

## **Open Meeting & AGM – 18 May 2024 – Minutes**

*Text in underscored italic is post meeting information*

**Present:** Sennen Chiu, Lyn Duffus, Matt Edwards (Practice Manager), Purminder Gandhu, Joe Hamilton, Rhian Ingram, Keith Marshall (Chairman), Noreen Marshall, Phiroze Munshi, Bharti Sadhu

**Apologies:** Jean Alden, Harsha Mortemore (Vice-Chair), Mark Turkish

### **1. Welcome**

1. Keith welcomed everyone; and everyone introduced themselves.

### **2. Minutes of the Previous Meeting**

1. The minutes of the Open Meeting on 3 April 2024 were agreed and signed.

### **3. Annual Report**

1. Keith introduced the Annual Report for 2023-24, previously circulated.
2. Highlights included:
  - Another year of marking time, for many reasons and not just Covid restrictions.
  - The group currently has 85 patient members who are split fairly evenly between direct members and those joined to the Facebook group (with a small overlap).
  - There were 5 meetings during the year; the sixth (March) meeting was postponed to April 2024 so will be counted in the current year).
  - 14 patient members attended at least one of the five meetings.
  - The monthly informal calls were not well attended and not continued in 2024.
  - Keith, Purminder and Matt started looking at what we can do to improve patient engagement, access etc. with both the group and the Practice.
  - There were three talks at the meetings, Nurse Karen on asthma; Matt on the role of the Practice Manager; and Keith on sleep apnoea.
  - The Practice's distribution of their newsletter *Barnabas Bulletin* (which we edit) was disappointing due to a constraint on the number of text messages the Practice can send. Matt advised that this constraint was getting worse, and we need to investigate alternatives. **Action: Matt/Keith**
3. Looking Forward
  - We must continue the patient engagement work and agree priority actions.
  - We would all like more in-person meetings; Zoom is very useful but not as good. Matt indicated that the Practice could host a third Saturday morning meeting. **Action: Matt/Keith**
  - We should have more talks at our Open Meetings. **Action: Keith**
4. The Annual Report was unanimously approved.

5. Keith pointed out that the election of officers was not required this year, as he and Harsha (Vice-Chair) were elected at last year's AGM for two years.
6. Sennen proposed a vote of thanks to Keith for his efforts on behalf of the group. This was unanimously approved.
7. Keith reiterated the group's thanks and appreciation for everyone at the Practice for the continuing excellent care. We remain one of the best teams around.

#### **4. Talk: The Journey to Kidney Dialysis**

1. Noreen talked about her journey over the last several years having been diagnosed with very rare hereditary amyloidosis (A-fib). She highlighted:
  - About 8 years ago, Dr Jey was concerned with a high level of protein in my urine. She insisted that the relevant department at Hammersmith Hospital find the cause – and thank goodness that she did!
  - Many tests (including a rather painful kidney biopsy) later, I was told that I had hereditary amyloidosis.
  - That means that I've inherited it from my family. Family history has long been an interest of mine, so it's tempting to say this is my ancestors getting their own back for my poking my nose into what earlier generations were up to!
  - My mother died of kidney failure in 1993. She wasn't diagnosed with amyloidosis; at that time it was known about in concept but had not been studied.
  - The amyloidosis evidently does come from my mother's family: one of her nephews had it, and two of his children have it. What I had forgotten was that my father's father also died of kidney failure in 1936! So I may get it from both sides of my family.
  - Like all amyloidosis patients in the UK I was referred to the National Amyloidosis Centre (NAC) at the Royal Free Hospital. However as there is no treatment, there is little they can do other than give me an annual checkup.
  - Hereditary Amyloidosis is extremely rare. The NAC has a total of around 5000 registered patients – that's everyone in the country with any form of amyloidosis. The vast majority have the other basic type 'wild' amyloidosis; this can affect any part of the body, and can result in multiple disabilities.
  - So what is it? Basically my amyloidosis is a condition where amyloid proteins gradually clog up the kidneys. It's a bit like water pipes getting blocked with limescale, or kettles furring up.
  - We watched and waited while my kidney function declined at about 1% a month. The kidneys filter fewer and fewer toxins from the blood into urine, so the patient is slowly being poisoned. At my worst (end of April this year, with kidney function down to 2-3%), I could eat no more than a slice of bread smeared with cream cheese a couple of times a day; I had no energy; was feeling sick much of the time; and was constantly falling asleep.
  - The only quickly available treatment for my form of amyloidosis is dialysis. There are two types:
    - Haemodialysis is where a machine removes and cleans the patient's blood, and puts it back again. This happens three times a week, usually in hospital.
    - Peritoneal dialysis uses the lining on the inside of the abdomen (the peritoneum) as a natural filter for blood. This is carried out by the patient at home, using a cleansing fluid that is drained out of the body into a bag.
  - Having experience of my mother doing peritoneal dialysis – several times a day, every day – I opted for haemodialysis and am currently being transported to and

from Ealing Hospital three evenings a week for it. There is so much demand for dialysis that most patients get no choice over which hospital they go to, or which days or times of day, at least to begin with.

- Haemodialysis is normally done through a fistula in the arm; this is where an artery and vein are joined to facilitate access. I cannot have this as my veins are too small (although there is a more complex alternative, called a graft, which may be possible). Consequently I have a Tesio line in my chest for access.
- I'm now three weeks into dialysis. Even just the first couple of sessions of dialysis made such a vast improvement. Within days I was feeling many times better, although I'm still recovering my energy and appetite.
- One of the downsides of dialysis is having to follow a fairly restricted diet, to reduce both potassium and phosphate. That takes out many foods, including a lot of fruit and vegetables (unless the vegetables are boiled to remove the potassium) – but somehow you're still supposed to get your 5-a-day!
- I'm looked after by a number of different groups:
  - I go to Ealing Hospital for dialysis,
  - I go to a renal clinic at Hammersmith Hospital,
  - once a year I have an all-day checkup at the National Amyloidosis Centre,
  - the Practice deals with my prescription drugs for blood pressure and my phosphate blockers.
- As there is no treatment for amyloidosis, the only other option is a kidney transplant, but that may take years to achieve. It's a complex process with some risks, and involves taking a great many drugs.

## 5. Members Feedback & Issues

1. Keith provided a quick update on the Covid situation.  
Infection rates are now low, although they're rising again due to waning immunity and the new KP.2 variant.  
However Covid is not (yet?) at the stage of being a seasonal cold.
2. Matt volunteered to talk at the September meeting about his back operation.  
**Action: Matt/Keith**
3. In response to a question, Keith committed to find the publicly available data on patient use of online services. **Action: Keith**
4. Matt was asked to recap on the situation with the proposed "same day hubs".
  - The proposal was poorly conceived and not consulted; the consequent uprising against it caused it to be postponed – but it could still happen next year.
  - If it is implemented it will be much more built around the needs of the patients and the practices.
  - Any use of Physician Associates (PAs) means an increased workload for GPs, as there has to be one GP to supervise every three PAs. This is not sustainable.

## 6. Practice Updates

1. *Staff Updates*
  - Dr Carey has now left
  - Sadly the Practice is also losing Dr Fong; she is leaving for personal reasons.
  - Two new salaried GPs have been appointed and the Practice is interviewing further candidates next week with the aim of having five salaried GPs.
  - Receptionist Nicole is also sadly leaving, again for personal reasons.

- The Practice will be interviewing for additional receptionists in the coming weeks.
- 2. *Phone System*
  - The call-back facility is expected to be in place in the next month or so.
- 3. *Refurbishment*
  - This may or may not happen as there is a problem with the quotes provided.
  - Keith still has to reinstate the noticeboards. **Action: Keith**
- 4. *Statutory Medical Examiners*
  - From September all deaths, which are not otherwise referred to the Coroner, have by law to be reviewed by a Medical Examiner (a Senior Doctor) before the Death Certificate can go to the Registrars.
  - The intention is to avoid occurrences such as those of Harold Shipman and Lucy Letby.
  - Many areas have been operating this process voluntarily for some time. Matt commented that this has been in place in Ealing for a while and works well.

## 7. Other Group Updates

1. *PPG Awareness Week*

Phiroze asked if we were planning anything for PPG Awareness Week (3-9 June).

  - Keith hopes to publish the June *Barnabas Bulletin* that week.
  - Keith is also planning a couple of walk-in clinics on use of online resources such as the NHS App. Dates/times to be agreed. Anyone who can help with this, please get in touch with Keith. **Action: All**
2. *Barnabas Bulletin*
  - Please let Keith know of any ideas or suggestions for articles. **Action: All**

## 8. Matters Arising, AOB

1. There was no further business.
2. **Next Open Meeting:** Wednesday 17 July; 13:00.

Keith C Marshall, Chairman  
19 May 2024

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## Proposed 2024 Meeting Dates

- Wednesday 17 July; 13:00; Zoom (or Church Hall)
- Saturday 14 September; 11:00; Medical Centre
- Wednesday 20 November; 13:00; Zoom (or Church Hall)

**Dates/times may change depending on the availability of venues (especially the Church facilities). Watch the Members' Monthly Update for confirmation of dates and venues.**

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## Link for all Zoom Meetings

Link: <https://us02web.zoom.us/j/7279594414?pwd=VmYwODdoWGg2eTFvTlVjVlZyRmhSQ09>  
Meeting ID: 727 959 4414  
Passcode: 149417

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