From Edinburgh to Dundee: Research Interest Groups - a success story

Ken Bowler

Chair

Edinburgh Research Interest Group

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

WPC Review Symposium Speakers



Parkinson's UK Edinburgh Branch

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Research Interest Group

Motivation

Research towards a cure is a principal aim of Parkinson's UK

Surveys confirm that the overwhelming majority of members support this

Despite this, relatively few members actively engage in researchrelated activities – other than fund-raising

Aims

To increase the number of members actively engaged in research activities of some sort and to raise awareness of research projects and outcomes



Research Interest Group

The objectives are:

- To encourage and develop all members' interest in research.
- To provide opportunities for members with an interest in Parkinson's research to meet, communicate, work together and generally further the cause of research

Approx 40 members



The Early Days: 2011-2012

- July 2011 Inaugural meeting: objectives set
- Sep 2011 Development of action plan
- **Dec 2011** Meeting at CRM on Nutrition member-led
- Feb 2012 Medication Workshop outside experts
- Mar 2012 Talk to ERIG by Dr Anton Gartner
- May 2012 Public lecture by Professor Roger Barker

Special thanks to Dr Tilo Kunath and Sheila Edward



Medication Workshop

A selection of comments from participants:

Well done, the Edinburgh Branch.

An interesting and well-organised meeting. Well done, Marian, Leo and Liz.

Grateful to organisers for putting on informative event; first time I have attended such an event, met some nice people.

An excellent event.

Well supported event, shows that there is support for further meetings.

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Research Talk

Saturday 24 March 2012:

Talk to ERIG by Dr Anton Gartner, University of Dundee, at SCRM, 10:30-12:30.

Exploiting and Exploring simple non-vertebrate animal models for Parkinson's research, what do we learn?

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Scottish Centre for Regenerative Medicine



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The Edinburgh Parkinson's Lecture Professor Roger Barker (Cambridge)

How close are we to solving the problem of what goes wrong in Parkinson's ?





Some comments on the lecture:

"What an inspirational talk....thank you so much for helping " organise that." FT Edinburgh

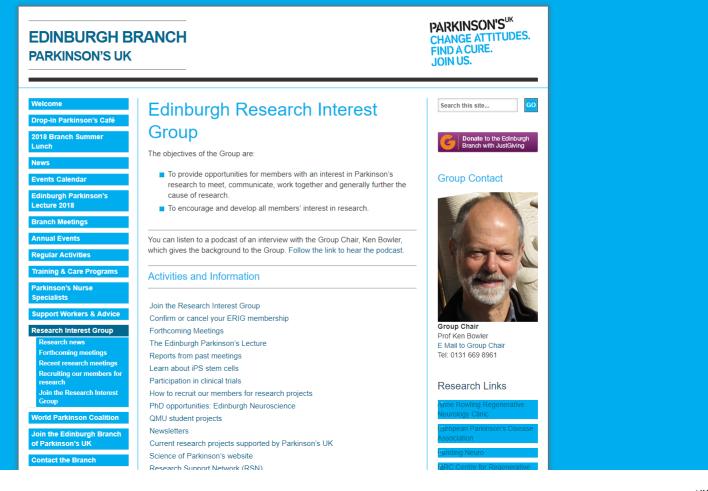
"I attended Tuesday's lecture by Professor Roger Barker at the Royal College of Physicians and would like to thank everyone at Edinburgh Parkinson's for organising it and bringing such an eminent, inspirational speaker to the city. His presentation was fascinating and highly informative and was much appreciated by all who attended." SH Edinburgh

"Thank you for an excellent session tonight" HS Edinburgh

"Well done organising such an interesting and well-run event, thank you all very much indeed." MM Edinburgh

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Parkinson's UK Edinburgh Branch

ERIG Newsletter

Parkinson's UK Edinburgh Branch Research Interest Group

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Newsletter December 2011 Issue No. 1

Objectives

The Group held its inaugural meeting on 2 July, 2011. The Objectives of the Research Interest Group were agreed to be:

- To provide opportunities for members with an interest in Parkinson's research to meet, communicate, work together and generally further the cause of research.
- 2. To encourage and develop all members' interest in research.

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For the first time Parkinson's UK-funded scientists have grown new nerve cells from a person with one of the most rapidly progressing inherited forms of Parkinson's. This research, led by the University of Edinburgh in collaboration with UCL (University College London), has been published in the iournal Nature Communications: see
http://www.nature.com/ncomms/journal/v2/n8/full/ncomms1453.html
Lead researcher Dr Tilo Kunath works in the Institute for Stem Cell Research at the University of Edinburgh. You can hear him in discussion with Mary Wamock on a recent BBC World Service programme The Forum at <u>http://www.bbc.co.uk/programmes/p00inf02#p00k1ym1</u> or listen to an extract from the programme at <u>http://www.bbc.co.uk/programmes/p00k1ylz</u>
Stem cells transformed into brain cells
New York researchers led by Dr Lorenz Studer have reported in the journal <i>Nature</i> on recent work on transforming stem cells into brain cells in an animal model. To read a report in the Guardian dated 6th November, 2011 go to <u>http://www.quardian.co.uk/science/2011/nov/06/stem-cells-brain-</u> <u>parkin sons-disea se?newsfeed=true</u> . For those interested in more technical details, the abstract of the <i>Nature</i> article may be found by going to <u>http://www.nature.com/nature/journal/vaop/ncurrent/full/nature10648.html</u>
Anne Rowling Clinic, Edinburgh
Building work has begun on the new Anne Rowling Regenerative Neurology. Clinic. The clinic will be an addition to the front of Chancellor's Building at Little France and is due to be completed in mid 2012. The clinic will focus on patient-based studies to help find treatments that could slow the progression of Multiple Sclero sis and other progressive, incurable diseases such as Motor Neurone Disease, Alzheimer's disease, Parkinson's disease and Huntington's disease. It was established in 2010 following a £10M donation from JK Rowling and is named in memory of Ms Rowling's mother who died from MS at the age of 45.
ch web site is at <u>http://www.edinburghparkinsons.org</u> and the Research Interes <u>www.edinburghparkinsons.org/branch_news.php</u>
e directed to the Editor and Chair of the Research Interest Group, <u>Ken Bowler</u> er@talk21.com





Professor Ray Chaudhuri Non-motor symptoms of Parkinson's: Important yet often neglected. Why?

25th April 2013 at RCPE

7.15 pm

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Professor Tony Schapira UCL

Recent Advances in the Cause and Treatment of Parkinson's







Professor Patrik Brundin

The battle to beat Parkinson's: the end of the beginning

22nd April 2015 at RCPE

7.15 pm

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Professor Bastiaan Bloem

The Future of Parkinson Care



Legacy?

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Professor Andrew Lees (UCL)

The quest to find a cure for Parkinson's disease Mentored by a Madman: The William Burroughs experiment



20th September 2017 Royal College of Physicians Edinburgh, Queen Street 7.15 pm

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Professor Giovanna Mallucci (Cambridge)

The Road to New Treatments for Dementia and Parkinson's



17th September 2018 QMRI Royal Infirmary of Edinburgh, Little France 7.15 pm

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Seminars, Workshops and other Activities

- Sep 2012 Parkinson's and Exercise: Gill Baer (QMU) & Jane Hislop (QMU & Napier)
- Dec 2012 Dr Miratul Muquit (Dundee)
- Mar 2013 Pain Workshop (member-led)
- Feb 2014 Dr Carl Counsell (Aberdeen)
- **Nov 2014** WPC Scientific Update Workshop
- Jan 2015 Visit to Parkure

Julie Jones (RGU Aberdeen) on Physiotherapy

Feb 2015 Professor Dario Alessi FRS (Dundee)



May 2016 Parkinson's: Let's Get Moving

- **Nov 2016** WPC review by Alison, David and Tilo
- Jan 2017 Dr Alison Green, University of Edinburgh, Possible biomarker for Parkinson's
- Apr 2017 Dr Esther Sammler, University of Dundee, Genes in Parkinson's, from "bench to bedside"
- Dec 2017 Talks by Dr Tilo Kunath on "Stem Cell Therapy for Parkinson's" and Leona Braund on "Living with Parkinson's"
- Jun 2018 Prof Wlady Gedroyc (IC) MR guided focused ultrasound of the brain



A few more things.....

Research projects: the woman who can smell Parkinson's

Student projects: QMU physio, UoE med

Spreading the word: invited paper describing our activities "Adventures with Parkinson's: Empowering Parkinson's patients to become active partners in research and treatment"

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And now..... DRIG

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- •Lubna Arif, Emily Hughes, Claire Stephenson, Claire Bale, Anna Louise Smith (Parkinson's UK)
- •Many other members of the Edinburgh Branch

