

Public Information for the web

Rickets in Children caused by Vitamin D Deficiency

This web information provides information about a new research study of rickets. It aims to provide information about the condition, why this study is important and what we hope to show by doing it. It also provides contact details of the researchers undertaking the study and a link to the website where the results will be published.

What is Rickets?

Rickets is a disease of growing children. It results in softening of their bones, so that they bend (bow-legs or knock-knees, widening of the wrists and ankles, curved spines) and in very severe cases, can break. Rickets also causes pain in the bones so children may be reluctant to walk. In the long term, if not treated, it can cause poor growth so that children are smaller than usual when they grow up. Women may have difficulties with childbirth if rickets has deformed their pelvis. It is a completely preventable disease, and is also easily treated.

The commonest cause of Rickets is a lack of vitamin D. (There are also rare genetic causes of rickets). The main source of Vitamin D is the sun. While there is some vitamin D in certain foods, we cannot get enough vitamin D just from eating a balanced diet.

Why does Rickets develop?

Rickets was common in Victorian times and was eradicated by the use of cod-liver oil and by fortifying food with Vitamin D. However, recently the number of cases of rickets appears to have been increasing. There are many possible reasons for this - lack of good quality sunlight in the UK, not exposing ourselves to sunlight (covering up with clothing, sun creams, staying indoors, and immobility e.g. disabled children). Children with darker skin e.g. African, Caribbean, Asian and Middle Eastern, are also at risk because they need more sunlight to make Vitamin D. Those who are growing rapidly (premature babies, infants, toddlers, adolescents) and overweight children are also more at risk, because they need more Vitamin D. The government has issued advice about how to prevent Vitamin D deficiency (<http://www.nhs.uk/Conditions/Rickets/Pages/prevention.aspx>), but we do not know how effective this is.

What are the aims of this study?

There have been many media reports about rickets, but we do not know for sure how great a problem it is in the UK.

To inform policy and guidance on prevention and treatment, we would like:

- to identify the number of children who are diagnosed with rickets in the United Kingdom each year;
- to collect information about rickets, how it presents in children and how it is treated.

How will the information be collected?

Paediatricians who see children with rickets will complete a confidential questionnaire via a secure online website which will be accessed by the study investigators in London. The questionnaire is anonymised and the child's identity is only known to the doctor caring for them.

How will the information be used?

British Paediatric Surveillance Unit (BPSU) researchers do not contact families or children with the condition. Children with rickets will continue to get the normal standard of care and treatment from their doctors.

We hope that this study will have benefits for future children with the condition by providing us with more information on how many children are affected by this condition.

Data collected on young people with rickets will help us to improve our understanding of the current problems associated with this condition. This will help shape future approaches to preventing and managing the condition. All data collected will be held securely and confidentiality maintained at all times.

The NHS uses medical records for audit or research to improve future health and care. Hospitals and health professionals record when you do not want your child's notes to be used for audit or research so you must always let your child's consultant paediatrician know if you do not wish their medical notes to be used for research. If so, their data will not be used in BPSU studies.

Where is this study happening?

The study is being led by the Research and Policy division of the Royal College of Paediatrics and Child Health with clinical support from clinicians from Royal Free Hospital, Northwick Park Hospital in London and Birmingham Children's Hospital. Data is being collected in all hospitals across the UK.

Who can be contacted for further information?

If you have further questions or would like more information please contact Dr Priscilla Jules, Consultant Paediatrician, Royal Free Hospital, Email: p.julies@nhs.net or Karina Pal, research administrator, Royal College of Paediatrics and Child Health, Email: karina.pal@rcpch.ac.uk or the British Paediatric Surveillance Unit (see below for details)

How long will the study go on for?

The study will continue for 25 months, starting in March 2015

Who is funding this study?

This study is being funded through an unrestricted educational grant from Nutricia through the research grant committee of the Royal National Orthopaedic Hospital.

British Paediatric Surveillance Unit (BPSU)

What is the British Paediatric Surveillance Unit (BPSU)?

The aim of the BPSU is to encourage the study of rare conditions in children. It was founded in 1986 by the Royal College of Paediatrics and Child Health, Public Health England and the University Of London- Institute Of Child Health.

What does the BPSU do?

It allows doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by the particular disease or condition each year - this is called epidemiological surveillance. Doctors can also gather information about all the cases of a particular rare condition so they can begin to understand what might have caused it and how to diagnose and treat. BPSU studies can benefit future patients with rare conditions.

How does the BPSU work?

Each month the BPSU sends an orange card to almost 3500 consultant paediatricians and specialists; the card lists the rare conditions currently being studied. If any doctor has seen a child affected by one of these conditions they tick a box on the card and send it back. The BPSU informs the research team who send the doctor a short confidential questionnaire asking for more information. Researchers are not told the names and addresses of patients, and families are not contacted.

What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 100 rare conditions which may affect children. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

Who to contact if you have any questions:

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