Patient and Family Myeloma Infoday

Birmingham

Saturday
20 September 2014

Holiday Inn Birmingham Airport Hotel

www.myeloma.org.uk/infodays
Dear Attendee

Welcome to our Birmingham 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, small 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 this information will be helpful and you find the day to be worthwhile, interesting and informative. Your feedback is vital for the planning of future events and we would be most grateful if you could complete the enclosed evaluation form at the end of the day.

If there is anything you need help with, please don’t hesitate to ask one of our team – we are at your complete disposal throughout the day.

Kind regards

Eric Low OBE
Chief Executive

Breakout Q&A discussion sessions (2.15pm – 3.15pm)

Afternoon breakout sessions offer an opportunity to ask further questions on any aspect of myeloma including treatment and side-effects/complications.

**Group A:** Patients with a red dot on name badge  
(and any carers/family members who do not want to attend Group C)

**Group B:** Patients with no red dot  
(and any carers/family members who do not want to attend Group C)

**Group C:** Carer and family perspectives  
(please note patients are kindly requested not to attend this session)

If you are a carer/family member/supporter and do not wish to attend Group C, please join either Group A or Group B.

Please ask a member of Myeloma UK staff if you need assistance.
Programme for the day

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

8.45am
Registration and refreshments

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

9.50am
Initial treatment for myeloma
Dr Mamta Garg, Consultant Haematologist, Leicester Royal Infirmary
University Hospitals of Leicester NHS Trust

10.20am
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

11.00am Morning refreshments

11.30am Peripheral neuropathy, pain and fatigue: complications of myeloma and
side-effects of treatment
Angela Young, Haematology Clinical Nurse Specialist, Russells Hall Hospital,
The Dudley Group NHS Foundation Trust

12.00pm Living well with myeloma
Christine Protheroe, Clinical Nurse Specialist, Russells Hall Hospital
The Dudley Group NHS Foundation Trust

12.30pm Patient experience
Mr Andrew Borley

12.50pm Myeloma UK Clinical Service Excellence Programme: an update
Gail Porte, Project Manager, Myeloma Best Practice Standards, Myeloma UK

1.00pm Lunch (served in the restaurant)

2.15pm Breakout Q&A discussion sessions
A. Group A (Harrier 1 & 2 – first floor)
B. Group B (Main room)
C. Group C Carer and family perspectives (Harrier 3 – first floor)

3.15pm Afternoon refreshments

3.30pm Future strategies for myeloma: new insights and treatments in development
Dr Premini Mahendra, Consultant Haemato-oncologist, Queen Elizabeth
Hospital, University Hospitals Birmingham NHS Foundation Trusts

4.20pm Final comments
Dr Supratik Basu

4.30pm Close
Dr Supratik Basu, Consultant Haematologist, New Cross Hospital, Royal Wolverhampton Hospitals NHS Trust (Chair)

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 RCPATH 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.

Dr Mamta Garg, Consultant Haematologist, Leicester Royal Infirmary, University Hospitals of Leicester NHS Trust

Dr Garg trained in haematology in Manchester and has been a Consultant Haematologist since 2002. She moved to Leicester in 2005 and is currently Head of Service at the Leicester Royal Infirmary. Dr Garg has a specialist interest in:

- Plasma cell dyscrasias such as myeloma and amyloidosis
- General haematology, including disorders such as: anaemia (low haemoglobin), polycythaemia (high haemoglobin), low and high white cell counts, iron overload (haemachromatosis and high and low platelets)
- Immune haematology such as immune thrombocytopenia (ITP), autoimmune haemolytic anaemia (AIHA) and acute interstitial nephritis (AIN)
- Myeloproliferative neoplasms/disorders (MPD), PV, ET, MF

Dr Garg is actively involved in research and is principal/investigator in many commercial and National Cancer Research Network studies and feels passionately about the development and use of database records in haematological disorders, as they provide a source of invaluable information for research purposes.
Dr Premini Mahendra, Consultant Haemato-oncologist, Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trusts

Dr Mahendra trained in haematology at the The Royal Marsden Hospital, London and Addenbrooke's Hospital, Cambridge and was appointed Consultant Haemato-Oncologist 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.

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

Biography not available at time of print.
Speaker profile

Angela Young, Haematology Clinical Nurse Specialist, Russells Hall Hospital, The Dudley Group NHS Foundation Trust

Angela Young trained at St Bartholomew’s Hospital in London qualifying in 1993. She worked at St Bartholomew’s Hospital and Charing Cross Hospital in oncology/haematology units for eight years and gained a Cancer Nursing BSc in 2001 at The Royal Marsden Hospital.

Angela moved to the West Midlands and Russells Hall Hospital in 2001 and worked on the haematology/oncology unit for nine years before gaining her first haematology clinical nurse specialist post in 2010 at Worcester Royal Hospital. Angela returned to Russells Hall in 2011 to take up her current post.

Eric Low OBE, Chief Executive, Myeloma UK

Eric has been involved in the field of myeloma for over 16 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.

Today’s Myeloma UK staff team includes:

Ruth Harris – Fundraising Support
Maggie Lai – Senior Research and Clinical Information Specialist
Kate Morgan – Senior Policy Officer
Lindsay Perera – Head of Major Gifts
Gail Porte – Project Manager, Myeloma Best Practice Standards
Local Support Groups

**Chesterfield**
Myeloma Support Group  
Conservatory, Education Centre, Chesterfield Hospital, Calow S44 5BL  
Time:  12.30 – 2.30pm, Friday afternoon, every eight weeks  
Contact:  Angela Gascoigne, Haematology Clinical Nurse Specialist  
Tel:  01246 512 792  
Email:  Angela.Gascoigne@chesterfieldroyal.nhs.uk

**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:  Gail Fellows, Haematology Clinical Nurse Specialist  
Tel:  07852 342918  
Email:  gail.fellows-moore@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:  Jenny Rogers, Macmillan Haematology Nurse Specialist  
Tel:  0116 258 7246 or Helen Webb House 0116 223 0055

**Lincoln**
SMYLLLE 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  
Web:  www.lincolnsmylle.co.uk
Local Support Groups

**Nottingham**
Myeloma Support Group
Maggie’s Centre, Nottingham City Hospital, Hucknall Road, Nottingham NG5 1PB
Time: 3.30 – 5pm, third Monday of every month
Contact: Sarah Henshaw, Myeloma Clinical Nurse Specialist
Tel: 0115 9691169 ext 54967 Email: sarah.henshaw@nuh.nhs.uk

**Wolverhampton**
Haematology Support Group
Clinical Haematology Unit, Heart and Lung Centre, Royal Wolverhampton Hospital, Wednesfield Road, Wolverhampton WV10 0QP
Time: Wednesday afternoon every six weeks
Contact: Karen Sheldon
Tel: 01902 695276 Email: karen.sheldon1@nhs.net

**Worcester**
Myeloma Support Group
St. John’s Youth Centre, Swanpool Walk, St Johns, Worcester, WR2 4EL
(opposite Sainsburys, alongside Pearmain Walk)
Time: 2 – 4pm, Tuesday
Contact: Duncan Henderson
Tel: 07870 225 695 (please only use if email contact is not possible)
Email: duncanhenderson@blueyonder.co.uk

Not a Support Group near you? Why not set up your own?
Contact Sue Perkins, Service Development Manager on 0131 557 3332 for further information.
Call our Myeloma Infoline on 0800 980 3332

www.myeloma.org.uk

Myeloma UK
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Charity No. SC 026116

Myeloma Awareness Week 21 – 28 June