

A person with Parkinson's

The relationship with Research

Marc van Grieken

My diagnosis

Keen(ish) runner

GP and Physiotherapist

Referral: “I think I know what you’ve got, I am fairly certain that you have Parkinsons disease. What do you think of that?” and he wrote:

“Thank you for referring this 49 year old Landscape architect. He presented a fascinating history. “

It wasn’t fascinating to me. I didn’t think much.

I didn’t know what to think.



CONGRATULATIONS

to

Marc Van Grieken

on successfully completing the

2003 NEW YORK CITY MARATHON

on Sunday 2 November

for

TEAM MACMILLAN

*And with many thanks for your commitment to helping
Macmillan Cancer Relief improve the lives of people with cancer*

Peter Carey
Peter Carey
Chief Executive

Craig Fordham
Craig Fordham
Events Co-ordinator

Macmillan
cancer relief
macmillan.org.uk

From denial to campaigning

I didn't know what to do, what to say, what lay in store.

I was in denial and frightened

How did this change?

Family and friends

Remaining active and working

Inspiring professionals

Many people offering support



Shakes

Shaking and Blank expression

Poker face

Turning 60

'60 raise 60'

“Shaky Team from Shaky Toun”

£60,000

Overwhelming support

More than 25 events

Concentrate on what we can do: help to fund research.



Local Connections

Started following Parkinson UK research opportunities

Commented on a PhD Research Grant Application

Visited MRC PPUU

Inspired by Dario, Esther, Miratul and colleagues

Incredibly sophisticated research

12years..... LRRK2 - PINK1

Discovery of inhibitors

But,



Somewhat depressing:

50 years since Levodopa

PARKINSON

CANCER

Pharmaceutical companies withdrawing (Pfizer)

Long road from discovery to treatment.

Are we condemned?

NO: 'We won't wait'.



Science

MRC PPUU: Protein Phosphorylation and Ubiquitylation Unit

Molecular level science and research

Break through discoveries

Committed, ambitious world class scientists and clinicians

Virtual biotech

Dundee – Edinburgh Parkinson's Research Initiative

Welcome PwP involvement

Dundee-Edinburgh Parkinson's Research Centre Proposal: Developing an integrated health informatics platform for Parkinson's

Purpose of this proposal

This 3-year proposal is to fund the development and implementation of an integrated health and research informatics platform for Parkinson's: Clinical Audit Research Evaluation – Parkinson's Disease (CARE-PD) as part of the recently created Dundee-Edinburgh translational research partnership. This prospective and longitudinal phenotypic platform, that is also biologically annotated (genetics/stem cells etc.), is at the core of our vision and will embed patient-centred clinical research within routine clinical care. This investment will place Scotland at the forefront of patient-centred Parkinson's research. We will position our 'research-ready' cohort as one of the best characterised prospective longitudinal Parkinson's cohorts, ideal for recruitment into both investigator and Pharma led-clinical trials.

Vision

Our vision is to become a centre of excellence for scientific innovation, patient-centred research and clinical care, and in doing so, transform the care of people with Parkinson's in the East of Scotland and beyond.

The ultimate goals of our translational programmes are to deliver a pipeline of first-in-human studies aimed at:

- Slowing the progression of Parkinson's
- Reversing Parkinson's
- Predicting and preventing Parkinson's

What can we (PwP's) do?

Join and contribute to Parkinsons UK Research Interest Groups

Edinburgh and elsewhere in the UK

Dundee Research Interest Group (DRIG)

FIFE, Tayside and surrounding areas.

Ambitions with research, disseminate information and socialise

Taking 'some control'

Collaborate

To take part in research, And

Our ambition: to rename Dario's Unit (PPUU)

PPARKINSON'S

PERMANENTLY

&

UNIVERSALLY

UNARMED

