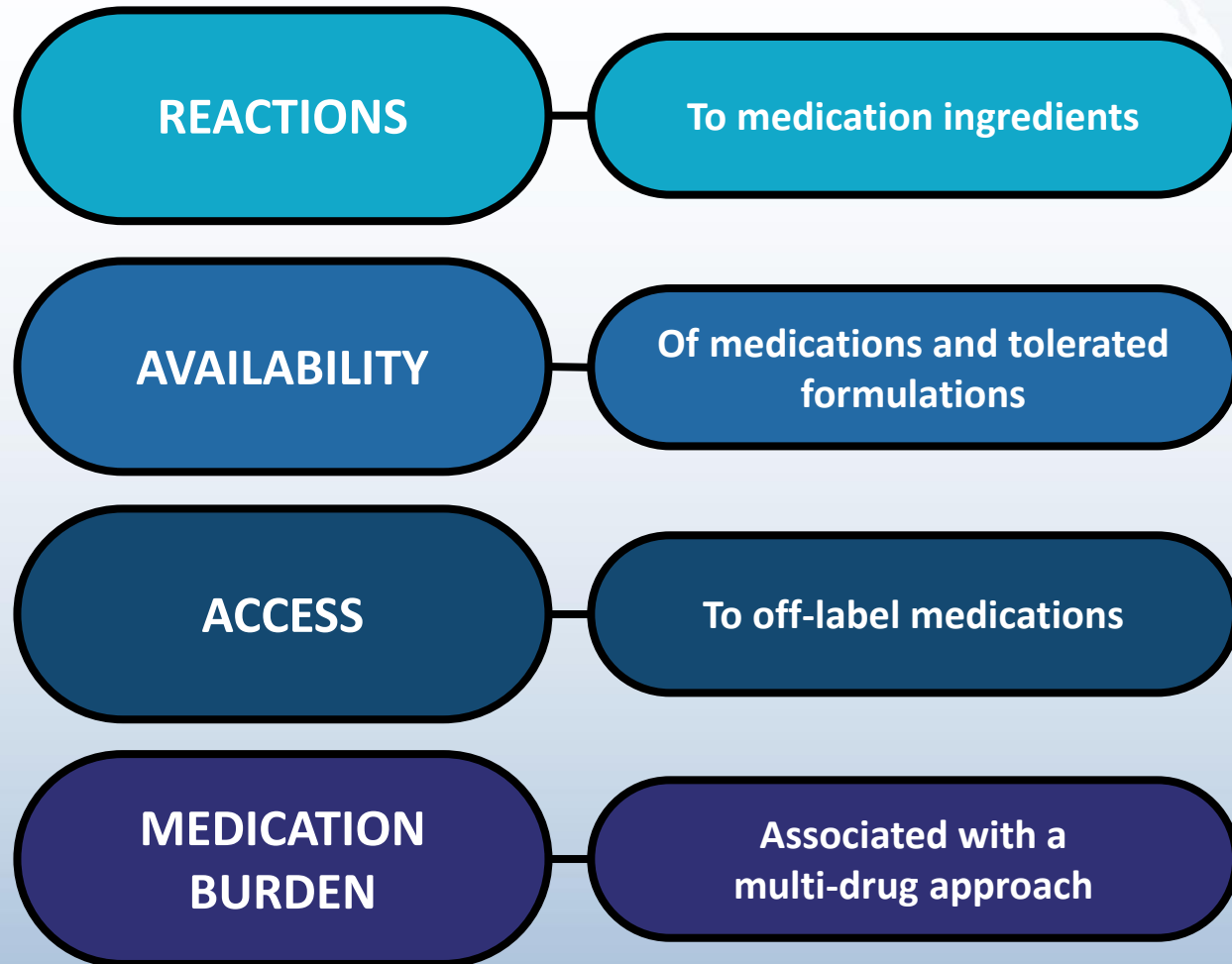
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ACCESS TO MEDICATIONS



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MULTIDISCIPLINARY CARE




IMPROVED
COMMUNICATION

STANDARDS
OF CARE

CENTERS OF
EXCELLENCE

MENTAL
HEALTH CARE

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GLOBAL COLLABORATION



- Registry
- Education
- Consensus guidelines for managing MCAS
 - Anesthesia
 - Emergency care
 - Vaccinations
- Collaborative partnerships



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PATIENT REPORTED ISSUES BY TOPIC	ACTIVE PLAYERS INVOLVED IN SOLUTIONS
Shortage of MCD-proficient HCPs	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Shortage of CoE/RCs	HCPs, Physician Networks, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Multidisciplinary/local care coordination	HCPs, Physician Networks, Researchers, CoE/RC, Government/Regulatory, Patients, PAGs, Rare Disease Organizations, Funders
National/international multi-specialty networks	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Research/support/advocacy collaboration	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Patient registries	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Patients, PAGs, Rare Disease Organizations, Funders
Access to care including mental health care	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Access to appropriate medications	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Access to skilled emergency care	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
MCAS diagnostic criteria	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Diagnostic process/prognosis	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
National/international MCD standards of care	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
More effective treatments	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Recognition of trigger diversity	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Acknowledge symptom heterogeneity	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Care plans for children	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders
Information for patients/families	HCPs, Physician Networks, Researchers, CoE/RC, Government/Regulatory, Patients, PAGs, Rare Disease Organizations, Funders
Patient support/advocacy groups	HCPs, Physician Networks, Researchers, CoE/RC, Government/Regulatory, Patients, PAGs, Rare Disease Organizations, Funders
Educate society about MCDs	HCPs, Researchers, CoE/RC, Government/Regulatory, Patients, PAGs, Rare Disease Organizations, Funders
Advancement of research	HCPs, Physician Networks, MCD Educators, Researchers, CoE/RC, Government/Regulatory, Biopharma, WHO, Patients, PAGs, Rare Disease Organizations, Funders

FIGURE LEGEND

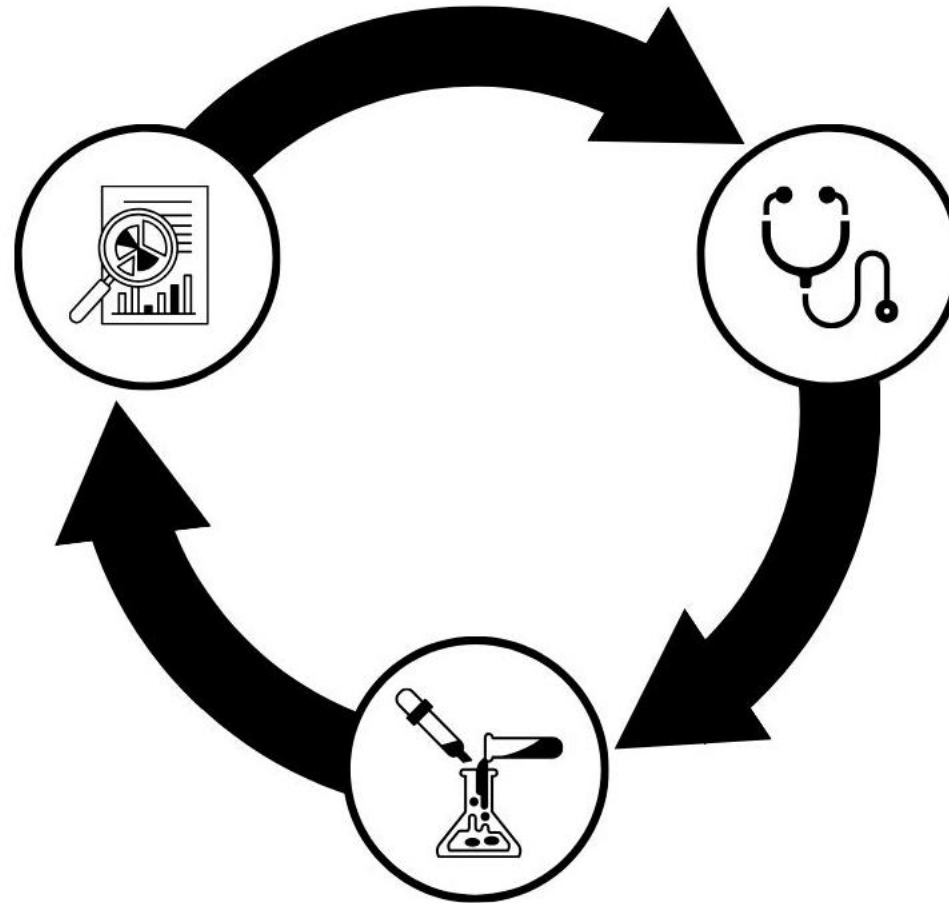
MCD, mast cell disease; HCP, health care professional; CoE/RC, Centers of Excellence/Reference Centers; MCAS, mast cell activation syndromes; SoC, standards of care; WHO, World Health Organization; PAGs, patient advocacy groups.

Mast Cell Diseases in Practice and Research: Issues and Perspectives Raised by Patients and their Recommendations to the Scientific Community



THE RARE DISEASE CYCLE

LACK OF INFORMATION
AND AWARENESS



UNDERDIAGNOSIS

LACK OF RESEARCH



**Thank you for
your attention**