



BDS Trustees Meeting 2015-2016

28-12-2015

AGENDA

- **Welcome and introductions**
- **Present:** Anna Schurer, Annemarie McNish, Gary Manley, Birgir Gislason, Gemma Matthews, Dr John Glees
- **apologies:** Judith Proctor
- **not present** Mr Henk Giele
- **2015 work done** (Groningen conference and Gary presentation, NICE Dupuytren's appraisal and appeal (Anna and Henk), website (Anna Gemma Gary), Groningen book (Anna), NICE Peyronie scoping (Birgir), ongoing patient support, contact with doctors, Sobi, Say Comm, Paget society (Anna), secretariat function (Gemma), any other work)
- **2015 finances** see pdf emailed around. Financial report accepted without questions.
- **2016 priorities**

Trustee board We voted to appoint Birgir as trustee on the Peyronie's side. Henry Orton and Judith have been named permanent founder members, Judith to remain trustee if she wants but will have to commit to attending few meetings per year as required if we become a registered charity. Annemarie remains treasurer but no trustee, Gemma remains secretariat but not a trustee. We need to look for trustees with special skill such as fund raising. A job description for what is needed will be written by Anna and discussed by the present trustees. Ideally we need a urologist and an foot-and-ankle surgeon on board to represent Peyronie's and Ledderhose.

Objectives for 2016

All objectives must help to meet aims of charity; to raise awareness of illnesses and treatment available, to provide support, advice and information to people with Dupuytren's and related conditions, to support research.

Develop website

Website content needs checking and updating. Discussed hiring medical website writer (average cost £300 a day) for a couple of days to overhaul content with an expert checking their copy. Discussion about newsletter possibly launch first one in March– Add ask the expert email function and sign up for newsletter function. List of contacts for all treatments for all conditions. All trustees may make suggestions of changes to website, Gemma will continue to use secretariat time to go through website and suggest changes. John Glees will forward his video on radiotherapy when it is available for inclusion.

An FAQ page on Peyronie's and Dupuytren's would be a good addition.

Becoming a charity All agreed this was the aim once BDS has raised £5,000. Anna will lead and Gemma will support. John Glees recommended we contact Les Biggs at Ralph Bates Pancreatic Cancer Research Fund for advice if needed.

Case for support and fundraising We need to decide what to raise money for- for now eg a GP campaign to raise awareness of the cluster of related conditions and the possible treatments especially at an early stage seems a good project. Other options are a urologists/hand surgeons campaign to educate on treatment options through mailings and conferences, developing website and developing resources available for patients e.g. leaflets, posters, videos, symptom checker, treatment pathways. Any grants applied for will be for one of these projects.

Communicating with supporters Communication at the moment is mainly via internet, email and Facebook. A telephone line would be good but the feeling is that at the moment we don't reach enough people for a specialist line to be worth it.

Name and logo

-Name to remain the same as we could not get a short charity name that covers all conditions and the BDS name is getting known among

patients and doctors. Should we change tag line under logo to say 'supporting those with Dupuytren's, Peyronie's and Ledderhose disease and related conditions' or something like that? Seems like a good idea.

- logo- we still want a new logo, will keep looking for a good design or designer. Ideally we'd have a foot with a lump and a hand with a cord and contracted finger on it, but it has to be simple and easily recognisable.

- **Peyronie's campaign – Gemma**

SOBI have provided some money for Say Comms to run a small awareness campaign about Peyronie's to include a survey (hosted on BDS and My Peyronie's sites), some media and social media work using case studies if possible, and developing the website. Gemma to forward more information when available. All agreed for Gemma to progress this work. Birgir and John will be involved in this. Radiotherapy gives pain relief for 50% of Peyronie's patients thus reducing the need for surgery (the best results are seen if treatment is given early, before a deviation can be seen). John has over 30 years experience with this and treats patients private for the condition. . We need to get this message out to patients and doctors.

<http://www.channel4embarrassingillnesses.com/video/consultations/consultation-peyronie-s-disease/> A Channel 4 program that showed a Peyronie's patient on TV, may be worth contacting them and asking if he/they would be willing to help in the campaign?

- **Say Communications fundraising event** To be done in February 2016, a sponsored bike ride the distance of London-Paris but on an exercise bike rather than through the channel! We need some more information so we can post it on Facebook and the website.
- **Virgin Money Giving fee** Agreed to spend £120 on becoming a member of Virgin Money Giving website to boost online fundraising.
- **Any other business**

John Glees suggested looking into the **CCR expo** 6-7 October 2016, a conference of plastic surgeons where a lot of leading Dupuytren's doctors will be present, maybe the BDS can have a presence there, even a stand? Cost is £99 per day for a stand.

David Warwick would be a good person to approach (hand surgeon), Anna has met him at the NICE appeal, Anna and Gary heard him speak in Groningen and Henry has chatted to him in Italy. He has stated he is willing to help the charity if he can.

We need to check who in the **Urology Association** is interested in treating Peyronie's, as some surgeons will have more expertise than others.

Check out the **Ralph Bates Pancreatic Cancer Research Fund**, John Glees is a founder and trustee and they might be able to give us some pointers on how to become registered and raise funds or raise our or the diseases profile.