Recent Developments in Neurofibromatoses and Rasopathies: their management, diagnosis, current and future therapeutic avenues

30th September - 1st October 2013
Radisson Blu Hotel, Cardiff

This international meeting will provide a most comprehensive and up to date account of recent developments in neurofibromatosis and rasopathies. Internationally recognised outstanding speakers in this field will contribute to the meeting.

The meeting will be suitable for medical geneticists, oncologists, dermatologists, neurologists, endocrinologists, psychiatrists, molecular and cellular biologists, genetic counsellors and general practitioners and members of lay groups.

Internationally recognised experts from the UK, Europe and USA who will be speaking at the event include:

Professor Luis Parada, Texas, USA
(Winner of von Recklinghausen award, USA)
Professor David Gutmann, St Louis, USA
(Winner of von Recklinghausen award, USA)
Professor Vic Riccardi, California, USA (Winner of von Recklinghausen award, USA)
Professor Nancy Ratner, Cincinnati, USA
(Winner of von Recklinghausen award, USA)
Professor Eric Legius, Leuven, Belgium
(Winner of European NF award)
Dr Sue Huson, Manchester, UK
(Winner of European NF award)
Professor Kate Rauen, San Francisco, USA
Professor Juha Peltonen, Turku, Finland
Dr Bronwyn Kerr, Manchester, UK
Dr Diana Baralle, Southampton, UK
Professor Ros Fener, London, UK
Professor Gareth Evans, Manchester, UK
Professor Mike Patton, London, UK
Professor Oliver Hanneman, Plymouth, UK
Professor Meena Upadhyaya, Cardiff, UK
Professor Mark Zenker, Magdeburg, Germany
Professor Miikka Vinkula, Louvain, Belgium

Topics covered will include
• Neurofibromatosis type 1
• Neurofibromatosis type 2
• Schwannomatosis
• Noonan syndrome
• Noonan like with multiple lentigines
• Costello syndrome
• Legius syndrome
• Cardio-facio-cutaneous syndrome
• CM - Arteriovenous malformation syndrome
• Familial gingival fibromatosis

For further information please contact -

Angela Burgess,
Education Project Manager
Wales Gene Park

burgessam@cf.ac.uk
Tel: 029 20 687 267
# Recent Developments in Neurofibromatoses and Rasopathies:
their management, diagnosis/current and future therapeutic avenues

**30th September - 1st October 2013**

### Monday 30th September 2013

<table>
<thead>
<tr>
<th>Time</th>
<th>Session/Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>08.30</td>
<td>Registration &amp; Coffee</td>
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<tr>
<td>9.25</td>
<td>Welcome &amp; Introduction Professor Meena Upadhyaya</td>
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<tr>
<td><strong>Session I -</strong></td>
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<tr>
<td>9.30</td>
<td>Diagnosing the different forms of neurofibromatosis : a practical approach</td>
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<td><em>Dr Sue Huson, Manchester, UK</em></td>
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<td>9.55</td>
<td>Complex NF1</td>
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<td><em>Professor Rosalie Ferner, London, UK</em></td>
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<tr>
<td>10.20</td>
<td>Tumour burden and whole body MRI in NF1</td>
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<td><em>Dr Said Farschtschi, Hamburg, Germany</em></td>
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<tr>
<td>10.45</td>
<td>Coffee</td>
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<tr>
<td>11.15</td>
<td><strong>Session II-</strong></td>
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<td>New developments in Mouse Modeling of NF1</td>
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<td></td>
<td><em>Professor Luis Parada, Texas, USA</em></td>
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<td>12.00</td>
<td>Preclinical testing in NF1</td>
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<td><em>Professor Nancy Ratner, Cincinnati, USA</em></td>
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<td>12.45</td>
<td>Patient Group Speaker: Paddy Griffin, NF Ireland</td>
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<td>12.50</td>
<td>Lunch</td>
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<tr>
<td><strong>Session III-</strong></td>
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<tr>
<td>13.50</td>
<td>Social skills and overlaps with autism in NF1 patients</td>
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<td><em>Professor David Viskochil, Salt Lake City, USA</em></td>
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<tr>
<td>14.20</td>
<td>Learning problems in NF1</td>
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<td><em>Professor Eric Legius, Leuven, Belgium</em></td>
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<tr>
<td>Time</td>
<td>Session</td>
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| 14.50 | Clinical trials for NF1  
*Professor David Gutmann, St Louis, USA* |
| 15.35 | Patient: *Julia Mogridge - Living with NF1* |
| 15.40 - 16.10 | Tea/Coffee |
| 16.10 | NF2 and related syndromes  
*Professor Gareth Evans, Manchester, UK* |
| 16.50 | Preclinical and Clinical trials for NF2  
*Professor Oliver Hane mann, Plymouth, UK* |
| 17.20 | Schwannomatosis  
*Professor Gareth Evans, Manchester, UK* |
| 17.55 | Patient: *NF2 Patient* |
| 18.00 | Close |

**Session IV**  
*Professor Ros Ferner & Professor David Gutmann*

**Tuesday 1st October 2013**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>8.30-9.00</td>
<td>Registration and Coffee</td>
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</table>
| 9.00 | Understanding neurofibromin function-a Clinicians perspective  
*Professor Vic Riccardi, USA* |
| 9.40 | Molecular basis of MPNSTs in NF1  
*Professor Meena Upadhyaya, Cardiff, UK* |
| 10.00 | NF1 and bone health  
*Professor Juha Peltonen, Turku, Finland* |
| 10.30 -11.00 | Coffee/Tea |
| 11.00 | Overview of Rasopathies  
*Professor Kate Rauen, San Francisco, USA* |
| 11.50 | Legius Syndrome  
*Prof Eric Legius, Leuven, Belgium* |

Programme may be subject to minor changes
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<tr>
<th>Time</th>
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<th>Speaker Details</th>
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<tbody>
<tr>
<td>12.20</td>
<td>Costello Syndrome</td>
<td>Dr Bronwyn Kerr, Manchester, UK</td>
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<td>12.50</td>
<td>Patient Group: Colin &amp; Cath Stone, Costello Syndrome Association</td>
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<tr>
<td>12.55-14.00</td>
<td>Lunch</td>
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**Session VI**
*Professor Kate Rauen & Professor Mike Patton*

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<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>14.00</td>
<td>Noonan and NS with multiple lentigines</td>
<td>Professor Mike Patton, London, UK</td>
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<td>14.30</td>
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<td>Ian Legg – Noonan Association</td>
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<tr>
<td>14.35</td>
<td>Cardiofaciocutaneous syndrome</td>
<td>Dr Emma Burkitt-Wright, Manchester, UK</td>
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<tr>
<td>15.00</td>
<td>CM-Arteriovenous malformation syndrome</td>
<td>Professor Miikka Vikkula, Louvain, Belgium</td>
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<tr>
<td>15.30</td>
<td>Registering the Faces of RASopathies</td>
<td>Professor Gareth Baynam, Perth, Australia</td>
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<tr>
<td>16.00</td>
<td>Animal Models and Treatment Trials for Noonan Syndrome</td>
<td>Professor Martin Zenker, Magdeburg, Germany</td>
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<tr>
<td>16.30</td>
<td>Summing up, Vote of thanks &amp; Close</td>
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**Course Director:**
Professor Meena Upadhyaya  Institute of Medical Genetics, University Hospital of Wales, Cardiff

**Clinical Advisor for the programme:**
Dr Susan Huson, Manchester, UK

Approved for 12 CPD points by The Royal College of Physicians, London

Meeting supported by:
- NF Ireland
- Neuro Foundation
- Children Tumour Foundation
- Costello Syndrome Association
- Biomarin
- NewGene
- Noonan Syndrome Association
- Sheila and Clive Owen

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Please reserve a place for me to attend the above event:

Please use Block Capitals

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<th>Surname</th>
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Address for Correspondence:

Tel: 
email:

Organisation:

Position:

Registration (includes all refreshments during symposium)

Please tick as appropriate

- Registration Both Days, inc conference dinner £260
- Registration Both Days £235
- Registration Day 1 only (places limited) £135
- Registration Day 2 only (places limited) £135
- Conference Dinner, Monday evening, inc Wine Reception £40

A limited number of student bursaries are available (please enquire for details)

There is a 20% discount for block bookings of 5+ places (please enquire for details)

Accommodation is NOT included but a list of suggested, discounted accommodation is available on request

Special dietary requirements:

I enclose a cheque for £……………….. made payable to 'Cardiff University'

Please note that payment must be received prior to the event

Credit card payments are possible but incur a 1.5% charge. Please contact us for details.

Please return one form per delegate

Terms and Conditions: Registration fees include access to meeting, lunch and refreshments. Fees do not include accommodation or travel. Shared places are not permitted. Payment must be received prior to the event. All registrations will be acknowledged. If you have not received registration confirmation within 14 days prior to the event please contact us.

Cancellation Policy: Cancellation less than 6 weeks before the course date (after 19.08.13) will incur a 50% cancellation charge. No money will be refunded for cancellations less than 3 weeks before event start (after 09.09.13) Cancellation must be made in writing. Substitutions are acceptable but must be made in writing. The organisers cannot accept liability for costs incurred in the event of the conference having to be cancelled as a result of circumstances beyond its reasonable control.

I have read and agree to the conditions of registration and cancellation and enclose my remittance in full

Signature: ___________________________ Date: ___________________________

Please return form and registration fee to:

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Tel: 029 2068 7267, Fax: 029 2068 7659, Email: burgessam@cf.ac.uk