

First Birthday Celebrations

Over 300 children have volunteered to take part in research supported by the Children's Clinical Research Facility (CCRF) since it opened in April last year. The CCRF has participated in research to improve treatment for children with conditions such as leukaemia, asthma, cystic fibrosis, allergy and rheumatoid disease.

The CCRF is a purpose built, child friendly unit, which comprises a two bed clinical room, a consulting room, reception and play area. It is part of the University of Edinburgh accommodation within the hospital, with easy access to the main wards and emergency facilities to ensure patient safety.

It was made possible thanks to a donation of £67,000 from the Sick Kids Friends Foundation, a £50,000 investment from the University of Edinburgh and ongoing funding worth in excess of £20,000 a year from NHS Lothian's Research and Development Fund.

The CCRF is jointly managed by the University and NHS Lothian, with a dedicated team of three paediatric research nurses who support clinicians from across Scotland to carry out studies into a range of childhood illnesses.

Kay Riding, Lead Paediatric Research Nurse, said: "Our first year has been a great success with the number of projects we are working on increasing from four to 10. These facilities have also given us the opportunity to strengthen our partnership with the University of Edinburgh as we work together to advance the way we treat patients and manage diseases."

Prof. Jürgen Schwarze, Edward Clark Chair of Child Life and Health, University of Edinburgh, said: "We are delighted to celebrate the first anniversary of this fantastic research facility. Clinical research is pivotal for improving the way we treat patients and we would like to thank all of the children and families who have given their time, energy and

support to help with our research over the past year. Together we are making a real difference to young people in Scotland and further afield.”

Maureen Harrison, chief executive of the Sick Kids Friends Foundation, said: “The new Children’s Clinical Research Facility has played a vital role in improving young lives by providing an area dedicated to researching children’s illnesses. Without the ongoing support of the public we would not have been able to help fund this vital unit.”

Project case study

The Royal Hospital for Sick Children is one of a small number of the UK’s children’s hospitals involved in large scale research into conditions such as cystic fibrosis and rheumatoid disease.

Eight children and young people aged between seven and 18 from the Edinburgh area have been recruited to take part in the Paediatric Osteopenia Study (POPS) trial over three years, funded by the medical research charity the Arthritis Research UK and run by paediatric rheumatologist Dr Joyce Davidson.

The study aims to reduce brittle bones (also known as osteopenia) associated with steroid medication in youngsters with arthritis and other related rheumatic diseases such as juvenile-onset lupus, juvenile dermatomyositis and vasculitis. Many children develop osteopenia as a result of taking steroids to treat their diseases.

A further nine participating centres from around the UK are aiming to recruit a total of 270 patients. The trial is being co-ordinated from Belfast, and run on behalf of the British Society of Paediatric and Adolescent Rheumatology.

The team hope their research will lead to new guidelines on the treatment of steroid-induced osteopenia, which will improve the lives of the tens of thousands of children with arthritis who are affected throughout the world.