

BRIEFING FOR THE CITIZEN PARTICIPATION 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](#)

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