Dear Attendee

Welcome to our West Midlands Patient and Family Myeloma Infoday which is one of several held each year throughout the UK and Northern Ireland.

Patient and Family Myeloma Infodays are about people affected by myeloma learning from experts in the field and meeting others in a similar situation. A typical Infoday includes various slide presentations, Q&A sessions, group breakouts, networking and discussion time.

Please take some time to visit the Myeloma UK Information Table where you will find copies of all our publications. You can also order these, along with copies of the presenters’ slides by completing the enclosed order form and handing it to a Myeloma UK staff member. Information from this Infoday, and copies of the slides, will also be posted on our website www.myeloma.org.uk/infodays following the day.

We hope you find the day interesting and informative. Your feedback is vital for planning future events – please complete the enclosed evaluation form at the end of the day.

Our team is here to help throughout the day – if you need anything, please ask.

Kind regards

Sue Perkins
Service Development Manager

Today’s Myeloma UK staff team at the West Midlands Infoday includes:

Louise Farmer - PR and Media Manager
Zara Gilmour - Services Admin Support
Eric Low - Chief Executive
Kirstie McRae - Services and Events Coordinator
Zoe Meldrum-Craig - Community Fundraiser
Lucie Swindale - Fundraising Support
Ellen Watters - Myeloma Information Nurse Specialist
Programme

Chair          Dr Supratik Basu, Consultant Haematologist, New Cross Hospital
               The Royal Wolverhampton NHS Trust

8.45am         Registration and refreshments

9.30am         Welcome and introductions
               Eric Low OBE, Chief Executive, Myeloma UK and Dr Supratik Basu

9.50am         Initial treatment for myeloma
               Dr Premini Mahendra, Consultant Haemato-oncologist, Queen Elizabeth
               Hospital, University Hospitals Birmingham NHS Foundation Trust

10.30am        Treatment for relapsed and/or refractory myeloma
               Dr Guy Pratt, Consultant Haematologist, Heart of England NHS Trust and
               Senior Lecturer in Haematology, University of Birmingham

11.15am        Morning refreshments

11.45am        Myeloma kidney disease, pain and fatigue: complications of myeloma and
               side-effects of treatment
               Christine Protheroe, Clinical Nurse Specialist, Russells Hall Hospital
               The Dudley Group NHS Foundation Trust

12.20pm        Future strategies for myeloma: new insights and treatments in development
               Dr Supratik Basu

1.00pm         Participating in clinical trials
               Claire Beardsmore, Senior Haematology Research Sister, New Cross Hospital
               The Royal Wolverhampton NHS Trust

1.15pm         Lunch (served in the restaurant)

2.30pm         Breakout sessions:
               Group A: Living well with myeloma (Terrace Room)
               Group B: Ask the expert: Q&A discussion (Main Room)
               Group C: Carer and family perspectives (Colonial Room)

3.30pm         Afternoon refreshments

3.45pm         Patient experience
               Brian Norton, Birmingham

4.15pm         Final comments
               Dr Supratik Basu and Eric Low

4.30pm         Close

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After lunch there will be three simultaneous breakout sessions. Attendees should select from one of the following:

**Group A: Living well with myeloma – Terrace Room**

This session is open to all attendees and will explore the impact myeloma has on patients, carers and family members. We will discuss how taking control helps and where to get help and support including:

- Information and self-management to deal with myeloma
- Managing the relationship with your medical team
- Looking after yourself
- Diet and exercise
- Accessing support

The session will feature a presentation by Christine Protheroe, Clinical Nurse Specialist, Russells Hall Hospital, The Dudley Group NHS Foundation Trust. Following the presentation there will also be the opportunity for a Q&A discussion.

**Group B: Ask the expert: Q&A discussion – Main Room**

This session is open to all attendees and will offer the opportunity to ask further questions on any aspect of myeloma including treatment, side-effects and complications. The expert panel will include Dr Supratik Basu, Dr Premini Mahendra and Dr Guy Pratt.

**Group C: Carer and family perspectives – Colonial Room**

This session will be facilitated by Ellen Watters, Myeloma Information Nurse Specialist, Myeloma UK and will offer the opportunity for carers and family members to share experiences and to support each other. We request that patients do not attend this session.
Chair: Dr Supratik Basu  
Title: Consultant Haematologist  
Place of work: New Cross Hospital, Royal Wolverhampton Hospitals NHS Trust

Dr Basu’s undergraduate training was in India. Subsequently, he trained in London at The Royal Marsden Hospital and St George’s Hospital. He then did his research at the Royal Free Hospital, London. His research interest is in myeloma, specifically micro-environment in marrow. He is the Research Lead of Haematology for Greater Midlands Cancer Network and is also a member of RCPPath Regional Council and myeloma trials sub-committee. He is involved in the running (as the Principal Investigator) of several Phase III trials in myeloma and lymphoma with novel investigational agents. Another area of interest is on the diagnostic side of myeloma in laboratory settings especially with application of new technology like HeavyLite screening for plasma cell disorders.

Name: Dr Premini Mahendra  
Title: Consultant Haemato-oncologist  
Place of work: Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trust

Dr Mahendra trained in haematology at the The Royal Marsden Hospital, London and Addenbrooke’s Hospital, Cambridge and was appointed Consultant Haematologist at the Queen Elizabeth Hospital, Birmingham in 1998. On her arrival there she set up the bone marrow transplant services which is now the second largest bone marrow transplant centre in the UK and performs approximately 150 transplants per year. Her areas of clinical interests are care of patients with myeloma, leukaemia and lymphoma and those undergoing autologous and allogeneic stem cell transplantation. Her research interests are all related to clinical outcome of patients undergoing stem cell transplantation or having treatment for haematological malignancies. She has over 70 publications in peer reviewed journals.
Speaker profiles

Dr Guy Pratt
Consultant Haematologist
Heart of England NHS Trust and Senior Lecturer in Haematology, University of Birmingham

Dr Guy Pratt trained at Cambridge University qualifying in 1989. Following junior doctor training in London, Dr Pratt specialised as a registrar in haematology in Liverpool and Leeds. In Leeds he completed an MD thesis looking at the genetic events involving the immunoglobulin region in myeloma patients. Dr Pratt has been a Consultant Haematologist in Birmingham since 2001 working both at Birmingham Heartlands Hospital as an Honorary NHS Consultant and at the Institute for Cancer Studies in the University of Birmingham as a University Senior Lecturer. Dr Pratt’s main research interests are myeloma and chronic lymphocytic leukaemia. His main research aim is to develop myeloma research across the West Midlands with a view to it being a centre of excellence for myeloma research in the UK.

Christine Protheroe
Clinical Nurse Specialist
Russells Hall Hospital, The Dudley Group NHS Foundation Trust

Christine Protheroe trained at Kidderminster, Worcester and Redditch qualifying in 1995. Christine has worked at Russells Hall Hospital since qualifying; firstly as a staff nurse on a 28 bedded Acute medical ward with a Haematology speciality. She gradually became a junior sister, then ward manager when the Georgina Unit was built. This was a 22 bedded Haematology ward.

Since 2006 Christine has been a Clinical Nurse Specialist for Autologous stem cell transplants for Myeloma and Lymphoma patients. She co-ordinates the management of patients pre, during and post-transplant and performs most of the stem cell collections and the subsequent reinfusion of stem cells providing specialist knowledge, advice and support to the ward staff in the clinical area.

Claire Beardsmore
Senior Haematology Research Sister
New Cross Hospital, The Royal Wolverhampton NHS Trust
Name: **Eric Low OBE**  
Title: **Chief Executive**  
Place of work: **Myeloma UK**

Eric has been involved in the field of myeloma for over 18 years. Working as a volunteer in the United States for the International Myeloma Foundation, he recognised the need and the benefit of providing information and support to people affected by myeloma. Returning to the UK, Eric identified the need for a similar organisation in the UK and as a result he set up Myeloma UK in 1997.

Under Eric’s direction Myeloma UK has grown and developed and is the only UK cancer organisation dealing exclusively with myeloma. Today, Myeloma UK reaches over 12,000 people affected by myeloma and the majority of healthcare professionals involved in their care.

Eric’s achievements have included establishing a national Myeloma Early Phase Clinical Trial Network and a myeloma genetics and drug development research programme. He has also ensured that myeloma patients in the UK have been able to access novel treatments through advocating solution-oriented approaches to the way drugs are made available on the NHS.

Eric was awarded an OBE for services to charity as Chief Executive, Myeloma UK in the Queen’s Birthday Honours 2012.
Myeloma Support Groups provide an informal and comfortable atmosphere in which members can share experiences and information. Some Support Groups are run by patients and family members, others by healthcare workers or professional group facilitators. See below for a list of groups in your area.

**Derby Myeloma Support Group**  
Education Centre, Level 3, Royal Derby Hospital, Uttoxeter New Road, Derby DE22 3NE  
Time: 1.30 – 3.30pm, second Friday every other month  
Contact: Christine Skeet, Myeloma Clinical Nurse Specialist  
Tel: 07879 115 881 (Monday – Wednesday)  
Email: christine.morris3@nhs.net  
Contact: Susan Robb, Myeloma Clinical Nurse Specialist  
Tel: 07879 115 881 (Wednesday – Friday)  
Email: susan.robb3@nhs.net

**Dudley Haematology Support Group**  
The White House, 10 Ednam Road, Dudley DY1 1JX  
Time: 6.30 – 8.30pm, second Wednesday, every three months  
Contact: Angela Watts, Senior Research Nurse  
Tel: 01384 456 111 ext 2513/2879  
Email: angela.watts@dgh.nhs.uk  
Contact: Christine Protheroe, Clinical Nurse Specialist  
Email: christine.protheroe@dgh.nhs.uk

**Hereford Marches Myeloma Support Group**  
Kindle Centre, Asda Supermarket, Belmont Road, Hereford HR2 7JE  
Time: 2 – 4pm, third Thursday of every other month  
Contact: Philippa Hurlow, Haematology/Oncology Clinical Nurse Specialist  
Tel: 01432 355444 ex: 5712  
Email: philippa.hurlow@wvt.nhs.uk

**Leicestershire and Rutland Myeloma Support Group**  
Helen Webb House, 35 Westleigh Road, Leicester  
Time: 10am – 12pm, second Wednesday of every month  
Contact: Tony Farquharson  
Tel: 0116 258 7246 or Helen Webb House 0116 223 0055  
Email: tony.farquharson@btinternet.com

**Lincoln SMYLLE Haematology Support Group**  
St Barnabas Hospice, Day Care Centre, Hawthorn Road, Lincoln LN2 4QX  
Time: 7 – 9pm, last Thursday of every month  
Contact: Denise tel: 01673 861475  
Email: info@lincolnsmylle.co.uk  
www.lincolnsmylle.co.uk
Nottingham Myeloma Support Group
Maggie’s Centre, Nottingham City Hospital, Hucknall Road, Nottingham NG5 1PB
Time: 1pm – 3pm, second Thursday of the month
Contact: Sarah Henshaw, Myeloma Clinical Nurse Specialist
Tel: 0115 9691169 ext 54967
Email: sarah.henshaw@nuh.nhs.uk

Peterborough Myeloma Support Group
The Cresset, Rightwell, Bretton, Peterborough PE3 8DX
Time: 2 – 4pm, second Tuesday of every month
Contact: Hilary Pilarski
Tel: 01733 261069
Email: hilarypilarski@yahoo.co.uk
www.peterboroughmyelomasupportgroup.com

Stoke on Trent Myeloma Support Group
London Road Bowling Club, London Road, Newcastle-under-Lyme, Staffordshire ST5 1LZ
For meeting dates and further information contact Nicola Coleman
Tel: 01782 672635
Email: nicola.coleman@uhns.nhs.uk (08:30-16:30 Mon-Fri or leave answerphone message)
Contact: Barry Smith
Tel: 01630 672144
Email: smithybc@aol.com

Wolverhampton Haematology Support Group
Clinical Haematology Unit, Heart and Lung Centre, Royal Wolverhampton Hospital,
Wednesfield Road, Wolverhampton WV10 0QP
Time: Last Thursday of every month at 3pm
Contact: Andy Finch
Tel: 07411 705169
Email: andy.finch1@gmail.com

Worcester Myeloma Support Group
St. John’s Youth Centre, Swanpool Walk, St Johns, Worcester WR2 4EL
(opposite Sainsburys, alongside Pearmain Walk)
Time: 2.30 – 4.30pm, Tuesday, every two months
Contact: John Collins (email preferred)
Tel: 01299 832 781
Email: myelomaworcs@gmail.com

“If there isn’t a Support Group in your local area, why not consider setting up your own? For more information, or for an informal chat, give me a call on 01874 731202.” Sara Morgan, Support Group Lead, Myeloma UK
Your Notes
We hope you enjoyed the West Midlands Infoday.

For further information about myeloma and Myeloma UK visit www.myeloma.org.uk or call the Myeloma Infoline on 0800 980 3332.