

# Patient focus...

The newsletter for patients and our foundation trust members

Spring 2011

## Trust faces threat to children's services

As many of you will be aware, a review of children's cardiac surgery has been underway for over a year. 'Safe and Sustainable: Children's Heart Surgery in England' is managed by NHS Specialised Services on behalf of the 10 specialised commissioning groups in England and its recommendations were agreed by a Joint Committee of Primary Care Trusts (JCPCT). Despite Royal Brompton's excellent record in this area, the committee chose to exclude our paediatric heart surgery services from any of the five recommendations put forward for public consultation. We were shocked and disturbed to hear of this decision.

On 17 March, the Trust issued legal proceedings against the JCPCT in respect of their proposal to end paediatric cardiac surgery at Royal Brompton Hospital. After much careful deliberation and with expert legal advice, it was felt that the recommended options which have been put to the public are fundamentally flawed, and that a consultation based on them would be unlawful.

Although this is a decision that was taken with the greatest reluctance

and regret, the Trust Board felt it had to act in the best interests of patients. The Trust has always supported the principle that all babies and children who undergo heart surgery deserve the best possible care, and that this is likely to be in larger centres. But what cannot be accepted is that a large, successful centre like ours is not even included as an option in the consultation process, despite it being of the required size and despite our impressive record – we were highly rated in a national assessment undertaken by Sir Ian Kennedy.

The Trust's legal challenge identifies a number of issues relating to the review process and the corresponding public consultation. It provides evidence to show that the consultation's exclusion of Royal Brompton from the available options is not rational, that a decision to close a London site was taken in spring 2010 based on PCT commissioners' subjective views rather than clinical reasons, and that the analysis of the pre-consultation business case is flawed, failing to take into account the impact of the closure of paediatric cardiac surgery on other

services at Royal Brompton.

The failure of the JCPCT to take into consideration the full impact of the removal of children's heart surgery from Royal Brompton has far-reaching consequences for the Trust. Loss of the service would:

- Render the Paediatric Intensive Care Unit (PICU) unsustainable, because heart surgery accounts for 90 per cent of cases that go through the PICU.
- Make it impossible to maintain a paediatric anaesthetic service – taking away surgery would mean activity levels would not warrant keeping the expertise on site.
- Mean that interventional cardiology would become unsustainable because it depends on the ability to undertake surgery in certain cases and often requires the presence of paediatric anaesthesia and PICU.
- Mean that paediatric respiratory services, including those for cystic fibrosis, would be unsustainable, because these depend upon the presence of paediatric anaesthesia and PICU.

*(continued on back page)*

## How you can help...

The Brompton Fountain charity has launched a major campaign to support us and is urging our members to:

- **Sign** the Brompton Fountain's petition at [www.thebromptonfountain.org.uk](http://www.thebromptonfountain.org.uk). The petition will be presented to the Prime Minister.
- **Attend** the public consultation event at Emirates Stadium, London N5 1BU on Saturday 7 May. To pre-register go to: [www.rbht.nhs.uk/consultationevent](http://www.rbht.nhs.uk/consultationevent)
- **Write** to your MP. There is a template letter [www.thebromptonfountain.org.uk](http://www.thebromptonfountain.org.uk)
- **Share** your stories of Royal Brompton's paediatric unit on Facebook at: [www.facebook.com/SaveBromptonchildrenscardiacservices](http://www.facebook.com/SaveBromptonchildrenscardiacservices)

If you have a personal story to tell you can also contact Aba Noah by email at [a.noah@rbht.nhs.uk](mailto:a.noah@rbht.nhs.uk)



# First annual members meeting



*Dr Miles Dalby, consultant cardiologist, speaking at the members meeting*

**The Trust's inaugural members' meeting was held at Harefield Hospital on 6 October with a turnout of around 100 members.**

Following a brief welcome from chairman Sir Robert Finch, chief executive Bob Bell summed up Royal Brompton & Harefield's successful first 10 months as a foundation trust, which included successful registration with the Care Quality Commission and an impressive record in infection control.

Other speakers included Ray Puddifoot, with a report from the

governors, Dr Olga Jones and Peter Rust (both governors) who spoke about patient environment and facilities projects, and modern matron Steve Barton who talked about involving patients in developing cystic fibrosis services.

The audience enjoyed a lively presentation from consultant cardiologist Dr Miles Dalby, illustrating the speed at which patients are treated with primary angioplasty at Harefield's Heart Attack Centre.

The meeting ended with a screening of the Trust's moving new DVD, featuring interviews with patients describing how our hospitals have touched their lives.

Comments on the meeting included: "an excellent meeting, useful to hear how the hospital raises its money"; "the film about primary angioplasty was very interesting"; "a very valuable way to spend an afternoon"; "I especially enjoyed Dr Dalby's talk, he is obviously very enthusiastic about his work" and "it is reassuring to see how medicine has advanced over the years."

# New patient governors elected



*Peter Kircher*

**Last November, in the first elections since the Trust gained foundation status, members voted for governors who will represent their views and influence the Trust's strategic direction.**

Following the elections, the Trust welcomes two new patient governors to the governors' council, Sheila Cook and Peter Kircher.

Sheila Cook has been a Royal Brompton patient for the past 39 years. She is currently a cabinet member for Children and Young

People's Services in a South Gloucestershire Unitary Authority, which provides education, health and social care support services to meet the specific needs of young people. She is actively involved with the British Lung Foundation and Radio Lollipop, an international children's charity whose volunteers provide a care, comfort, play and entertainment service on the wards of children's hospitals. Sheila has a particular interest in cystic fibrosis and is a passionate supporter of the patient voice. Sheila said: "I aim to fulfil the confidence of those who voted have placed in me. I look forward to the challenge."

Peter Kircher is a former Harefield patient and since his heart operation in 1994, has been an active member of the Re-Beat support group for people who have had heart surgery at Harefield. For four years, he was also a member of the Public Patient Forum for Dacorum district, visiting local GP surgeries, an elderly persons' respite centre and a local prison medical unit. He spent much of his working life at Rolls Royce as a quality manager. Peter said: "I am looking

# Farewells

*We would like to thank Irving Shaw and now retired Ralph Gartenberg for their valued contributions as patient governors since we became a Foundation Trust.*



*Irving Shaw*

*Ralph Gartenberg*

*The Trust's governors' council has 23 positions, of whom 17 have been elected from the public, patient and staff constituencies. For further information about the work of our governors, please visit the governors' area of the Trust website.*

# Date for your diary

**Annual members meeting**

**1-3pm, Wednesday 12 October 2011**

**Paul Wood Lecture Theatre,  
National Heart and Lung Institute,  
Imperial College London,  
Dovehouse Street,  
London SW3 6LY**

**To register for this event email  
members@rbht.nhs.uk or call  
020 7351 8208.**

forward to taking on this new role and the challenges that it presents, as it will be my way of making a contribution to the continuing work and success of these world famous hospitals."



*Newly-elected governor Sheila Cook*



# Now showing on a computer near you

*In recent months, we have launched two exciting initiatives to give people all over the world new ways to find out more about the work we do.*

Firstly, our Trust DVD, introduced by TV presenter Phillip Schofield, is a short



Phillip Schofield

film featuring staff and patients talking about their experiences at our hospitals. The film uses the Trust's values as its theme: 'we care, we respect, we are inclusive, we believe in our staff, we are responsible,

we discover, we share our knowledge.' To watch the video go to: [www.rbht.nhs.uk](http://www.rbht.nhs.uk)

Secondly, the Trust's YouTube channel is now live, where you can watch a range of videos about our work, vox pops from patients' relatives and find out about our work with Sustain on hospital food. To see these videos please visit: [www.youtube.com/rbandh](http://www.youtube.com/rbandh)

## From ideas come real benefits

*The Trust's Charitable Fund was set up in 1998 to raise money for projects outside the scope of NHS funding, such as research, medical equipment and activities for patients. Donations come from a number of sources including grants, donations and legacies.*

Every year the Fund gives £100,000 to our Patient Amenities Fund. All staff are invited to give ideas to the Patient Amenity Fund Committee for projects to improve the patient experience in our hospitals.

*Patient Focus* spoke to Trust colleagues about some of the successful bids for 2010:

Recently retired modern matron Steve Barton said: "Thanks to the Patient Amenity Fund we have been able to upgrade patient armchairs for the entire NHS bedside on Foulis Ward, with the style, colour and design chosen by the patients so that they complemented the existing colour scheme. We also used a donation from Jeff and Brenda Morgan and their family to transform the bathroom on Foulis Ward into a

shower room, as requested by the patients themselves."

Harefield's principal chief cardiac physiologist, Julie Rochelle, described how funds have been used to install a TV in the patients waiting area in Cardiology: "As our clinics grow in number and sometimes patients have to wait, the TV helps to pass the time."

Senior paediatric physiotherapist Emma Dixon has used funds to buy non-invasive ventilators, which are used for airway clearance for children with cystic fibrosis in the home environment. Emma said: "There are many benefits for patients. This treatment is usually provided on an in-patient basis so we are continuing the best quality care from hospital to the comfort of the patient's home. The ventilators will also help patients to manage their condition better and improve their quality of life."

**For more information about the Fund, please contact Eve Cartwright, head of the Patient Advice and Liaison Service (PALS), on 020 7352 8121 ext. 2803.**

## Heart transplant patient walks 192 miles and raises £3,500



*Tilman Marsh and his family celebrate the end of his epic walk on the beach at Robin Hood's Bay in North Yorkshire*

*Mr Tilman Marsh had a heart transplant at Harefield Hospital in 2006, following 10 months of being supported by an artificial heart. Before becoming ill Tilman had led a very active life, so two years after his recovery he wanted to undertake a long distance walk with his family. The advice from his Harefield doctors was 'do not overdo it'.*

He trained at the weekends with long walks in the Chiltern Hills, before embarking with his family on Wainwright's famous coast-to-coast walk – all 192 miles of it - from St Bees in Cumbria to Robin Hood's Bay in North Yorkshire! In total he raised £3,517 from the walk. Tilman said: "To think, I couldn't climb a flight of stairs a few years ago, now five years on I've climbed over some of the toughest terrain in this country."

## Fun in a run

*The Harefield Hospital Fun Run continues to make an invaluable contribution towards our £1.5 million MRI scanner appeal, helping us exceed the £1 million mark last year. MRI offers speedy and more accurate early diagnosis of such conditions as coronary heart disease, heart failure, congenital heart disease and lung cancer.*

The 30th annual Harefield Fun Run will take place on Sunday 4 September, so get in training! For further information contact Desiree Zimmerman, fundraising assistant, on 01895 828 820.



*An impressive 999 participants, including patients and their relatives, staff and friends of the hospital, took part in the 2010 Fun Run*

## Smoothing the discharge process



**Carol Gadd, nurse manager and modern matron responsible for Harefield's Medical Care Unit (MCU) said: "Patient**

feedback from surveys, questionnaires, complaints and general conversations told us that the discharge process was something we were not doing very well, so we made it our priority to improve."

The problems identified included:

- Patients for admission were waiting for a bed because patients awaiting discharge had not vacated them.
- Time was wasted while patients waited for doctors to discharge them formally.
- Patients were waiting a long time for their medicines to take home with them.
- Patients were waiting to see other professionals before they could leave such as cardiac rehabilitation nurses, cardiology nurses and physiotherapists.

Following consultation with patients and staff, it was decided to create two dedicated discharge nursing posts. Under their leadership the following has been achieved:

- A dedicated discharge team and area was created to provide a personalised and improved service.
- Better communication began with other departments.
- Closer working with pharmacy took place, giving priority to patients ready for discharge, thus reducing the waiting time for their medicines.
- A point of contact for discharged patients was created.
- A comprehensive leaflet to support other patient information was developed.

Following a good response from patients, we are now looking to replicate the MCU model in other areas of the Trust.



## Improving our service to you

*Providing excellent quality care and services to our patients is at the heart of our Trust values. In order to continuously improve, we always want to hear from our patients about their experiences of our hospitals.*

One way we do this is by asking patients for their views on the comment forms we give them before they go home.

Following suggestions made by patients and relatives on the comment forms, these are some of the improvements we have made:

### At Harefield Hospital:

- All patient areas now have a wall or ceiling mounted television complete with remote control.
- We have purchased armchairs that are higher, firmer and more comfortable for the High Dependency Unit.
- To reduce waiting times for ECG and ECHO, we have an ECG

technician who comes to do ECGs in the paediatric outpatient department on Thursday mornings for all age groups. ECHOs are also done in the department on Tuesdays and Thursdays for small babies.

### At Royal Brompton Hospital:

- We have stopped using the NHS plastic water jugs and water is now served in vacuum flasks after being refrigerated. This means the water stays fresh, chilled, and is hygienic.
- We are currently implementing a 'mixed waste' recycling scheme, with a commitment to recycle 50 per cent of general waste over the next three years.
- We have purchased some new chairs for Victoria Ward, providing greater comfort for those who have to sit for long periods.

## Trust achieves top award from NHS Litigation Authority

*The Trust was recently assessed by the NHS Litigation Authority (NHSLA), our 'insurers' for clinical and non clinical claims.*

The assessors reviewed aspects of the Trust's risk and safety arrangements across 51 areas such

as infection control, consent and being open with patients and awarded the Trust their highest level of compliance. This places us as one of only three trusts in London and 19 nationally who have achieved this award.



# Major landmarks for research at the Trust

2010 was a landmark year for research at the Trust, with the openings of both the Respiratory and Cardiovascular Biomedical Research Units (BRUs).

In partnership with Imperial College London, we won BRU status for both our heart and lung research programmes, enabling our best researchers and clinicians to work together. The new units will investigate medical conditions that are currently under-represented in research and have a high level of disease and clinical need.



## Respiratory BRU

During 2010, two special events took place to mark the launch of the Respiratory BRU, including a visit from Trust patron HRH Princess Alexandra who officially opened the Respiratory BRU Clinical Research Facility (CRF).

These events provided guests with the opportunity to see the state-of-the-art facilities being put through their paces and view some of the techniques used by our researchers.

In the months following the BRU's opening, Professor Eric Alton, director of the Respiratory BRU, said the reaction to the unit had been very enthusiastic: "We are pleased with the response from investigators and patients and have numerous studies ready to start using the facility. This is an important step forward in changing the way respiratory research is conducted within the Trust."

Research currently underway is investigating the treatment of and biomarkers used in asthma, COPD, cystic fibrosis, bronchiectasis, sleep apnoea and emphysema.

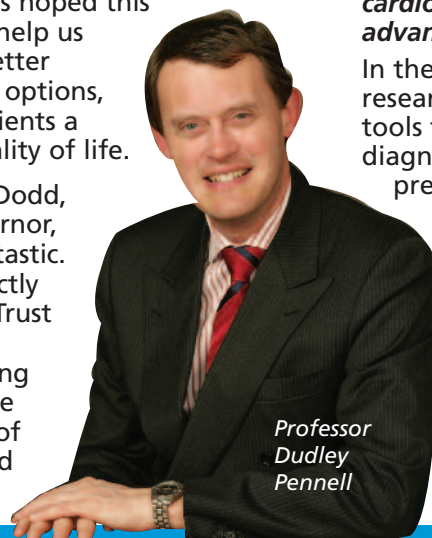
## Cardiovascular BRU

Guests from all over the world came to London on 15 November 2010 for the opening of our

Cardiovascular BRU. Professor Dudley Pennell, director of the Cardiovascular BRU, gave a lively introduction to the new unit and its capabilities: "Through our collaboration with the NIHR, we have created state-of-the-art facilities to advance our research. The BRU has five key pieces of equipment, each working to help us tap into a rich vein of genetic and cardiac research into many life-threatening and debilitating conditions."

The research centres around new heart treatments using genes, imaging techniques, stem cells, tissue engineering and devices, and aims to increase understanding of poor heart function in people living with cardiomyopathy, arrhythmia, coronary heart disease and heart failure. It is hoped this work will help us provide better treatment options, giving patients a better quality of life.

Mr Philip Dodd, Trust governor, said: "Fantastic. This is exactly what the Trust should be doing; being right at the forefront of science and research."



Professor  
Dudley  
Pennell



## STOP PRESS:

In an exciting development, on 4 March 2011 the Cardiovascular BRU welcomed its first patients in both the Cath lab and the 3T CMR scanner.

## Biobank

Both the Cardiovascular and Respiratory BRUs have an active biobank, which collects samples from patients to fuel research into cardiovascular disease and advanced lung disease.

In the long term, it is hoped the research will provide the necessary tools to clinicians to better predict, diagnose, treat and possibly prevent a range of conditions.

The biobank recently collected samples from its 1,000th cardiovascular patient. Biobank manager Sara Giesz said: "This is a truly exciting milestone for the biobank and shows that patients are interested in assisting the research process and want to be involved."

## How you can get involved

**Patients and the public are encouraged to get involved in the research projects of the BRU units.**

Patients attending our hospitals are sometimes asked if they are happy to be involved in our research studies.

Patients, carers and the public can also contribute to the future development of our research by joining our patient groups and public forums. In doing so, they will be able to help influence what research takes place, as well as gain an understanding of the background to our research and how research money is spent. There will be opportunities to look over proposals and help plan activities to involve other patients and the public.

Our public and patient involvement coordinators will be progressing exciting new programmes to increase public awareness of our research by linking with local schools, colleges, patient groups and attending organised events run in local community settings.

To find out more about getting involved, please contact:

**Zahra Aden, Respiratory public involvement coordinator:**

Tel: 020 7352 8121 ext 4960  
Email: z.aden@rbht.nhs.uk

**Julia Coffey, Cardiovascular public involvement coordinator**

Tel: 020 7352 8121 ext 2746  
Email: j.coffey@rbht.nhs.uk

# Involving our patients and their families

*At the Trust we are committed to staying in touch with and involving our patients, their families and the public. Here is a brief summary of a few of the events held over the past year to do just this.*

## COPD tea party

*The COPD team held an afternoon tea party on 9 March 2010 for respiratory patients and to thank those that have participated in Chronic Obstructive Pulmonary Disease (COPD) clinical trials.*

Patients also heard about the upcoming research programmes due to take place in the Respiratory BRU, and learned about the causes of COPD and new treatments. It was a great success, with one patient commenting: "The day was very interesting and well organised, with good catering and superb attendance."

In conjunction with the British Lung Foundation, the COPD team runs a 'Breathe Easy group' on the second Tuesday of every month for patients with respiratory disease.

## Arrhythmia event

*On 7 June 2010, the third annual patient and public awareness evening took place at Royal Brompton as part of Arrhythmia Awareness Week.*

During the evening patients had the chance to learn more about arrhythmias and the treatments available from presentations by our consultant cardiologists.

Arrhythmias are abnormal rhythms of the heart. Most arrhythmias are temporary and not serious, however some may be life-threatening and require treatment.

Among the speakers was a 13 year old patient, Henry Jennings. Henry talked about his experiences of living with an arrhythmia, including the times when he collapsed prior to his diagnosis. He was referred to Royal Brompton and had an ICD fitted three years ago. Henry said:

"Since having my ICD fitted I feel so much more confident and secure that I forget I have a heart condition! I play golf three times a week, go to the gym, attend film club, have a part in a production of *Bugsy Malone* and am looking forward to a trip to the battlefields of the Western Front. I feel so lucky to be looked after by Royal Brompton. I visit Jan Till and the

pace clinic every six months and send my Carelink between those visits (which are so cool!) It is such an amazing place with the best doctors - I owe them a life debt."

## Pulmonary hypertension event

*On 13 September the Pulmonary Hypertension (PH) team held their first public and patient interaction event.*

Hosted by Dr Phil Marino, consultant in critical care and pulmonary hypertension, and clinical nurse specialist Carl Harries, the day covered the role of the PH team at Royal Brompton and their research programme. Further presentations were given by the chair of the PH Association, nursing staff and the administration team on their roles, followed by a Q&A session.

Overall, the patients said the team and service at Royal Brompton were excellent. One patient said: "The doctors make you feel like you have lots of time with them", and another commented: "It is such a good team who are so friendly; in fact it feels like having another family."



*Staff apply blue lipstick in a world record attempt as part of Pulmonary Hypertension Awareness Day*

## Asthma day

*Suzie Regan, the Trust's clinical nurse asthma specialist, organised the second Asthma public and patient event in the Respiratory BRU on 7 October.*

Key outcomes of the day were suggestions to set up an asthma section on the Trust's website and to produce a newsletter. The website will have information to help patients and their families, such as current clinical research and ways to be involved, medication updates and tips for patient self-management of asthma.

Overall, it was an extremely successful day with positive feedback from all who attended. One patient said: "I am really glad I came, I found the whole day was full of information."

## Interstitial lung disease patient day

*Lucy Pigram, clinical nurse specialist for Interstitial Lung Disease (ILD), organised the first ILD patient and carer event on 11 February 2011.*

The day comprised a mixture of presentations by staff on our research projects in the areas of ILD, a tour of the Respiratory BRU, a review of therapies to improve quality of life, information about benefits available to patients and carers and an opportunity to provide feedback about the service.

Patients and carers were keen that this is an annual event and asked for future sessions to be devoted to research nationally and internationally in the area of ILD.

Jane Milton, one of the patients who attended the event said: "It was an excellent day, an interesting mixture of factual information, discussion, a chance to try out relaxation techniques and to hear about other people's experiences."

Another patient, Irene Reeve, commented on the service she receives from the Trust: "It couldn't be run any better. All respiratory departments should come to Royal Brompton to see how it's done. You are always kept informed and made to feel in control of your own person and medication."



*The ILD patient and public event in progress*



# The Trust in the news

## Children's heart surgery review

Chief executive Bob Bell appeared on the Six O'Clock BBC News in February, giving his reaction to the proposed re-configuration of children's heart services and the recommendation that services at Royal Brompton Hospital should be discontinued. News of the proposals was covered extensively by the national press including The Independent, Guardian and Daily Mail, and the regional media.

The Times reported on the far-reaching impact of the closure, highlighting the threat to Royal Brompton's paediatric cystic fibrosis services. A strongly worded editorial about the review on 1 March was followed by a letter highlighting how the closure would destabilise children's CF services, signed by experts including the CF Trust.



Editorial in The Times on 1 March

Parents also spoke about their commitment to Royal Brompton's children's cardiac services, with one mum telling the Kensington & Chelsea Chronicle that she and her six year old son will do "...whatever it takes..." to keep services open. Kerry Roger's son Macauley has undergone open heart surgery three times and had 15 operations to treat heart and respiratory conditions at the hospital.

## Cooking good

Mike Duckett joined the BBC Breakfast team on the sofa in February. As catering manager at Royal Brompton he described work to provide fresh, nutritious and locally sourced meals, ahead of Channel 4's Dispatches programme on hospital food.

Mike was proposed as a candidate to lead government initiatives in a later comment piece from the Daily Mail's Martin Samuel.

## Thirty years and going strong

The local press in Uxbridge reported on celebrations at Harefield Hospital for Mike Broberg, who had his pacemaker fitted there 30 years ago. Chief cardiac physiologist, Julie Rochelle who is responsible for cardiac testing and implantation and follow up visits for pacemakers and ICDs, was at the hospital when Mike first visited. He said: "The hospital has been absolutely brilliant and so have the staff."



Mike Broberg celebrates with Julie Rochelle

## A good tune could cure all our ills

The Daily Express featured Royal Brompton's clinical trial into whether singing can improve breathing control for people with serious respiratory diseases. The article looked at how scientists believe music can soothe pain, and described the groundbreaking work of the Trust's Singing for Breathing programme. "We can't claim music will cure their conditions but we have strong evidence that it's helped them maintain a standard of living they thought was lost to them," said Victoria Hume, arts manager.

## Counting sheep

The April edition of Easy Living magazine spoke to "sleep-spert" Professor Michael Polkey, consultant respiratory physician at Royal Brompton. He described what happens at the hospital's sleep clinic and how our teams are supporting patients with sleep problems. "Our sleep clinic is one of the largest centres in Europe and treats more than 1,500 patients a year. We provide treatment for all types of sleep disorder, including snoring, obstructive sleep apnoea, narcolepsy and restless leg syndrome."

## Generous donation

In February, local media in the Outer Hebrides featured news and pictures of a £3,000 donation presented to Mr Andre Simon, director of transplant, and the ventricular assist device team at Harefield Hospital.



## rb&hArts activity

rb&hArts has been working on a number of projects that harness the creativity of patients. The 7th annual staff and patient exhibition was our biggest yet, with over 100 entries and for the first time, we had more entries from patients and their relatives than from staff.

During 2010 we finalised a project to design new curtains for Rose ward, working with designer Michelle Johnson and printers Duffy London. The designs are based on drawings by children attending the Chelsea Community Hospital School and reflect the themes: Amazon, Monsoon, Oasis, Safari and Woodland.

## A new name for Patient Focus?

The Trust has produced the *Patient Focus* newsletter since 2004. Since becoming a foundation trust in 2009, the newsletter is now sent to all of our members who include patients, carers, staff and members of the public. We are keen to ensure that the publication continues to fully reflect the interests of our readers and one way we would like to do this is by asking you for your views about a possible new name for the newsletter. If you have ideas that you would like to share with us, please email: [members@rbht.nhs.uk](mailto:members@rbht.nhs.uk).

# Useful contacts for Trust members

## Foundation Trust Membership

### ■ Melanie Foody

Membership and User Involvement Manager

Email: members@rbht.nhs.uk  
Tel: 020 7351 8208

### ■ Anthony Lumley

Foundation Trust Office

Email: governors@rbht.nhs.uk  
Tel: 020 7351 8264

## Royal Brompton & Harefield Hospitals Charity - fundraising

### ■ Emma Cassley

Fundraising department, Royal Brompton Hospital

Tel: 0207 352 8121 ext 2210  
Email: e.cassley@rbht.nhs.uk

### ■ Desiree Zimmerman

Fundraising department, Harefield Hospital

Tel: 01895 828 820  
Email: d.zimmerman@rbht.nhs.uk

## Local Involvement Networks

### ■ Kensington & Chelsea LINK

Address: Unit 25, Shaftesbury Centre,  
85 Barlby Road, London W10 6BN

Tel: 020 8968 7049  
Email: rbkclink@hestia.org  
Website: www.rbkclink.org

### ■ Hillingdon LINK

Address: 26 Market Sq, The Mall Pavilions, Uxbridge UB8 1LH

Tel: 01895 272 997  
Email: office@hillingdonlink.org.uk  
Website: www.hillingdonlink.org.uk

## Other useful contacts

### ■ Harefield Hamsters

Harefield Transplant Club

Chairman: Lewis Sander  
Secretary: Alan Lees  
Email: secretary@harefieldhamsters.org  
Website: www.harefieldhamsters.org

### ■ Re-Beat

Harefield Patient Support Group

Chairman: David Potter  
Secretary: Dennis Gulliford  
Tel: 01923 243 672

### ■ League of Friends, Harefield

Contact: Dawn Haase  
Tel: 01895 828 678

### ■ League of Friends, Royal Brompton

Contact: Elizabeth Henderson  
Tel: 020 7351 8277  
Email: e.henderson@rbht.nhs.uk

### ■ Cystic Fibrosis Trust

Address: 11 London Road, Bromley, Kent BR1 1BY  
Tel: 020 8464 7211  
Helpline: 0300 373 1000  
Email: enquiries@cftrust.org.uk  
Website: www.cftrust.org.uk

### ■ GUCH

The Grown Up Congenital Heart Patients Association

Address: 25 St Margaret's Green, Ipswich IP4 2BN  
Tel: 01473 252 007  
Helpline: 0800 854 759 (ansaphone only at weekends)  
Email: admin@guch.org.uk  
Website: www.guch.org.uk

### ■ Tiny Tickers

Tiny Tickers is concerned with improving the care of babies with congenital heart disease, before birth

Tel: 0844 414 0411  
Email: info@TinyTickers.org  
Website: www.tinytickers.org

### ■ The Brompton Fountain

Family support group for families of children with heart and lung conditions at Royal Brompton Hospital

Tel: 020 7776 9000  
Email: admin@thebromptonfountain.org.uk  
Web: www.thebromptonfountain.org.uk

### ■ Primary Ciliary Dyskinesia (PCD) Group

The PCD Family Support Group supports adults and families with children with Primary Ciliary Dyskinesia

Contact: Fiona Copeland  
Tel: 01908 281 635  
Website: www.pcdsupport.org.uk

### ■ Duchenne Family Support Group

Address: 78 York Street, London W1H 1DP  
Tel: 0870 241 1857  
Helpline: 0800 121 4518  
Email: info@dfsg.org.uk  
Website: www.dfsg.org.uk

### ■ Raynaud's & Scleroderma Association

Address: 112 Crewe Road, Alsager, Cheshire ST7 2JA  
Tel: 01270 872 776  
Email: info@raynauds.org.uk  
Website: www.raynauds.org.uk

## Threat to children's services

(continued from page 1)

Although not accountable for enough activity to support an entire PICU or a team of anaesthetists, several respiratory procedures cannot be undertaken without anaesthesia (e.g. bronchoscopy) and are fundamental to, and commonplace in, the treatment of paediatric cystic fibrosis (e.g. the fitting of gastrostomy feeding tubes).

- Cripple the Trust's adult congenital cardiac surgery service because those

operations are also performed by the paediatric surgeons who specialise in these diseases.

The Board firmly believes that a collaboration and network agreement between the three existing London centres, based on a model such as the one that was developed with Great Ormond Street in 2009, will deliver the best care for patients. We will continue to pursue this approach irrespective of legal action.

Using the courts is a route that has been taken with great regret. Two separate approaches were

made to the JCPCT in order to avoid legal action. The first request to delay the start of the consultation to enable discussions to take place was rejected, the second request to suspend the consultation was ignored.

The Trust has a first-class paediatric service. This legal action is about some of the most vulnerable people in society – children, some of them tiny babies, who begin their lives with the odds stacked against them. It is for them that the Trust will fight this case, and for them that we will fight hard.