



STOP

THE BLEEDING



HAEMOPHILIA
ASSOCIATION
OF MAURITIUS

NEWSLETTER

MAY 2019 / Edition 5

Message from HAM President Mr. Rajesh Neelayya



I am pleased to be associated with the first newsletter of the Haemophilia Association of Mauritius (HAM) for the Year 2019. This year marks the 10-Year existence of the HAM.

Much has been accomplished since then to make HAM stand where it is today. That would not have been possible without the unflinching support and commitment of all the Executive Members, HAM Staff, the Government, the officials of the Ministry of Health & Quality of Life (including the Doctors and Nurses), our stakeholders (local & international) and last but not least the determination and patience of the patients.

However, there is still a long way to go to meet the challenges ahead. With the determination and team spirit of the Executive Committee Members, dedicated HAM Staff and together with all our stakeholders, we are confident that we shall attain our objectives for the coming years. We shall strive to ensure that home therapy becomes a reality within the next two years.

Our objectives for this year are, inter-alia, to:



Consolidate the established relationship with our stakeholders;



Enhance our outreach programme for the benefits of our patients;



Standardize the treatment for Haemophilia in all the main hospitals;



Advocate for home therapy;



Ensure availability of factor concentrates for all our patients (those on prophylaxis as well as on-demand treatment)



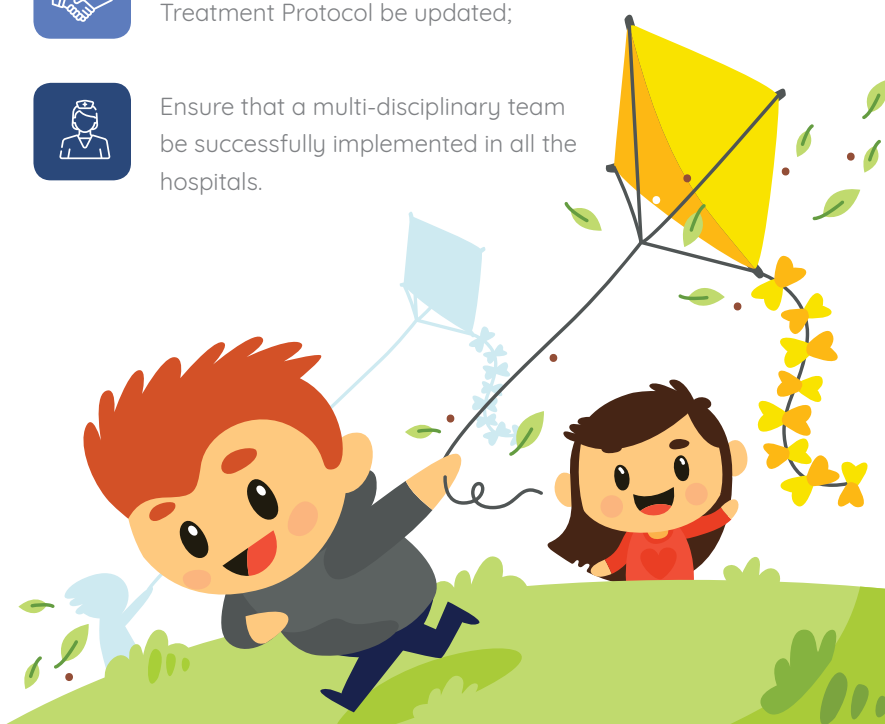
Continue to create awareness, putting all facilities in place to detect new cases of bleeding disorders to ensure that the new patients get the appropriate treatment;



Ensure that the MASAC Committee be set up and the Treatment Protocol be updated;



Ensure that a multi-disciplinary team be successfully implemented in all the hospitals.





Executive Committee Members

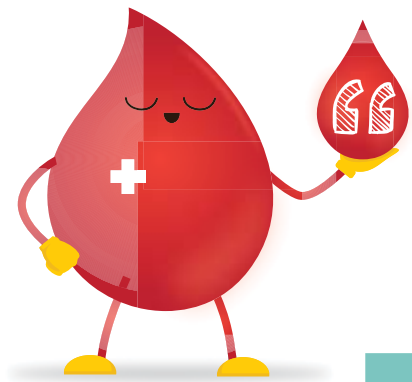
Rajesh Neelayya - President | **Dr. Janaki Sonoo** - Vice President | **Tatiana Bathfield** - Secretary | **Roshan Gudgadhur** - Assistant Secretary | **Kavish Chuttooree** - Treasurer | **Sabrina Planteau De Maroussem** - Assistant Treasurer | **Jodarsen Arnachellum** - Responsible for Youth Empowerment | **Julie Tyack** - PRO and Event Coordinator | **Elysée Legrand** - Responsible for Youth Empowerment | **Custnea** - Co-Opted Member | **Siam Bissessur** - Co-Opted Member

Haemophilia What?

10 years ago, not much was known about this life-threatening bleeding disorder. When people were asked what it was, 9 out of 10 were unable to answer. Over the years, HAM, together with the Ministry of Health has done a formidable job in raising awareness about this very rare condition that affects 1 in 10,000 people worldwide.

HAM's Executive Committee members are happy to say that today, this condition is better understood by the medical community, and the public at large no longer reply "Haemophilia What?" when asked about the bleeding disorder.

More and more people are becoming aware of the implications of this disorder in Mauritius; although the Association still has a lot to do to ensure that all those suffering from haemophilia and other bleeding disorders are properly diagnosed and treated.



Haemophilia is a severe and life-threatening bleeding disorder that prevents blood from clotting properly. People with haemophilia do not bleed any faster than normal, they just bleed longer.

Bleeding, if it occurs internally, can lead to tissue, joint and organ damage. Even a small bump or fall can start internal bleeding. Bleeding into the brain can be fatal. With proper treatment people with haemophilia can lead happy, productive lives. Without proper treatment, people with haemophilia will either die young or grow up severely disabled.

10 years – A Milestone!

2019 is a special year for HAM.

In 2009, HAM was created by a group of desperate parents and patients who wanted to see a change in the medical care being given to people living with haemophilia in Mauritius. For lack of space and amenities, they met regularly in a small office at the National Blood Bank and had a clear vision:

The creation of a haemophilia treatment care centre where people with haemophilia and other inherited bleeding disorders would receive safe and effective treatment products as well as proper diagnosis, management and care by a multidisciplinary team of trained specialists.

Through a lot of hard work, dedication and consistency, a valuable collaboration with the Ministry of Health, as well as a formidable network of international support, HAM has achieved the unthinkable:

- 225 members and volunteers to date
- 95 Registered cases of haemophilia and other bleeding disorders diagnosed
- 29 Obligate Carriers and 14 Potential Carriers of Haemophilia identified
- More than 400 family members sensitized on Haemophilia

- CFC (Medication for Haemophilia patients) made available to all patients suffering from all bleeding disorders throughout all Hospitals
- Prophylaxis available to all children under 18 years of age and 96 % of adult patients suffering from severe bleeding disorders
- A new online Electronic & Scientific National Registry implemented
- Training of medical doctors, nursing officers, lab technicians, physiotherapists, orthopaedic surgeons, paediatricians in the management and treatment of haemophilia healthcare both locally and internationally
- Outreach Program developed and psychosocial support available to all patients and family members
- 4 Treatment Care Wards now available in 4 Regional Hospitals for haemophilia management
- Participation in 4 World Congresses
- 2 successful Twinning Partnerships implemented via World Federation of Haemophilia (Medical Twinning still in progress)
- National and International Awards: WFH Twins of the Year 2013, SADC Gender Protocol 2018 Award, Grand Winner of the National Productivity Quality Convention 2018 and Gold Award at the International Convention Quality Circle in Singapore 2018
- Ongoing collaboration with the Ministry of Health & Quality of Life
- Continuous partnership with international bodies: Fully-fledged member of WFH
- Continuous partnership with local NGOs: Thalassemia Society of Mauritius
- Implementation of a brand new and dynamic Youth Committee



01

10 years ago, clotting factor concentrate (CFC) was not available in Mauritius and patients were being treated inadequately, if at all.



10 years later, patients are treated by qualified staff in dedicated treatment wards throughout all Regional Hospitals where Clotting Factor Concentrate is readily available and easily accessible to all.

02

10 years ago, very little was known about the treatment and management of Haemophilia in local hospitals, private clinics and generally by the medical staff at large.



10 years later, all haemophilia children receive preventative treatment and are living next to normal lives. As a result, both government and society benefit from an investment in children's health when, as adults, they can work, contribute to the community, pay taxes and raise a healthy family.

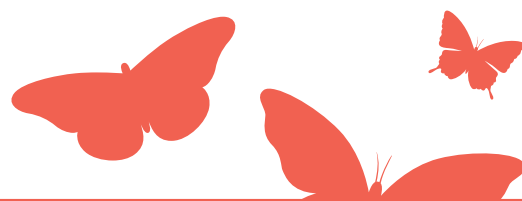
03

10 years ago, Haemophilia patients suffered in silence and living a normal life was not even thinkable.



10 years later, the quality of life of all haemophilia patients has greatly improved by reducing long term complications and disabilities.

“ We can't believe how far we have come in such a short period of time and we can't wait to see what the next 10 years will hold!



Our Patients' Perspective

01



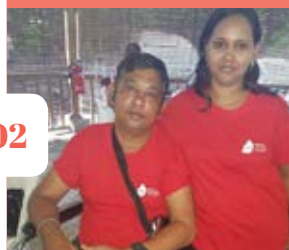
Sunil

53 years old suffering from severe Haemophilia A, residing at Triolet.

He lives alone and is not married. He works as a tailor and has a positive outlook towards his disorder and his treatment.

“ Mo ti p souffert beaucoup Longtemps, pa ti ena traitement, mo ti p ress lopital beaucoup jours, mo ti p absent beaucoup lecole avant mai zordi mo vivre mo lavi bien, tou les mercredi mo al met mo medicament lopital, mo pa admet aster. Grace a lassociation Haemophilia, mo p resi sorti e zoine bane lezot camarade hemophile.

02



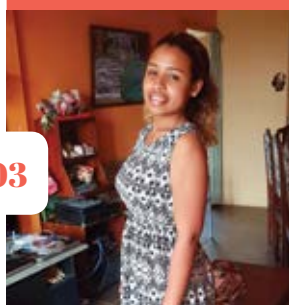
Tabrez

Suffers from moderate haemophilia. Tabrez is a shoemaker by profession, a family man, married with a very supportive wife and is the father of two daughters.

Tabrez is unable to walk due to his disability which occurred by a motorbike accident. He goes to hospital only when he feels pain and receives on demand treatment.

“ Mo bien mo ene member lassociation Haemophilia e mo encourage bane lezot hemophile vin member, zot in faire beaucoup pour moi.

03



Daphné

Adolescent Carrier of Haemophilia, who bruises easily.

“ Mo remercie lassociation hemophilia pou tou ceki zot in faire pour mwa, mo bien satisfait, Dr Sonoo in bien guet mwa e in done tou information ki mo ti p roder.

04



Alessio Christophe

9 years old suffering from severe Haemophilia A, on prophylaxis twice per week, goes to school normally.

“ Mo ene hemophile, mo faire pique tou les semaine, mo vivre normale, mo jouer, galouper pareil Cuma mo bane camarade.



1st Quarter 2019 at a glance

World Haemophilia Day 2019



Light it up red 17 April 2019

On World Haemophilia Day, the WFH encourages the global bleeding disorders community to come together and show support in raising awareness for global bleeding disorders by lighting it up red.

HAM has taken part in this initiative for the past 3 years and this year joined over 70 other landmarks in **lighting it up in red!** A big thank you to the MCB whose Building at St. Jean proudly shone RED in support of all our haemophilia heroes.

The images of those landmarks were shared on social media worldwide and Mauritius is proud to form part of this global family.

Every year on April 17, World Hemophilia Day is observed around the world to increase awareness of haemophilia and other inherited bleeding disorders. This is a critical effort with an ultimate goal of ensuring better diagnosis and access to care for the millions who have a rare bleeding disorder yet remain without treatment.

This year, on World Haemophilia Day, the global bleeding disorders' community celebrated the theme of Reaching out - connect to your community.

In celebration of HAM's 10th anniversary, the Executive Members decided it was time for the patients and their families to have some fun! Meeting and connecting with others who share similar experiences and know what it is like was invaluable.

On Sunday, April the 14th, HAM's Executive Committee Members welcomed 180 patients, parents, caregivers and family members at Les Vallee des Trois Couleurs in Chamouny. The day was animated by Raj Gokhool and HAM's extended family enjoyed a buffet lunch while watching sketches and dances, face painting, "barbe à papa" and an Easter hunt for the children made this day a memorable moment.



HAM Drop of blood in red (patients, family members, staff and committee members came together to form a Human Drop of Blood to sensitize the public at large about haemophilia)

Symposium on rare bleeding disorder on 4th April 2019.

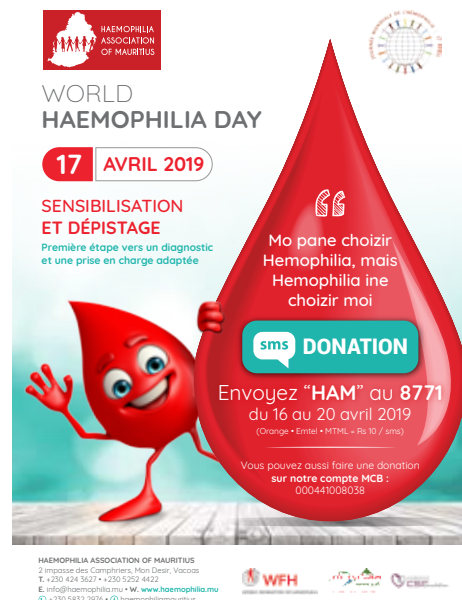
Dr. Monica Vaithilingum, a Pediatric Haematologist from Durban, South Africa, shared her vast experiences, best practices, current updates, unique practical insights into the management of rare bleeding disorders with a focus on Glazmann Trombastenia. The workshop was attended by members of HAM Executive Committee and Medical Practitioners of different hospitals.

Fundraising.

For its 10th anniversary and in celebration of World Haemophilia Day, HAM was looking at raising funds in a different way. A highly publicized SMS donation campaign was put into place and the public at large was asked to donate via SMS over a period of 4 days.

This campaign was highly mediatized on radio, newspapers and social networks and HAM takes the opportunity to thank all those who donated to support this cause!

1,032 SMSs' were sent but more importantly, a total amount of RS 208,114 was raised in order to help improve the treatment and management of those suffering from haemophilia in Mauritius.



Medical Twinning between Maxeke Hospital, Johannesburg, South Africa and Jawaharlal Nehru Hospital, Rose-Belle.

One week training was conducted by Mrs. Lioma Dipuo Maria of South Africa from 18th to 22nd April 2019 with Laboratory Technicians at the Central Laboratory, Candos on improving testing on Coagulation disorders.

A workshop on importance of Multidisciplinary Care team in managing Haemophilia and other bleeding disorders was conducted on the 21st of March 2019 by Professor Johnny Mahlangu, Professor of Haematology, Faculty of Health sciences, University of the Witwatersrand, Johannesburg.

Another full day workshop was conducted by Professor Johnny Mahlangu at Gold Crest Hotel on 22nd March 2019 on the Bleeding Assessment Tool (BAT) which was attended by Anaesthetists, Surgical Nurses and other Health Care Professionals.



Upcoming Activities 2019

We have a fully booked agenda this year and believe by the end of 2019 to be able to improve the treatment and management of our patients twofold:

- Outreach Programme
- Capacity Building of Healthcare Professionals
- Upgrading of Electronic Online Scientific Registry
- Training of parents and patients on self-infusion
- Youth, adult and children camp
- Awareness and Sensitization Campaign on Haemophilia and Other Inherited Bleeding Disorders
- Muscular Skeletal Training and Care for patients with Haemophilia
- Mobile Application to register bleeds of patients
- Parent empowering Parent Programme
- Check up and educational sessions by Haemophilia expert
- Medical And Scientific Advisory Committee (MASAC)
- Group, Psychosocial and Educational Sessions
- Psychosocial and Physiotherapy sessions
- Advocacy with Government in favour of improving the quality of lives of patients with bleeding disorders
- Diagnosis of Von-Willebrand Disease



CSR Partners 2018 / 2019

All of our achievements and advances in haemophilia treatment and management in Mauritius would not be possible without the help of our donors. You are our backbone:
Thank you!

International

NovoNordisk Commercial •
NovoNordisk Haemophilia
Foundation • World Federation
of Haemophilia – Twinning

National

AI Broker • Le Tamarinier Ltee • La Sentinelle L'Express • Street Performance • NCSRF
• MSJ Unicorn • Phoenix Beverages • Hardy Henry • Zell Contracting • Cottonium Ltd
• Street Performance • Change Express • Medine Horizon • Publi Promo • Nutricorp
Ltd • NCSRF • Distripharm Ltd • My Web Ltd • NCSRF • Silver Clean

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.



Our Staff

Mohsena Olath-Carramtally – Operations Manager
Minackshi Dhurmoo-Luchmun – Operations Officer
Komal Jogarah – Administrative Clerk

HAM CONTACT DETAILS

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