



# SCH Congenital Diaphragmatic Hernia (CDH) Clinic

Sydney Children's Hospital, Randwick

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## What is congenital diaphragmatic hernia (CDH)?

Congenital diaphragmatic hernia (CDH) is a congenital defect resulting in an opening in the diaphragm, the muscle that usually separates the lungs and chest cavity from the abdominal cavity. Depending on the size of the opening, abdominal organs (such as stomach, intestines, spleen, liver, kidneys) can move into the chest cavity and compress the lungs. The opening can occur on the left or right side of the diaphragm.

As a result of compression by the abdominal organs, the lung on the affected side can be compressed and underdeveloped. The lung on the other side may also be affected. There may also be abnormalities in the blood vessels of the lung.

Babies with CDH are more likely to have another birth defect, including congenital heart defects. After the initial surgery and recovery period, your child may develop medical complications associated with CDH. This may include chronic lung disease requiring ongoing breathing support (such as oxygen) and medication (such as bronchodilators, Ventolin®), gastroesophageal reflux disease, surgical complications (such as recurrence of the hernia and bowel obstruction), feeding and growth issues, skeletal or chest wall deformity, developmental delays, and hearing deficit. Hence long-term follow up care from a team of health professionals, including doctors, nurses, and other care providers (such as dietitians and speech pathologists) is recommended.

## Our Mission

The CDH Clinic at the Sydney Children's Hospital, Randwick is a family centred multidisciplinary clinic which offers comprehensive care to children 0-18 years with Congenital Diaphragmatic Hernia.

As CDH is a life-long condition that affects not only your child's lung, but possibly their heart, their bowel, and their development, hence it is important to assess your child in a holistic manner by a team of health professionals who have a special interest in CDH.

The goal of the clinic is to assess all aspects of your child's medical, nutritional, developmental and psychosocial wellbeing, and systematically screen for possible complications associated with CDH annually. Your usual physicians (including general paediatrician, surgeons and GP) will continue to be your child's primary doctors, coordinating the day to day care of your child.

## Team members

Ms Catherine Sumsky – Respiratory Clinical Nurse Consultant (CNC), Clinic coordinator

Dr Sandra Chuang – Respiratory paediatrician

Gastroenterologist

General surgeons

Referral to other health care specialists (such as cardiologist, orthopaedic surgeons, developmental paediatricians, and allied health professionals (such as dietitians, speech pathologist, social worker and physiotherapist) will be made as required for your child.

### Structure of the Clinic

Clinics will be held on a Thursday afternoon on level 0 in the Children's Outpatient Department at SCH. Your child will be reviewed by Dr Sandra Chuang (Respiratory Paediatrician) and Ms Catherine Sumsky (Respiratory CNC) and other specialists (such as gastroenterologist, paediatric surgeons, or allied health professionals) as required in your child's case.

Investigations to screen for possible complications associated with CDH will be conducted during or close to the time of the **annual** clinic assessment at SCH or at your local hospital (depending on the investigations required):

- If your child is < 5 y.o – chest X ray; hearing test (at 12 months then annually); screening questions on child development; infant lung function tests (in certain cases); gastrointestinal imaging studies (if clinically indicated); heart ultrasound (if clinically indicated).
- If your child is ≥ 5 y.o – chest X ray; lung function testing; exercise testing; skin prick testing for aeroallergens (if clinically indicated); gastrointestinal imaging studies (if clinically indicated); heart ultrasound (if clinically indicated).

It would be helpful if you bring your child's Blue Book and any previous documentations / correspondences regarding your child's health on the day of your child's clinic visit.

### New Patient and Follow up Appointments

All parents can contact Ms Catherine Sumsky (Respiratory CNC, CDH clinic coordinator) to arrange an appointment for their child with CDH. A referral made to Dr Sandra Chuang from your local GP (preferred) or specialists such as paediatrician, neonatologist, or surgeon is required.

### Transport cost

Any transport costs would need to be met by the individual families or assistance from state agencies will be sought. For those in NSW who live more than 200km away, there is a support scheme called IPTAS (Isolated Patients Transport and Accommodation Services) to help. Local paediatricians, physicians, and GPs can fill this request which is signed by the specialist in Sydney.

**Please do not hesitate to contact us if you have any questions regarding the clinic**