



A lifetime of specialist care

Royal Brompton & Harefield **NHS**  
NHS Foundation Trust

# My PH passport

Pulmonary hypertension  
care record



pha  | Influence.  
Hope.  
Integrity.



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*This 'PH passport' contains all the information you need about your pulmonary hypertension (PH) care and treatment. It is a good idea to carry this with you at all times, if possible.*

**If you need urgent medical attention at any point, give this to any healthcare professional who treats you.**

*If you require surgery, or any medical procedure, please show your healthcare professional this passport and please let your PH team know you have had the procedure.*

## Patient details

Name:

Date of birth:

Hospital number:

My PH diagnosis:

Date of diagnosis:

Shared care centre name:

My contact number:

GP name:

GP contact number:

Please refer to the Royal Brompton and Harefield patient information booklet called *What is pulmonary hypertension?* for further details about your condition.



# Important information about my PH

PH medication:

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Do not stop IV therapies without speaking to your PH team.

Please remember to show your IV therapy letter when you see any healthcare professional.

Anticoagulation?      Yes     No

Type/dose:

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Long-term oxygen?    Yes     No

\_\_\_\_\_ L/min

Baseline O2 sats (*measured after five minutes of rest*):

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Diuretics:

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Dry weight with date:

Date                      Weight                      Date                      Weight

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Date                      Weight                      Date                      Weight

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Date                      Weight                      Date                      Weight

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Date                      Weight                      Date                      Weight

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Date                      Weight                      Date                      Weight

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Date                      Weight                      Date                      Weight

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Date                      Weight                      Date                      Weight

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## Other medical history

It is important to inform healthcare professionals of other health problems that you have. Please list your conditions here.

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Other medications:

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Allergies/intolerances:

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## Red flags


Contact your PH team if you notice any of the following (either as a new symptom or worsening of an old symptom):

-  Feeling faint or losing consciousness
-  Coughing up blood
-  Increased shortness of breath
-  Chest pain
-  Gaining weight quickly and/or stomach bloating
-  Swollen ankles and/or legs
-  Heart palpitations (your heart pounds, flutters or beats irregularly)
-  If you have a Groshong line: leaking, not working properly, or pain or redness around the site
-  Side effects related to PH medication

## Other important information

Don't stop any of your PH medication without contacting a member of your PH team.

- If you need to have an anaesthetic for surgery or sedation for a procedure such as an endoscopy, having PH means you are at a much higher risk of complications. Please contact your PH team and tell any other healthcare professionals of your diagnosis. Please ask them to contact us for further advice.
- If you are planning to travel abroad, let your PH team know, as they will be able to offer advice. For example, you may need a 'fitness to fly' test. If you need, or are on, long-term oxygen, you will need to tell the airline you are flying with. We strongly advise that you arrange travel insurance.
- Pregnancy is associated with higher health risks in people with PH. If you have any concerns or questions, please speak to a member of your PH team, who will be able to advise you and help you reach decisions about family planning.
- Regular physical movement is good for your health, but avoid heavy lifting. If you are on anticoagulation drugs (such as warfarin), also avoid contact sports. Be aware of your limitations and take care not to over exert yourself. Becoming breathless is normal when exercising. However, if breathing becomes painful, stop exercising.
- Vaccinations against flu and pneumonia are recommended. Both are available free of charge from your GP or at some pharmacies.
- It is common for people with PH to experience anxiety. There is help available. PHA UK members have free access to a dedicated helpline and email service provided by the mental health charity Anxiety UK. Call **0844 332 9010** or email [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk).

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- If you are admitted to another hospital, either in the UK or abroad, it is important to inform the staff that you are a patient of the PH service at Royal Brompton Hospital, and ask them to contact us.
  - You must notify the Driver and Vehicle Licensing Agency (DVLA) about your PH condition – this is now mandatory.

### **If you have congenital heart disease:**

- Do not have blood drawn (venesection) to reduce haemoglobin
- Make sure you stay hydrated especially in hot weather.
- If you need endocarditis prophylaxis (antibiotics) to prevent a heart infection, for dental or medical procedures, contact your PH team for advice.
- See your GP if you have symptoms of a chest infection.



## PH research and clinical trials

**Today's research is tomorrow's care.**

Research has transformed our understanding of PH and changed the way we care for patients.

Along with all the other specialist centres in the UK, the pulmonary hypertension service at Royal Brompton Hospital is involved in research, so you may be asked if you would like to take part in a clinical trial or other research study. If you can, please think about getting involved and playing a part in helping us understand more about PH.

Before a new drug can be given to patients, it must be shown to be safe and effective in clinical trials and must be approved by the Medicines and Healthcare Products Regulatory Agency. Without clinical trials, and the patients who agree to be involved in them, these drugs would not be available.

We greatly appreciate volunteers who take part in our clinical research, but it is your choice. If you would prefer not to get involved, your decision will always be respected.



## My research

<b>Study title</b>	
Study contact	
Type of study	
Location	
Frequency of visits	
Start date	End date

<b>Study title</b>	
Study contact	
Type of study	
Location	
Frequency of visits	
Start date	End date

<b>Study title</b>	
Study contact	
Type of study	
Location	
Frequency of visits	
Start date	End date





## Planning for the future

It is important to discuss future plans with your care team, including issues such as resuscitation and transplantation. Use the spaces below to write down your thoughts and plans.

Resuscitation

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Advance care planning

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Pulmonary endarterectomy

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Transplantation

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## My PH team

Consultants	Write here
Specialist nurses	<b>Bleep 1165</b> , telephone <b>ext 82156</b> , email <b>phnurses@rbht.nhs.uk</b>
Coordinator / secretary	<b>0330 12 88121 ext 88362</b>
Scheduler	<b>0330 12 88121 ext 88618</b>
Pharmacy	<b>0330 12 88121</b> ask for <b>bleep 7076 or 7418</b>
Outside office hours	Call <b>0330 12 88121</b> and ask to speak to cardiology registrar on-call or PH consultant on-call, or for Paul Wood Ward <b>ext 82500</b>
Healthcare at Home	<b>0800 088 4412</b> or email <b>care@hah.co.uk</b>

## The Pulmonary Hypertension Association (PHA UK)



The PHA UK is the only charity in the UK dedicated to supporting those affected by PH, including patients and loved ones.

With over 4,000 members it is a community like no other.

Membership is completely FREE and includes:

- Access to free online resources and printed publications
- Award-winning member magazine, Emphasis, every quarter
- Support and advice
- Free access to emotional support via our partnership with Anxiety UK
- Free access to financial advice via our partnership with Turn2Us

Find out more or join online:

Website: [www.phauk.org](http://www.phauk.org)

Website: [www.phocusonlifestyle.org](http://www.phocusonlifestyle.org)

Tel: **01709 761 450**

Email: [office@phauk.org](mailto:office@phauk.org)

Address: PHA UK Resource Centre  
Unit 1, Newton Business Centre  
Newton Chambers Road  
Thornccliffe Park  
Chapelton  
Sheffield S35 2PH

Facebook: @PULHAUK

Twitter: @PHA\_UK

Registered Charity No. 1120756



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If you have any concerns about any aspect of the service you have received in hospital and feel unable to talk to those people responsible for your care, call Patient Advice and Liaison Service (PALS):

- Royal Brompton Hospital – 020 7349 7715
- Harefield Hospital – 01895 826 572

Alternatively email [pals@rbht.nhs.uk](mailto:pals@rbht.nhs.uk). This is a confidential service.

*Please show this if you need to use toilets urgently when out and about*

# Please help, can't wait!

I have a medical condition  
and require to use your  
bathroom facilities urgently.



pha  UK | Influence.  
Hope.  
Integrity.

## Thank you for your understanding

PHA UK is the national patient  
organisation for people with  
pulmonary hypertension.  
[www.phauk.org](http://www.phauk.org)



Royal Brompton Hospital  
Sydney Street  
London  
SW3 6NP  
Tel: 0330 12 88121

Harefield Hospital  
Hill End Road  
Harefield  
Middlesex  
UB9 6JH  
Tel: 0330 12 88121

Website: [www.rbht.nhs.uk](http://www.rbht.nhs.uk)

إذا كنت ترغب في الحصول على ترجمة فورية لمضمون هذه الوثيقة إلى اللغة العربية، يرجى منك الاتصال بأحد مستخدمينا بجناح المصلحة التي يتم فيها استشفائك. أحد موظفينا سيسعى لترتيب إجراءات الترجمة وإتمامها في الوقت المناسب لك.

Brosurteki bilginin Türkçe tercumesi için tedavi görüyor olduğunuz bölüme bas vurunuz. Bölüm personeli tercümenin gerçekleşmesini en kısa zamanda ayarlayacaktır.

