



"....Mighty oaks from little acorns grow.."

Our Chairman, Prof Adrian Copplestone writes:

Welcome to our new form of Newsletter which I hope you will enjoy reading. This edition is about how PMF is helping our local Medical Research groups and endeavouring to help patients, particularly those suffering from brain and nerve tumours and Parkinson's Disease. We have ambitious plans for the coming year, and we hope you will be able to help. In the sections below we have information about Parkinson's Disease, how technology may improve the care of these patients, a new scanner for tumour research, and tours of the research labs. Lastly, we have some ways in which you can further these efforts.

Firstly, I would like to explain why we need your help. One of the most difficult challenges any charity faces is securing funds which it can use flexibly. The PMF is no different. In the thirty years or so of our existence we have been exceptionally 'lean' by keeping our overheads down, conducting the fundraising support ourselves and much appreciated, local pro bono input by professionals. We will continue in this parsimonious vein but if we are to expand our work, we do need a steady amount each year to fund our fixed costs and all-important small grants. These can make a huge difference – for example, last year we were able to step in at short notice and make up the shortfall in a researcher's salary, which otherwise may have foundered.

We are asking supporters to focus on Parkinson's this year and help the charity achieve the £48,000 target for Professor Carroll and her research work with Parkinson's patients, but we also absolutely need a base of subscribers who will give regularly each monthly/quarterly a modest amount of at least £10 or £20 through standing order. If donated by Gift Aid, your contributions will be increased by 25%. If lots of people make small donations regularly, this can build to larger sums which will be used flexibly by the PMF Trustees in pursuit of our charitable purposes and will add considerably to our effectiveness. Information about the different ways you can donate, and an easy 'Donate Here' button can be found at the end of this e-bulletin. Thank you.

Professor Adrian Copplestone FRCP FRCPathProfessor Adrian Copplestone FRCP FRCPath



We need to do something about Parkinson's!

Denis Wilkins, retired surgeon and PMF trustee writes:

This miserable condition is on the increase. Most of us know of someone who has been diagnosed. Approximately 140,000 people in the UK are affected and another 18,000 will be diagnosed this year. It is no respecter of class, status or lifestyle. Recently, Jeremy Paxman has become the latest high-profile casualty, but there are many others. My wife and I went to see a terrific concert by Neil Diamond in Belfast in 2018 and were so sad to hear a fortnight later that he had been diagnosed with the condition. The problem with many diseases affecting the nervous system is that sufferers – and their families – have to put up with a predictable, slow decline during many years. Parkinson's is no exception. Nothing illustrates the problems better than the following fictional but fairly typical case history:

John is a 52-year-old, married man. He is a self-employed electrician. His wife works in the local council offices, and they have no children. They work hard and can afford a comfortable lifestyle which includes owning their own home, regular holidays abroad, some hobbies and a plan to retire to Spain at the age of sixty.

John gradually becomes aware of a tremor affecting his right hand. Week by week it becomes more noticeable and is accompanied by a weakness of his arm and a tendency to trip. He and his wife look up possible causes on the internet and when they go to see his GP their worst fears are confirmed. The doctor diagnoses early Parkinson's and starts him on treatment at the same point referring him to a neurologist. Their world is shattered. But they are a resilient, loving couple and after the first shock and many tears, informed by websites and literature, they come to terms with what lies ahead. The medication makes a big difference, and John manages reasonably well for the time being. His tremor is well controlled, and he is able to carry on working.

Gradually the symptoms – particularly his tremor, arm weakness and unsteadiness – increase, and respond less well to medication. After the first year or two, more frequent and stronger doses of medication are required. It is clear he must give up his business and he is forced to retire at the age of fifty-six. Fortunately, the mortgage insurance relieves some of their financial worries, although money is now tight. He, his wife, and his GP work together to manage the dose and frequency of his medication but the local health services are under strain and there are long waits between appointments for specialist advice and services.

During the next few years, John ages more rapidly than would be expected. His face becomes increasingly immobile and expressionless. He doesn't smile and his speech gradually becomes hesitant, slow, and slurred. He cannot get out of bed or walk without help. He is supported by outreach services, but his wife must give up her job as her husband becomes increasingly incapacitated. Other symptoms emerge as the years pass. Frequent painful muscle cramps, insomnia, constipation, and urinary incontinence reduce his quality of life still further. By the age of 65 he is spending much of his time sitting or in a wheelchair with an indwelling catheter. It is little wonder that he becomes depressed, and his wife worn out with coping. They manage independently for a few more years, supported by outreach care teams, but by the age of 67 John is totally incapacitated, mentally and physically. His quality of life is negligible, and he passes away from pneumonia at the age of seventy.

So, what can be done for patients such as John and their families? Across the globe, there is an intense focus by researchers and clinicians into the causes and treatment of Parkinson's. When I was at Medical School back in the 1960s there was virtually no treatment which could be offered. Nowadays, the situation is much improved and although there is no cure, new treatments are available and can make life much more bearable. But....and there is always a but.... nowhere is it more important to have ready access to skilled clinicians and therapists. It is essential to detect and act on any deterioration before changes become irreversible. To delay detection of change and alter therapy is to fail.

It is here in this part of Devon and Cornwall researchers are applying practical solutions using cutting edge IT technology to monitor patients' condition remotely, consult via Zoom or similar and adjust treatment schedules. Please take a moment to read Professor Carroll's account of the work which she and Dr. Meinert are conducting and how a relatively small amount of money can make a huge difference.

Tour of the Brain Tumour Research Centre of Excellence



A researcher explains how she receives a small piece of a brain tumour, isolates the cells and grows them in an incubator to enable further genetic tests to be made. She is also able to test different drugs that may help new treatments for patients. Photograph: Adrian Copplestone

In September the scientists at the Derriford Research Facility kindly took a group of Plymouth business leaders on a tour of their laboratories demonstrating the techniques used in their research on brain tumours. We saw how human brain tumour cells are grown so

they can be tested for changes in the genes causing the cancer. They also can test drugs to see if they can alter the growth pattern which can give clues to future treatments.

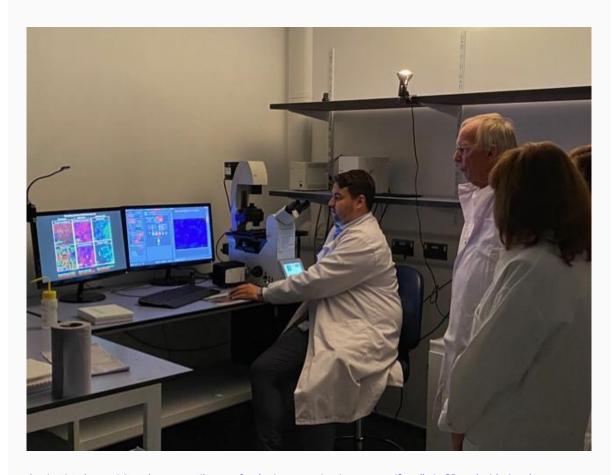
In another lab, we saw a machine that can separate individual cells based of parameters using fluorescence labelled antibodies and lasers. Lastly, we saw cells using a confocal microscope which enables 3 dimensional relationships in real-time to be recorded. This helps understand how cancers cells relate to their local microenvironment.

This tour was highly educational, and we are grateful to the scientists for the time they spent with us. Afterwards some members had the opportunity to see the Clinical Skill Centre where medical and other health students are taught how to examine patients, undertake procedures and work as a team, before they enter the clinical arena.

Some of the members were able to meet Professor Camille Carroll to discuss her work on supporting Parkinson's Disease patients on a daily basis using new technology.

We hope that we may be able to arrange more tours in the future. If you are interested in join one of them, please contact <u>Louisa Gillett.</u>

Adrian Copplestone



A scientist shows visitors how versatile a confocal microscope is - it can magnify cells in 3D and with time lapse can see how cells interact with each other. Photograph: Adrian Copplestone

Scanner installed at the Derriford Research Facility

Research into brain tumours has been boosted by the delivery and installation of a bioluminescence detector at University of Plymouth labs, funded through support from PMF. This new research equipment is being installed and commissioned in November.

"A major part of the research we do is into a kind of tumour called a meningioma. These tumours can grow in many sites around the brain and spinal cord and treatment options are limited at the moment to surgical removal.

The new bioluminescence equipment will allow us to directly measure meningioma tumour size in our work and test new therapies for how they affect tumour growth and, importantly, whether our treatments can shrink tumours and reduce the need for multiple surgeries in patients." Prof David Parkinson – Professor of Neuroscience – who is working on meningioma and Shwannoma tumours in the Brain Tumour Research Centre of Excellence in Plymouth University.



University of Plymouth Research Facility Photograph: Adrian Copplestone

Ways to donate

You can support the work of the PMF and its beneficiaries in several ways:

- A regular donation by Standing Order to our unrestricted funds. This provides the Trustees with maximum flexibility to dispense within its charitable purposes.
- A single or regular donation to a designated fund (for example, Parkinson's Research, Roger Harris Fund for Brain Tumour Research, Student Bursaries).
- Making provision in your will for a donation from your estate.
- Running a sponsored charitable event of your own choosing.

Ways to donate:

- By BACS. Please email me at: admin@peninsulamedicalfoundation.org.uk and I will send you the bank details. (If you wish your donation to go to a specific fund please mark accordingly, otherwise it will be treated as 'unrestricted')
- If you would like to set up a standing order, please do so through the same BACS portal and again it would be much preferred if this could be left unrestricted.
- You can send a cheque made out to Peninsula Medical Foundation to the PMF Treasurer, Metherell Gard, The Old Memorial Hall, Looe, PL13 1PN.
- Just Giving https://www.justgiving.com/peninsulamedicalfoundation
- If you are a UK taxpayer, please don't forget to submit the <u>Gift Aid form which is</u> attached.
- I can be contacted on 07531 898272 or by sending an email to admin@peninsulamedicalfoundation.org.uk.

Thank you on behalf of the Trustees and beneficiaries.

Louisa Gillett - PMF Administrator

Finally... there are a few tickets left

... for this year's Charity Ball to raise funds for Parkinson's research. Come and join us at the New Continental Hotel Plymouth, on Saturday 26th November.

Information about the event, and how to book can.be.found.here (you can book a ticket or a table).