



Keratoconus Group

West Midlands Local Meeting 8th July 2017

Context - Some Numbers

- The incidence of KC in the last decade has generally been quoted as 1 in 2000 of the population (0.05% - hence title)
- Relatively recent talks at Moorfields Eye Hospital have quoted 1 in 1750 for those of Caucasian heritage and up to 1 in 500 for those of 'Asian' heritage
- Moorfields Eye Hospital website currently states KC affects up to 1 in 1000 people
- Truth is that we probably don't know an exact figure as there is an increasing awareness of the condition and ever-improving detection methods so more cases are being found.

Total UK Numbers

- The 2015 census gives the UK population as 65.1 million with about 7% of them as 'Asian of all groups' (i.e. about 4.5 million)
- 1 in 2000 of the 65.1 million means there are over 32,000 people with KC in the UK (though many likely very mild cases)
- Alternatively, taking KC as 1 in 1750 of 60.6m (non-Asian) gives about 34,600 and 1 in 500 of 4.5m (Asian) gives another 9,000 for a total of nearly 44,000 people
- We thus have a range of 32,000-44,000 so a working number of about 40,000 with KC seems reasonable but this is still only 0.06% of the population - we are definitely a rare lot! (but only about 2500 are known to the KC Group)

Where Does This Go?

- UK population is forecast to hit 70 million in 2026 which translates to at least another 3000 people with KC by then
- It is unlikely that a genetic method of detecting KC and 'killing' it before onset is going to be found anytime soon
- The nearest thing we have to a 'cure' is Corneal Cross-Linking (CXL) but this needs to be applied in the very early stages of KC - hence early detection is vital
- We are all going to have to keep supporting others with KC for some time to come - and push the CXL message.

Explaining KC

- **Another significant conclusion is that trying to explain KC to most of the other 99.95% of the population is going to continue to be a problem**
- It's not helped by the fact that nearly everyone with KC has a different experience depending on how their corneas deform
- There are no simple 'simulation spectacles' for KC
- Most people have just never heard of it, can't pronounce it...
- ...and they all know that any vision problems involving contact lenses must be correctable with glasses!!

Some KC Simulations

- <http://kcvision.org/images/>
- <https://keratoconusgb.com/2014/03/23/what-is-it-like-to-have-keratoconus/>

KC at Work

- Two-thirds of blind and partially sighted people are unemployed so it is not surprising that there is a natural tendency for us not to tell anyone about our KC
- Sometimes all an office worker needs is a bigger screen or the ability to set up specific colour/font schemes and to get away from air conditioning outlets
- It is just not obvious if we have our contact lenses in or out or if we are having a 'bad eye day' so it can look like a try-on if we say there is a problem that no-one else can detect
- The concept of 'partial disability' is not understood or recognised in legislation (there is no temporary vision impairment registration).

Advice About Work

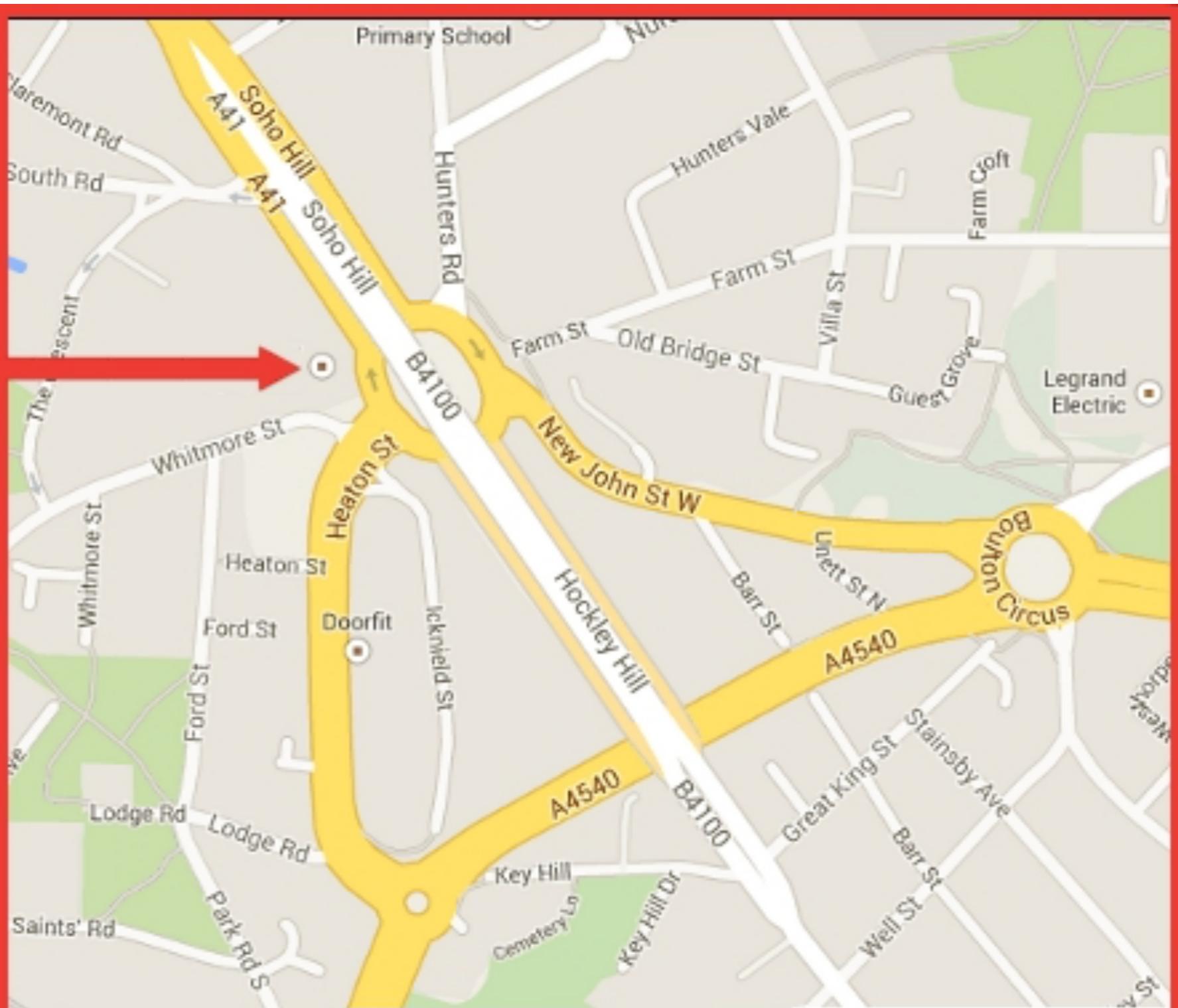
- Action for Blind People have a good record in providing practical advice; they are now part of RNIB but still provide that service
- The 2011 KC Conference in London had a very good session on Access to Work given by Action for Blind People and here is a short extract on disclosure (*minutes 8.06-16.00*):
<http://www.keratoconus-group.org.uk/conferences/2011/>
- Action for Blind People local offices are in Birmingham, Stafford, Stoke and Loughborough
- <http://www.rnib.org.uk/action-for-blind-people>

Discussion Points

- At least 3 of those present gave first hand accounts of how Action for Blind People had been very helpful to them in the workplace, this is clearly the organisation to go to if you have issues (& AFBP have a rep at Coventry Eye Hospital)
- Notable comment from one corneal consultant to a member, “KC patients put up with a lot of eye discomfort and don’t normally complain - so when they do it should be taken seriously!”
- Other ways of describing KC are ‘like looking through frosted glass in a bathroom’ or ‘looking through a car windscreen in heavy rain without the wipers on’.

Sight Village 18/19 July

- New Bingley Hall, 1 Hockley Circus, Birmingham, B18 5PP
- <http://www.qac.ac.uk/exhibitions/sight-village-birmingham/1.htm#.WV9RRDPMYRs>
- Doors open at 9.30am both days and close at 5pm on the 18th and 3.30pm on the 19th.
- Sight Village events are FREE to enter
- I will be on the KC stand with Anne Klepacz both days.



sight village

Post-Meeting Note

2018 KC National Conference

Advance Notice

- The 2018 KC National Conference is going to be held in Birmingham on a Saturday possibly in early September
- The KC Group National Committee will be meeting in August to confirm this and make the booking
- John will email the date and venue as soon as it is confirmed and details will appear on the main website
- It would very helpful to have a few local members to help with running things on the day so if anyone wants to volunteer now it would be much appreciated - please email John to register interest.