Hello PID UK members,

We hope you are all well and looking forward to springtime as much as we are.

In recognition of Rare Disease Day this newsletter focuses on recent advances in the diagnosis and treatment of PIDs as well as updating you on all our activities in working on your behalf. We hope you enjoy reading it!

We also want to share the wonderful news that PID UK is the UK national member of the International Patient Organisation for Primary Immunodeficiencies (IPOPI). It is as an important landmark in recognition of our work over the last twenty months.

Thank you for your valuable support.

With all best wishes,
From the PID UK team.

PID UK out and about

Over the last few months of last year we attended many regional PID patient meetings, where we had the pleasure of meeting many patients to tell them about the work we do, as well as the chance to talk to medical professionals about the important issues affecting patients. These included several meetings of the Immune Deficiency Patient Group of Wales, the North West Regional Immunology patient day, the Oxford University Hospitals and John Radcliffe patient day and a patient/GP engagement event for Birmingham Hospitals. We were delighted that Hannah and Drew, two young members of our patient representative panel, were invited to give their perspective on living life with a PID at two of these events. You can read their inspirational stories here.

Oxford University Hospitals and John Radcliffe Patient Day
Ask the experts

If you have a question about your PID then get in touch with us.

Can I make a difference to my PID condition by changing my diet?
Diet, exercise and lifestyle can make a difference. Healthy eating is good for everyone as is exercise. Diet can affect the microflora in the body and this may affect how the bowels work. Dietary changes may help some patients who suffer from inflammatory bowel disease (IBD).

I have a PID and been on long-term steroids and worried about osteoporosis, weight gain and cholesterol levels?
Doctors when they prescribe steroids carefully weigh up the benefits versus health risks. They will carefully monitor your health and tailor the doses given and will keep them at the lowest level needed to give clinical benefit. Calcium and vitamin D supplements may be recommended to help prevent bone thinning (osteoporosis).

Are there any plans for gene therapy for XLA?
There are no clinical trials of gene therapy for XLA at present. However, there is quite a bit of work ongoing in the laboratory and so trials may start in the not too distant future.

I’m on immunoglobulin (Ig) therapy but I have been getting a lot of infections lately. Is this normal and why does this happen?
Ig replacement therapy should protect against the common circulating bacteria and viruses but some common viral infections do not generate good lasting protective antibodies or these are not helpful in preventing recurrence, for example of the common cold. Patients with underlying lung, ear or sinus disease (e.g. bronchiectasis) may still get infection from infectious reservoirs in those tissues. Occasionally trough Ig levels dip for a variety of reasons. If the infections need further antibiotic therapy this should be discussed with your immunology team.

How do I know that I am receiving immunoglobulin frequently enough and at the right quantity?
Doctors will look at how often you have an infection (infection frequency) and the levels of immunoglobulin in your blood just before an infusion, to make sure its adequate (trough level). It’s a good idea to keep a diary of any infections you have. This will help your doctors and nurses understand how your immunoglobulin treatment is working.

What more do we know about the causes of CVID?
This is a complex group of patients. We know that 10 genes can cause CVID but for the vast majority of patients the cause is not known. About 90% of CVID are caused by sporadic genetic changes. Clinicians and researchers are starting to unravel the genetics of CVID using faster and cheaper ways of sequencing the DNA of patients.

Why is it vital to keep your lungs as healthy as possible when you have a PID?
To prevent them deteriorating, by limiting the damage caused by infection and inflammation.
Volunteer focus

Drew is a member of our Patient Representative Panel (PRP). He gives his reasons on why he is helping PID UK.

‘Hello! I was diagnosed with CVID aged 9 after becoming critically ill over an 18 month time period. However, skip to 2015 and now aged 27 you wouldn’t even consider I was ‘sick’ when you look at me. I couldn’t say no when I was offered the chance to work with PID UK as I remember the lack of knowledge and worse still, the isolation I felt when growing up with this condition. I wanted to work with PID UK to help patients learn to manage their condition, but more importantly see they are not alone.’

Drew is a patient representative for the London area.

Would you like to be a PID UK volunteer?

Do you think you can help PID UK in some way? We’re always looking for volunteers to help us improve the services we offer. Whether this is by helping us improve the content of our website in an area you are passionate or knowledgeable about, or by providing us with a few hours each week to offer specialised support to our members in areas you are familiar with such as benefits.

If so please contact us at hello@piduk.org.

Trouble with your employer? Our volunteer Michelle can offer you advice on human resources issues and employment law if you’re having trouble at work. Michelle is a qualified Human Resources professional. To ask her a question email hello@piduk.org

Information, information, information

New on the PID UK website

Check out our new patient information sheets on:

- IgG subclass deficiencies
- Selective IgA deficiency
- Antibiotics and PID
- Immunoglobulin therapy

Take a look at our

- Frequently asked questions on XLA and CVID.
- Resources for children and young people.
- Information on fungal molds and PIDs.

HyQvia - a new subcutaneous immunoglobulin treatment for adult patients has been launched in the UK.

Want to find out more? Visit our website for answers to frequently asked questions about this new product.

Your story can help other patients. We’re always looking for more patient stories to help inspire others. If you’d like to add your story to our website please email hello@piduk.org
A simple test boosts rates of new CVID diagnoses

A team of Immunologists and Biochemists working at the Immunodeficiency Centre for Wales, have tweaked a commonly performed blood test to enable screening for antibody deficiency.

The test is called ‘calculated globulin’ and uses information from a commonly requested test assessing liver function. The test’s usefulness has already been shown in Welsh and UK centres where it has boosted rates of new CVID diagnoses, with the additional bonus of identifying several early stage blood cancers.

‘We see calculated globulin screening as a simple means of identifying people who may have a primary antibody deficiency (PAD) so shortening any diagnostic delay’, said Dr Ponsford, on behalf of the team. The work has been published in the journals Clinical and Experimental Immunology and the Annals of Clinical Biochemistry.

Dr Jolles takes up the story. ‘The diagnosis of primary antibody deficiency (PAD) and particularly CVID, the most common type of PAD in adults, is challenging for the medical profession as there may not be a strong family history to prompt early investigation. There is an average delay of over 7 years from symptoms to diagnosis and over that period there is a significant risk of lung and sinus damage becoming irreversible. This is clearly not acceptable, so we knew we had to make improvements in the way we identify PAD patients. Our strategy was to develop a laboratory-screening test.’

‘Approximately 2 million blood tests for liver function are carried out in Wales to provide information on the level of proteins produced by the liver (mainly albumin) as well as the total protein content of the blood. The difference between total protein and albumin content is known as the globulin fraction and includes antibodies. This difference is referred to as ‘calculated globulin’ and has been used in medical practice until now to look for high levels of antibody, such as in myeloma but - until now - nobody had thought to screen for a low level that would signifying an antibody deficiency’.

‘This approach has several attractive aspects. It is part of a widely used blood test, allowing opportunistic screening of patients to prompt doctors or laboratory staff to investigate further with more accurate tests including antibody levels and early specialist referral. Moreover, because most liver panels already include total protein and albumin - it's free!’ said Dr Ponsford.

So are there any limitations of the test? (continued on page 5)

Dr El-Shanawany comments ‘The globulin fraction includes ‘acute-phase reactant’ proteins which are produced in greater levels during times of stress or infection and these could potentially mask a low immunoglobulin level. Also the test is not specific for PADS, it will also pick up what we call secondary immunodeficiencies. These are conditions where antibody levels may be low due to drugs, cancer or protein loss. However, we see this as an important, extra outcome of this simple screen’.

‘Early results have also suggested some patient groups who might be at higher risk of antibody deficiency, including treatment with drugs not previously associated with antibody deficiency and this an area we are actively investigating’ said Dr Jolles.

With thanks to: Dr Mark Ponsford, Academic Core Trainee, Dr Stephen Jolles and Dr Tariq El-Shanawany, Consultant Immunologists, Immunodeficiency Centre for Wales.

Stem cell transplants and CVID

A recent publication in the *Journal of Allergy and Clinical Immunology* has brought together results from 14 centres worldwide on the outcomes of using stem cell transplants for people with CVID.

Twenty-five patients with CVID, aged 8 to 50 years old, who had serious health complications and who were not responding well to more conventional treatments such as immunoglobulin treatment and anti-inflammatory drugs at the time of transplantation were included in the analysis.

The study covered the period 1993 to 2012 and found an overall survival rate of 48% with the survival rate for patients undergoing transplantation for lymphoma of 83%.

‘Clearly there was a high mortality rate associated with this procedure and we need to consider carefully which patients might best benefit from stem cell transplant going forward’, said Dr Claudia Wehr, lead-author on the paper.

‘This will involve extensive examination of the immunologic and/or genetic defect underlying the CVID diagnosis. We are hopeful that recent refinements of transplantation protocols and optimising the timing of transplant will help improve outcomes for this group of patients’.

Have you or your child had a stem cell transplant?

Then PID UK would like to hear from you about your experience. Susan, mum to Josh has already shared their story with us to help other parents who are thinking of this treatment.

Please get in touch with us at hello@piduk.org.
Dr Andrew Gennery, Consultant in Paediatric Immunology and Haematopoietic Stem Cell Transplantation (HSCT) at the Great North Children’s Hospital shares the latest information on transplantation for PIDs.

**New HSCT techniques**

Two new techniques were described. In an oral presentation, Dmitry Balashov, from Moscow, described a method of removing the majority of T cells from a mismatched marrow, but leaving behind T cells which help counter viral infection. Previously, transplantation for patients without a well-matched donor was difficult, particularly if they had severe pre-transplant infection. Using this transplantation technique in 25 PID patients a survival rate of almost 90% and no severe graft versus host disease was reported. In addition, a poster from our Newcastle group described 4 patients transplanted using this technique, all of whom survived.

Work by Isabelle André-Schmutz and colleagues from IMAGINE Institute, Paris is helping address the problem of severe immune deficiency present in the first few weeks following transplant, by trying to accelerate immune reconstitution. They are doing this using a soluble chimeric protein to induce the early T-cell commitment of cord blood stem cells infused after the initial transplant. The preclinical studies have been very encouraging, and clinical trials are now planned.

**Importance of large datasets**

Virginie Courteille, on behalf of the IEWP, presented the latest data from the largest worldwide PID transplant registry, known as the SCETIDE database. A total of 3747 transplants were reported between 1968 and 2013, (a third of which were performed for patients with SCID), demonstrating the power of such a large dataset to perform detailed and meaningful analyses.

**Transplant for adolescents and young adults**

Emma Morris from University College, London, and Michael Albert from Munich reported important studies of HSCT for PID in adolescents and young adults. Both groups showed excellent outcomes in this patient group, which is traditionally considered difficult to treat, offering real hope for older patients with severe PID.

**Transplant for specific PID conditions**

A number of studies addressed outcome of HSCT in specific diseases. Francesca Ferrua, on behalf of IEWP, presented an impressive preliminary outcome of 64 patients undergoing HSCT for CD40L deficiency in Europe between 1993-2013 in 18 different centres. Overall survival was 78%, and 88% in transplants performed after the year 2000.
Professor Andrew Cant becomes the first British President of ESID

Professor Cant, Consultant in Paediatric Immunology and Infection at the Royal Victoria Infirmary in Newcastle, gives us his thoughts on taking up this important role.

‘Can I firstly congratulate PID UK on a very successful inaugural year. I am honoured and delighted to be the first British President of the European Society for Immunodeficiencies (ESID). I am sure this is a tribute to the vibrant, clinical and research PID community within the UK and it is no coincidence that there are so many members of ESID in the UK. It is very exciting to be involved in PID at a time when our understandings are accelerating at an unprecedented rate. At my first ESID meeting in 1990 I understood the molecular basis for only 2 PIDs, now over 200 have been elucidated! At the same time treatment has improved remarkably. We perhaps forget that IVIG was only introduced in the 1980’s and subcutaneous immunoglobulin within the last 15 years. Which means patients enjoy much longer and healthier lives, with SCIG bringing flexibility for easier home treatment. At the same time bone marrow transplantation has become much safer and successful, curing 90% of PID patients undergoing this procedure, and revolutionising the quality of life and life expectancy for patients with conditions such as Chronic Granulomatous Disease and Wiskott Aldrich Syndrome.

Great achievements, but still so much to do. We need to harness the new genetic breakthroughs to ensure quick, accurate, diagnoses and then corrective treatments that are close to 100% safe and successful as possible, whether that is gene correction, gene therapy or stem cell transplantation with new techniques that eliminate the risks of graft versus host disease and infection. In these days when the importance of patients, nurses, doctors and scientists working closely together is finally recognised, the close working relationships between ESID, the international nursing group INGID, and IPOPI offer a tremendous opportunity to ensure high quality patient centred services that make a real difference to people’s lives.’

Professor Andrew J Cant.

ESID update on HSCT (continued from page 6)

Other studies looked at single centre results for transplant of X-linked SCID using parental haplo-identical grafts, where there is a 50% match to the patient, and HSCT for patients with activated PI3K-Delta Syndrome, and GATA2 deficiency.

Finally, a number of single case reports were presented. Michael Albert described a woman who was a carrier for X-linked Chronic Granulomatous Disease, who underwent successful transplant for CGD-like complications including inflammatory bowel disease. Other case reports included HSCT for Griscelli Type-2 syndrome, LRBA deficiency, DOCK8 deficiency, and MHC II deficiency. Whilst not remarkable in themselves, these were described by centres in Turkey, Tunisia and Mexico, demonstrating the on-going purpose of ESID to educate, and share knowledge, to serve our patients, wherever they live, and improve outcomes for these rare diseases.

Dr Andrew Gennery
Campaign for full clinical immunology services in Lothian region.

The Lothian (Edinburgh) area of Scotland does not have a Consultant Immunologist leading and coordinating PID patient care. The position, left vacant due to retirement over five years ago, has never been filled. In 2013 promises that the position would be advertised have not come to fruition.

PID UK has been working over the last year to help rectify the situation and working with Genetic Alliance UK, PID UK were delighted to have the opportunity to put our concerns to the Cross Party Group on Rare Diseases meeting on the 18th November at Holyrood, the Scottish Parliament.

At the event, Rae McNairney, our patient representative for Scotland, spoke about PID UK’s current campaign assisted by patients in Lothian. Rae explained the current situation: very ill patients were having to travel considerable distances and due to lack of transitional arrangements patients in their mid 20’s are still being cared for by a Paediatric Consultant. Rae asked that NHS Lothian engage and consult with patients and patient organisations to form their plans for a robust immunology service for patients and before they make any appointment.

Several patients then gave their own personal stories of how the lack of a robust immunology service is impacting on their health. Their powerful testimonies were strengthened further by Dr Laura Jones, a Paediatric Consultant at the Royal Hospital for Sick Children, who outlined how the service operates at present and what is needed to provide a full immunology service for patients at NHS Lothian. Dr Jones answered a number of questions, all of which highlighted the urgent need for this position to be filled.

The outcome from the meeting was that Malcolm Chisholm MSP will continue to raise the matter with his colleagues. A formal communication will be sent to the Health Secretary from the Cross Party Group tofollow up on this issue. The Genetic Alliance UK Policy Group will be working to see how they can assist the campaign and PID UK will be working actively with them to resolve this important issue for patients.

Read more about this campaign here.

Rae McNairney,
PID UK patient representative for Scotland

Rae also represented PID UK at the Specialised Healthcare Alliance (SHCA) Parliamentary Reception at Holyrood, Edinburgh in November.

The meeting discussed services for people with rare and complex conditions and the future opportunities and challenges they face and the progress made following publication of the Scottish Implementation Plan for Rare Diseases.

Here is Rae’s update:

‘The meeting was sponsored by Annabel Goldie MSP and I took the chance to talk with to give her some background of PID UK. John Murray, Director of SHCA, set the scene by giving the results of their mini survey showing the main challenges ahead for services are budgets, increasing demand, complex needs and access to treatment. This was followed by a speech by Alex Neil, MSP, the then Cabinet Secretary for Health & Wellbeing. He talked about the importance of tackling delayed diagnosis and how difficult it is for GP’s to make a diagnosis, not because of knowledge, but because a GP may only see one to three patients with a rare condition in their professional lifetime. However, he was optimistic about the future with new technology being developed by Edinburgh’s Digital Health Institute. Although some years away, the principle is based on having databases of every rare condition aligned with applications that help doctors identify people with a rare disease. Alex Neil also spoke about the Scottish Government’s New Medicines Fund. In pledging an extra £40million, steps could be taken on new medicines that would benefit rare disease patients. Overall there was a keen desire to see action, as well as oversight, in the delivery of implementation plan for rare diseases’.
Guest article: The contribution of genetics to the understanding of CVID

By Dr Natalie Frede and Professor Bodo Grimbacher from the Centre for Chronic Immunodeficiency, University Medical Centre, Freiburg.

Common variable immune deficiency (CVID) is considered the most common symptomatic primary immunodeficiency.

In the majority of cases, CVID occurs sporadically with no other affected family members. However, in about 10% of CVID patients other family members with the same condition are reported, indicating a genetic background of disease.

Due to advances in technology, a growing number of underlying genetic defects have been identified during recent years. Gaining a better understanding of these single gene disorders may help to unravel the mechanisms leading to the development of disease.

During recent years, a number of mutations have been shown to affect the activation of B cells. These B-cells do not develop into antibody-producing cells (plasma cells) as they usually would, so antibody production is reduced and patients have an increased risk for infections. Many of these activation defects are found in proteins on the B cell surface, which play a role in the communication of the immune cells with each other (e.g. in CD19 deficiency, CD21 deficiency or CD81 deficiency).

CVID and T cell defects

However, recently a number of genetic defects have been identified, which highlight the importance of T cells in the development of CVID. T cells, like B cells, are another kind of white blood cells, which belong to the adaptive immune system; whose primary role is to protect us against re-infection. In order to induce antibody production, B cells need assistance from T helper cells. Therefore, T cell defects may also lead to a reduced antibody production, which is a hallmark of CVID. However, having T cells that don't work properly may also have a more serious impact on the regulation of the immune system. For example, this can result in an accumulation of immune cells in the tissue in absence of specific infection triggers such as bacteria, viruses or fungi.

These immune cells may then attack healthy cells and cause chronic inflammation and tissue damage. Patients may then suffer from a variety of autoimmune diseases, gut disease with chronic diarrhea, or lymphoproliferation (non-malignant increase of white blood cell numbers). Therefore, patients with one of these novel genetic defects, such as cytotoxic T-lymphocyte-associated Protein 4 (CTLA4) deficiency or Activated PI3 Kinase Delta Syndrome (APDS) have an increased risk, not only for infections, but also for autoimmunity and inflammation. Continued on page 12.

About the CCI: The Centre for Chronic Immunodeficiency (CCI) at the University Hospital Freiburg in Germany is a unique integrated research and treatment center that has been supported since 2008 by the Federal Ministry of Education and Research. The CCI aims, by integrating experts from different areas, to achieve a better understanding of immune diseases, to allow earlier diagnosis and a better treatment of patients with chronic immunodeficiency diseases.
Taking part in a genetics study

Hannah, one of our patient representatives, is taking part in a study in Oxford to help understand the genetic analysis of immunity and infection. Hannah and the chief investigator of this study Dr Smita Patel, Consultant Immunologist and Dr Fatima Dhall, Specialist Registrar in Immunology at John Radcliffe Hospital, have kindly agreed for PID UK to interview them about this important project.

What’s the aim of the project?

To identify the genes that cause or control conditions that are characterised by a failure of the immune system to function normally. This will help us understand why and how certain infections, PIDs and inflammatory conditions occur.

Why Hannah was happy to take part in this study

"I have always felt that as a patient with a rare condition it is important to take part in any studies that may benefit patients in the future, be it one that may improve understanding and treatment or one that may lead to a cure. Whilst the results found from these studies may not help me personally, if it can lead to helping the next generation of patients receiving treatment for a primary immunodeficiency then I could not pass up the opportunity to take part in the study. My family have the same thoughts as I do, so they had no qualms about also taking part in the study. The fact that taking part only meant having a few mls of blood taken meant that I did not even have to do anything extra during my appointment. Fingers crossed that the results from this investigation will enable progression in understanding of conditions such as mine."

What have Hannah/her family had to do?

After agreeing to take part in the study, Hannah and her parents have each had to have a small amount of blood taken for genetic analysis. Depending on the findings we may ask for further blood samples.

Why have DNA samples also been taken from Hannah's parents? How will the help with the study?

Whole exome sequencing will be performed on Hannah and her parents’ DNA. Since we know that her parents are not affected by the same condition as Hannah we will be able to compare the sequencing results we get for Hannah to those that we get from her parents and this will help us identify possible disease causing mutations.

How are patients chosen to take part in this project?

We select patients in whom we suspect a genetic defect in the immune system that has not been successfully identified using conventional testing. This includes patients with immune deficiency and/or severe or unusual infections, as well as those with inflammation of the gut, joints or skin.

How many people are taking part and how long will it go on for?

We have ethical approval to recruit up to 500 people to the study over 10 years. This includes relatives of patients as well as the patients themselves.
What will the results from this study show you?

For individual patients or families we’ve already been able to identify the genetic mutations causing their conditions. We hope that we will also be able to do this for Hannah and future study participants. From a scientific perspective this study will enhance and expand our knowledge of which genes are important in the immune system and how.

Why is Hannah having her exome sequenced and not her genome, what is the difference?

DNA is composed of a sequence of molecules called nucleotides, designated A, C, G, and T. Mistakes in this sequence are called mutations and these can cause disease. DNA is arranged into genes, which code for and can be translated into proteins, and large areas of non-coding DNA. The genes themselves are composed of exons, the parts of the genes that actually code for proteins, and introns, which contain non-coding DNA.

Whole exome sequencing refers to sequencing all of the exons, or protein coding parts, in all of the genes of an individual. On the other hand, in whole genome sequencing, an individual’s entire DNA sequence, including coding and non-coding parts, is obtained (see diagram).

As only 1-2% of the human genome is comprised of protein coding sequences, whole exome sequencing is faster to perform and analyse, and less expensive than sequencing the entire genome. In addition, whilst we have a good understanding of how mutations in the protein coding parts of the genome cause disease, we are still learning about the regulatory functions of the non-coding parts of the genome.

How is this project different from the 100,000 Genome Project?

The genetic analysis of immunity and infection project is a local research project sponsored by the University of Oxford, which aims to identify the genetic mutations causing problems with the immune systems of patients/families that we see here in Oxford. We have ethical approval to carry out whole genome or exome sequencing but have generally adopted a whole exome sequencing approach due to its cost.

The 100,000 Genomes Project on the other hand is a government-run project which aims to sequence the entire genomes of 100,000 NHS patients with either rare diseases or cancer.
Contribution of genetics to the understanding of CVID (continued from page 9)

From genetics to better treatments

Researching these defects is, however, not only important to increase our knowledge on antibody deficiencies in order to improve counseling of patients regarding their management, inheritance and prognosis, but might also allow for the development of new treatment options. If the exact genetic defect is known, a therapeutic approach targeting this very defect may be possible by substituting the missing protein or by inhibiting an overactive component. One example is the drug abatacept and CTLA4 deficiency. Low levels of the CTLA4 protein can cause an overreaction of the immune cells and lead to autoimmunity. Abatacept substitutes CTLA4, inhibits the activation of T-cells and thereby helps stop the autoimmune reaction. In the case of APDS, specific inhibitors of the overactive PI3 Kinase that can normalize the T-cell function, are in development.

Knowing the effect of a single gene mutation on the immune system in a disease like CVID leads also to a better understanding of the complex mechanisms of immune regulation. This knowledge helps to better understand and eventually to treat many other diseases with involvement of the immune system.

About the authors: Natalie Frede is a physician scientist at the CCI. Her research specialty is the genetic background of PIDs. Bodo Grimbacher is a physician scientist and the scientific director of the CCI. He leads a research group on experimental immunodeficiency at the CCI.

Fundraising news

The Metropolitan Police Federation Constables’ Branch Board, who donated £1,000 to PID UK via Dan and Emma Owens. Dan took part in many sporting challenges and raised over £4,700 for us.

Ritchie Hunt-King who cycled around the Isle of Wight with his daughter Kyra and raised over £1,239.

Your donations

We are extremely privileged to have received a lot of individual donations in the last five months. Sincere thanks to all our donors and especially to

Mrs Kathleen Ingleston and friends Susan Wood and Mr & Mrs Thompson;
Mrs Dovey, Mrs Rose, Mrs Joan Berger, Mr Trail, Mrs Dovey, Mr Beddows,
Mr & Mrs Carvel and Mrs Joan Hart.
Fundraising

Inspired?
There are many ways you can fundraise for PID UK. For you or your sporty friends and family there are many events you can part in. This is just a sample.

**Cycle events**
Take part in this June event for PID UK & cycle through spectacular London by night.

**Running events**
A range of distance events from 5km to marathons is available.

**Trekking challenges**
Classic treks taking in stunning countryside and spectacular views.

If you are interested in fundraising for PID UK please email events@piduk.org.

For the mere mortals amongst us here are some ideas our members have used to raise money for us:
- Baking cakes and selling them
- Holding a garden party
- Having a coffee morning
- Holding a raffle/car boot sale
- Asking your local shop to have one of our collection boxes.

Donations in memory of loved ones
We have received many donations in memory of loved ones. We would like to thank all these families and friends for thinking of others and in particular PID UK at this sad time.

**In memoriam** of Christopher Pratt, Philip James Archer, Mrs Ellen Maureen Prudence Mo Ward and from the family of Mrs Mortimer.

We also received a legacy donation left by Mr Walker, for which we are extremely grateful.

Would you like to donate to PID UK?
We want to do as much as we can to help people with PIDs and to make this possible we are reliant on donations. If you would like to support us you can make a donation online or send a cheque in the post payable to ‘PID UK’ to the following address:

PID UK
199a Victoria Street
London
SW1E 5NE

If you’d like to donate by text:
Text PIDS14 and your amount to 70070 to donate to PID UK e.g. PIDS14 £10