

## PatientFocus

The newsletter for patients and our foundation trust members | Autumn 2015

## Largest gathering of heart transplant patients in Europe

On 6 September, 185 people who have undergone heart, or combined heart and lung transplants, formed a heart shape in the grounds of Harefield Hospital in what we believe is the largest gathering of heart transplant recipients in Europe.

Members of the group ranged from some of the world's first transplant recipients, treated in the 1980s by Professor Sir Magdi Yacoub, to those who received their life-saving organs only this year.

Most of them had undergone surgery at Harefield Hospital, but some were patients from other centres in the UK.

Some had travelled from as far away as Newcastle and Cornwall.

The event, which was one in a series celebrating the hospital's centenary, aimed to break the Guinness World Record for the largest gathering of heart transplant recipients, which was set at 189 last year by Duke Heart Transplant Program in North Carolina, USA. Despite missing the record by just four, the group is thought to be the largest European gathering.

Tracey Baker, transplant manager, said: "We were thrilled to have so many heart transplant recipients at the event. It was a real team achievement

and a wonderful way to celebrate 100 years of dedicated work at Harefield.

"Very importantly, it shows that people who have heart transplants go on to live long and healthy lives, and are keen to spread the word about organ donation in recognition of their donors."



▲ Heart transplant recipients with the Mayor of Hillingdon

#### A productive summer

It's been a busy time at Harefield with all the centenary events through the summer. And there's still more to come, with an exhibition celebrating 100 years of Harefield and the history of medicine – see page 2.

At Royal Brompton, the new state-ofthe art hybrid operating theatre is almost complete. Consultants have described the new facility as "transformational". More details can be found on page 4. I am planning a tour of the facility in early 2016 (date to be decided). If you are interested in reserving a place, please let me know.

We have governor elections coming up and there are a number of positions available. If you are interested in helping shape the Trust's future, this may be the perfect role for you.



# Annual members' meeting and meeting of council of governors

The combined annual general meeting of the council of governors and the members' annual meeting was held on 22 July 2015, with around 60 Trust members in attendance, including staff, patients and governors.

Following a brief welcome, Sir Robert Finch, Trust chairman, and Bob Bell, chief executive, both gave updates on strategic issues, including property redevelopment at both sites and the Trust's financial situation. Bob also noted that the Trust was recently ranked as one of the best places to work in the NHS by the Health Service Journal and an independent research firm that specialises in identifying and recognising the best places to work in the US, Canada and UK. Bob said this was testimony to the "commitment and dedication" of our staff.

The following reports were given:

- Nomination and remuneration committee (Ray Puddifoot, lead governor)
- Membership steering committee (Edward Waite, patient governor)
- Findings and recommendations from the 2014/15 quality report external assurance review (Deloitte – auditors)
- Annual accounts (Richard Paterson, associate chief executive – finance)
- Quality report (Richard Connett, director of performance and Trust secretary, and Anne Middleton, interim head of quality and safety)
- Annual report (Richard Connett).

The meeting ended with a presentation by Mr Babulal Sethia, consultant in congenital cardiac surgery and President of the Royal Society of Medicine, entitled "Affairs of the heart – overcoming adversity".

Mr Sethia discussed the history of congenital cardiac surgery noting many



Mr Sethia addressing the meeting

of the "giants of surgery" throughout the years.

He remarked on the extraordinary advances that have been made, particularly in the 40 years he has been working in the NHS, the bravery of patients and their families and the fact that some low-risk procedures performed today previously carried a high mortality rate.

"My experience has transformed from accepting that some patients will die, to expecting they will survive," he said.

He then talked about the teaching and training that he and his colleagues at the Trust undertake around the world and the impact this has in reducing mortality rates in countries outside Europe.

Mr Sethia added: "There is a huge number of people involved in the care of patients with congenital heart disease at the Trust. We have the largest cohort of patients in Europe and our results are as good as any in the world. It's a privilege to know that I and my colleagues have contributed to transforming the lives of patients with CHD, the great majority of whom live very full lives with next-to-normal mortality."

Feedback from the day was positive, with members finding Mr Sethia's talk very informative and enjoyable.

HAREFIELD HOSPITAL



CELEBRATING & MAKING HISTORY

## 100 years of Harefield and the history of medicine

Visit the centenary exhibition and find out about Harefield Hospital's fascinating history; from its beginnings in 1915 as a hospital to treat soldiers from Australia injured at Gallipoli and on the Western Front, through its years as a tuberculosis sanatorium in the 1930s, to its present day role as a leading heart and lung specialist centre, with international expertise in transplantation.

When to visit:

- General admission
   Tuesday 13 October and
   Tuesday 1 December, 11am-2pm
- Historical talks
   Monday 19 October and
   Tuesday 24 November, 5.30pm
- Family Fun Day
   Tuesday 27 October, 12pm-2.30pm
- History Day
   Saturday 14 November, 12pm-4pm

Venue: Concert Hall, Harefield Hospital

NB: times are subject to change. Please check the website or telephone **01895 823 737** before your visit.

## Pacemakers in 2015 – what the future holds

On Monday 8 June, Dr Mark Mason, consultant cardiologist, gave a talk to Trust members about pacemakers.

A pacemaker is a device that regulates the heartbeat and can help if someone's heart beats too slowly.

Dr Mason has led the pacemaker device service at Harefield Hospital since 2001 and has seen huge, positive changes over the years. He described the history of pacemakers, how they are implanted, and talked about the latest pacemakers and future developments.

New pacemakers include:

 A leadless pacemaker – a small implantable device that sends electrical pulses to the heart whenever it senses that the heartbeat is too slow. Leadless pacing devices are placed directly in the heart without the need for a surgical "pocket" and insulated wires (leads). They are very small – approximately 23mm long.

- The subcutaneous implantable cardioverter defibrillator (S-ICD) – this subcutaneous (under the skin) device simplifies surgery. It has two main benefits over current devices – no leads are actually placed into the heart and removal or replacement is much simpler, reducing the potential risk of infection. These ICDs are particularly good for young patients who may have to have several ICDs implanted throughout their lives.
- Implantable loop recorder a subcutaneous, single-lead monitoring device used to diagnose patients with "unexplained" cardiac rhythms.

Dr Mason also explained developments in out-of-hospital monitoring:

 Home monitoring of cardiac pacemakers allows Trust clinicians to observe a patient's heart rhythm over the internet, potentially reducing the number of hospital admissions.



Dr Mark Mason, consultant cardiologist

 Remote monitoring implants for patients with chronic heart failure alert doctors remotely to any decline in a patient's condition even before symptoms are experienced. The microelectromechanical system (MEMS) is inserted into the pulmonary artery.

Members found the talk fascinating. One member commented: "The total hourand-a-half talk was engrossing".

## Join a patient experience group

We had a tremendous response when we recently contacted members who had told us they wanted to be involved in the Trust's patient experience groups.

Now we are looking for more people to join.

Examples of some of the things patient and carer members are now doing include:

- providing valuable input into our plans for a patient web portal
- participating in our patient experience advisory group
- setting up a peer support group for families of patients in our adult intensive care group.

If you are interested in becoming involved in a patient experience group, please email Jan McGuinness: j.mcguinness@rbht.nhs.uk, director of patient experience and transformation, to find out more.



## Charity celebrates new hybrid theatre

Royal Brompton now has one of the largest and best equipped hybrid theatres in the UK and possibly in Europe. The theatre will enable many different procedures to be carried out on the same day, making recovery quicker and safer.

Realising the Trust's ambition to have a hybrid theatre has only been possible thanks to the thousands of people who gave to the fundraising appeal. If you were one of them, thank you.

Meanwhile, experts at Harefield Hospital have been able to perform more heart transplants than ever before due to the remarkable Organ Care System, also known as "heart-in-a-box". This new technology simulates the conditions of the human body, pumping oxygenated blood inside the heart so it can continue to function as it would in a living person and so can be safely transported from much further afield than previously. Fundraising efforts have helped to fund more of these life-saving systems.

Royal Brompton & Harefield Hospitals Charity is also supporting the provision of a new intensive care unit at Harefield. This will provide state-of-the-art individual, specialist rooms for patients recovering from major surgery.

The Charity is immensely grateful to all the donors who participate in and contribute to fundraising events, and to the many people who support those events and sponsor friends and colleagues.

Now in its third year, the Charity exists to make a real difference to patients. So much has been achieved, but there is so much more to do to support our two world-class hospitals and help with projects and programmes that fall outside the day-to-day funding of the NHS.

If you would like to know more about how you can support the hospitals, please visit the website – rbhcharity.org – or call 020 7351 8613.

## Meet our two new Trust governors

Our two new governors – Caroline Karlsen and KD (Katherine) Denney – both have close links with the Trust. It is with great pleasure that we welcome them to their new roles.

#### Caroline Karlsen – carer governor

Caroline's daughter has been a patient at Royal Brompton Hospital since she was diagnosed with cystic fibrosis shortly after birth. Caroline and her family have been impressed by the excellent care and support they have all experienced from Royal Brompton's paediatric respiratory team.

As a trustee of the Cystic Fibrosis Trust, Caroline has gained important experience in the medical non-profit sector. She has held senior management and director roles at companies including Expedia, MySpace International and Kingfisher and specialises in e-business consultancy at executive level. She hopes to use this experience to support the Trust as it delivers world-class clinical care, such as her daughter has experienced, while remaining an important centre for medical trials and at the cutting edge of global research.



 Caroline Karlsen, whose daughter has been a patient at Royal Brompton since just after birth

## Governor elections

The Trust is holding elections for the council of governors this autumn. As well as elections being held in public and patient constituencies, there is a vacancy for a governor in the staff constituency.

Being a governor is a great way to become involved in helping shape the Trust's future. You have the opportunity to work with board members and senior staff to improve patient care and to give your views on future strategy. Knowledge gained in your community, working life or through your personal experience of Royal Brompton and / or Harefield hospitals, as well as your enthusiasm and commitment, could be of great benefit to the Trust.

### What are the responsibilities of a governor?

The main responsibility of a governor is to represent the interests of both the Trust's members and the public. Other responsibilities include: advising the board of directors and holding the non-executive directors (NEDs) to account for the performance of the board; consulting on proposed strategic decisions; appointing the chairman and NEDs; setting the remuneration of the NEDs; appointing the external auditor, and approving major financial outlays.

### How much time would I need to commit?

Governors typically attend four council meetings each year along with the annual members' meeting. They can also become involved in working groups and committees, such as our patients and quality group and the membership steering committee, which both meet periodically. Governors' terms are for three years.

#### How are the elections run?

Council of governors' elections are run by an independent company. All interested members are asked to complete a nomination form. If more nominations are received than the number of positions available, a ballot will take place. Members will receive a voting paper either electronically or by post and

#### KD (Katherine) Denney – staff governor



KD Denney, our newly elected staff governor

KD has been employed as head of marketing communications and web editor at the Trust since 2010.

She is continually impressed by the commitment and dedication of staff and management to deliver an NHS service that is second to none. As a member of the communications team, she has gained knowledge and understanding of departments and services right across the organisation and believes that this, along with her expertise in communications and marketing, will be of great benefit to the council of governors.

She was a member of the membership steering committee from its inception in 2011 until June this year, helping to find and implement new ways of recruiting members.

are entitled to vote for the governor(s) within their constituency.

For the autumn elections, staff members will vote electronically only and not by postal ballot. All public and patient members for whom we have email addresses will be sent an email instructing them how to vote. All other members in these categories will be sent a ballot pack, which will contain instructions on how to vote electronically or by post.

### Who can vote in these elections?

To vote in these elections you must be a Trust member resident in one of areas listed below or a staff member.

Patient members resident in Bedfordshire and Hertfordshire, South of England and Elsewhere are *not eligible* to vote in these elections. Carer members and public members in North West London are also *not eligible* to vote.

#### Invitation to stand

The Trust invites members resident in one of following areas and staff members to consider standing for election:

Public - Bedfordshire and Hertfordshire

Public - South of England

Public - Rest of England & Wales

Patient - North-west London

Staff (one vacancy)

Please note: to stand for governor, you must be a *public member*, or a staff member. Patient members resident in Bedfordshire and Hertfordshire, South of England and Elsewhere are *not eligible* to stand in these elections.

Nomination forms for interested candidates will be available following Notice of Election from our electoral administrators, Electoral Reform Services, from Friday 2 October by calling 020 8829 8424 or by emailing Jonathan. Tait@electoralreform.co.uk.

Nomination forms must be received by 5pm on Friday 30 October. The poll opens on 20 November and closes on 16 December.

If you would like any additional information regarding the role of governor, please contact Anthony Lumley, corporate governance manager – 020 7351 8264 or email governors@rbht.nhs.uk.

### Why be a Trust governor?

by Edward Waite, patient and carer governor – South of England

Being a governor allows you a fascinating and real insight into how both Royal Brompton and Harefield hospitals work and into understanding the Trust's goals for the future. It's also a great way to give back to the NHS if you have ever experienced the specialist, often life-saving care, from either of these hospitals. You may not realise the value of your skills and knowledge, gained throughout your career or life, and how useful they may be in helping the Trust achieve its goals.

On the practical side, there are four meetings a year, which alternate between the two sites, for which there is some reading to do. There are also various sub-committees and working groups that you can be involved in if you wish to, and you are always welcome to volunteer your time to help out at either site.

The Trust is very inclusive and ensures that all governors are able to participate. To assist with this, the Trust covers the costs of various



training sessions for governors, which are a great way to learn about the responsibilities of the role and to meet governors from other trusts. Although governors are not paid for their time, the Trust does reimburse governors' transport costs to all meetings.

I find the role of governor very rewarding and cannot recommend it highly enough.

▼ Edward addresses the annual members' meeting in July



## Update on new congenital heart disease review

The new congenital heart disease (CHD) review replaced the discredited "Safe & Sustainable" review in 2013.

It differed in many respects: it covered CHD for patients of all ages, not just children; it was not just about congenital cardiac surgery, but all CHD services; it did not set out to designate certain centres and "de-commission" others, but instead to set standards with which all services should seek to comply; it recognised that population changes mean that services are going to have to grow in future, not contract.

A report was presented and approved by the NHS England board in July this year following a public consultation. It made recommendations on a model of care, standards and service specifications, earlier diagnosis and better information.

The report proposed a "three tier" model whereby all hospitals providing congenital heart disease care would work within "regional, multicentre networks, bringing together fetal, children's and adult services".

Each network would have at least one specialist surgical centre as the first tier.

Some networks would have a second tier specialist cardiology centre. However, "because of the increasing number of adults living with CHD, specialist adult CHD centres are expected to be more common," the report said.

Local cardiology centres, which form the final tier, would employ a paediatrician with expertise in cardiology and run outpatient clinics.

NHS England hopes to receive formal submissions for its proposed new service models from October, and to commission CHD services under these new models from April 2016 onwards.

The Trust is actively participating in the London & South of England Network.

Discussions so far have been positive and we look forward to continuing to work closely with other centres in the network. One thing is certain: Royal Brompton and Harefield hospitals will continue to provide CHD services for children and adults in the future.



Neil West, clinical nurse educator, supervises Emma Stratton, staff nurse on rotation from Chelsea and Westminster

## Developing our partnership with Chelsea and Westminster

The close and successful relationship that exists between the Trust and Chelsea and Westminster Hospital NHS Foundation Trust has been a vital aspect of paediatric care over recent years.

When children with heart or respiratory conditions need a clinical procedure of any kind, anaesthesia and intensive care are major issues. Babies and children under the care of Royal Brompton who need general, ear, nose or throat (ENT), or dental surgery, for example, have traditionally had their operations on site, supported by specialist paediatric anaesthetists and intensive care teams, but the surgery is undertaken by visiting consultants from Chelsea and Westminster Hospital.

Teams at each hospital also provide outpatient clinics and inpatient support to the other, across a number of specialties, and some are undertaken jointly. Having a specialist heart and lung centre so close to a lead centre for specialist paediatric and neonatal surgery offers both hospitals the advantage of specialist opinion and expertise not available on site.

Last year, the boards of the two Trusts agreed to pursue collaboration, initially in children's services, with the potential to lead to a formal joint venture in maternal and child health. A steering group meets monthly to oversee the

first phase of the collaboration. Three working groups have been established across high dependency (HDU), non-cardiac surgery and IT.

Recent progress includes:

- Suitable (less complex) Royal
  Brompton patients for general, ENT and
  dental care are now having their
  surgery at Chelsea and Westminster
  with a joint team, rather than surgery
  automatically being scheduled at Royal
  Brompton.
- Vacant beds in Chelsea and Westminster High Dependency Unit are starting to be used by long-term ventilation (LTV) patients, supported by the Royal Brompton team. Chelsea and Westminster staff are being trained to care for these children.
- A Royal Brompton and Chelsea and Westminster nursing rotation has been set up to develop skills. It is hoped that enough of Chelsea and Westminster's nursing staff will have gone through the rotation in time for this year's "winter pressures" period. Study days have also started at Royal Brompton for Chelsea and Westminster nursing staff.

The scope of a joint venture between the two trusts will be set out once further projects across the working groups have been implemented and assessed.

## Diary dates

#### Singing for Breathing

Aimed at those with respiratory conditions, or breathlessness associated with cardiac conditions, sessions are relaxed, informative and fun. They aim to teach basic singing techniques, which can help with breath management and release stress.

#### **ROYAL BROMPTON HOSPITAL:**

Open workshop for all patients (except those attending Foulis Ward)

#### Date and time:

Every Monday, 2.00pm-3.00pm

#### Venue:

The Quiet Room, Victoria Ward, 2nd floor, Fulham Wing, Royal Brompton Hospital

#### HAREFIELD HOSPITAL:

### Open workshop for all patients Date and time:

Every Tuesday, 3.30pm-4.30pm

#### Venue:

Rehabilitation & therapies seminar room, 2nd floor, Harefield Hospital

**Contact:** Karen or Grace in the arts team before your first session and to make sure the class is running as usual – or to buy the Singing for Breathing CD.

Email: arts@rbht.nhs.uk

Tel: 020 7351 4087

Web: www.rbht.nhs.uk/arts

bloodstream, as well as the movement of the chest and abdomen, the heart rate, airflow and the electrical activity in the brain. The team will explain the procedures performed in the unit and you will have an opportunity to see how the equipment works.

Space is limited so booking is essential.

#### Thursday 8 October 2015

*Time:* 1.30pm

Venue: Children's sleep and

ventilation unit, 4th Floor, Sydney Wing, Royal Brompton Hospital

#### Learn about lung diseases

Hear from Professor Michael Polkey about lung conditions, including chronic bronchitis, emphysema and chronic obstructive airways disease. They are collectively known as chronic obstructive pulmonary disease (COPD) and people affected have difficulty breathing, primarily caused by the narrowing of their airways (airflow obstruction).

#### Monday 2 November 2015

Time: 2.00pm-3.00pm,

**Venue:** CRF Education Centre, 1st Floor, Fulham Road, Royal

**Brompton Hospital** 

#### MEMBERSHIP EVENTS

### Visit the children's sleep and ventilation unit

Dr Hui-leng Tan and her team will show you the unit, which offers comprehensive evaluation and care for children with sleep and sleeprelated disorders. It has state-of-theart equipment to monitor the oxygen and carbon dioxide levels in the

#### Hybrid theatre tour

Details coming soon.

If you would like to attend a member event or want more information, please contact Philippa.

Follow us on Twitter @RBandH to keep up to date with all our news and events.

#### TRUST BOARD MEETINGS

Members of the public are welcome to attend.

#### • 28 October 2015

Time: 2.00pm-4.00pm Venue: Board Room, Royal

Brompton

#### 25 November 2015

Time: 10.30am-1.00pm Venue: Concert Hall, Harefield

#### 27 January 2016

*Time:* 2.00pm-4.00pm *Venue:* Board Room, Royal

Brompton

#### • 30 March 2016

*Time:* 10.30am-1.00pm *Venue:* Concert Hall, Harefield

#### • 27 April 2016

Time: 10.00am-12.00pm Venue: Board Room, Royal Brompton

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#### • 25 May 2016

*Time:* 10.30am-1.00pm *Venue:* Concert Hall, Harefield

### COUNCIL OF GOVERNORS' MEETINGS

#### 22 October 2015

*Time:* 11.00am-1.30pm *Venue:* Concert Hall, Harefield

#### 25 February 2016

Time: 11.00am-1.30pm Venue: Board Room, Royal

Brompton

#### • 11 May 2016

*Time:* 11.00am-1.30pm *Venue:* Concert Hall, Harefield

#### 20 July 2016

Combined Council of Governors AGM & Members Annual Meeting. Venue and time to be confirmed.

### Useful contacts for Trust members

#### **Foundation Trust**

Membership Office

Contact: Philippa Allibone
Tel: 020 7352 8121 ext 2811
Email: members@rbht.nhs.uk

Corporate Secretariat

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

### Royal Brompton & Harefield Hospitals Charity

■ Alice Eastwood

Community fundraiser, Royal Brompton Hospital

*Tel:* 020 7352 8121 ext 2210 *Email:* a.eastwood@rbht.nhs.uk

Desiree Zimmerman

Community fundraiser, Harefield Hospital

Tel: 01895 828 820

Email: d.zimmerman@rbht.nhs.uk

■ Nick Fry

Marketing and communications manager
Tel: 020 7352 8121 ext 4267
Email: n.fry@rbht.nhs.uk

Karen Higgs

Executive assistant

 Tel:
 020 7352 8121 ext 4269

 Email:
 k.higgs@rbht.nhs.uk

#### Healthwatch

■ Healthwatch – Kensington and Chelsea

Address: Unit 25, Shaftesbury Centre,

85 Barlby Road, London W10 6BN

Tel: 020 8968 7049 / 6771 Email: healthwatchcwl@hestia.org

Website: healthwatchcwl.co.uk/kensington-chelsea

Healthwatch – Hillingdon

Address: 26 Market Square, The Pavilions, Uxbridge UB8 1LH

Tel: 01895 272997

Email: office@healthwatchhillingdon.org.uk
Website: healthwatchhillingdon.org.uk/

#### Other useful contacts

■ Harefield Hamsters

Harefield Transplant Club Chairman: Brian Unwin Tel: 01494 472 470

Email: chairman@harefieldhamsters.org
Website: www.harefieldhamsters.org

■ Re-Beat

Harefield cardiology patient support group

Chairman: Ken Crisp Tel: 020 8868 7571

Email: ken.crisp1@btinternet.com

■ Friends of Harefield Hospital (volunteers)

Contact: Don Chapman Tel: 01895 828 678

**■** Friends of Royal Brompton (volunteers)

Contact: Elizabeth Henderson
Tel: 020 7351 8272
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

■ The Somerville Foundation

For patients with congenital heart disease

Address: 25 St Margaret's Green, Ipswich IP4 2BN

Tel: 01473 252 007

Helpline: 0800 854 759 (ansaphone only at weekends)

Email: admin@thesf.org.uk Email: helpline@thesf.org.uk

Tiny Tickers

A source of information on prenatal heart disease

Tel: 020 3286 1250
Email: info@TinyTickers.org
Website: www.tinytickers.org

**■** The Brompton Fountain

Supporting families of children with heart and lung conditions

Address: 1 Love Lane, London EC2V 7JN

Tel: 020 7776 9000

Email: admin@thebromptonfountain.org.uk
Web: www.thebromptonfountain.org.uk
Facebook: /thebromptonfountain

Twitter: @BromptonSupport #hereforyou

■ The Octavia Appeal – Friends of Royal Brompton

The Octavia Appeal is specifically to help the paediatric intensive care unit and paediatric ward fund specific items

Contact: Lynda Mackie

Address: 39 Coniger Road, London SW6 3TB

Email: lynda@ctaviaappeal.org
Web: www.octaviaappeal.org
Facebook: /OctaviaAppeal
Twitter: @OctaviaAppeal

Primary Ciliary Dyskinesia (PCD) Group

Contact: Fiona Copeland (chairman)
Tel: 0300 111 0122 (helpline)
Email: chair@pcdsupport.org.uk
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 or 0800 9172494

Email: info@raynauds.org.uk Website: www.raynauds.org.uk

