

ISHAM Patient Representation and Advocacy Working Group

Make Fungal Infections Understandable
for Everyone

Kick-Off Meeting 10 November 2025

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ISHAM Patient Representation and Advocacy WG

Objectives

- Identify **needs and challenges** faced by patients and caregivers
Patient interviews / story-telling
- Establish a **platform for patients** and caregivers
virtual hub: Lay summaries / patient-to-patient advice
- Filling the **gap in research activities**
Patient advisory board / advocacy



Your expertise - scientific, clinical, or personal - can help patients and caregivers better understand fungal infections.

ISHAM Website

[Patient representation and advocacy in invasive fungal infections - The International Society for Human & Animal Mycology \(ISHAM\)](#)

Patient representation and advocacy in invasive fungal infections

Convenors

[Irina Reinhold \(Co-chair\)](#)
[Laura Wight \(Co-chair\)](#)

Accessible articles addressing key aspects of fungal infections

We welcome contributions to our series of concise, accessible articles addressing key aspects of fungal infections and their management. To facilitate clarity and consistency, we provide a [template for Contributions](#) that may be adapted to the specific topic. Contributions from both junior and senior fellows are particularly encouraged. In case of interest in contributing on a topic, please contact the convenors by email (see above).

Postcards to promote our activities

The ISHAM Working Group 'Patient Representation and Advocacy' is developing resources to make information on Invasive Fungal Infections more accessible for patients and caregivers. The postcards [Doutard Patient Advocacy](#) and [Pastard Patient Advocacy](#) highlight how experts and interested colleagues can contribute to this initiative. Take a look to learn how you can get involved – and please feel free to share with your networks.

Objectives

Invasive fungal infections (IFI) represent a significant burden for patients and are often underestimated in clinical practice and public awareness. Patient perspectives remain inadequately addressed in research and healthcare initiatives. This includes missing patient and healthcare professional education, diagnostic delays and side effects of treatments, leading to prolonged and complex patient journeys. The Working Group aims to improve awareness, advocacy, and to integrate patient-centered outcomes into clinical practice and research by actively involving patients and caregivers.

Objective 1: Identify needs and challenges faced by patients, relatives and caregivers

Structured interviews to document patient journeys with IFI to incorporate individual experience into advocacy efforts and research proposals. Interviews are planned with IFI patients from low, middle, and high-income countries, to identify and address needs aligned with their local requirements. Results will be analyzed and published to gain visibility.

Objective 2: Establish a platform for patients, relatives and caregivers

To foster patient education and disease awareness, we will create a virtual hub for patients and relatives to exchange experiences, access educational materials, and participate in webinars on IFI topics relevant to patients as identified in objective 1 and led by experts in the field. Such material may include information on fungal diseases, diagnostics, treatments, and follow-up care tailored for patients and caregivers in accessible language. Translation of all educational material in several languages is planned to allow worldwide access. Peer-to-peer support programs will be promoted on this platform. We aim to connect with existing regional and/or disease-specific initiatives such as the Aspergillus Patient Group (NHS-funded, UK) and the Mycology Advocacy, Research and Education (MyCARE) based in the US.

Objective 3: Filling the gap in research activities

We aim to include the patient's perspective in research development and support patients to access specialized health care services including clinical trials. The Working Group will therefore serve as a link between patients, clinicians, and researchers to address unmet needs in the management of invasive mycoses. The development of patient-related outcome measures (PROMs) for IFI will be developed together with IFI patients and survivors in order to be integrated into trials. For coccidiomycosis, the first ever IFI-specific PROMs were recently developed based on interviews of 25 patients ([Larvev et al., 2024](#)). By embedding patient experiences (PREMs) and needs into the picture of clinical research and public advocacy, the group aims to improve diagnostic processes, therapeutic outcomes, and the overall quality of life for individuals affected by IFI. Lastly, the continuous exchange with patients in objective 1 and 2 will help revealing priority research questions.

Links to educational information and patient advocacy

- Aspergillus Patient & Carer Support: <https://aspergillus.org/>
- Mycology Advocacy, Research & Education (MYCARE) Foundation: <https://ishamfungus.org/>
- GeH Education: <https://gehl.org/where/education/>
- Patient and Caregiver Education, Patient Videos - Fungus Education Hub: <https://funguseducationhub.org/patient-and-caregiver-education/>
- Educational material including games and books for all ages (Portuguese) [Euro](#)

Other resources, contacts

- Mycoses Study Group: <https://msgpc.org/>
- ECMM Excellence Centers: <https://www.ecmm.info/ecmm-excellence-centers/excellence-centers/>



Platform for patients: lay summaries

How you can contribute:

- ✍️ Write lay summaries
- 📄 Review drafts
- 💡 Share ideas & resources

Writing: Encouragement of junior-senior co-writing



Author Contribution Invitation Template

Dear [Name],

We are preparing a series of brief, easy-to-understand contributions on important topics related to fungal infections and their treatment. To keep the contributions clear and structured, we offer the following template for your guidance. Depending on the topic, you may adapt or omit sections as appropriate.

Contribution Title

Please provide a concise title for your contribution.

Author

Name, role, institute

Background

A brief introduction of yourself and your motivation for contributing.

Suggested Sections (please select and adapt according to your topic):

1. Scientific Background

(Explain the topic in simple terms)

- What is [Fungal Species]?
- What types/variants exist?
- How dangerous can this infection be?

2. Diagnostic Approaches

- What diagnostic methods are used (microbiology, radiology, etc.)?
- How is the infection diagnosed?

3. Treatment

- How is the infection treated?
- What medications are available?
- What are the challenges in treatment?
- Possible side effects and how to manage them

4. Current Research and Clinical Trials (optional)

- Brief overview of relevant ongoing scientific projects or clinical studies

5. Patient Story / Experience Report (optional)

- Personal experiences from your own patients with diagnosis, treatment, side effects, or caregiving

6. References and Useful Links

- Important resources, literature, patient organizations, websites

We would be delighted if you are interested in contributing. Please feel free to contact us for any questions or further details.

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Proposed topics for summaries (n=min.12)

Fungal Infections

- Mucor
- Fusarium
- Lomentospora

Antifungal Therapy

- **Echinocandins; Amphotericin; Azoles** (Fluconazole, Isavuconazole, Voriconazole, Posaconazole); **new AFT:** Fosmanogepix, Olorofim, Rezafungin (CPA), including clinical trial links
- Therapeutic drug monitoring (TDM)
- Therapy-related complications (Azoles, Amphotericin)

Diagnostics & Procedures

- Microbiology
- Bronchoscopy
- Serum markers / Next-generation sequencing (NGS)

Special Populations

Pediatrics

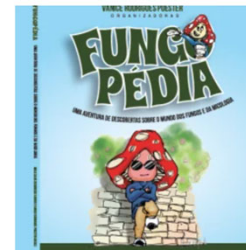
Further topics (e.g. *Candida*, *Aspergillus*) broadly covered by:

- Aspergillosis Patient & Carer Support: <https://aspergillosis.org/>
- Mycology Advocacy, Research & Education (MYCARE) Foundation: <https://fightfungus.org/>
- Gaffi Education: <https://gaffi.org/where/education/>
- Patient and Caregiver Education, Patient Videos – Fungus Education Hub: <https://funguseducationhub.org/patient-and-caregiver-education/>



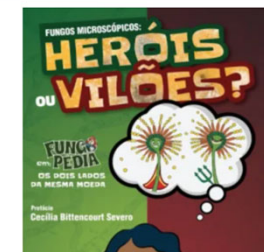
Special Populations: Pediatrics

- ✓ Provide information in language aimed at parents.
- ✓ Overview of treatment options.
- ✓ Explain Expanded Access Programs (EAP) and other relevant pathways.
- ✓ Ensure content is clear, accessible, and supportive for families.



Fungopédia: Uma Aventura de Descobertas sobre o Mundo dos Fungos e da Micologia

[VER SOBRE O LIVRO](#)



Fungos Microscópicos: Heróis ou Vilões?

[VER SOBRE O LIVRO](#)

Patient-to-Patient Advice / Patient Advisory Board/ Story-telling

Goal

Engage patients **with IFI at your institution who are interested in advocacy.**

How

Identify suitable **patients** for:

- Patient-to-patient advice
- Facilitate contributions to advocacy activities (e.g. open letters /call for access issues)
- Story-telling and interviews
- Reviewing lay summaries (e.g. research proposals), interested in advisory boards

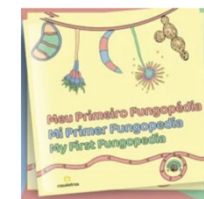


Topic-based Subgroups

The Working Group will be a platform for several **sub-groups and network** opportunity.

Possible topics of subgroups:

- **CPA-specific score** development (Lead: Inderpaul Singh, India, possible cooperation with Aspergillosis Patient Care)
- **Pediatrics:** development of education material (exchange with Melissa Orzechowski Xavier, Brasil) translation of material [Furg](#)
- ...



Meu Primeiro Fungopédia

Regional coordination

Goal

- Establish **regional coordination for local projects and patient/caregiver support.**
- Connect patients and caregivers in a specific region with information on IFI and advocacy opportunities.
- Appoint 1 regional coordinator per area (to be adapted, as WG member grow) → listed on the webpage

Coordinators manage:

- Care coordination: Patient or caregiver enquiries, networking to specialists, referral patient-to-patient advice
- Engagement of patients interested in advocacy.
- Facilitate communication and collaboration across regions.

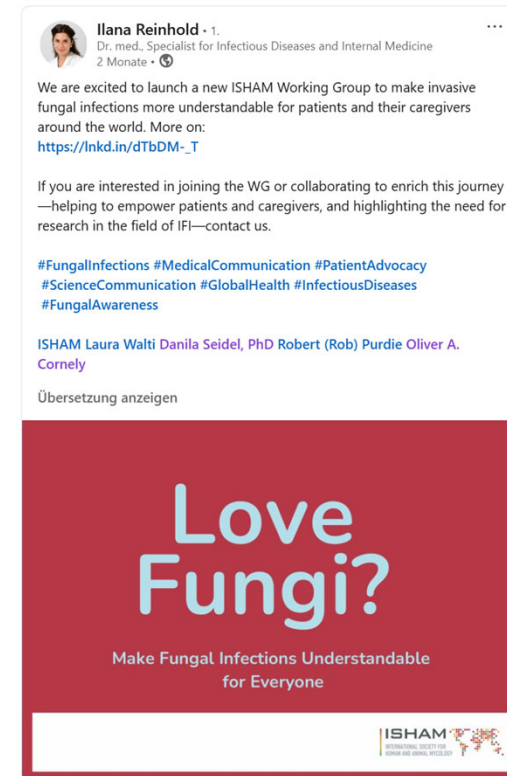


Working Group Meetings / Timeline

- End of November 2025: share interests (next slide)
- Timeline for content creation and discussion:
 - lay summaries by end of December 2025
- Regular meetings to share updates and coordinate efforts: **suggest every 2-3 months, timezone adapted** (ensure smooth communication across regions)
- Outlook beginning of 2026: Publication in “Medical Mycology” presenting the WG aims/ objectives, ongoing projects, create visibility and engage potential new members, underline importance of patient advocacy

Final Remarks

We look forward to working with all of you and warmly welcome your own topic suggestions. Please feel free to **spread the word** and encourage colleagues to join — especially also younger team members who may be interested in contributing.



Social Media Updates

Contact

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Laura Walti (Co-Chair):
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Big thanks to:

Janina Leckler, Danila Seidel, Johanna Brustkern,
Cornelia Lass-Flörl

How would you like to engage for which topics/ region? → One Drive Link

Name	Topic
	Coordination of interested patients (for patient-to-patient advice /patient advisory board / advocacy)
	Regional coordinator of XXXREGION
	Write /Review lay summaries regarding XXXTOPICXX
	Participation in Sub-Group XXX

Make Fungal Infections Understandable
for Everyone

- Who are you?
- Particular interests of activity?
- Favorite IFI-related topics?
- Further inputs for WG fields of work?