

The addresses of the four Supra Craniofacial Units, set up by the National Commissioning Group (NCG) which is part of the NHS, are:

Alder Hey Children's Hospital
Eaton Road, West Derby
LIVERPOOL, L12 2AP
Phone: +44 (0)151 252 5025

Birmingham Children's Hospital
Steelhouse Lane,
BIRMINGHAM, B4 6NH, UK.
Phone: +44 (0)121 333 8147

Great Ormond Street Hospital for Children
Great Ormond Street,
LONDON, WC1N 3JH
Phone: +44 (0)207 813 8444

Oxford Children's Hospital
LG1 West Wing
John Radcliffe Hospital
OXFORD OX3 9DU
Phone: +44 (0)1865 231085

The NCG website is
www.ncg.nhs.uk

Some of the information included in this leaflet
is extracted from the NCG web-site.

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Registered Charity No 1058461
www.headlines.org.uk

Other leaflets and help are available from **Headlines** - Craniofacial Support.
Please contact Gil Ruff (Group Administrator) for details.
tel: 01454 850557 or email: gilruff@headlines.org.uk

Headlines Information Sheet No 6



National Commissioning Group (NCG) and the Four Designated Craniofacial Units

NCG is part of the NHS. They are responsible for funding, managing and developing 'specialist services'. They advise the Ministers on arrangements for the provision of highly specialised services and on the funding required for those services, which are funded centrally and overseen by NCG.

There are four centres, nationally designated, to provide specialist services for Children and Adults born with Craniofacial problems in the United Kingdom

- Birmingham Children's Hospital
- Great Ormond Street Hospital, London
- Oxford Children's Hospital
- Royal Liverpool Children's Hospital (Alder Hey)

The purpose of the nationally designated service is to make sure that anyone affected by a Craniofacial condition can be seen by an appropriate hospital. Below is the directive, issued by the NCG, which defines who should be referred to one of the designated units:

The craniofacial surgery service provides assessment, surgical and non-surgical treatment and long-term follow-up of patients with congenital deformities of the skull and face. Around 330 complex procedures are undertaken per year.

This service has been nationally designated and commissioned since April 1988 on behalf of the residents of England, Scotland, Wales and Northern Ireland.

There are five main groups of congenital conditions managed by the centres for which corrective surgery is required:

- craniofacial clefts - defects in the bones of the base of the skull
- craniofacial dysostosis - complex disorders of the skull and face with typical ('syndromic') features due to abnormalities of the sutures (joints) between the bones of the skull (e.g. Apert's, Crouzon's, Pfeiffer's, Saethre-Chotzen, Muenke Syndromes)
- craniosynostosis - premature fusion of the sutures of the top of the skull (e.g. sagittal, unicoronal, bicoronal, metopic, lamboid and total synostosis)
- encephalocele - protrusion of brain membranes and tissue through an opening in the skull
- overgrowth or undergrowth of bones of the skull resulting in orbital dystopia (excessive width between the eye sockets or eyes at different levels).

The centres may also see children with other complex abnormalities of the skull and face who might benefit from the expertise of the service, e.g. fibrous dysplasia (abnormal bone growth resulting in weakened bone and deformities), severe hemifacial microsomia (asymmetry of the face), and neurofibromatosis (a genetic condition in which benign growths of nerve tissue may lead to progressive facial deformity).

Most patients referred to the service are children under the age of two, but care may continue into adulthood and a few patients are referred for the first time as adults.

The service includes:

- diagnosis and assessment that involves specialist techniques to define the nature of the problem (imaging; genetic studies; assessment of speech, language and swallowing; clinical psychology; ophthalmology; audiology) and the type and timing of surgery as some operations are better performed soon and others need to be planned around the development of the child
- surgery: the main components are neurosurgery, plastic and maxillo-facial surgery, but orthodontics and ENT may also be involved
- non-surgical treatment: clinical psychology, speech and language therapy.

What if you are not at one of the four units, but have one of the conditions, specifically mentioned above?

NCG would like to ensure that all patients with 'qualifying' conditions have access to treatment at one of the four designated units. **Headlines** is well aware that a number of families with such conditions do NOT attend one of these units. It may be because they aren't aware they have that option, or it may be that they are entirely happy where they are, for a variety of very valid reasons.

If you have not yet been referred to one of the designated units and need some help, please contact **Headlines** (see overleaf). Either your GP or Paediatrician can refer you to a Craniofacial Unit (Note: GOSH will not accept a GP referral). They are often not aware that there is no cost to their Primary Care Trust associated with referring anyone with Craniosynostosis or a Craniofacial syndrome to one of these four centres. In fact, the funding for the four centres has already been made available from the overall National Health Budget via NCG.

If you are happy where you are, but after reading all this, you need reassurance that you are being seen by the most appropriate type of hospital, please get in touch with your consultant. Feel free to contact us here at Headlines as well. We would be very interested to hear any comments or concerns you may have on this subject.

NCG are very interested in any feedback we can give them about your experiences at the four units. This is absolutely **NOT** a type of complaints process. It's about highlighting areas of excellence and areas where there is room for improvement and sharing this feedback with the four units, so that hopefully everyone can benefit.

One of NCG's visions is for the four units to provide as equal a service as possible.