Citizen Participation and Public Petitions Committee

4th Meeting, 2021 (Session 6), Wednesday 22 September 2021

PE1886: Establish a specialist paediatric liver centre in Scotland

Note by the Clerk

Petitioner	Ryan Gowran
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to establish a specialist paediatric liver centre in Scotland. https://petitions.parliament.scot/petitions/PE1886

Introduction

1. This is a new petition that has been under consideration since 22 July 2021.

2. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe A.**

3. While not a formal requirement, petitioners have the option to collect signatures and comments on their petition. On this occasion, the petitioner elected to collect this information. 230 signatures have been received.

4. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered. This response is included at **Annexe B** of this paper.

5. The petitioner has provided two submissions. These are included at **Annexe C** of this paper.

Scottish Government submission

6. In its written submission, the Scottish Government explains that although there are Paediatric Gastroenterologists in Scotland who can provide initial clinical

assessment and baseline diagnostics for children presenting with paediatric liver disease, there is at present no specific highly specialised service nor is there the clinical expertise to deliver either paediatric liver transplantation or complex paediatric hepato-biliary surgery within Scotland, due to the specialist training required.

7. The submission states that NHS Scotland therefore commissions services from NHS England to deliver care to NHS Scotland patients who are referred as clinically appropriate.

8. The services commissioned are to investigate and manage all forms of medical and surgical liver disease including metabolic liver disease, acute liver failure and pre and post liver transplant management for patients.

9. NHS Scotland patients access these services at—

   - Kings College Hospital, London;
   - St. James's University Hospital in Leeds; and
   - Birmingham Children's Hospital.

10. In terms of follow up care, the submission notes that paediatric transplant centres do provide outreach clinics, and transition their patients to adult services when they are judged to be ready.

11. It highlights, however, that in some cases the original place of treatment may prefer to continue following up with their patients in their own centres. It stresses, however, that such decisions will be based on the individual clinical need of the patient.

12. The submission states that it is the expectation that any referral to England is made by either a Scottish Secondary or Tertiary Care Consultant and, following investigation or treatment, that where appropriate children will be discharged back to their regional specialist in Scotland for ongoing monitoring and shared care.

13. In its submission, the Scottish Government notes that reimbursement of travel and subsistence for children and their families is the responsibility of the NHS Board where the child resides. The family will often be offered accommodation close to the hospital in a facility such as that offered by Ronald McDonald House.

14. NHS Scotland's National Services Division (NSD) work on an ongoing basis to monitor and highlight any potential services that could be provided in Scotland.

15. Based on available data for the last five years, NSD have funded an average of five children per year to be assessed and/or treated by the specialist paediatric liver services in England each year.

16. The submission explains that such a level of need would not be consistent with ensuring the case volumes seen/treated in Scotland would be adequate to sustain a safe, fully staffed, highly specialised service.

17. In conclusion, NSD has no plans at this current time, to make alterations to the treatment pathway which allows for children to access the Highly Specialised care and expertise which they require from the three providers commissioned on their behalf by NHS England.

Petitioner submissions

18. In his written submissions, the petitioner explains that there are significant costs involved when supporting a family member so far away from home.

19. The petitioner states that costs were even higher during 2020 as a result of COVID-19 related restrictions.

20. He highlights that it needs to be easier for families to be reimbursed for these costs and states that long term hospital families need much better support as the new Young Patients Family Fund (YPFF) does not provide any true form of assistance for travel to other nations.

Action

21. The Committee is invited to consider what action it wishes to take on this petition.

Clerk to the Committee

PE1886: ESTABLISH A SPECIALIST PAEDIATRIC LIVER CENTRE IN SCOTLAND

Petitioner

Ryan Gowran

Date Lodged

19 August 2021

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to establish a specialist paediatric liver centre in Scotland.

Previous action

I have contacted all of my local councillors, my MSP, my MP and the health secretary directly but to date the only replies I get are “I’ll pass this on.”

Background information

A young family member has, to date, been in hospital for most of their life with a liver condition and forced to travel to England repeatedly for prolonged stays to get the care Scotland’s NHS simply doesn’t offer our children. During such times families face immense mental, physical and financial pressures with minimal assistance from the health board whilst down south. I believe that there are hundreds if not thousands of Scottish children who also have no other option but to travel hundreds of miles to attend either Leeds, Birmingham or London hospitals for specialist medical treatment, for assessments, treatments and procedures. It is only when they reach adulthood that the NHS in Scotland can offer that care. Scotland requires its own paediatric liver centre so we no longer have to rely on the NHS in England to help us out when it comes to the health of our own children.

Annexe A

BRIEFING FOR THE CITIZEN PARTICIPATION AND PUBLIC PETITIONS COMMITTEE ON PETITION PE1886: ‘ESTABLISH A SPECIALIST PAEDIATRIC LIVER CENTRE IN SCOTLAND’, LODGED BY RYAN GOWRAN

Background

There are a number of different childhood liver conditions and problems. The Children’s Liver Disease Foundation, a UK charity, has information on them including symptoms, diagnosis and treatment.

The petitioner would like to see a specialist service for children with liver conditions established in Scotland. For many years, some children from Scotland have been referred to specialist centres in England; in London, Birmingham and Leeds. These centres have specialist services and staff to look after and treat children with certain liver and gastrointestinal conditions. The report highlighted was written in 2004, and considered services for children with gastrointestinal, hepatic (liver) and nutritional conditions, stating that they were not adequate in Scotland. In 2009, the Scottish Government published Better Health, Better Care: National Delivery Plan for Children and Young People’s Specialist Services in Scotland.

The NHS in Scotland approves and hosts a number of specialist services. These are services in particular centres of excellence where people would be referred if clinically appropriate, regardless of where they live in Scotland. There are also national networks whereby health professionals with particular specialisms and other stakeholders will work together to agree and provide co-ordinated care and treatment for a number of conditions. The national networks are organised as clinical, diagnostic, strategic and cancer networks. Many of the clinical networks relate to paediatric conditions, such as allergies, children with exceptional health care needs, epilepsy,blood disorders, immunology and rheumatology for example.

Regional networks operate - Paediatric Gastroenterology, Hepatology and Nutrition Networks, sharing services, information and best practice across a number of health boards. These are not administered by NHS National Services Division. There is one covering the north of Scotland, one for the south east of Scotland and one covering the west.

There are specialists working in the NHS in Scotland (see for example information on NHS Lothian's system for advising GPs about paediatric referrals for gastrointestinal disorders. However, it is considered better, for rarer conditions, or where the number of patients might be relatively small, to provide treatment in highly specialised centres, where expertise can be concentrated.

Data isn't available on the *total* number of children in Scotland accessing gastroenterology services, which are the responsibility of health boards, and delivered locally or through specialist centres.

Referrals to specialist centres in NHS England

Data from NHS National Services Division (NHS NSD) confirms that for the last five years, **five children on average per year have been funded to receive treatment from one of the specialist services in England** (personal communication with Scottish Government). This level of need is not sufficient to provide a sustainable, fully staffed and safe service in Scotland.

The criteria for referral is prescribed by the Royal College of Paediatrics and Child Health in 'Referral list for supra-regional paediatric liver services', referenced in the relevant NHS England Service Specification for Paediatric Liver Services.

Patients from Scotland are normally referred by either Consultants in General Paediatrics, Paediatric Intensive Care, Neonatology or Paediatric Gastroenterology located in one of the regional children's hospitals in Edinburgh, Glasgow, Aberdeen or Dundee. Following agreement of need, the consultants will either contact NHS NSD to seek funding authorisation (copying in the Out of Area Team in the patient's NHS Board).

Children’s transplant centres provide outreach clinics in Scotland and most will transfer to adult services when appropriate. Continuity of care is important for some patients so, even if local services are available, so it might be deemed best for the patient to continue their treatment at the original place of treatment – such as a transplant centre in England.

The child’s health board is responsible for covering the cost of travel and subsistence for the child and family member under a discretionary reimbursement scheme.

The NHS in Scotland does not pay NHS England health trusts for treatment of these children, and treatment is funded directly by the UK Government via NHS England through long-standing arrangements.

Scottish Government Action

In 2009, the Scottish Government published Better Health, Better Care: National Delivery Plan for Children and Young People’s Specialist Services in Scotland. The plan focuses on improvements in the hospital facilities for children in the main cities in Scotland. In the plan gastroenterology is listed as an immediate priority for investment, but there is no promise of dedicated paediatric liver centre. The observations and commitments of the Plan for Gastroenterology (including Hepatology) were:

> “**Gastroenterology**
>
> 107. Paediatric Gastroenterology, Hepatology and Nutrition (PGHN) services are coming under increasing pressure in Scotland. This is due to recognised gaps in staffing and service provision; a reduction in the involvement of adult clinicians in the care of children and a significant and ongoing rise in the incidence of inflammatory bowel disease in children and young people. The impact of this latter issue is magnified by the progressive introduction of the raised age limit for children’s services.
>
> 108. These issues were recognised in an earlier review of Tertiary (specialist) Paediatric Services in 2004 and the present consultation exercise has drawn specific attention to

> the urgency with which some elements of service provision in Scotland require to be addressed.
>
> **We will:**
>
> **Invest in an additional consultant post in PGHN to support services in the South East and Tayside Region. Provide support to strengthen the paediatric gastroenterology network in the North Region. Work with Regional Planning Groups to ensure appropriate investment in PGHN services across Scotland during 2009-2011"**

This plan was incorporated by NHS boards, and they are responsible for delivery.

At the present time NHS NSD have no plans to make alterations to the treatment pathway which allows for (on average five children per year) to access the highly specialised care and expertise which they require from the three providers commissioned on their behalf by NHS England.

Scottish Parliament Action

The Scottish Parliament has not looked into this particular issue in the past. A Parliamentary Question was asked in 2014 about the number of referrals over the previous ten years, giving a longer view of the demand for such a service.

Key Organisations and relevant links

Children's Liver Disease Foundation

British Liver Trust

British Association for the Study of the Liver

Foundation for Liver Research

Primary Care Society for Gastroenterology

Anne Jepson
Senior Researcher
19 August 2021

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Annexe B

Scottish Government submission of 18 August 2021

PE1886/A – Establish a specialist paediatric liver centre in Scotland

The Scottish Government is committed to making sure all people living with any liver condition in Scotland are able to access the best possible care and support, and benefit from healthcare services that are safe, effective and put people at the centre of their care.

Liver transplantation is available for adults over the age of 16 in Scotland. Whilst there are currently a number of Paediatric Gastroenterologists in Scotland who can provide initial clinical assessment and baseline diagnostics for children presenting with paediatric liver disease, there is at present no specific highly specialised service nor is there the clinical expertise to deliver either paediatric liver transplantation or complex paediatric hepato-biliary surgery within Scotland, due to the specialist training required

There are currently no plans to have a paediatric specialist transplant service in Scotland for livers. Patients from NHS Scotland currently have access to three Highly Specialised Paediatric Liver Services which are commissioned by NHS England on our behalf. The three centres are located in Kings College Hospital, London, St. James's University Hospital in Leeds and Birmingham Children's Hospital.

Paediatric transplant centres do however provide outreach clinics, and transition their patients to adult services when they are judged to be ready. It is important to highlight that in some cases the original place of treatment may prefer to continue following up with their patients in their own centres, however this will be based on the individual clinical need of the patient.

Patients from Scotland are normally referred by either Consultants in General Paediatrics, Paediatric Intensive Care, Neonatology or Paediatric Gastroenterology located in one of the regional children's hospitals in Edinburgh, Glasgow, Aberdeen or Dundee. Following agreement of need, the consultants will either contact NHS Scotland's National Services Division (NSD) to seek funding authorisation (copying in the Out of Area Team in the NHS Board of residence), or will contact Out of Area Team who can submit the funding application to NSD on their behalf.

Acceptance to the services in England is based on the criteria prescribed by the Royal College of Paediatrics and Child Health in their document “Referral list for supra-regional paediatric liver services”, which is referenced in the NHS England Service Specification for Paediatric Liver Services.

The provision of general paediatric gastroenterology services (including hepatology and paediatric surgery) in Scotland is the responsibility of the local NHS Boards who will either deliver these services locally, or will do so via one of the specialist paediatric hospitals in Scotland.

Many of the basic investigations required to confirm the diagnosis and ongoing monitoring of paediatric liver disease are available within Scotland. In line with evidenced best practice, though, children can be referred as clinically appropriate to one of the three English centres which have the full resources available to them in terms of clinical expertise, critical care, diagnostics and therapeutics available to manage the needs of this group of patients.

The English centres are commissioned to investigate and manage all forms of medical and surgical liver disease including metabolic liver disease, acute liver failure and pre and post liver transplant management. The majority of the new referrals they receive are infants or young children with neo-natal or childhood liver disease. The services require specialist laboratory diagnostics, diagnostic and therapeutic endoscopy, diagnostic and interventional radiology as well as specialist surgical expertise to carry out specific procedures necessary to manage the complexity of disease presentation and ongoing care.

There is the expectation that any referral to England is made by either a Scottish Secondary or Tertiary Care Consultant and following investigation or treatment that where appropriate children will be discharged back to their regional specialist in Scotland for ongoing monitoring and shared care.

The responsibility for the reimbursement of travel and subsistence for children and their families is the responsibility of the NHS Board where the child resides. The family will often be offered accommodation close to the hospital in a facility such as that offered by Ronald McDonald

House.

NHS Scotland’s National Services Division (NSD) work on an ongoing basis to monitor and highlight any potential services that could be provided in Scotland. Some highly specialist services, due to the low volume of patients requiring treatment, will need to be provided on a centre of excellence basis to maintain high quality clinical expertise.

Based on available data for the last five years, NSD have funded an average of five children per year to be assessed and/or treated by the specialist paediatric liver services in England each year. Such a level of need would not be consistent with ensuring the case volumes seen/treated in Scotland would be adequate to sustain a safe, fully staffed, highly specialised service.

At the present time NSD have no plans to make alterations to the treatment pathway which allows for children to access the Highly Specialised care and expertise which they require from the three providers commissioned on their behalf by NHS England. With such providers clinicians, patients and families can be assured that the services are of a high quality, have the required expertise and equipment, appropriate case volumes and are clinically safe.

Annexe C

Petitioner submission of 19 August 2021

PE1886/B

I have read over the information provided in response to my petition and understand what is being said, however reimbursement for travel and subsistence is extremely difficult to claim.

It took us months to get any real amounts of out of pocket expenses back after jumping through hoops.

If the Scottish government have no cares to provide real care for its citizens they should at least make it easier to get assistance with the massive costs of literally having to live in a different country for months on end.

Petitioner submission of 8 September 2021

PE1886/C: Establish a specialist paediatric liver centre in Scotland

The aim of my petition was to draw attention to the hundreds of children forced to England for treatment relating to paediatric liver conditions.

In England there are 3 specialist centres spread evenly to give the population of England easy access to these services.

In Scotland we have tons of children who require this treatment and the 3 centres in England are almost always at capacity, showing that there is a growing need for a new centre within the UK and Scotland. Scotland leads the way on so many fronts, this should be one for our children.

I don’t think that the general care in English hospitals is as good and the constant uprooting of families for this treatment even against our will has such a major mental impact on families of patients.

In the reply I received, the Government have told me that travel and subsistence will be covered but there is no easy way to go about this the system has flaws and makes you jump through hoops. In 2020 we were approx £10k out of pocket, most of that was borrowed from family members, to cover so many expenses especially during the pandemic where public spaces where closed and we had no access to cooking facilities while in England. The system needs looking at and long term hospital families need much better support as the current Young Patients Family Fund (YPFF) which just came in to place does not provide any true form of assistance for travel to foreign nations.