

# Guide for families with children receiving Proton Beam Therapy abroad



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## Introduction

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The doctors looking after your child have recommended that they should be considered for a certain type of Radiotherapy known as Proton Beam Therapy as this is felt to be the best treatment for them. This treatment is not currently available in the UK so at the moment NHS patients travel abroad.

We know that travelling overseas for treatment can be a worrying time for families so this leaflet hopes to answer some of the questions you and your family may have. The leaflet explains how Proton Beam Therapy works, the benefits and the possible side effects. You will also find lots of practical information to help make it easier to organise you and your child's travel overseas.

# Proton Beam Therapy explained

## What is radiotherapy?



Radiotherapy is the use of high energy X-rays and other types of radiation to treat diseases - usually cancer. The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease where the growth of some cells becomes uncontrolled, producing a lump or a 'tumour'. Radiotherapy is used to try and destroy these lumps or tumours. Patients can undergo radiotherapy on its own or whilst receiving another form of treatment such as chemotherapy.

Radiotherapy is often given after surgery because it can help to get rid of any tumour cells that may have been left behind. This reduces the risk of the disease coming back and it is successful for many, although not all, patients.

Radiotherapy has to be planned with great care as it can cause side effects, especially in areas of the body where the tumour lies very close to important normal healthy structures and developing tissue.

## What is Proton Beam Therapy?



Proton Beam Therapy is a type of radiotherapy. It uses protons, which are small parts of atoms, rather than high energy X-rays. This particular type of radiotherapy enables a dose of high energy protons to be targeted directly at the tumour whilst significantly reducing the dose to surrounding healthy tissues and vital organs.



An example of a Proton Beam therapy treatment machine.

## What are the advantages and disadvantages to Proton Beam Therapy?



Proton Beam Therapy specifically targets cancer cells, reducing the radiation dose to certain normal tissues or cells. Despite this, patients may still experience similar side effects and risks to those experienced by other forms of radiotherapy. Strong evidence of the clinical benefit of Proton Beam Therapy is currently limited and because the service has only been nationally commissioned since 2008 there is relatively little long-term side effect and survival time follow-up data.

It is extremely important that you discuss the treatment options available to your child with your Clinical Oncologist. This will help you and your child to make an informed decision about whether Proton Beam Therapy is the most suitable option.

## Proton Beam Therapy explained

### How is my child referred for Proton Beam Therapy?



Your child's Clinical Oncologist will refer their case (with your agreement) to the UK Proton Clinical Reference Panel who will review your child's your clinical information and consider the case for referral. Proton Beam Therapy is centrally funded through NHS England for patients who might benefit clinically from Proton Beam Therapy treatment compared to other forms of radiotherapy.

Your child's Clinical Oncologist will inform you of the UK Proton Clinical Reference Panel's decision. If your child's case is approved, the Clinical Oncologist will contact one of the Proton centres abroad and send the appropriate medical records to them. The specialist team at the Proton Centre will then discuss and review your child's case in their multidisciplinary team meeting. They will then decide if they can accept your child's case.

Additional investigations (for example; scans, blood tests, tests of hearing and vision) may be requested to help assess the suitability of your child's case. Sometimes further surgery in the UK may be recommended before Proton Beam Therapy to achieve the best possible outcome.

### If my child's case is accepted by the Proton Beam Therapy Centre, what happens next?



Your child's Clinical Oncologist will meet you to discuss the decision to treat your child with Proton Beam Therapy. If you agree for your child to be treated, your child's Clinical Oncologist will let you know which Proton Centre will be providing your child's therapy.

The diagram on page 16 shows the typical timescale between a case being approved and treatment.

## Financing Proton Beam Therapy

### Do I have to pay for Proton Beam Therapy?



Proton Beam Therapy is now centrally funded. If you are an NHS patient living in England, the medical costs of Proton Beam Therapy are paid for by the NHS in England. The medical costs for patients in Scotland, who are approved for treatment, are paid for by NHS ENgland with costs recharged to the NHS in Scotland. For patients living in Wales or Northern Ireland, funding has to be agreed by the local Health Boards.

### Do I have to pay for any other medical treatment costs related to Proton Beam Therapy?



If any other treatment related to the course of Proton Beam Therapy for your child becomes necessary whilst you are abroad, these costs are covered by the NHS in England. The Proton Centre will approach the NHS directly, should this occur. Very occasionally we have found that patients are recommended further surgery even after they have travelled abroad. A decision would then need to be made to either stay abroad for the surgery (funding would have to be agreed by your local NHS commissioners) or to come back to the UK for surgery.

Any other medical treatments your child receives abroad that are **NOT** related to your child's Proton Beam Therapy treatment will **NOT** be covered by the NHS. No medical costs for parents or carers will be covered by the NHS. Please see Page 11 for information about travel insurance.

## Financing Proton Beam Therapy

### Do I have to pay for our travel costs?



- For paediatric patients, the NHS will fund economy travel costs for two parents / carers accompanying the patient.
- NHS England will fund transport costs between your accommodation and the treatment centre but costs must be carefully managed and are based on public transport where available or locally agreed low cost car hire contracts. Please talk to the Proton Centre's 'Intake Coordinators' about car hire. Please do NOT arrange car hire yourself.

**Important:** Any claimed travel and accommodation costs for patients, parent(s) or carer(s) are subject to specific conditions outlined in the 'Guidance on the Funding Policy for Travel and Accommodation ~ NHS Proton Overseas Programme' available online.

NHS England will not pay for any additional costs incurred due to upgrades or optional extras which are not clinically justified or outlined in the above Guidance. If you have any questions you should talk to your referring NHS Trust.

### Do I have to pay for our accommodation?



NHS England will fund accommodation for the patient and their parent(s) / carer(s). Talk to the Intake Coordinators at the centres overseas about the best options for you and your family. If extended family are travelling with you then you will need to fund any necessary accommodation upgrades yourself.

## Financing Proton Beam Therapy

### What type of accommodation is funded by the NHS?



Only accommodation suggested by the Proton Beam Therapy Treatment Centre is funded by the NHS. If different accommodation is requested, you must pay for any additional costs. The types of accommodation available will vary to accommodate your child's specific needs. Accommodation is only funded for a short time after finishing the course of treatment. If your child needs to stay longer than originally planned for a medical reason, the NHS will fund a longer stay.

For more information about what type of accommodation the NHS will fund please see the 'Guidance on the Funding Policy for Travel and Accommodation ~ NHS Proton Overseas Programme'. For more advice on accommodation please see the 'Useful Contacts' section of this leaflet.

### Is there any financial support provided for meals?



The NHS will not fund the cost of meals or refreshments.

## Travel advice

### How will the Proton Centre contact me?



The Proton Beam Therapy teams work hard to ensure that you and your child are supported as much as possible. A member of the Proton Beam Therapy care team at your child's designated Proton Centre will contact you after your referral has been accepted. Most communication is conducted via email and we suggest you provide your NHS Trust and your designated Proton Centre with your email address at the earliest available opportunity.

### Do I have to organise travel and accommodation?



Following the acceptance of your child's case by the Proton Centre, your child's referring NHS Trust will contact you to discuss the travel arrangements. They will book the flights and accommodation with help from the Proton Centre. You and your child will be consulted throughout the process to cater for any particular needs you might have.

There are also other important aspects to consider when organising your child's journey, such as:

- Ensuring your passport is valid and has 6 months travel time remaining
- Obtaining visas and travel insurance
- Organising any medical supplies your child might require.

The following guidance and your child's referring NHS Trust will help to support you with this. We have suggested a checklist to assist your travel preparation (Page 15).

## Travel advice

### Who will help me with my travel and accommodation arrangements?



The Proton Centre's care team (normally a Nurse Case Manager or a Social Worker assigned to your child's case) will be able to discuss accommodation with you and help organise you and your child's accommodation and transportation needs during your stay. The Proton Centre will produce a provisional schedule of dates and times for your child's first set of appointments and you should normally receive this once your flights and initial accommodation are booked.

### Do we need a visa to travel?



If you are travelling to North America, an ESTA Visa Waiver will need to be completed for each person travelling to the USA. The ESTA Visa allows you and your child to stay in the USA for up to 90 days. The NHS will refund the cost of ESTA Visas for patients and parents / carers. Applications for ESTA Visas can be found at <https://esta.cbp.dhs.gov/esta/>. If parents or carers are not eligible for the ESTA Visa Waiver scheme you will have to apply for a US Visa. Your referring Trust will help and support you through this process.

## Travel advice

### Do we need travel insurance?



It is important when travelling overseas to make sure that you and your family have the appropriate travel insurance to ensure you are financially protected against the unexpected. Insurance to cover the cost of care relating to your child's cancer treatment is not needed because these costs are covered by the NHS. Travel insurance is refunded if you are travelling to North America but it is not refunded if you are travelling to Europe.

If your child is receiving treatment in Europe, a European Health Insurance Card (EHIC) is needed for each member of the travelling party. The EHIC entitles the holder to state-provided medical treatment within the country you are visiting. You and your child can apply for an EHIC card from <http://www.ehic.org>.

You may also want to make sure you have home insurance as you will be away from home for an extended length of time.

### What about exchanging money?



When travelling to the US centres it's important to make sure you exchange plenty of money before you leave the UK as it can sometimes be difficult to exchange money once you are there.

## Travel advice

### Do we have to make any special arrangements with the airline before travelling to the destination?



Your child's referring NHS Trust will make the necessary arrangements with the airline however, we advise that your NHS Trust and the airline are alerted if:

- Wheelchair assistance is required
- Extra baggage allowance is needed
- If you need to carry additional medical equipment on-board the aircraft, including medicines or fluids.
- Your child has a tracheostomy and requires oxygen for the duration of the flight

Your child's referring NHS Trust should supply you with a letter from the Clinical Oncologist that such medicines or fluids are a medical requirement in order to pass them through airport security. Some airlines also require your child's doctor to complete a 'fit to fly' certificate.

**Note:** Please bear in mind that if you and your child are travelling to the USA and you have a connecting flight on your outbound journey, you are required to pass through immigration and customs, claim and re-check your baggage and you may have to go through security again for the connecting domestic flight. Please ensure you allow enough time for this process.



## When you arrive

### What happens once we get to our destination?



Representatives from your Proton Centre should be able to meet you at the airport to help direct you to your accommodation. Once you arrive at the Proton Centre there will be a number of appointments you must attend prior to starting Proton Beam Therapy treatment.

The Proton Centre team will also provide contact details for any queries you might have. Please see Page 16 for the approximate timescales of appointments.

It is important that the medical team can reach you at all times during your stay abroad. In order to keep any mobile phone charges to a minimum, you could consider purchasing a foreign mobile phone or SIM card with pre-paid minutes, local to the specific country where your child is receiving treatment once you have arrived. Such pre-paid mobile phones are readily available in the USA for approximately \$15-\$30. The Proton Beam Therapy Centre's Social Worker can help organise this or discuss this with you.



The Florida Proton Therapy Center

## Travel checklist



### Checklist Items

Passport(s) up to date with 6 months travel time remaining?

ESTA Visa completed at least 72 hours before departure (USA only)?

EU Health Insurance Card (Europe only)?

Flight arrangements confirmed?

Travel insurance confirmed?

3-month supply of all regularly prescribed medicines?

Driving License (Photo card and Paper Counterpart) if intending to drive?

Please make sure you take any documentation or correspondence that contains information about your Proton Treatment and accommodation details (copies of such correspondence or confirmation may be required by Customs and Immigration/Passport Control).

If you are travelling with a small child, do you require a car or booster seat? If you do, we advise you take one with you so you have it as soon as you pick up the car from the airport.

If you need to carry more than 100ml of liquids on the flights (such as liquid medicines) have you obtained a letter from your Consultant that states this for the travel regulations? Your local NHS Trust can give you further advice about travelling with any medicines.

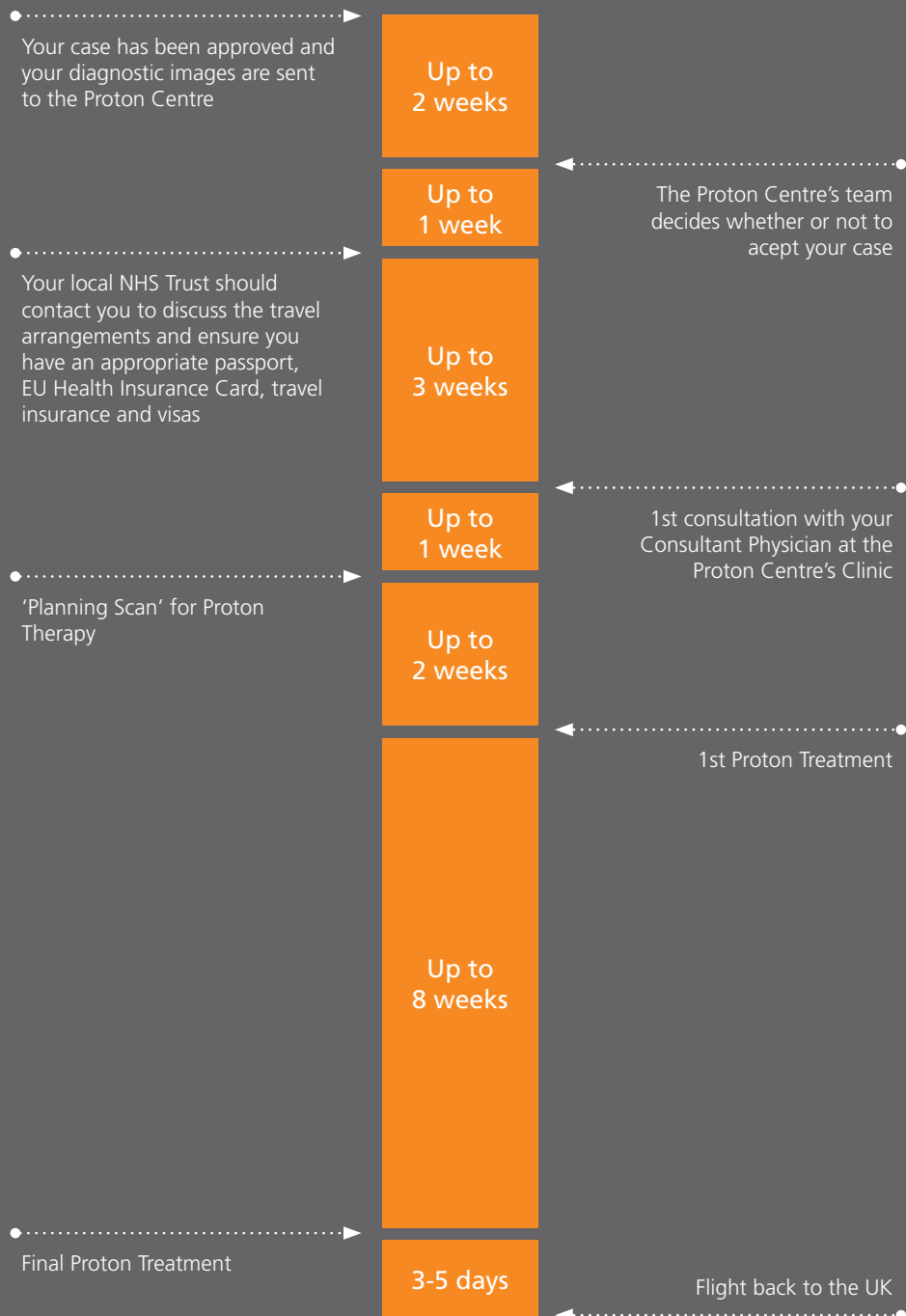
Appropriate travel adapters for electrical items?

Have you informed your bank that you are staying abroad?

Have you changed an appropriate amount of money?



## Timeline once your case has been approved



## When you arrive

### What will happen at the first appointment?



Your first visit to the Proton Centre will be to meet your child's Radiation Oncologist (a specialist in Proton Beam Therapy) and his/ her team. They will discuss; the planning and preparation process, what your child can expect in the room when they are having treatment, the aims of Proton Beam Therapy treatment and the side effects that might occur. There will be ample opportunity to ask any questions about the treatment and the side effects prior to giving informed consent on behalf of your child.

### How do we prepare for my child's treatment?



There are several steps in the preparation process. It is very important that your child is as still as possible during the treatments to allow accurate delivery of the Proton Beam Therapy. To help your child lie very still for the treatment they may need to be anaesthetised and might be fitted with some type of immobilisation device during the preparation stage. For example, when treating the head, a face-mask or a device with a bite-block might be used (See Figure 1). Some centres use several tiny beads, known as fiducial markers, implanted under the surface of the skull under anaesthesia. These serve as landmarks to help ensure the proton therapy is precisely located at each daily treatment.



Fig 1

To plan your child's treatment they will need to have a CT scan whilst immobilised. A further MRI scan may also be required to help doctors identify target the Proton Beam Therapy accurately.

Your child will also need to see a Paediatric Oncology Specialist regularly and this might be at a separate site from the Proton Centre.

## When you arrive

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Why is there a gap of 2 weeks between the Planning Scan and the first treatment in the timeline?



Whilst you might find the first week at the Proton Centre busy with various medical appointments for your child, there is normally a gap between the CT Simulation or Planning scan and the start of the Proton Treatment of up to two weeks. This is to allow a personalised Proton Beam Therapy Treatment Plan to be calculated and prepared for your child's treatment. You are likely to have this time to yourselves; your designated social worker can help with ideas for what to do during this time.

## Treatment

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How often is Proton Treatment delivered?



A treatment course is usually delivered daily (Monday to Friday) and may last up to seven or eight weeks. Appointment times may vary, however the Proton Centres in the USA are normally open from 6.30am and can in certain circumstances, finish as late as 11pm. Your child will be given a provisional start date for their Proton Beam Therapy but due to the highly individual and complex planning required this provisional date may change. In addition, many patients are, on average, abroad for nine weeks. For this reason, you must take a three-month supply of your child's regularly prescribed medicines with you to the Proton Centre.

For more information about travelling with medicines, please speak to your referring NHS Trust.

## Treatment

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How long does each treatment take?



Each day your child may spend up to 1 hour in the treatment room. During this time, your child will be fitted into their immobilisation device and correctly positioned. Daily positioning checks are taken prior to delivering radiation treatment.

For those children who require daily anaesthesia, total time spent at the Proton Centre is typically 3-3 ½ hours. For children who do not require anaesthesia, the total average time spent at the Proton Centre is approximately 1-1 ½ hours.

Can I stay with my child whilst they are having their treatment?



Since radiation is used for the treatment your child must be alone in the Proton Beam Therapy room but they will be monitored closely at all times by a specialist team through closed circuit TV monitors.

Some patients have reported that the treatment machine can be noisy but your child will not feel anything during treatment. Music can be played during treatment and there is also an intercom so that your child can speak to the medical team looking after them.

## Treatment

### What are the side effects of Proton Beam Therapy?



The range of possible side effects vary according to which part of the body is being treated. However, in general proton treatment gives fewer side effects compared to high energy X-ray treatments, (i.e. the more usual radiotherapy) because it is a more precise form of treatment and therefore affects fewer of the healthy cells. Side effects vary from person to person and can be affected by factors such as the total dose and duration of treatment and other existing conditions.

Side effects can occur during treatment, immediately after treatment or months to years afterwards. The doctors in the UK and at the Proton Treatment Centre will give information regarding specific side effects on an individual basis before your child's referral and treatment. During treatment there will be regular reviews by the medical team who will ask about any side effects your child might be experiencing and will be available if you or your child have any concerns.

### Once all of the Proton Beam Therapy treatments are over, when can we fly home?



Most patients are able to fly home immediately after completing their treatment. In most cases, your child's referring NHS Trust will book your return flight 3-5 days after your child's anticipated final treatment date to cover any unexpected delays during the treatment procedure. If a longer stay abroad is needed for a medical reason, your child's referring NHS Trust can change the return flight dates and any excess costs will be paid for by the NHS.

## Follow-up

### Will my child have follow up appointments in the UK?



Your child will require regular detailed assessments following their Proton Beam Therapy. These are likely to continue for many years, perhaps even more so than conventional high energy X-ray radiotherapy. After treatment your child will be reviewed by the local Oncology team who will work closely with the Proton Centre to share your child's clinical information and ensure that your child receives the best care possible follow-up is undertaken. Your child's clinical information will be passed between the team overseas and in the UK to make sure they have the best care possible. Individual Proton Centres have different follow-up recommendations and the plan will be discussed with you and your child.



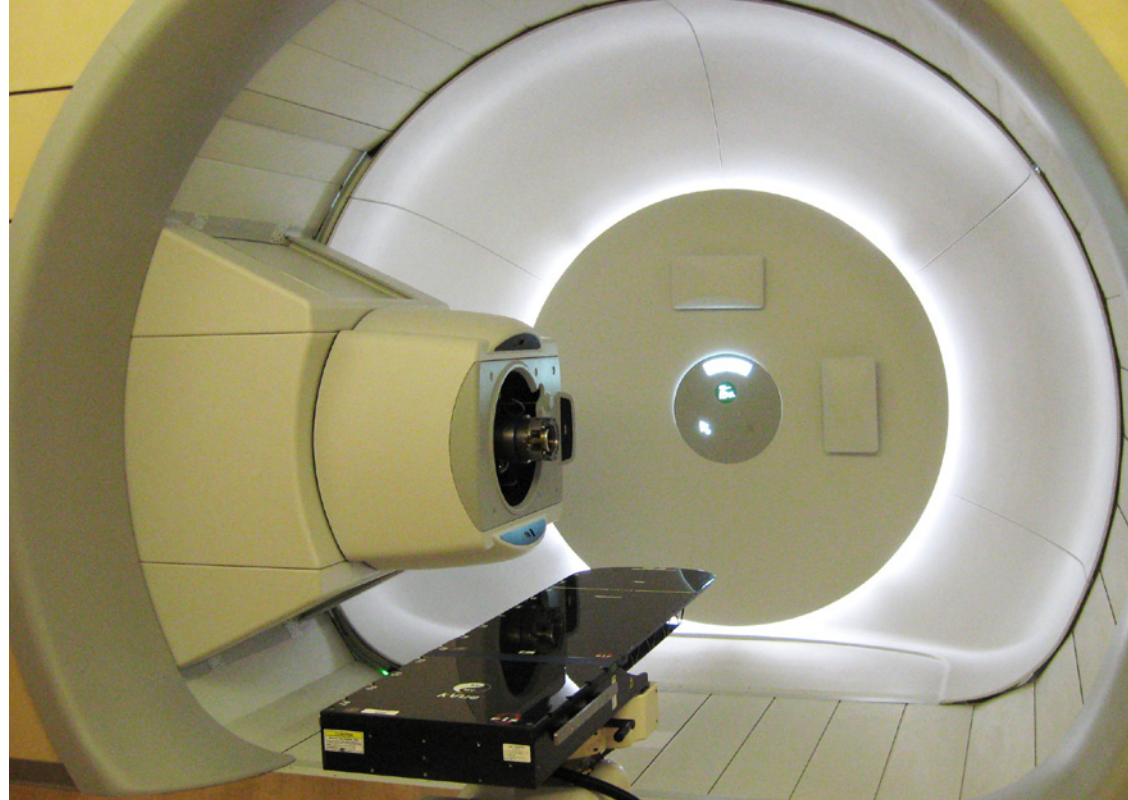
### Advice on talking to the media



We understand that you and your family may wish to talk to your local papers about travelling abroad for Proton Beam Therapy, especially if you choose to do fundraising to cover living costs whilst you are away. Whilst we are happy for you to speak to journalists about your child's treatment, it would be helpful if you could inform our communications team if you are liaising with any journalists so that we can be prepared to provide further comment should we receive a request.

We would also like to request that families make the following points clear is speaking to journalists about your experiences:

- The Proton Beam Therapy service is a nationally commissioned service funded by the NHS in England
- The NHS funds all Proton Beam Therapy treatment for the patient and pays for travel costs including flights and accommodation for the patient and a family member or carer



### Useful contacts

Your referring clinician is responsible for discussions regarding potential treatment, referral to the treatment centre and with follow up care following Proton Beam Therapy. If you have any queries or wish to discuss your child's treatment further, please contact your referring clinician.

If you have any queries regarding the travel and accommodation arrangements, you should contact your referring NHS Trust. The following contacts for the various Proton Beam Therapy Centres are able to give you more advice about the accommodation arrangements:

- **Jacksonville, Florida:**  
NHSpatients@floridaproton.org
- **Oklahoma City:**  
intakenurse@okc.procare.com

### The websites of each of the Proton Beam Therapy Centres are:

ProCure, Oklahoma City, USA:  
[www.procare.com/OurLocations/Oklahoma.aspx](http://www.procare.com/OurLocations/Oklahoma.aspx)

UFPTI, Florida, USA:  
[www.floridaproton.org](http://www.floridaproton.org)

Further information about Florida and Jacksonville regions can be found here:

[www.visitjacksonville.com](http://www.visitjacksonville.com)

[www.visitflorida.com](http://www.visitflorida.com)

Further information is available on the NHS England website.

Or contact the NHS using the following details:

**Email:** [leedsth-tr.ProtonNCG@nhs.net](mailto:leedsth-tr.ProtonNCG@nhs.net)

**Tel:** 0113 206 8602

