

RNIB Campaign update

for campaign supporters

January 2009

Dear campaign supporter,

We would like to extend a big thank you to all of you for your support during 2008 to tackle the exclusion faced by blind and partially sighted people. We look forward to working together with you during 2009 to build on this success.

We would also like to welcome all the new campaign supporters who have joined the Campaigns Supporters Network following the largest ever lobby of Parliament by blind and partially sighted people on 15 October 2008 for the Disability Living Allowance (DLA) campaign. As part of the network you will receive this campaign update three times a year in your preferred format. If you wish to be removed from the network, please contact our Campaigns hotline on 020 7391 2123 or email campaign@rnib.org.uk

Name your update – deadline extended for new campaign supporters

September's Campaign update asked for suggestions for a new and more exciting title for this publication. Thank you to everyone who sent in their great suggestions. We would like to give the hundreds of new campaign supporters who have just joined us a chance to "name your update", so we have extended the deadline. Please contact the Campaigns hotline on 020 7391 2123 or email campaign@rnib.org.uk with your suggestions for a new title.

“During autumn 2008, RNIB’s campaigns team expanded to include six Regional Campaigns Officers (RCOs).

They are looking for up to ten blind or partially sighted volunteer Campaign Co-ordinators in each region. If this interests you, please get in touch.”

See article on page 10

Inside this issue:

Campaign news

- Next steps for the Disability Living Allowance campaign 3
- Audio Description targets: now there’s no excuse 4

Campaign success

- Access to treatment for wet age-related macular degeneration 5
- Bad bus decision reversed for East Dorset residents 6
- Campaign voice 7

Contribute to new RNIB campaigns

- Action for independent living: what should councils do? 8
- Parent power: what changes can blind and partially sighted children and their families expect in 2009? 9

Regional campaigns update

- Meet RNIB’s regional campaigns team 10

Take action

We would really welcome your feedback on this update, and we are particularly keen to hear from campaign groups and individuals who have stories to tell about their experience of campaigning in their local communities.

Please contact Sally on the **Campaigns hotline** on **020 7391 2123**, or email **campaign@rnib.org.uk**

Campaign news

Next steps for the DLA campaign

Your continued support for the Disability Living Allowance (DLA) campaign is making a huge difference. An amazing 1,500 campaigners attended the lobby on the 15 October and hundreds of letters have been sent to MPs urging them to support you and to support the campaign. More MPs have signed EDM1982 than those that signed the one tabled in 2006.

Campaign jargon buster

An “Early Day Motion (EDM)” is a kind of parliamentary petition which helps to draw ministers’ attention to campaigns and demonstrate the level of parliamentary support for a particular cause or point of view.

“We have never been on anything like this before and thoroughly enjoyed the day and were lucky enough to meet our MP, Gwynn Prosser, who fully supports our case, and we would now feel confident enough to do a lobby again, if and when the need arises.” Diane Buse, RNIB campaign supporter, on her experience of the DLA lobby of Parliament in October.

Jonathan Shaw, the new Minister for Disabled People, spoke at the lobby. He said that the Government needs to look at how and when the changes could be made. The Government has asked RNIB to work with officials on further points around DLA.

We will keep on campaigning and there is action that Campaign Supporters can take too. The Queen’s Speech in early December heralded the start of a new Parliamentary Session, giving us the chance to table a new Early Day Motion that truly reflects



Campaign update

the Government announcement made after EDM1982 was tabled.

The new EDM340 notes the incredible support from MPs for this change and calls on the Government to make the change soon. Please write to your MP to ask them to sign the new EDM. We must keep up the pressure on the Government.

Working with MPs, we hope to have a debate on this issue in March or April and will be working with campaigners and local societies to encourage MPs to sign the new EDM340.

Take action

Local councils have been supporting the campaign too. Has yours? Please write a letter to your local paper asking if your council is supporting you and the campaign.

An update mailing with draft letters for MPs and local newspapers was sent out recently. If you haven't received this and would like to write to your MP or your local paper, please contact the **Campaigns hotline** on **020 7391 2123**.

Audio Description targets: now there's no excuse

"Audio description is brilliant – just fantastic. But there are still so many programmes that need it and don't have it. Why isn't there more audio description?"
Jean, Carlisle.

In 2006 Ofcom (the media regulator) said they would not increase the current 10 per cent audio description targets for broadcasters until awareness of audio description increased. So that's what we did. You may have seen some of the adverts on TV in early 2008. Awareness has increased from 42 per cent to 72 per cent amongst blind and partially sighted people.

Ofcom also said they needed to be "clearer" about usage of audio description. There is now much more equipment available that gets audio description. Over the next four years every registered blind

or partially sighted person will, for a maximum payment of £40, receive equipment that gets audio description as part of the Government help scheme for Digital TV switchover.

Now there's no excuse. It's time for the Government to double the audio description targets to 20 per cent.

Take action

In order for this to happen, MPs need to hear that you, their constituent, want more audio description. Please support the campaign by writing, phoning or emailing your MP.

We've provided draft letters that you can send to your MP or use as a basis to write your own letter. Contact us on **020 7391 2123** or email **campaign@rnib.org.uk**

Campaign success

Access to treatment for wet age-related macular degeneration (AMD)

On 24 November 2008 guidance from the National Institute for Health and Clinical Excellence (NICE), the body that decides which drugs and treatments are available on the NHS, came into force regarding the sight loss drug Lucentis used to treat wet age-related macular degeneration (AMD).

Wet AMD is the main cause of severe sight loss in the UK and after a two-year battle with NICE and the NHS, RNIB and campaign supporters successfully secured the provision of Lucentis for people with the condition.

From November, Primary Care Trusts (PCTs) in England and Health Boards in Wales are legally required to provide Lucentis as a treatment for wet AMD if prescribed by a consultant. The Government in Northern

Ireland has also made funding available to ensure all patients can be treated.

The success follows a hard fought campaign, won with the help of thousands of campaign supporters. Well done to all campaign supporters who helped achieve this victory.

But it's not over yet. Although PCTs are now legally required to provide treatment, we are aware that some health authorities are still dragging their feet or are convincing patients to accept treatment with an unlicensed alternative, Avastin. In some areas there are also problems because clinics do not have the capacity needed to deliver treatment.

Take action

If you are aware of anyone who is experiencing problems with access to Lucentis please contact the **Campaigns hotline** on **020 7391 2123**.



Bad bus decision reversed for East Dorset residents

Thanks to pressure applied to East Dorset Council by local blind and partially sighted campaigners, RNIB and Dorset Blind Association, concessionary bus pass holders now travel free in peak hours.



When blind and partially sighted people in East Dorset heard that the implementation of a government-wide concessionary bus pass would mean that they would no longer be able to use their pass before 9.30am they were outraged.

East Dorset residents were not alone. RNIB received a number of complaints from blind and partially sighted people whose local authorities have cut the existing discretionary travel scheme previously operated by their council.

RNIB, working with Dorset Blind Association contacted the council to

outline the impact that this decision would have on blind and partially sighted people. East Dorset Council subsequently announced, that as from the 1 December 2008, concessionary bus pass holders will now be able to travel free at all times. This is fantastic news for people who need to get to work early or attend appointments. Lancashire and Hampshire councils have reversed their decision too. However, other councils have refused to reverse their decision. Where this has happened, RNIB has made a complaint to the Local Government Ombudsman, and we expect to hear their decision soon.

We will of course let our campaign supporters know the result. If we are successful, we intend to use the Ombudsman's decision to challenge a number of authorities up and down the country to reverse their policies.

Take action

RNIB are trying to build up a national picture of where blind and partially sighted people have been affected by this issue.

If your peak time travel or companion pass has been affected, please let us know. Contact the Campaigns hotline on **020 7391 2123** or email

campaign@rnib.org.uk stating where possible which local council is involved, whether you have lost peak travel or companion passes (or both) and when you first realised that concessionary travel had been affected. It would also be helpful to know if you are aware of any consultation exercises that took place locally before the cuts were made.

Campaign voice

East Dorset resident, Michael Hall, felt it was vital to challenge the council decision on bus passes: “At the time I was having to attend early morning hospital appointments and it was costing £5 return for my wife and I. I thought – this isn’t really right. Other people, who have less eye sight than myself, would be inconvenienced too.”

Michael decided to write to the local council to ask them to reverse their decision and his story was covered in the local paper. He also contacted RNIB’s senior legal officer, Samantha Fothergill, who with the support of the Dorset Blind Association, wrote to East Dorset council.

Samantha comments:

“Our view is that the council acted unlawfully in withdrawing their discretionary travel schemes. Withdrawing free travel before 9.30am and/or withdrawing companion passes disadvantages blind and partially sighted people in a number of ways. It causes difficulty in travelling to work or to GP and hospital appointments or, in the case of the withdrawal of the companion pass, restricts travel at any time of day as a companion is prevented from travelling free with them.”

Jonathan Holyhead, Chief Executive Officer of Dorset Blind Association, who worked with RNIB to challenge the original decision, says:

“I’m really pleased that the council have recognised the impact which their original decision had on blind and partially sighted people and I applaud them for having both the sense and decency to reinstate the free travel before 9.30am. I hope that other councils will take notice of this and follow East Dorset’s lead”



Contribute to new RNIB campaigns

Action for independent living: what should councils do?

Growing numbers of campaign supporters have challenged their local authorities on the support that is available to blind and partially sighted people, using the Action for Independent Living campaigns pack. If you would like a copy of the pack, please contact the Campaigns hotline on 020 7391 2123, or your Regional Campaigns Officer (see “Meet RNIB’s Regional Campaigns Team” at the end of this update for contact details), stating your preferred format.

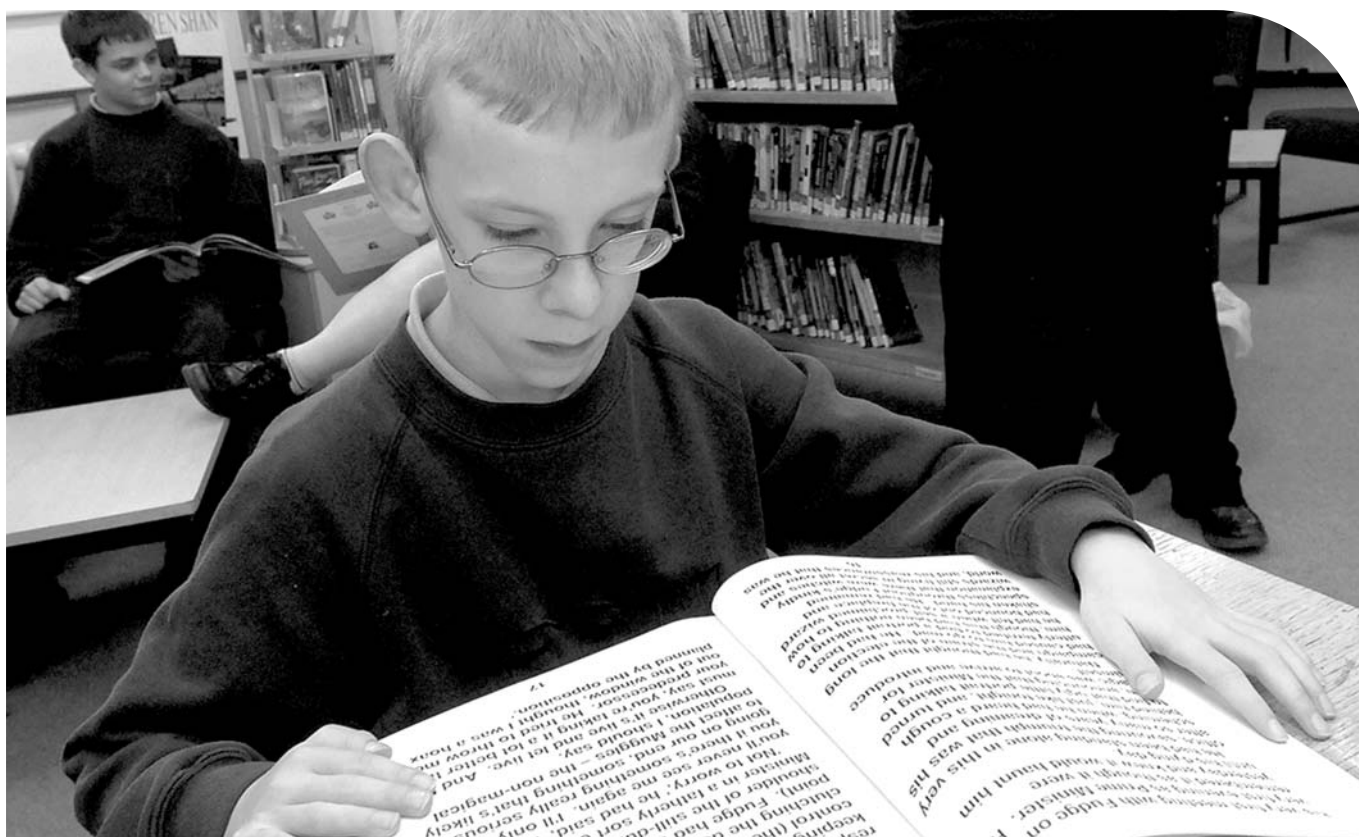
The campaigns team at RNIB are pressing central government to do all it can to improve the social care system at a national level. That means ensuring local authorities are judged on key things of importance to blind and partially sighted people, including high-quality assessments, carried out by skilled social care workers, the offer of timely emotional and practical support and training in the use of new equipment. At present local authorities are judged on a number of priorities, mainly defined by Government and social care inspectors. Over the next few months the Government is keen to work with organisations like RNIB so that in the future, social care services can be evaluated on outcomes defined by service users.

Take action

The Government wants to find out how it should judge whether councils are providing the services that people need. What do you think is important? How do you think local authorities can demonstrate they are enabling blind and partially sighted people to live independent lives? Should they be judged on the choices they offer to service users? Or perhaps dignity and respect with which service users are treated should be the priority?

If you would like to help influence central government thinking on this, please contact the **Campaigns hotline** on **020 7391 2123** and ask to speak to Andy Kaye.





Parent power: what changes can blind and partially sighted children and their families expect in 2009?

We hope 2009 will be the year that blind and partially sighted children and their families get greater clarity on the entitlements and local services they can expect.

For the first time parents of disabled children will get an opportunity to participate in a Government survey designed to explore their experiences of local education and health services.

The “Core offer” for disabled children and their parents will be implemented by every local authority and Primary Care Trust (PCT). This means families should be better informed and involved as children have their needs assessed.

It should be easier to find out what services are available. Government plans mean that from 2009, assessment of needs should be improved and parents should be able to get more information about their child’s school performance compared with their classmates.

Take action

What aspects of education do you think should be a priority for campaigning? Is higher attainment in school a priority? Do we need to campaign for greater access to the school curriculum? Or do you think there are other things the Government and public services need to focus on? We are interested in hearing your views on how we can campaign to ensure blind and partially sighted children get the education they deserve. Please call the **Campaigns hotline 020 7391 2123** and pass your thoughts on to Andy Kaye.

Regional campaigns

Meet RNIB's Regional campaigns team

During autumn 2008, RNIB's campaigns team expanded to include six Regional Campaigns Officers (RCOs) based in Liverpool, Leeds, Loughborough, Birmingham, Bristol and London. They have been getting out and about in their regions, talking with people about issues that affect blind and partially sighted people locally.



We are looking for up to ten blind or partially sighted volunteers in each region who will become a vital part of the organisation and development of the campaigns network across England. If this interests you, please do get in touch with your RCO. Support and training will be given.

Roy Ruddick

Regional Campaign Officer for Yorkshire, Humberside and the North East, based in Leeds

Previously, Roy worked in community based projects, human resources management and military aviation engineering.

“Since joining RNIB I have been mobilising support for the higher rate DLA and promoting the Action for independent living campaign. I'm looking forward to working to improve both eye health and services for blind and partially sighted people under the umbrella of the UK Vision Strategy.”

Telephone 0113 239 9410
Email roy.ruddick@rnib.org.uk



Lindsay Armstrong

Regional Campaigns Officer for the North West, based in Liverpool

Lindsay has worked at RNIB for over seven years in a variety of roles in information, marketing, delivering visual awareness training and managing the resource centre.



“I’ve spent the first few months in this post building relationships with a range of organisations across the region to raise awareness of our regional campaigning network and looking at how we can work in partnership. I am looking forward to working with our volunteer campaigners to achieve better services for blind and partially sighted people.”

Telephone 0151 298 3233

Email lindsay.armstrong@rnib.org.uk

Tara Melton

Regional Campaigns Officer for the South West, based in Bristol

Before joining RNIB Tara worked for Help the Aged in Wales as a Campaigns Officer.



“Over the next few months I am looking forward to working with blind and partially sighted people across the South West in engaging with local issues. I am also excited about the Action for Independent Living campaign which has huge potential to influence local councils to ensure that they provide high quality social care provision for blind and partially sighted people.”

Telephone 0117 934 1707

Email tara.melton@rnib.org.uk

Rebecca Swift

Regional Campaigns Officer for the West Midlands, based in Birmingham

Before becoming an RCO at RNIB Rebecca worked in mental health – both as a mental health worker and in mental health promotion.



“Since I started at RNIB I’ve been trying to get out and about as much as possible to introduce myself to local groups and societies and to get a good idea of what the local issues are. I’m looking forward to recruiting volunteers and getting started with some local campaigning work.”

Telephone 0121 665 4260

Email rebecca.swift@rnib.org.uk

Richard Holmes

Regional Campaigns Officer for London and the South East, based in London

For the past decade Richard has worked in a campaigns and parliamentary role. Most recently he was parliamentary officer at Action for Blind People, a position he held for three and a half years.



“It is very clear that there are a number of opportunities where RNIB and local societies can work together in my region to enhance the lives and opportunities for blind and partially sighted people. I have also started to recruit volunteer campaigners across my region and believe that our volunteers will provide the key to making a real success of this role.”

Telephone 020 7391 2112

Email richard.holmes@rnib.org.uk

Ruth Stockdale

Regional Campaigns Officer for East Midlands and the East, based in Loughborough

Before starting at RNIB Ruth was working as a communications officer for a regional museum programme.



Previous to that, she spent five years as a regional campaigner for Oxfam, urging people to take action to get more children to school as well as working on the “Make Poverty History” campaign.

“My first three months at RNIB have been a learning curve, finding out what issues blind and partially sighted people face in their local area and planning how to overcome them. I’m really looking forward to getting stuck in to the issues and trying to get bins off the streets, cyclists off the pavement, bus drivers being more helpful and local councils delivering better services for blind and partially sighted people.”

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Email ruth.stockdale@rnib.org.uk

RNIB is actively campaigning across six priority areas: eliminating avoidable sight loss; improving access to health and social care; improving access to information and information systems; increasing employment amongst blind and partially sighted people; increasing income for blind and partially sighted people; and improving access to television, audio visual culture and life long learning.

If you would like to find out more about campaigns that are not covered in this campaigns update, you can visit the RNIB website at **rnib.org.uk** or call our **Campaigns hotline** and speak to one of our campaigners on **020 7391 2123**.