

‘Hemophilia Patient Assistance Prog’:

Need to bridge gap between medical care, social support systems for Hemophilia patients: Experts

KU organises day-long awareness camp



Srinagar, Sep 11: To improve treatment outcomes of Persons with Haemophilia (PwH) through continuum of care approach, the University of Kashmir (KU) Wednesday organised a one-day awareness camp focussing on early detection, management and generating awareness regarding the disorder among the people.

Titled ‘Haemophilia Patient Assistance Programme’, the camp organised by the varsity’s Department of Social Work, in collaboration with INTAS Foundation, brought together experts from the fields of hematology, pathology and social work to discuss the significance of early detection and proper management of Hemophilia, a genetic bleeding disorder that is prevalent in the region.

On the occasion, Dean, Academic Affairs, KU, Prof Khursheed Ahmad Butt, underlined the importance of such collaborative efforts between academia and medical experts to bridge the gap between medical care and social support systems for Hemophilia patients.

“We expect our young students to educate others and disseminate the message and pass it on to their loved ones after they have understood this disorder,” he said, adding that the camp will have a multiplier effect on society, “as you talk to one, they talk to others and it will go on”.

He further emphasised there must be a provision for complete medical check-ups at institutional level.

Head, Department of Pathology, Government Medical College (GMC), Srinagar, Prof Bilal Ahmad Sheikh, advised the participants not to call 'Persons with Haemophilia (PwH)' 'Patients', stating: "It is important that we do not label them as diseased persons as Haemophilia has not yet been declared a disease for it is a genetic disorder."

Outlining the objectives of INTAS Foundation, Tanveer Ahmad (Project Associate) reiterated the Foundation's mission and efforts in promoting awareness and providing support for individuals affected by Hemophilia.

"Hemophilia patients in Kashmir face many challenges, particularly the need for increased awareness and access to Factor 8 medicines, which are essential for managing the disorder," he said, adding that the foundation provides cancer patients with free accommodation, transportation, genetic counselling and other social economic support services under the 'Apna Ghar' intervention.

Head, Department of Social Work, KU, Prof Shazia Manzoor, underlined the need to sensitise the community members and students alike to educate people about haemophilia and contribute as future ambassadors and trainers.

"There should be a counsellor, a psychotherapist and various other people from this field, so they work as a team. Because Haemophilia is not only a biological phenomenon, we need a proper case management and students and volunteers from different backgrounds to work together and contribute in spreading awareness about the disorder," she reiterated.

She further said that social workers can play a critical role in addressing the needs of individuals with Hemophilia, especially in underserved regions like Kashmir.

Programme Coordinator and faculty, Department of Social Work, KU, Dr Javaid Rashid, conducted the proceedings of the event.

The other highlight of the workshop was a panel discussion where experts from the medical field, faculty from the Department of Social Work and members of the INTAS Foundation engaged in a thoughtful exchange of ideas.