Lack of knowledge about hemophilia in India, IMA

Though it is not a disorder that kills, adequate care must be taken to curtail bleeding in any form.

New Delhi, 24 July 2017: According to a recent study, about half of the world's hemophilia population lives in India. Further, about 70% of those with this disorder don't have adequate knowledge or access to treatment. Apart from this, there are about 16,000 registered patients suffering from hemophilia in the country. However, studies indicate that the number could be seven times more.

A genetic and life-threatening bleeding disorder, in hemophilia, the blood does not clot normally due to the absence of clotting proteins called factors, when there is an injury or a cut. Provided care is taken, recurrent and prolonged bleeding into joints and muscles can even lead to permanent disability and at times, death.

Speaking about this, Padma Shri Awardee Dr K K Aggarwal, National President Indian Medical Association (IMA) and President Heart Care Foundation of India (HCFI) and Dr RN Tandon – Honorary Secretary General IMA in a joint statement, said, “What is peculiar about the transmission of hemophilia is that only males suffer from it and females are only carriers. It is not a killing disorder unless the bleeding extends into a vital organ. However, it can severely cripple a person due to all the pain. There is no known cure for this disorder. About a third of new cases are caused due to a new mutation of the gene in the mother or the child. In such cases, there need not be a previous history of hemophilia in the family. Women with the hemophilia gene can pass it on to their children. In cases where the mother is a carrier and the father does not have the disorder, there is a 50% chance of the male child having hemophilia and 50% chance of the female child being a carrier.”

Hemophilia is of three types: A, B, and C and the difference between the three lies in the deficiency of a specific factor. One should see a doctor in case the following symptoms show up: a severe headache, repeated vomiting, neck pain, blurred or doubled vision, extreme sleepiness, and continuous bleeding from an injury.

Adding further, Dr Aggarwal, said, “In pregnant women, there is no way of knowing whether the baby has the condition. For women, whose eggs are fertilized in a clinic using in vitro fertilization, this condition can be tested for and the eggs without hemophilia can be implanted. Preconception and prenatal counseling can help in understanding the risk of having a baby with hemophilia.”
It is possible to live with hemophilia and manage the condition with the following tips.

**Get physical activity** Adequate physical activity can help maintain body weight and improve muscle and bone strength. However, those with hemophilia should avoid physical activity that can cause injury and resultant bleeding.

**Avoid certain medications** Avoid blood-thinning medication such as warfarin and heparin. It is also better to avoid over-the-counter medicines like aspirin and ibuprofen.

**Maintain dental hygiene** Clean your teeth and gums thoroughly. Get tips from your dentist on how to do this without making the gums bleed.

**Get yearly checkups and vaccinations** Get tested regularly for blood infections and get your doctor’s advice on hepatitis A and B vaccinations.

-Ends-

**About IMA:** Indian Medical Association is the only representative, national voluntary organization of Doctors of Modern Scientific System of Medicine, which looks after the interest of doctors as well as the well being of the community at large. It has its Headquarter in Delhi and State / Terr. Branches in 30 States and Union Territories. It has over 2, 60,000 doctors as its members through more than 1765 active local branches spread across the country.

For further information please contact:
Sanjeev Khanna - 9871079105
Md Adib Ahmad – 9873716235
mediaimahq@gmail.com
IMA Public & Media Advocacy Cell