



Seeing Beyond the Gene

Second National Conference on Huntingtons Disease

26th April 2012
Stoke-on-Trent Moat House

North Staffordshire **NHS**
Combined Healthcare

Dear Delegate,

Having received overwhelming support and approval of our first national conference in 2010, it gives me great pleasure to invite you to our second event.

You will agree that the HD community has come a long way over the last few years at academic, clinical and service development levels. Whilst we should never settle for second best when it comes to service quality and availability for our patients and families, it is acknowledged that all of us will have a vital role to play. Experience tells us that no one's role is by any means less important than another. Nonetheless, it is equally acknowledged that pursuing effective education for patients, carers and professionals should always be at the top of our priority list. This will not only help our patients in their difficult journey and ensure a high standard of care; it will also ensure that negative attitudes towards the illness would become a shameful page in history books rather than a sad everyday reality.

I hope that you will find our educational conference; Seeing Beyond the Gene, a step in the right direction and I look forward to welcoming you on 26 April 2012.

George El-Nimr
Consultant Neuropsychiatrist

What Delegates said About Our 2010 Conference:



"I will come back next year!"

An Attendee from Germany

"Thank you for a wonderful conference, I really enjoyed taking part"

A conference Speaker



Agenda

09:00	Registration and Coffee	12:30	Lunch
09:30	Introduction Dr George El-Nimr Consultant Neuropsychiatrist	13:25	HD and Law Mr Doug Feery Barrister
09:35	Welcome Fiona Myers CEO North Staffs Combined Healthcare trust	14:00	HD; Brain Mind and Body
09:45	HD All Around the World Dr George El-Nimr		Brain and Body Changes Over Time Prof. Sarah Tabrizi Professor of Neurology
10:15	Personal perspectives, living with genetic test results Charles Sabine & Michelle Burston TV Journalist Carer		Theoretical Basis of Abnormal Behaviour Dr Hugh Rickards Consultant Neuropsychiatrist and Hon Reader
11:00	Refreshment Break	15:00	Refreshment Break
11:30	Decision making in clinical settings	15:30	Research Advances in HD
	Predictive and prenatal genetic testing - practical and ethical challenges Dr Oliver Quarrell Consultant Clinical Geneticist		Finding a Cure; Hopes and Challenges Prof. Bernard Landwehrmeyer Professor of Neurology, Chair of European HD Network
	Treating neuropsychiatric symptoms Dr David Craufurd Consultant Neuropsychiatrist and Senior Lecturer		Cell and Tissue Transplantation Prof. Anne Rosser Professor of Clinical Neuroscience, Hon Consultant Neurologist
		16:30	Question Time and Conclusion

What Delegates said About Our 2010 Conference:



"Well organised and very informative" NHS Consultant

*"Very useful update on developments, well worth the journey!"
A Care Giver*



Speakers

Dr George El-Nimr

A consultant Neuropsychiatrist and lecturer working in North Staffordshire. Dr El-Nimr runs a holistic service for Huntington's disease (HD). He looks after pre-symptomatic abnormal gene carriers and HD patients at different clinical settings (eg inpatients, outpatient, day services and care homes). He supports HD related training at Keele and Birmingham Universities. He has completed a number of audits and service evaluation projects on HD that were presented both nationally and internationally (some with Award winning). His HD service won the Improving Experience; Chairman's Award in 2009. He published HD treatment guides for GPs and HD literature for care givers. He has facilitated the development of a support forum for young adults with HD in the family that was advertised nationally. Last year, he published a paper, jointly with a carer, that outlines the service model that he developed. He also developed a DVD that outlines the main aspects of HD and related service issues. More recently, he contributed to another national training DVD that was organized by the HD Association. Dr El-Nimr has written an on line module on HD with a colleague for the Royal College of Psychiatrists and reviewed HD related papers for the British Medical Journal. Dr El-Nimr has participated and taken on the Principal Investigator role in national and international research initiatives in relation to HD. He is an active member of the European Huntington's Disease Network (EHDN) and a number of its working groups. His HD unit is recognized by the EHDN for research purposes. His areas of interest include HD service developments and Neuropsychiatric manifestations of HD.



Charles Sabine

Emmy-award winning TV journalist, Charles Sabine, worked for the US network NBC news for 26 years. That career took him; via twelve wars, six revolutions, and four earthquakes; to most of the news events of Europe, the Middle East, Africa and Asia since the early 1980s. There, he learnt first-hand the extraordinary limits that the human spirit is capable of reaching, in the face of tragedy inflicted by both nature and mankind. In 2008, he decided to put the lessons of those experiences to a different use, when he became a pioneering spokesman for freedom of scientific research, and sufferers of degenerative brain illnesses - in particular, Huntington's disease, which has ravaged his family. That role has led to Sabine speaking at prestigious venues across the world, among them; the European and British parliaments; the Royal Institution in London and the World Congress on Freedom of Scientific Research.



Dr Oliver Quarell

Oliver is a Consultant Clinical Geneticist in Sheffield. He did his MD on Prediction and Prevention of Huntington's Disease at Cardiff 1984-1996. At that time, the gene for HD had only been localized to chromosome 4 so genetic testing was complex but most of the ethical considerations surrounding predictive testing were developed in this period. Oliver has been involved in the recent European Working Group on Predictive testing which initiated the process of reviewing and updating the guidelines for genetic testing. Oliver is an active member of the European Huntington's Disease Network; he has participated in drug trials for HD, written 2 books on the subject and published peer reviewed papers on HD.



Speakers

Dr David Craufurd

A Senior Lecturer in Medical Genetics at the University of Manchester, and Honorary Consultant in Neuropsychiatric Genetics at the Central Manchester University Hospitals NHS Foundation Trust. He is also an Honorary Consultant Psychiatrist at the Manchester Mental Health and Social Care NHS Trust. He graduated in Medicine from London University (St. Bartholomew's) in 1976 and moved to Manchester to study Psychiatry in 1979. After completing general psychiatry training, he arranged a temporary secondment to Genetic Medicine in 1986 to pursue an interest in the genetic aspects of psychiatric disorders, and ended up 'going native'. His research interests are concerned mainly with the neuropsychiatric aspects of Huntington's disease (HD), and with the psychological and social impact of predictive genetic testing for late-onset disorders. He set up the UK's first multidisciplinary management clinic for HD, currently one of the largest sites in the European HD Network (EHDN), and is actively involved in a number of European and world-wide research projects and clinical trials. He is a member of the Scientific and Bioethics Advisory Committee of the EHDN, leads the EHDN Behavioural Phenotype Working Group and is a former Secretary-General of the World Federation of Neurology Research Group on HD.



Doug Feery (Barrister)

Court of Protection Department. Doug Feery is based in Leeds, but works in many areas of the north of England. Doug joined Switalskis in November 2010. He is a specialist in Court of Protection matters and has a particular interest in cases where there is a human rights element. In recent years, he has been a leader in testing the effectiveness of the European Convention on Human Rights and the Human Rights Act 1998 in protecting the rights of those who lack capacity. Doug is also a highly experienced lecturer and trainer in the fields of equalities, mental health and mental capacity law, and has provided training in the academic, not-for-profit and public sectors for many years. He addressed the conference of the Mental Health charity, Rethink on community care law matters on September 28th 2011.



Professor Sarah Tabrizi

Sarah graduated in biochemistry and medicine in Edinburgh. She has worked on research into neurodegenerative diseases since her PhD as an MRC clinical training fellow at University College London UCL and was awarded one of the first HEFCE/NIHR New Blood Clinical Senior Lecturerships, and in the last 5 years has generated over £7 million grant funding for her research. She has published over 120 peer-reviewed research articles and her main areas of interest are in understanding neurodegeneration particularly Huntington's disease, at both the cellular and clinical levels. Sarah is currently Professor of Clinical Neurology at UCL Institute of Neurology.



Dr Hugh Rickards

is a Consultant in Neuropsychiatry and Honorary Reader in Neuropsychiatry at Birmingham University. He is interested in general clinical neuropsychiatry and is part of a service that offers assessment and treatment for the full range of neuropsychiatric disorders. He is the course director for the UK's only MSc course in clinical neuropsychiatry. From the research angle, he is interested in the interaction between motor and psychiatric disorders, particularly in relation to Tourette syndrome and Huntington's disease.

Hugh is the outgoing chair of the European Society for the Study of Tourette syndrome.



Speakers

Professor Bernhard Landwehrmeyer

Currently Full Professor of Neurology “Clinical Neurobiology” at the University Hospital of Ulm where he is also Chair of the Executive Committee of EHDN (European Huntington’s Disease Network). The European HD Network provides a platform for professionals and people affected by HD and their relatives to facilitate working together throughout Europe. In 2011 he was predominately in New York due to his sabbatical during which he is a Medical Advisor to the CHDI Foundation. He coordinates the scientific work in Europe on behalf of CHDI Foundation.

Landwehrmeyer received his degrees in the M.D. Albert-Ludwigs-University Freiburg, Germany and his Doctorial Thesis at the Albert-Ludwigs-University Freiburg, Germany. He has also studied at the Royal Victoria Hospital, Queen’s University in Belfast, in the UK, Kantonsspital Basel, Switzerland and MGH and Harvard Medical School, Boston. . He has shown his expertise especially in the field of Huntington’s Disease in numerous clinical trials and researches both nationally and internationally.



Professor Anne Rosser

Is a Professor of Clinical Neuroscience and Honorary Consultant Neurologist at the University Hospital of Wales, Cardiff. She is also joint Director of the University’s Brain Repair Group. She has worked in the area of neurodegeneration since 1994 and brings to the Research Institute specialist knowledge in Huntington’s disease, in particular the development of new therapies for this and related neurodegenerative conditions. She leads the South Wales HD clinical service, which provides care for HD patients at all stages of the illness and supports clinical research activities ranging from observational to interventional clinical studies.



Conference Fees

Please see below fees for this years “Seeing Beyond the Gene” national conference. If you are interested about exhibiting at this event, or sponsoring this event, please see the back page of this booklet.

Early Bird Rate £75 inc VAT.

This rate is available until Wednesday 29th of February, from this date the full rate will be effective.

Carers and Student rate £30 inc VAT.

There are a limited number of carer and student rates, these will be on a first come first serve basis.

Full Rate £95 inc VAT.

This rate will be effective as of Wednesday 29th February 2012.



**Stoke on Trent Moat House
Etruria Hall, Festival Way, Stoke-On-Trent, Staffordshire ST1 5BQ**

Directions:

From the North or South: M6 Junction 16 to A500 Stoke-on-Trent. Take the A53 towards Leek, immediately get into the left hand lane and take the first left at the roundabout into Festival Park. The hotel is straight over the mini roundabout with the entrance on the left.

From the A50: A50 to A500 Stoke-on-Trent. Take slip road for A53 towards Leek, immediately get into the left hand lane and take the first left at the roundabout into Festival Park. The hotel is straight over the mini roundabout with the entrance on the left.

Railway: Stoke on Trent 2 miles.

This event is kindly supported by The Priory Group and St George Healthcare Group, both will be exhibiting on the day.



If you would like more information on sponsoring or exhibiting at this years national conference, please contact us on the details below.

To register: www.kc-jones.co.uk/hd

Event queries: 01332 227777

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