



**THE BRITISH PAEDIATRIC ORPHAN LUNG DISEASE REGISTRY
UNDER 8 PATIENT INFORMATION SHEET**

Please ask for a translation or interpreter if you wish

What is the BPOLD Register and why is it being set up?

BPOLD stands for British Paediatric Orphan Lung Disease. We call some very rare lung problems “Orphan” diseases because they don’t get so much care and attention as common lung problems like asthma.

We want to help people like you have these rare lung problems by asking for some details to be kept on a computer.

This would help doctors to look after children like you better.

We are inviting you to be on this list.

What will happen now if I agree to be on the BPOLD Register?

Your doctor will give a small amount of information about you to the BPOLD doctors to put on their computer. The only information that will go on the computer will be:

- Your hospital number
- Your name initials
- When you were born
- The names of your doctor and your hospital
- The chest problem that you have

This is all that we are asking from you at present.

What will be done with this information and what may happen later?

We have some doctors called researchers who may want to use this information to try and help you and other children like you.

Do I have to take part?

No. If you don't want your name to be on the BPOLD register you don't need to do anything else. Your decision not to take part will not upset anyone.

Can I have my details taken off the Register?

Yes. If you change your mind at any time you can tell your mum and dad or doctor.

Can anyone find my name from the BPOLD register?

No. Even if someone managed to break into the computer, they would only see jumbled letters and have to have a special code which is a secret.

Who do I speak to if problems arise?

If you have any complaints then your mum and dad can speak with one of the doctors who is in charge. His name is Dr Steve Cunningham.

Another person to contact is Emma Pendleton. Your mother and father will be given their details.

Thank you for reading this.