

## FAiTh – Fight Against Thalassemia

ACTIVITY REPORT 2018-2019

2019

January



- FAiTh conducted a Patients & Parents Session at United Foundation Kohat, Khyber Pakhtunkhwa on 10th January 2019. The team traveled from Karachi to Kohat for 34 hours.

United Foundation was established in 2011. They have a database of 400 registered patients

The team also conducted a session with Frontier Foundation Kohat having more than 700 registered Thalassemia patients on 11<sup>th</sup> January 2019.



Both organization help in providing safe blood

transfusions with self-help & limited resources. They also provide blood & blood components to different hospitals in the city. FAiTh have plans to help improve their blood banking system after identifying the weaknesses & to sponsor patients for iron chelation medicines, since due to center's limited resources & no support from Government patients are unable to take iron chelation medicines hence have high ferritin levels.



- FAiTh conducted a Patients & Parents Session at SMT Thalassemia Center Haripur District Hazara in Khyber Pakhtunkhwa on 13th January 2019. SMT



Thalassemia Center was established in 2010 and has approx. 170 registered patients where 120 patients visits regularly for transfusions. 10 patients are sponsored for iron chelation medicines by private donors. It is the only center working in Haripur with proper blood banking system

catering patients from Haripur, Abbottabad, Haveliyan, Swat, Hasan Abdal etc.

- CEO Saylani Blood Bank & Thalassemia Center invited team FAiTh to visit their blood bank & thalassemia center on 22<sup>nd</sup> Jan 2019. They have state of the art blood banking system with 30 bedded thalassemia center. They have 250 patients registered at the moment who receive timely transfusions & proper iron chelation medicines.



## February

- FAiTh conducted a Patients & Parents Session at Saylani Thalassemia Center on 28th January 2019. Saylani Thalassemia Center was established in 2016 and has approx. 250 registered patients who visits regularly for transfusions.



## March

- FAiTh donors donated Blood Bags to a thalassemia center in Swat in March 2019.

- FAiTh organized One Day Iron Chelation Camp at Saylani Thalassemia



Center Karachi on 14th March 2019. 15+ fellows got detailed hematologist consultation. Got their Hepatitis C, Hepatitis B, HIV, Calcium, Ferritin & Vitamin D tested for free. 12 fellows received iron chelation as per their required dose for 12 hours. And management also

gave another 12 hours dose as take home medicine. The camp was called off due to unforeseen circumstances.

- Team FAiTh participated in Walk For Cause / Walk For Thalassemia Free Pakistan & Tribute To Pak Armed Forces organized by Help International Welfare Trust on 23rd March 2019 in Karachi aiming for a Thalassemia free Pakistan in future.



## April

- FAiTh General Secretary Muhammad Hammad travelled to Vehari on 26th



April 2019 for meeting volunteers of Team FAiTh Vehari. On 27th April he had a fruitful meeting with the entire team, distributed membership cards & informational material. Briefed them regarding thalassemia and how they can contribute in raising awareness about the disease. On 28th April he visited DHQ Hospital Vehari along with the team. He

also met DHQ thalassemia ward incharge Dr Quratulain and discussed issues regarding blood bank, iron chelation medicine and FAiTh collaboration with DHQ thalassemia ward.



## May

- Team Vehari celebrated Thalassemia Day on 14th May 2019 at Thalassemia Ward DHQ Vehari with thalassemia fellows. Cake cutting was followed by gifts distribution with MS DHQ Vehari, Thalassemia Ward Incharge Dr Quratulain & Child Specialist Dr Hafeez.



- President FAiTh Ayesha Mehmood was invited at Ehd E Ramazan Iftar Transmission at Express TV on 21st May 2019 along with three thalassemia heroes @Muhammad SaaD, Aqil Aziz & Iqra Sheraz as guests to share their life journey and about FAiTh..



-FAiTh Patients & Parents Association held its first Interactive Session & Clinic On Diabetes and Endocrinology on 16th May 2019 & 25th May 2019 at FAiTh Head Office Karachi. Event was conducted by Dr Ayesha Sheikh Consultant Endocrinologist The Aga Khan University Hospital. The session was attended by thalassemia fellows and their parents from different thalassemia centers. 24 fellows has been thoroughly examined for endocrine & diabetes issues and have been prescribed treatment.



## June



- Chand Raat Celebration was organized by FAiTh at FAiTh office Karachi on 4th June 2019. More than 50 fellows and their parents attended the event.

The activities included iftar dinner, Mehendi application, Eid gifts and meet & greet with other fellows. Some parents met FAiTh President Ayesha Mehmood to discuss their children health issues.

- FAiTh conducted Patients & Parents Session at Thalassemia Ward in Bahawalpur Victoria Hospital on Thursday 27th June 2019.

The session was attended by patients, parents & staff of Bahawalpur Victoria Hospital & Regional Blood Center.

Initially 700 patients were registered at BVH but soon after Regional Blood Center Bahawalpur was established

in December 2017 the number started to increase. Currently 2700 patients are registered with the Thalassemia unit. Lack of space compels 4 to 5 patients to share a single bed. Regional Blood Center since December has started to provide safe & screened blood to the thalassemia patients according to their need without any charges and without any donor. On daily basis Regional Blood Center is providing 50+ blood pints and on Thursday they provide 100+ blood pints. Among 2700 patients, 100 patients are



getting iron chelation medicines from government on monthly basis.

Government is providing them tablet Asunra. We met 100+ patients on our visit, briefed them about how can they take better care of themselves, maintain their hemoglobin and ferritin, about prevention, about

FAiTh Patient Support Group, how can they spread awareness & how can they help themselves & thalassemia center regarding blood donations. We distributed gifts and informative material among them.

- FAiTh Visited Regional Blood Center Bahawalpur on 27th June 2019.  
Regional Blood Centre Bahawalpur (RBC) Safe Blood Transfusion



Programme. A development project of the Islamic Republic of Pakistan, co-financed by the Federal Republic of Germany through KfW Development Bank. RBC Bahawalpur was inaugurated in December 2017. It is situated inside Bahawalpur Victoria Hospital. FAiTh is thankful to Dr Col (R) Ali Nadeem, Zahid Qazi &

all the staff of RBC for their hospitality. The staff thoroughly briefed the team about all the procedures and protocols involved in blood donation, screening, component making, storage & distribution. Thalassemia patients in Bahawalpur Victoria Hospital now receive blood from RBC without any charges and without any donor. Patients receive blood as per their requirement. RBC is daily providing 50+ blood units to thalassemia patients and Thursdays they provide 100+ units. Till June 2019 they have provided more than 18 thousand blood units to thalassemia patients of Bahawalpur Victoria Hospital.



work.

- Thalassemia Awareness Session was organized by FAiTh & Cure and Care Foundation CEO Azhar Mehmood in E-Library Multan on 28<sup>th</sup> June 2019, many students attended the event and got briefing about thalassemia awareness, prevention and FAiTh

## 2018

### July

- FAiTh - Patients and Parents Association president Ayesha Mehmood had a meeting with Alessandro Da Pieve - Technical Adviser / ECMEA GLT Medical Co., Ltd on 20<sup>th</sup> July 2018 discussing thalassemia scenario in Pakistan, and statistics on leukocyte depletion filter importance.

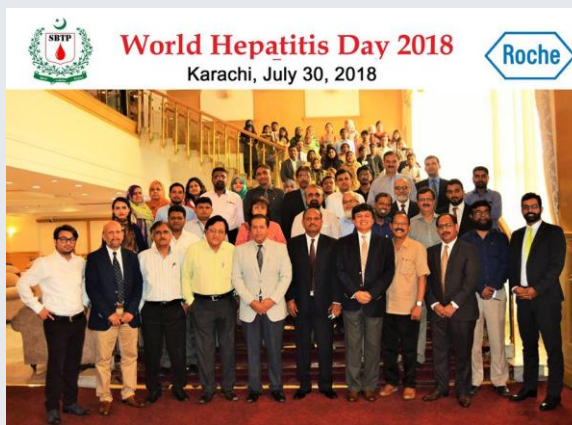






- An Interactive Session for Thalassemia Patients & Parents was organized by FAiTh with speaker Dr. Usman Sheikh consultant hematologist Aga Khan University Hospital on 22nd July 2018 in Karachi. The event was attended by thalassemia patients & their parents from different thalassemia centers followed by open Q/A session with the speaker.

- FAiTh Patients & Parents Association Karachi chapter attended the seminar on World Hepatitis Day organized by Safe Blood Transfusion Programme, Pakistan & Roche on 30th July 2018 at Marriot Hotel Karachi. SBTP has been kind enough to regularly engage thalassemia patients providing them with first-hand knowledge about the treatment and create mass awareness on provincial and national level.



## August

- Team FAiTh from different cities celebrated 71st Independence Day in their thalassemia centers on 14th August 2018.

## September



- Ms. Ayesha Mehmood, President FAiTh, held a meeting with Prof. Dr. Hasan Abbas Zaheer, National Coordinator, Safe Blood Transfusion program (SBTP) and his team at SBTP office, Islamabad.

- FAiTh Islamabad / Rawalpindi Chapter meetup was held at Jinnah Park Rawalpindi on 4th September 2018 where chapter fellows were provided guidelines regarding standard treatments. Information Session regarding career guidance was also conducted the same day.



## November

- FAiTh conducted its 2nd Patients & Parents Session at Khairpur Fatimid Foundation on 10th November 2018. The session was attended by patients, parents & staff of Fatimid



Foundation Khairpur. According to the administrator there are 300 active patients who visit Fatimid Foundation Khairpur regularly for their treatment. The team briefing session focused on how they can maintain their hemoglobin and ferritin, prevention methods and FAiTh Patient Support Group. The emphasis was also drawn upon

spreading awareness, self-care and helping thalassemia centers regarding blood donations. The session was made interactive with the help of Sindhi Thalassemia Fellow interpreter Ms. Areeba Gulzar.

- FAiTh Visited Regional Blood Bank Sukkur on 12th November 2018. RBC (Regional Blood Centre Sukkur) Safe Blood Transfusion Programme. A development project of the Islamic Republic of Pakistan, co-financed by the Federal Republic of Germany through KfW Development Bank. RBC Sukkur was inaugurated in February 2018 by Khursheed Ahmed Shah, Sindh



Health Minister Dr Sikander Ali Mandhro and Country Director KfW Development Bank Wolfgang Moellers. It is situated inside Civil Hospital Sukkur. We were delighted to see the commitment of RBC team, their devotion, the hard work, standard, protocol which is being followed there. We wish the similar standard / protocol could be followed in other blood banks / thalassemia centers too. Safe blood provision should be the top most priority of all blood banks & thalassemia centers like Regional Blood Banks.





- FAiTh conducted its 3rd Patients & Parents Session at Sukkur Blood Bank & Drugs Donating Society on 12th November 2018. The session was attended by patients, parents & staff of Fatimid Foundation Khairpur. According to the administrator there are 1500 active patients who visit at Sukkur Blood Bank & Drugs Donating Society regularly for their treatment. The team briefing session focused on how they can maintain their hemoglobin and ferritin, prevention methods and FAiTh

Patient Support Group. The emphasis was also drawn upon spreading awareness, self-care and helping thalassemia centers regarding blood donations. The session was made interactive with the help of Sindhi Thalassemia Fellow interpreter Ms. Areeba Gulzar.



- FAiTh celebrated the opening of FAiTh Karachi office on 27th November 2018.

## December

- A successful thalassemia awareness & interactive session was held in Vehari Punjab on 4th December 2018 attended by general public, media, civil society, patients & their parents. We came to know that there are more than 400 patients in Vehari, living



more vulnerable to deaths.



with low hemoglobin in the 4-5 gram range and 5000 ferritin. There is a District Headquarter Hospital but they transfuse whole blood to all the patients, they don't have any proper doctor for guidance and machines to make components. Better treatment is provided in Multan and Bahawalpur making it difficult for Vehari patients to travel this far. Unfortunately the patients have to compromise on whole blood transfusion and their life span is reduced to 14-15 years only making the region

- An Interactive Session for Thalassemia Patients & Parents was organized by FAiTh on 13th December 2018 in Karachi. The event was conducted by Dr Adil Akhter - Pediatrician, Thalassemia Consultant at Amina Bashir Memorial Trust & Project Manager at The Indus Hospital.

## Key Achievements:

- FAiTh has sponsored more than 30 patients for Desferal & Asunra from all over Pakistan.
- FAiTh has now more than 400 members from all over Pakistan connected to WhatsApp / Facebook group.
- FAiTh has facilitated the consultation of 10 patients with Dr Usman Sheikh, consultant hematologist for follow up checkups, proper guidance and for hydroxyurea confusion.

- FAiTh team in Vehari / Bahawalpur conducted walk for thalassemia & blood donation awareness throughout the year.
- FAiTh teams & fellows conducted blood drives all over Pakistan for different thalassemia wards / thalassemia centers.
- FAiTh has written to blood transfusion authorities & highlighted issues regarding the malpractices, lack of facilities, lack of blood banking machines and usage of substandard manual screening kits all over Pakistan.
- Our professionally designed general informative brochures and information manuals are distributed at every event. These included fact checks about thalassemia, prevention and how can the general public help thalassemia patients. For Thalassemia Patients the brochures are designed, briefing them about normal hemoglobin / ferritin level, routine tests and chelation guidelines.