

## **Myeloma UK's Communications Campaign**

### **Access Denied Campaign**

#### **What was the purpose of the campaign and who was your target audience?**

Our national 'Access Denied' campaign began back in 2005 when we recognised the need for a campaign to ensure access to the best possible standards of treatment and care for all myeloma patients, no matter where they live, their ability to pay or their status.

This umbrella campaign lent itself to enabling us to campaign on specific, time sensitive issues of relevance. The primary focus over the last year has been to obtain access to Velcade for myeloma patients on the NHS. Velcade is the first drug to be specifically developed and licensed for use in myeloma for over a decade. The foundation of the campaign was ultimately to secure a NICE approval for Velcade (NICE began an appraisal of Velcade in 2005), whilst meantime working hard to help patients secure access locally.

Myeloma is a relatively rare cancer so there was substantial ground work to do in gaining an understanding of and support for the issues. Our primary target audience was political: lobbying Ministers and officials at the Department of Health to highlight the well-documented clinical benefits of Velcade and the necessity of its availability to doctors in their toolbox of treatments; raising and maintaining the profile of Velcade in parliament; and ensuring persistent and visible political support from key parliamentarians so as to apply pressure on NICE.

Our secondary audiences were patients, to make them aware of this new treatment and how to get access to it; the general public, to raise awareness of this little known cancer and to gain their support for equality of access to cancer treatments; and Primary Care Trusts, to reinforce their obligations to consider applications for treatments on a case by case basis until completion of a NICE appraisal.

#### **What media/action did you choose and why?**

We realised the need for a multi-pronged yet targeted approach to involve all of our stakeholders in our campaign to secure access to Velcade. We used a number of methods to get across our messages:

- **Mailings** – we rallied our supporters to participate in a postcard campaign to MPs and a letter-writing campaign to the Secretary of State for Health, Health Ministers, constituency MPs, and NICE
- **Petition** – to harness support and use as a tool to reinforce our message to Downing Street and the Department of Health
- **Myeloma UK website** – we provided downloadable template letters and up to the minute news updates were available on a dedicated campaigning section of our website
- **Media** – we developed and expanded our list of case studies and worked to place articles in a variety of press to capture attention of decision makers in NICE and Government, as well as increasing support in the general public

- Political – we had a targeted Parliamentary Question and Early Day Motion strategy to raise and maintain the political profile of the issue

### **What were the campaign messages?**

Our campaign message was clear and simple – that no patient should die without having had access to Velcade, should they need it.

### **How did the campaign work?**

#### Background – June 2005

'Access Denied' was the focus of Myeloma Awareness Week 2005, during which our supporters sent over 4,000 postcards to MPs highlighting the issue of access to treatments.

Because of this structured approach to raising the profile of access, our supporters were mobilised and the political audience was aware of the background to the issues.

#### Velcade receives a preliminary negative recommendation – July 2006

Throughout the consultation period following the negative recommendation, we mobilised the myeloma community through emails, our bimonthly newsletter and website, asking them to respond to NICE and to write to their MPs about Velcade.

The response was overwhelming - supporters embraced the letter-writing campaign and met with their MPs at advice surgeries. Myeloma UK also met with several MPs who became political champions of the campaign, including Jessica Morden MP, Ian Gibson MP and Andrew Lansley MP.

Through proactive media work and having built up relationships with key health journalists in broadsheet, online and broadcast media, we ensured the decision featured heavily in the news, making front page news in the Telegraph.

#### Velcade receives a final negative recommendation – October 2006

In response to the negative final decision, we launched our 'Access Denied' petition using a user-friendly online petition and also a hard copy petition for maximum accessibility. We promoted this through our website, e-bulletins, our newsletter and in all organisational mailings.

We worked tirelessly to ensure that there was intense publicity around the negative decision. We galvanised our advocates to become key media case studies and worked with doctors to get the medical messages across about the important clinical benefits Velcade can offer patients.

We increased our efforts to mobilise patients and their families and friends to lobby the government through:

- Writing directly to the Secretary of State for Health with a letter we drafted and made available to download from our website
- Going to see their local MP
- Asking MPs to raise the matter in the House of Commons
- We invited a dozen vocal advocates to the Britain Against Cancer Conference to challenge the Secretary of State for Health and relay their own personal experiences

#### Formal appeal against negative NICE ruling – November 2006 to February 2007

Myeloma UK spearheaded the formal appeal against the decision which was upheld by the NICE Appeals Panel. The Panel ruled in February 2007 that NICE's decision to oppose the use of Velcade should be reviewed and a revised recommendation issued.

#### Velcade receives a second preliminary positive recommendation – June 2007

Patients are now one step closer to being able to access Velcade, an important treatment to help them fight this complex and challenging disease. Being informed of the decision in advance of the public, we again were able to proactively contact an extensive media list and get the message across.

#### **Evidence of the campaign results**

- First Oral Health Question in Parliament in October 2006, followed up with nine supplementary questions that spanned across the political parties, demonstrating the strength of support from MPs. A subsequent House of Lords debate followed in January 2007 on the impact of the recent negative Velcade decision, again with multiple participants putting forward their views and speaking on our behalf
- An Early Day Motion tabled in January 2007 regarding the impact of the negative ruling received many influential signatures.
- Key politicians made reference to myeloma and Velcade in their speeches at the Britain Against Cancer conference in November 2006.
- The Access Denied petition has attracted 30,000+ signatures signifying great support for the campaign
- Over 1,000 people are now signed up to our campaigning e-bulletin. Out of the 10,000 on our database, this is a strong campaigning force
- Since the Velcade issues, over 30 new patients have approached us to be media case studies, allowing us to place human interest stories to raise awareness of the disease
- The Velcade u-turn was headline news on 4 June 2007:
  - Lead item on BBC Breakfast, BBC News 24 BBC 1 o'clock news
  - Covered by newswires, 7 major broadsheets/tabloids, 9 regionals/locals, 4 trade publications and replicated on over 20 online news sites