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**FAMILIES for FAMILIES DAY**

**Saturday 23rd April 2016**

**THE HILTON BIRMINGHAM METROPOLE HOTEL**

**NATIONAL EXHIBITION CENTRE, BIRMINGHAM B40 1PP**

**Programme**

**09.15 The Registration Desk opens**

**10.00 Chairman’s Welcome and the Annual General Meeting of the NSA charity**

Ian Legg, NSA Chair, welcomes families and introduces the day, starting with the AGM, a short open meeting, at which the various positions on the charity board are confirmed for the coming year.

**10.20 Who’s Going Where?**

Time to decide which break-out groups the young people and children will join. For everyone else, staying in the Main Room, the main programme begins.

**10.30 The Chairman sets the priorities for the future**

Ian Legg sums up progress over the last 12 months for the charity and looks ahead

**10.50 Mijn Verhaal -** **My Story**

Judith Van De Meerakker from Holland talks about her experience of having Noonan Syndrome and how it relates to her career as a geneticist.

**11.10 The RASopathies – An Update**

Professor Michael Patto**n** explains some of the latest developments in the understanding and responses to Noonan Syndrome.

**11.20 Updates on Research**

Progress and outcomes of research into NS and the Lymphatic System, Hypertrophic Cardiomyopathy , the CASPER Study, the future NSA funded research into Epilepsy and Brain Disorders and the proposed 30 Year Follow Up Study.

**12.10 “Reach Out For Noonans”**

Ian Legg explains the Regular Giving Scheme and how the wider family and friends can help.

**12.20 Contact-a-Family**

A representative of Contact-a-Family explains the ways in which they can help families.

**12.30 Lunch**

**A**n informal buffet giving you more opportunities to talk to the guest specialists and other families, learn

more about fundraising for NSA and buy one of the new NSA t shirts!

**13.30 The Medical Panel – Questions & Answers**

**Professor Michael Patton, Consultant Clinical Geneticist & Adviser to the Noonan Syndrome Association**, chairs a Q&A session when you can ask your questions to our team of medical experts and we also have someone to answer your queries about Education.

Already confirmed:

**Professor Bronwyn Kerr -** Consultant Clinical Geneticist, St Mary’s Hospital, Manchester

**Professor Sahar Mansour -** Consultant in Clinical Genetics, St George’s Hospital

**Professor Jonathan Green -** Child and Adolescent Psychiatry, University of Manchester and Manchester Academic Health Sciences Centre

**Dr Juan Pablo Kaski -** Consultant Paediatric Cardiologist/Honorary Senior Lecturer, Great Ormond Street Hospital

**Dr Vin Diwakar -** Executive Medical Director and Consultant Paediatrician, Great Ormond Street Hospital

## **Dr Shruti Garg -** Clinical Senior Lecturer in Translational Child Psychiatry University of Manchester

**Dr Pia Ostergaard -** Senior Lecturer in Human Genetics, St George’s

And more guests to be confirmed…

**14.30 Refreshments** and **Education questions to Sue Miller,** Family Partnership Co-ordinator. Staffordshire SEND

**15.00 Social Media and the new NSA Website launch!**

Trustee Katie Ballard explains NSA’s social media activities and introduces the brand new NSA website.

**15.30 Important messages from the day, closing remarks and farewell**

Ian Legg sums up the day and looks to the future…

**Day Closes by 16.00 at the latest**