

The Mycetoma Appeal

Mycetoma is a neglected tropical disease (NTD) that predominantly affects the poorest populations living in remote, underserved communities within tropical regions. It is characterised by chronic, progressive infection caused by filamentous fungi or actinomycetes, leading to severe disfigurement, disability, and, if untreated, eventual death. The disease typically manifests as swelling and the formation of sinus tracts that discharge grains. It primarily affects the feet, legs, or hands, and its progression often destroys underlying tissues and bones. Despite its significant health impact, mycetoma remains under-recognised and underfunded, classified among neglected tropical diseases due to its limited awareness and inadequate research focus.

The burden of mycetoma is particularly heavy in impoverished, rural communities where access to healthcare services is minimal. These populations often lack the means to seek timely diagnosis and treatment, which leads to advanced disease stages and poor outcomes. The disease perpetuates a cycle of poverty, as affected individuals are frequently unable to work or perform daily activities, further impoverishing their families and communities. The social stigma associated with disfigurement and disability caused by mycetoma also contributes to social isolation and psychological distress.

Sudan is recognised as the epicenter of mycetoma globally, bearing the highest disease burden worldwide. The country's environmental conditions, such as arid and semi-arid climates, along with socio-economic factors, foster the endemicity of the disease. Sudan's unique position as the focal point for mycetoma has catalysed efforts to understand and combat the disease at national and international levels. It is home to the world's only dedicated Mycetoma Research Center (MRC), which has become a global hub for scientific research, clinical management, and training related to mycetoma and other neglected tropical skin diseases. (www.mycetoma.edu.sd)

The Mycetoma Research Center in Sudan is distinguished by its comprehensive approach to patient care and scientific research. It operates as the only WHO Collaborating Center on Mycetoma and Skin NTDs, collaborating with international agencies to develop strategies for disease control and management. The MRC provides holistic medical care to patients, integrating surgical, medical, and rehabilitative services, all free of charge. Beyond individual patient care, the center engages in socioeconomic support programmes aimed at improving the livelihoods of affected communities. It recognises that addressing mycetoma requires not only medical intervention but also social and economic empowerment.

In addition to its clinical services, the MRC actively involves itself in community engagement initiatives to raise awareness, promote early detection, and prevent disease progression. These initiatives include outreach programmes, community improvement initiatives, health educational campaigns, and training sessions for community health workers. The center also conducts cutting-edge scientific research to understand better the disease's epidemiology, pathogenesis, and optimal treatment strategies. It fosters innovation through super patients vocational and entrepreneurship training programmes, equipping local health professionals and researchers with advanced skills to sustain long-term efforts against mycetoma. (www.mycetoma.edu.sd)

The MRC's influence extends through its satellite centers established in endemic villages, bringing services directly to remote populations. These satellite centers are vital in ensuring timely diagnosis and treatment, reducing the burden on centralised facilities and improving patient outcomes.

However, the April 2024 conflict in Sudan destroyed the main MRC, severely impacting ongoing scientific research, patient care, training and community programmes. The loss of this vital infrastructure underscores the urgent need for reconstruction and recovery efforts. Restoring the MRC and its satellite centers is crucial to resume services for affected patients, support affected communities, and continue global scientific research, training, and education initiatives essential for controlling and eventually eradicating mycetoma. The rebuilding process is not only about infrastructure but also about reaffirming a commitment to global health equity and neglected tropical disease control (www.mycetoma.edu.sd).