



# Alport Syndrome

## **The patient perspective**

Susie Gear

Royal Society of Medicine, 5 July 2013

# The patient perspective

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- **Facts and figures**
- **The patient 'journey'**
- **Alport support group**
- **Activities to get involved in**

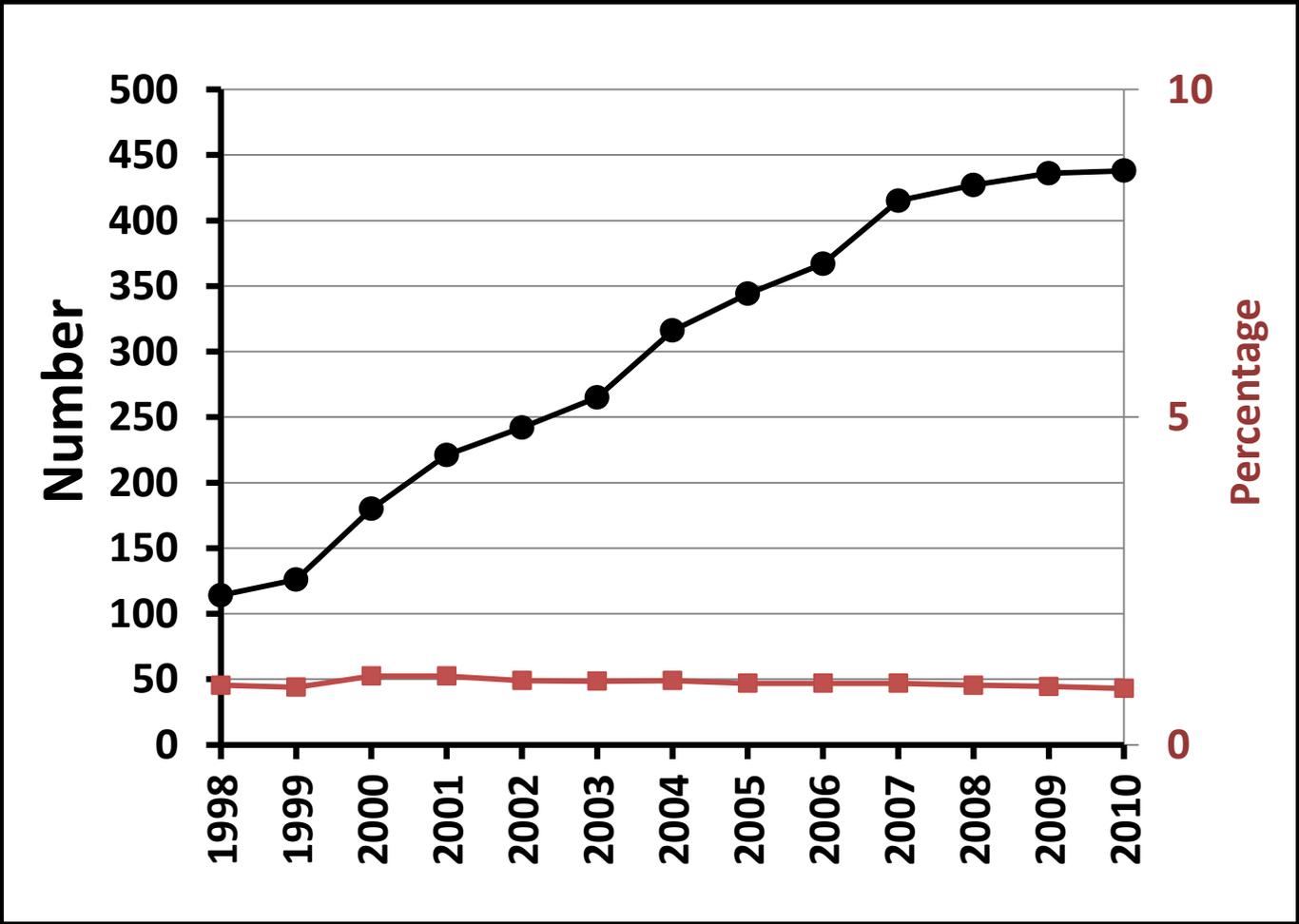
# Alport Syndrome

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...is an inherited condition that can cause **kidney failure, deafness** and **eye** abnormalities. Those that inherit it will probably require a kidney transplant when they are young adults. It can impact a large number of people in a family. It is the second most common form of inherited kidney disease.

# Patients with Alport Syndrome on RRT in the UK



# How many have Alport Syndrome in the UK?

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450 on dialysis/ transplanted

? How many not on RRT

Carriers – 1000?

Total – maybe 2000?

Neil Turner Dec 2012

**But the numbers are more interesting if you also include other countries, for example**

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- USA
- China
- Australia
- Europe

# How many hospital appointments a year?

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# A year in the life of...

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- 56 appointments
- 12 different specialists
- £360-400 petrol
- £168 hospital parking
- 224 hours out of school
- 32 days out of working week

Walker family year up to July 2013

# The patient perspective

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# Patient journeys

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- 'Normal'
- Uncle/Grand parent
- Cousin
- Children
- Carer/parent

# Outcomes and achievements

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# The patient perspective

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# Most families have never met another person with Alport Syndrome

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*“It was such a relief to find friends where hearing aids and blood tests were normal.”*

# We started with a meeting in London

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The meetings are being organised by a group of volunteers – individuals and families living with Alport Syndrome: Colin Baigent, Katie Fry, Steve Fry, Susie Gear, Catherine Kent, Julie Kiddie, Thomas Kiddie, Clare Norrie, Jules Skelding, Oliver Skelding, Richard Stanton, Julie Tippett, George Walker

In partnership with the Rare Diseases (UK) Working Group for Alport Syndrome. For more information on rare diseases:

[www.raredisease.org.uk](http://www.raredisease.org.uk)

# Alport UK



*Why?*  
**Vision**

To ensure that all individuals and families with Alport Syndrome feel empowered to enjoy the best quality of life

*How?*  
**Mission**

Working in partnership with individuals, families and the scientific community we will:

- Facilitate a **support network** for patients and families
- Be a conduit for high quality, **accessible information**
- Raise the **profile of Alport Syndrome** in the scientific community
- Contribute to **the international research agenda**
- Collaborate on the development of a **UK patient registry** and alliance of international patient registries.

*How?*  
**Strategic imperatives**

**Support**

**Information**

**Research**

**Collaboration**

# A collaboration drawing on different strengths

National

International



# The international Alport team helping us to design the workshop agenda



**Bertrand Kneblemann**  
Paris

**Professor Neil Turner,**  
Edinburgh

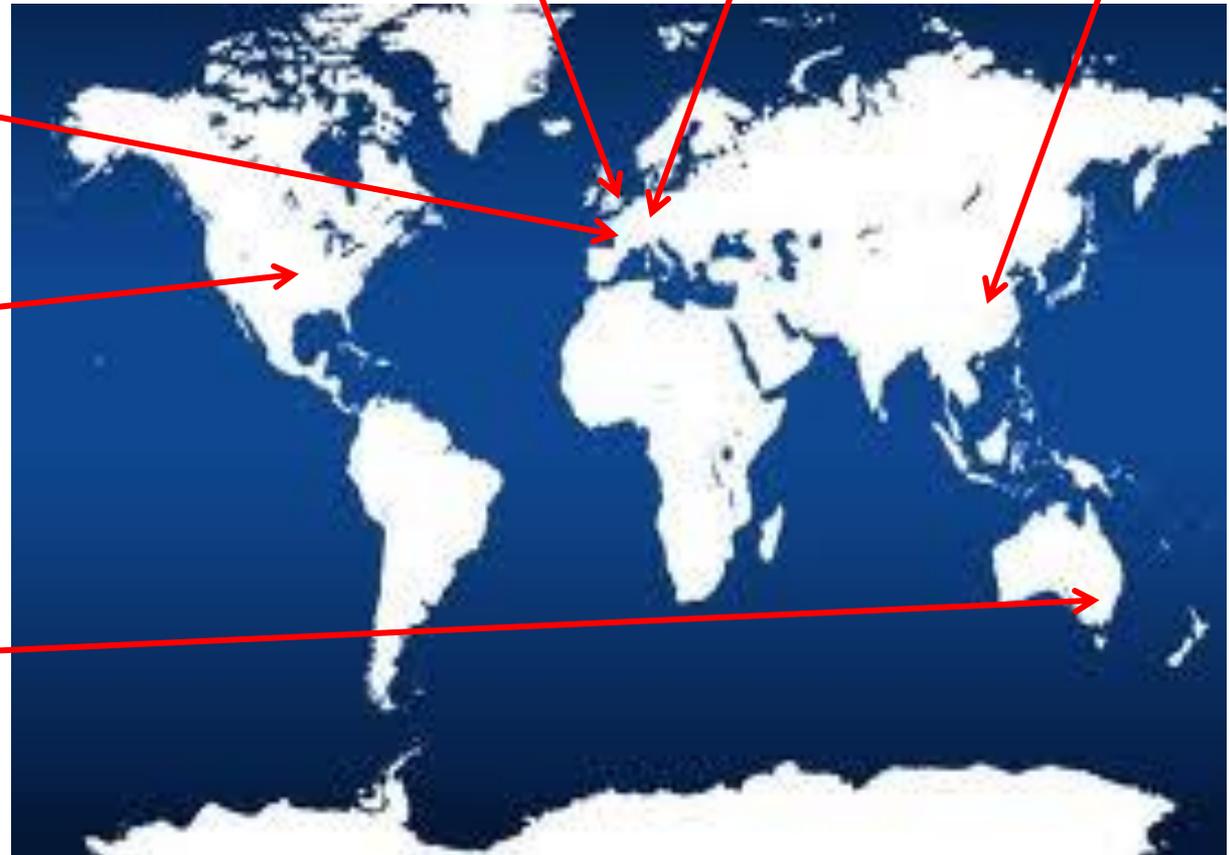
**Professor Frances Flinter**  
Guys, London

**Professor Oliver Gross**  
Gottingen, Germany

**Professor Jie Ding**  
Shanghai

**Professor Cliff Kashtan**  
Minnesota

**Professor Judith Savige**  
Brisbane



# The patient perspective

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# Local and international meetings for patients and clinicians



**DRAFT**

## Shining a light on Alport Syndrome

**Calling medical professionals, scientists, geneticists, academics, researchers...**

### International Conference on Alport Syndrome Autumn 2013

- Listen to the latest findings
- Participate in workshops
- Present your own research or case studies
- Meet families affected
- Network with experts in related fields
- Find out about the future of Alport Syndrome

An exciting international event designed to bring the experts together to collaborate on ideas for the future.

Supported by:

### What to do next...

Simply register your interest in attending by emailing your details (name, address, phone number, email and specific topics of interest) to: [meetings@alport.info](mailto:meetings@alport.info)

By registering you will receive updates and information



## 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*

  
Kidney Research UK  
*Improving lives for kidney patients*

  
ALPORTS  
FOUNDATION  
*Improving lives for kidney patients*

- 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](mailto:meetings@alport.info) or call 01793 847 264

# The future

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Video

# The aspirations of the next generation

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**Benny (10)** wants to meet others like him

**Sasha (11)** wants her brother to be better and for the family to spend more time together rather than in hospital

**Patrick (15)** wants to be known for his drama rather than the fact that he wears hearing aids

**Tom (15)** wants to be a musician

**Jess (18)** wants to understand how she could pass it on

**Jamie (9)** would rather be playing rugby than having blood tests

**Jack (8)** would like a cure to his Alports

# Exploring other communities

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# Thoughtful language required



**Alport Syndrome**...is an inherited condition that can cause **kidney failure, deafness** and **eye** abnormalities. Those that inherit it will probably require a kidney transplant when they are young adults. It can impact a large number of people in a family. It is the second most common form of inherited kidney disease.

~~Disease  
Syndrome  
Sufferer  
Cure~~

*Respect for individuals and families with differing views*

# Questions

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- How many patients are there?
- How to effectively engage them?
- How to connect with those who
  - are at different stages?
  - are carriers and are not necessarily renal patients?
- How to get better clinical help across the units?
- How to get better support for patients and families?
- How to work with the other national Alport groups?
- How to sustain activity over time.

# Ideas, thoughts, questions?

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One word to describe your  
reaction to this patient perspective