Using Data

The Patient Focus

NCIN Brain / CNS Clinical Leads Workshop

16th May 2012



Brain Tumour Research



Brain Tumour UK



International Brain Tumour Alliance



Samantha Dickson Brain Tumour Trust



Campaigning for improved brain tumour policy and services

Priorities

- Presented Manifesto to APPG MPs in 2010:-
 - Ensure early diagnosis and treatment for brain tumour patients
 - Implement NICE's best practice guidance
 - Increase Government investment in brain tumour research

Raising the profile

- All Party Group Meeting
- Brain Tumour Summit
- Website and toolkit
- Mass Lobby on June 13th

Tools to raise awareness

- Statistics
- Secondary Tumours
- Survival

Early Diagnosis and Treatment

- Routes/time to diagnosis
- Life expectancy
- Improve diagnosis
 - Headsmart campaign
 - MacMillan research

Implementing NICE IOG

- New Health bill threat to the IOG
- NICE IOG saves money
- Tools supporting implementation:-
 - Evidence
 - Peer review

Increase investment in research

- Clinical trials
 - 19.8% of new cancer cases recruited 2010/11
 - Only 10.8% brain tumour patients entered
 - Only 1.1% into randomised trials
- Spend: NOT ENOUGH!

SUMMARY

We've achieved a lot in the past year – but we need your help to achieve more!

Thank you for your attention

Jenny Baker OBE Chief Executive Brain Tumour UK Wendy Fulcher
Founder
Brain Tumour Research Campaign











www.braintumourconsortium.org.uk