# BMT CTN PatIENT AND CAREGIVER ADVOCACY CoMMITTEE

## Introduction

This committee was formed and operates under these tenets:

* Patient and caregiver advocacy and engagement is important for successful clinical research that addresses issues that are important to the patients being served
* Patients and patient advocates provide important insights into barriers to transplant and trial access
* A patient-centric approach minimizes trial-imposed burdens to patients and increases participation of patients from all ages, genders, and racial, ethnic and socioeconomic groups
* Increased engagement by patients and care givers through diverse avenues, including social media, can lead to increased awareness of and participation in trials

## Purpose

The purpose of the Patient and Caregiver Advocacy Committee is to ensure that patient and caregiver perspectives are included in the BMT CTN research portfolio and trial conduct.

## Scope

The Committee’s scope includes providing input on:

* Evaluation and prioritization of study concepts
* Interface with patient advocacy and/or community organizations
* Protocol team patient and caregiver engagement plans
* Patient, caregiver and family-facing materials, including protocols, consent forms and study and results summaries
* Website and social media content and communication plans.

## Responsibilities

The Committee will meet routinely by teleconference at least quarterly. There may also be work on projects outside of teleconferences, as needed. Responsibilities include:

* Identify areas of research most important to patients and caregivers
* Advise the BMT CTN on ways to increase patient participation in research with a focus on increasing access to a diverse group of patients
* Provide feedback on patient and caregiver-facing materials, including:
  + Final draft protocol and informed consent documents before or at the time of submission to the Protocol Review Committee (PRC), including study-related procedures and visit schedule
  + Protocol team patient engagement plan prior to study activation
  + Website and social media content
  + Study updates and results summaries
* Promote awareness among patients regarding research opportunities
* Address misconceptions about clinical trial participation

## Membership

Members are identified from a slate of candidates put forth by the Nominating Committee and approved by the Steering Committee. They include:

* Up to 12 voting members involved with HCT either as a patient, caregiver, family member, donor, healthcare provider or staff person/volunteer with an agency that interacts with HCT patients or donors
* Committee Chair to serve 2-year term
* BMT CTN ex-officio members from the DCC and NIH

In addition, committee membership strives to represent a diversity of backgrounds, including persons who:

* Understand adult, adolescent and young adult, and/or pediatric HCT issues
* Understand issues that affect access to or outcomes of HCT secondary to demographics and diversity
* Have been or understand the needs of a related and/or unrelated donors
* Are actively involved in HCT-related research
* Have marketing, communications, social media and/or professional writing experience

Non-ex-officio members serve for three-year terms that are staggered to permit annual rotations.