Support for individuals and families affected by Noonan Syndrome and related conditions (on the Ras/MAPK pathway) in the UK

Registered Charity No. 1140671
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THE HILTON BIRMINGHAM METROPOLE HOTEL
NATIONAL EXHIBITION CENTRE, BIRMINGHAM B40 1PP

Programme

09.15 The Registration Desk opens and refreshments available

10.00 Chairman’s Welcome and Who’s Going Where?
Ian Legg, NSA Chair, welcomes families and introduces the day; and it’s time to decide which break-out groups the young people and children will join. For everyone else, stay in the Main Room for the main programme:

10.10 The Annual General Meeting of the NSA charity
Starting with the AGM, a short open meeting, at which the various positions on the charity board are confirmed for the coming year, Ian Legg sums up progress over the last 12 months for the charity and looks ahead.

10.25 The Chairman introduces the Medical Advisory Group

10.30 The CASPER Study
Dr Shruti Garg reports on the official outcomes of the CASPER Study (Cognitive and Social Profiling: Exploring Rasopathies) and the practical implications for families

10.50 GenIDA Patient Registry
Dr Florent Colin introduces this ground breaking development which you can be a part of.

11.20 The Medical Panel and guests – Questions & Answers
Professor Michael Patton, Consultant Clinical Geneticist & our Medical Adviser chairs a Q&A session when you can ask your questions to our team of medical experts from the NSA Medical Advisory Group. Our Panel:

Professor Bronwyn Kerr - Consultant Clinical Geneticist, St Mary’s Hospital, Manchester
Dr Juan Pablo Kaski - Consultant Paediatric Cardiologist, Great Ormond Street Hospital
Dr Pia Ostergaard - Senior Lecturer in Human Genetics, St George’s Hospital
Dr Shruti Garg - Clinical Senior Lecturer in Translational Child Psychiatry, University of Manchester
Dr Kostas Dimopoulos - Consultant Cardiologist in adult congenital heart disease & pulmonary hypertension, Royal Brompton Hospital
Dr Vin Diwakar - Regional Medical Director, NHS England London
Judith Van De Meerakker - Department of DNA Diagnostics, Amsterdam Academic Medical Centre
Dr Florent Colin - GenIDA project manager
Linda Shaughnessy - Clinical Nurse specialising in adult congenital heart disease, Royal Brompton Hospital

12.40 Fundraising/“Reach Out For Noonans”
Ian Legg briefly explains the Regular Giving Scheme and how the wider family and friends can help.

12.45 Lunch
An informal buffet giving you more opportunities to talk to the guest specialists and other families, learn more and register with the GenIDA project and become a regular giver to NSA.
13.45 Discussion Groups
Delegates gather in their pre-chosen groups:
  • Speech & Feeding
  • Education
  • Adulthood

14.30 Refreshments available
And another opportunity to talk to the specialists and other families

14.45 The Quest For Finding More Genes For Noonan Syndrome
Dr Pia Ostergaard and her team from St George’s Hospital update us on the latest developments

15.15 Potential Future NSA Funded Research
Professor Michael Patton, Professor Bronwyn Kerr and Ian Legg discuss what areas might be addressed by future research

15.30 The Break Out Group Presents…!

15.45 The 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