

MULTIPLE MYELOMA INTERNATIONAL BILL OF RIGHTS

	Access to Treatments and Medications	Access to Support	Privacy and Confidentiality	Diagnosis
Patients	<p>Equitable & timely access to safe, high-quality myeloma treatments.</p> <p>The right to second opinion and/or to change their primary physician.</p>	<p>Myeloma information, education and care that takes into account a person's age, culture, religion, personal wishes, language and schooling.</p>	<p>Privacy and confidentiality of personal information is protected. Personal privacy is maintained and proper handling of personal health and other information is assured.</p>	<p>Timely diagnosis and advice from the primary physician, nurse and other appropriate specialists and advocates.</p>
Caregivers		<p>Emotional and mental health support. An understanding that the patient is receiving the best possible care.</p>		
Health Care Providers	<p>Work where support from specialists who provide myeloma care can be obtained within a reasonable time.</p>	<p>A right to ongoing training, funding and the tools needed to provide high quality myeloma care.</p>	<p>Ensure the privacy and confidentiality of personal information is protected. Personal privacy & proper handling of personal health information is assured.</p>	<p>Diagnose people living with myeloma as early as possible with a multidisciplinary approach.</p>
Government	<p>Provide safe and appropriate treatment to all myeloma patients.</p>		<p>Ensure the privacy and confidentiality of personal information is protected. Personal privacy & proper handling of personal health information is assured.</p>	
Pharmaceutical Industry	<p>Provide safe, tested & trialed and approved medications that deliver the efficacy that they promote.</p> <p>Make true & proven claims regarding the efficacy of medications & treatments.</p>			
Myeloma Support Organizations including GMAN	<p>Advocate for equitable and affordable access to myeloma treatments, care, medications, clinical trials and latest treatments regardless of where a person lives or their income, and wherever and whenever possible to ensure the delivery of these principles.</p>			

	Education and Information	Equitable Access	Policies and Strategies
Patients	<p>Be an active partner in decision making with their health care providers.</p> <p>To have access to their medical records and other health information and have it easily understood.</p> <p>Information, education and care that takes into account a person's age, culture, religion, language & schooling.</p>	<p>Affordable and timely access to medications and high-quality care, regardless of a person's, race, religion, income or where they live.</p>	<p>Equitable access to safe, high quality myeloma treatment, care and support.</p>
Caregivers	<p>Information & education that takes into account a person's age, culture, religion, personal wishes, language and schooling.</p>		<p>The right to be able to navigate the health care system in their country/state/region.</p>
Health Care Providers	<p>A right to ongoing training, funding and the tools needed to provide high quality myeloma care.</p>		<p>Help people with myeloma and their caregivers navigate the health care system in their country/state/region.</p>
Government	<p>Collect data on myeloma, including costs, incidence, survival, mortality, complications, and to regularly evaluate whether progress is being made.</p>	<p>Guarantee fair access to myeloma treatments, care and education, no matter what a person's income or where they live.</p>	<p>Form comprehensive policies and plans for the diagnosis, and treatment of myeloma.</p>
Pharmaceutical Industry	<p>Provide safe, tested & trialed and approved medications that deliver the efficacy that they promote.</p> <p>Make true & proven claims regarding the efficacy of medications & treatments</p>		
Myeloma Support Organizations including GMAN	<p>Raise public awareness about myeloma.</p> <p>Work to ensure the accuracy and currency of information about myeloma in the public domain.</p>	<p>Advocate and provide for equitable access to myeloma education, medications, clinical trials and latest information regardless of where a person lives or their income and wherever and whenever possible ensure the delivery of these principles.</p>	<p>Strongly advocate for the rights of people living with myeloma and where necessary represent the myeloma community to government, health professionals and/or systems and the pharmaceutical industry.</p> <p>Partner with researchers and health professionals to improve the planning, provision and quality of myeloma treatments and care by promoting and applying research.</p> <p>Implement and measure impact of Myeloma Patient Charter of Rights.</p> <p>Ensure achievable goals and metric and the tools required are available to the stakeholder in this charter and member groups in GMAN.</p> <p>Hold each stakeholder in this charter and member groups accountable for their role in the charter.</p>