

Haemochromatosis Society of South Africa

We have just returned from Cape Town where the HSSA was represented at the 4th Annual Conference of the Africa Genome Education Institute held on 24/25 March in Somerset West. During this visit to the Cape, we also took the opportunity to hold an inaugural meeting of the Western Cape Branch of the HSSA.



Having taken some early steps, to date, to establish the Society in Johannesburg and now in the Western Cape, it is perhaps appropriate to assess what has been done and what still needs to be done in achieving the objectives for which the HSSA was established.

Our Focus

To remind you of the key objectives of the HSSA:

- ▶ To promote awareness of Haemochromatosis amongst the public and the medical profession.
- ▶ To provide current information on Haemochromatosis.
- ▶ To establish support groups for HH patients and families.

Firstly, some of the activities so far:

- ▶ A launch meeting in Gauteng, attended by some 18 people.
- ▶ A launch in Cape Town attended by 18 people.
- ▶ The creation of strong links with the Canadian Hemochromatosis Society, Genecare and several local experts in the HH field including Prof Patrick MacPhail, Dr Maritha Kotze, Prof Erna Mansvelt, Dr Nico de Villiers and Dr Monique Zaahl.
- ▶ An interview on Cape Talk Radio
- ▶ Recent articles in "Our Genes" (the publication of the Africa Genome Education Institute) in the Independent on Sunday, also in Die Burger, Beeld.
- ▶ The continuing development of the HSSA web-site and arrangements to possibly take over the Canadian internet-based support group/ forum.
- ▶ Links from other health-based web sites to the HSSA site.
- ▶ The start of a data base of HH patients and those interested.

Good
early
progress

In addition to the above, other activities are in the pipe-line including a broadcast to all Netcare doctors on HH in May and articles in the Discovery, Click's Club and Dis-Chem magazines.

All of these activities have been undertaken by a very limited number of volunteers using their own time and resources. The results so far, are difficult to measure but there is no doubt that some progress has been made in increasing the awareness of HH, establishing some patient support and 'bringing HH to the table'.

What now?

We believe that we have now reached a critical point in the development of the HSSA. We need to consider whether and, if so, how we deliver the objectives of the Society in a more focused and organized manner. The contacts that we have made so far have all indicated the need and value of the work of the Society.

There appear to be several matters that need to be addressed as we consider the future:

- ▶ The development and *upkeep* of the **web site** so that it is more effective and interactive.
- ▶ The formalisation of the **Gauteng and Cape Town branches** of the Society.

- ▶ The preparation of packs of information and other forms of **communications** with the medical profession, the media and the public.
- ▶ **Meetings** with key role players from The National Blood Transfusion Service, the medical schools and professional bodies.
- ▶ To keep in touch with various **research projects** being undertaken in South Africa which are looking at issues such as the role of the disease and iron overload in other ethnic groups.

Your support! In short, to make things happen at a more effective level, we need the support of those who are willing to become more involved in the Society. In addition, we need some limited funding, properly administered, to allow us to pay for direct costs such as printing, telephones, some travel, web development, etc. We are hoping that we will find a sponsor to provide some funding or to undertake specific activities for us. Assuming that we can only obtain funds from our members, we will have to look at an annual fee – possibly in the range R50 to R250 per annum.

Accordingly, we need each person who has an interest in the future of this Society, to complete the attached form and return it to info@haemochromatosis.za.org Once we have these responses we will take the matter further.

During our visit to the Cape, we met Dr Monique Zaahl who leads HH research at Stellenbosch University. She is looking for members of the public (including HH patients and *families*) who would like to have their HH/genetic status tested. She is also researching the relationship between iron and Oesophageal cancer, iron and Multiple Sclerosis, and HH and Porphyria. If you or your relatives or friends are willing to participate in this research, and have the genetic tests done free of charge, please send an email to Monique at mjulies@sun.ac.za and let her know. She will then contact you.

We feel passionate about the need to spread the message of this relatively ‘unknown’ disease. In the interim, thank for your expression of interest.

Kind regards



Kirsten Alberts

Roger Keyte



Our HH stand at the Conference in Cape Town



Dr Maritha Kotze, Prof Patrick MacPhail, Kirsten Alberts and Roger Keyte at the Gauteng launch in November 2005



Kirsten Alberts, Roger Keyte, Prof Erna Mansvelt and Dr Nico de Villiers at the Cape launch in March 2006

Haemochromatosis Society of South Africa Request for Information



Please will you complete the following questions.

1 FULL NAME:

2 CONTACT TELEPHONE NUMBERS:

Home:

Cell:

Business:

3 eMail address

4 What is your interest in Haemochromatosis (HH)?

I am being treated as a patient for HH.

Yes

I am a carrier.

Yes

A member of my family has HH.

Yes

I am a medical practitioner with an interest in knowing about HH.

Yes

I have no direct association with HH.

Yes

5 To fund limited activities of the Society, would you be willing to pay an annual r

R100?

Yes	No
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R200?

Yes	No
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R500?

Yes	No
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6 Mark the areas of the Society's need in which you would be willing to play a role

Web site design and implementation?

Yes

Development of a member/interested person data base?

Yes

Writing articles for the Society to publish?

Yes

Writing your own story of HH?

Yes

Playing a lead role in establishing/running your local branch?

Yes

Fund raising in your community or nationally?

Yes

Attending meetings to represent the Society?

Yes

Becoming a member of the Society?

Yes

Offer support to newly diagnosed sufferers when necessary/regularly

Yes

If you are a specialist in any aspect of HH, would you present a talk?

Yes

7 Any Comments?