

The Mycetoma Research Centre, University of Khartoum WHO Collaborating Centre on Mycetoma

# **The Mycetoma** Holistic Management 2018

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# Contents

Mycetoma at the World Health Organisation (WHO) Global Mycetoma Advocacy Local Mycetoma Advocacy **Research & Development** Post-graduate Students **Research Grants** The Publications Institutional Review Board (IRB) **Conferences & Symposia Presentations Training Workshops** Patients' management The Establishment of in vitro drug sensitivity Unit **Outreach Community Activities** Health education & Community Development **MRC** Visiting fellows **MRC** Visitors MRC Laboratory upgrade Mycetoma Patients Friends Association (MPFA) Fundraising MRC Collaboration

# Preface

It is our pleasure to present the 2018 annual report on the activities and achievements of the Mycetoma Research Centre (MRC), University of Khartoum, WHO collaborative Centre on Mycetoma. The MRC mission is to promote the continuing discovery and development of scientific knowledge and clinical skills for better care of Mycetoma patients. The MRC is an interdisciplinary Centre with a worldwide rapidly expanding network of mycetoma and NTDs experts.

In this annual report, we are reporting the MRC 2018 activities, events and achievements aiming to share experience and to improve the MRC patients' care quality, scientific research, teaching and community activities. These activities were achieved by a proficient and strongly committed and well-trained staff.

The MRC has initiated numerous research projects with collaborators from different institutions and universities both nationally and overseas and that had contributed notably to the medical literature. You will find a short overview of these activities in this annual report.

In this report, we have also presented the new 2018 publications. Due to the uniqueness of our holistic management of Mycetoma experience and the field campaigns and activities in the endemic areas in Sudan, the PloS Neglected Tropical Diseases Journal had reported it in 2018 with a special press release.

Together with our many associates and allies in various parts of the world, we will continue to fight mycetoma, as a life-mutilating disease, through the advancement of medical care, research, education and disease prevention. This annual report, reports on these actions and activities.

On behalf of the Mycetoma Research Centre team, we want to deeply thank all of our collaborators and associates for their commitment, diligence, and passion. By working together, we made further significant progress last year and laid the foundation for a successful future.

Prof Ahmed Hasan Fahal MRC Director

# Mycetoma at the World Health Organization (WHO)

#### The World Health Organization, Director-General visit

Dr Tedros Adhanom Ghebreyesus, The World Health Organization, Director-General on Sunday 24<sup>th</sup> October 2018 had visited the MRC as a WHO Collaborating Centre on Mycetoma. He pledged to support the MRC initiatives that produce better diagnostics and medicines for mycetoma patients. Dr Ghebreyes also had called for more research into mycetoma, particularly on its epidemiology, diagnostics to produce a simple point of care test, and called for new cost-effective medicine and disease control.

This visit by the Director-General and his senior staff illustrates the current vision of WHO to promote health, to keep the world safe and serve the vulnerable. The visit did not only boost the MRC staff morale, but it opens a new chapter of collaborative activities between the MRC and the WHO for better patients care and community improvement and to find innovative treatment and diagnostic tools for this most forgotten disease.

#### **Online links:**

- https://www.who.int/neglected\_diseases/news/Mycetomadevelopment-of-prevention-tools-and-diagnostics/en/
- http://www.mycetoma.edu.sd/index.php/archive-mrc/146director-general-of-who-calls-for-more-mycetoma-researchduring-visit-to-mycetoma-research-centre



# The World health organization, Deputy Director-General visit

As always we were delighted by the kind visit of the World Health Organization, Deputy Director-General Dr Soumya Swaminathan on February 6<sup>th</sup>, 2018. She was accompanied by the State Minister of Health, Sudan and Dr Neema Al Gasseer WHO Representative for Sudan and Head of Country Office. During the visit, they ensured their active advocacy for operational research, and to support the MRC to achieve its objectives and activities.



## Global Mycetoma Advocacy

The MRC had created the following social media sites for global mycetoma advocacy and awareness and these included:

#### Mycetoma Facebook page

This page actively posts the events and activities taking place at the MRC. https://www.facebook.com/pages/Mycetoma-Research-Center/533892649995569?ref=notif&notif\_t=fbpage\_fan\_invite

# Mycetoma YouTube

https://www.youtube.com/user/MycetomaSUDAN

The MRC had produced 56 video clips for mycetoma advocacy and awareness, and they were posted on the MRC YouTube website.

## Mycetoma Newsletter

http://mycetoma.edu.sd/news/

The MRC published several issues of its Newsletter that enclosed several news and events conducted by the MRC. http://www.mycetoma.edu.sd/news/

#### **Mycetoma Twitter**

https://twitter.com/MycetomaRC

# Annual report for the MRC twitter account

The MRC established a Twitter account in 15th October 2018, and currently, there are:

- 73 followers
- 114 tweets (including MRC visitors, awareness videos, updates about MRC publications and workshop and conference posts)
- Followed 51 pages
- Most of the tweets were linked and posted in the MRC Facebook account and vice versa.





# Local Mycetoma Advocacy

Many activities on mycetoma advocacy were done, and that included:

- Several advocacy short video clips were produced for mycetoma awareness and promotion.
- A short drama film on mycetoma advocacy.
- Production of Mycetoma story in the cartoon.
- Several interviews were conducted by Sudan, Sennar, EL Shorag, and Blue Nile TVs channels.

# All these material were posted on the MRC YouTube website.

https://www.youtube.com/user/MycetomaSUDAN

Mycetoma socio-economic impacts were addressed in many national newspapers in Sudan, and that included articles on:

- 1. The collaboration of Sudanese artists with the Mycetoma Research Center, Akher Lahaza newspaper, March 2018.
- 2. The visit of Artists and celebrities to Mycetoma Research Center, Al-Ahdath News, August 2018.
- 3. The prostheses campaign in Sennar State, Al-Watan Newspaper, October 2018.
- 4. Honouring of Professor Fahal for the Donald Mackay Medal, Al- Mejhar November 2018.
- 5. The commitment of the Sudan Ministry of Health for free treatment of mycetoma, Al- Mejhar, December 2018.

# Mycetoma as a neglected tropical disease was discussed in many social media

http://mycetoma.edu.sd/index.php/fruit-encyclopedia/links

# Mycetoma in the International Media

- Drugs for Neglected Diseases initiative (DNDi) had created many links on mycetoma advocacy at its website addressing the different aspects of the DNDi and MRC collaboration https://www.dndi.org/?s=mycetoma
- The Royal Society of Tropical Medicine and Hygiene (RSTMH), London had posted the announcement of the 2018 Donald Mackay Medal which was awarded to Prof Ahmed Hassan Fahal, the MRC Director.

https://rstmh.org/blog/2018/oct/2/our-2018-medal-and-awards-winners

The WHO website was updated to include various news and posts on mycetoma as a neglected tropical disease for more advocacy

https://www.who.int/news-room/fact-sheets/detail/mycetoma



# Mycetoma Panting and Photography Exhibition

Mr Khalid Hamid, an artist, photographer, and painter at Zebra Art Project, Sudan had kindly donated more than 50 collections of oils, inks, watercolours paints and photographs showing the mycetoma patients' agony and suffering for more awareness and support.





# **Research & Development**

The MRC is currently conducting several research projects in collaboration with several national and international research institutes and centres and these are:

#### • The first-ever double-blind clinical trial on eumycetoma treatment.

A good number of patients with confirmed eumycetoma due to Madurella mycetomatis were enrolled so far in this first-ever double-blind clinical trial on eumycetoma treatment. The trial is a randomised, double-blind phase II proof-of-concept superiority trial of fosravuconazole 200 mg or 300 mg weekly dose versus itraconazole 400 mg daily dose, all three arms in combination with surgery, in patients with eumycetoma in Sudan. It is sponsored by the Drugs for Neglected Diseases Initiative (DNDi), Geneva and Eisa Ltd., Japan Company.

#### • Spatial Epidemiology of Mycetoma in Sudan project

Still there a massive knowledge in mycetoma epidemiology, disease distribution, and its incidence and prevalence. Presently MRC is conducting a collaborative research project with Brighton and Sussex Medical School, UK (BSMS) supported by the National Institute of Health Research, UK. The project is targeting three mycetoma endemic states; Gaziera, Sennar and White Nile states. They were selected due to their high endemicity based on the MRC records. The study objectives are to determine the prevalence of mycetoma in Sudan, determine the role of environmental risk factors in the disease occurrence, population at risk and the so-cioeconomic impact of the disease in the affected population. The project duration is three years.

#### • Mycetoma diagnosis and pathogenesis project

Mycetoma is a unique neglected tropical disease caused by a substantial number of microorganisms of fungal or bacterial origins. Identification of the causative organism and the disease extension are the first steps in the management of the affected patients and for predicting disease treatment outcome and prognosis. This project is a joint PhD programme between the Mycetoma Research Center and Erasmus Medical Center, Department of Medical Microbiology and Infectious Disease. The project aims to validate the M. mycetomatis specific PCR in a daily clinical setting, and identification and characterisation of the second most common causative agents in Sudan, the development of a multiplex specific PCR for the most common causative agents of mycetoma in Sudan. Moreover, designing and validation of M. mycetomatis specific real-time PCR directly on grains to ensure rapid identification and reduction in diagnosis time.

#### • Metagenomic analysis of environmental samples from mycetoma endemic areas in Sudan project

Mycetoma is a distinctive neglected tropical disease caused by a significant number of microorganisms of fungal or bacterial origins. However, currently, the route of infection in mycetoma is unclear. The project aims to study the soil-borne or thorn-prick-mediated theory of infection in this infection as well as the environmental factors roles in the disease transmission.

#### • Arthropod vector in eumycetoma transmission in the endemic area project.

The present project aims to determine the possible role of arthropod vectors in the transmission of eumycetoma in an endemic area in the poor savanna belt in Eastern Sennar locality, Sennar State, Sudan.

#### • Protein biobank project

The project aims to establish a Protein Biobank at the MRC in collaboration with the Department of Biochemistry, Faculty of Medicine, University of Khartoum. The material will be available for future protein identification and rapid mycetoma test design.

#### • The MRC Biobank Project

The MRC is establishing a biobank for the available biological material at the Centre. The material includes culture isolates, tissues, grains, sera, blood, and tissue blocks. With this system, this material will be handy and available for future research and collaboration with other research institutes and centres. We have developed a specific designed software for archiving all the biobank specimens

#### • Development of a novel rapid, sensitive and affordable point of care diagnostic test for eumycetoma project.

This project is sponsored by the Ministry of Higher Education and Scientific Research in collaboration with the Institute of Endemic Diseases, University of Khartoum and Elzaim Alazhari University. Its main objective is to design a point of care diagnostic test for mycetoma.

#### The Immunopathology project.

This project aims to study in depth the immunopathology of mycetoma, and that is in collaboration with the Infection and Inflammation Centre, York University, UK.

#### • The Mycetoma Genetic project

In collaboration with Brighton and Sussex Medical School, UK (BSMS) supported by the National Institute of Health Research the MRC is conducting a research project on the genetics of mycetoma. The project is examining the genetic background of mycetoma patients in certain endemic areas in Sudan, with the objective to bridge the knowledge gap in the susceptibility and resistance to mycetoma.

#### • The Social impact of mycetoma

As a joint PhD programme between the MRC and Brighton and Sussex Medical School, UK (BSMS) supported by the National Institute of Health Research, UK an in-depth study on the various social impact of mycetoma on patients, families, community, and health system is currently conducted in Eastern Sennar, Sennar State.



# Post-graduate Students

#### PhD Thesis in Progress

- 1. Dr Rowa Fath EL Rahman, Epidemiology of mycetoma in Sudan in collaboration with Brighton and Sussex Medical School, UK (BSMS) supported by the National Institute of Health Research, UK.
- 2. Miss Rayan Ali, genetics of Mycetoma, in collaboration with Brighton and Sussex Medical School, UK (BSMS) supported by the National Institute of Health Research, UK.
- 3. Dr Mohamed Nasar, the social aspects of Mycetoma, in collaboration Brighton and Sussex Medical School, UK (BSMS) supported by the National Institute of Health Research, UK.
- 4. Miss Hoyam Mohamed, Mathematical modelling for the Diagnosis of Mycetoma, in collaboration with Tours University, France.
- 5. Dr Lamis Yahia, Drug repurposing for the treatment of Mycetoma, in collaboration with Tours University, France
- 6. Mr Emmanuel Edwar Siddig, New molecular diagnostics for Mycetoma, in collaboration with Rotterdam University, The Netherlands



# Supervision of Medical & Health Students Research

The MRC staff had supervised many Medical & Health Students in their dissertations in Community Medicine and Medical Microbiology Scientific Meetings Attended

# National and international meetings attended:

- 1. The 20th ISHAM congress 2018 -Amsterdam, The Netherlands, from 30<sup>th</sup> June 4<sup>th</sup> July 2018.
- National Institute of Health Research, Global Health Research Unit Project, Annual Meeting, Addis Abba Ethiopia, 22nd September 2018.
- Global Mycetoma Working Group meeting, Addis Abba Ethiopia, 26th September 2018
- 4. NNN meeting, Addis Abba Ethiopia, 24th-26th September 2018
- Global Mycetoma Working Group, Amsterdam, The Netherlands, 4<sup>th</sup> July 2018.
- 6. National Institute of Health Research project, consultation meeting, Addis Abba Ethiopia, 22<sup>nd</sup> September 2018
- 7. The First International Podoconiosis conference, Addis Ababa, Ethiopia, 2018.
- 8. National Institute of Health Research, Global Health Research Unit Project, proposal and partnership development Meeting, Addis Abba Ethiopia, 22nd November 2018.





# **Research Fellowships**

The MRC offers training and research fellowships to distinguished researchers and clinicians. In 2018 the MRC has offered three scholarships to international visiting clinicians for training in various aspects of mycetoma, and these were:

- Dr Iftin Osman Moussa, Ministry of Health, Republic of Djibouti supported by the WHO, EMRO.
- Dr Steven Van Den Broucke, Institute of Tropical Medicine, Belgium 13<sup>th-21st</sup> October 2018.
- Dr Till Frederik Omansen, NTD Department, WHO, Geneva, supported by the WHO, Geneva

# **Research scholarships**

Four research scholarships were offered to

- Miss Salama Ahmed Ramadan on protein study.
- Dr. Ammar Isam EL Din Sagid on in vitro drug sensitivity testing.
- Miss Khadiga Algaili Izzaldin on Microbiology
- Mr Abdelgabbar Siddig on Microbiology



# **Research Grants**

The MRC had received several research grants and these included:

Awarding body	Grant holders Name	Project Title	Start date	End date
York University	Paul Key (PI) Ahmed Fahal (Co-investigator)	Mycetoma immunopathology	2018	2019
DNDi Switzerland & GIHAT Japan	Ahmed Fahal (PI)	Clinical trial of fosravuconazole	2017	2020
NIHR UK	Melanie Newport (PI) Ahmed Fahal (Co-investigator)	NIHR Global Health Research Unit	2017	2021
Ministry of Higher Education and Scientific Research	Nagwa Joda (PI) Rasha Azrag (Co-investigator)	Mycetoma vectors transmission	2018	2019
Ministry of Higher Education and Scientific Research	Dr Yousra A azzium (PI) Sahar Bakhiet (Co-investigator)	Protein Biobank	2018	2019

# The MRC Publications

- 1. Kloezen W, Parel F, Brüggemann R, Asouit K, Helvert-van Poppel M, Fahal A, Mouton J, van de Sande W. Amphotericin B and terbinafine but not the azoles prolong survival in Galleria mellonella larvae infected with Madurella mycetomatis. Med Mycol. 2018; 1;56(4):469-478. doi: 10.1093/mmy/myx064.
- 2. van de Sande W, Fahal A, Ahmed SA, Serrano JA, Bonifaz A, Zijlstra E. Closing the mycetoma knowledge gap. Med Mycol. 2018; 56:153-164. doi: 10.1093/mmy/myx061.PMID:28992217
- 3. Bakhiet SM, Fahal AH, Musa AM, Mohamed ESW, Omer RF, Ahmed ES, El Nour M, Mustafa ERM, Sheikh A Rahman ME, Suliman SH, El Mamoun MAG & El Amin HM. A holistic approach to the mycetoma management. PLOS Neglected Tropical Diseases (2018), 12(5): e0006391. doi.org/10.1371/journal.pntd.0006391
- Abdallah MOE, Algizouli UK, Suliman MA, Abdulrahman RA, Koko M, Fessahaye G, Shakir JH, Fahal AH, Elhassan AM, Ibrahim ME Mohamed HSEBV Associated Breast Cancer Whole Methylome Analysis Reveals Viral and Developmental Enriched Pathways. Front. Oncol. 2018; 8:316. doi: 10.3389/fonc.2018.00316
- 5. Lim W, Eadie K, Horst-Kreft D, Ahmed SA, Fahal AH, van de Sande WWJ. VNTR confirms Madurella mycetomatis heterogeneity and is a promising typing tool for Madurella mycetomatis. Med Mycol. 2018 Jul 31. doi: 10.1093/mmy/myy055.
- 6. Sahar Mubarak Bakhiet, Emmanuel Edwar Siddig, Omnia Babekir Abdallah, EL Samani Wadaa Mohamed, Ahmed Hassan Fahal. Fine Needle Aspiration Cytology Utility in the Identification of Mycetoma Causative Agents: The Mycetoma Research Center Experience. Khartoum Med J. 2018: 11(0): 1499 – 1506.
- 7. Bertrand Nyuykonge, Wilson Lim, Ahmed Fahal, Wendy W.J. van de Sande. Mycetoma. Dutch Journal of Infectious Diseases. 2018; 13(6): 143-150.
- 8. Ahmed Hassan Fahal, Suliman Hussein Suliman, Roderick Hay, Mycetoma The Spectrum of Clinical Presentation. Trop. Med. Infect. Dis. 2018, 3, 97; doi:10.3390/tropicalmed 3030097
- 9. Mustafa Abbas, Peter Siordet Scolding, Abubaker Ahmed Yosif, Roa Fath EL Rahman, Melka Osman EL-Sayed, Mohamed Kamal Elbashir,

Nora Groce, Ahmed Hassan Fahal. The Disabling Consequences of Mycetoma. PLoS Negl Trop Dis. (2018; 12(12): e0007019. https://doi. org/10.1371/journal.pntd.0007019

- 10. Sahar Mubarak Bakhiet, Samani Wadaa Mohamed, Najwa A Mhmoud, Emmanuel Edwar Siddig, El, Dania Mohammed Ibrahim, Eiman Siddig Ahmed, Ahmed Hassan Fahal. Madurella mycetomatis causing Multiple mycetoma lesions: A rare presentation. Accepted Khartoum Med J.
- 11. Suleiman Hussein Suleiman, Abubaker Ahmed Yosif, Sahar Mubarak Bakhiet, Ahmed Hassan Fahal. Massive progressive scroto-perineal eumycetoma and its therapeutic challenges. Accepted Khartoum Med J.
- 12. Chaetomium Catrobrunneum causing Human Eumycetoma: The First Report. Najwa A Mhmoud, Antonella Santona, Maura Fiamma, Emmanuel Edwar Siddig, Massimo Deligios, Sahar Mubarak Bakhiet, Salvatore Rubino, Ahmed Fahal. PLoS Negl Trop Dis. Accepted
- 13. Emmanuel Edwar Siddig, Najwa Adam Mhmoud, Sahar Mubarak Bakhiet, Omnia abekir Abdallah, Salwa Osman Mekki, Nadia I El Dawi, Wendy Van de Sande, Ahmed Hassan Fahal. The Accuracy of Histopathological and Cytopathological Techniques in the Identification of the Mycetoma Causative Agents. PLoS Negl Trop Dis. Accepted
- 14. Emmanuel Edwar Siddig, Ali Mahmoud Mohammed Edris, Sahar Mubarak Bakhiet, Wendy WJ. van de Sande, Ahmed Hassan Fahal. Interleukin-17 and Matrix Metalloprotease-9 expression in the Mycetoma granuloma in Sudanese. PLoS Negl Trop Dis. Accepted
- 15. Amir Abushouk, Amre Nasr, Emad Masuadi, Gamal Allam, Emmanuel E. Siddig, Ahmed H. Fahal. The Role of Interleukin-1 cytokine family (IL-1β, IL-37) and interleukin-12 cytokine family (IL-12, IL-35) in eumycetoma infection pathogenesis. PLoS Negl Trop Dis. Accepted.

# The MRC Institutional Review Board (IRB)

The MRC had established a new Institutional Review Board (IRB), which consists of 12 members with vast experience in ethics, research and clinical practice and they are of medical, health and social backgrounds.

The IRB has a chair, two Co-chairs, and it consists of a medical microbiologist, biostatistician, public health/community medicine physician, ethicist, educationist, sociologist, two community representatives, and a WHO technical officer. Additional experts are invited upon need.

The board term of office is three years, however, membership can be terminated if a member is transferred, resigned, showed repeated, unjustified absenteeism, have been accused of proved misconduct, or have passed away. The IRB has clear terms of references, bylaws, and standard operating procedures. The board has regular meetings to review the research proposal from the centre and elsewhere.



# **Conference & Symposium Presentations**

The MRC members had contributed to many national and international conferences and symposia, and that included

- 1. Mycetoma, Guest Lecture, Pan Arab League of Dermatology 16<sup>th</sup> Conference joint with the 16th Conference of Sudanese Association of Dermatology, Khartoum, Sudan, 2018.
- 2. The Pan Arab Conference of Dermatologists, Khartoum, Sudan, 2018.
- 3. Mycetoma a neglected medical and health problem, The Mycetoma Seminar, Ministry of Higher Education and Scientific Research, Khartoum, Sudan, 2018
- 4. Scientific Research funding, Ministry of Higher Education and Scientific Research, Khartoum, Sudan, 2018.
- 5. Ethics of clinical trials, Clinical Research, Operational Management & Ethical Implications Workshop, University of Applied Sciences and Arts, Hochschule Hannover, Germany, 2018.
- 6. Mycetoma a forgotten medical problem. Tours University, Tours, France, 2018.
- 7. Closing the mycetoma gaps, ISHAM 2018, Amsterdam, The Netherland, 2018.
- 8. The Holistic Management of Mycetoma, ISHAM 2018, Amsterdam, The Netherlands 2018.
- 9. Mycetoma what is it, The Infection and Immunity Centre, York University, York, UK, 2018
- 10. Mycetoma a neglected tropical disease, the Royal Society of Tropical Medicine and Hygiene, Annual Conference, London, 2018
- 11. Mycetoma Epidemiology, Pan Arab League of Dermatology 16th Conference joint with the 16th Conference of Sudanese Association of Dermatology, Khartoum, Sudan, 2018.
- 12. Mycetoma Genetics, Pan Arab League of Dermatology 16th Conference joint with the 16th Conference of Sudanese Association of Dermatology, Khartoum, Sudan, 2018.
- 13. Mycetoma genetics. The First Young Researchers on Genomics and Human Health in Africa Conference, Khartoum, Sudan, 2018.

# Training Workshops organised by the MRC

The MRC had organised several training workshops, and continuing professorial development events for its staff, fellows and other medical and health personnel on different aspects of mycetoma and related research activities and that included the following:



# Quality control workshop

A Quality Control workshop was organised by the MRC during the period of 14<sup>th</sup> till <sup>17th</sup> of April 2018 in collaboration with Kassala University, sponsored by the Italian Association for Solidarity among People (AISPO). The workshop had provided in-depth training in Good Clinical Laboratory Practice and was attended by 30 participants.

# Molecular Biology Workshop

It was organised during the period of 18 - 24th April 2018 in collaboration with the Central Laboratory, Port Sudan, AISPO and MRC. The participants were introduced to different molecular techniques, and these include:

- Conventional PCR
- Multiplex PCR
- RT PCR
- PCR RFLP



# Medical Microbiology Workshop

This training was conducted in the period of 4 - 27<sup>th</sup> December 2018 in collaboration with AISPO and the Central Laboratory, Port Sudan. It aimed to make the participants familiar with the routine microbiological tests and mycological identification techniques.



# The MRC Staff had attended many training workshops and courses

Training workshops attended by the MRC staff

- Dr Eiman Saddig attended the Summer Training Program in Clinical Research and Epidemiology hosted by Hochschule Hannover University of Applied Sciences and Arts, Department of Information and Communication, Hannover, Germany in the period 16<sup>th</sup> of May 2018 and 30th of June 2018. The program included many sessions related to epidemiology as a basis for clinical research. Also, other topics of clinical research and trials, drug development and ethics in research were covered in depth.
- Miss Hana Elsir Abd Elbasit Alhaj has attended the Global Health Bioethics Network (GHBN) Summer School at the Ethox Centre, Oxford, UK in the period of 30th June to 6th July 2018. The workshop focused on many aspects of ethical issues such as ethics of community engagement, vulnerability and agency, ancillary care and research in emergencies.
- Dr. Najwa Joda and Mr Emmanuel Siddig had training at the University of Sassari, Italy in the period from February 1st to May 20th 2018. During that period, they were trained on several new techniques, and that included ITS sequencing and analysis of the sequence using different software. Also, they were able to identify new mycetoma causative species using mycological and molecular tools, these species were added to mycetoma list, and a manuscript on that was accepted for publication on PLoS Neglected Tropical Disease Journal. They worked on environmental samples to identify the environmental occurrence of mycetoma causative agents in different samples.
- Dr.Mohamed Nasr Elsheikh, PhD student on the social aspects of Mycetoma, in collaboration Brighton and Sussex Medical School, UK (BSMS) supported by the National Institute of Health Research, UK had spent a training period from 15- Nov. to 14 Dec. 2018 on qualitative research Methods in social sciences. He has attended more than ten workshops.
- Dr Sahar Bakhiet and Mr Waleed Mudawi had attended a Good Financial Practice (GFP) training workshop at Nairobi, Kenya sponsored by the DNDi, Africa in the period from 26th -27<sup>th</sup> July 2018
- Mr Mohamed Adam had attended a workshop on flow cytometry which was held during the period of 12th 16th August 2018.

The workshop offered training in the applications of the flow cytometry in general practice and haematological malignancies.

• Miss Rayan Ali had participated at the East Africa Open Science Workshop in the period November 18-19th, 2018 at the University of Khartoum. That was organised jointly with by Mozilla, H3ABioNet and Sage Bio networks.

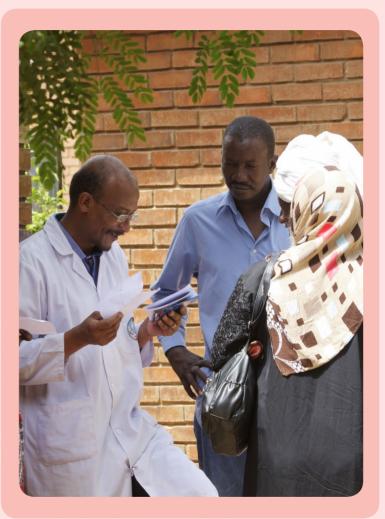


# Patients' management

The Mycetoma Holistic Management

During 2018, 7927 patients were seen at The MRC Mycetoma Clinic of them 456 were new cases. 1036 had eumycetoma, and 357 had actinomycetoma. MRC had offered them high-quality free management and medical treatment. 2048 patient had free medications. In this year free 660 ultrasound examination of the affected parts were offered.

MRC offered medical consultation and treatment for patients from Yemen, Kingdom of Saudi Arabia, Chad, Benin, Senegal, and Eretria.



# The Establishment of in vitro Drug Sensitivity Testing Unit

An in Vitro Drug Testing and Sensitivity Unit was established at the MRC, its main objective is the determination the different antifungal and antibiotics sensitivity of the different mycetoma causative agents, and we hope that will a routine test for every patient with mycetoma.





# Patients' Rehabilitation Service Unit

#### The artificial limbs prostheses mission

MRC in collaboration with the Ministry of Health, Sennar State and the zakat Fund had organised a massive campaign for the provision of artificial limbs prostheses to the affected mycetoma amputees at the mycetoma endemic villages at Eastern Sennar locality, Sennar State, Sudan.

The campaign was launched on Monday 22nd of October 2018, at the MRC and was attended by the Federal Zakat fund, Secretary General, The National Artificial Prostheses Cooperation, Director General, Haggar Charity Foundation, CEO, and the International Welfare Voluntary Group members.

A well-equipped mobile workshop with well-trained technicians travelled from Khartoum to Wad Onsa Village in Eastern Sennar Locality. They managed to make around 200 artificial limb prostheses to the amputees. The campaign had provided the prostheses to these amputees at their villages. That had reduced the difficulties in mobility to and accommodation in Khartoum which are not affordable by most of them. That had changed the lives of these amputees.

The campaign had provided the prostheses and patients' training free of charge to the affected amputees. The mission was funded by the Zakat Fund, Sennar State, MRC, the Mycetoma Friends Support Association and cost was around 700 000 SDG.



# MRC Community Out-Reach Activities

#### Mycetoma Medical & Health Missions to Mycetoma Endemic villages

The MRC in collaboration with Sennar and White States Ministries of Health and Association of Aids and Relief, Japan had conducted several medical and health field missions to several mycetoma endemic villages, and that was as follows:

- 1. Sennar State, Wad Onsa village, February 2018.
- 2. Sennar State, Wad Onsa village, July 2018
- 3. White Nile State, Um Garr village, October 2018.
- 4. White Nile State, Um Garr village, 15-17th November 2018.
- 5. Gaziera State, Northern Gaziera locality, visit to seven villages (Giad, Almasodia, Alnoba, Almassed, Alti, Altikaina and Alkamleen), August 2018.
- 6. Sennar State, Wad Onsa village, August 2018.
- 7. Gaziera State, Abu Qutah and Goz Al-Nagah villages, October 2018.
- 8. Sennar State, Wad Onsa village, the mobile workshop for prostheses, October 2018.

# **Research Field Missions**

- 1. Sennar State, pilot Survey for mapping Mycetoma in Eastern Sennar locality, July- August 2018.
- 2. Sennar State, Wad Onsa and Wad EL Nimear Villages, a research project entitled "Assessment of The Environment and Geographical Factors Associated with Mycetoma."





# MRC Mycetoma Advocacy Activities:

- 1. The MRC had conducted a health education morning session for Kotrang agricultural workers, DAL Food Group, 8<sup>th</sup> August 2018
- 2. The MRC organised a one-day training workshop for medical assistants at Alkamleen locality, Gaziera on early case detection and management of mycetoma, it was attended by 60 medical assistants, on 2<sup>nd</sup> September 2018.
- 3. In collaboration with the College of Fine and Applied Arts, Sudan University of Sciences and Technology to produce a fine art exhibition on mycetoma.
- 4. The MRC had posted more than 56 video clips at the MRC YouTube addressing different aspects of mycetoma



# The Mycetoma Holistic Management

Certainly, 2018 was the Mycetoma Holistic Management Year, the MRC had organised several medical and health missions to various mycetoma endemic villages in Sudan in collaboration with the Ministries of Health of Sennar and White Nile states and various NGOs. The MRC had established two Regional Mycetoma Centers at these states; the Wad Onsa and It is Alandalus now villages.

The patients have been treated locally in these centres, the local medical and health personals were trained on early case detection and management. The local community activists were trained on mycetoma advocacy and environmental conditions improvement. This comprehensive approach had also addressed the patients' socioeconomic constraints that hinder early presentation and treatment. This approach has also included the local health authorities, community, and civil society participants with the objective to deliver the best management.

This holistic approach for mycetoma patients' management proved to be effective for early case detection and management, optimal treatment and treatment outcome and favourable disease prognosis. During the study period, the number of patients with massive lesions and the amputation rate had dropped and that had reduced the disease medical and socioeconomic burdens on patients and families. Due to the uniqueness of this experience, the PloS Neglected Tropical Diseases Journal had reported it in 2018 with a special press release.

Bakhiet SM, Fahal AH, Musa AM, Mohamed ESW, Omer RF, Ahmed ES, El Nour M, Mustafa ERM, Sheikh A Rahman ME, Suliman SH, El Mamoun MAG & El Amin HM. A holistic approach to the mycetoma management. PLOS Neglected Tropical Diseases. (2018); 12(5): e0006391. doi.org/10.1371/ journal.pntd.0006391.

# Awards and Prizes

#### **Donald Mackay Medal**

The Donald Mackay Medal was awarded to Prof Fahal for his outstanding work in tropical health to improve the health of rural or urban workers in the tropics. The medal was awarded on 21<sup>st</sup> September 2018 at the Royal Society of Tropical Medicine and Hygiene Annual Conference, London. Prof Fahal gave a Guest Lecture at this occasion on Mycetoma as a unique neglected tropical disease and stated the challenges facing mycetoma and why eumycetoma treatment is suboptimal.

#### The Knight of Merit of the Republic of Italy

The Republic of Italy had awarded Prof Fahal, The Knight of Merit of the Republic of Italy on the 20th of January 2018 in appreciation of his great efforts to promote the collaboration between Italy and Sudan in different educational and cultural aspects. It was presented by HE Mr Fabrizio Lobasso, the Italian Ambassador in Sudan



#### The Knighthood of Palmes Académiques, The Republic of France, 2018

In obligation of the outstanding work and efforts to improve the scientific cooperation between Sudan and France, the Republic of France had awarded Prof. Fahal, The Knighthood of Palmes Académiques as one the most prestigious awards given by the Republic of France. The Knighthood of Palmes Académiques is an order of knighthood of France for academics and cultural and educational figures, and it was instituted on 17 March 1808.

It was given to him on the 7th of July 2018 by HE French Ambassador in Khartoum, Mrs Emmanuella Blatmann.



## The Animal enclosures Project Wad El Namir Village

To improve the village hygiene, reduce the contact with the animals and their excreta and to eradicate the thorny cages, 72 modern animal enclosures were constructed outside Wad EL Nimear village. This project was conducted by a kind donation from an engineering company as its social reasonability activity. These new animals' enclosure were distributed free of charge to the villagers.



# MRC Laboratory upgrade

The MRC had established two new units, and these are

- In vitro drug sensitivity testing unit
- Protein Identification unit





# **MRC** Collaboration

The MRC has various collaboration with many research institutes and centres, NGOs and pharmaceutical companies in different mycetoma aspects, and that include patients' management, research and development, and community development activities.



### **Research Collaboration**

- The MRC is conducting the first ever double-blind clinical trial in mycetoma using a new drug; Fosravuconazole in collaboration with DNDi and Esia Pharmaceutical Company, Japan.
- Collaboration with The Brighton and Sussex Centre for Global Health Research, Brighton, UK, currently three PhD students are registered with Sussex and Brighton University.
- Faculty of Pharmacy, Tours University, France, presently the MRC has two PhD students there.
- Department of Medical Microbiology & Infectious Diseases, Erasmus Medial Centre, Rotterdam University, Rotterdam, The Netherlands.
- Division of Pharmacy, Radboud University Medical Center, Nijmegen, The Netherlands.
- Department of Immunology, Institute of Endemic Diseases, University of Khartoum, Sudan.
- Department of Molecular Biology, Institute of Endemic Diseases, University of Khartoum, Sudan.
- School of Public Health, Addis Abba University, Ethiopia.
- CBS Fungal Biodiversity Centre, Institute of the Royal Netherlands Academy of Arts and Sciences, Utrecht, The Netherlands.
- School of Microbiology, University of Newcastle, UK.
- Department of Social Sciences, Faculty of Economics, University of Khartoum, Sudan.
- Faculty of Medical Laboratory Sciences, ALazhari University, Sudan.

### **Community Development Activities**

- The Federal Ministry of Health, Sudan.
- The Sennar State, Ministry of Health, Sennar.
- Association of Aids and Relief, Japan.
- The International Voluntary Welfare Group, Sudan
- Sudanese American Medical Association, USA
- Community leaders in endemic areas.
- The Sudan Rotary







### **MRC Visitors**

The MRC had received several honourable guests during the year 2018, where various aspects of collaboration and networking were discussed. The centre was pleased to receive the following visitors:

- The World Health Organization, Director-General, Dr Tedros Adhanom Ghebreyesus
- The World Health Organization, Deputy Director-General Dr Soumya Swaminathan.
- Prof Sumaya Abu Khashwa, the Minister of Higher Education and Scientific Research, Sudan.
- Dr Neema Al Gasseer, WHO Representative for Sudan and Head of Country Office.
- Dr The Federal State Minister of Health, Dr. Fardas Mohammed
- Dr The Federal State Minister of Health, Dr Suad EL Karb Sudan.
- Dr Nathalie Strub-Wourgaft, Neglected Tropical Diseases Director, Drugs for Neglected Diseases Initiative.
- Dr Pierre-Yves Bello, the Regional Counselor, for Global Health Affairs for Eastern Africa, the French Government.
- Prof Philippe Vendrix, the President of University of Tour
- Prof Guillaume Desoubeaux, Faculty of Medicine, University of Tours
- Several DNDi, Geneva and Nairobi delegates had visited the MRC for monitoring of the clinical trial on fosravuconazole.
- Mr Michel Roy, the cultural attaché, the French Embassy Sudan, NAPATA program for scientific cooperation between France and Sudan coordinator.
- Mr Pascal Hanse, Conseiller de coopération et d'action culturelle, the French Embassy, Sudan.
- Dr Karlyn Beer and Dr David Bland, the Centers for Disease Control (CDC), USA.
- Dr Steven Van Den Broucke the Institute of Tropical Diseases, Belgium.

- Dr Vincenzo Racalbuto, The Head Office of Agenzia Italiana Per Cooperazione Allo Sviluppo Khartoum Sudan
- Prof. Abdel Nasser B. Singab, Vice president, Ain Shams University, Egypt.
- HE Mr Tetsuro YANO, President, Association of African Economy & Development, Japan.
- Mrs Jendayi Frazer, The former Assistant to the US Secretary of State, USA.
- HE The French Ambassador, for Sudan Mrs Emmanuella Blatmann
- Mr Mohamed A. Razig, Secretary General, The Zakata Fund
- Mr Anis Haggar, President, The Mycetoma Patients Friends Society
- The President of International Voluntary Welfare Group, Mrs Norma Khafouri and the council member.
- Miss Anna Kajino the Association for Aid and Relief, Japan.
- Centres of Excellence, Ministry of Higher Education and Scientific Research delegates had visited the MRC for inspection.





### Mycetoma Research Centre Alumni

The MRC had established a web platform designed to help its alumni connect with the Centre with friends, colleagues and with each other globally. It will allow them to keep in touch with the MRC latest events, news, and opportunities and to become more engaged with the Mycetoma Research Centre.

#### Recently the following has joined the MRC Alumni

- 1. Dr Bouthyna Mamoun, Consultant Surgeon
- 2. Dr Mohamed Taufour, Surgical Registrar





# **MRC Fundraising Activities**

The MRC had organised many meetings and brainstorming sessions with national and international donors, civil society activists and NGOs to raise funds to support the mycetoma patients and their treatment and for research projects and community development in particular for environmental improvement.

The MRC is planning to organise with the Mycetoma Patients Mycetoma Patients Friends Association (MPFA) many fundraising activities, and that will include photos and posters exhibition in collaboration with some international bodies in Sudan.

#### In 2018 the MRC received funds from:

- Sudanese American Medical Association: Surgical consumable for surgeries in rural areas.
- Association for Aid and Relief: support of the Medical and Health missions to endemic areas.
- International Volunteer Women Group: support the social aspects of mycetoma patients.
- Different individuals for the prostheses project.



## Mycetoma Ambassadors 2018

in appreciation of the active, dedication, enthusiasm and passion, the MRC Executive Committee, had appointed the three community activists as the 2018 Mycetoma Ambassadors and these were

- Miss Hanan Mohamed A. Karium, Community Activist, Sudan
- Mr Jamal Hassan Saaed, Celebrity, and comedian, Sudan
- Mr Omer A. Rahman, The Mycetoma Project Coordinator, Sennar State.

Mr Omer A. Rahman The Mycetoma Project Coordinator, Sennar





## Memorandum of Understanding

The MRC had signed Memorandum of Understanding with

- Association of Aids and Relief, Japan for collaboration and partnership to execute the MRC objectives.
- ASIPO for the training of laboratory technologists in various molecular techniques from Port-Sudan and Kassala.



### A Japanese Volunteer

The Mycetoma Research Centre is pleased to welcome Miss. Erina Gotanda, a Japanese nurse who is kindly volunteering to work at the Centre for two years to improve the nursing quality at the Centre. She is supported by the Japan International Cooperation Agency (JICA) Volunteering Program



## Mycetoma Patients Mycetoma Patients Friends Association (MPFA)

The MRC has established a Mycetoma Patients Mycetoma Patients Friends Association (MPFA) for patients' care, community behaviour change and to raise funds for research and community works. It is now a registered charity society in Sudan with the number 2088. The society had received several funds and donations from different individuals and NGOs.

The society had supported many patients with free laboratory investigations and prostheses acquisition.

