



## **The National Centre for Hereditary Coagulation Disorders Registry**

The National Centre for Hereditary Coagulation Disorders (NCHCD), St. James's Hospital is a Comprehensive Care Centre (CCC) for adult patients (>16 years of age) with Haemophilia, related bleeding disorders and clotting disorders. The NCHCD takes a lead role in the provision of high quality Haemophilia care nationally.

Multi-disciplinary comprehensive care and services are provided in a custom designed building on the St James's Hospital campus for out-patient and dental care. This building also contains the National Specialist Haemostasis Laboratory and the National Molecular Genetics Laboratory for Haemophilia and bleeding disorders. A new in-patient ward and assessment unit opened on October 7<sup>th</sup> 2013. It contains six designated in-patient beds (single room accommodation) and a six bay acute assessment area, specifically designed to cater for patients who require emergency assessment and treatment

### **What is the Registry?**

The Registry is an electronic patient record which stores important clinical information about persons with bleeding disorders.

### **Who Can Access Data?**

Data is only available to authorised haemophilia doctors, nurses and administrative staff at the NCHCD and other CCCs and to authorised Haematology Consultants at named participating regional treatment centres.

The Registry is hosted at St James's Hospital and is accessed electronically by other designated centres through a secure network link.

### **For more information please contact:**

Rachel Bird  
National Haemophilia Data Manager  
rbird@stjames.ie