

## Young Lungs Community Consultation – Outcomes Report

### **Background**

Approximately 50% of all acute paediatric illness affects the respiratory system but apart from asthma and cystic fibrosis, Australia offers very little in the way of information and support services specifically for families who have a child with a chronic or rare lung disease. It is acknowledged that there are newly formed organisations to help children with specific rare diseases such as congenital diaphragmatic hernia and primary ciliary dyskinesia, but there is no overarching coordinated approach in Australia.

While Lung Foundation Australia has previously developed some educational brochures on paediatric lung disease such as: 'Interstitial Lung Disease in Children' and 'Understanding Cough, Wheezing and Noisy Breathing in Your Child' the Foundation does not have a specific program that focuses on paediatric lung disease, in particular rare or chronic lung diseases.

In 2015, Lung Foundation Australia will establish a 'Young Lungs' national program as our first paediatric specific program. This program will be led by Professor Adam Jaffe, a paediatric Respiratory Specialist and Chair of the Young Lungs Clinical Advisory Group. Lung Foundation Australia held the inaugural Young Lungs meetings in Sydney at the Randwick Children's Hospital.

The meetings were held on Saturday 28<sup>th</sup> February to coincide with international Rare Disease Day and consisted of two meetings being:

1. the formation and first meeting of the Young Lungs Clinical Advisory Group
2. a Young Lungs community consultation.

This report focuses on discussion and outcomes from the community consultation.

The Young Lungs program will work with health professionals, families and disease-specific organisations for improved outcomes for all paediatric rare lung diseases.

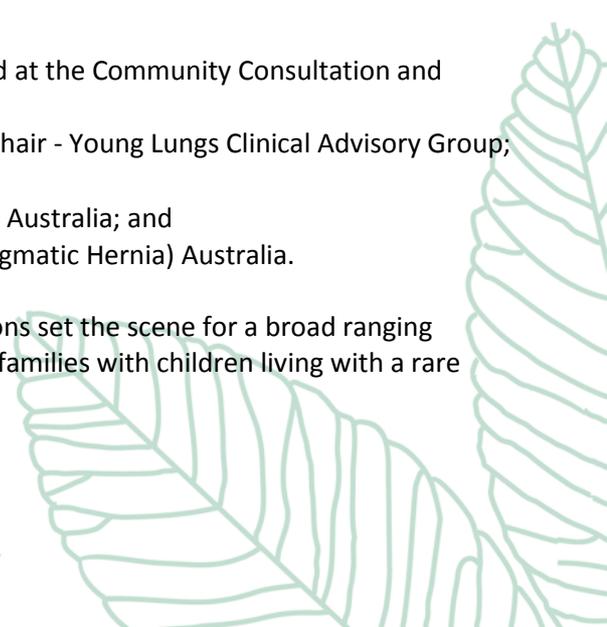
### **Introduction and acknowledgements**

Lung Foundation Australia would like to thank all attendees for their active participation in the Young Lungs Community Consultation. The Young Lungs Clinical Advisory Committee found it to be a very valuable experience and the feedback and advice received from the parents, disease-specific rare lung disease organisations and health professionals will form the basis of the Young Lungs program's short and long term goals.

Lung Foundation Australia would like to thank those who presented at the Community Consultation and gave their generous time to support this initiative:

- Professor Adam Jaffe – Paediatric Respiratory Specialist, Chair - Young Lungs Clinical Advisory Group;
- Ann Gettys – Director of the chILD Foundation US;
- Catherine Kruljac – CEO of PCD (Primary Ciliary Dyskinesia) Australia; and
- Margaret Polacska – President of CDH (Congenital Diaphragmatic Hernia) Australia.

Heather Allan, CEO Lung Foundation Australian and the presentations set the scene for a broad ranging and robust discussion about the information and support needs of families with children living with a rare lung disease.



### **Young Lungs – Forming a Community Coalition**

An important aspect that formed the discussion and was carried over from the Young Lungs Clinical Advisory Group was the role of Lung Foundation Australia in this space especially given there are already some established paediatric lung disease-specific organisations that the Foundation would look to work with and respecting their history.

Heather Allan, CEO noted Lung Foundation Australia saw their role as the provider of broad information and support services, a referral point where a specific group or organisation exists, and importantly this platform also creates a united voice for advocacy messages across the paediatric rare lung diseases in Australia.

In addition, Lung Foundation Australia envisages that disease-specific organisations could benefit from the Lung Foundation's infrastructure and experience in helping smaller support groups or organisations. Working closely with the organisations that are already established and empowering others as the need is identified for further paediatric lung disease-specific groups.

Fundraising was also discussed as a key topic of interest. Lung Foundation Australia will undertake broad fundraising when a common initiative or focus is developed. It was acknowledged that the individual paediatric lung disease-specific organisations would maintain their specific focused fundraising efforts with all funds raised maintained by that individual group.

### **Young Lungs Community Forum - Facilitated Discussion Key Points**

The facilitated discussion provided an opportunity to hear what stakeholders in the paediatric rare lung disease space saw as the most pressing unmet needs. This section of the report aims to summarise the common themes highlighted by health professionals, families and disease-specific rare lung disease organisations.

These outcomes have been split into two distinct sections, namely: *Information* and *Support*.

#### ***Information***

- Trustworthy literature and reputable evidence-based resources.
- A directory of what is available to families who are living with a child diagnosed with a rare lung disease, this may include:
  - Experts;
  - Access to medications devices (e.g. oxygen);
  - Support services; and
  - List of available and practical support, including:
    - financial support;
    - social worker/case manager; and
    - peer support



- A guidebook for families living with a child with a rare lung disease including:
  - Mapped out clinical pathways (e.g. how to navigate the journey);
  - A glossary of common related medical terms translated into layperson language to reduce misunderstandings, anxiety and fear of the unknown;
  - Practical advice on how to manage the needs of a child with a rare lung disease;
  - How to work with your doctor regarding your child's rare lung disease; and
  - Questions to ask your child's doctor.
- Moderated Online Forums and webinars including:
  - FAQs (both disease specific and generic)
  - Q and A sessions with specialists/social workers/physiotherapists etc.
- Educating doctors to raise awareness of the various rare lung diseases. This could potentially be done through an internet portal or intranet.
- A community nurse in each State who could champion paediatric rare lung disease issues and provide one-to-one support/information to their peers and families of children with a rare lung disease.

## Support

- A network to link parents of children with rare lung diseases.
- Vertical and horizontal peer support programs:
  - Vertical support would involve someone who has been through the experience before mentoring/supporting someone new to parenting a child with a rare lung disease and in turn that person going on to mentor another.
  - Horizontal support would involve people sharing their experiences as they go through them together.
- Holistic family support programs including:
  - Sibling support and/or educational material for siblings of children with a rare lung disease;
  - Specific support for fathers;
  - Camps (such as SNUG through the Steve Waugh Foundation or Camp Breakaway);
  - Respite care that allows parents to take a break (a dinner out or a movie) that also covers childcare for all the children, not just the sick child.
- Support for teenagers with a rare lung disease such as:
  - Educational material and support for preparing for the transition to adult care;
  - An online space for teenagers with a rare lung disease (similar to 'Live Wire'); and
  - Online gaming for teenagers with a rare lung disease (e.g. chILD Minecraft).
- Conferences where health professionals, disease-specific groups and parents can all meet and share information (this could also be an opportunity for the children/teens to meet up).
- Those speaking on behalf of disease-specific rare lung disease organisations suggested support in setting up support groups, infrastructure, advocacy and promotion.

## **Conclusion**

This report was designed to capture key discussion points and messages from Lung Foundation Australia's young lungs community consultation. This consultation will assist with setting possible goals on which the Young Lungs program will focus its efforts.

The Young Lungs program will seek funding through grants and sponsorship and many of the suggestions provided at the Community Consultation will be dependent on securing these funds. However, the development of information and other practical resources can begin development immediately.

Lung Foundation Australia will call for consumer (parents/children) feedback on developing resources and initiatives and will be sure to keep Consultation attendees up to date with any new activities undertaken by the Young Lungs Program.

For more information about the Young Lungs National Program or this consultation please contact Lung Foundation Australia on 1800 654 301 or [enquiries@lungfoundation.com.au](mailto:enquiries@lungfoundation.com.au)

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