More information on insurance and genetic conditions can be found on the **Genetic Alliance UK** website, specifically:

- · Insurance, family history and genetic testing
- · Code on Genetic Testing and Insurance
- · Refusal of insurance cover

Insurance companies

Below are some of the insurance companies that people have previously gained cover from or that Immunodeficiency UK has spoken to and they have agreed to consider cover for patients on a case-by-case basis.

 Aviva
 0800 068 5549

 LV
 0800 678 1890

 Pulse Insurance
 01280 841430

The following companies have stated that they will consider insuring patients with pre-existing medical conditions:

 Aston Lark
 020 7543 2833

 Claybrooke
 0203 150 1349

 The Insurance Surgery
 0800 083 2829

 Your Life Protected
 01275 404 268

 Reassured
 0808 256 5894

Reassured is a life insurance broker with a team that specialises in finding insurance for those who are considered a higher risk and more difficult to insure. It will compare quotes to find the cheapest policy.

Other useful information

You can find answers to frequently asked questions on life insurance at www.gocompare.com/life-insurance/frequently-asked-questions/

A consumer guide for patients thinking of taking a genetic test and who wish to know how it may affect their insurance is available at www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetic-testing/

The British Medical Association has worked with the Association of British Insurers to compile a pack that includes a standard covering letter for insurers to send to GPs and an overview of the types of information that are relevant to different types of insurance. The pack can be accessed at www.bma.org.uk/advice/employment/ethics/confidentiality-and-health-records

You can find information on travel insurance on our website at www.immunodeficiencyuk.org

About Immunodeficiency UK

Immunodeficiency UK is a national organisation supporting individuals and families affected by primary and secondary immunodeficiency.

We are the UK national member of the International Patient Organisation for Primary Immunodeficiencies (IPOPI), an association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for patients worldwide.

Our website at www.immunodeficiencyuk.org provides useful information on a range of conditions and topics, and explains the work we do to ensure the voice of primary and secondary immunodeficiency patients is heard.

If we can be of any help, please contact us at hello@immunodeficiencyuk.org or on 0800 987 8986, where you can leave a message. Visit www.immunodeficiencyuk.org for further information.

Support us by becoming a member of Immunodeficiency UK. It's free and easy to do via our website at www.immunodeficiencyuk.org/register/ or just get in touch with us. Members get monthly newsletters.

Immunodeficiency UK is reliant on voluntary donations. To make a donation, please go to www.immunodeficiencyuk.org/donate

Registered charity number 1193166. First edition October 2021.

IMMUNO DEFICIENCY UK

Supporting families affected by primary and secondary immunodeficiency

Life insurance

Life insurance

www.immunodeficiencyuk.org hello@immunodeficiencyuk.org 0800 987 8986



Supporting families affected by primary and secondary immunodeficiency Life insurance is a way to protect your loved ones financially when you die. It works similarly to other insurance products you may have, such as home or motor insurance. The insurer provides you with an agreed level of cover in exchange for a fee. When you die, the insurer pays a sum of money either to your named beneficiaries or your estate.

When calculating the price you pay (the premium) for a life insurance policy, an insurance provider will take several factors into account. These include:

- vour age
- any pre-existing medical conditions you have
- your general health at the time the policy is underwritten
- whether or not you are a smoker
- the level of cover you require.

The provider collects this information from your completed application form and from any medical evidence that it gathers as part of the standard application process. Insurance underwriters then assess the information and try to establish the level of risk they are taking in insuring you – basically, the likelihood that they will have to pay out a claim on the policy you are looking to set up with them. The higher the risk, the higher the premium will be. Having a pre-existing medical condition, such as an immune deficiency, will also increase an insurance premium.

Life insurance premiums are person-specific

Life insurance is unique to a person's circumstances, so there are no hard and fast rules as to who a company will insure or what the premium will be. Our advice is to shop around to find a competitive quote.

A comparison website is a good place to start. **Compare the Market** has an excellent guide to life insurance policies for people with pre-existing medical conditions. You will also find a list of recommended companies at the end of this leaflet.

When you have a pre-existing medical condition, the number of insurance providers willing to cover you is limited, and this in itself can mean higher premiums. It is important to declare all your pre-existing medical conditions to ensure that you are covered and that your family will be financially secure when you die.

What questions will you be asked?

All life insurance providers will ask you questions as part of the application process. The types of questions you can be expected to answer are as follows:

- What is your age, your weight and height? Generally, the older you are, the more your premium will be. You may also be asked for your trouser/dress size.
- Describe your lifestyle. Do you smoke? How much alcohol do you drink (if any)? What kind of exercise do you take (if any)?

Being a smoker automatically increases your premium. You will also be asked if you take part in any high-risk activities, such as sky diving and rock climbing.

- Are there any major health problems in your family?
- Do you have any pre-existing medical conditions? If yes
- When was your condition diagnosed?
- What was the exact diagnosis/name of your condition?
- What parts of the body have been affected in the last five years?
- What are your current symptoms?
- How frequently do symptoms occur on average (e.g. daily/monthly/yearly)?
- When did you last suffer any symptoms?
- How would you describe your symptoms (mild/moderate/severe)?
- What treatment have you received in the last five years?
- Are you receiving treatment now? If so, what is the name of your medication and the dosage?

Explaining your current treatment is important because it shows that your condition is treatable. With your permission, the insurance company may request a letter from your consultant to seek further information on the treatment you receive and its effectiveness.

Will you need a medical examination?

You may be required to attend a medical examination conducted by your GP or an independent medical practitioner at the insurance company's expense. This will give you the opportunity to explain your condition and how it affects you, and will provide the insurance company with information to help it reach a decision.

What to do if the insurance company has not heard of primary or secondary immunodeficiencies?

If your condition is uncommon, it is more difficult for an insurance company to insure you. The company may consult its chief medical officer or other experts. It may also request information from your GP or consultant to better understand the risk and your condition. An insurance company will always ask for your permission to contact your GP or consultant. Insurance companies employ medical doctors to help them with unusual and difficult cases.

Once you have got life insurance, you are not required to advise the company of any new treatment unless it specifically requests this. If at a later date you take out a new life insurance policy, then you will need to disclose to the insurance company the new treatment you receive. Receiving treatment can have a positive effect on your insurance premium. If the treatment works well, then providers may charge you less.

If you are awaiting the results of any tests or investigations, you should declare this, stating the date and the nature of the test. You do not need to declare any predictive genetic test results. Predictive genetic testing is the use of a genetic test in an asymptomatic person to predict future risk of disease. See the important information below on declaring genetic testing.

Declaring genetic testing

If you have undertaken genetic testing for a new condition and the result comes back 'positive' but you are not showing any symptoms of the condition, then currently you do not have the disease and you do NOT need to disclose the result of this predictive genetic test to the insurance company. The only exception is in the case of a predictive genetic test for Huntington's disease if the life insurance cover is for over £500,000.

Participating in research projects, including the 100,000 Genomes Project, will not affect insurance premiums in most cases. If you are taking part in the 100,000 Genomes Project, then this link will answer any questions you may have on how the project may or may not affect your cover: www.genomicsengland.co.uk/the-100000-genomes-project/insurance/