



Shining a light on Alport Syndrome

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



The 2017 International workshop on Alport Syndrome

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

- Understand the latest findings and new ideas – hearing, kidneys (basic science and treatments), eyes, clinical trials and patient registries
- Collaborate with International colleagues in workshops on specific topics, e.g. novel approaches to treatment
- Present your own research or case studies
- Hear patient perspectives
- Network with experts in related fields or related disease areas
- Be part of the future of Alport Syndrome research and treatment

An exciting international event designed by people living with Alport Syndrome in partnership with the leading International experts to collaborate on ideas for the future.



a brighter future for people living with alport syndrome

Travel and accommodation bursaries available for a limited number of students in return for bringing a poster with some new ideas and input for our discussions.

What to do next...

Application process now open. Simply email your details (name, address, phone number and a short paragraph indicating your specific area of interest) to: research@alport.info by **30 June 2015**.

In your short paragraph, please indicate your particular activities which justify favourable consideration of you as a participant and contributor to this workshop. This information is important, as it allows the Workshop Organising Committee to make an informed decision when reviewing and accepting applications.

By applying you will receive details of how to register plus updates and information about the agenda.



Outline agenda and outputs

Participants invited to arrive for the morning of Monday 4 September

To encourage open communication, each member of the workshop will need to agree that any information presented at this International workshop on Alport Syndrome, whether in a formal talk, poster session, or discussion, is a private communication from the individual making the contribution and is presented with the restriction that such information is not for public use. Prior to quoting or publishing any such information presented at the workshop in any publication, written or electronic, we will obtain written approval of the contributing member.

Monday morning

- National Alport groups and registration for all participants in the workshop

Monday afternoon - Current work and basic science

- Information updates (in plenary) from all participants
- Basic science – what's new?

Tuesday morning – Genetics and clinical science

- Genetics update
- Clinical science and registries

Tuesday afternoon – breakout groups

A1) Basic science and translational science, including gene- and chaperone-based therapies

A2) Diagnosis and genetics

A3) Standard of care, repurposing therapies, carriers, management of extrarenal symptoms, registries, biobanks and clinical trials

Wednesday – groups running in parallel

B1) Optimising outcomes in Alport Syndrome - current practice, clinical trials and future therapies

B2) Alport genetic variant meeting

Thursday, Friday, Saturday – ESPN 50th anniversary meeting that workshop attendees can also attend

Alport topics on the agenda for Thursday 7 September: speakers include Professors Jeff Miner, Rachel Lennon and Oliver Gross. Note: if you want to attend the entire ESPN 50th anniversary meeting, you will need to register at espn2017.org.

Outputs

- Documented developments in Alport Syndrome research
- Identification of new research priorities
- International networking for Alport Syndrome:
 - New collaboration with the European Society for Paediatric Nephrology (ESPN)
 - Identification of collaborative research projects and funding calls
 - Strengthening collaboration with industry
- Publication of workshop proceedings
- An alliance of national patient organisations and agreed ways of working together to support clinical trials and how to fund international research



Workshop Organising Committee and key contributors

Scientific Committee

Professor Colin Baigent, MRC Scientist, Hon Consultant in Public Health, Oxford, UK

Professor Constantinos Deltas, University of Cyprus, Molecular Medicine Research Center, Nicosia, Cyprus

Professor Jie Ding, Department of Pediatrics, Peking University First Hospital, Beijing, China

Professor Frances Flinter, Consultant in Clinical Genetics, Guy's Hospital, London, UK

Dr Daniel Gale, UCL Centre for Nephrology, London, UK

Professor Oliver Gross, Department of Nephrology and Rheumatology, Georg-August-Universität Göttingen, Germany

Dr Laurence Heidet, Necker Hospital, Paris, France

Professor Clifford Kashtan, Department of Pediatrics, University of Minnesota, USA

Professor Bertrand Knebelman, Necker Hospital, Paris, France

Professor Rachel Lennon, Wellcome Trust Centre for Cell-Matrix Research, University of Manchester, UK

Associate Professor Julian Midgley, Department of Paediatrics, Alberta Children's Hospital, Canada

Professor Jeffrey Miner, Washington University in St. Louis, USA

Dr Laura Perin, Saban Research Institute, University of Southern California, USA

Professor Judith Savige, University of Melbourne, Australia

Dr Michelle Rheault, Department of Pediatrics, University of Minnesota, USA

Professor Roser Torra, *Fundació Puigvert, Barcelona, Spain*

Professor Neil Turner, Professor of Nephrology, University of Edinburgh and Consultant Nephrologist, Royal Infirmary of Edinburgh, UK

Representatives from national Alport organisations

Dave Blatt, Alport Foundation of Australia

Susie Gear, alport uk

Sharon Lagas, Alport Syndrome Foundation, USA

Daniel Renault, AIRG France/FEDERG

Julia Schifter, Alport Foundation Israel

Thomas Simon, Alport Selbsthilfe, Germany

Jessie Zhang and Mr Cai, Chinese patient group, China

Maria José Cacharron, Spain

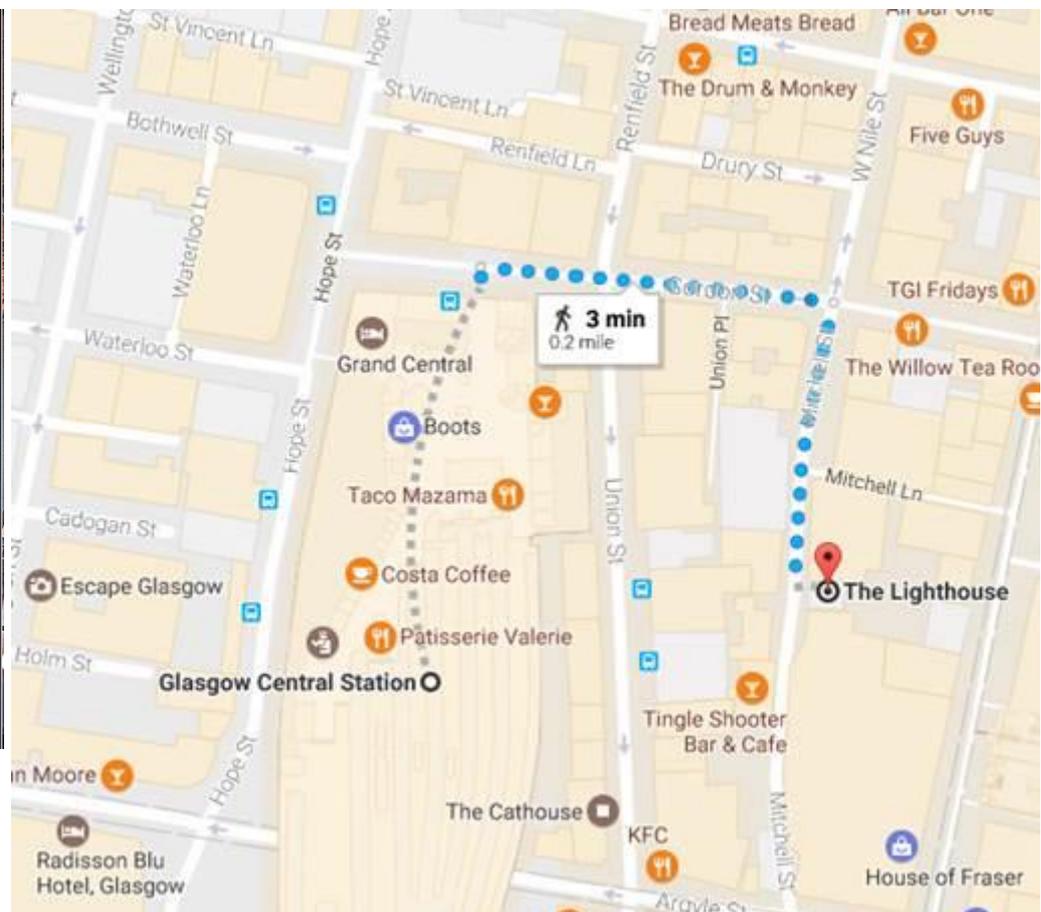


Venue and accommodation

Venue details

The Lighthouse, Scotland's Centre for Design and Architecture
11 Mitchell Lane, Glasgow, G1 3NU

As well as being an events venue, The Lighthouse hosts exciting exhibitions and events as well as having a whole floor dedicated to the life and work of Charles Rennie Mackintosh, a Scottish architect and designer. We will also have the opportunity to take in the views of Glasgow from the top of the Mackintosh tower or from the Viewing Platform.



Accommodation

Hotels nearby can be booked nearby with preferential rates. Email research@alport.info for details.