**The 2014 International workshop on Alport Syndrome**

*3-5 Jan 2014, Said Business School, Oxford, UK*

**Draft of detailed agenda**

**Approach to inviting people and submission of abstracts**

1. Invite sent to specified list of invitees (compiled by Workshop Organising Committee) encouraging people to list:

* their broad area of interest
* if they wanted to submit an abstract.

1. Workshop Organising Committee reviewed abstracts and allocated the topics to be covered either as:

* short 10 minute presentations to group in plenary sessions – note all these speakers are also invited to do a poster to encourage further debate and discussion.
* Poster.

1. All those who submitted abstracts will be notified of the need to produce a poster and, for the relevant group will also be invited to prepare a presentation.

**Format, style and tone of meeting**

* We aim for a maximum of 120 people attending, hoping that we will get approximately 80
* It is an ‘International workshop’, so speaking slots are limited to allow as much time for dialogue and discussion. We very much welcome participants who are not presenting either in plenary or posters; these participants have a key role to encourage questions and deeper debate.
* Only the breakout groups on day 3 will run in parallel, so all will hear each speaker
* **Speakers on day 1** are invited for a 30 minute session allowing for 20 minute presentation with ‘key questions for research’ followed by 10 minutes of questions and answers/discussion.
* **Speakers on day 2 and day 3** to be invited for 10 minute speaking slots, followed by 5 minutes of questions, to encourage debate and discussion. Note these speakers should also present their work as a poster presentation, to encourage further debate and discussion
* At the end of each session on each day there would be a wrap up discussion of 30 minutes to an hour, chaired by the Session chair to allow for a deeper dialogue into preferred topics.

**Workshop Organising Committee**, October 2013

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

**Professor Jie Ding**, Department of Pediatrics, Beijing, China

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

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

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

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

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

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

**Mr Moin Mohamed,** Consultant Ophthalmic Surgeon, St Thomas' Hospital, London, UK

**Professor Judith Savige,** University of Melbourne, Australia

**Dr Judy Taylor,** Consultant Paediatric Nephrologist, Evelina Children's Hospital, London, UK

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

**Representatives from the following national Alport family support organisations:**

**Dave Blatt**, Alport Syndrome Foundation, Australia

**Susie Gear** and **Jules Skelding**, Alport support group, UK

**Sharon Lagas**, Alport Syndrome Foundation, USA

**Daniel Renault**, AIRG France/Europe

**DAY 1: Friday 3rd January – Current work and new ideas**

08.00 Alport variant group meeting Judith Savige

11.00 Registration and buffet lunch at Business School

**Current work and new ideas**

*Session Chair: Chris Winearls*

13.00 Welcome and introductions (including patient survey) Susie Gear

**State of the art: what is known about Alport Syndrome?**

13.30 Introduction to Alport Syndrome Frances Flinter

14.00 Biology Jeff Miner

14.30 Clinical management and natural history Cliff Kashtan

15.00 Patient views on research into Alport Syndrome Sharon Lagas,

Daniel Renault

?Fang Wang

*15.30 Discussion All*

16.00 *Break*

16.30 Revealing the Secrets of Type IV Collagen Assembly Billy Hudson

17.15 Poster viewing and networking

19.00 Welcome drinks and Informal networking dinner

**DAY 2: Saturday 4th January – Getting into the detail**

**Basic science, genetics and diagnosis**

*Session chair: Billy Hudson*

08.30 **Basic science of Alport Syndrome**

New insights into Alport Syndrome biology (20’ +5’) Dominic Cosgrove

Abstracts (10’ +5’) (Paul Potter, Rachel Lennon, Christoph Licht)

9.40 Discussion (40 mins)

*10.20 Tea/coffee*

10.45 **Genetics**

Recent findings from next generation sequencing (20’+5’) Michael Yau

Abstracts (10’ x5) (Daniel Gale, Jenny Kruegel, Mato Nagel*, Alessandra Renieri (TBC)*

12.10 Discussion (20 mins)

12.30 Lunch (and poster viewing)

**Registries, clinical trials and management**

*Session chair(s): Cliff Kashtan*

13.30 **Registries**

A review of current Alport Syndrome registries (10’+5’) Parminder Judge

13.45 **Trials**

Who should participate? What are the endpoints? What are the

potential endpoints? Where does the money come from?

Challenges in trials of renal disease (and some solutions) Colin Baigent

(10’+5’)

EARLY PRO-TECT Alport (10’+5’) Oliver Gross

14.15 Discussion (15 mins)

14.30 **Current clinical management strategies** (10’+5’x3)

Ocular abnormalities in Alport syndrome Judy Savige

Management of Alport syndrome in China Dr Fang Wang

*(note this talk may be better put on first day as covers patient perspective)*

Topic of discussion to be confirmed Dr Rosa Torra

15.15 Discussion (15 mins)

*15.30 Tea/coffee*

16.00**Future management directions and****novel treatments** (15’ x3)

Cell based therapy Laura Perin

Anti-microRNA and collagen receptor blockade Oliver Gross

Chaperone proteins as potential therapeutic targets Constantinos

Deltas

17.30 Discussion – ideas to take forward All

*Possible summary through use of technology - tbc*

18.10 Workshop Organising Committee meeting (5 minutes)

18.15 Meeting for patient/funding organisations (45 minutes)

19.00 Reception and dinner (at Trinity College, Oxford University)

**DAY 3: Sunday 5th January – our future research strategy**

**Chair: *TBD***

08.30 *Future* c*hallenges of trials in rare diseases: EUVAS ExperienceDavid Jayne*

09.00 The future of Alport syndrome: A biologist's perspective Karl Tryggvason

09.30 Workshops *(ideas for future research directions and collaboration)*

- Genetics Chair: Frances Flinter

- Basic Science Chair: Billy Hudson, Karl Tryggvason

- Trials and Registries Chair: Colin Baigent, Oliver Gross and

Cliff Kashtan

- Clinical Aspects of Alport’s Chair: Clifford Kashtan, Neil Turner

10.00 Re-group with summary from each group chair and open discussion

Discussion ( 60 minutes) with moderator: Karl Tryggvason

11.00 *Tea/Coffee*

11.30 *?Strategies for* *Funding Medical Research ?Wellcome Trust*

12.00 Responses from patient/funding organisations *TBD*

13.00 Lunch and informal group discussions

14.00 Meeting close and depart

14.30 Practical next steps (Workshop Organising Committee)

16.00 Workshop Organising Committee depart

**Posters**

Deidre MacKenna