

Final: Contacts

Name: Dr. Delia Belevi

Title: Senior Lecturer

Organization: University of Aberdeen

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Dates of Communication: 1/5/11, 1/19/11

Brief Description: Dr. Belevi works with GABAA receptors, which are important in some aspects of primary dystonia. GABAA receptors contribute to the function of muscles, by controlling inhibition within the brain. One medication used for dystonia activates these receptors (Clonazepam) and this is also a possible explanation for ethanol-responsive dystonia.

Name: Dr. Guy Bewick

Title: Senior lecturer

Organization: University of Aberdeen – Institute of Medical Sciences

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Dates of Communication: 1/4/11, 1/5/11, 1/7/11

Brief Description: Dr. Bewick's current research involves neuromuscular transmission and he is studying this in ALS (another neuromuscular disorder).

Name: Prof. Kailash Bhatia

Title: Professor

Organization: University College London – Institute of Neurology, Institute of Movement Neuroscience, Clinical Neurosciences

Address: Institute of Neurology, UCL, 12 Queen Square, London WC1N 3BG

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Dates of Communication: 12/22/10, 12/25/10

Brief Description: One of Professor Bhatia's key research interests is dystonia. He has been published in several articles that I have cited in my bibliography.

Name: Dr. A G Butler

Title: Dystonia Epidemiologist, Board member - The European Dystonia Federation, Honorary Researcher - Newcastle University Medical School, Chairman - Tees Valley Durham and North Yorkshire Neurological Alliance, and Medical Advisory Board Member on ADDER's National Executive Committee.

Organization: European Dystonia Federation, Newcastle University Medical School, and Durham and North Yorkshire Neurological Alliance

Address: European Dystonia Federation, 69 East King Street, Helensburgh, United Kingdom, G84 7RE

Telephone & Fax: +44 1436 678799

Email: butler.adder1@btinternet.com

Dates of Communication: 12/23/10, 1/5/11, 1/7/11

Brief Description: Dr. Butler was the first person in the world to gain a PhD in dystonia, and his work through the European Dystonia Federation allows him to know how Europe as a whole is handling dystonia, in addition to how the UK specifically deals with this disorder. Also, his work at the Neurological Alliance gives him to have access to all neurological conditions, which will allow me to make comparisons between dystonia and other disorders.

Name: Prof. Iain Crombie

Title: Head of Department of Public Health

Organization: University of Dundee

Address: Division of Community Health Sciences, The MacKenzie Building, Kirsty Semple Way, Dundee DD2 4BF

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Dates of communication: 1/4/11, 1/5/11, 1/5/11

Brief Description: Iain Crombie will be great to interview to further understand the public health system in the UK, and how that contributes to the diagnosis treatment process.

Name: Dr. Mark J Edwards

Title: Professor/Researcher

Organization: University College London – Institute of Neurology

Address: Institute of Neurology, Queen Square, London, WC1N 3BG

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Email: m.edwards@ion.ucl.ac.uk

Dates of Communication: 12/23/10, 1/6/11, 1/7/11

Brief Description: Dr. Edwards research deals with neurological conditions, including dystonia.

Name: Dr. Tom Foltynie

Title: Senior Lecturer and Honorary Consultant Neurologist in the Unit of Functional Neurosurgery

Organization: University College London – Institute of Neurology, Unit of Functional Neurosurgery, University of Cambridge - Movement Disorder Group

Address: Institute of Neurology, Queen Square, London, WC1N 3BG

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Dates of Communication: 12/31/10, 1/3/11

Brief Description: Dr. Tom Foltynie also works with DBS.

Name: Prof. Marwan Hariz

Title: Neurosurgeon, Edmond J. Safra Chair of Functional Neurosurgery

Organization: University College London – Institute of Neurology, Unit of Function Neurosurgery, Deep Brain Stimulation Team

Address: IoN- Motor Neuroscience, Institute of Neurology, National Hospital Queen Square, London WC1N 1BG

Telephone: 020 7679 0021

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Dates of Communication: 12/23/10, 12/29/10, 12/30/10, 1/8/11, 1/10/11

Brief Description: Marwan Hariz (MD, PhD), is a neurosurgeon on the deep brain stimulation team. I am interviewing him to learn more about DBS and its influence on the treatment process of dystonia, and the affectivity of it on dystonia.

Name: Prof. Marjan Jahanshahi

Title: Clinical Neuropsychologist on the Deep Brain Stimulation Team, Head of the Cognitive-Motor Neuroscience Group

Organization: University of College London – Institute of Neurology

Address: UCL Institute of Neurology (Box 146), The National Hospital for Neurology & Neurosurgery, 33 Queen Square, London WC1N 3BG

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Email: m.jahanshahi@ion.ucl.ac.uk

Dates of Communication: 12/31/10, 1/4/11, 1/5/11

Brief Description: Professor Jahanshahi performs research on the cognitive, motor, and psychosocial aspects of Parkinson's disease and other movement disorders (like primary dystonia).

Name: Prof. Roger Lemon

Title: Professor of neurophysiology, head of Sobell department of motor neuroscience

Organization: University College London – Institute of Neurology

Address: Institute of Neurology, UCL, 12 Queen Square, London WC1N 3BG

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Dates of Communication: 12/20/10, 12/21/10, 12/22/10, 12/23/10

Brief Description: Professor Lemon's research interests deal with motor control, which is a key part of dystonia. He is familiar with dystonia and has agreed to meet with me for an interview to discuss his knowledge on the topic.

Name: Dr. Patricia Limousin

Title: Reader in Clinical Neurology, neurologist

Organization: University College London – Institute of Neurology, Department of Motor Neuroscience & Movement Disorders

Address: Box 146 Queen Square, London, WC1N3BG

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Dates of Communication: 12/23/10, 12/24/10, 12/30/10

Brief Description: Dr. Patricia Limousin works with movement disorders, and one of her research purposes is to investigate the mechanism of action of DBS (important treatment option) in dystonia. She has agreed to meet with me to share her knowledge on this topic. "She is among the most experienced neurologists worldwide with regard to setting the optimal parameters for deep brain stimulation and post-operative management of patients." – UCL website

Name: Huw Morris

Title: Clinical Senior Lecturer

Organization: Cardiff University School of Medicine

Address: Department of Psychological Medicine & Neurology, Cardiff University School of Medicine, Henry Wellcome Building, Heath Park, Cardiff CF14 4XN (2nd Floor, B-C Link Corridor)

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Email: huwmorris@gmail.com

Dates of Communication: 1/6/11, 1/8/11

Brief Description: Huw Morris is performing research on Myoclonus Dystonia, which is a rare form of primary dystonia.

Name: Alistair Newton

Title: Executive director of European Dystonia Federation

Organization: European Dystonia Federation

Address: European Dystonia Federation, 69 East King Street, Helensburgh, United Kingdom, G84 7RE

Telephone & Fax: 44 1436 678799

Email: alistair@newton1.co.uk

Dates of Communication: 12/23/10, 12/26/10, 12/31/10, 1/3/11, 1/4/11

Brief Description: Alistair Newton is the Executive Director of a very influential organization in the world of dystonia called the European Dystonia Federation. His job allows him to oversee the progress of advancements in medicine that influence dystonia. He will be vital to interview to get an overview of how Europe, particularly the UK, is dealing with dystonia.

Name: Ruth Ross

Title: Chair in Molecular Pharmacology, Institute of Medical Sciences,

Organization: University of Aberdeen – Institute of Medical Sciences

Address: University of Aberdeen, Aberdeen. AB25 2ZD. Scotland. UK.

Telephone: +44 (0)1224 555705

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Dates of Communication: 1/4/11, 1/5/11, 1/6/11

Brief Description: Professor Ross has her PhD in pharmacology with a focus in metabolite pharmacology and prostanoid receptor pharmacology. Her current research involves cannabinoid receptors and their therapeutic uses.

Name: Anne Rosser

Title: Professor

Organization: Cardiff University

Address: Cardiff School of Biosciences, Biomedical Sciences Building, Museum Avenue, Cardiff, CF10 3AX

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Fax: +44 (0)29 208 76749

Email: RosserAE@cardiff.ac.uk

Dates of Communication: 1/4/11, 1/5/11, 1/7/11

Brief Description: Professor Rosser is well versed in the mechanisms of cell death, plasticity, and regeneration within the nervous system.

Name: Prof. John Rothwell

Title: Professor

Organization: University of College London – Institute of Neurology, Institute of Movement Neuroscience

Address: Institute of Neurology, WC1N 3BG

Telephone: 020 3108 0045

Fax: 020 7278 9836

Email: J.rothwell@ion.ucl.ac.uk

Dates of Communication: 12/31/10, 1/1/11

Brief Description: Professor Rothwell's research helps give further understanding to the mechanisms of action of DBS that is used to treat Parkinson's and dystonia, also to the "disorganization of cortical and brain stem circuitry in different forms of myoclonus."

Name: Diane Ruge

Title: Neurologist and Research Fellow on the Functional Neurosurgery Team.

Organization: University of College London – Institute of Neurology

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Dates of Communication: 12/31/10, 1/4/11

Brief Description: Dr. Ruge has studied, in depth, topics such as focal dystonia and DBS, and is currently researching pre and post surgery patients who have had DBS surgery.

Name: Professor Keith Sillar

Title: Professor of Neuroscience

Organization: University of St. Andrews, School of Biology

Address: Bute Building room A25, University of St Andrews, St Andrews, Fife KY16 9TS, UK

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Dates of Communication: 1/4/11, 1/5/11, 1/6/11

Brief Description: Professor Keith Sillar is a neuroscience professor that will probably be able to give me a lot of information on

Name: Dr. Peter Teismann

Title: Senior Lecturer

Organization: University of Aberdeen

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Email: p.teismann@abdn.ac.uk

Dates of Communication: 1/5/11, 1/7/11

Brief Description: Dr. Teismann's research interests include movement disorders, primarily parkinsons, and how inflammation plays a part in cell death in Parkinson's.

Name: Dr. Thomas Warner

Title: Reader in Clinical Neuroscience, Supplement Editor European Journal of Neurology 2010, 17

Organization: University College London – Institute of Neurology, Clinical Neurosciences

Address: Dept Clinical Neurosciences, UCL Institute of Neurology, RoyalFree Campus, Rowland Hill St, London NW3 2PF

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Dates of Communication: 12/23/10, 12/29/10, 12/30/10

Brief Description: Dr. Thomas Warner researches dystonia in several different capacities. He is researching the epidemiology and clinical phenotypes exhibited from the specific molecular genetics. He is also working on mapping the genetics of families with primary dystonia's and studying the genetic mutation in myoclonus dystonia.

Name: Douglas E. Wilcox

Title: Senior lecturer and honorary consultant clinical geneticist

Organization: University of Glasgow

Address: Medical Genetics, Duncan Guthrie Institute, Yorkhill Hospitals, Glasgow G3, 8SJ, Scotland, UK.

Telephone: 0141 201 0365

Fax: 0141 357 4277

Email: D.E.Wilcox@clinmed.gla.ac.uk

Dates of Communication: 1/5/11, 1/7/11

Brief Description: Dr. Wilcox does research on muscle dystrophy, and he has emailed recently saying that he has a new patient with dopa-responsive dystonia. I will be interviewing him to get the perspective of a Doctor who is new to treating dystonia in addition to the use of L-dopa to treat dystonia.

Name: Dr. Ludvic Zrinzo

Title: Consultant neurosurgeon and senior clinical researcher in the Unit of Functional Neurology

Organization: University of College London – Institute of Neurology

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Dates of Communication: 12/31/10, 1/2/11, 1/3/11, 1/8/11

Brief Description: Dr. Zrinzo has “improved the accuracy of anatomical targeting during DBS procedures.” I’m planning on interviewing him about how DBS works for primary dystonia and the success rates of this particular treatment option.