



The 1st National Alport Family Support Day

Agenda

Saturday
1 December 2012
10am-5pm

Note slightly later finish time to allow for networking. Tea will be available till 6pm.

Where: Westminster Boating Base, 136 Grosvenor Road, London SW1V 3JY

- ❑ Lunch will be provided as well as activities for children.
- ❑ There will be a separate workshop for teens and young adults
- ❑ Although the meeting finishes at 5pm, tea will be available for those that want to talk informally till 6pm
- ❑ Travel bursaries available if your journey costs more than £20 (with receipts)

An informal, family event created by those living with Alport Syndrome and supported by:

BRITISH KIDNEY
Patient ASSOCIATION
improving life for kidney patients



RARE DISEASE

UK

The National Alliance for people with rare diseases & all who support them

- ❑ Learn more about Alport Syndrome with Kidney, Genetics, Organ transplant, Hearing and Sight experts - put your questions to the medical team that includes Professor Frances Flinter (Genetics), Professor Neil Turner (Kidneys and Alport patient registry), Mr Moin Mohamed (Eyes) and Mr Oswald Fernando (Kidney transplants)
- ❑ Find out about the latest research from Sharon Lagas (Alport Syndrome Foundation USA), including ACE inhibitors from Professor Oliver Gross (Nephrologist from Germany leading the research) and the latest project funded in the UK (Deborah Fielding, Action for Alports Campaign)
- ❑ Hear about the experiences of others living with Alport Syndrome and meet families in similar situations and share your experiences

Please bring with you

1. **A copy of a favourite recipe – with your name on it.**
We are planning to print a recipe book (with some renal diet-friendly recipes) that we can get families and friends to buy to raise money for future events.
2. **Be prepared with a few words to introduce yourself at the beginning of the event, so we can meet everyone, including:**
 1. Your name and nearest village/town
 2. A short sentence about one of the interesting/fun things you have done this year.

If you have any ideas or questions about the day

Simply email Susie Gear and Jules Skelding at meetings@alport.info or call 01793 847 264