



# **Jamaica Multiple Myeloma Support Group**

## **Report on**

## **Multiple Myeloma Symposium**

**25 February 2018**



**Dr Matthew Streetly, visiting myeloma expert, presenting to a full house:  
New developments in myeloma diagnosis and treatment**

## 1. Introduction and background

Following the Inaugural Multiple Myeloma Symposium held in March 2016, the Second Symposium was held on February 25, 2018 at The Jamaica Pegasus Hotel, Kingston Jamaica. The Symposium was organised by Jamaica Multiple Myeloma Support Group, in association with the Jamaica Cancer Society, and the Department of Pathology/Haematology of the University of the West Indies. The theme for the Symposium was **New Developments in the Diagnosis and Treatment of Multiple Myeloma**.

The day was divided into three sessions: session one was chaired by Dr Gilian Wharfe, Consultant Haematologist and Head of Department of Pathology (UHWI); session two was chaired by Dr Dwight Lowe, Consultant Haematologist (UHWI); and session three was chaired by Dr Doreen Brady-West, Consultant Haematologist and Head of Haematology (UHWI).

## 2. Attendance

The Symposium was attended by over 200 participants comprising medical doctors, other medical practitioners, myeloma patients and their caregivers as well as members of the general public. Medical doctors accounted for the largest single group of participants. Among those in attendance were Dr Sophia Skyers, Chair of the Basil Skyers Myeloma Foundation from the UK, and Ms Beverley Stephenson, who had travelled to the Symposium from the United States.

Mrs Yulit Gordon and Dr Tamu Davidson brought greetings from the Jamaica Cancer Society and the Ministry of Health respectively. They both congratulated the Support Group for organising the second Symposium and pledged to do whatever they could to support future efforts of a similar nature.

## 3. Speakers/Presentations in chronological order

### 3.1 Dr Doreen Brady-West: Consultant Haematologist and Head of Haematology (UHWI)

**When to suspect myeloma:** Dr Brady-West made it clear that in her experience, myeloma is not a rare disease and that up to six patients at any one time on her ward had a diagnosis of myeloma. Dr Brady-West explained that multiple myeloma is a complex multifactorial disease: it is more than plasma cell proliferation, and while the bone is one of the main target organs, it is not the only target organ; for example, the kidney is another target organ. She also explained that 68% of patients present with bone pain, and that over the course of the disease, the majority will have some bone involvement (70%), evidence of pathological fractures (30%) and spinal cord compression (5%). In terms of an index of suspicion in the diagnosis of multiple myeloma, Dr Brady-West explained that where there is evidence of lytic bone disease, anaemia, and evidence of renal impairment, myeloma should be suspected. Dr Brady-West also explained that orthopaedic surgeons and neurosurgeons should also have a high index of suspicion (which they do at the University Hospital of the West Indies), as should general practitioners when presented with loss of weight, weakness, recurrent infection and so forth. She concluded by saying that the evidence suggests that there is also a case for paediatric services also retaining a high index of suspicion.

### **3.2 Dr Matthew Streetly: Consultant Haematologist (Guys and St Thomas Hospital, UK)**

**New developments in myeloma diagnosis and treatment:** Dr Streetly explained that there are 5,000 diagnoses of multiple myeloma in the UK in a population of around 60 million people, representing 2% of all cancers in the UK, with the majority being over the age of 70. Dr Streetly also explained that there were more men than women, and that people of black African ancestry have double the incidence compared with the population generally, with the rate of myeloma diagnoses generally increasing, not as a result of increased sensitivity in diagnoses, but reflecting a true increase in occurrence. Dr Streetly further explained that the disease had previously had a poor prognosis but that there had been significant improvements in survival across the board with over half of patients surviving at least five years or more and that this picture was continually improving.

Dr Streetly pointed out that while myeloma was not curable, there were a number of lines of treatment available. In the case of smouldering myeloma, some patients within that category have a high risk of progression to multiple myeloma at an early stage, specifically those who have 6% or more of plasma involvement. Dr Streetly stated that while there were new drugs continually coming on stream, stem cell transplants were the mainstay of therapy as the outcomes are better. In terms of older patients who may not be eligible for a transplant, Dr Streetly explained that there were different combinations of treatment, and sequencing in different ways balancing toxicity with efficacy. In terms of patients who relapse, there has been marketing approval for more myeloma drugs over the last few years than for most other cancers.

### **3.3 Dr Peter Charles: Consultant Neurosurgeon (UHWI)**

**Surgical options in myeloma spine disease:** Dr Peter Charles highlighted the difficulty of surgery where there are multiple lytic lesions by explaining that putting bolts into bone to bring stability to the patient was akin to putting bolts into sand. He outlined a number of case studies in which appropriate surgical decisions had extended quality of life for the myeloma patient.

### **3.4 Dr Venslow Greaves: Radiation Oncologist (KPH and Oncology Radiation Centre)**

**Radiation therapy in myeloma management:** Dr Greaves explained that the major treatment goals for radiation were pain relief, preservation of mobility function, prevention of future complications, maintenance of skeletal integrity, optimisation of quality of life and shrinkage of tumours. Radiation plays a supportive role in the management of multiple myeloma. Total body radiation as a regime is no longer used because of toxicity, but radiation is an important modality in the radical curative management of plasmacytomas. Dr Greaves cited radio immunotherapy as a treatment for the future.

### **3.5 Dr Jodie Taylor: Consultant Haematologist-Oncologist (CRH)**

**Supportive care in myeloma treatment:** Dr Taylor explained supportive care as a holistic multi-disciplinary approach that helps the patient and family to cope with the diagnosis, treatment, cure, continuing illness or death into bereavement. Pointing out that bone disease is a common feature at presentation in 80-90% of patients, Dr Taylor talked about treatments, the importance of end of life care that is both patient-centred and family focused, and about complementary therapies. She suggested that while there may not be a wide body of evidence on efficacy, if these therapies met the patient's needs re symptom and pain management, they should be embraced.

### **3.6 Dr Gilian Wharfe: Consultant Haematologist, Head of Department of Pathology (UHWI)**

**Minimising chemotherapy-induced peripheral neuropathy:** Dr Wharfe defined peripheral neuropathy as damage to the peripheral nerves and explained that in myeloma the neuropathy is

usually sensory and can be a result of the disease, as well as a result of the specific interventions used to treat the disease; this damage tends to be progressive. Neuropathy affects quality of life as patients may have difficulty walking and managing, and the symptoms may require reduction (sometimes total ceasing ) of treatment. The neuropathy (depending on the therapy used) is usually permanent and severe as in the case of Thalidomide, and mild in relation to Bortezomib which is dose dependent, schedule dependent, and route dependent. Dr Wharfe suggested that it is important to monitor each patient for risk of neuropathy and that the future may include a genetic profile.

### **3.7 Miss Gail A. Nelson: Lecturer, Section of Physical Therapy (UWI)**

**The role of exercise in the management of chemotherapy-induced peripheral neuropathy:** Miss Nelson talked about peripheral neuropathy as a side effect of treatment, and its impact on quality of life. Her presentation outlined that while exercise has not been proven to reduce the incidence or severity of CIPN, it may counteract the consequences of CIPN through reducing fall risk, improving muscle strength and balance. Miss Nelson cited a 2014 Cochrane Review that pointed to exercise as a means of enhancing quality of life when added to standard care.

## **4. Panel: Patients'/ Caregivers' Perspectives**

**A phenomenological account of the stem cell transplant experience:** The panellists were Robin and Michael Tuohy, Lillieth Callam , Dianne Clayton , and Godfrey Taylor. Highlights of the presentations on their experiences as patients and caregivers are given below.

### **4.1 Robin (caregiver) and Michael Tuohy - 18 years post-SCT (USA) – via video recording**

- Get to know the side effects of different treatments and try to prevent them from occurring.
- Take mitigating action when blood counts are low to prevent complications.
- Knowledge is power; learn as much as you can.
- All questions are important questions so ask them of doctors and take a tape recorder with your doctor's permission.
- Caregivers, take care of yourselves.

### **4.2 Lillieth Callam (SCT done in the USA)**

- Diagnosed December 2009 and had the SCT done in the USA
- Found the information packages about the SCT process helpful
- She was awed by the harvesting experience - was wonderful to realise what the machine could do
- Transplant was the easiest part of the process; the real challenge came afterwards.
- Support of husband Bevan as caregiver was crucial.

### **4.3 Dianne Clayton (SCT done in Cuba)**

- Diagnosed 2012 and had stem cell transplant in 2015
- Aunt caregiver helped through anxious moments.
- She was encouraged to exercise by a cousin but not by health providers who were over-cautious.

#### 4.4 Godfrey Taylor (caregiver for wife Monica - SCT done at H.Lee Moffitt Cancer Center in the USA)

- Once cancer enters your family, everything changes.
- The SCT experience was tough but brought closeness with his wife.
- Hope is important to the healing process.
- Helplessness was a common temptation as there is often a feeling that there is nothing you can do. However, there is a lot one can do.
- Get a voice, speak up and ask questions.
- You need to care for yourself to be helpful.
- Remember hand washing as the single most effective measure against infections.
- Most importantly, remember that you are not alone!

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