

Building Blocks of Hope®: A Model for Advanced Practitioner Global Advocacy

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Background:

Living with cancer requires life-long learning and adaptation. The episodic nature of health care today, places the patient and their caregivers in a position of vulnerability with the expectation that they will take the primary role in managing their care despite having little or no formal training. Patient-centered communication and educational tools may expand treatment options, including access to clinical trials, may improve management of symptoms, extend survival, and increase quality of life.

Patient and caregiver empowerment through education and training for self-management is a core component of the Hematology/Oncology Advanced Practitioner (AP) role.

APs involved in clinical management of cancer patients interact with individual patients to mitigate disease or treatment related adverse events (AEs), empower the patient and caregiver for health self-management and improve quality of life.

The MDS Foundation (MDSF) is a global non-profit advocacy organization that for over 25 years has supported patients and their families as well as healthcare providers in the fields of MDS and its related diseases. AP involvement in the MDSF informs MDSF initiatives through understand myeloid diseases, the patient experience, and health care delivery dynamics globally.

Engagement of health care professionals, including APs, in global advocacy initiatives extends this reach beyond the individual patient.

Intervention:

The Building Blocks of Hope® (BBoH®), is a global print and online resource providing a personalized educational program for patients and caregivers to prepare, participate, and LIVE with MDS, MPNs and AML.

The BBoH® was created by an AP together with a multidisciplinary group of experts as advocacy volunteers to the MDSF. The BBoH® resources are continuously updated, allowing for rapid integration of changes in the therapeutic and diagnostic landscape for these diseases. Live links are embedded throughout the BBoH® to guide the patient and caregiver to vetted resources.

The BBoH® provides the foundation for global patient forums moderated by APs, physicians, and nurses together with MDSF staff.

References:
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International Handbooks

	Armenian		Australian
	Chinese		Danish
	Dutch		English (Canada)
	French (Canada)		French (France)
	German		Hebrew
	Spanish (Latin America)		Spanish (Spain)
	Turkish		

"It took me three days, but I have read the entire BBOH book. What a magnificent undertaking on your part. Your book is the most comprehensive source I have read. My understanding of MDS and possible treatment options has been greatly increased. Thank you for all your work."

Implications:

APs in Hematology and Oncology can extend the impact of their expertise through collaborations with patient advocacy organizations beyond individual patients to local, regional, national, and international groups.



[Building Blocks of Hope | MDS Foundation \(mds-foundation.org\)](http://www.buildingblocksofhope.com)

