



HEMOPHILIA SOCIETY OF MALDIVES

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Annual Report of Hemophilia Society of Maldives September 2012 to September 2013

Hemophilia Society of Maldives was founded on August 8th 2011, since then we have been working very hard to find ways to provide better care and medical assistance to all with blood disorders, especially Hemophiliacs A & B.

For the past 2 years we have been trying to work closely with Ministry of Health and IGMH (Government Hospital) in order to find ways to provide better care for Hemophiliac patients. Since the beginning of Hemophilia Society we have found a total of 15 Hemophiliacs in the Maldives as per the date. According to statistics of World Federation of Hemophilia (world Statistics) there may be up to 36 or more Hemophiliacs in the Maldives.

During a meeting with the Minister of Health Dr. Ahmed Jamsheed Mohamed last year promised about including the Factor VIII injections in the 2013 budget however this was not successful and our request to include the factor injections in "Aasandha" (Government Medical Insurance) and make Factor VIII available in the National Pharmacy was also not successful. We have been continuously discussing with Ministry of Health verbally and in writing to help us to get a solution for the above-mentioned difficulties we have been facing as a Society. It is our opinion that due to the economic and political situation our repeated efforts are not successful.

In addition to this we have been trying to send 4 medical professionals to Christian Medical College in Vellore, India for training under the directions of Dr. Alok Srivastava (Vice President of Medical at the World Federation of Hemophilia). All costs being covered by World Federation of Hemophilia and Christian Medical College and Hemophilia Society of Maldives. However this has been impossible since IGMH had failed to provide the medical staff to go for one month training.

In 2012 we had received 128 Factor VIII injections (worth USD.25, 000.00 from the World Federation of Hemophilia and these were stored at IGMH, we also had continuously briefed the medical staff about the disease and treatments. In spite of this, the treatment and care was not given to a reasonable level by IGMH.

In 2013 we received an additional donation of 194 injections through the Italian Hemophilia Society, which has an approximate market value of US\$ 30,000. After



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repeatedly requesting the new CEO of IGMH to accept these injections and to store them at the Hospital they have failed to comply.

Therefore the Vice President of Maldives Hemophilia Society Mr. Ahmed Naseer had to personally invest and maintain the storage facility for the injections. From time to time he has been attending and supplying to the known 15 hemophiliacs whenever they are in need of the injections together with other members of the executive committee of HSM.

With the consent from World Federation of Hemophilia we have started discussions with ADK Hospital (Private Hospital) in order to train medical staff and establish medical care for Hemophiliacs at ADK Hospital. Recently 2 serious cases, one was a 3 year old boy and the other a 33 year old man were successfully treated at ADK Hospital under the direct guidance and personal attendance of the Mr. Ahmed Naseer. We believe that our discussion will be successful with ADK shortly.

In the recent months Hemophilia Society have been working hard to send the Vice President (a hemophiliac) of Hemophilia Society of Maldives together with an accompanying person (a hemophilia carrier) to represent Maldives at World Congress of World Federation of Hemophilia, sponsored by Hemophilia Federation of Australia, to participate in the Global NMO training program which will be held from (8 - 10th May 2014) and (WFH Congress 11 - 15th May 2014) and (WFH General Assembly on 16th May 2014 at the Convention Hall, Melbourne, Australia)

In order to establish professional care and awareness for the Hemophilia A & B, Von Willebrand's Disease, other acquired and hereditary disorders of haemostasis and coagulation, as well as to maintain the supply of Factor VIII injection through World Federation of Hemophilia it is highly important to the Hemophilia Society of Maldives to take part at this very important humanitarian gathering of World Federation of Hemophilia at Melbourne from 8 - 16th May 2014

SIGNED BY Ahmed Naseer.

Founder and Vice President of HEMOPHILIA Society of Maldives