



Shining a light on Alport Syndrome

4-6 September 2017
The Lighthouse,
Glasgow, Scotland,
United Kingdom

The 2017 International workshop on Alport Syndrome

In collaboration with the 50th Anniversary Meeting of the European Society for Paediatric Nephrology (ESPN)



Monday 4th September

0830 National Alport groups and

1100 Registration for all workshop participants with lunch

1230 **Susie Gear** *alport UK*: Introductions and definition of workshop focus

Sara Ryan *University of Oxford*: Alport syndrome Healthtalks project

Basic science – what's new?

Billy Hudson *Vanderbilt University Medical Center*: Evolution and function of collagen IV

Wilhelm Kriz: *University of Heidelberg*: The GBM- turnover and response to mechanical challenge

Selected talks and Patient Perspective

1545 Break

Dan Jagger: *University College London*: Hearing research and Alport syndrome

Laura Perin: *University of Southern California*: Update on Stem Cells

Selected talks

Posters and buffet dinner

1900 Close

Tuesday 5th September morning: Genetics update

0830 National Patient Organisation Update

Judy Savage: *The University of Melbourne*: Genotype-phenotype correlation for COL4A3 and COL4A4

Ron Korstanje: *The Jackson Laboratory, Bar Harbor*: Genetic analysis of Alport modifier genes in mice

Constantinos Deltas: *University of Cyprus*: Collagen IV nephropathies and the search for genetic modifiers.

Selected talk

1045 Break

Frances Flinter: *Guy's and St Thomas' NHS Foundation Trust*: 100K genomes project

Alessandra Renieri: *University of Siena*: Autosomal Dominant Alport Syndrome: a well-defined clinical entity

Selected talks and Patient Perspective

1245 Lunch and posters

Tuesday 5th September afternoon: Clinical Science

1400 **Roser Torra** *Fundació Puigvert, Barcelona* & **Daniel Renault** *AIRG France/FEDERG*: ERKNet and ERNs.

Moin Saleem: *University of Bristol*: Precision medicine for kidney disease.

Jie Ding: *Peking University Health Science Center*: mir21 and podocyte loss in human Alport kidneys

Selected talks and Patient Perspective

1615 Break

1630 **Breakout groups** 1) Basic science: **Rachel Lennon and Jeffrey Miner**; 2) Diagnosis and genetics: **Judy Savage and Frances Flinter**; 3) Clinical care: **Neil Turner and Michelle Rheault**

1800 Close

1845 Tour and awards dinner





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Wednesday 6th September: Free to ESPN participants

0815 ESPN participants register

0830 **Susie Gear** *alport UK*: Introductions

Alport Collective *alport UK*: Improving communication



Current practice

Rachel Lennon *University of Manchester*: Diagnostic evaluation of persistent haematuria in childhood

1000 **Break**

Patient perspective

Cliff Kashtan: *University of Minnesota & Oliver Gross*: *University of Göttingen*: Clinical practice recommendations for adults and children with Alport syndrome

Clinical trials

Danny Gale *University College London*: Clinical trials in practice

Michelle Rheault *University of Minnesota*: Prospects for other novel therapies

1230 **Lunch and Pharma updates** 10 mins each with small groups rotating

Transition and young adult care

Matt Hall *Nottingham University Hospitals NHS Trust*: Alport syndrome in pregnancy

Neil Turner *University of Edinburgh* & **Arvind Nagra** *University Hospital Southampton NHS Foundation Trust*: Transitional care in adolescence

New developments in basic science

Karl Kadler *University of Manchester*: How is collagen exported from cells and assembled into matrix?

Tom van Agtmael: *University of Glasgow*: *Col4a1* kidney phenotype and chaperone treatment

Workshop feedback and conclusions

Feedback and actions from workshop **breakout groups** (held on Tuesday 5th September 1630-1800)

1630 **Susie Gear** and **Rachel Lennon**: Closing remarks

1730 ESPN opening ceremony