Shared Vision for Improving Outcomes for Serious Fungal Diseases: Report of a Patient, Caregiver, and Clinician Summit

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Background: Recently, increasing focus on patient input into research and healthcare improvements has fostered expanded patient-centered advocacy efforts. This first pan-fungal disease summit, part of the MYCology Advocacy, Education & Research (MyCARE) effort, brought together patients, caregivers, and mycology experts to better document patient experiences

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with invasive fungal disease (IFD) and establish priorities for mycology education, advocacy, and research.

**Methods:** Patients who had suffered from IFD, their caregivers, clinicians, industry representatives, government officials, and patient advocacy professionals were invited. Patients and caregivers shared their stories and struggles with IFD. Breakout sessions separated mycology experts from patients and caregivers for further discussions to identify commonalities and perceived gaps and to formulate recommendations. The two groups then reconvened to develop consensus recommendations.

**Results:** IFD patients and their caregivers shared experiences reflecting the typically lengthy pre-diagnosis, acute treatment, long-term treatment, and post-treatment recovery stages of IFD. They reported substantial physical, psychological, and financial burdens associated with the IFD experience, particularly related to delayed diagnoses. They reaffirmed a need for coordinated patient-centered education, peer support, and advocacy to document the burden of serious fungal infections. Mycology experts discussed strategies to address gaps in the mycology field, such as insufficient training, inadequate workforce support, and a need to partner more with patient groups.

**Conclusion:** A summit involving patients with IFD, family caregivers, and mycology experts identified a substantial non-clinical burden of disease associated with IFD. Patients and mycology experts prioritized several goals for education, advocacy, and research to raise awareness of IFD and improve outcomes.

**Keywords:** invasive fungal disease, mycology, patient advocacy, patient-important outcomes, patient-reported outcomes, disease burden, diagnostic delays.

**INTRODUCTION**

The increasing burden of serious fungal diseases is a growing public health concern, with an annual incidence of 6.5 million cases worldwide and 2.5 million directly attributable deaths. (Denning 2024) However, the true disease burden of serious fungal disease is likely underestimated. Indeed, priorities in mycology include defining the public health burden of fungal diseases, understanding the geographic distribution of endemic fungi, and identifying the groups of people at highest risk for invasive fungal disease (IFD). (Benedict K et al 2022; CDC 2023) Antifungal resistance is also a global public health concern. (World Health Organization, 2022; Denning, 2022; Fisher et al., 2022; Wiederhold, 2017) The incomplete picture of the fungal disease burden is intertwined with a lack of knowledge among healthcare providers, patients, and the general public, particularly regarding emerging threats.

Some of the most effective disease-awareness efforts are led by or supported by patient-centered nonprofit organizations. Examples include work in amyotrophic lateral sclerosis, (Song, 2014) human immunodeficiency virus/acquired immune deficiency syndrome, (Shilts R, 1987; Wolfe,
(Mayer-Hamblett, Ramsey, & Kronmal, 2007) In fungal disease advocacy, a global advocacy initiative by the Global Action for Fungal Infections (GAFFI, 2023) aims to improve fungal diagnosis and treatment models for low-to-middle-income countries. To capture patient perspectives on treatment experiences, disease outcomes, and unmet needs across medical mycology, the Mycoses Study Group Education & Research Consortium (MSGERC) led the Faces of Fungal Infection video effort, capturing patient stories and clinician discussion across a range of fungal diseases. (MSGERC, 2023) Some disease-specific advocacy efforts have been advanced in mycology. Patients suffering from coccidioidomycoses (Valley Fever) have been the most successful in advocacy but only on limited scale. (Valley Fever Americas Foundation, 2023; McCarthy, May 19, 2022) However, a pan-fungal disease patient-led advocacy effort has been lacking until this effort.

The vision for this effort began nearly a decade ago. Key leaders have been involved with patient advocacy initiatives in specialized fungal disease areas (e.g., pediatric fungal diseases, mucormycosis, and coccidioidomycosis) and in oncology (Henry Schueler Foundation; Mayer-Hamblett, Ramsey, & Kronmal, 2007; O'Shaughnessy et al., 2022; Savage et al., 2022; Walsh, Bloom, & Kontoyiannis, 2012; Wood et al., 2019). Collectively, patients, clinicians, and advocates recognized the need for a more comprehensive fungal disease patient advocacy effort, given the commonalities of challenges and experiences across medical mycology. The medical community in general as well as the US Food and Drug Administration have emphasized the critical importance of including the patient voice in education, research, and drug development. (Patel, Fiebig, & Muszka, 2021) (Food and Drug Administration, 2023) Inclusion of the patient’s voice is the new normal.

This pan-fungal disease advocacy effort was initiated during a collaboration between the MSGERC, Terranova Medica, LLC, Integrita Healthcare Education & Research Foundation, and the Valley Fever Institute through a Centers for Disease Control and Prevention (CDC) cooperative agreement related to COVID-19-associated IFD. The collaborating individuals established the Mycology Advocacy, Research, & Education (MyCARE) initiative.

The first MyCARE Pan-fungal Disease Patient, Caregiver, and Clinician Summit was held on May 19-20, 2023, in Denver, Colorado. Stakeholders came together to hear patient/caregiver stories and experiences and prioritize next steps in education, research, and advocacy for IFD. The summit was held to provide an avenue for patients and caregivers to share their experiences, explore unique patient and caregiver needs, identify the patient-important outcomes, and establish priorities for MyCARE’s initial planning efforts. The purpose of this paper is to share the methods and outcomes of the summit.
METHODS

The day-and-a-half summit included patients who have experienced IFD, their family caregivers, physician researchers, nurses, medical educators, patient advocacy organization members, government officials, and industry representatives. The summit was designed to document the patient’s and caregiver’s perspectives on the disease journey and to define unmet needs and goals for education, fungal research, and mycology advocacy.

Patients were chosen to represent a variety of types of IFD, through collaboration with physicians who supported the summit. They had been diagnosed with the following IFDs: COVID-19-associated pulmonary aspergillosis; disseminated histoplasmosis; scopulariopsis, cryptococcal meningitis, mucormycosis, and coccidioidomycosis. All patients were male, one was a teenager and the rest were working-age adults at the time of diagnosis. Host characteristics included stem-cell transplantation, solid organ transplantation, COVID-19, diabetes mellitus, and normal characteristics (for the two endemic cases). One patient was Latinx, the rest were white. While most patients were insured, one was without insurance and receiving public assistance at the time of diagnosis. Each participant had a female family caregiver who also attended to share their perspectives. Most patients were invited to the summit by their clinicians, who were also key participants in the summit. MyCARE paid for travel to the summit and provided a stipend. Six clinicians, including two advanced practice provider nurses, attended. In addition to the MyCARE staff and MSGERC representatives, representatives from three pharmaceutical companies supporting the summit and one representative from CDC attended.

The summit began with the patients and caregivers sharing their stories in an open-forum discussion. After this, two groups (patient/caregivers and mycology experts/clinicians) broke into separate discussion rooms to brainstorm on educational, research, and advocacy priorities. After each breakout, the groups were brought together to summarize their sessions and to reach consensus recommendations. The attendees also listened to summaries of research priorities from the experts and examples of advocacy efforts from other organizations. The collective discussion forum and breakout sessions were repeated two additional times. Before the meeting closed, participants completed an evaluation of the process and priorities. After the meeting, a follow-up survey was sent to the patients and caregivers via email to capture quantitative data about their personal experiences.

The institutional review board of the Washington University School of Medicine deemed the summit and the reporting of outcomes as exempt from review.

RESULTS

Patient and Caregiver Stories
The extremes of emotions were present in the stories shared by patients and their caregivers. Fear, exhaustion, and profound sadness peaked during periods of ICU admissions, uncertain diagnoses, worsening symptoms, and when patients were given difficult survival odds. Hope, optimism, and gratitude highlighted periods of diagnostic certainty, eased suffering, treatment successes, and discharges to home. The experiences of these individuals were informative, emotionally profound, and they visibly affected every person present in the room. Recognizing the importance of hearing these stories, the group unanimously agreed to extend the session well beyond the allotted time. Any attempt to capture their stories in a few paragraphs here would be a disservice to their experiences. Rather, we will honor their shared experiences by identifying areas of need and guiding the future efforts of this group.

Several recurrent themes emerged as patients and caregivers shared their experiences: 1) delayed IFD diagnosis—(reported by 5/6 [83%] of patients), 2) importance of caregivers as surrogate decision-makers and patient advocates, 3) impact of diagnosis and treatment on quality of life (QoL), 4) gratitude for their healthcare provider(s), and 5) strong commitment to improve the experience of future patients. These themes were ubiquitous throughout the summit and repeatedly discussed during subsequent breakout sessions.

To further probe on these themes, a follow-up survey was completed by three patients. Participants reported typically seeing multiple healthcare providers in different settings before fungal diagnosis, except for the patient diagnosed with COVID-associated pulmonary aspergillosis. For one patient, several putative diagnoses including lung cancer and gall bladder disease were advanced before the fungal diagnosis was finally obtained.

As mentioned previously, cognitive issues, sleep disturbances, and posttraumatic stress syndrome (PTSS) plagued the patients and their caregivers. Moreover, financial toxicity was an issue that emerged, not only due to diagnostic delays and unnecessary testing, but also given the length of treatment, hospitalizations, and the inability of either the patient and/or the caregiver to work regularly. For some patients, lingering issues with fatigue and cognitive changes necessitated a career change or retirement. The figure summarizes the reported experiences across the stages of IFD diagnosis, acute therapy, follow-up therapy, and long-term recovery. Because symptoms consistent with PTSS were experienced (and continue to be experienced) in patient and caregiver participants, the recovery process continues for most of them.

Identifying Unmet Needs and Key Priorities

During general discussions and breakout sessions, unmet needs were explored in terms of educational, research, and advocacy needs. Consensus on key priorities was reached (Table).

Educational Unmet Need and Priorities

Patient and caregivers prioritized web-based opportunities for peer-to-peer interactions to support patients and caregivers who want to talk about and gain insight about their fungal disease.
experience from others with shared experience. Many of the caregivers (and some patients) tried
to research their disease on the internet yet found little to no information. Therefore, they stressed
the importance of developing a website that provides vetted information and supports those peer-
to-peer interactions. It should define what each fungal disease is and how it is contracted, advise
how to speed the time to diagnosis, review optimal treatment (with a review of efficacy and side
effects), and provide financial resources. Caregivers also wanted specific guidance on how to best
provide care during the different stages of the journey, specifically regarding a) the diagnostic
process, b) hospitalizations; c) through treatments and recovery; and d) while addressing long-
term disabilities and psychological impacts. The clinicians requested a resource to hand patients
to direct them to the MyCARE site to drive traffic Side effect trackers could also be a resource that
the MyCARE site could include, as patient reported outcome instruments are developed.

The clinician participants agreed with these priorities for patients’/caregivers’ education and
outreach needs. They also emphasized the importance of educating patients about recognizing and
working collaboratively with their health care providers to manage side effects so patients can get
the best from therapy. They also thought patients would benefit from information about prognosis
and what to expect, but they emphasized the importance of fostering hope rather than focusing on
negative statistics.

The mycology expert and clinician participants also prioritized a role for education to encourage
the medical community to “think fungal” and employ effective diagnostics. One key issue that was
discussed and supported by the patient stories was the significant lag-time in diagnosis of IFD. The clinicians corroborated this experience, relaying that by the time the patient is hospitalized
with an infectious diseases’ consultation or referral to infectious diseases by their primary care
physician, lag times have occurred that may have dire consequences. The clinicians also agreed
that they need more documentation about the patient’s experience to inform their treatment
practices and communication strategies. This can be difficult to quantify when signs and symptoms
may start off ambiguously. They acknowledged the importance of making quality fungal education
easy to find at initial web searches and expressed concern about patients accessing misinformation
from unverified sources of information.

During the mycology expert/clinician breakout session, major deficits in undergraduate medical
education were highlighted as a potential reason for shortages in the infectious diseases’ specialty
and in particular, mycology. They highlighted that the foundation of mycological education is
established in medical school; however, as more demands are placed upon the curriculum, there is
less time dedicated to fungal diseases. They suggested that the protracted delays of diagnosis in
five of the six patient participants may have been potentially averted by a more robust medical
mycological education. Reinforcing these principles of medical mycology in residency training in
the primary care specialties would also contribute to improved diagnostic acumen.

**Research Unmet Needs and Priorities**
The mycology experts and clinicians attending the summit were also clinical mycology researchers who emphasized key research priorities for the field. They identified a major unmet need as diagnostics. The group discussed that there is little federal support for advances in clinical mycology diagnostics and emphasized that better and easier-to-use diagnostic options should reduce diagnostic delays. They discussed the need for developing new rapid molecular, immunodiagnostic, and biomarker assays. Moreover, they also stressed the importance of establishing large fungal isolate banks to support diagnostic development. Similarly, as antifungal resistance and increased frequency of drug-drug interactions emerge as issues, new antifungal drug development is needed. The clinical research participants stressed the need for meaningful incentives from sponsors such as the National Institutes of Health (NIH), the FDA, and diagnostics/pharmaceutical companies to support these efforts.

Participants also discussed a need for novel clinical-trial designs that include validated patient-important (reported) outcome measures to better define success and failure of antifungal medications. One researcher stated that “Current clinical trial outcomes use “mortality” and “complete cure”, as criteria for success; but we must move beyond these.” Another pointed out that the MSGERC Desirability of Outcome Ranking (DOOR) initiative, which uses an innovative approach to considering global benefits and risks of antifungal drugs with patient-important outcomes, is addressing this issue. From an epidemiology standpoint, the participants reached consensus to prioritize updated definitions of disease burden and evidence-based definitions for risk across IFDs. As one clinician researcher pointed out: “New science has identified genetic predispositions and concomitant medications such as biologics that can impact fungal disease risk.”

Both the patient/caregiver and mycology expert/clinician groups concurred about these general research priorities. Together, they stressed the importance of documenting the current epidemiology and burden of illness for fungal diseases to provide an evidence base to advocate for additional funding and resources to “think fungus” and “fight fungus”. Collectively, they expressed hope that the MyCARE advocacy initiative can serve as a means to increase patient access for the patient-important outcomes validation and clinical-trial recruitment. Overall, there was considerable concurrence between attendee groups on mycology research needs.

**Advocacy Unmet Needs and Priorities**

The patients/caregivers agreed that part of the advocacy effort is education of the public and healthcare community. They want all the people who are involved with mycology—family, friends, health care providers, as well as regulators and elected officials—to have a better understanding of the burden of fungal disease on a personal level. This will make it easier to advocate for additional research and access to effective diagnostics and antifungal medications. On a very practical level, patients/caregivers want financial resources, questions to ask their doctor, and peer-to-peer support programs.

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The mycology experts and clinician researchers agreed with these priorities but also reiterated that clinicians do not get enough education about fungal disease during their training. In general, there is a need to improve advocacy for the field of clinical mycology. This includes ways to motivate medical students and residents to consider specializing in infectious diseases and medical mycology. Moreover, once a career track in infectious diseases is selected, early-career investigators need mentoring to become committed to academic careers in medical mycology, including mentoring in clinical trials. In addition, the training of all fellows in pediatric and adult infectious diseases training programs should provide core competency in the field of medical mycology to expand the national expertise. The future advocacy and advancement of the field depends on this as the key opinion leaders in mycology begin to retire. MyCARE should have an active role in ensuring the future of mycology.

Final priorities

The final session asked the groups address the highest priorities to support clinical mycology. Patients and caregivers want an increase in resources and funding for medical mycology, improved diagnostic testing, and meaningful input into patient-centered research. Clinician researchers want to collaborate with advocacy groups and learn more about that process, they too want an increase in patient-centered research and a better understanding of how to use patient important outcomes and real-world evidence in future clinical research in drug and diagnostics development. They also want to understand current epidemiology on risk factors and true impact of IFD in the US and global populations.

The groups recognized the importance of bringing fungal disease to the forefront—doing whatever it takes to raise awareness, funding, and capture of the patient’s voice. Two patient advocacy groups: the Henry Schueler Foundation and the Save Our Sick Kids Foundation were introduced by Dr Thomas Walsh, based on his work in mucormycosis and pediatric IFD. Establishing collaborations with those groups are planned. Overall evaluation responses revealed enthusiastic commitment by the patient/caregiver and clinician researcher attendees to continue working with MyCARE and to develop future goals and objectives for its meaningful growth.

DISCUSSION

This first ever pan-fungal disease patient, caregiver, and mycology expert/clinician summit captured many unmet needs and priorities to advance clinical mycology goals. Stakeholders agreed that much needs to be done to improve the awareness of serious fungal infections and that we need better tools to manage them. Awareness can be enhanced by inclusion of fungal diseases in priority lists (eg, neglected tropical diseases) and emphasizing antifungal resistance by international organizations such as the World Health Organization.
One of the highest priorities identified by the group is accelerating the diagnosis of suspected fungal diseases. Indeed, delayed IFD diagnosis occurred in 83% (5/6) of patients attending the summit and is consistent with IFD diagnostic delays reported in the literature. The deleterious effect of diagnostic delay was not felt in isolation but pervaded other aspects of patient experiences. Because of diagnostic delays, caregivers report the need to request second opinions to find a diagnosis or push for facility transfer for escalation of care. Earlier diagnosis is also an opportunity to improve patient outcomes through earlier treatment initiation.

In patients with IFD, diagnostic and treatment delays are associated with prolonged hospitalization and worse morbidity/mortality. Moreover, the financial burden of invasive fungal diseases is skyrocketing. A major component of burden for IFD includes productivity loss (work absenteeism) and premature death. As mentioned previously, more research is needed to better quantify this burden.

Another patient-centered burden is reduced quality of life (QoL), a problem that remains woefully understudied in the patient with IFD and caregiver populations. Every patient and caregiver at the summit described symptoms/complications that worsened their QoL including "brain fog," depression, suicidal ideation, worry about familial responsibilities, excessive fatigue, PTSS, persistent nightmares, hyper- and hyposomnia, and others. For other disease states (eg, cancer), researchers have more extensively studied the impact of diagnosis, treatment, and chronic symptoms on QoL measures. The urgent need for more research on QoL in patients with IFD is evidenced by the shared experiences of the patients and caregivers at our summit. Similarly, as in other diseases, the economic burden for caregivers is often an underrecognized negative consequence of IFD. In the United States, 2 out of 10 caregivers have to stop working, while 4 in 10 reduce their working hours to make time to care for a loved one. Documentation of the caregiver burden in IFD is an area that requires additional investigation.

Patient and caregiver participants reported long-term sequelae frequently seen in post-intensive care syndrome (PICS), including exertional dyspnea, vocal changes related to prolonged intubation, reduction of muscle mass and function, memory loss, impaired executive function, and PTSS. The lasting impact of these conditions can greatly affect QoL and require multidisciplinary support and ongoing follow-up care. Symptoms directly attributable to opportunistic IFD are not well-defined in the literature and may be complicated by the presence of underlying illness. Further research in this area would help to establish realistic recovery expectations and enhance the overall understanding of the disease for survivors and their families.

There were limitations of the patient selection that affected the generalizability of the results of this summit. The patients were selected to represent a range of IFDs and because of their
commitment to sharing their experiences in a group setting. The patients at this summit were all male, and the majority were insured. For future work, we propose to balance out sex, social determinants of health, and other factors when selecting patients. Of note, the male predominance is reasonable, given that male patients are more likely to be diagnosed with IFD than female patients. (Rayens 2022). Nevertheless, the impact of fungal disease on female patients needs to be documented. In addition, we anticipate that the burden of disease will be more profound in patients who are less resourced, and we seek more balanced participation in the future.

CONCLUSION

The inclusion of patients and caregivers in the drug, device, and diagnostics development arena is a priority goal across disease specialties. The MSGERC DOOR working group has been established; new research to study patient reported and important outcomes tools for IFD, such as coccidioidomycoses, and MyCARE international collaborations are underway. This initial pan-fungal disease stakeholder summit was an important step in identifying IFD burden, educational needs, and research goals from a patient-centered approach. Efforts are underway to expand the MyCARE website (www.fighfungus.org) and recruit patients and caregivers to build a community, assist in designing research protocols, and support peer-to-peer efforts in the United States and internationally. Future summits are planned to maintain momentum on key priority needs and capture the voice of patients in resource-limited settings.

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Patient Consent Statement: The institutional review board of the Washington University School of Medicine deemed the summit and the reporting of outcomes as exempt from review.

The patients who attended the summit are coauthors on the manuscript and agreed to the content of the publication.

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Table 1. Key mycology priorities identified at the summit

<table>
<thead>
<tr>
<th>Main Topics</th>
<th>Top Priorities</th>
</tr>
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</table>
| **Education** | • Web-based information  
|             | • What to expect across disease stages and settings  
|             | • Material to help caregivers optimize care for loved ones  
|             | • Guidance on dealing with long-term effects  
|             | • Identifying and getting help for mental health side effects |
| **Research** | • New diagnostics development |
New drugs that are effective and safe
Patient-reported outcomes
Desirability of Outcome Response (DOOR)
New clinical trial methodologies
Documenting risks and disease burden
Fungal isolate banks

Advocacy
Public and provider education about fungal diseases – educating them to “think fungal” at all levels of training
Reaching primary care for streamlined referrals
Financial resources, funding
Frequently asked questions with responses
List of questions for patients to ask providers
Peer-to-peer programs for patient/caregiver support
Creating educational programs for medical students, clinicians

Figure. IFD treatment journey with common challenges faced at different stages.

Issues Experienced by Patients and Caregivers Across Stages of Delayed Diagnosis and Recovery

<table>
<thead>
<tr>
<th>Pre-Diagnosis</th>
<th>Acute Treatment</th>
<th>Long-Term Treatment</th>
<th>Long-Term Recovery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncertainty*</td>
<td>Isolation</td>
<td>Medication side effects</td>
<td>Difficulty accepting a new normal</td>
</tr>
<tr>
<td>Exhaustion</td>
<td>Dependence</td>
<td>Brain fog</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>Memory loss</td>
<td>Hyperosomia</td>
<td>Depression*</td>
</tr>
<tr>
<td>Frustration*</td>
<td>Agitation</td>
<td>Hyposomia*</td>
<td>Financial toxicity*</td>
</tr>
<tr>
<td>Anxiety*</td>
<td>Fear*</td>
<td>Grief*</td>
<td>Hyposomia*</td>
</tr>
<tr>
<td>Depression</td>
<td>Stress*</td>
<td>PTSS*</td>
<td>PTSS*</td>
</tr>
<tr>
<td>Stress*</td>
<td>Lack of communication*</td>
<td>Loss of function</td>
<td></td>
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<tr>
<td>Time demands (delays/HCP visits)*</td>
<td>Loss of awareness</td>
<td>Fatigue</td>
<td></td>
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<tr>
<td>Financial toxicity*</td>
<td>Financial toxicity*</td>
<td>Employment, reduced*</td>
<td></td>
</tr>
<tr>
<td>Time demands*</td>
<td></td>
<td>Decreased ADL</td>
<td></td>
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<tr>
<td>Financial toxicity*</td>
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<td>Financial toxicity*</td>
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Note: ADL = Activities of daily living; PTSS = Post traumatic stress syndrome
*Issues also affecting caregivers as well as patients
Graphical Abstract

Shared Vision for Improving Outcomes for Serious Fungal Diseases: Report of a Patient, Caregiver, and Clinician Summit

May 2023 1.5-Day Summit
Patients with IFDs, caregivers, clinicians, industry representatives, government officials, patient advocacy professionals

Objectives
- Share patient and caregiver stories
- Identify commonalities and gaps in perceptions
- Formulate common recommendations for education, research, and advocacy

Shared Stories (Commonalities)
- Substantial physical, psychological, and financial burdens
- Many suffered because of delayed diagnosis
- Challenges across the treatment journey

Priorities
- Provide patient-centered education
- Establish peer-support
- Advocate to document the burden of illness
- Address insufficient mycology training
- Support the ID workforce
- Partner with patient groups
- Develop relevant patient-centered outcomes (PRO and DOOR)
- Increase focus on diagnostics

DOOR = desirability of outcome ranking; ID = infectious disease; IFD = invasive fungal disease; PRO = patient-reported outcome; PTSD = post-traumatic stress syndrome