

What if I have questions?

If you have any questions regarding this database, please contact any of the following:

Irish Haemophilia Society 1850 872872
Irish Kidney Association 1890-Kidney (1890 543639)
Positive Action 1850 200231
Transfusion Positive 01 6398855

Hepatology Liaison Nurses in the designated liver units:

Beaumont Hospital
01 8092220

Mater Misericordiae University Hospital
01 8032048

St James's Hospital
01 4103417

St Vincent's University Hospital
01 2094248

Cork University Hospital
021 4922274

University College Hospital, Galway
091 544370

St Luke's Hospital, Kilkenny
056 85308

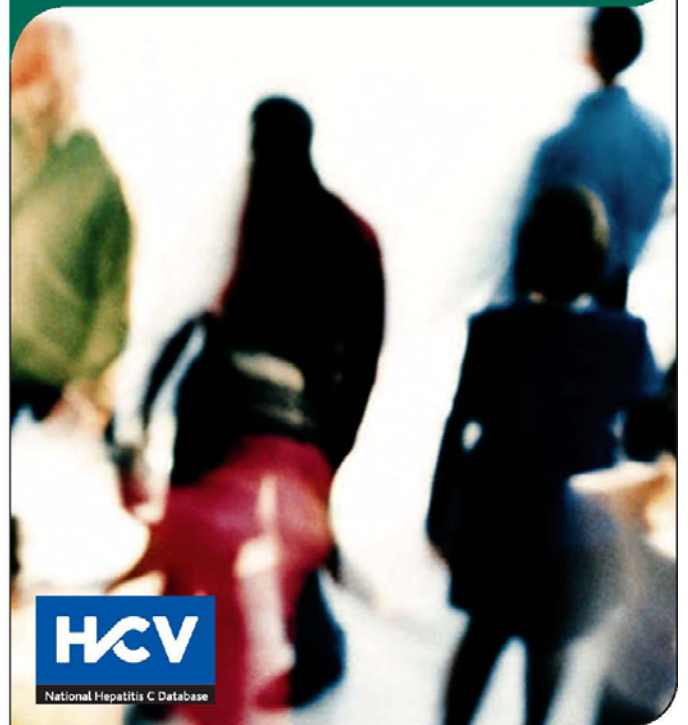
Our Lady's Hospital for Sick Children, Crumlin
01 4096742

Michele Tait,
Regional Hepatitis C Liaison Officer,
HSE
01 6201750

National Hepatitis C Database

for infection acquired through blood
and blood products

Information for families of deceased
persons



What is the National Hepatitis C Database for infection acquired through blood and blood products?

A clearly defined group of people in Ireland were infected with hepatitis C virus by contaminated blood or blood products. This presents an important opportunity to study the disease caused by hepatitis C. The Consultative Council on Hepatitis C recommended that a national database should be set up for research purposes. The database (a type of register) is a way of collecting medical information on the people who were infected with hepatitis C in this way.

Why do we need this database?

The virus that causes hepatitis C was identified relatively recently. Doctors are still learning about the kind of illnesses it can cause. By collecting medical information on people who were infected with hepatitis C, the Hepatitis C Database will help us to learn more about the disease caused by the hepatitis C virus.

It can also be used to help in planning the services needed in the future by those who have hepatitis C infection.

What progress has been made so far?

The database has been set up by the Health Protection Surveillance Centre (HPSC) in conjunction with the eight designated liver units and with the support of the patient support groups mentioned below. The HPSC is Ireland's national specialist centre for the surveillance of infectious diseases.

The collection of baseline information on persons living with state-acquired hepatitis C has been successfully completed. The information has been collected from hospital records of those who consented to participate. The following information has been collected: age,

gender, how the person became infected, their medical conditions, results of tests, treatment received. All information is treated in strictest confidence. The database does not contain people's names or addresses or other personally identifying information.

Why is it important to include information on deceased persons?

The inclusion of information from the hospital records of deceased persons is vital to ensure a full understanding of hepatitis C infection. The information collected is invaluable for the future well-being and health care of persons living with State-acquired hepatitis C. Information on persons with state-acquired hepatitis C who have died will be collected in the same manner as for those who are still living, that is, from their hospital records. Information on cause of death will be collected, whether death was due to hepatitis C, other related illness or illness completely unrelated to hepatitis C.

Who oversees the database?

A Database Steering Committee monitors the running of the database. Its membership includes representatives from the patient support groups, the consultant hepatologists, liaison officers/nurses, and the Department of Health and Children, as well as the HPSC.

Who has access to the database?

Access to the database is strictly controlled. Apart from relevant staff in the HPSC and the consultant hepatologists and nurses in the designated liver units having access, other requests for information have to be approved by the Database Steering Committee. It will not be possible to identify an individual from any reports produced from the database.