bsaci
improving allergy care
through education, training and research

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improving allergy care
BSACI registry for immunotherapy

Information for parents

Your child is being invited to take part in a patient registry for people receiving immunotherapy for allergies and urticaria. Before you decide whether your child should take part, it is important that you understand why this project is taking place and what it will involve.

Please take time to read the following information carefully and talk to others about it if you want to. You can also ask the doctors and nurses looking after your child if there is anything that you do not understand or if you would like any more information. Take time to decide if you wish your child to take part in this project.

What is the BRIT Registry?

A patient registry is a database or collection of information about people affected by a disease, or having a specific treatment or operation. BRIT is a registry for people being treated with immunotherapy. It is held on a secure internet based database. BRIT keeps track of what treatment has been prescribed and any side effects or reactions from these medicines.

The data from the Registry will be used to help develop specialist immunotherapy around the UK and to review the safety and effectiveness of these medicines.

What will happen if I take part?

Your child's data will be uploaded by the clinical team and if you have agreed to be included in emails, you will start to receive emails from the Registry. These will occur at regular intervals and ask you to complete an online questionnaire. Many immunotherapy centres use paper questionnaires to monitor treatment, the online questionnaires will be very similar. We will also send newsletters and updates about the Registry.

Many forms of immunotherapy continue to provide benefit for a period after they have been stopped. This can be months, years or even lifelong in some cases, depending upon what treatment has been given. Ask your child's specialist about what you might expect from your child's treatment. Once your child's treatment has finished, we will ask you if you would like to continue to receive emails. This will help is to monitor the long-term effectiveness of these treatments.

Why have an Immunotherapy Registry?

Immunotherapy for tree, grass, venom, house dust mite and animal allergy is a highly specialised treatment. The registry will record the number of people in the UK on immunotherapy and where they are being treated. It will also show how treatments are working and what side effects can be expected. It will help to provide better care for people with allergies in the future. It will also help your child's consultant to maintain best practice, and will show how access to these specialist treatments varies around the country.

What information is kept in the Registry?

The information kept in the Registry is like the information that is recorded during visits to Clinic. It will include information that might identify your child to others. We will ask you to complete a form with these identifiers – so that you know exactly what is being included. It also includes details about allergies, the type of treatment and if the treatment was a success, based on the online questionnaires that you complete. It also lists any side effects from the medication that you or your child's doctor have reported.

Do I have to take part?

It is up to you decide to take part in the Registry. You will be asked to sign a consent form and the personal information that you wish to be included in the Registry. Children under sixteen can countersign their assent to take part. In Scotland children between 12 and 15 will also be asked to sign consent as the law is different in that part of the country. Your child's care will not be affected in any way if you decide not to take part.

Can I change my mind later?

You will be able to opt out of the Registry at any time without giving a reason. Any information held about your child will be removed from the Registry. You are free to opt out of the Registry at any time without giving a reason. You can also unsubscribe from Registry emails at any time.

If you want to opt out, please contact your child's specialist or email registry@bsaci.org.

Will my information be kept confidential?

The BSACI is the professional society for Allergy specialists and Clinical Immunologists in the UK. The data on the Registry is owned by BSACI and managed by the Registry Steering Committee, which is made up of specialist doctors and nurses and patient representatives from the Anaphylaxis Campaign and Allergy UK.

BSACI control the data and most analysis will be undertaken by specialists of the Registry Steering Committee. Only anonymous data will be downloaded for analysis by the RSC.

All the information in the Registry is held on secure internet servers behind an NHS firewall. It is managed in accordance with relevant data protection laws and ethical principles. The Registry is managed by Dendrite Clinical Systems.

Only a few people will have access to the identifiable information stored about your child in this Registry. Your child's consultant specialist and their clinical team will have access to the personal information stored about your child, so that they can easily update their records and see how treatment is working.

A very small number of experienced administration staff at BSACI (these are referred to as 'trusted third parties') will also be able to see Your child's personal information. This is to enable the information to be updated or deleted if you want to opt out, and to keep the system maintained in accordance with data protection laws.

Each Registry participant will be given a unique number which does not identify them to others. This number will be used when the Registry data is analysed by the BSACI.

The Registry has been paid for by some of the companies who provide immunotherapy treatments but they do not control or own the data.

Further information about how we handle your personal information is available in our **Privacy Notice**. Ask your consultant specialist for a copy or contact the Registry.

What will happen to the data?

Other researchers in the UK and abroad may also request to use this important dataset. The RSC will review requests by other researchers and pharmaceutical companies to use the data collected by the Registry. Only anonymous data will be downloaded for these purposes.

How to contact the Registry

If you have any questions about the use of your child's data or you want your child's information removed or updated, please contact the registry administrator by email registry@bsaci.org or phone 0207 50 3910.

Thank you for taking time to read this information sheet and for considering taking part in the Registry.

If you have any questions or require any further information, please talk to a member of the care team at your Allergy Clinic.