

REPORT
on
Inaugural Myeloma Symposium



Jamaica Multiple Myeloma Support Group

In Association with the Department of Pathology/Haematology, University of the West Indies
Sunday March 20, 2016

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The Jamaica Multiple Myeloma Support Group

Formed in March 2013 with the help of the International Myeloma Foundation, the Group's focus is support, education, and the building of public awareness and sensitivity.

For many persons a diagnosis of multiple myeloma feels as if the bottom has fallen out of their world, but the Support Group provides a place of refuge where myeloma patients find kindred spirits facing similar challenges; where myeloma is not the end of the world but the beginning of another journey. Our regular monthly meetings are a source of strength and comfort for anyone touched by multiple myeloma.

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What is Multiple Myeloma? Multiple myeloma, commonly known as myeloma is a cancer of the blood cells that are made in the bone marrow. Myeloma develops when these blood cells start to reproduce themselves in an uncontrolled and aggressive way, pushing out the healthy red blood cells and platelets. While some persons may have no symptoms or complications in the early stages, the common symptoms of myeloma include bone pain particularly in the lower back and in the ribs, as well as anemia, frequent infections, and bruising and bleeding. Multiple myeloma affects some 750,000 persons worldwide, with around 114,000 new diagnoses each year. Anecdotal evidence suggests that the cases are growing in Jamaica. We look forward to receiving the incidence figures for Jamaica in the near future.

Myeloma is incurable at the present time but eminently treatable. There are a number of therapies that enable people to live well with the disease for many years and even decades. We are particularly encouraged by the ongoing work of the International Myeloma Foundation and its affiliates to find a cure for myeloma.

Acknowledgements

The Jamaica Multiple Myeloma Support Group acknowledges the active support of its membership and co-opted assistants who worked tirelessly to make the Symposium possible. The Support Group also sincerely thanks all of the agencies that helped to facilitate the staging of Symposium. These include: Professor Horace Fletcher, Dean of the Faculty of Medical Sciences, Dr Gilian Wharfe HOD, Pathology and Dr Doreen Brady-West Head of Haematology, and the Department of Marketing, Recruitment and Communication UWI; the National Health Fund, Intas Pharmaceuticals, the Scotia Foundation, TOPS Jamaican Teas of Perishables Ja Ltd., and Dr Taher Sheybani.

We acknowledge with deep gratitude the ongoing support of the International Myeloma Foundation (IMF) with which we are affiliated, and in particular for educational material distributed at the Symposium.

We are also grateful to the Basil Skyers Foundation for providing printed copies of its landmark reports for persons attending the Symposium.

The Jamaica Multiple Myeloma Inaugural Symposium



Members of the Multiple Myeloma Support Group planning the Symposium

About the Jamaica Multiple Myeloma Support Group and the Symposium: The Support Group has among its key aims and objectives: the provision of support for patients with multiple myeloma, caregivers, family members and friends; raising awareness about multiple myeloma, and support for patients, their caregivers and families. The Multiple Myeloma Symposium was held on 20 March 2016 at the Faculty of Medical Sciences Teaching and Research Complex, University of the West Indies (UWI) Kingston, Jamaica and took place during the internationally designated Myeloma Awareness Month. The Symposium was held in association with the Departments of Pathology and Haematology, University of the West Indies, Mona Campus.

The Focus of the Symposium: The causes of myeloma are not yet known but there is ongoing research about why this happens. We now understand that while myeloma affects all communities, and particularly older people, it is more common in the black population in Jamaica, in other parts of the Caribbean, and in the US and the UK. The Inaugural Multiple Myeloma Symposium marked an unprecedented step in the Caribbean in bringing together a multi-disciplinary group of national and international experts comprising clinicians, patients, caregivers, researchers and government and non-governmental agencies, to begin to develop a nuanced dialogue about the disease, its effects, why there are differences in outcomes, and why people tolerate therapies differently. The Symposium was designed to raise awareness about multiple myeloma, and to widen understanding about who is affected, how they are affected, and to learn more about strategies for dealing with the disease. The Symposium provided opportunity, unprecedented in Jamaica, to encourage a dialogue between various stakeholders in a single forum, giving voice to the varying and diverse needs of patients and caregivers, and at the same time, meeting the educational needs of general practitioners who are critical as the first line of action for patients, as well as the needs of oncologists, nurses, allied health professionals, and the wider research community.

The Jamaica Medical Council and the Nursing Council approved Continuing Education Credits for the scientific component of the Symposium which was endorsed by Lord Morris of Handsworth (Bill Morris) and Dr Fran Wadelin, Consultant Haematologist and Trustee of the Basil Skyers Myeloma Foundation, UK.

Dr Gilian Wharfe, Chair of the Symposium (morning session)



Dr Gilian Wharfe Head of the Department of Pathology University West Indies chaired the morning session. The Department provides laboratory and clinical training for undergraduate and graduate students, and maintains modern laboratories in haematology, chemical, surgical pathology, and a cytology offering service to the hospital and the region. The Department is heavily involved in collaborative research with the National Cancer Institute and the National Institutes of Health in the USA.

Other research projects with which the Department headed by Dr Wharfe is involved include epidemiology, and natural history and the descriptive pathology of various cancers.

The morning session heard messages from **Robin Tuohy**, Senior Support Group Director of International Myeloma Foundation; **Yulit Gordon**, Executive Director of the Jamaica Cancer society; **Monica Taylor**, Group Leader of the Jamaica Multiple Myeloma Support Group; and **Dr Sonia Copeland**, who represented the Minister of Health.

Dr Sonia Copeland, Director of Health Promotion and Protection representing the Minister



of Health: Dr Sonia Copeland highlighted the need for explicit attention to be paid to cancers that are less known. This includes cancers such as multiple myeloma. Dr Copeland also stressed the importance of a holistic approach to cancer treatment and cancer care, and applauded the work of the Jamaica Multiple Myeloma Support Group in the filling of a vacuum in much needed support for patients and caregivers. The Group was encouraged by Dr Copeland to submit a grant application to the Minister

of Health to support its ongoing programme of much needed services, activities, and support.

Understanding Multiple Myeloma - Synopsis of Presentations



Dr Sophia Skyers, Chair of the Basil Skyers Myeloma

Foundation, London, England: Dr Sophia Skyers spoke about the creation of the Basil Skyers Myeloma Foundation, set up in memory of her brother Basil who died of myeloma, at age 49, two years following his diagnosis. Dr Skyers explained that the death of her brother is emblematic of inequalities in outcomes between black and white patients in the UK, and that the fact of this inequality had prompted her to undertake research, exploring inequalities in outcomes across communities. The title of her presentation, *Listen Up – Multiple Myeloma in Black Communities: An Unequal Risk Burden*, examined the changing demographic profile in the UK and ageing across all

communities, including the black community, and the implications for an increasing incidence of myeloma, and for the delivery of services and support. The presentation also explored the epidemiological evidence about myeloma in black communities, and the need for clinical research and practice to reflect diversity. The publication on which the presentation is based can be accessed via this link: <http://dev.basilskyersfoundation.org/wp-content/uploads/2015/09/Listen-Up-Multiple-Myeloma-in-Black-Communities-An-Unequal-Risk-Burden17-June-2015.pdf>

Dr Beth Faiman, International Myeloma Foundation and Department of Hematologic



Oncology and Blood Cancers at Cleveland Clinic, Ohio: The theme of Dr Faiman's presentation was: 'Living Well With Myeloma and was extensive and intensive: it was a comprehensive coverage of myeloma diagnosis and treatment, the management of side effects, health maintenance and quality of life issues relating to both patients and caregivers.

Beth Faiman is an active author, presenter, and educator on the topic of multiple myeloma, amyloidosis, plasma cell dyscrasias, general cancer diagnosis and treatment, as well as management of skeletal and other cancer complications. She has written extensively on diagnosis and treatment of myeloma, pain, palliation and cancer symptom management. A copy of Dr Faiman's presentation is available on request from jamaica@imfsupport.org.

Dr Kenneth Vaughan, Consultant Orthopedic Surgeon, University of the West Indies: The



theme of Dr Vaughan's presentation was centered on diagnostic and treatment challenges related to myeloma bone disease, and the need for those working in orthopedics to maintain a 'high index of suspicion' when patients present with symptoms that can be associated with myeloma. Dr Vaughan's presentation made clear that a challenge for diagnosis is that no two patients with myeloma will present in the same way. Thus, anyone presenting with unexplained pain and/or other classic symptoms of myeloma, will be screened for the disease, working with clinical colleagues in haematology. In that manner, Dr Vaughan explained, diagnoses of patients who are initially referred to orthopedics are picked up.

Dr Wendi Peart, Registered Physiotherapist: Dr Peart focused on safety and health at home for



people with myeloma. She presented a range of exercises and simple management tips for achieving safe and effective physical rehabilitation in the home environment.

In her over 10 years as a physiotherapist Wendi Peart has worked mainly in private practice and home health managing a range of orthopaedic, cardiopulmonary, neurological and sports medicine related patients.

Miss Beverley Anthony, Regional Dietitian, Southeast Regional Authority: Miss Beverley



Anthony focused on nutrition essentials for myeloma patients. She presented numerous simple, nutritious meal ideas using local foods to deal with the side effects of myeloma.

Miss Anthony has worked as a dietitian for more than 20 years.

Mr Godfrey Taylor founding member of the Jamaica MM Support Group chaired the afternoon session of the Symposium, which saw presentations from Dr Kenneth Vaughan, Dr Wendi Peart and Miss Beverley Anthony.

Expert Panel Discussion



The presentations were followed by a panel discussion moderated by **Dr Doreeen Brady-West**, Head of Department of Haematology, University of the West Indies.



The panel comprised **Dr Sophia Skyers**, Chair, Basil Skyers Myeloma Foundation, **Dr Andre Williams**, Consultant Haematologist, Cornwall Regional Hospital, **Dr Venslow Greaves**, Radiation Oncologist, and **Francine Williams**, Patient advocate from the Jamaica Multiple Myeloma Support Group.

Panelists (l-r): Dr Andre Williams, Mrs Francine Williams, Dr Venslow Greaves and Dr Sophia Skyers

The discussion centered on the challenges of treatment in resource limited settings with the aims of bringing to light, the challenges facing medical practitioners as well as patients and caregivers, as they try to make the best of a health environment strapped by limited resources of all kinds.

The concerns raised by the Panel included but were by no means limited to the following:

- a) A lack of resources in the health sector resulting in heavy patient loads, long waits in uncomfortable settings, periodic shortages of essential drugs (esp. thalidomide).
- b) The high cost of drugs and impact on management options for patients of limited means.
- c) The tendency for GPs to abandon their roles once a patient has been diagnosed with myeloma.
- d) The need for careful and timely articulation of all medical partners impacting the lives of myeloma patients (first line GPs, nurses, haematologists, radiologists, orthopaedic surgeons and others) for more timely diagnoses, referrals and general patient management leading to better outcomes and better quality of life for the patient.
- e) The impact of the costs of being diagnosed with myeloma on patients and caregivers, and the role of agencies in meeting those costs.



Some of the participants during the coffee break

Conclusion

The Multiple Myeloma Symposium was a timely gathering of key local, regional and international stakeholders including patients, caregivers, haematologists, researchers, and so forth, providing invaluable information and resources, in a supportive environment. Equally as important, the Symposium provided a forum in which questions were voiced about the diagnosis and treatment of myeloma, and its inextricable link with broader questions of inequality concerning those disproportionately more likely to be diagnosed and who have poorer outcomes. The Jamaica Multiple Myeloma Support Group will play its role in helping to push the boundaries of current thinking. This requires a concerted approach to engagement at local, regional and international level centered on the exchange of ideas and knowledge, underpinned by a robust and up to date evidence base that more accurately captures the incidence and prevalence of myeloma.

We look forward to the start of a continuing partnership centred on the exchange of ideas and knowledge, and doing what we can to extend the discussion around myeloma, and to play our part in helping to push the boundaries of current thinking to improve outcomes for everyone living with myeloma.

The Jamaica Multiple Myeloma Support Group
Kingston, Jamaica
April 2016