Keratoconus Group

Newsletter Summer 2019

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West Midlands Group Meeting

Saturday 10th August 2019 at 11:00am. The speaker will be John Thatcher talking about sighted guiding.

The venue is the **John Lewis Birmingham Community Hub GRAND CENTRAL** above New Street Station. Go to the 4th floor, turn right at the top of the escalator, in the corner on left by Audio & TV. For further details ring John Thatcher: 01743 625138.

London Speaker Meeting

Saturday 21st September, 2019 at 11:00am. Our guest speaker is Dr Vijay Anand, Deputy Head of Optometry at Moorfields Eye Hospital and his talk will be 'Visual Correction for Keratoconus'. This will cover: spectacles, soft contact lenses, corneal cross-linking, corneal rings, medical contact lenses (RGP, hybrid, scleral) and post graft corrections.

The venue is the lecture theatre of the **Moorfields Clinical Tutorial Unit** which is now located at 15 Ebenezer Street, N1 7NP (go up Provost Street which is across the road from the main hospital and you'll find 15 Ebenezer Street on the next corner). For further details ring Anne on 020-8993 4759.

Brighton KC Group Meeting

Saturday 9th November at 11:00am. Mr Mayank Nanavaty will outline the various treatment options and update us on the latest developments. This is a good opportunity to ask questions and share experiences.

The venue is **Sussex Eye Hospital**, Eastern Road, Brighton, BN2 5BF (in the Doctors' Mess which is on the Ground Floor and immediately opposite the main entrance to the Eye Hospital). For further details ring David on 020-8554 5578.

2019 AGM Guest Speaker: Professor Alison Hardcastle, Professor of Molecular Genetics, UCL Institute of Ophthalmology

Update on the Moorfields Genetic Research Study

The large audience at our recent AGM on 23rd March were treated to a superb talk by Professor Alison Hardcastle which provided an update to research partly funded by the KC Group and which holds the promise of major developments in the long-term treatment of keratoconus.

Alison boldly took us into the complicated world of genetics and succeeded in making it accessible to most of us most of the time! Her enthusiasm for the subject shone through and we were left in no doubt that a breakthrough has been achieved - but it is important to note this is by no means the end of the story, rather we maybe just at the start of something new.

Alison began by telling us she was one of the first 'Fight for Sight' PhD students, beginning her career on retinal and corneal conditions at Newcastle University. She is now a Professor of Molecular Genetics, Deputy Director of UCL Institute of Ophthalmology and Deputy Director of Research. University College London (UCL) works closely with Moorfields Eye Hospital. She went on to say that we understand surprisingly little about the mechanisms behind KC, ie why the cornea loses its biomechanics properties.

In fact, detailed images of the stroma (the bulk of the cornea) provide no clue as to any differences between 'normal' and thinned corneas.

It is known that genes play a role in KC along with environmental factors and possibly eye rubbing (but that may be because of associated allergies; so which is cause and which is effect?) which means that KC is a 'complex disease' or, in other words, there is no one gene which causes KC.

Alison and her team's goal is to find the genes causing KC and use that information to predict the risk of the disease in suspect cases and also to develop new therapies to prevent progression. There is evidence for a genetic predisposition to KC showing family history in about 10% of cases. However, KC is not a classic genetic condition linked to a specific gene; for example, identical twins can develop KC several years apart.

Getting into the genetics but trying to avoid too much detail, there are about 3 billion nucleotides (the building blocks of DNA) spread over our 23 pairs of chromosomes. Genes are made up of DNA and some genes act as instructions to make molecules called proteins which in turn make up our body's cells. Only about 2% of our DNA carries the code for a protein but we all have slightly different gene sequences due to genes changing. The challenge is to identify which changes affect eyes. The vast majority of our DNA is non-coding but determines where, when, how much and for how long to express genes. There are millions of differences in the human genome so any study needs lots of DNA samples to analyse and lots of control DNA samples.

Alison explained her recent key experiment across the human genome to get a comparison of the frequency of occurrence of any genes in people with KC versus a non-KC control group and the care that had to be taken to ensure a solid data set. Much numerical analysis was needed and the funding the KC Group had provided enabled some of this work which is now approaching completion with a paper soon to be published entitled Genome-Wide Association Study Identifies Novel Variants Associated with Corneal Biomechanical Properties and Potentially Conferring Susceptibility to Keratoconus.

In summary, the exciting news is that 5 new genes have been found with some association with KC and the results are giving real insight.

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Alison stressed again that it is going to be gene combinations linked to KC, not single genes.

Looking ahead to build on this work, they have secured funding for a really big experiment in collaboration with other groups in the UK, Australia and the Czech Republic to combine DNA samples covering some 3300 individuals of various ethnicities. A large sample is needed to provide a significant statistical base and find a large number of genes likely to be involved. The next phase needs significant funding to eventually work out the mechanisms causing KC.

In conclusion, there is now the hope that if a person's risk of developing KC can be identified genetically then there could be early intervention to prevent it ever causing loss of vision! That is quite a claim and I think we can only say to Alison and the team 'Keep Going!"

The Keratoconus Symposium April 2019

Once again, the Group sponsored, exhibited and presented at this event (see our winter 2019 newsletter for an account of the previous symposium). It was held over 3 days in Hertford Castle and organised by **Ken Pullum** and his team. It was attended over the three days by 25+ delegates, mostly optometrists, along with our own David Gable, Julia Barby and Mike Oliver. The delegates were not just from the UK, but from as far afield as Gibraltar, Italy, The Netherlands, Serbia and the USA.

The group funded two delegates and this was match-funded by the organisers so a further two places were supported. Moorfields Eye Hospital was heavily represented amongst both speakers and delegates, all happy to engage with us and listen to patient comments and worries. As a result, **Vijay Anand** (of Moorfields) has agreed to speak at a forthcoming Group meeting (others have also promised to do so in the future).

Sight Village

(The UK's leading exhibition of technology, equipment and services for people with a visual impairment)

Tuesday 5th &
Wednesday 6th
November 2019
Kensington Town
Hall, London
W8 7NX

Moorfields Eye to Eye Walk

Sunday
8th March 2020
To Join the KC
team Contact
David on
07927 178716

On the last day, **Prof. Roger Buckley** also took an active role, while Julia played a “specimen” patient trying various lenses and working with delegates in the practical sessions.

Other sponsors included Bausch + Lomb, Jack Allen contact lenses and Eaglet Eye. As sponsors, we had the opportunity to present. This provoked considerable interest/response and a number of promising contacts were made. Not least, discussions with Bausch + Lomb have led to an invitation to present to their team in Hastings. David and Mike were asked to visit them in June and it is hoped this may lead to a productive working relationship.

Events like this are crucial in letting the current and next generation of optometrists know not only how much we need and appreciate them, but also helping them better understand our fears, concerns and needs - both individual and general – along with the benefits of mutual understanding and exchange of information. Thankfully, it seems they think the same way!

After a generous donation by one of our members, the Group has already confirmed sponsorship of a further two places at the next of these events (in October this year) which Mike Oliver has been invited (for the first time) to chair.

Visit to Bausch + Lomb’s Factory in Hastings

Mike Oliver and David Gable were invited to Bausch + Lomb’s Hastings facility to see how RGP contact lenses and specialised Scleral lenses are made and speak to the staff.

They received an enthusiastic welcome and production was put on hold for an hour to allow all the staff to gather in their meeting room. **Alan Bennett**, Quality Assurance Manager gave a short history of how their niche division within such a large organisation came to specialise in this sector of the market, producing finely crafted Scleral lenses which have kept many keratoconic patients away from the surgeon’s knife. He impressed upon his staff the importance of their work, saying, “what we make is not just cosmetic”, and gave an example of making a lens enabling a woman to see her granddaughter for the first time. He was, rightly, particularly proud of a card and photos from a Downs Syndrome parent thanking him for the difference their lens had made to her son.

In turn, a presentation was made to the staff about the problems and concerns facing those with Keratoconus, how everyday life – not least education and work – are affected and the benefits we derive from the lenses they produce. The ways in which the Group strives to address these issues were also explained.

As **Linda Griffin**, Technical Manager said afterward, “This has been an excellent learning event for us all, and to be able to hear about how our products impact your lives was truly inspiring!”

When the staff returned to their highly specialised diamond cutting equipment, Mike and David were given a tour of the plant and laboratory where they saw first hand the skilful processes and care taken to personalise each lens to meet precise specifications.

It is both reassuring and encouraging to see a small, dedicated team of approximately 20 motivated staff, working in such an efficient and cohesive way for our benefit. This is a particularly positive development since they form part of such a substantial organisation, operating internationally and producing contact lens, solutions and other products. Their interest and support in the products we rely upon helps provide a more secure outlook in what remains a niche, though expanding and developing, area.

> *“This has been an excellent learning event for us all”*

My First Year as Chairman by David Gable

It has been a pleasure being Chairman this past year and a challenge to take over from Mike Oliver who has loyally performed this role for many years. I have enjoyed the opportunity to get involved with the nuts and bolts of what we are about.

The more the group progresses, the more choices there are, compromises to be made and decisions to be taken; by the bodies who fund the activities, the healthcare professionals and the patients. All this requires information and cross-pollination between the interested parties. Patient groups like ours are becoming increasingly important, respected and valued.

Our meetings in London and Birmingham have been a great success and we have made a promising start in Brighton. We are hoping to start a new group in Bristol.

This year we have upgraded our website which is now much easier to use and keep relevant. In this regard, we welcome comments and ideas for things to post. It is not an authoritative source, more a directory to point visitors in the right direction.

It would be good to say that our work is done in that screening programmes were identifying KC at an early stage, access to cross-linking was readily available, contact lenses were always comfortable, and completely safe and guaranteed surgical procedures were on hand when contact lenses cease to do the job.

But life is not like that and living with KC is a series of decisions and compromises. There is no definitive solution. To navigate we need information. We need to talk to each other and share coping strategies. We need to meet the professionals in a non-clinical environment where we can ask questions and develop lines of thought from other people's questions. We need to play our part in research projects and feedback the results of those projects.

The future is bright and I am looking forward to spreading the message in 2020.

Outbreak of preventable eye infection in contact lens wearers

A new outbreak of a rare but preventable eye infection (Acanthamoeba keratitis), that can cause blindness, has been identified in contact lens wearers in a new study led by UCL and Moorfields Eye Hospital researchers.

“People who wear reusable contact lenses need to make sure they thoroughly wash and dry their hands before handling contact lenses, and avoid wearing them while swimming, face washing or bathing. Daily disposable lenses, which eliminate the need for contact lens cases or solutions, may be safer and we are currently analysing our data to establish the risk factors for these,” said Professor Dart.

The full article can be found on the Moorfields Website:

https://www.moorfields.nhs.uk/news/outbreak-preventable-eye-infection-contact-lens-wearers

Get Involved

Thanks to our fundraisers

A huge thank you to **Bill Jaspal**, who raised £2,020 for our charity by giving up alcohol for October last year. On his Justgiving page, Bill talked about wanting to raise money for research into KC. We have again partnered with the charity Fight for Sight to fund a Small Grant Award for research into KC for the year 2019/20. Researchers should apply here: https://www.fightforsight.org.uk/apply-for-funding/funding-opportunities/small-grant-awards-schemes/

Thank you also to the KC team who signed up for the Moorfields Eye to Eye Walk in March. Between them, they raised over £1,000 which will be used for research into KC at Moorfields.

2020 Conference

We are busy planning our next big event and the year is very appropriate. Because of the relevance of 20/20 vision we had to continue the theme and hold it on 6/6. So the date will be 6th June 2020.

We are really excited by the prospect of having some excellent speakers to inform and enlighten us.

So don’t forget to put the date in your diary and look out for further details.

Remember to visit our website for up to date information at:

https://www.keratoconus-group.org.uk

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