

## A Charitable View

### Introduction - Self

1. Before go any further, let me tell you a story; on 18 April – 10 days ago - UK Vision Strategy was launched and 650 – yes, the figure is correct – sight loss organisations signed up to it, signed up to cooperate with each-other. CEO of RNIB said, and I quote “I was astounded that we did not all get along with each other. Mythology, misunderstanding and resentment had developed over decades – we had to get together. Other groups setting up coalitions could learn from this – they tend to become talking shops so you need to prevent this but you still need to listen to people”
2. Gentlemen, I think this is a humbling lesson to all of us.
3. Why? Because this is effectively what you are all here today to talk about, to discuss, to make decisions on. I say you, not us, because it is actually nothing whatsoever to do with me – I run a charity, not a support group , and I while I am delighted to facilitate what you do, I would never try to tell you what to do.

### AIM

4. So what actually is the aim of my brief talk to get this day started? It is to give you one charity’s view – that of Prostate UK - of how vital we think you are, and to suggest that, by cooperating together you will be able to achieve even more.
5. Kipling said “bwanso ko tagat hul ho, tara hul ko tagat bwanso ho” and I am sure that, for you who speak nepali, this is obvious – in English ----. I commend it to you as a credo.

### PUK

6. But just who is this organisation which I have the honour to represent? Who are Prostate UK?
  - a. All Prostate diseases/ Info/ Awareness/ Fund Research /Training of Med professionals. All FREE. People not just men.
  - b. More detail – Diseases –
    - i PCa – 35K, 10 K
    - ii BPH – may not kill, but – half of all men

- iii Prostatitis – 25% of med appt with urologists in USA, not even NICE guidelines in UK – treat like STD
- c. Info – DVDs, Web, Brochures, magazine UPDATE – on each disease, plus intro, plus IIB for women, plus Sex and Prostate, plus health.
- d. Research –Grants in Oct, awards in March, 10% up per year – always more than half total income – 33%, 24%, 11%. 120 projects in last 8 years mainly PCa, problems, dry topic. £3.4M since 2000
- e. Training – main area of expansion
  - i Individual – Australia and France in July
  - ii Group – Seminars – UK wide – Cardiff, Belfast, Edinburgh, Southampton London, Manchester etc. 6 per year - next in Reading on 9 May. On 18 April we ran our 9<sup>th</sup> in Leeds – 1000<sup>th</sup> medic. 60% admit little or no knowledge, 100% Very good or excellent.
  - iii Why? First Contact – NICE
  - iv Fund orgs like BAUN, Federation etc.
- f. Seven years ago income - £360K, this FY £1.5M.

## 7. Why we involved here?

- a. First, what we are not involved in.
  - i Not an attempt to take over Sp GPs
  - ii Not an attempt to dictate, to tell you what should be doing – that is up to you.
  - iii Not an attempt to interfere with or even get involved with, the running of any federation or whatever organisation that emerges from today.
- b. What are we involved in ?
  - iv It is an attempt to improve the lot of people affected by PCa.
  - v It is an attempt to urge you to cooperate in helping each other, be it with just help and comfort on one side to maybe advocacy on the other
  - vi It is an attempt to remind you of Kipling.
  - vii From a purely selfish reason, it is an attempt to get you to produce a UK wide web of contacts so that, when a woman in tears or a man in distress telephones me and asks me for someone to whom they can talk, I can give him the phone

number or address of someone like you who is nearby, who will understand, who can help, who will make real difference to that persons life at a time when help is so desperately needed. That actually is all we would love to see come out of this.

### So what do we think of you?

8. Well, I have learnt that support Groups are a curates egg, and suggest to you that they are probably range from:
  - a. Those groups, often founded and led by a charismatic individual, but whose membership is more by chance than intention and which, when the founder moves on, go into terminal decline.
  - b. At the other extreme to groups which are properly organised so that they can survive the loss of the motivating individuals, who ensure that the local hospitals, GPs, Urologists, Oncologists, newspapers, radio stations, Rotary clubs , charities etc know of their existence, who are easy to contact, who have an open arms approach, a clear aim and a future.
  - c. I said nothing about size. Does it matter if there are 3 or thirty members – I personally believe not. Graham Fulfords organisation – and he is here today – is tiny, yet by goodness me do they deliver the goods.

### Are you important?

9. I think you are absolutely vital. You deliver something no one else can – the interface between the medical professional and real life. You know what having PCa means better than the best expert, better than the chap like me running a charity, better than the nurse at the end of the telephone helpline.
10. You may not know what the latest drugs are, what the latest NHS guidelines are - that is a problem for charities like mine or the medical professionals – but you do know what it is like to have PCa, or to have had a loved one suffer from it – and you are prepared to share this with others who need your help and love at what will be possibly the most terrifying and traumatic period of their lives. With respect, that is the best possible qualification in the world.

### How can we help you?

11. Treat us as your own resource. You want information Booklets – simply ask. You want our magazines – ask. You want to know more about prostate diseases – come along to one of our seminars – you will find that you may know more than many healthcare professionals.
12. We are already funding the formation of the federation, and those involved quite rightly demanded assurances from us that we were in no way trying to dictate how or what you do, or try to influence events. We are funding this first meeting. And assuming you get off the ground, Prostate UK will give the Federation a sum of money to disburse to help support groups get going – be it for setting up a website, paying for adverts in local papers or whatever. We have committed £12,500 of our hard-earned funds to you because we believe in you.
13. I could witter on about the Objectives of the Federation, which range from simply helping the formation of local support groups throughout UK to the acting as a forum for patient led groups to make their views known on everything from necessary improvements in the health Service, research priorities, and raising awareness, and whether and how you translate agreement into action. But all this is your business, not that of Prostate UK.
14. But I will wish you success, and I do hope that you are able to work together, whether it be simply a loose cooperation to close collaboration.
15. All we would love to see emerge is that when someone who needs help contacts us, we have someone to whom we can refer them to easily and with confidence: anything else is a bonus.
16. Thank you.

## 18 Apr 2008 - UK Vision Strategy Launched!

The UK Vision Strategy is a VISION 2020 UK initiative, led by RNIB working with partners from all areas of the sector, to develop a unified plan for action on all issues relating to eye health and sight loss, across the four countries of the UK. The strategy was developed in response to a World Health Assembly resolution in 2003, which urged the development of national plans to tackle sight loss. The development has also been supported by representation from all the UK governments.

Sight is the sense that nine out of ten people most fear losing, according to the findings of a survey released today (18 April 2008). The UK Vision Strategy - developed by a major new eye health and sight loss alliance - is calling for action to prevent their fears becoming a reality.

Over 650 organisations and individuals, with support from the UK Governments, developed the UK Vision Strategy, launched today, to set the direction for a radical improvement in the eye health of the nation.

Lesley-Anne Alexander, Chair of the group leading the development of the UK Vision Strategy and Chief Executive of the Royal National Institute of Blind People (RNIB), said: "Nine out of ten people in the UK tell us that sight is the sense they most fear losing. But, despite being one of the richest nations in the developed world, we aren't doing enough to protect it. Sight loss increases with age and the UK has an aging population, so the number of people losing their sight is set to double in the next few decades if we don't intervene now. We're sitting on a sight loss time bomb!"

"The UK Vision Strategy enables us to build on past progress and the eye health and sight loss sector is committed to working together, with the UK Governments, to improve the eye health of the nation. We all need to take responsibility both professionally and personally - to improve eye health, eliminate avoidable sight loss and enhance the quality of life of people who have lost some or all of their sight."

The UK Vision Strategy is launched today (18 April) at a conference in central London.

### UK Vision Strategy

The UK Vision Strategy is a VISION 2020 UK initiative led by RNIB to develop a unified plan for action on all issues relating to vision, across the four countries of the UK. The UK Vision Strategy has brought together people with sight loss, users of eyecare services, eye health and social care professionals and statutory and voluntary organisations for the very first time to set the direction for eye health and sight loss services across the UK.

Three strategic outcomes areas are identified in the UK Vision Strategy:

- Improving the eye health of the people of the UK
- Eliminating avoidable sight loss and delivering excellent support for people with sight loss

#### Description of VISION 2020 UK

VISION 2020 UK is an umbrella organisation which facilitates greater collaboration and co-operation between organisations within the UK, which focus on vision impairment and operate on a national, regional or international basis.

[VISION 2020 UK is a supporting member of the VISION 2020 Global Initiative. For details of the worldwide programme or to make enquiries, please click anywhere on this text.](#)

VISION 2020 UKs objectives are:

- To prevent avoidable blindness
- To improve the quality of services to visually impaired people
- To improve the training available to professionals providing advice and services
- To improve communication between organisations within the VI Sector
- To improve the availability of information to visually impaired people
- To ensure that the voices of the visually impaired are heard when planning services and their opinions sought on key issues affecting their lives
- To raise public awareness of the issues and problems relating to sight loss

In addition to the above, VISION 2020 UK will seek to provide a unified response on key issues affecting

visually impaired people and to provide visual impairment sector representatives for consultation groups, working parties and project groups.