

## **Finding children with Hepatitis C**

### Who we are

We are the National Hepatitis C Paediatric Operational Delivery Network (pODN) funded by NHS England.<sup>1</sup> The World Health Organisation has a target to eliminate Hepatitis C by 2030<sup>2</sup> and our ODN and the UK Health Security Agency (UKHSA) have been working together since 2021 towards this goal. We are delighted to say that the UK is ahead of the game in doing so.<sup>3,4,5</sup>

Our network is hosted by Birmingham Women's and Children's Hospital (BWC). Professor Deirdre Kelly is the Clinical Lead, and our team is made up of specialists in Hepatitis C providing advice and treatment to children.

We are working also with UKHSA who have shared records of children and young adults (CYP) who at one time tested positive for Hepatitis C but do not have any follow up on their status, this is our 'Track and Trace' project. I am the Track and Trace Project Coordinator, and my role is to trace these CY&P to confirm their HCV status. In the event any person is found to have an active HCV infection information is provided to the GP on how to refer them for treatment.

Adopted children can be difficult to trace and we are working with adoption agencies and are delighted to interact with Ace Adoption.

This short article is to raise awareness of HCV to highlight what has worked in ensuring these vulnerable children are traced, their HCV status is determined and where appropriate receive treatment.

### What is Hepatitis C and why does it matter?

Hepatitis C (HCV) is a viral infection, which in children has no symptoms and is therefore 'silent'. The problem is that the virus can cause serious health problems including liver cancer and damage to the liver structure (e.g. cirrhosis) several years down the line. Effective medication was licensed in 2020 for treatment of HCV in children over the age of three: it is curative and removes the long-term health risks.

The virus is mostly transmitted by blood and the most common way for children to be infected is through the process of birth. However, HCV is not part of ante-natal screening and children are only tested shortly after birth if their mothers are at risk of having the infection, so many infected children could be missed.

### How the system works

Because of the potentially serious consequences of HCV, any positive tests are 'notified' to UKHSA under legislation, Public Health (Control of Disease) Act 1984 and the Health Protection (Notification) Regulations 2010.

At Track and Trace, we receive identifying data (name, NHS number, date of birth, GP, and test results) from UKHSA. We then contact the patient's GP, request subsequent test results, and ask them to re-test as necessary. It is impossible for us to find adopted children as in most cases, their identifying details i.e. NHS Number and name, have changed and we may only know their original details plus a possible locality of adoption.

This is where it has been so helpful to make contact with agencies such as your organisation, where you have been able to act as intermediaries with the adoptive families. We do not expect to be given any details of the child's new identity. We send a letter explaining what information and tests are required, which can be forwarded to the GP to action. We have a Children's Liver Specialist Nurse who is available to speak to your staff or families for any support or queries. Confidentiality is maintained at all times.

#### What happens if a child's repeat blood test is positive for HCV?

In the vast majority of cases, on re-testing, we find that children no longer have any trace of infection, and no further action is needed. In the minority of children whose test remains positive, we can arrange treatment through the paediatric ODN by a Paediatrician close to their home. The oral treatment takes 8 or 12 weeks. We have now treated hundreds of children with few side effects and is effective in over 99% of cases. Blood tests are required occasionally for up to one year afterwards to check that the virus has permanently cleared. At that point, no further follow up is required.

Ace Adoption has acted as intermediary in finding one child who may need blood tests, and we are so grateful for this. As children who are adopted are already vulnerable, we are delighted to be able to help them in this way. We thank you for liaising with us-this is a great example of inter-agency working.

We hope this article highlights the importance of identifying and treating HCV. What we would like to see in the future is that re-checks for HCV in any child who has been identified to have an earlier positive test form part of the pre-adoption checklist for these children in order to further streamline elimination of this infection.

If you have any queries about our programme, please contact us on:  
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The following links may be useful

Information on Hep C <https://www.hepculater.com/hep-c-information/>

1. Hepatitis C ODNs  
<https://www.england.nhs.uk/publication/list-of-hepatitis-c-operational-delivery-networks-in-england/>
2. World Health Organisation  
[https://www.who.int/health-topics/hepatitis/elimination-of-hepatitis-by-2030#tab=tab\\_1](https://www.who.int/health-topics/hepatitis/elimination-of-hepatitis-by-2030#tab=tab_1)
3. Elimination of Hepatitis C in UK  
<https://www.england.nhs.uk/2022/12/nhs-set-to-eliminate-hepatitis-c-ahead-of-rest-of-the-world/>
4. Gov UK <https://www.gov.uk/government/publications/hepatitis-c-in-the-uk/hepatitis-c-in-england-2024>
5. <https://www.hepculater.com/hepatitis-c-elimination-successes/>