

Information for families

Great Ormond Street Hospital for Children NHS Foundation Trust

This information sheet from Great Ormond Street Hospital (GOSH) explains about the research we do and how to find out more.

Research can improve children's lives, offering new ways of treating diseases or developing new medicines. For some families where there is no existing treatment, research may offer some hope of a new therapy. It can help us understand why diseases occur and how to prevent them in the future.

Research can also be about improving the care children, young people and families receive in the hospital. Some research directly benefits the people taking part, but other research is longer-term so may help people in the future. Our philosophy is that research is a key part of developing better care.

The research we carry out at GOSH is only possible because our children, young people and families volunteer to become involved. All our research projects are checked by an independent panel of experts (a Research Ethics Committee) to make sure that the research is necessary, of a high standard and will be carried out

with the necessary safely checks.

"We wanted
to make sure
we were involved in
the most cutting edge
genetic tests."

Georgia, aged 4, and her family took part in a genetic study



Did you know?

In 2014-5, staff
undertook over 200
research studies of
medicines or therapies
with children at
GOSH.

"I joined the
trial to help me and
my family with my genetic
condition. Being in a trial is
fun, you get to do fun things
and the injection and blood tests
only take a few minutes and
then the rest is all fun."

Lottie, aged 10 years took part in a kidney study with her brother Ashley who is 9 years old

Did you know?

Research takes places in over 50 specialties at GOSH every year.

Who does research at GOSH?

All grades and groups of staff are involved in research to

some level – we also have some staff who only work on research studies. It is likely that whichever ward you visit or team you see, a number of them, the people ordinarily looking after you, will also be involved in a research study.

Did you know?

Over 3000 patients
take part in
research at GOSH
every year.

What could taking part involve?

take place and what

it might involve.

This depends on the type of research project, some involve just a questionnaire, others a sample such as saliva (spit), urine, blood or an X-ray or imaging scan. Some studies for instance of a new medicine, will involve more visits and checks on safety and whether it is working. Study visits will aim to coincide with routine clinical visits but where more visits are needed, often travel and other reimbursements may be offered. The researcher will be able to tell you where the research project will

Hearing about research opportunities

We are keen to highlight to you research studies that may be relevant to your child. So you may be approached by a member of staff during your visit or stay to discuss research. The researcher will give you as much information as you want about the study and answer any questions. If everyone is in agreement, a formal consent will take and when possible, your child will be asked if he/she is willing to take part.

Nearly always, there will be plenty of time for you to consider this carefully and talk to others about it before reaching a decision. However and in rare situations, for instance for studies in critically ill children, the doctors and nurses will have worked with the independent Ethics Committee to understand how to ensure participating families can provide consent.

The decision whether to take part or not is entirely up to you. Whatever you decide, we respect that decision and it will not affect your child's care at GOSH at any point, now or in the future.

Alice, aged 11,
took part in a trial to
find out if a drug licensed
for use in adults would also
work for children. It needed
to be tested to see if it was
effective in the smaller doses
needed for children without
causing serious side
effects.

Finding out about our research

If you are interested in finding out more about the research we are doing at GOSH or want to ask about a particular research project, please speak to your child's clinical team.

For more general information about research, you can also look at our website at www.gosh.nhs.uk/research-and-innovation or call our Research and Innovation team on 020 7905 2700.

You can also
follow us
on Twitter –
@GreatOrmondSt
and hashtag
#GOSHresearch



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www.gosh.nhs.uk/research-and-innovation