

# ISHAM Patient Representation and Advocacy Working Group

Make Fungal Infections Understandable  
for Everyone

Working Group Meeting 22 January 2026

Dr. Ilana Reinhold, University Hospital Cologne, Germany  
Dr. Laura Walti, University Hospital Bern, Switzerland

# Agenda

1. Updates on logo, website, summaries
2. Repartition of topics for summaries
3. Identification of patients interested in engagement in the Patient Advisory Board (PAB), including networking with patient coordinators and physicians
4. Presentations of subgroups and ongoing projects:
  - CPA Quality of Life (QoL) – Inderpaul Singh
  - Pediatrics Subgroup – Zoi Pana
  - IFI PRO QoL on filamentous probable/proven IFI – Terenzio Cosio
5. Statement paper

# Logo



**Patient Advocacy  
for Invasive Fungal Infections**

***Credit: Terenzio Cosio***

# 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

[Ilana Reinhold \(Co-chair\)](#)

[Laura Walti \(Co-chair\)](#)

### Launch and opportunities to contribute

The first online Zoom meeting of this newly established ISHAM working group took place on 10 November 2025 ([slides kick-off meeting](#)).

Working group members can contribute by:

- Identifying and engaging patients at their institutions
  - interested in storytelling, giving interviews, patient-to-patient advice, reviewing lay summaries, participating in patient advisory boards, or other forms of advocacy
- Helping to establish a virtual platform for patients:
  - by writing lay summaries, reviewing drafts, and sharing ideas on IFI topics
    - For lay summaries, we provide a [Template for Contributions \(Template for Contributions\)](#) that may be adapted to the specific topic. All summaries will undergo expert review and be translated into multiple languages to facilitate broader accessibility.
- Care coordination: patient or caregiver enquiries, networking with specialists, referral patient-to-patient advice;
- Being local coordinators: facilitating communication and collaboration across regions;
- Engaging in dedicated topic-based subgroups (e.g., pediatrics).

### 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 Aspergillosis 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 ([Harvey 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.

# Update on lay summaries

- ***Living with chronic pulmonary aspergillosis (CPA): Understanding and managing a long-term fungal lung infection***  
by Inderpaul Singh Sehgal, Valliappan Muthu, Ritesh Agarwal
- ***Hidden Mould in the Air: What High-Risk Patients Need to Know***  
by Cornelia Lass-Flörl, Stephan Steixner, Angelika Bauer
- ***Sporothrix is among us, in the environment, in cats, in humans -, let's learn together about sporotrichosis.***  
by Amanda Ribeiro dos Santos, Dayvison Francis Saraiva Freitas, Isabella Dib Ferreira Gremião, Sandro Antonio Pereira, Vanice Rodrigues Poester, Luisa Helena Monteiro de Miranda



**Thank you!**

# Repartition of topics for summaries

Deadline: end of March 2026

[Repartition of topics.xlsx](#)

## 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.

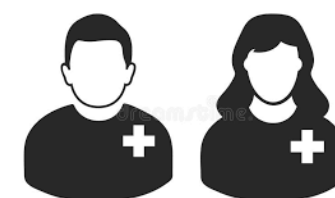
**Include Key Messages / Graphical Abstracts**

| Summary topic   | Main Person involved             | Other person (eg. junior researcher at institution or from another institution) |  | Review           |
|---|----------------------------------|---|--|------------------|
| <i>Fungal infections</i>  |                                  |   |  |                  |
| Mucor   | Nidhi Singla                     |   |  |                  |
| Fusarium  |                                  |   |  |                  |
| Lomentospora/Scedosporium   | Abby Douglas                     |   |  |                  |
| Chronic Vulvovaginal Candidiasis (Candida)  | Riina Richardson                 |   |  |                  |
| (Aspergillus)   |                                  |   |  |                  |
| CPA   | Inderpaul Singh and Team         |   |  | Completed        |
| <i>Antifungal therapy</i>   |                                  |   |  |                  |
| Echinocandins   | Pao-Yu Chen                      |   |  |                  |
| Azoles, complications, therapeutic drug monitoring  | Ran Wang                         |   |  | Pharm?           |
| New agents (Fosmanogepix, Olorofim, Rezafungin)   | Rosanne Sprute                   |   |  |                  |
| LAMB?   |                                  |   |  |                  |
|   |                                  |   |  |                  |
| <i>Diagnostics &amp; procedures</i>   |                                  |   |  |                  |
| Microbiology  | Vanbiervliet Yuri (focus moulds) | Plinio Trabasso   |  |                  |
| bronchoscopy  | Simon Feys                       |   |  |                  |
| serum markers, next-generation sequencing (NGS)   | Terenzio Cosio                   |   |  |                  |
| Radiology (CT thorax, and head in context of Mucor, Aspergillosis and severe immunocompromised vs. ICU)                                     |                                  |   |  |                  |
| <i>Other topics</i>   |                                  |   |  |                  |
| Prevention  | Cornelia Lass-Flörl              | Angelika Bauer  |  | Peter Schreiber? |
| Zoonotic Sporotrichosis   | Amanda Ribeiro Santos and Team   |   |  | Completed        |
| <i>Review activity</i>  |                                  |   |  |                  |
| Review of summaries according strategies of IFI in LMIC facing medical gaps / social and economic realities that shape a patient's journey. | Olga Mashedi                     |   |  |                  |
| <i>Patient coordination</i>   |                                  |   |  |                  |

# Patient Advisory Board (PAB) – interested patients

## Goal

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



- Identify interested patients through
  - own clinical network
  - patient self-help groups
  - social media

## How

Identify suitable **patients** for:

- Patient-to-patient advice
- Facilitate meaningful contributions to advocacy activities
- Story-telling and interviews
- **Reviewing lay summaries of research proposals**



- Connect with physicians & patient coordinators



- Onboard to PAB

# Presentations of subgroups and ongoing projects:



**CPA Quality of Life (QoL)**  
Inderpaul Singh



**Pediatrics Subgroup**  
Zoi Pana



**IFI PRO QoL on filamentous  
probable/proven IFI**  
Terenzio Cosio

# Statement Paper

## Purpose:

- Present the Working Group's objectives and perspective and achievements so far
- Raise awareness
- Provide recommendations and calls-to-action

**Submission mid 2026, Medical Mycology**



# Working Group Meetings / Timeline

- End of January 2026: **Repartition of topics for summaries, aim end of March 2026 for drafts and review process**
- Regular meetings to share updates and coordinate efforts: **suggest every 3 months, timezone adapted** (ensure smooth communication across regions)
- Mid of 2026: **Publication in “Medical Mycology”** presenting the WG aims/ objectives, ongoing projects, create visibility and engage potential new members




# Stay connected



Let's connect on LinkedIn to spread the word, grow our reach, and engage more interested people.

@Ilana Reinhold  
@Laura Walti

 **Ilana Reinhold** · 1.  
Dr. med., Specialist for Infectious Diseases and Internal Medicine  
2 Monate · 🌐

We are excited to launch a new ISHAM Working Group to make invasive fungal infections more understandable for patients and their caregivers around the world. More on:  
[https://lnkd.in/dTbDM-\\_T](https://lnkd.in/dTbDM-_T)

If you are interested in joining the WG or collaborating to enrich this journey —helping to empower patients and caregivers, and highlighting the need for research in the field of IFI—contact us.


[#FungalInfections](#) [#MedicalCommunication](#) [#PatientAdvocacy](#)  
[#ScienceCommunication](#) [#GlobalHealth](#) [#InfectiousDiseases](#)  
[#FungalAwareness](#)

ISHAM [Laura Walti](#) [Danila Seidel, PhD](#) [Robert \(Rob\) Purdie](#) [Oliver A. Cornely](#)

Übersetzung anzeigen

## Love Fungi?

Make Fungal Infections Understandable  
for Everyone



# Contact

Ilana Reinhold (Chair):  
[ilana.reinhold@uk-koeln.de](mailto:ilana.reinhold@uk-koeln.de)

Laura Walti (Co-Chair):  
[laura.walti@insel.ch](mailto:laura.walti@insel.ch)

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Janina Leckler, Johanna Brustkern

