



## PARTICIPANT INFORMATION SHEET CHILDREN AGED 7-11



### **What is the UK Inflammatory Bowel Disease Nixon Twin and Multiplex Registry?**

My name is **Dr William Blad**. I work with a team of doctors and scientists who are keen to learn more about Crohn's Disease and Ulcerative Colitis. We would like to understand why some people are more likely to get these diseases than others. We are collecting and storing information about people with these conditions. We are particularly interested in families where many people have these diseases, and twins where one or both twin has Inflammatory Bowel Disease. The registry is a large computer file which stores this information. It also stores the names, addresses and emails of people taking part.

At first we only collected information about adults. However the parents of several young people with these illnesses were keen to help. So we started collecting details about children with inflammatory bowel disease too.

I have given more information about the registry to your parent or guardian. However I also want to make sure you are happy for us to see your medical information. Please read this leaflet. If you would like to take part there is an agreement for you to sign at the back.

## **So why do you want me to join the Registry?**

You have been asked to join because you are from a special and unique family. We think you will be able to help us understand a bit more about why some people get Crohn's Disease or Ulcerative Colitis. Perhaps you have a twin brother or sister, and one or both of you has Crohn's Disease or Ulcerative Colitis. Or perhaps you are from a family where three or more close relatives have inflammatory bowel disease.

## **If I want to join the Registry what will happen?**

Your parent or guardian will fill in a survey about your health. We will also ask your family doctor or gastroenterologist (expert in tummy problems) to tell us some more about your health.

From time to time we will tell you and your parent or guardian about research studies you may want to take part in. However you do not have to take part in any of these projects if you do not want to.

## **Do I have to take part?**

No. If you do not want to take part no-one will be upset or angry.

## **What happens if I agree to take part then change my mind?**

You can take your details out of the registry at any time. No-one will be upset or angry.

## **Will you share my information with other people?**

No. Only people working for the registry will be able to see your name. All staff have been specially trained to keep your information private.

When we learn useful information about inflammatory bowel disease from the registry this information may be shared. However things I have learned from you will be put with things I have learned from other children and adults, and your name will not be included.

## Assent Form

- My name is **Dr Hannah Gordon / Dr William Blad**. I am trying to learn more about Crohn's Disease and Ulcerative Colitis. If you would like, you can be part of my research registry.
- I have invited you to be part of the registry because you are from a unique family. Perhaps you have a twin brother or sister, and one or both of you has Crohn's Disease or Ulcerative Colitis. Perhaps you are from a family where several close relatives have inflammatory bowel disease.
- If you decide to be part of the registry we will ask your parents or guardian to fill in a survey about your health. We will also ask your doctor for information about you. We will sometimes ask if you want to help with other research projects. You do not have to join any of these projects if you do not want to.
- Other people will not be given your personal details, such as your name and telephone number
- Your parents or guardian have to give permission for you to be in the registry. However we will only include your details if you want to do it too. If you do not want to be part of the registry no-one will be upset or angry with you. If you join you can later decide you no longer want to be part of the registry.
- My email is [hannah.gordon@chelwest.nhs.uk](mailto:hannah.gordon@chelwest.nhs.uk) / [william.blad@nhs.net](mailto:william.blad@nhs.net). You can email if you have any questions about the registry, or decide later you no longer want to be part of the registry.
- I will give you a copy of this form to keep in case you want to ask questions later

### **Agreement:**

I have decided to be part of the registry even though I know I don't have to take part.

---

**Print Name**

---

**Signature of Study Participant**

---

**Date**