

CHILDREN'S HEART SURGERY FUND

CHD CONSULTATION EVENTS



Alongside NHS England's consultation on draft standards for the congenital heart disease review, CHSF has been holding a series of consultation meetings across Yorkshire and the Humber for patients and families.

Meetings

Sheffield

- The meeting took place on Saturday 15th November.
- This was for patients and families in the areas comprising Sheffield, Rotherham, Doncaster, Chesterfield, Derbyshire and Barnsley.
- There were 25 attendees.

Leeds

- The meeting took place on Sunday 16th November.
- This was for patients in the areas comprising Leeds, Wakefield and Kirklees.
- There were 32 attendees.

Bradford

- The meeting is taking place on Saturday 29th November, 11am-1pm in the Midland Hotel Bradford, Forster Square, Cheapside, Bradford BD1 4HU.
- This is for patients in the areas comprising Bradford, Halifax and Huddersfield.
- 25 people have confirmed their attendance.

York

- The meeting is taking place on Sunday 30th November, 11am-1pm in the Marriott Hotel, York, Tadcaster Road, Dringhouses York YO24 1QQ.
- This is for patients in the areas comprising York, Harrogate, Scarborough and Selby.
- 10 people have confirmed their attendance.

Hull

- The meeting in Hull has unfortunately had to be cancelled.

Issues and themes discussed

- The most discussed issues so far have concerned **staffing and skills, the network approach, transition, communication with parents, and fetal diagnosis.**
- These subjects seemed to prompt many personal stories, mostly being around the lack of understanding at regional hospitals. Nearly all patients said once they arrive at Leeds they were dealt with professionally and appropriately. In contrast, they felt very vulnerable at local centres due to lack of cardiac knowledge. Parents also expressed concern about referral times.
- Parents said they wanted an instant referral, stating 3-7 days was too long as the bad news is hard enough to bare and not knowing the severity of the unborn baby's condition is deeply distressing from the point of knowing there is a problem.

Transition

- This is a real issue for patients. Attendees have stated they felt the leap from children's services at the young age of 16 to the adult service is a leap too far.
- To be put on a ward with patients who are non-congenital and a lot older than them, they felt was not only inappropriate, but also depressing.

The Network Approach

- Families were quite keen to ask for re-assurance regarding the current support they receive whereby the Leeds staff visit them in the peripheral clinics for follow up appointments.
- Families have spoken about how they have valued this service and would hope it would continue as Leeds for some people is just too far.

Staffing and Skills

- We also received a considerable amount of questioning about the need for **4** surgeons performing 125 operations.
- Some parents felt the most important issue was a surgeon's capabilities and most people seemed to think performing a reasonable amount of surgery with varied case mix was more important than the stipulated 125 number of procedures.
- Many of the attendees at the Leeds meeting had done some fact finding and were quite clued up on the fact surgeons in other countries perform fewer operations, yet have very good outcomes.
- People also commented on the fact we don't have an abundance of heart surgeons in this country therefore this standard is a hard one to reach considering the lack of available surgeons in this field of medicine.

Fetal Diagnosis.

- This is the point where people are genuinely traumatised and had very vivid memories about the way they were treated. In fact many of the attendees talked about the 'post trauma' they felt once there child's condition had been stabilised through an operation or some sort of intervention.
- Lots of people talked about the need for training in this area, and how surprised they were that this has not been readily available in some centres.
- They also welcomed the use of pulse oximetry which is being trialled at the moment.