

- ☐ Please add me to the mailing list to receive copies of the free quarterly publication, LungNet News
- ☐ Tick this box if you would prefer to receive the LungNet News electronically
- ☐ **Please note:** Lung Foundation Australia and/or its partners/agents may contact you occasionally regarding educational opportunities, research, events, fundraising, promotions and special offers. If you do not wish to receive this additional contact and only wish to receive our quarterly LungNet News, please tick the box
- ☐ Please send me information about becoming a financial member of Lung Foundation Australia

☐ I would like to make a tax deductible donation of \$ \_\_\_\_\_

☐ CHEQUE/MONEY ORDER

Payable to: Lung Foundation Australia  
PO Box 1949, Milton, QLD 4064

☐ CREDIT CARD

Card Type: ☐ Visa ☐ Mastercard ☐ AMEX

Name on card: \_\_\_\_\_

Card No: \_\_\_\_\_

Card Expiry: \_\_\_\_\_ CVC Number: \_\_\_\_\_

Signature: \_\_\_\_\_

If you would like to make a donation via our website, please visit [www.lungfoundation.com.au](http://www.lungfoundation.com.au) and click on the *Donate* button.

Donations of \$2.00 or more are tax deductible. A receipt will be issued.



medications include: anti-inflammatory medications, steroids, methotrexate and hydrochloroquine.

Oxygen may be needed either during activity, sleep or all of the time, depending on the severity of symptoms. The oxygen is supplied in a pressurised bottle and inhaled via either a tube in the nose or a mask that covers nose and mouth. If the child cannot breathe then a mechanical ventilator that assists or replaces breathing is necessary. In very rare cases the only treatment option might be a lung transplant.

The length of treatment depends on how the disease progresses. In many cases it is difficult to predict the long-term outcomes for children with chILD. More research is needed to learn more about this group of rare and often serious childhood diseases.

It is important for children to be fully vaccinated according to the National Immunisation Program and to have annual influenza vaccination to prevent infectious diseases which can have serious health consequences for children with chILD.

#### Useful resources and parent support

There are no specific support groups set up for children with chILD and their families. TLung Foundation Australia provides information and support to patients with all kinds of lung diseases and advocates on their behalf. Please call the Lung Foundation's Information and Support Centre on 1800 654 301 (toll free)

#### Internet resources you may find useful:

##### Lung Foundation Australia

[www.lungfoundation.com.au](http://www.lungfoundation.com.au)

##### American Thoracic Society

[www.patients.thoracic.org/information-series/en/resources/interstitial-lung-disease-in-chILDren.pdf](http://www.patients.thoracic.org/information-series/en/resources/interstitial-lung-disease-in-chILDren.pdf)

##### ChILD Foundation (USA)

[www.chILD-foundation.com](http://www.chILD-foundation.com)

##### ChILD Lung Foundation (UK)

[www.chILDlungfoundation.org](http://www.chILDlungfoundation.org)

##### National Immunisation Program Schedule

[www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/nips-ctn](http://www.immunise.health.gov.au/internet/immunise/publishing.nsf/Content/nips-ctn)

This brochure is one in a series produced by Lung Foundation Australia to provide information on lung disease, its treatment and related issues.

The content for this brochure on chILD was developed in collaboration with the Australian Paediatric Surveillance Unit (APSU) according to latest research information available at the time of printing.

The APSU conducts national surveillance for rare diseases including chILD. To learn more please visit: [www.apsu.org.au](http://www.apsu.org.au)

The information published by Lung Foundation Australia is designed to be used as a guide only, is not intended or implied to be a substitute for professional medical treatment and is presented for the sole purpose of disseminating information to reduce lung disease.

Any information relating to medicine is correct at the time of printing. Lung Foundation Australia has no control or responsibility for the availability of medicine which may occasionally be discontinued or withdrawn.

Please consult your family doctor or specialist respiratory physician if you have further questions relating to the information contained in this leaflet.

For details of patient support groups in Australia please call 1800 654 301.

✉ Lung Foundation Australia  
PO Box 1949  
Milton Qld 4064

📞 Toll Free: 1800 654 301

💻 Website: [www.lungfoundation.com.au](http://www.lungfoundation.com.au)

Lung Foundation Australia ABN 36 051 131 901 Liability of Members Limited

## Children's Interstitial Lung Disease (chILD)

Information for Parents



*"When you can't breathe... nothing else matters"*®



*"When you can't breathe... nothing else matters"*®



Australian Paediatric Surveillance Unit



TD1214V2KILD

Advocacy • Awareness • Education • Support • Research

### What is Children's Interstitial Lung Disease (chILD)?

Children's Interstitial Lung Disease (chILD) is the name given to a group of rare diseases of the lung that occur in infants, children and adolescents. It may also be called chILD Syndrome or children's Diffuse Lung Disease. "Interstitial" refers to the part of the lung where oxygen from air is absorbed into the blood. In chILD this absorption of oxygen is impaired, resulting in difficulty breathing and decreasing the oxygen supply to other organs in the body.

### Diseases that are in the chILD group of diseases

- Alveolar capillary dysplasia
- Neuroendocrine cell hyperplasia of infancy
- Genetic surfactant protein deficiency
- Desquamative interstitial pneumonitis
- Chronic pneumonitis of infancy
- Hypersensitivity pneumonitis
- Pulmonary interstitial glycogenosis
- Idiopathic interstitial lung disease

**It is not known exactly how rare chILD is. Each type of disease in the chILD group is very rare.**

**For example, four in a million children have the disease called Hypersensitivity Pneumonitis.**

### What causes chILD?

In most cases it is difficult to determine the exact cause as there are many different causes of chILD. Some types of chILD are caused by genetic defects. In such cases the disease might also be present in other family members, but in other cases the faulty gene might only occur in the child with the disease. chILD can result because the lungs have not developed properly. This can occur in both babies born at term and babies born premature. A few types of chILD are caused by sensitivity to bacteria, chemicals or other particles in the air but these types of chILD are very rare. Doctors and researchers are just beginning to understand more about chILD and more research is needed.

### Signs and symptoms of chILD

Since there are many types of chILD the symptoms and severity vary widely. ChILD is a chronic disease, which means that children tend to have symptoms constantly for a long period of time and symptoms can get worse over a number of months or years. Symptoms may also be worse when the child has a chest infection (colds and flu) or when exposed to high air pollution (e.g. dust, cigarette smoke, smoke from forest fires).

#### Common signs and symptoms:

- Fast breathing (tachypnea)
- Chronic cough (either constant or it comes and goes often)
- Shortness of breath with physical activity or exercising

#### Other signs and symptoms are:

- Abnormal enlargement of the tips of the fingers or toes (clubbing)
- Frequent chest infections



- Abnormal chest sounds heard via a stethoscope (wheezing/crackles)
- Poor weight gain or growth (failure to thrive)
- Using muscles between the ribs or in the neck when breathing (retractions)

### How severe is chILD and what are the outcomes?

How bad the disease is and what course it takes is different for every specific type of chILD and can even vary widely among children with the same type of chILD. Some cases are very mild and over time symptoms disappear without treatment while some cases are very severe and children may need to be on oxygen all of the time. Sometimes symptoms of varying degrees will remain for life. In the majority of cases children with chILD do improve and are able to lead normal lives. However, some forms of chILD do result in death (eg. 100% in babies with surfactant B deficiency).

### How is chILD diagnosed?

Diagnosing chILD is usually difficult because these diseases are rarely encountered, and the symptoms and severity vary enormously. Sometimes a precise diagnosis can be obtained after genetic testing. In many cases of chILD it is not possible to give a precise diagnosis and the types of the chILD disease may never be known. In addition to a physical examination and careful medical history of the child and family, the doctor might request tests such as:

- Chest X-ray and/or CT scan of the chest
- Blood test (sometimes including genetic testing)
- Lung function test (requires the child to be old enough to cooperate)
- Lung biopsy (removal of a small piece of lung, can confirm the exact disease but as it requires surgery it is usually only performed when symptoms are severe or getting worse)
- Bronchoscopy (passing of a tube down the throat under anaesthetic) and bronchoalveolar lavage (washing up of any secretions in the airway)
- Sweat test (to exclude cystic fibrosis)
- Overnight sleep test (to monitor breathing and oxygen in the blood)

Some or all of these tests might be necessary depending on the symptoms and severity.

### How is chILD treated?

Treatment depends upon the specific type of chILD and the severity of symptoms. Currently there is no treatment that will cure chILD but treatments can be used to lessen symptoms. The most common treatments are drugs that open the airways in the lungs or suppress inflammation some examples of

*"When you can't breathe...nothing else matters"®*

## Like more information?

Please complete both sides of this tear-off form and post to:

Lung Foundation Australia  
PO Box 1949, Milton, QLD 4064

Or fax to: 07 3368 3564

First Name \_\_\_\_\_

Surname \_\_\_\_\_

☐ Dr ☐ Prof ☐ Mr ☐ Mrs ☐ Ms ☐ Miss

Address \_\_\_\_\_

Suburb/Town \_\_\_\_\_

State \_\_\_\_\_ Postcode \_\_\_\_\_

Phone \_\_\_\_\_ Mobile \_\_\_\_\_

Email \_\_\_\_\_

I am a ☐ Patient ☐ Health Professional  
☐ Carer ☐ Other

What is your lung condition?

\_\_\_\_\_