

PATIENT AND CAREGIVERS COMMITTEE CHARGE

Number of Members 6 - 8

Composition

Members shall consist of a Chair and a Vice Chair, one of whom shall be an electrophysiologist and one will be an Allied Professional, and between 4-6 at-large members, including at least one Allied Professional, one pediatric member, one patient and one patient-caregiver. For specific meetings or projects, the Chair may invite volunteer HRS members (both physicians and allied professionals), international HRS members, members of appropriate patient advocacy groups, and additional patients or patient caregivers. Working groups will be assembled as needed to engage in specific projects.

Method of Appointment

The Committee Chair, Vice Chair and members shall be appointed by the President-Elect in consultation with the President and Chief Executive Officer.

Term of Office

One year. Reappointment for two additional consecutive one-year terms is permissible.

Accountability

Reports to: Board of Trustees

Key Relationships: Education Committee and Subcommittees, Allied Professional Council, Health Policy Committee, Communications Committee, Scientific Sessions Program Committee, Membership Committee, and HRS Communities.

Purpose

To drive the Society's patient-centered initiatives as the leading source of information on heart rhythm disorders for patients and their lay caregivers, including parents and other family members or nonprofessional caregivers.

Responsibilities

- Work collaboratively with the Patient and Caregivers Committee staff liaison to set the Committee's annual work plan, timeline, budget (if any) and meeting schedule consistent with the Committee's overall priorities and agenda.
- Work closely with key Board Liaisons (Patient and Caregivers, Education and Allied Professional Council) to ensure alignment of proposed projects with the Strategic Plan.

- Maintain open communications with Key Relationship committees on projects/issues of mutual interest via regular reports and two-way communications.
- Plan, execute and oversee the development and implementation of the Society's patient-centered programs and activities, including culturally sensitive patient education materials and programs, with a focus on awareness, diagnosis and treatment of AF and SCA.
- Seek patient and caregiver input to develop patient-centered programs and activities, including projects/activities addressing patient health-care advocacy.
- Explore opportunities to collaborate with other professional health care organizations, to design, develop and execute programs for the non-EP community (primary care and general cardiologists), to help improve referral protocols, patient care and outcomes.
- Explore opportunities to collaborate with patient health care advocacy organizations, to design, develop and execute programs for patients and their caregivers, to improve patient awareness, and health outcomes.
- Oversee the relationship between the Society and external patient groups.
- Periodically assess members' needs for patient and caregiver information, and evaluate their satisfaction with the Society's patient-centered content and activities.
- Work collaboratively with the Education Committee and Business Development staff to incubate ideas for potential funding, in alignment with the Strategic Plan and annual Board priorities.
- Act as a resource to the Communications Committee for educating media professionals about heart rhythm disorders and care.
- Review external sponsor proposals involving patient and patient caregiver education and offer recommendations to the Education Committee.
- Explore opportunities to partner with international members/non-members to identify educational and/or advocacy needs for patients with heart rhythm disorders that cross national, racial, social, and economic borders.
- Seek specific opportunities to develop publications, media-products for patients and patient care givers.
- Ensure fiscal responsibility within approved budgets and for new program and services development.

Decision-Making Authority

- Establish Committee procedures.
- Develop strategy and decision criteria for internal patient initiatives, in alignment with the Strategic Plan and the Board's priorities.
- Make recommendations to the Board of Trustees.
- Build collaborative relationships with possible partner organizations and sponsors.

Work with key Board of Trustees Liaisons.

Meeting Frequency

Quarterly meetings by teleconference or face-to-face. Additional proposed meetings include:

- Annual patient advocacy group. In addition to the members of the Patient and Caregivers Committee, an additional 5-7 invited patient and caregiver participants and/or members of appropriate patient advocacy groups and key HRS staff will be invited.
 - The focus of this group will be to gain insight into patient, caregiver and health care provider concerns regarding education in order to develop meaningful products and initiatives. Appropriateness of pursuing donor and sponsor funding will be considered following these meetings.
- A Generative Idea meeting to be held at the annual HRS Scientific Sessions. This group would be formed of 8-10 additional ad hoc HRS member volunteers, in addition to the members of the Patient and Caregivers Committee.
 - The purpose of this group is to identify potential ideas that could be pursued over the following year using working groups. Projects of minimal financial commitment would be identified and opportunities to pursue potential grant funding.

Estimated Time Commitment

Varies depending on project/program assignments. Estimate 4 hours per month.

Scheduled

Chair and Vice Chair Conference Calls (every 4-6 weeks)

In-Person Meetings annually at HRS Scientific Sessions

Full Patient and Caregivers Committee Quarterly meetings via Conference Calls or in-person

Patient Advocacy meeting annually

Generative Idea meeting annually

Ad Hoc

Committee Conference Calls and meetings (as needed)

Busiest Times of the Year

Budget preparation cycle (July - August)