Birdshot Patient and Professional Day

Presentation to Moorfields Board
By BUS – The Birdshot Chorioretinopathy Uveitis Society
Rea Mattocks and Annie Folkard
The Birdshot Patient Journey

- Rea and Annie’s story - Two people with Birdshot

- Common issues
  - Rare diseases and medication issues
  - Little consistency in diagnosis and treatment
  - Poorly understood by professionals
  - Lack of whole system approach
  - Mental health and physical side effects of medication
The Formation of BUS

- Founded by Annie & Rea November 2009
- Supported by leading ophthalmologists
- Part of UIG
- Operates in four distinct fields
  - Eye world
  - Uveitis world
  - Rare Disease world
  - Auto-immune world
BUS and the Eye World

- Member of Vision 2020 UK
- Member of London Vision Impairment Forum
- Works with RNIB
- Contributes to All Party Parliamentary group on Eye Health
- In regular contact with RCO and Fight For Sight
- Links to international eye organisations (including INTUPIA) and sister Birdshot organisations in US and France
BUS and Uveitis

- Part of UIG
- Supports all people with Uveitis and provides information for professionals
- Developed MCN in Scotland
- Supported by leading national and international experts
- Displays at national and international uveitis and retinal conferences
- Lay member of CHRE and INVOLVE
BUS and Rare Diseases

- Member of EURORDIS and Orphanet
- Contributes to European wide surveys
- Contributes to All Party Parliamentary Group on Rare Diseases
- Member of Rare Disease UK
- Contributed to Rare Disease Strategy - presented to Parliamentary Reception on 28th February 2011
- Works with pharmaceuticals specialising in orphan diseases
BUS and Auto-immune Diseases

- In touch with auto-immune organisations nationally and internationally
- Posts all information on trials and studies on website
- Developed close links with charities working in the field of genetics and auto-immunity
- Member of the UK Genetic Alliance
BUS and Birdshot

- International Expertise on Birdshot including patient data-base, knowledge of all current treatment options, data-base of research and trials on Birdshot and uveitis
- 220 registered members + 200 patients in US and France
- Between 2,000 and 4,000 hits per month on website
- Displays Birdshot posters and leaflets in every specialist eye clinic in the UK
- Writes articles on Birdshot in popular publications
BUS and Patient Involvement

- Member of National Voices - regularly contributes to government consultation exercises
- Annie and Rea are expert patients
- Aim of BUS to empower all Birdshot patients

‘According to research, people who have trained in self-management tend to be more confident and less anxious. They make fewer visits to the doctor, can communicate better with health professionals, take less time off work, and are less likely to suffer acute episodes requiring admission to hospital’ – Dr Colin Tidy, MBBS, MRCP, MRCGP, DCH
Aims of BUS

- Raising profile of Birdshot
- Lobbying government, AGNSS, NHS to ensure fair share of funding
- Supporting patients, families and healthcare professionals
- Providing up-to-date information and advice
- Preventing avoidable blindness
- Holding Data-base of Birdshot, Nationally and internationally
- Promoting international links and international research networks
BUS / Moorfields Partnership

- Commenced in November 2009
- Miss Narciss Okhravi as Moorfields lead.

Aims

- Raising profile of Birdshot
- Developing a Birdshot network/community
- Improving expertise on Birdshot
- Developing protocols and guidelines for diagnosis and treatment
- Undertaking research
BUS / Moorfields Birdshot Day

Held in September 2010 for patients and professionals

Aims:

- Reducing isolation of patients
- Developing Birdshot Community
- Exchanging information - professionals and patients
- Improving knowledge base
- Helping to obtain better visual outcomes
- Providing base for research
Outcomes of the Day – Education

Greater understanding of:

- Individual nature of disease
- Need for individualised medication regimes
- Side effects of toxic medication regimes
- Genetic issues and multi generational effects
Outcomes of the Day – Treatment and Management

- Increased diagnosis rate and faster initial treatment
- Greater patient empowerment; patients in control of their disease, rather than the disease controlling them
- Greater understanding of, and compliance with medication regimes
- National and international recognition of the expertise held in the UK on Birdshot via BUS / Moorfields Partnership

6 month evaluation indicates all aims met.
Patient Responses

- “It was good to meet fellow sufferers and be able to empathise about the side effects of the drugs which puts things into perspective.”

- “Thank you again for all the hard work you have done to not only educate all of us but to also bring together a community where we can share in each others experiences and not feel alone.”

- “I no longer feel hopeless about my future – I now think I have a future. More importantly, I now think my children have a future.”
Professional Responses

“Birdshot Day was highly extraordinary and an opportunity for us as Healthcare professionals to reflect and gather our thoughts pertaining to our patients.”

“I am so glad I came! I now have a new vision!”

“I can’t begin to tell you how much I gained from attending the birdshot day – just from a research management viewpoint! I think we ought to set up a series of meetings like this involving patients, patient groups, clinicians and researchers.”
Getting the Message Out

The BUS Moorfields Partnership has exhibited at key conferences including:

- Vision 2020 UK
- Involve 2010
- RCO 2010
- Uveitis conference
- ARVO
Getting The Message Out

The example of this outstanding patient/professional partnership has been used to teach and educate:

- The NHS including ophthalmologists and students
- Other charities
- The government and the DH through Vision 2020, RCO, INVOLVE, RNIB, Rare Disease UK, the parliamentary reception on 28 February 2011
Benefits to the NHS and whole System

- Saving on NHS budget through compliance with medical regimes
- Preventing avoidable blindness and associated costs
- Saving on future health and social care (whole system)
- Saving on welfare budgets (keeping people in work)
- Saving on marital disharmony
- Improving expertise, leading to early diagnosis and treatment
- Empowering patients to be in control of their disease
- Prevention and self management
- Developing expert patients
Benefits of a Patient Organisation - Research

From EURORDIS Survey on “European Rare Disease Patient Groups in Research: current role and priorities for the future” November 2009, reporting 2010

- Patient Organisations (POs) have a high commitment to research
- POs show strong will to collaborate with researchers, not only by triggering encounters between clinicians, researchers and patients, but also by giving them logistical and financial support
- POs in Europe have devoted a total minimum of 13 million euro to research last year
Benefits of Patient Organisations to NHS

- POs not bound by NHS governance, confidentiality, protocol issues and have free access to their members
- Are non-political and not beholden to statutory agencies - Can freely lobby government, NHS, politicians, local authorities
- Can undertake speedy non-medical research
- Can develop data-bases and provide information and expertise to professionals
- Can help develop patient centred approaches and work with patients to take more responsibility for their own health and manage their health appropriately
- Can support and train professionals
Effectiveness of Birdshot Day

This model has proved to be:

- Extremely cost effective (costs of the conference and time of each individual involved)
- Extremely empowering for patients and healthcare professionals
- Extremely effective at getting the ‘message out’, leading to better diagnosis, treatment, and leading to prevention of avoidable blindness
- Extremely effective in raising the profile of Moorfields, BUS and Birdshot
- Extremely effective in providing a base for research
The Future

The model adopted by BUS / Moorfields Partnership is one that should be widely advertised and adopted across the public and third sectors (including the NHS, local authorities and welfare systems)

It meets all current requirements for patient empowerment, patient involvement, training for professionals, cost effectiveness and best outcomes

It meets current agenda for strategy for rare diseases (required to be implemented by 2013)
Thank You

BUS would like to work with Moorfields to disseminate this model more widely

BUS would like to thank you for allowing us this opportunity to present to the Board
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