



Alport Information Day

Saturday 7th September

10 am – 4.30 pm

Alport's Syndrome is genetic kidney disease that can also cause deafness. It most commonly affects young men but can affect women too. Maybe 2000 people in the UK carry the faulty gene. It gets its name from Dr Cecil Alport, an Edinburgh graduate who described it in 1927.

Venue

Surgeons' Hall
The Royal College of Surgeons
Nicolson Street
Edinburgh
EH8 9DW

Surgeons' Hall is in the centre of Edinburgh, 5 mins walk from Waverley Station. It's famous for its gruesome museum and you'll be able to visit that if you dare!



Arthur Cecil Alport, M.D. was a South African physician who first identified the Alport syndrome in a British family in 1927

Programme

Introductions

Coffee & Registration
Welcome, introductions

Susie Gear

Short talks

What is Alport's?
A patient's story
Genes and genetic testing
About kidney transplants

Neil Turner
Mark Hewitt
Frances Flinter
John Casey

Lunch

Short talks

Why join a Registry?
What Alport's means for families
Hearing and hearing aids

Neil Turner
Susie Gear
Stamatia Staikoudi

Tea

Q&A & Feedback