



FAMILIES *for* FAMILIES DAY

Saturday 21st April 2018

including *Be Your Self* activities for children and young people
at

Whitemoor Lakes Activity & Conference Centre
Barley Green Lane, Lichfield, Staffordshire, WS13 8QT

Programme

09.15 Welcome!

The Registration Desk opens and refreshments available

10.00 Opening Session

Chairman's Welcome and Who's Going Where?

Ian Legg, NSA Chair, welcomes families and introduces the day; and it's time for the children and young people and children to join their groups. For everyone else, stay in the Main Room for the main programme:

The Annual General Meeting of the NSA charity

A short open meeting, at which the various positions on the charity board are confirmed for the coming year and Ian sums up progress over the last 12 months for the charity and looks ahead.

Two Family Stories

New Trustees, Andrea Reid-Kelly and Brian Carlton, both of whom have Noonan Syndrome, tell their own stories of how it has affected them and their families.

11.00 The Medical Advisory Group

Noonan Syndrome and Pregnancy

Professor Sahar Mansour, St George's Hospital

Noonan Syndrome and The Heart

Congenital heart problems and Cardiomyopathies in NS/RASopathies in both children and adults

Dr Juan Pablo Kaski, Great Ormond Street Hospital

11.50 Short Refreshment Break

The Medical Panel – 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 including Professor Bronwyn Kerr, Professor Sahar Mansour, Dr Juan Pablo Kaski and Dr Shruti Garg.

13.00 Lunch

An informal buffet giving you more opportunities to talk to the specialists and other families and find out ways to help NSA.

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

Registered Charity No. 1140671

Medical Adviser: Professor Michael A Patton FRCP

14.00 What's The Latest On...

Noonan Syndrome Research

International Developments – an update by Professor Bronwyn Kerr
The 30 Year Study – an update by Professor Michael Patton & Dr Alistair Patton

Fundraising – Do It Today For NSA!

Trustee Katie Ballard with Eve Martin and some of our leading fundraiser members talk about how they raised funds, the Regular Giving Scheme and how the wider family and friends can help.

Refreshments available

14.50 Time to talk!

Group discussions confirmed so far include:

Education

Supporting a child from as young as 2 until 19 and sometimes beyond, can be a daunting and difficult task for families especially when considering the changing impact of Noonan Syndrome on their child during this time. From the earliest years through to agreeing an Education, Health & Care Plan (EHCP), discussions will focus on how to find the right pre-school and school provision and getting the transition right from one phase of education to the next. Sue Miller, Katie Ballard and Anna Swift will lead these discussions.

Adulthood

As people with Noonan Syndrome enter adult life, and later as they grow into middle age and beyond, they can be presented with different challenges. Professor Mansour, Ian Legg and Andrea Reid-Kelly will lead this group.

15.30 The *Be Your Self* Groups Present...!

The children and young people tell us what they've been doing during the day

15.45 A Look Back and a Look Forward

Ian Legg looks at the important messages from the day and looks to the future...

Day Closes by 16.00 at the latest

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