

Other staff

Receptionists

Receptionists play a vital role in keeping the practice running but can sometimes appear uncooperative. Stay calm and remain polite. Tell them that you have a serious condition and that there is an alert on your notes. Explain that Dr X or Dr Y is familiar with your case and that you need to speak to them if no appointments are available. Most practices have a policy for emergency appointments, so do ask for one. If you feel that a medical problem is developing, seek help sooner rather than later. It is better to ask for help on a Thursday morning than late on a Friday afternoon.

Practice nurses

Get to know the nursing staff at your practice. They are usually responsible for immunisations and for monitoring long-term health conditions, such as diabetes and hypertension. It may be helpful to provide your GP practice with the contact details for your immunology nurse, who can give specialist advice.

Pharmacists

Pharmacists may query prescriptions, particularly if you are prescribed high doses of antibiotics for long periods or unusual combinations of drugs. It is helpful to always visit the same pharmacy, to get to know the pharmacist and share with them any prescribing information from your GP or hospital specialist.



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 (IPOP), 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. Second edition October 2022.



Supporting families affected by primary and secondary immunodeficiency

Working with Immunodeficiency UK, AmDel Medical and Koru proudly support all patients with an immune deficiency in the UK and Ireland

AmDel
Medical
A James Lyon & Co. Company

GP practice

How to work with your GP practice

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



Supporting families affected by primary and secondary immunodeficiency

Your GP is a vital part of your healthcare team and it is important to have a strong doctor-patient relationship. This leaflet offers advice about how to develop and maintain a good relationship with your GP as well as other practice staff.

The average GP practice has 8,757 patients on their list (NHS Digital, October 2019). The average person sees their GP about six times a year. For some GPs, a 12-hour working day is typical – their time spent consulting with patients, dealing with correspondence, interpreting lab results, issuing prescriptions, arranging referrals, and so on.

GPs are well trained and knowledgeable about common health issues. They are often familiar with conditions that cause secondary immunodeficiencies, even if they're not fully aware of all the implications of being immunodeficient. GPs, however, tend to be less informed about primary immunodeficiency disorders (PIDs). A reason for this is that PIDs are rare.

According to the British Society for Immunology, about 5,000 people in the UK have a PID. The incidence of CVID is between 1 in 25,000 and 1 in 50,000 of the general population, and for other PIDs the incidence is much lower. Therefore, a GP can spend their whole career without ever seeing someone with a PID.

If you have been diagnosed with a PID, then you may be better informed about your condition than your GP. But remember that your GP is highly experienced in looking after your overall health needs, addressing your concerns and implementing management plans.

How to find a GP practice

In England, you can search for your nearest GP practices by entering your postcode on the Care Quality Commission (CQC) website (www.cqc.org.uk). Immunodeficiency UK suggests you only register with a practice that is rated either outstanding or good.

Aim for a positive relationship

When registering with a GP practice, request that your named accountable GP is a permanent member of the practice who is not about to retire or take extended leave. For your first meeting, it is a good idea to ask for a double appointment. You may not always be able to see your named GP, so get to know two or three GPs at the practice and allow them to become familiar with your medical history and needs.

Ask for your notes to be flagged

This simple request will trigger an alert every time your notes are accessed and remind all staff at the practice that you have a significant condition and should be given quick and easy access to a GP.

Keep a folder containing your hospital notes

Ask your hospital clinicians to copy you in on all correspondence, then file it in a dedicated folder. Similarly, ask your GP for a printout of the notes that they hold about you and make sure you have the most up-to-date version if anything changes. Take the folder to all your GP appointments, along with any guidelines your consultant may have given, for example antibiotic prescribing protocols. Also have your folder ready in case you need to attend A&E or if you see any other healthcare professionals, such as your dentist.



Take notes at each appointment

During each appointment, jot down information that your GP shares with you about your condition and make sure you understand what is said. Take a relative or friend with you to an appointment if you think this would be helpful.

Educate your GP

Direct your GP to the Immunodeficiency UK website (www.immunodeficiencyuk.org) or take to your appointments any Immunodeficiency UK leaflets that are relevant to your condition. We have leaflets on specific PIDs and secondary immunodeficiencies, and a booklet for GPs.

Stay positive!

Your GP is your advocate. They can liaise with your specialist team, provide advice about your general health, manage any other conditions you may have and be supportive. A good relationship with your GP is beneficial and achievable.