



NEWSLETTER

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2019 has been a very busy year for HAM and as we move into our last quarter, we are thrilled to be able to give you a sneak peek into what we have been up to over the last four months.

Our objective this year, has been to be more patient-centric: focusing on the needs of those suffering from this chronic, life-threatening bleeding disorder and at the same time still advocating with Government to improve the care and management of Haemophilia in Mauritius.



Selinda Kistan (Social Worker)

Since June 2019 and in line with our initial objective for 2019 (improving our outreach program), HAM is happy to welcome Ms. Selinda Kistan on board. Selinda joins HAM's team as its new Outreach Social Worker. She has earned her BA in Counselling and an MSc in Human Resource Management from the University of Technology, Mauritius. Selinda has over 8 years of experience working with families, youth and children. Selinda is the liaison between HAM and its patients and their families: she does home visits, counselling and refers patients to other service providers when needed.

HAM Youth Camp: 3rd & 4th August 2019

ARTICLE By Arshad & Aadarsh (Youth Members)

3rd and 4th August 2019: dates that will be forever deeply etched in the minds of the youngsters of the Mauritian Haemophilia family. For the first time, a stay-over youth camp was organised with the ultimate aim of strengthening the bond among the young haemophiliacs.



25 youngsters participated in an amazing stay-over event held at Holiday Inn Hotel, which began with an ice-breaking session animated by the President and the Operations Manager of HAM to enable us to get to know each other better and to set the right tone for the upcoming activities.

The ice-breaking session was followed by a well-designed and effective self-infusion training session – theoretical and

practical - conducted by Kavish and Wenda - two dedicated nurses of the Thalassemia ward of the Victoria Hospital and also members of HAM. The more daring managed to self-infuse themselves while others chose to have the intravenous training done on those who volunteered.

Prior to the mouth-watering open buffet dinner, Jacques Lafitte – Trainer – delivered an unforgettable session on how to deal with our emotions by putting '*les mots sur les maux*'.

The dinner was followed by an outstanding entertainment session, whereby the youngsters showcased their hidden talents of musicians, singers and dancers.

The second day was as interesting as the first day: after a succulent breakfast we had a session on the basics of haemophilia conducted by Kavish which was followed by the intervention of the representatives of the Disability Board and that of the Ministry of Youth who enlightened us on the Duke of Edinburg International Award.



We were undoubtedly honoured to have Jean François Favory (wheel-chair basketball player) in our midst, who through his intervention made us realise the importance of being ourselves and how to boost our confidence.

After that terrific motivational inspiration, a physiotherapy session (theoretical and practical) was conducted by Ms. N. Ramdin, physiotherapist of the MoH&QL, whereby the latter laid much emphasis on the importance of regular exercises by the haemophiliacs.

We ended the day with a brainstorming session for the forthcoming HAM Strategic Plan.

Thank you HAM for having left no stone unturned in the organisation process and making the event a memorable one.



Just for the Smiles!



A day with different activities was just what our younger patients needed during their Winter School Holidays. The annual kids outing took place at Casela Nature Park and World of Adventures on the 8th of August where the children had the opportunity to spend a full day with other children suffering from the same bleeding disorder.

The purpose of this annual outing is to ensure our kids have a fun day out, far away from their numerous hospital visits and constant injections.

The day was jam-packed and started off with a 4D Cinema followed by a Safari where they got to see all the animals found in the park. The children got to feed the Giraffes and the Ostriches and enjoyed interacting with the animals at the petting farm.

HAM's Executive Committee was thrilled to spend a half day full of activities with approximately 20 of our patients and a few of their siblings. These outings serve to increase their self-confidence and resilience but most importantly to create friendships and close future bonds with other children sharing the same plight.

It was great to see them interacting together away from their daily hardships and finally seeing them smile!



Fundraising: Heritage Southern Peaks Trail 2019

Sunday, August the 11th saw 825 runners coming together in the South of the island to run the Heritage Southern Peaks Trail.

These mountain trail lovers took part in 4 different races: 55km, 21km, 10km, and a 3km Kids Fun Jog; and all for a good cause!

The Haemophilia Association of Mauritius would like to say a big thank you to Heritage Bel Ombre as well as to the race organizers Racing Republic; but most importantly to all those who donated and helped support our cause once again this year.

HAM volunteers spent a great day at the Race Village welcoming all the finishers who gave of their best on race day.

Thank you for making a difference! Thank you for helping us Stop the Bleeding!



Africa Summit - Johannesburg: September 2019

The World Federation of Haemophilia (WFH) Africa Summit 2019 on haemophilia and other inherited bleeding disorders took place in Johannesburg, South Africa on 3rd and 4th September 2019. Key stakeholders - patients, physicians, government officials, and national member organisation (NMO) members - in the African community came together at this important event, to inter-alia, look at the current state of the bleeding disorders community in Africa, with the goal of sharing learnings, building connections, and developing a realistic action plan for the future.

Mauritius was represented at the Summit (fully sponsored by the WFH) by:

- Mr. Rajesh Neelayya, President of HAM;
- Dr. Janaki Sonoo, Vice President of HAM;
- Dr. Sivalingum Ramen, Director MoH&QL.



The Summit, which was represented by eminent personalities of the WFH and the African countries, was indeed an ideal platform for networking, sharing of experiences and last but not least learning from the Haemophilia Experts.

A remarkable presentation was made by Dr. J. Sonoo at the Summit whereby the advancement made over the years by Mauritius for the benefit of the haemophilia patients, was highlighted.

Such international exposure is undoubtedly a catalyst for HAM to uphold its achievements and to pave the way for a better future for the haemophilia patients of Mauritius.



Youth Group Therapy Psychotherapy

A few of HAM's Youth were lucky enough to spend some time with a Psychologist (Mr. Vijay Ramanjooloo) at HAM's office on the 31st of August.

Haemophilia is much more than a bleeding disorder: it affects a person's entire life. There will be ups and downs, and having the help of a qualified psychologist to help the patients and their families with emotional, social and/or practical concerns has been one of HAM's concerns since its inception.

This first session was warmly welcomed by all those who participated and future group therapy sessions have been placed on HAM's list of priorities.



Successful Surgery in Mauritius! Temoignage: Mr. Roshan Gudgadhur



Finally, a happy ending! HAM is pleased to share the very first Total Knee Replacement to take place on a haemophilia patient in Mauritius. Owing to sufficient medication being obtained

through Humanitarian Aid, Roshan, one of HAM's founding members, is today walking again, without pain.

"Haemophilia was diagnosed on me at the age of eight months when I fell from the baby-walker and had a bleed on my lips. I belong to the second generation of haemophiliac in the family and just hope I am the last one too: my eldest maternal uncle being the first haemophilia kinfolk.

Being a severe haemophilia A patient, I have had several joint bleeds since childhood and much time was spent in hospital. The unavailability of factor concentrates at that time worsened the condition of my joints: the most affected joints over time being my left knee. Owing to inadequate treatment, no surgeon was willing to take the risk to perform a surgical operation on my knee.

With time, the condition of my left knee deteriorated and became less functional to a point where I was using my left leg only as a support to my body for moving about, which eventually started to weaken my muscles.

Since my whole-body weight was resting on my right leg, my right knee also started to get damaged.

Fortunately, I met with Dr S. Karunagaran, an orthopedic surgeon from a private hospital in Mauritius, who performed several Total Knee Replacement (TKR) surgeries on haemophilia patients in Chennai. I was reassured! He advised a TKR on my left knee for better mobility of my left leg and also to prevent my right knee from deteriorating further.

After having received the comfort from HAM to the effect that factor concentrates would be available from the WFH Humanitarian Aid Program, I confirmed my TKR surgery for early July 2019 at Welkin Hospital, Mauritius. My surgery was successfully undertaken on the 2nd July 2019. Bleeding was controlled with Factor VIII transfusion in line with the WFH TKR Protocol for the pre, during and post operation and pain management was more than satisfactory.

Being a haemophilia patient, I was retained at the hospital for a fortnight. Physio sessions started 2 days post operation and in the beginning it was quite painful with minimum mobility. However, day after day mobility improved and I was advised to continue the physio sessions for at least ten weeks.

Three months following the surgery, I can feel a huge improvement in my left knee – no pain, more flexibility and straightening of my knee is possible today.

My heartfelt thanks to all those who have supported me during that critical period and who are still supporting me."

“Hommage a Alessio Christophe”

Agé de neuf ans seulement, Jean Aléssio Désiré Christophe (plus connu comme Aléssio) qui souffrait d'une hémophilie sévère de type A, et qui suivait un traitement prophylactique deux fois par semaine à l'hôpital SSR dans le nord, fut parti aux petites heures du matin le 12 Juin 2019. Après avoir été hospitalisé pendant cinq nuits, il n'a malheureusement pas survécu à son traumatisme crânien malgré l'intervention des personnels soignants.

Aléssio, était pour la communauté d'hémophilie de Maurice, un petit très jovial qui participait à toutes les activités organisées par l'association. Il vivait une vie normale et partait à l'école comme tous les petits enfants de son âge. Mais le bon dieu en a décidé autrement.

Aléssio fut parti là-haut, mais malheureusement trop tôt. À travers les nuages, son âme s'est envolée, recueillie par des anges. Sans doute, il doit être en sécurité dans ce ciel bleu, dans ce monde lointain qui est maintenant le sien.

La communauté d'hémophilie de Maurice est très attristée et secouée par cette disparition soudaine. Évidemment, sa joie de vivre et son sourire enfantin va nous manquer. Hélas, c'est le côté obscur de l'hémophilie.



Aléssio a quitté derrière lui ses trois frères et sœurs. Nos plus sincères condoléances à la famille d'Aléssio.

Repose en paix petit champion.

Adult Camp: September 2019



Further to the success of the Youth Camp organised in early August 2019 and to pursue our objective towards making home therapy a reality, HAM embarked on a very first stay-over adult camp in favour of its adult haemophilia patients during the last week-end of 28th and 29th September 2019 at Holiday Inn Hotel.

Some twenty-male adult haemophilia patients under the supervision of abled HAM Executive Members and Staff participated in this event whereby much emphasis was held on self-infusion training. The interactive training (theoretical and practical) session was conducted by two dedicated nurses, Kavish (VH) and Sabeena (JNH) whereby patients had the

opportunity to learn various techniques of self-infusion with relevant factor concentrates. Others had the opportunity to train on the two arm dummies which were generously donated to HAM by Ms. Sugania of NBI, South Africa.

Other sessions which were organised during the camp for the benefit of the patients were to:

- consolidate the bond among the adult patients;
- inculcate the basics of haemophilia and the precautionary measures they need to take in their day-to-day life;

- better deal with their emotions and boost their self-esteem;
- accept themselves as they are and motivate them to advance in their life;
- have a better understanding of the various facilities and benefits offered by the Ministry of Social Security;
- realise the importance of physiotherapy and simple exercises to keep them fit.

The Adult Camp which was a huge success would not have been possible without the invaluable support of our stakeholders: Novonordisk Haemophilia Foundation- which fully funded both the Youth and the Adult Camps; the representatives from the Disability Board of the Ministry of Social Security; Ms. N. Ramdin – physiotherapist of the MoH&QL, and Motivational spokesperson – Jean François Favory.

Last but not least a special thanks to all the Executive Members and Staff of HAM for their everlasting dedication.



Upcoming Activities

The end of year is approaching fast and the Association still has a jam-packed Agenda.

September 2019:

Nurses Training and MASAC (Medical and Scientific Advisory Council) Meeting.

October 2019:

Visit of Prof. Jean-Francois Schved, a Doctor and Professor of Haematology at the Faculty of Medicine, Montpellier University who will be consulting with our patients as well as lecturing our medical personnel on the Management of Haemophilia.

November 2019:

Prof. Johnny Mahlangu, clinical haematologist from Johannesburg, South Africa will be visiting Mauritius in

light of the Medical Twinning between Jawaharlal Nehru Hospital and the Charlotte Maxeke Johannesburg Academic Hospital, where HAM's Treatment protocols will be reviewed and updated, with a view to further improving the treatment and management of our patients throughout the 5 national hospitals.

December 2019:

Visit of Tony Roberts, Psychologist from the South African Haemophilia Foundation, will be leading a PEP (Parents empowering Parents) Workshop whereby parents will be educated with the necessary support to better manage Haemophilia within the home environment.

December 2019:

End of Year Family Gathering.

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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