



Mycetoma

Research Centre

Innovation & Excellence

University of Khartoum
Khartoum – Sudan

Mycetoma the Flesh Eating Tropical Disease

Background

Mycetoma is a common health problem in many tropical and subtropical regions and has many serious medical and socioeconomic impacts on patients and communities. It's characterised by massive deformity, disability and high morbidly, yet it is one of the badly neglected tropical diseases worldwide.

It has Only recently been included in the Neglected Tropical Diseases Department/ WHO list as a special condition.

There is a massive knowledge gap in the epidemiology, pathogenesis and management of mycetoma which has severely affected patients' management and proper planning for mycetoma prevention and control measurements.

To bridge this gap, the Mycetoma Research Centre (MRC), University of Khartoum was established.







The Establishment

Mycetoma Research Centre (MRC) was established in 1991 under the umbrella of the University of Khartoum. It was set up at Soba University Hospital to provide an integrated high quality medical care for mycetoma patients, superb research, excellent education, teaching and training in the various aspects of mycetoma and exceptional community development activities.

MRC is a WHO Collaborative Centre, that is recognized globally as a world leader and an authoritative advisor in mycetoma management and research. It is one of its kindworldwide as a specialised centre to deal with the mycetoma patients.

The centre is dedicated to the continuous discovery and development of scientific knowledge and clinical skills that is applied that to the care of mycetoma patients.



MRC Vision

To continue to be the world leader in mycetoma management & research

MRC Mission

To eradicate mycetoma, which is a life-mutilating disease, through the advancement and innovation of patients' care, scientific research, education and community advocacy.

MRC Objectives

The MRC objectives are to:

- Provide the state-of-the-art, multidisciplinary care to individual patients, combining medical, surgical, nursing and social expertise.
- Conduct outstanding superb scientific research.
- Offer energetic and effective programme of teaching and education.
- · Deliver effective community development activities.
- Establishment of national and global databases on mycetoma.
- Establishment of national and international partnership to achieve its objectives.

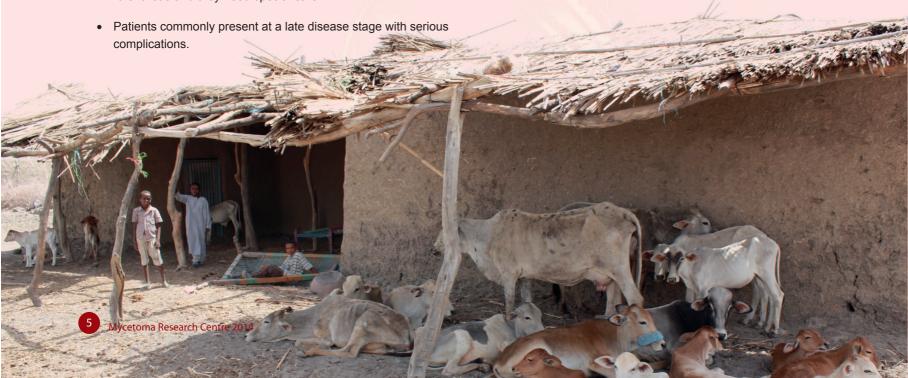




The MRC Justifications

- Mycetoma is a common health problem, endemic in many tropical and subtropical regions, reported throuout the globe and Sudan is considered the mycetoma homeland.
- Mycetoma enjoys meager attention by medical, health and social communities across the globe, as it is not a glorious disease.
- Mycetoma commonly affects the poor of the poorest in unrich rural areas and they need special care.

- The lack of an excellent holistic approach to patient care.
- The absence of patients' management guidelines and protocols.
- To attract national and international support and ignite donors' interest for new drugs discovery, effective diagnostics development and community advocacy.



MRC Committees

The centre has four committees to plan, monitor and evaluate the centre's activities and they are:

The Research Committee.



The Clinical Committee.





The Community Development

Committee

The Education & Continuing **Professional Development** Committee.

MRC Staff

The MRC staff members are of medical, health and scientific backgrounds who are interested in all facets related to mycetoma. They have rich track records in patients' management, teaching & learning, scientific research and community development activities.



Prof. Ahmed Mohamed EL Hassan, DKSM, DCP, FRCP, PhD, FRCPath Emeritus Professor of Pathology



Prof. EL Sheikh Mahgoub, MBBS, MD, PhD, FRCPath Professor of Medical Microbiology



Prof. Ahmed Hassan Fahal, MBBS, FRCS, FRCSI, MD, MS, FRCP(London) Professor of Surgery



Dr. Abdulla Osman Abdulla Ahmed, BSc, MSc, PhD Associate Professor of Microbiology



Mr. El Sammani Wadatlla, MBBS, MD Consultant Surgeon



Miss. Eshraga Abker, MBBS, MD Consultant Surgeon



Dr. Sara Mohamed, MBBS Research Assistant



Dr. Ali wadaa, MBBS Research Assistant



Dr. Amal Abusabaa, MBBS Research Assistant



Dr. Ahmed Hashim, MBBS Research Assistant



Dr. Duaa Hassan, MBBS Research Assistant



Dr. Huda Ahmed, MBBS Research Assistant



Dr. Safa Khadir, MBBS Research Assistant



Dr. Mohamed Yahia, MBBS Research Assistant



Dr. Hagier Elzaien, MBBS Research Assistant



Sister Safa A Moneium, BSc Senior MRC Sister



Mr. A Razig Osman, Senior MRC Nurse



Miss Nagwa Joda, BSc, MSc Senior Technologist



Mr. Yassir Adam, Medical Photographer



Abdalla Abdelrazig Research Assistant



Mr. Edris Ahmed, Porter



Mr. Haroun Sharaf, Porter



Mr. Mosa Ibrahim, Porter



Mrs. Fatima Abdlerahman, Porter



The Venue

MRC is nicely constructed has a reception with a gallery, two laboratories; molecular & microbiology, library, meeting room, seven patients' consultation rooms, minor theatre, patients' waiting area, medical information unit and green landscape with rare plants and trees

MRC host the National Mycetoma Control Programme, Ministry of Health

Mycetoma Research Centre Activities: Patients Management

MRC prides itself on a multidisciplinary approach to individual patient's care and combines both medical and surgical expertise with specialist nursing and paramedical skills.

MRC has a long history of providing exceptional care for the mycetoma patients by putting the welfare of patients first. The medical care at MRC is one of continuous change and challenge.

During the last few years, more than 6700 patients with mycetoma have been seen and managed at MRC and they were from the Sudan and overseas and that included Ethiopia, Somalia, Yemen, Saudi Arabia and Chad. Through the internet and Skype, MRC had advised on the management of patients from Bangladesh, India, Kenya, Ukraine and USA.



The patients' distribution



MRC had managed through some donors such as MSF, national pharmaceutical companies, EL Zakat Chamber fund and individuals to provide free drugs for some patients. All patients had free medical consultation at the center and some of them had free surgical treatment at Soba University Hospital.

The Mycetoma Clinic

The Mycetoma Clinic at the MRC was established in 1991, aiming for the provision of mycetoma patients with excellent medical care. More than 6700 patients are registered in the clinic and they are seen regularly there. The clinic accepts patients from different parts of the country and overseas. The clinical services are offered by a group of well-trained clinicians, pathologists, microbiologists and radiologists as well as an expert team of nurses and social workers.

Treatment guideline for the patients' treatment was produced by an expert group of experts in mycetoma management.

Health education sessions, organized by health workers, are conducted regularly. Patients' counseling is done by the MRC social workers.



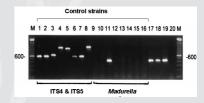


Development & Utilization of New Diagnostic Tools.

MRC had developed many diagnostic tools and techniques for accurate, sensitive and safe diagnosis of mycetoma and that included:

- Fine Needle Aspiration Cytology & Cell Block Technique
- Ultrasonic Imaging
- Magnetic Resonance Imaging
- Molecular Identification of Mycetoma Causative Organisms by (PCR)

Currently two novel serological and molecular based tests are under development in collaboration with the Erasmus Medical Centre, University of Rotterdam, The Netherland by a MRC Research Assistant.



Health Education & Advocacy

MRC has produced many CDs, video films, booklets and posters on mycetoma for public health education and advocacy and these included:

- o The Mycetoma Story
- o Medical Treatment of Mycetoma
- o Coping with Mycetoma
- o Taking Mycetoma Treatment
- o Going Home after Mycetoma Surgery
- o Your Centre Social Worker "Can I be of help to you?"
- o Investigations for Mycetoma Patients information





The WHO Khartoum office & groups of medical students at the University of Khartoum had produced several video films and they are posted at MRC website at: www.mycetoma.edu.sd



Mycetoma as a neglected medical, health and socio-economic problem was presented several times to the public through:

- Sudan National TV
- o Khartoum State TV
- o Al Jazeera TV Channel, Qatar
- o Al Hurra TV Channel, Washington
- o Local Newspapers.

The MRC has educational websites at: www.mycetoma.edu.sd. & http://mycetoma.uofk.edu/

MRC has Facebook page at:

https://www.facebook.com/pages/Mycetoma-Research-Cent er/533892649995569?ref=notif¬if_t=fbpage_fan_invite

Linked page at:

http://www.linkedin.com/groups/Mycetoma-Consortium-7431076?trk=groups management edit group info-h-dsc

YouTube page at: www.mycetoma.edu.sd















Community Development Activities

Many patients tend to present late with advanced disease where amputation of the affected part may be the only possible treatment. Most of these patients are from under-developed communities and hence one of the MRC objectives is to reach these patients at their communities, to conduct health education sessions and promote advocacy.

To achieve this, staff members have conducted many field trips to various mycetoma endemic areas and that included Sinnar, Gazeria and the White Nile States. In these areas, out-patients clinics were established, house to house surveys were conducted and patients were encourage to attend these clinics. Patients were treated and complicated cases where referred to MRC or nearby general hospitals for further treatment.

An integrated management approach was adopted and conducted by the MRC at Al Andal-



ous village, an endemic village at the White Nile State. The various problems associated with mycetoma were addressed simultaneously at the village level. House to house survey was conducted to detect early mycetoma cases. A mobile surgical unit at the village was established and 70 patients underwent surgical treatment. Health education sessions were conducted.





Medical students from the local university; Bakht-El-Ruda University were involved in these activities. These activities were conducted by generous assistance and funding from the Association for Aid and Relief, Japan, a Japanese NGO.

Medical & Paramedical Staff Training

The centre had trained a core of medical, nursing and health personnel from different parts of the country in various medical, health and nursing aspects of mycetoma and now they are the change leaders in the management of mycetoma patients.



MRC Scientific Research & Publications

At the heart of MRC mission is to improve the patients' care through the conduction of the state of the art scientific research. To achieve this, the MRC conducted many scientific researches across the biomedical spectrum, from fundamental basic science and experimental to clinical trials and field survey.

That was done locally and in collaboration with many highly reputable international centres. MRC gives a high priority to research that is likely to make a real difference to clinical practice and the health care of mycetoma patients.

MRC had produced more than 90 original articles published in distinguished journals and textbooks, one textbook and guidelines for patients' treatment and that had contributed notably to the world literature on mycetoma.



MRC International Collaboration

MRC has collaborated with many highly reputable international institutes and centers in the field of mycetoma and other endemic and tropical diseases. This has resulted in knowledge and experience exchange, technology transfer and the conduction of high calibre research and publications.

Collaborative Centres & Focal Persons:

Department of Medical Microbiology & Infectious Diseases, Erasmus Medical Center, Rotterdam University, Rotterdam, The Netherlands

Dr. Wendy W.J. van de Sande

Centraalbureau voor Schimmelcultures, Utrecht. The Netherlands.

Prof. Sybren De Hoog

School of Biology, University of Newcastle, United Kingdom.

Prof. Michael Goodfellow

Department of Dermatology, Dr. Jose E Gonzalez University Hospital, Universi-

dad Autónoma de Nuevo León, Monterrey, Mexico

Prof. Oliverio Welsh

Drugs for Neglected Tropical Diseases initiative (DNDi) Geneva

Dr. Nathalie Strub-Wourgaft

Department of Plant Physiology, Institute for Biological Research "Sinisa

Stankovic", Bulevar Despota Stefana, Belgrade, Serbia.

Dr. Dejan Stojkovic









Strathclyde Institute of Pharmacy and Biomedical Sciences. Strathclyde University, Glasgow, United Kingdom

Dr. Paul Hoskisson

Medicimage Foundation United Kingdom

Mr. Steward Goldstein

The Swiss Tropical and Public Health Institute, Basel, Switzerland

Prof. Marcel Tanner

The School of Pharmacy & Bimolecular Sciences, Liverpool John Moores University

Dr. Kehinde Ross

The WHO Khartoum Office

Dr. Anshu Banerjee

Neglected Tropical Diseases Department, WHO, Genvea

Dr. Denis Paul Daumerie





Students Teaching & Education

MRC staff is highly committed to provide enthused and inspired teaching for under-graduate and post-graduate students as well as continuing professional development for medical and health professionals.

MRC offers the international exchange programme students from different parts of the world teaching and training opportunities.

MRC has students' corner at its website where active learning opportunities are offered. www. mycetoma.edu.sd

MRC organises students' competitions on mycetoma health education issues. www.mycetoma. edu.sd

Post-Graduate Training & Education & Career Development Programme

The Centre has ongoing multi-disciplinary research programmes and projects dedicated to basic research on the pathogenesis and progression of mycetoma, to facilitate the translation of new knowledge and technology into novel treatments and diagnostics and the provision of state-of-the-art patient's care.

MRC provides research opportunities and training for graduate students who wish to study for a 4-year PhD degree and 2-year master degree registered at different national or international universities and institutions.

MRC also provides Training & Career Development Programme for young clinicians and biomedical scientists at every stage of their careers to improve their capacities' to plan and conduct sound and high-quality research.

MRC offers a comprehensive training programme on various research issues for MRC researchers and researchers nationwide, and continually assess their training needs and update their training strategy accordingly. The following workshops and training courses are conducted regularly and they are:

- Research Methodology
- Research Ethics
- · Good Clinical Practice,
- Bio-Statistic Principles
- Scientific Writing
- Proposal Writing
- Literature Search
- Different Laboratory Techniques

MRC is committed to produce skilled researchers and to advance and disseminate knowledge, technology and innovation to improve the life quality of the mycetoma patients and humanity in general.

Post - Graduate Degrees Obtained

The following students had obtained different post-graduate degrees under the supervision of MRC staff

Master Degrees:

- 1. Miss Amel F. Farouk, MSc Molecular Biology, University of Khartoum, HLA frequency in Sudanese mycetoma patients.
- 2. Miss Rasha W. Shanteir, MSc Molecular Biology, University of Khartoum, Monitoring of antibody response in Sudanese mycetoma patients.
- Miss Israa O. Elrayah, MSc Molecular Biology, University of Khartoum.
 Analysis of the cellular immune response of mycetoma patients, IFNg and IL-10 profiles.
- Dr. Abdel EL Badie Mustauim, MSc Pharmcokinetics, University of Khartoum.
 The pharmacokinetics and pharmacodynamics of ketoconazole in the treatment of mycetoma patients.
- Dr. Intasar A Rahman, MSc Pharmacology, University of Khartoum.
 The efficacy of ketoconazole in the treatment of eumycetoma Patients.
- Mr. Abdulla Osman Ahmed, MSc Molecular Biology, University of Khartoum.
 Development of a Species-Specific PCR-Restriction Fragment Length Polymorphism Analysis Procedure for Identification of Madurella mycetomatis.
- Dr. Ihab EL Agab, MSc Immunology, University of Khartoum.
 Peripheral Blood Mononuclear Cells of Mycetoma Patients React Differently to Madurella mycetomatis Antigens than Healthy Endemic Controls.
- 8. Miss Hana Awad, MSc mycology, University of Khartoum. The use of Western blot in the diagnosis of mycetoma.

Clinical MD Thesis:

- 9. Dr. Ahmed A Fatih, MD Clinical Surgery, University of Khartoum. The predictors of recurrence in mycetoma
- Dr. Mubark Aouda, MD Clinical Surgery, University of Khartoum.
 The clinical presentation of mycetoma.
- 11. Dr. Nada Osman Yousif, MD Clinical Paediatrics, University of Khartoum. Clinical presentation of mycetoma in children, knowledge, attitude, practice towards the disease.
- 12. Hagir AM Zein, MD Clinical Surgery, SMSB The Predictors of Cure, Amputation & Follow-up dropout among Myce toma Patients as seen at The Mycetoma Research Centre, University of Khartoum.
- 13. Dr. Eshraga Abu Bakhir, MD Clinical Surgery, SMSB The effectiveness of Moringa Oleifera in the treatment of mycetoma, in progress.



PhD Students:

- 14. Dr. Abdalla Osman Ahmed, Erasmus Medical Centre, Rotterdam University, The Netherlands "Molecular and biological studies on Madurella mycetomatis infection in man and mice".
- 15. Dr. Wendy Van de Sande, Erasmus Medical Centre, Rotterdam University, The Netherlands "Genetic variability, antigenicity and antifungal susceptibility of Madurella Mycetomatis".
- 16. Dr. Erika T. Quintana, Newcastle University, UK "Streptomyces sudanensis sp. a new pathogen".
- 17. Dr. Hassab EL Rasoul El Fadi, Gazeria University "Plant-based Pharmacotherapy a Novel Model for Madurella mycetomatis Eumycetoma Treatment".



Organisation of Scientific Meetings

MRC has organised many international and local conferences, seminars and meetings which aimed to act as a medium for medical and health professionals and scientists who are interested in mycetoma to maintain contacts, to exchange and update knowledge and experience, to provide continuous professional development in mycetoma and also to provide advices and recommendations to the concerned authorities.

These included:

- Mycetoma Workshop, The American Society of Tropical Medicine & Hygiene Washington DC, USA, 2013.
- Mycetoma Workshop, The International Society of Human and Animal Mycology, Berlin, Germany, 2012.
- The 5th International Conference on Mycetoma, Khartoum, Sudan, 2011
- The Mycetoma International Week, Khartoum, Sudan, 2009
- Mycetoma Workshop, The International Society of Human and Animal Mycology, Paris, France, 2006.
- The 3rd International Conference on Mycetoma, Khartoum, Sudan, 2002
- Mycetoma Seminar, Sinnar University, Sinnar, Sudan, 2005.
- Mycetoma Seminar, Gazeria University, Madani, Sudan, 2000
- Mycetoma Seminar, The Sudan Association of Surgeons, Annual Conference, 1990, Khartoum, Sudan

Communication to Learned Societies

MRC members attended and gave more than 50 presentations in many local, and international conferences, meetings and seminars.

They attended different consultation meetings such as:

- The Strategic and Technical Advisory Group on Neglected Tropical Diseases, WHO, Geneva
- Drugs for Neglected Tropical Diseases Initiative, Geneva.
- The World Health Assembly, WHO, Geneva.



The Mycetoma National Programme

The National Mycetoma Control Program (NMCP) is an integrated joint venture between The Federal Ministry of Health & Mycetoma Research Centre, University of Khartoum. It is a service integrated program. Its aim is to eradicate the Mycetoma from Sudan through provision of high quality treatment and averting disease complications. To do so, the program focus on improvement of Mycetoma patients treatment through provision of free treatment, capacity building of health providers in diagnosis and management of patients, provision of information on disease burden and impact of treatment to help in publishing and dissemination of country's experience to the globe.

The program policy is focused around six strategies:

- Early diagnosis and management of patients to prevent disease complications.
- Training of health personnel to ensure adoption of the program guidelines and proper treatment of patients by competent teams.
- Timely and regular supply of drugs to ensure patient access to care and avoid interruption of treatment.
- Regular supervision to maintain good performance, problem solving and sharing of knowledge and experience.
- Recording and reporting system to ensure flow of information about disease burden, appropriateness of used regimens and assessment of program performance to shape the appropriate strategies.
- · Increase the community awareness on the disease and its complications through adequate health education

The Mycetoma Consortium

MRC has established with many international partners, the Mycetoma Consortium (MC). Its mission is to eradicate mycetoma globally as it is a mutilating and harming disease affecting the poor of the poorest around the world.

MC Justification:

Mycetoma is a badly neglected disease, it is not included in most of the neglected disease lists although it enjoys all the Neglected Tropical Diseases Department/ WHO criteria for that and these are:

- o A proxy for poverty and disadvantage.
- Affect populations with low visibility and little political voice.
- Do not travel widely.
- o Cause stigma and discrimination, especially of girls and women.
- Have an important impact on morbidity and mortality.
- o Are relatively neglected by research.
- o Can be controlled, prevented and possibly eliminated using effective and feasible solutions.

Mission:

To eradicate mycetoma globally as it is a mutilating and harming disease affecting the poor of the poorest in poor communities around the world.

Through, research to develop new, effective, affordable diagnostics and treatments that can be used in the field to treat patients and avoid amputations.

To reach out to partners, funders and friends to raise funds to bridge the gap between **Aspiration & Reality** to bring hope and help to patients.





The Objectives

- · Raise awareness globally.
- · Disease burden assessment.
- · Early diagnosis and treatment.
- · Health promotion.
- · Disabilities prevention and rehabilitation promotion.
- · Discrimination prevention.
- · New and affordable diagnostics and treatment development

Activities:

- · Patients care promotions.
- Advocacy to raise the profile of the diseases to be part of the national and international health plans.
- Fund campaigns for patients care, diagnostic & drug discovery and advocacy.

Contact us: www.mycetoma.edu.sd --mail: consortium@mycetoma.edu.sd





Mission,
Objectives
& Activities.

They work together to execute the consortium's

The Partners, Donors and Friends





The Network to Bridge the Gap Between

Aspirations & Reality

The objectives of the Consortium are:

- o Awareness rising.
- o The disease burden assessment.
- o Early diagnosis and treatment promotion.
- Disabilities prevention and rehabilitation promotion.
- o Discrimination prevention.
- o Human and financial resources mobilization.
- Scientific community involvement.

Consortium Website: http://www.mycetoma.edu.sd/demo/

The Mycetoma Research Center Foundation

MRC has established this non-profitable foundation which is a registered charity body (No 18889) aiming at promoting the treatment and care of affected patients, research and education in mycetoma.

Mycetoma Research Center Foundation has an office which consists of

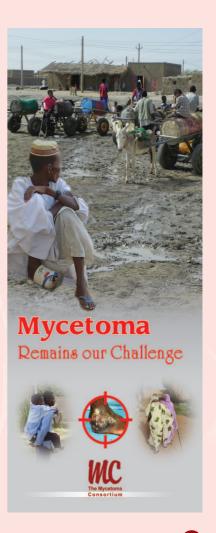
- Chairman of the Trustees.
- Secretary.
- · Fund Raising Co-coordinator.
- Office Administrator.

Mycetoma Research Center Foundation office is responsible for the day-to-day management of MRC Foundation funds and fund raising. Certain key events are held during the year in support of the Foundation.

The Foundation welcomes the support and donations of private individuals, companies and charitable trusts.

The Foundation Website:

http://www.mycetoma.edu.sd





Sudanese Traditional Medicine Museum

MRC had established a Sudanese Traditional Medicines Museum at the center where a good number of items used in treating different diseases in the Sudan were collected and displayed.



MRC Visitors

Through the years, many national and international visitors had visited the MRC. A delegate of 19 ambassadors from Europe, Asia and Africa had visited the MRC in response to kind invitation by the WHO Representative in the Sudan to discuss the means and ways to help the mycetoma patients. The visit was fruitful and many issues were discussed.



Memorandums of Understanding & Agreements

MRC had signed many memorandums of understanding and agreements with national and international bodies and associations for collaboration and partnership to promote the welfare of the mycetoma patients, scientific research and community development.

These included memorandums of understanding and agreements with:

- The Federal Ministry of Health, Sudan
- Dr. Jose E Gonzalez University Hospital, Universidad Autónoma de Nuevo León, Monterrey, Mexico
- The University of Medical Sciences and Technology, Sudan
- The Japanese Association for Relief & Help, Japan
- The International Association for Relief & Help, USA
- El Zakat Chamber, Sudan



Publications

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- 2. Fahal AH, Suliman SH, Gadir AFA, EL Hag IA, EL Amin FI, Gumaa SA, Mahgoub ES. Abdominal wall mycetoma: an unusual presentation. Trans R Soc Trop Med Hyg. 1994; 88(1):78-80. PMID: 8154012.
- 3. Fahal AH, Suliman SH. Clinical presentation of mycetoma. Sudan Med J. 1994; 32: 46-66.
- 4. Fahal AH, El Hassan AM, Abdelalla AO, Sheik HE, Cystic mycetoma: an unusual clinical presentation of Madurella mycetomatis. Trans R Soc Trop Med Hyg. 1998; 92:6-67.
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- 15. Fahal AH, Sharfi AR, Sheikh HE, EL Hassan AM. Mycetoma: Uncommon complication. Trans R Soc Trop Med Hyg. 1996; 89: 550-552.
- 16. Fahal AH, Sadig ME, Suliman SH, EL Razig SA, Mahgoub ES. Lack of association between ABO blood groups and Rh factor and the tendency to develop mycetoma. East Afr Med J. 1996; 11: 769. (Letter). PMID: 8997873
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- 18. Fahal AH, Sheikh HE, EL Lider MA, Homeida MA, EL Arabi YE, Mahgoub ES. Ultrasonic imaging in mycetoma. Br J Surg. 1997; 78: 765-766. PMID: 9278658
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Electronic Publications

· Virtual Patients Campus

Had created 20 cases
At the University of Khartoum website at
http://classes.uofk.edu/course/view.php?id=433

Ongoing Research Projects

MRC is currently, conducting several research projects addressing different mycetoma problems. Different research groups working locally and in collaboration with different international centers and institutes to execute that.





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