

AGA KHAN UNIVERSITY
Department of Pathology and Laboratory Medicine

SUMMARY REPORT

Pak-IMD Net: Patient Support Group Meeting: Living Better with IMD's in Pakistan

Principal Investigator: Prof Aysha Habib Khan (aysha.habib@aku.edu)

Date of Award letter: 26th May.2020

Start date of project: Sep-2020 to April 2021

Date of Ethical committee approval: 2020-5050-14504 Approved on 29-Oct-2020

Objectives:

- Organize an event for patients and families with inherited metabolic diseases (IMDs) in Pakistan
- Launch of an e-portal for patient and family education

Report of activities conducted Sep 2020 – April 2021

A hybrid event was organized on 1st March 2021 at the occasion of world rare disease day at the Auditorium of Aga Khan University, Karachi, Pakistan in collaboration with Pak-IMD Net (a working group of Pakistan Society of Chemical Pathology). Due to Global, pandemic situation only selected patient's families and healthcare professionals were invited physically; others were connected virtually. Wife of Governor of Sind Province, launched an E-portal, 'EK-SATH' (meaning together) for patients with IMDs and their families to increase awareness, education & support. Mrs. Reema Ismail also showed her keen support for EK-Sath in her speech. Invited patients and professionals share their stories, which were discussed live during session to address challenges, diagnosis and better management of patients with IMDs. A Puppet show was also organized, to use art and theatre for promoting awareness on rare diseases and sending positive vibes to the patients and families. Overall, the agenda of the rare disease day was promoted and the concept of togetherness "EK-SATH" in the struggle for rare disease diagnosis and management was highlighted. Goody bags are being distributed to patients through metabolic physician at clinic to keep their smile shining.

Below Table shows the statistical report of people who participated from our country and other regions as well.

All countries	
Location	Unique views
Pakistan	97
United States of America	2
United Arab Emirates	1
Afghanistan	1
Canada	1
United Kingdom	1

Details of Program, E-portal and event highlights can be accessed on below portal link.
<https://www.aku.edu/ek-saath/Pages/home.aspx>

Publications, Talks, Presentations etc on Ek-SATH Event media links

1. https://www.aku.edu/news/Pages/News_Details.aspx?fbclid=IwAR3QONJwodQ4Y11K3hZTt-eNdYIocdwHH0IG5EsCinqvInznUkurB-EFuuG4&nid=NEWS-002461
2. <https://runwaypakistan.com/puppet-show-held-at-aku-to-create-awareness-on-rare-diseases/>
3. <https://images.dawn.com/news/1186655>
4. <https://www.dailyadvent.com/news/f568e442a91f9e04b54a06f1ead3bea6-Thespianz-Theatre-organises-puppet-show-to-educate-people-on-rare-diseases>
5. <https://www.facebook.com/watch/?v=723531471679809>
6. https://m.facebook.com/story.php?story_fbid=10165051423540245&id=644415244&sfnsn=scwspmo
7. Dr. Lena Jafri talk on Rare disease day
<https://www.youtube.com/watch?v=620gpCOJSm8>

Signature  Aysha Habib Khan	Date 04/05/2021
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