

March 2018 Newsletter

Bank account slowly progressing

We are in the process of changing bank account, the application with the HSBC is going through slowly. As soon as this is done I will endeavour to change all fundraising sites we use and maybe add new ones, such as Amazon Smile UK.

Patient support

Jan Clifton has started a patient group in the South East. She meets up with other patients in a coffee place to discuss experiences and support each other where possible. After a slow start it seems to be becoming popular! The next meeting is Monday 26th March at Costa Coffee, Bexleyheath, Kent 12.30pm.



Anyone is welcome, if possible let us know you are planning to come!

Miners compensation rejected.

In 2014 the Industrial Injuries Advisory Council concluded that the incidence of Dupuytren's in miners was significantly higher than in the general population. This was attributed to the work miners do with heavy drilling and vibrating equipment. The Council advised the government to set up a compensation scheme for miners suffering from the condition.

It has only taken the government four years to consider this, and the decision taken is they they will NOT compensate any miners for the loss of hand function caused at least partially by the job they have been doing. Durham Miners Union is considering appealing, we have offered our help if there is anything we can do.

Fundraiser for Dupuytren Award combined BDS and DDSG is a success

The BDS together with an America based Facebook group, DDSG, has done a fundraising drive in February, to raise funds for the Dupuytren Award. This award is given out yearly, by the International Dupuytren Society, to the author of the most promising scientific article on Dupuytren. This can be clinical or research, and in some years the amount awarded is split over two papers. In a month time we managed to raise \$4,000, enough to fully fund the award for this year and have some left over for next year.



The money raised came mainly from the US, there were only a few UK contributors. BUT there is still time to change that! I have asked Wolfgang Wach to keep the special *donate button* on the website, and give the UK a chance to catch up with the US in donations.

Let's all donate for research, it is our only hope for a cure, if not for ourselves then maybe for our children, grand children, nephews and nieces..

To donate use the top 'Donate' link on this page. <https://www.dupuytren-online.info/donations.html>

Dutch news

The Netherlands is getting pro-active! The newly formed Dupuytren Society (Stichting Dupuytren Nederland) has already had a very successful meeting on Dupuytren's, with some renowned speakers such as Prof P Werker from Groningen, who was co-organiser of the 2015 Dupuytren Conference.



For any dutch speaking (or reading) members, here is the link to the society's website: <https://dupuytren-nederland.nl/>

The second news item from the Netherlands is **LedRad**, a double blind trial using radiation for Ledderhose patients. The trial is for dutch speaking patients only, and will be held in several centra over the country. The organisers are hoping to treat 80 patients and follow their progress (or hopefully lack of disease progress) for several years.

This is the kind of research we need, to prove to patients and specialists alike what the benefits of radiotherapy can be, and what the side effects are short and long term, to allow a treatment decision based on facts and not suspicions.

A Nepalese patient found treatment with our help.

In 2017 we were approached on Facebook by a Nepalese man, Sunay, who had been diagnosed with Dupuytren's contracture and told he needed surgery, but the doctors in his local hospital had no experience with the surgery. So Sunay reached out to us, firstly considering travelling to the UK for treatment but this was not really a realistic option.

I had read about Mr Donald Sammut's charity Working Hands. Mr Sammut travels to Nepal once or twice a year to treat patients there, mainly those who have nerve damage in their hands due to leprosy, but also some with burn scars and contractures or other hand conditions. For a report on what the charity does, please read this news report from last year:

https://www.theguardian.com/artanddesign/2017/mar/12/the-art-of-surgery-life-drawing-and-leprosy?CMP=share_btn_link

I suggested to Sunay that he contact the charity to ask if Mr Sammut would be able to help him. As

per the suggestion, Sunay decided to contact Mr Sammut directly. Mr Sammut immediately replied to his email and agreed to perform NA (PNF) when he next visited Nepal. Sunay has now had PNF performed on one hand, and is already planning to have his other hand treated if necessary when Mr Sammut is in Nepal again sometime. He was a bit nervous at first, but afterwards he was very happy with the treatment and the result, hardly any time off work and his hand functions again!



Before



After

That is what Mr Sammut's charity is all about, helping people get their hands functioning again, regain the ability to look after themselves and work again, and teaching local surgeons how to perform the necessary procedures by themselves.

Please check the website of 'Working Hands', to see what wonderful work this charity does.

<http://www.workinghandscharity.org/>

In the words of Sunay: 'Mr Sammut is a very very very good man'.



Mr Sammut examining one of his many patients in Nepal

Website changes

On 16th March Anna met up with Simon Brophy from Sobi and Rhiannon from Crest Communications for a lovely lunch, to discuss how we can modernise the website and what changes are advisable or needed. One change that already happened is that I removed the link to the Zeemap with the radiotherapy units on. From April Zeemaps wants \$19.99 a month to use the 'free' version, and I decided the charity won't pay that.

We also hope for instance to sort out the fonts on the website (in case you've not noticed, one page can have many different letter types, and to change that you need to do html language. I speak Dutch, but html is not my forte! Some pictures need replacing as they are old or low resolution, and we hope to get the blog, twitter feed and maybe even the Facebook open page linked better. Lots of little things, so you may not notice directly, but the website should become easier to navigate.

Happy Easter

