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**Useful resources and parent support:**

There are no specific support groups set up for children with chILD and their families. Lung 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
- **American Thoracic Society**
- **ChILD Foundation (USA)**
  www.chILD-foundation.com
- **ChILD Lung Foundation (UK)**
  www.chILDlungfoundation.org
- **National Immunisation Program Schedule**

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

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 current 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Australia has no control or responsibility for the availability of medicine which may occasionally be discontinued or withdrawn.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.

**Medications include:** anti-inflammatory medications, steroids, methotrexate and hydroxychloroquine.

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.

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What causes chILD?

In most cases it is difficult to determine the exact cause as there are many different causes of chILD. Some may be 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 (other constant or it comes and goes often)  
- Shortness of breath with physical activity or exercising  
- 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 (e.g. 100% in babies with surfactant B deficiency).

How is chILD treated?

Treatment depends upon the specific type of chILD and the severity of the 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