

NEWSLETTER

MARCH 2020 / EDITION 7

STOP

THE BLEEDING





2019 has flown by and once again has been a very fruitful year for the Association.

2019 saw HAM continue to advocate with Government to improve the care and management of Haemophilia in Mauritius; but most importantly continued to place its focus on its patients.

50 home and hospital visits were made during the course of 2019 where patients were able to meet the Association's Social Worker and work together on improving their quality of life and achieve a better understanding of their bleeding disorder.

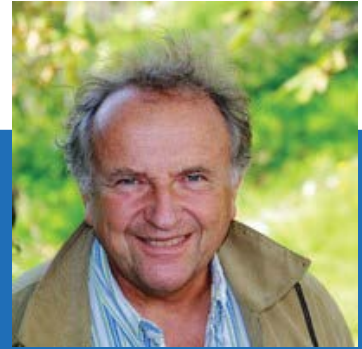
This new Outreach Program has helped HAM diagnose an additional 6 cases and we are slowly but surely moving towards closing the gap in care and treatment of all those living with bleeding disorders in Mauritius.

2020 will see HAM focusing on making Home Therapy a reality in Mauritius, while continuing to focus on the needs of its patients on a daily basis.

Home Therapy will change the lives of those suffering from this chronic, life-threatening bleeding disorder: medication will hopefully become available to the patients at home where prophylaxis and treatment of bleeds will be instantaneous.

The demonstrated benefits of home therapy for haemophilia include improved quality of life, less pain and disability, fewer hospitalizations, and less time lost from work or school.

2019's last quarter at HAM:



Visit of Prof. Jean-Francois Schved - October 2019

HAM was lucky enough to have Prof. Jean-Francois Schved visit us for 3 days in October. Prof. Schved is a Doctor and Professor of Haematology at the Faculty of Medicine, Montpellier University, France. He has extensive experience in haemophilia and rare bleeding disorders and was able to take the time off from his busy schedule to meet with our patients, parents as well as medical professionals over a weekend full of activities:



Medical Check-Up at Victoria Hospital

On the 12th October 2019, 22 patients were lucky enough to consult with Prof. Schved at Victoria Hospital. This medical check-up, organized by HAM, took place, in collaboration with the doctors and nurses from all four Regional Hospitals throughout the island.

Due to the absence of a clinical haematologist in Mauritius, HAM's patients do not have access to such specialized care and management. This was a great opportunity for adults and children alike to consult with one of the leading experts in the field.

"I am relieved. Now I know better about the disease of my daughter and I feel grateful towards the Association for the support." said Mrs. Kurmallee who is a mother of a little girl of six years old suffering from a rare bleeding disorder.

The main objective of the Medical Check-Up was to optimise care for patients with haemophilia, as more is required than simply the prompt treatment of an acute bleed; to improve patients' health and quality of life.

An in-depth check-up of people with Haemophilia is a must to ensure that treatment provided is accurate and for early identification of joint disease in order to initiate or modify treatment and thereby prevent arthropathy (joint damage).

These cases will now closely be followed by the local Health Care Professionals following the instructions and recommendations of the International Haematologist.



Medical Update at Wellkin Hospital, Moka

A presentation on the Approach to Diagnosis and Management of Rare Bleeding Disorders was held by Prof. Schved at Wellkin Hospital on the evening of the 12th of October 2019.

36 Health Care professionals attended a very informative session presented by means of case studies. Doctors, nurses as well as lab attendants were able to get in-depth knowledge on the latest developments in the field of haematology.

Such Medical Updates are indispensable in the capacity building of our Healthcare Professionals with regards to rare bleeding disorders for proper and adequate diagnosis in future.

HAM was delighted to have been able to facilitate the participation of a moderate number of medical professionals to such a workshop where they are constantly exposed to the constant changes in medical practice.



Education and Awareness Workshop at Voila Hotel, Bagatelle

A total of 82 patients and their families were present at Voila Hotel on the 13th of October where Prof. Schved led a Workshop on Education and Awareness of Bleeding Disorders.

This was the very first time our patients attended a workshop in French and it made a world of a difference. They were able to learn about the basics of Haemophilia, the importance of prompt treatment and correct management as well as how the disorder is transmitted through carriers.



This workshop was a huge success and all patients left with a better understanding of a condition they have been living with all their lives.

A big thank you goes out to the Professor who was extremely patient during the course of an extremely inter-active session. Our patients and their families are forever grateful to the wealth of knowledge that was shared during the course of the day.



Casela Youth Outing

November 2019

"The annual youth outing took place at Casela Nature Park and World of Adventures on the 30th of November where the youth had the opportunity to spend a full day with other friends suffering from the same bleeding disorder.

The day started off with the sightseeing of different animals. The youth enjoyed themselves by interacting with the animals at the petting farm and by taking selfies with the lions and giraffes. They equally embarked on a Safari where they got to see all the other animals found in the park. The highlight of the day was the Tulawaka ride. What a thrilling experience it was!

After the visit, the youth were able to enjoy a McDonalds at the nearby seaside for lunch.

Thanks HAM! We played some society games, swam and danced. The memories of that day will be etched in our memories for a long time...



The purpose of this annual outing is to bring the youth together and offer them a fun day out, far away from their frequent hospital visits and regular injections. These outings definitely strengthen the bonds among them and help build a stronger youth community."

By Auhammad Arshad - Ali





Parents Empowering Parents Training

Emotion at its Peak - December 2019

Raising a child with haemophilia and other rare bleeding disorders is a significant challenge that impacts the parents and the entire family.



With a view to addressing this challenge, HAM embarked on its very first Parents Empowering Parents (PEP) residential training which was held on the 6th and 7th of December 2019 at Pointe aux Piments Recreational Centre, whereby a group of 15 parents participated.

HAM privileged a one-night stay over training with the parents and the kids with the ultimate aim of strengthening the bonds among them. We were honoured to have in our midst Anthony Roberts – Haemophilia A patient and above all, an eminent psychologist from South Africa – to facilitate the 2-day training session.

On the first day, important issues, including, inter-alia, the impact of bleeding disorders on the child’s development; understanding and dealing with frustrations, anger and other feelings; compassionate discipline; child management skills; building self-esteem and confidence; parenting styles; and parent/family communication, were addressed.

Emotion was at its peak on the 2nd day when parents (Mums and Dads) shared their personal experiences and feelings of living daily as a haemophilia patient and /or raising a child/children with haemophilia or other rare bleeding disorders, an uphill battle both for the patients and the parents.

Although the emotional pain could be felt in their words, they were more than happy to be part of this wonderful family.

“Always remember that you are braver than you believe, stronger than you seem, smarter than you think and twice as beautiful as you’ve ever imagined.”





End of Year Gathering (EOY)

December 2019

Bidding farewell to the current year while organizing a family get-together has become one of HAM's main activities over the years.

HAM's 2019 EOY gathering was held at Pointe aux Piments Recreational Centre on December 08, 2019. The Association wanted it to be a bit more innovative this year and organized a two-day, one-night camp, to our patients' satisfaction.

The camp comprised of several components: be it informative, interactive as well as recreational. The two days included numerous activities: starting off with a visit to the Aquarium of Mauritius for our younger patients while the parents continued their "PEP" training conducted by Tony ROBERTS from South Africa.

some of them even prepared a few songs. All this added to the blissful atmosphere prevailing at our EOY event.

Patients and their families left the weekend with gifts donated by HAM and their hearts full of special moments once again spent together as one big Family.

A word of thanks goes to the organizers (HAM staff) and collaborators (Executive Members) for the time dedicated to the organization of this yearly tradition.

After an awesome 3-course lunch buffet, fun time was prioritised. Our guests were lucky enough to enjoy a mesmerizing Magic Show and



Upcoming Activities

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As we say goodbye to a very rewarding 2019, many challenges await us during the course of 2020 and the staff and the Executive Committee of HAM are thrilled to get started!

This is just a glimpse of the events programmed for the first quarter of the year:

January 2020:

Treatment Guidelines Validation Workshop conducted by Professor Johnny Mahlangu from South Africa.

February 2020:

Develop Training curriculum on Self-Infusion and conduct Training of Trainers by International expert from South Africa.

Haemophilia Youth of Africa Training hosted in Mauritius

March 2020:

Annual General Meeting

April 2020:

World Haemophilia Day
Education and training of patients



Want to help our Genuine Cause?

- Donations: by cheque to the order of Haemophilia Association of Mauritius OR by standing order OR JUICE to our account 000441008038, MCB, Quatre Bornes.
- CSR Support: each company, in terms of the law, needs to transfer a certain percentage of its profits to a social cause.
- Getting involved as a volunteer in our Association.
- Learning more about haemophilia by visiting our website www.haemophilia.mu or www.wfh.org
- Encouraging others to spread the word by mails and texts.



Your donation means we can:

- Save lives through the acquisition of blood treatment products.
- Provide anxious parents with the information they need to care for their children.
- Train doctors, nurses and other healthcare professionals.
- Increase public awareness.
- Distribute up-to-date information on haemophilia research and blood safety issues.

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