

BAPS - PATIENTS CHARITIES TELECONFERENCE

Tuesday 5th March 2019

Participants:

Richard Stewart	BAPS President
Kate Billington	Admin Sec BAPS
Beverly Power	CDH UK
Graham Slater	Hon Sec, TOFS
Alison Taylor	CEO, Children's Liver Disease
Jane Fisher	Antenatal Results & Choices
Neil Lightening	Mitrofanoff Support Group
Rachael Olley	Operations Manager, Childhood Cancer Parents Alliance

Apologises:

Julie Harrington	GutsUK
Andy Wynd	Spina Bifida Hydrocephalus Scotland

1. Richard Stewart welcomed everyone and asked for thoughts and feedback from the Liverpool Congress?

There was uniform agreement that it was beneficial to attend congress encouraging greater exposure of the charities to surgeons. The selection of which charities to invite will require careful consideration. All were enthusiastic to be involved again in 2019.

2. The group then discussed options for involvement at this year's congress in Nottingham.

- Wednesday am session
- Charity Board meeting
- 'Transition of care from Paediatric to Adult services'

- a. **Wednesday am** – A 90 minute joint session was proposed (11:00-12:30pm) giving charities/BAPS an opportunity to inform each other of their roles and to explore how they could mutually benefit from collaborating together. The audience (max 60) could comprise consultants, trainees and parents (invited by the charities). A request was made for a 'catchy title' to publicise the session. Would it be helpful to have a high profile chair eg the Earl of Listowel, House of Lords?

Charity themes could be:

- ⇒ Who we are & what we offer
- ⇒ Patient information
- ⇒ Patient pathways
- ⇒ Pre/post-op supportive care
- ⇒ Supporting research

BAPS could present on:

- ⇒ BAPS functions - Membership/Units
- ⇒ Results of 2018 Charity survey
- ⇒ Research
- ⇒ International work
- ⇒ Website – parents area
- ⇒ Patient information

Areas for roundtable discussion:

- ⇒ How surgeons engage with charities and patients groups
- ⇒ Identification of a “bona fide” charity
- ⇒ Multidisciplinary team working eg with neonatal, feto-maternal, genetics
- ⇒ Organisational themes
- ⇒ Fundraising

b. **Charity Board meeting-** for discussion and planning of future collaboration at a convenient time during the congress.

c. **‘Transition of care from Paediatric to Adult services’** -BAPS are planning a 60 minute session on Friday the 5th of July to discuss NICE guidance inviting a Royal College of Surgeons Council member to speak from his adult perspective. It was proposed that this was an opportunity for the charities to give a short presentation from their perspective. The draft format is for four 15 minute blocks – Charities - NICE – RCS – Roundtable discussion. This would allow for three 5min or four 3^{1/2} min presentations from patient charities.

3. ACTIONS

- All agreed to feedback with suggestions for the Wednesday am with ideas for a title of the session
- Charities to respond with speakers for the Transition session
- Date of next meeting - tbc

DRAFT