

# The Red Shoe Story

Leicester PCD Management Team

Information for Patients, Parents and Carers



University Hospitals of Leicester  
NHS Trust



*Caring at its best*

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## Introduction

This booklet has been produced to explain how genetic conditions such as Primary Ciliary Dyskinseia (PCD) and Cystic Fibrosis (CF) are passed on from the parents to their child.

The Red Shoe Story is part of the Leicester PCD Education Programme to help children and their families to understand PCD.

PCD is a rare genetic condition affecting approximately 1:15,000 compared with CF which is approximately 1:2500.

CF is an inherent autosomal recessive condition. PCD is predominantly but not exclusively, inherited via the autosomal recessive route.

### So what does all this mean?

Let's start with explaining some of the words.

**Inherited** means it has been passed on from the parents to the child through the genes.

**Genetic condition** occurs when there has been an alternation or change in a gene.

**Genes** are sets of unique instructions which make us who we are. Genes come in pairs and we get one copy from mum and one copy from dad.

**Autosomal** means that these conditions can affect boys and girls equally.

**Recessive** means that the child has an alteration in both copies of their genes, passed from their parents.

Let me explain this by telling you the **RED SHOE STORY**

**1 RED SHOE + 1 RED SHOE = A PAIR OF RED SHOES**

## Introduction

Imagine both mum and dad each have **One Red Shoe** – the **red shoe represents the part of a gene that as an alteration in its instructions**. It is like when you spell a word which looks right but is not correct. The instructions to make the shoe are correct but the detail to get the colour of the shoe right is altered or faulty, hence creating a **Red Shoe**.

However because the parents both also have a **Black Shoe**, the **black shoe** 'overshadows' the **red shoe**. This means the parents are both carriers (they each have one copy of the altered gene) but they do not have the condition.

Each time these parents have a child together, the chance or probability of two red shoes getting together is 25% or 1 in 4.

**One Red Shoe** + **One Red Shoe** = **A pair of Red Shoes**

Having a pair of Red Shoes gives you two copies of the altered or 'faulty' gene; one from each parent. This means the child will have the condition.

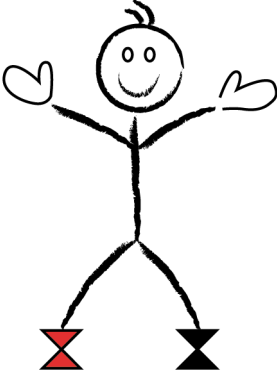
Equally there is a 25% or 1 in 4 chance the child could inherit two black shoes, which means they do not have the condition and are not carriers of the altered gene.

However, there is a 50% chance that the child could inherit one black shoe and one red shoe. This would make them carriers for the condition because the one black shoe 'overshadows', the red shoe and prevents the condition.



# The Red Shoe Story

Dad

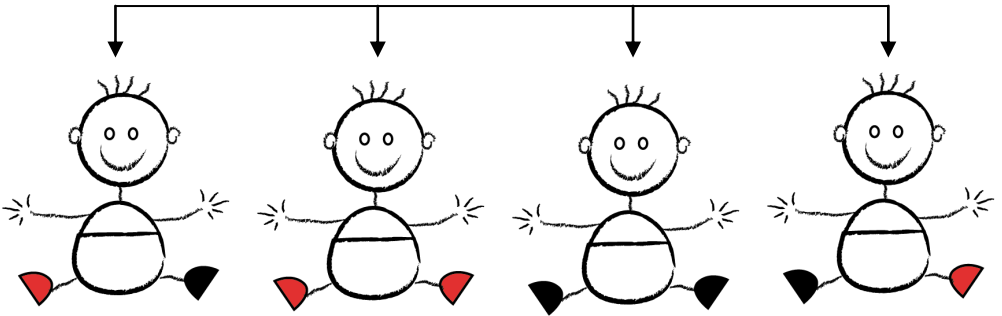
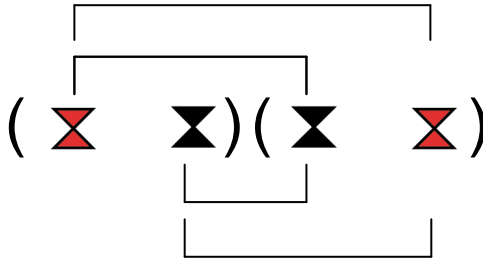


Mum



+

Both parents have **one RED SHOE** each. This makes them both carriers for PCD or CF



**Carrier**  
**25% chance**

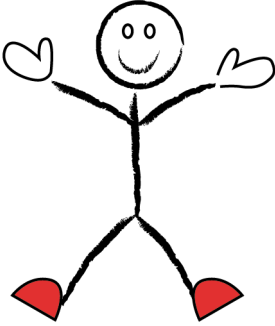
**A pair of Red Shoes**  
**25% chance**

**No PCD or CF**  
**25% chance**

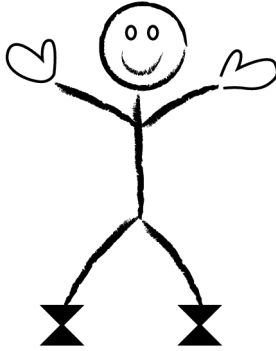
**Carrier**  
**25% chance**

# Passing on the **Red Shoes**

You

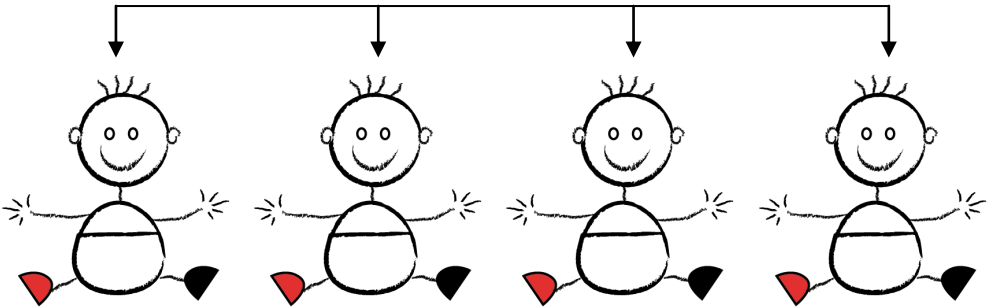
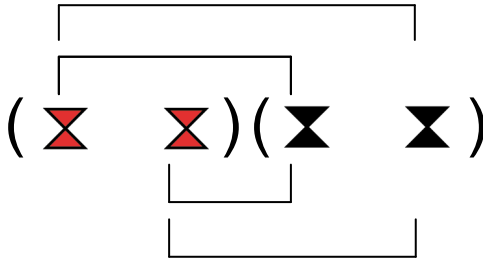


Partner



+

Does not have PCD or CF and is not a carrier.  
**No Red Shoes**

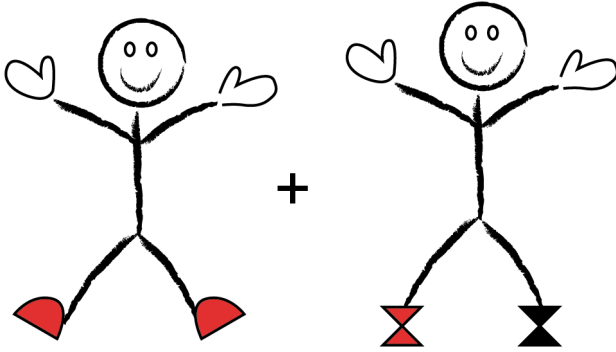


All carriers, each child has one **Red Shoe**

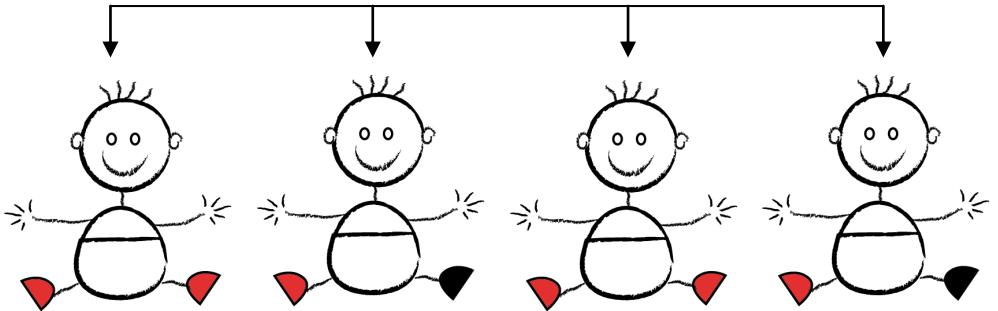
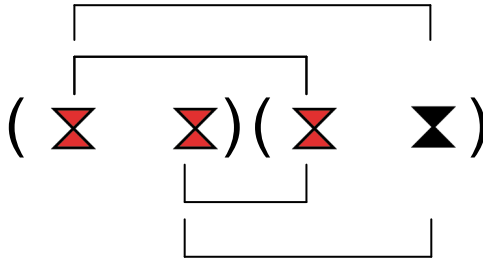
# Passing on the Red Shoes

You

Partner



Does not have PCD or CF but is a carrier.  
**One Red Shoe**

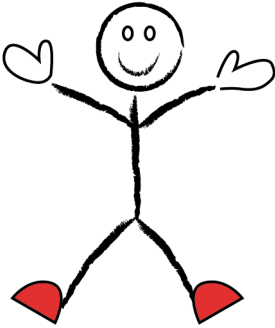


50% chance of having PCD or CF **Has a pair of Red Shoes**  
50% chance of being a carrier **One Red Shoe only**

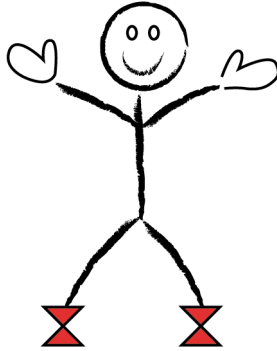
# Passing on the Red Shoes

You

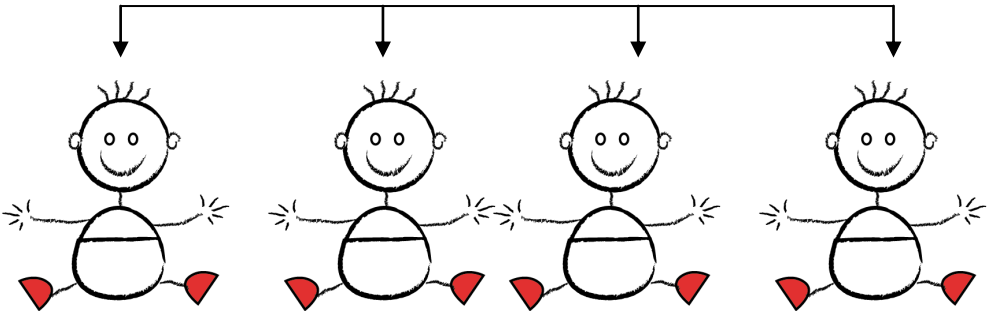
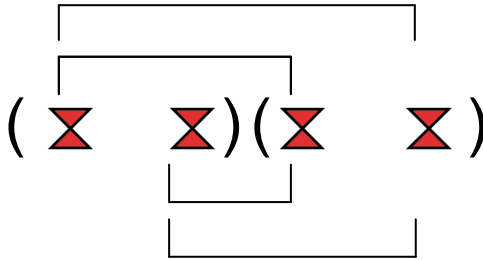
Partner



+



Has PCD or CF.  
Has a **pair of Red Shoes**

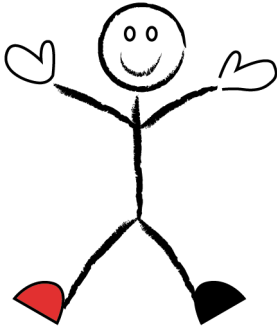


100% chance of having PCD or CF  
**Each child has a pair of Red Shoes**

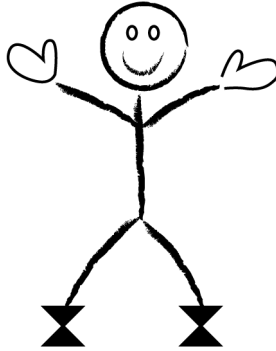


# Your Child: Passing on the Red Shoes

**YOUR CHILD;  
CARRIER  
ONE RED SHOE**

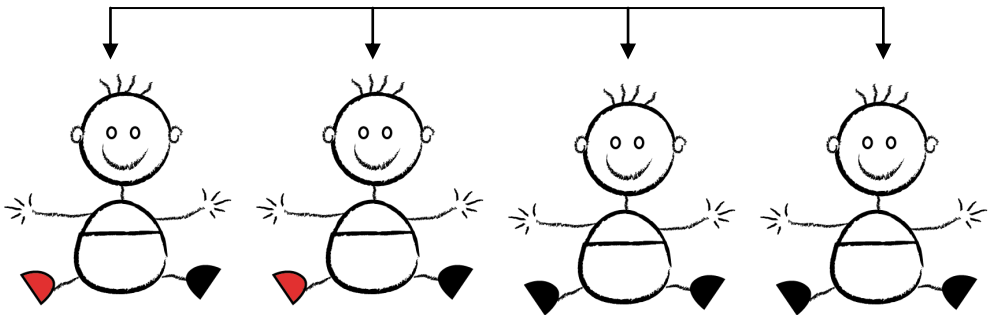
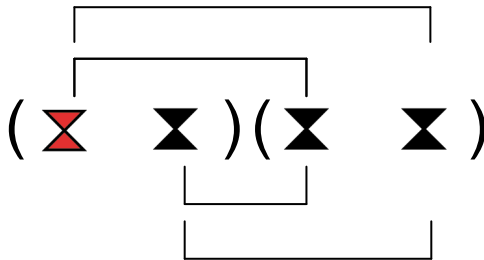


**Partner**



+

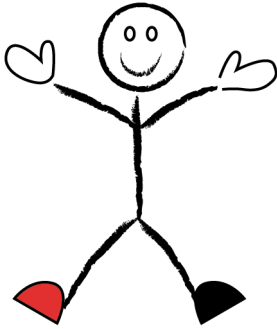
No PCD or CF.  
Not a carrier  
Does not have  
any Red Shoes



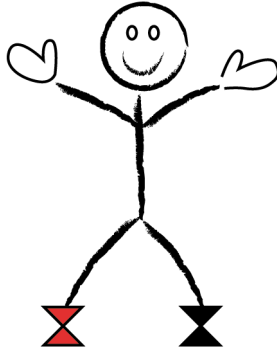
50% chance of being a carrier **Has one Red Shoe**  
50% chance of No PCD or CF **Has a pair of black shoes**

# Your Child: Passing on the Red Shoes

**YOUR CHILD;  
CARRIER  
ONE RED SHOE**

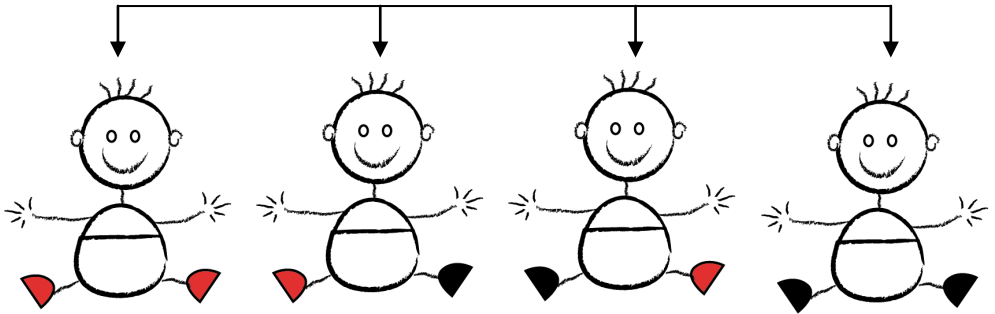
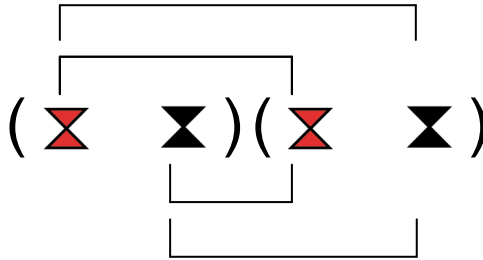


**Partner**



+

Carrier of PCD  
or CF  
Has one Red  
Shoes

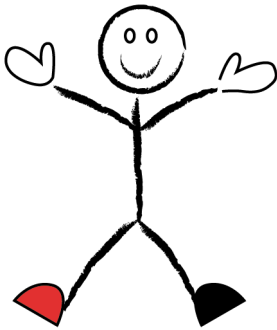


25% chance of PCD or CF Has a pair of Red Shoes  
50% chance of being a carrier Has one Red Shoe  
25% chance of no PCD or CF Has a pair of black shoes

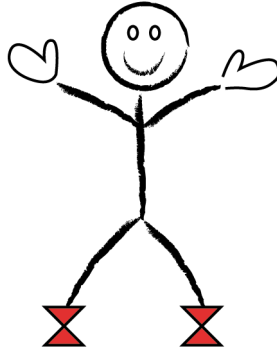
# Your Child: Passing on the Red Shoes

**YOUR CHILD;  
CARRIER  
ONE RED SHOE**

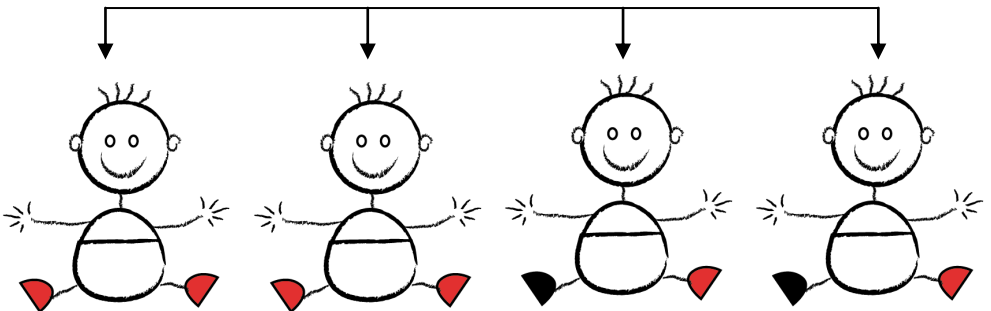
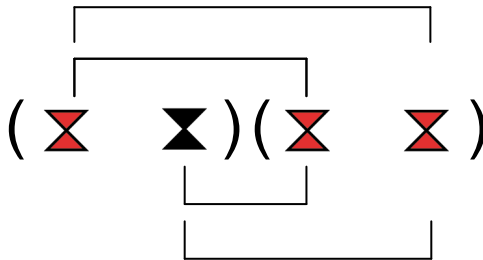
**Partner**



+



Has PCD or CF  
Has a pair of Red Shoes



50% chance of PCD or CF **Has a pair of Red Shoes**  
50% chance of being a carrier **Has one Red Shoe**



## Today's research is tomorrow's care

We all benefit from research. Leicester's Hospitals is a research active Trust so you may find that research is happening when you visit the hospital or your clinic.

If you are interested in finding out how you can become involved in a clinical trial or to find out more about taking part in research, please speak to your clinician or GP.

**If you would like this information in another language or format, please contact the service equality manager on 0116 250 2959**

إذا كنت ترغب في الحصول على هذه المعلومات في شكل أو لغة أخرى ، يرجى الاتصال مع مدير الخدمة للمساواة في 0116 250 2959.

আপনি যদি এই লিফলেটের অনুবাদ - লিখিত বা অডিও টেপ'এ চান, তাহলে অনুগ্রহ করে সার্ভিস ইকুয়ালিটি ম্যানেজার ডেভ বেকার'এর সাথে 0116 250 2959 নাম্বারে যোগাযোগ করুন।

如果您想用另一种语言或格式来显示本资讯，请致电 0116 250 2959 联系“服务平等化经理” (Service Equality Manager)。

જો તમને આ પત્રકાનું લેખિત અથવા ટેપ ઉપર ભાષાંતર જોઈતું હોય તો મહેરબાની કરી સર્વિસ ઇક્વાલિટી મેનેજરનો 0116 250 2959 ઉપર સંપર્ક કરો.

यदि आप को इस लीफलेट का लिखती या टेप पर अनुवाद चाहिए तो कृपया डेव बेकर, सर्विस इक्वालिटी मैनेजर से 0116 250 2959 पर सम्पर्क कीजिए।

Jeżeli chcieliby Państwo otrzymać niniejsze informacje w tłumaczeniu na inny język lub w innej formie, prosimy skontaktować się z Menedżerem ds. równości w dostępie do usług (Service Equality Manager) pod numerem telefonu 0116 250 2959.

ਜੇਕਰ ਤੁਹਾਨੂੰ ਇਸ ਲੀਫਲਿਟ ਦਾ ਲਿਖਤੀ ਜਾਂ ਟੇਪ ਕੀਤਾ ਅਨੁਵਾਦ ਚਾਹੀਦਾ ਹੋਵੇ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਡੇਵ ਬੇਕਰ, ਸਰਵਿਸ ਇਕੁਅਲਿਟੀ ਮੈਨੇਜਰ ਨਾਲ 0116 250 2959 'ਤੇ ਸੰਪਰਕ ਕਰੋ।

Ak by ste chceli dostať túto informáciu v inom jazyku, alebo formáte, kontaktujte prosím manažera rovnosti služieb na tel. číslo 0116 250 2959.

Haddaad rabto warqadan oo turjuman oo ku duuban cajalad ama qoraal ah fadlan la xirii, Maamulaha Adeegga Sinaanta 0116 250 2959.