

Pak-IMD-Net Report for the year 2019

From the Chair Pak-IMD-Net

On 1st Jan 2019 after approval from Pakistan Society of Chemical Pathology (PSCP) the working group of the society came into action. The working group formed for strengthening the diagnostics, education and research in the area of inherited metabolic disorders (IMDs) is a group for PSCP members and associate members with special interest in IMDs. With the mission of capacity building of laboratorians to develop diagnostics of newborn screening and IMDs all members of the Pak-IMD-Net collectively made significant contributions to our mission.

1. Launch of Pak-IMD-Net on Rare Disease Day 2019

The launch of this working group was held in a multidisciplinary Conference on Newborn Screening for Rare Disorders in Pakistan organized by the Section of Chemical Pathology, Department of Pathology and Laboratory Medicine, and Paediatrics and Child Health Aga Khan University (AKU) under the auspices of PSCP and International Federation of Clinical Chemistry (IFCC) on March 1, at Pearl Continental Hotel, Karachi.



2. Workshops Conducted: To encourage and support training for technologists and pathologists in the area of Biochemical genetics few workshops were conducted.

i. Case based Workshop on Rare Disease Day 2019 in line with World Rare Disease Day

“Hands on Workshop on Organic Acid Testing” was conducted at Aga Khan University that focused on the basics in urine organic acid testing, chromatogram labelling and interpretation for IMD diagnostics. It was followed by a group activity aimed at chromatography labelling and interpretation and case presentations by each group.

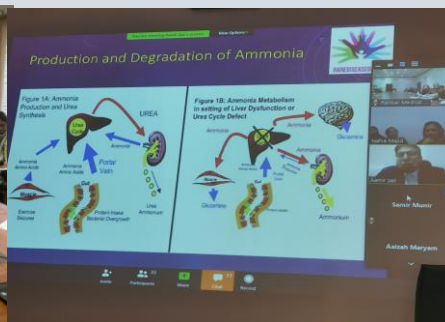
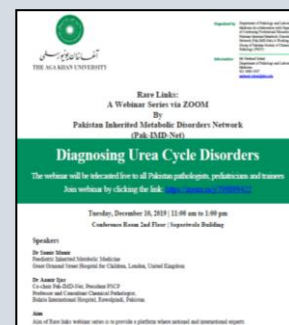


ii. Workshop in PGME Conference 2019 on Aminoacidopathies on September 20th, 2019

‘Aminoacidopathies from basics to diagnostic caveats’ was conducted by Section of Chemical Pathology, Dept. of Pathology & Lab Medicine.

3. Lecture Series ‘Rare Links’:

This educational lecture series was initiated from the platform of Pak-IMD-Net with the aim to conduct sessions via Zoom video conferencing on rare diseases quarterly. First Rare Link activity was conducted on 10th December 2019 on ‘Diagnosing Urea Cycle Disorders’. It was a very successful event, with more than 100 participants from different institutes and cities of Pakistan. We plan to conduct more such activities under the banner of ‘Rare Links’.

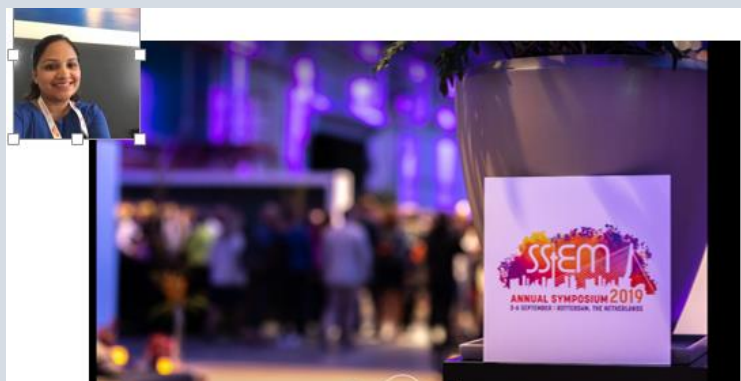


4. **National Satellite CME for Pak-IMD-Net Members in Aug 2019:** Satellite meeting was organized and successfully conducted for creating awareness regarding Multiple Carboxylase Deficiencies with case reviews and clinical audit findings related to challenges of reporting of cases with Multiple Carboxylase Deficiencies on urine organic testing.



5. **International Training and Meetings Attended:**

- i. Council & Advisory Council Members Meeting 2019 in Rotterdam Netherlands- Dr Lena Jafri represented Pakistan



- ii. Ms. Saba Abdul Mateen Technologist at Clinical Chemistry AKU was granted travel scholarship to attend SSIEM Conference 2019 in Rotterdam Netherlands. Ms. Saba presented her poster on MSUD.

- iii. Dr Sibtain Ahmed was selected by PSCP for IFCC FEN-SNIBE support a Professional Program to get trained from Akdeniz University-2019

Call for new members 2020: In 2019 seventeen PSCP members and associate members joined this working group. Dear PSCP members and associate members you may contact us if you are involved and interested in IMD testing. Additionally identify personnel around you who can contribute towards the goals of Pak-IMD-Net. We hope our contribution is helpful and community supportive.



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