



People With Haemophilia Newsletter

Central Haemophilia Foundation

4th Quarter 2019

MASAC 7-8 November 2019



The annual SAHF MASAC (Medical and Scientific Advisory Council) Education Symposium was held at OR Tambo Protea Hotel from 7-8 November 2019. MASAC is celebrating 25 years of

bringing together all the individuals, medical personnel and staff who look after the bleeding disorder community in South Africa. It was 25 years ago that a few determined individuals decided to make a difference in the diagnosis, management and welfare of patients with bleeding disorders. This year the Academic Session 1 was named “The Judy Butler Academic Session” in honour of Judy Butler who passed away at the beginning of the year. As most of you know she was the operational manager of SAHF and dedicated almost 50 years to SAHF. MASAC has grown over the years and this year’s symposium had a total of 162 attendees, up from 120 last year!



162 Delegates

MASAC chairperson, Dr Yagalen Naidoo, welcomed all the delegates and spoke about the developments in the web-based registry, expanding out-reach across the country and the challenges faced with the impending roll-out of NHI (National Health Insurance).

Presentations from haematologists, specialists, parents and The Department of Health covered topics from local research, managing difficult bleeders, haemophilia updates and ethics. Dr Steven Austin a haematologist from the United Kingdom spoke about inhibitor patients and also new therapies and cures in the future.



Sr Anne-Louise Cruickshank and Dr Steven Austin

Prof Luigi Solimeno, an orthopaedic surgeon from Milan, Italy gave presentations on chronic synovitis, diagnosis and treatment and the complications experienced by haemophilia patients and how to manage them.



Prof Luigi Solimeno

This year there were 5 formal pharmaceutical company exhibitions and 8 medical posters on display.

Thank you to the MASAC committee in delivering an exceptional symposium. This only helps to strengthen our community and share knowledge and expertise!



MASAC Nurses

GADI'S GIFT!

Gadi was born with Haemophilia which was diagnosed after his circumcision when he did not stop bleeding and needed 3 blood transfusions.



As parents we decided it was Gadi's turn to give back! We organised a blood drive on Sunday 15th September 2019 in Gadi's honour called Gadi's Gift! Hosted at Huddle Park gym, Linksfield. All people and all blood types were welcome and a total of 131 pints of blood was donated!

Drinks and snacks were provided and we held a raffle at R50 per ticket. Over R60,000 worth of prizes were generously donated and we raised R52,338.71.

All proceeds were donated to the South African Haemophilia Foundation.



Thank you to everyone who donated prizes and donated blood.

It was a huge success!

By Calli Rosin

TRAINING AROUND THE REGION

NURSES TRAINING IN MTHATHA



On 21 October 2019 a Nurses Haemophilia Training Session was held in Mthatha with a total of 30 nurses, including two nurses from Ghana and Nigeria, being trained.

Sr Anne-Louise Cruickshank and Sr Selo Tuswa led the training with



assistance from Sr Ncapayi.

HOME THERAPY TRAINING IN ZIMBABWE

On 11 September 2019 Home Therapy Training was conducted in Zimbabwe. Here you can see



Elliot being used as the "patient" during the training.

Well done!

WHD 2019 CELEBRATIONS IN MAFIKENG



Mafikeng celebrated World Haemophilia Day on 27 September 2019 with Sr Moloji.

Thank you for spreading awareness!

PRETORIA YOUNG ADULT GET-TOGETHER

Kgomotso Kgole organised a young adult get together for the patients in Pretoria at Mothakga Resort on 21 September 2019. The young adults shared their experiences in depth and their frustrations surrounding circumcision.



Talks and games were organised by Tebogo Mphahlele and Karabo demonstrated tips on how to do home therapy! Everyone then enjoyed a braai and refreshments! Sr Anna Motswagae from the District Health Genetic Services came along and everyone had a lot of fun and gained valuable knowledge and information!



Enjoying the day!

UPCOMING EVENTS

WORLD HAEMOPHILIA DAY! 2020



GET+INVOLVED

April 17, 2020 is the 30th anniversary of World Haemophilia Day! The longevity of this celebration is proof of the dedication and tight-knit nature of our community. The theme of World Haemophilia Day in 2020 is "Get+involved". It's a call to action for everyone to help drive the WFH vision of "Treatment for all" at the community and global level. Whether you are a patient, a family member or caregiver, a corporate partner, a volunteer, or a healthcare provider, we want to encourage you to help increase the awareness of inherited bleeding disorders and the need to make access to adequate care possible everywhere in the world. This landmark day also helps to illustrate the importance the WFH has developed to support the bleeding disorders community. The WFH Humanitarian Aid-Program provides a range of integrated care development training programs to ensure the local infrastructure and medical expertise are available to optimise and appropriately use donated products. The Global Alliance for Progress (GAP) Program was developed to greatly increase the diagnosis and treatment of people with bleeding disorders by closing the gap in treatment of people with bleeding disorders by closing the gap in treatment between developed and developing countries.

Stay tuned for the dates of celebrations at your clinics! **GET+INVOLVED!**

WFH WORLD CONGRESS

The WFH World Congress is a key event for the WFH and for the global inherited bleeding disorders community. It is the largest international meeting for the global bleeding disorders community and it is hosted in a different country every two years.

Every second year, doctors, scientists, healthcare workers, people with bleeding disorders and haemophilia organisations gather to learn about the latest developments in bleeding disorders treatment and care. It is during this important meeting that the discussions and debates that will shape our global organisation and community take place.



In 2020 this key event will take place at the Kuala Lumpur Convention Centre (KLCC), in Kuala Lumpur, Malaysia's

capital, from June 14 to 17, 2020.

Kuala Lumpur will surely be an exciting place for Congress participants to get to know. Take a look at The Congress 2020 website at <https://www.wfh.org/congress/en/>

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instructions. Simple as that! Scan the unique QR code below and pay your bills as well!



GET INVOLVED

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- Pay with SnapScan
- Support our fundraising efforts during the year
- Raise awareness in your companies or participate for PWH in public events
- Contribute to the newsletter. Anything haemophilia-related. Send your article to juliemal@mweb.co.za louiseellwood@me.com
- Follow us on Twitter @HaemophiliaSa
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