

WHY DO I STILL GET INFECTIONS EVEN THOUGH MY TROUGH LEVELS ARE GOOD?

The purpose of this leaflet is to try to explain why some people with a Primary Antibody Deficiency (PAD) or Secondary Antibody Deficiency (SAD) still get ill, even when they are having Immunoglobulin Replacement Therapy (IGRT). Immunoglobulin is another name for antibodies, IGRT is made from donations of other people's immunoglobulins.

So, why do people living with an antibody deficiency still get more ill **than those with a properly working immune system**, even when they have good trough levels? An immune system **which is working properly** is incredibly clever and from immunoglobulin it can make specific antibodies which can recognise what the bug is, and exactly what shape it is. It then makes an antibody which latches on to the bug - a bit like two pieces of a puzzle fitting together. It then kills the bug it is attached to; and another part of the immune system swallows the dead bug and gets rid of it. However, the bug too is very clever and once it has got into our bodies, it multiplies, making more and more of itself until it makes us ill. However, **a properly working immune system** is even more clever and it keeps on making those specific antibodies until the bug is removed completely

- Firstly, because there is only a certain amount of specific antibody in their replacement IgG and when the body has used it up, it cannot make any more to kill off the invading bugs. Replacement IgG therapy **only has antibodies to the bugs which the donors have come into contact with**.
- Secondly, people living with a serious antibody deficiency do not produce any or enough other classes of immunoglobulin. There are some bugs that cannot be killed without other types of Ig. What is more, each dose of IgG will contain a certain amount of antibodies and once they are all used up, they will not be topped up until the patient has their next infusion. Levels of antibodies are highest immediately after an intravenous infusions (IVIG), or 2 days after a Subcutaneous Infusions (SCIG) and get lower until the next infusion is given. This is why a blood test is taken regularly, to see how much of the IgG the patient has used up. This is called the **trough level test**
- Thirdly, people who have been ill for a long time before they are diagnosed, may well have damage to some of their organs and this damage makes it easier for invading bugs to make people ill. Without treatment, people living with a serious antibody deficiency will carry on getting infection after infection. Each time a serious infection happens, in the sinuses, lungs or gut, these organs get damaged and this damage can never be made better. Having damage to an organ means that bugs are able to find a

UK Primary Immune-deficiency Patient Support

Mobile: 07531 076409 **Email:** info@ukpis.org.uk **Website:** www.ukpis.org.uk

UKPIPS is a Registered Charity in England, Scotland and Wales - Charity Numbers **1148789** and **SCO44636** **UKPIPS** is a Company Limited by Guarantee Number **7957558**

UKPIPS Factsheet No. 038

safe place to “make their home” and to multiply safely where antibodies cannot get to them very easily. Many people living with an antibody deficiency have to wait about seven years after they start to get ill before they are diagnosed and treated. Many of them will have badly scarred sinuses, bronchiectasis (permanent damage caused to the lungs) or damage to their gut. Any of these will make people more likely to get an infection.

Diagnosis and good levels of treatment for a someone with serious antibody deficiency **will not usually make them as well as people with immune systems that work properly**, because immunoglobulin replacement therapy (IGRT) does not replace all of the actions of a working immune system. However, with good trough levels and using antibiotics that our clinical immunologists prescribe for us, most people will be much more well after they have been diagnosed than they would be without this treatment.

© UKPIPS Ltd, 2019

Publication Reference: ID038 v.1 Publication date: 1st December 2019

Next review date: 1st December 2022

For details of information sources, contact info@ukpis.org.uk

UK Primary Immune-deficiency Patient Support

Mobile: 07531 076409 **Email:** info@ukpis.org.uk **Website:** www.ukpis.org.uk

UKPIPS is a Registered Charity in England, Scotland and Wales - Charity Numbers **1148789** and **SCO44636** **UKPIPS** is a Company Limited by Guarantee Number **7957558**