

# Notes from the Patient Representative

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SCTS Patient  
Representative

**It is only eight months since I took my seat with the Executive Committee, but a lot seems to have happened since then. It cannot be easy for a group of professionals to have a layperson join them, but I have been warmly received and my perceptions are that my presence does not seem to have inhibited discussion or debate. In fact they must trust my discretion, for there have been some distinctly controversial topics under consideration.**

This concept of representation not only relates to the internal business of the Society but also to how it relates to the current and prospective patients out in the community, and to what cardiothoracic patients have to say about matters relating to them. Two issues have been questioned by us during the last few months, one being poor advice concerning post-operative cardiac rehabilitation emanating from the RCS (England) which was only rectified following strong intervention from our President, and the other where the Department of Health in an advisory note excused our post-operative ICU's from the implementation of same sex accommodation. The patients absolutely agreed with this advice, but neither the SCTS nor we can recall being consulted.

Most cardiac surgery patient representatives have come to be involved through their ongoing engagement with local support groups who tend to foster lively rehabilitation programmes. That is why we take cardiac rehabilitation so seriously. There is no agreed tariff for rehabilitation at present and so there is no comprehensive roll out post-discharge. That is why the BHF decided to take on its first ever political challenge and to sponsor the current Cardiac Rehabilitation Campaign. This campaign has been rolling for just over two years,

we haven't won the day yet, but the profile of rehab is certainly more prominent. Please don't forget to instruct your patients to get involved, in rehab that is, not necessarily the campaign. You have saved or certainly improved their lives with your surgery, now assist them to extend those same lives with ongoing rehabilitation.



*The Mayor of Rochdale, Councillor Jean Hornby, and her Consort, with David Geldard, President of Trans Pennine Cycling Club, starting on one of his club's eleven annual Over The Edge sponsored cycle rides in aid of the British Heart Foundation that so far have raised £130,000 in aid of the charity*

Talking about the British Heart Foundation, again this is a charity fondly embraced by patients, it is their leaflets that are prominent in providing broad advice and guidance about our conditions, and it is the BHF who often provide the pump-priming funds to

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establish rehab programmes. However, BHF is also a major supporter of research and I have been surprised at the small number of surgical professorships sponsored by them. Does this also reflect on the take-up of doctoral sponsorships amongst our trainee surgeon cohorts? It's the patients and their families who fund the charity and perhaps this is a question that would benefit from a dose of investigation.

By the time these notes appear the Blue Book will have been published. You surgeons and your teams must take great cheer and comfort from this document. In fact you should all throw Unit parties to celebrate your achievements, take photographs, place reports in your Trust journals, invite the Press. In fact have a ball!

It is a significant and comprehensive record of your commitment to patients, many run of the mill procedures to you, but to your patients from their perspective it's life or death. The record also

demonstrates that you are getting braver; you are regularly accepting more difficult cases, older people, more women, patients with other debilitating conditions and still your successes rise. My understanding is that this Blue Book also challenges the other surgical specialities to look to their laurels and to start to push back their own boundaries still further. It is a call to action to the whole profession. Ben Bridgewater has led up the writing team on your behalf, he and they have done a great job, but remember, what they are doing is displaying your wares. Really well done everyone.

As in life, so in medicine, women are a conundrum. In regard to cardiovascular disease women are under-presented,

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under-diagnosed, under-treated, and under-represented; these are the findings of the National Joint Working Group for Women's Heart Health. It's not just in the Home Waters; it's an international problem. The World Health Organisation statistics show that not only is cardiovascular disease (CVD) the leading cause of mortality, but more women than men die from this cause. The Blue Book mirrors some of these issues, which means that here is supportable evidence and we need to capitalise on this opportunity to make our contribution to Women's Heart Health (WHH). Would anyone be interested in giving WHH a good dose of looking at?

At the Annual Meeting in Bournemouth, which to me was a thrilling experience, we welcomed our first group of patients from the local cardiac network. Next year we are considering involving patients from the cardiac and the cancer networks of Merseyside and North Wales, Greater Manchester and Cheshire, Lancashire and Cumbria, West Yorkshire and possibly Ireland. That would be a huge population base to have represented at

our conference. We are thinking of asking the patients to identify their interests and their concerns so that we can tailor their experience at conference to match their queries. Patients will go back to their regions and report what is going on in our world. It's a great opportunity.

It's only in this previous paragraph that we have touched on thoracic surgery. We are mindful of the need to provide balanced representation in every way possible, and, again, if anyone has any specific suggestions please do have a word. It's a two way, open ended process, and please remember we have only been going eight months.

So, my sincere thanks to our hardworking President and his Executive Committee, and Isabelle and Tilly, for making me so warmly welcome. Comments and feedback are welcome. Enjoy your parties, you deserve them!