

Keratoconus Group News

Summer 2002

Keratoconus is a condition of the eye meaning cone-shaped cornea
Registered Charity 1057629



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SUPPORT THE THAMES PATH WALK

2001 CONFERENCE REPORT NOW AVAILABLE

FREE TO MEMBERS
£5 NON-MEMBERS

LARGE PRINT VERSION
AVAILABLE ON REQUEST

Diary Dates

Thames Path Walk

Saturday 7 September
- Wednesday 18 September

Welcome to the Summer 2002 edition of the Keratoconus Group newsletter. The past twelve months have been busy for the Group and the next twelve promise to be just as busy.

Enclosed with this mailing is the report of the first Keratoconus Group conference held at the King's Fund in March 2001. This report is provided free to all members so that all members, particularly those that were unable to come, have a record of what proved to be an extremely successful conference. Of course any contributions to offset the cost of producing the report will be gratefully received. Extra copies for friends, relatives or medical professionals can be ordered from the Group at the price of £5 per report. A large print version of the report is available free of charge – please contact the Group if you require this version.

On page 4 there are details of the Thames Path Walk and find enclosed with this newsletter a sponsor form. Please support this event, by joining in for a stage or sponsoring the participants.

The Group has also started a dialogue with health professionals at Moorfields Eye Hospital and we are one of the first patient group's to liaise with the new patient liaison service (PALS).

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AGM March 2002

The Group AGM was held at Moorfields on Saturday 16 March 2002. Although the guest speakers could not make it, Ken Pullum stepped into the breach with a talk and slides. He also took an active part in the general discussion. The meeting was well attended by members.

Committee members, Mark Bennister and Mike Oliver had met Dan Ehrlich and Dr. Moodaley along with the newly formed Patients Advisory Liaison Service (PALS) during the week before. Ours was the first patient group to have met with PALS at Moorfields. There were helpful discussions about clinic procedures, patient concerns and other issues (see below). As a result we have had direct input into the revised patient information leaflet.

At a short committee meeting before the AGM publication of the 2001 conference booklet was finalised. Funding was also agreed to secure our web name and further develop the web discussion group. The AGM reported on a successful past 12 months for the group, presented the annual accounts and elected the new committee. Accounts are available to all members on request. After the formal business the general discussion covered closer monitoring of web discussion group. We will be making the discussion page a more easily searchable resource. A summary report from Anne Klepacz listed the nature of telephone calls and queries received via post and telephone. This is a helpful indicator of people's concerns and ties in with the web discussion queries. Further booklets dealing with particular areas of concern are being actively considered and planned.

Dialogue with Moorfields March 2002

Mike Oliver and Mark Bennister met with Dan Ehrlich, Head of the Moorfields contact lens clinic and Dr Lali Moodaley, consultant ophthalmologist at Moorfield's on March 2002. Also present was Jessica Brinsmead of the new Patient Advisory and Liaison Service (PALS). This meeting is part of the initiative that came out of our first national conference in March 2001 to generate a dialogue with Moorfields and work together on improving the service. The meeting centred on the response to the member's meeting that we held in October 2001. The meeting was a successful first step in developing a regular dialogue (we are due to meet again in July 2002), and provided an excellent forum for exchanging patients experiences with those of the health professionals.. We were asked for our comments on an amended patient leaflet on contact lens provision, available at the clinic. We have subsequently provided comments some of which, (making the leaflet available in large print) were taken on board. Please let us know if you have any comments to feed into this process.

News News News News News News

My dream is my sight ...

Imagine a life and you barely can see,
Then remember the people who have KC,
A condition I have which affects my sight
Not only at day, but also at night.

I struggle at school,
Get help from a few,
But for the person I am,
Only perfect will do.

To look at me, you can see no wrong,
But inside the disease is fighting so strong.
The lenses I have fit so bad,
That at times it is hard not to feel sad.

Now imagine a place, deep in your mind,
Search for that something you long to find.
Finally it's there, just in your grasp,
Til you open your eyes and it's gone just as fast.

My dream is my sight,
So perfect and clear.
Yet when I wake in the morning
It's simply not here.

My wishes and dreams,
I cannot forget.
But maybe in time,
My wish I might get.

Emma Reilly

Information booklet for schools and colleges

Members with internet access will already have seen a lively correspondence on our website discussion group resulting from the problems one of our members was having persuading her school to take her difficulties seriously. As a result of this and similar experiences from other young people, we are planning to produce an information booklet aimed specifically at schools, colleges, and universities. It would give background information about keratoconus; the sorts of problems students may experience, and give suggestions to teachers and lecturers on how they can help.

One of our members, Janet Manning, a former teacher, has offered to draft the booklet. In her note on the discussion page she says "It would be particularly valuable if students (school and college) and teachers could comment on the draft and a few brief personal stories about good support received might encourage other institutions. These should also include what students with keratoconus have achieved." If you have a contribution or would like to see the draft for comments/additions, you can e-mail Janet at janetmanning@lineone.net or write to Anne Klepacz at the PO Box address.

Thames Path Walk

September is fast approaching, many members have expressed interest in taking part in the walk. Mike Oliver will be walking the whole distance, but anyone is welcome to take part and walk particular sections. The stages from Marlow to Shepperton are at the weekend. It would be good to have a decent number at the finish around Tower Bridge.

ITINERARY

SATURDAY 7 SEPTEMBER	KEMBLE TO CASTLE EASTON	17 MILES
SUNDAY 8 SEPTEMBER	CASTLE EASTON TO TADPOLE BRIDGE	17 MILES
MONDAY 9 SEPTEMBER	TADPOLE BRIDGE TO OXFORD	20 MILES
TUESDAY 10 SEPTEMBER	OXFORD TO DAYS LOCK	17 MILES
WEDNESDAY 11 SEPTEMBER	DAYS LOCK TO PANGBOURNE	17 MILES
THURSDAY 12 SEPTEMBER	PANGBOURNE TO SHIPLAKE	13 MILES
FRIDAY 13 SEPTEMBER	SHIPLAKE TO MARLOW	11 MILES
SATURDAY 14 SEPTEMBER	MARLOW TO WINDSOR	14.5 MILES
SUNDAY 15 SEPTEMBER	WINDSOR TO SHEPPERTON	13.5 MILES
MONDAY 16 SEPTEMBER	SHEPPERTON TO TEDDINGTON	11 MILES
TUESDAY 17 SEPTEMBER	TEDDINGTON TO PUTNEY	11.5 MILES
WEDNESDAY 18 SEPTEMBER	PUTNEY TO TOWER BRIDGE	10 MILES

A number of potential sponsors have been approached and we hope to raise money from individual sponsorship too. All money raised will be used to further the Group's aims and objectives and raise awareness of keratoconus. A sponsor form for Mike is enclosed with this newsletter. Individuals walking particularly stages can get personalised forms.

Mike Oliver, Chair 020 8318 9539

Can you help?

One of our members who had a graft 12 years ago has now been told that she has irregular vessel growth around and going into the graft. Has anyone else experienced this very rare complication? If so, please drop a note to me (Anne Klepacz) at the group address or ring me on the group telephone number.

New Committee

Mike Oliver	Anne Klepacz
Mark Bennister	Phil Davis
Moira O'Brien	Matt Allgood
Ivan Parrott	Nailah Smith
Amanda Stigle	Jacqui Danso
Val Pearman	