Wednesday, 27 February 2019

ARRIVAL IN TUNIS

Thursday, 28 February 2019

Venue: Institut Pasteur de Tunis

08:30 – 09:00 REGISTRATION

09:00 – 09:15 **Welcoming word and presentation of the rare disease day event**
Dr. Anis Ben Amor
University of Tunis El Manar, Tunisia & AGYA member
Dr. Olfa Messaoud
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia & AGYA member

09:15 – 12:30 **Session 1: Raising awareness for health care professionals**

09:15 – 10:00 **Challenges related to the investigation of rare diseases in the region**
Prof. Sonia Abdelhak
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis,Tunisia

10:00 – 10:30 COFFEE BREAK

10:30 – 11:30 **Clinical gene therapy for neurodegenerative diseases: Past, present, and future**
Prof. Nathalie Cartier
Université Paris-Sud, Université Paris-Saclay, Orsay, France

11:30 – 12:30 **Roundtable by various stakeholders on rare diseases**
Representatives of several Arab countries
Algeria, Egypt, Kuwait, Libya, Mauritania, Oman, Palestine, Sudan, Tunisia, UAE

12:30 – 14:00 LUNCH BREAK

14:00 – 18:00 SCIENTIFIC EXCURSION

Friday, 01 March 2019

Venue: Tunis Science City

09:00 – 17:00 **Session 2: Raising awareness for general public & civil society**

09:00 – 09:15 **Experience of the patient's support group 'Helping children with *Xeroderma pigmentosum*'**
Prof. Mohamed Zghal & Prof. Meriem Jones
Charles-Nicolle Hospital, Tunis, Tunisia

09:15 – 09:30 **Pour que nos anges ne perdent jamais le sourire**
Prof. Ichraf Kraoua
National Institute of Neurology Mongi-Ben Hamida, Tunis, Tunisia

09:30 – 10:00 MUSICAL PIECES PERFORMED BY PATIENTS

10:00 – 10:15 **Activities of the 'Tunisian Association of Lysosomal Diseases'**
Mr. Mouadh Saaied
Tunisian Association of Lysosomal Diseases, Tunis, Tunisia

10:15 – 10:30 **Après 3 ans de sensibilisation sur les maladies rares, quels résultats en Tunisie?**
Dr. Mariem Ben Rekaya
Association REACT «La Recherche en Action», Tunis, Tunisia

10:30 – 11:00 COFFEE BREAK

11:00 – 11:30 **Role of Tunis Science City in filling the gap between scientists and society**
Prof. Dorra Ghorbel
Tunis Science City, Tunis, Tunisia

11:30 – 12:00 **Patient`s sessions (Success stories presented by patients)**
Ms. Abir Mhamdi, المرض رحلة, Ms. Hiba Hamzaoui
Parents of Angelman patients

12:00 – 12:30 **Les modalités de prise en charge psychopédagogiques des élèves en difficultés scolaires: Les classes orthopédagogiques**
Dr. Noureddine Elhadawi
Faculty of Humanities and Social Sciences of Tunis, Tunis University, Tunisia

12:30 – 14:00 LUNCH BREAK

14:00 – 15:00 **Les boutiques des sciences: Un outil de la recherche participative. L'expérience de l'Institut Pasteur de Tunis**
Mr. Hichem Ben Hassine
Institut Pasteur de Tunis, Tunisia

15:00 – 16:00 **The voice of secondary school students for rare diseases (Twitter Project)**
Students of the Secondary School Gustave Flaubert, Tunis, Tunisia

16:00 – 17:00 **The history of music therapy**
Dr. Rami Chahin
Oldenburg University, Germany & AGYA member

17:00 – 18:30 DINNER

18:30 – 20:00 MUSICAL PERFORMANCE
by El Manar Conservatory Choir & Distribution of competition awards

Parallel session:
10:00 – 16:00 **Scientific workshops in the 'ADN pour tous' space in Tunis Science City**

Saturday, 02 March 2019

Venue: Institut Pasteur de Tunis

09:00 – 11:00 **Laboratory visits for secondary school teachers & students**

Molecular biology for genetic investigation of rare diseases
PhD student Rahma Mkaouar
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Genetic counselling and prenatal diagnosis
Prof. Mediha Trabelsi
Department of Hereditary and Congenital Diseases, Charles-Nicolle Hospital, Tunis, Tunisia

Genetics of neurosensory diseases
PhD student Rahma Mkaouar
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Genetics of cardiac diseases
PhD student Hager Jaouadi
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Rare forms of diabetes
PhD student Hamza Dallali
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

Introduction to microbiota applications in rare diseases research
PhD student Meriem Fassatoui
Biomedical Genomics and Oncogenetics Laboratory, Institut Pasteur de Tunis, Tunisia

11:00 – 13:00 **Scientific workshops in the 'ADN pour tous' space in Tunis Science City**

DEPARTURE FROM TUNIS

Conference Venue

Institut Pasteur de Tunis
Address: 13, Place Pasteur, Tunis Belvédère, Tunis
Tunis Science City
Address: Rue La Cité des Sciences, Tunis 1004

Conference Organizers

Dr. Olfa Messaoud
Associate Professor at Institut Pasteur de Tunis, University of Tunis El Manar; Tunisia
Member of the Arab-German Young Academy of Sciences and Humanities (AGYA)
Dr. Ahmed Hegazy
Charité - Universitätsmedizin Berlin (CBF), Medical Department, Berlin, Germany
Member of the Arab-German Young Academy of Sciences and Humanities (AGYA)

In collaboration with
- Institut Pasteur de Tunis
- Tunis Science City
- Biomedical Genomics and Oncogenetics Laboratory
- Association REACT (La Recherche en Action)
- Association des Jeunes Chercheurs de l'Institut Pasteur de Tunis
- The EC H2020 Project InSPIRES
- Twelfth International Rare Disease Day

Contact: **agya@bbaw.de**
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InSPIRES

Association des Jeunes Chercheurs de l'Institut Pasteur de Tunis

معهد باستور تونس Institut Pasteur de Tunis

agya ARAB-GERMAN YOUNG ACADEMY OF SCIENCES AND HUMANITIES

International AGYA Workshop

RAISING AWARENESS FOR RARE DISEASES

28 February - 02 March 2019

Tunis, Tunisia

Venues:
Institut Pasteur de Tunis (28 February & 2 March) and Tunis Science City (1 March)