



Osteogenesis Imperfecta Service

The Osteogenesis Imperfecta Service comprises a weekly multi-disciplinary clinic, an outreach service and an inpatient service for drug treatment and therapy interventions.

Osteogenesis Imperfecta (OI) is a rare disorder of collagen which commonly presents with spontaneous and unpredictable skeletal fracturing. It is a multi-system disorder which may result in bony deformity, can affect skeletal growth, and may cause pain and low endurance. Dentition and hearing may be affected, and neurological complications can occur.

The OI service aims to support children, their families and local teams where there is a confirmed or suspected diagnosis of OI, offering information and advice on treatment and management from a medical and practical perspective.

The service sees children from birth to 18 years of age. New referrals are accepted for children up to 16 who have a diagnosis or suspected diagnosis of OI. This service is one of four Nationally Commissioned Services for children with rare, severe or complex OI. Patients tend to be mainly from the South East region of the country but those from other regions may be seen.

Referrals

Referrals can be made to Dr Catherine DeVile, Consultant Paediatric Neurologist in the Osteogenesis Imperfecta Service at:
The Wolfson Neurodisability Service
Level 10, Main Nurses Home
Great Ormond Street Hospital
Great Ormond Street
London, WC1N 3JN
Or fax: 020 7813 8279

All referrals must include **written approval from a local paediatrician** who can oversee the child's care post assessment by the OI team.

Prior to acceptance of the referral, further information may be sought. This may include copies of DEXA scans, skeletal surveys and radiology, blood results and outcomes of any genetic consultations or testing.

Direct referrals from GPs, Orthopaedics, Genetics or Endocrinology cannot be accepted and will lead to a delay while we establish a general paediatrician link. Sometimes this may mean that parents need to return to their GP for a referral to a paediatrician.

Team

The Osteogenesis Imperfecta Service team comprises a consultant paediatric neurologist, a consultant orthopaedic surgeon, a consultant paediatric endocrinologist, a clinical nurse specialist, clinical specialist occupational therapists, clinical specialist physiotherapists, a clinical psychologist, and a social worker.

Depending on the questions to be addressed, other staff from the hospital may attend, such as from the pain management team. There is close working with paediatric dental team at the Eastman Dental Hospital. Referrals to the service may be initiated from the clinic. The team also works closely with the Brittle Bone Society.



For more information about the OI team, please see our service information sheet for families.

Assessment

Children may be seen at the clinic when a new diagnosis has been made, offering the opportunity to get to know more about each child and to address particular questions from the child, their family and from their local team. For example, an enquiry about surgical options, or contributing towards confirmation of a diagnosis.

During the clinic appointment, all children will meet with one or more of the clinic consultants and with other team members relevant to their requirements.

Appointments may include medical history or update, physical exam, physiotherapy assessment, and functional assessment. On the day of the appointment, some children will have annual monitoring investigations performed.

Follow-up outpatient appointments may be arranged at the hospital with Physiotherapy, Occupational Therapy or Psychology if a need is identified.

A full report is produced after the assessment, which will be sent to parents, GP, paediatrician, and to other professionals, as agreed at the appointment.

Outreach service

Outreach visits are primarily provided by an occupational therapist or physiotherapist, or both. Children may be visited at home, school or hospital. Whenever possible, visits are carried out with local team members.

Priority will be given when there is a referral of a new baby, if there are urgent management questions for the family and local team. These could include positioning, handling, bathing and advice on suitable equipment for everyday care.

Visits may be made to older children where there are specific questions to be addressed from family or school. These could include moving and handling, special seating, mobility, or management of personal care.

The service aims to work alongside the local services already in place and help increase understanding of some of the specific management.

Following a visit, a report is sent out to the family and relevant members of the local team.

Contact us

At Great Ormond Street Hospital (GOSH), contact the OI Team via our Administration Coordinator on 020 7405 9200 ext 5293.