

TIP SHEET FOR MEDICAL ADVISORY BOARD RECRUITMENT AND MANAGEMENT

Produced by the National Organization for Rare Disorders (NORD®)

OVERVIEW

1. Have a clear purpose and outline the goals for your Medical Advisory Board (MAB). Some organizations refer to this Board as a “scientific advisory board,” or by another similar name.
2. Know the difference between the roles and responsibilities of your Medical Advisory Board and Board of Directors:
 - a. Board of Directors:
 - i. Acts on behalf of the organization to advance its mission;
 - ii. Works toward financial stability and business success.
 - b. Medical Advisory Board:
 - i. Offers expertise on scientific projects, statements and publications;
 - ii. Provides expertise on the clinical needs of the patient population;
 - iii. Assures that the organization’s policies, research, marketing, communications and publications meet the highest scientific standards.

RECRUITMENT:

You may already have one or two physicians, researchers or scientific advisors who work with your family and your community. Talk with them about the Medical Advisory Board and ask them for feedback on whom your organization can recruit to serve on the MAB. Here are some helpful strategies:

1. Query Your Community:
 - a. Ask members of your community – patients, parents and other caregivers – which doctors, nurses, other health professionals and researchers they interact with for care and clinical trials.
2. Explore Connections in Medical and Research Communities:
 - a. Look for researchers who are studying the disease and also those who are studying similar, related diseases and comorbidities.
 - b. Seek out clinicians who treat patients with the disease and also clinicians who treat similar, related diseases and comorbidities.
 - c. Ask researchers and clinicians if they know others in the field that they can connect you with who might be interested in serving on the MAB.
 - d. Look through publications online related to the disease(s) your organization works with and reach out to the authors. Google Scholar and PubMed are useful resources.
 - e. Try to contact key opinion leaders in your disease area. These leaders may be influential in bringing attention and funding to your organization.
 - f. Reach out to as many experts as possible for suggestions on possible MAB members.

GENERAL TIPS:

1. If possible, have a diverse board of clinicians, researchers and general practitioners. Consider nurses or other health care professionals in the medical practice of your specific disease.
2. Look for MAB members who share your organization's vision.
3. Know that you have just as much to offer to researchers as they have to offer to you. Patients can write letters of support for grant applications and may provide access to other patients for research and/or medical care.

ON-BOARDING AND GOVERNANCE:

Train the members of the Medical Advisory Board. Discuss the vision, goals and expectations that you have for them.

1. Create a board governance document (see NORD's Template: *Policies and Procedures for Working with a Medical Advisory Board*). This will help set expectations and guidelines and avoid conflicts of interest – especially important as your organization grows.
2. At the start, agree to the frequency of meetings (quarterly, biannually, etc.). Many NORD member organizations use Doodle.com to poll members for availability and to schedule calls.
3. Hold a meeting of all MAB members at least once annually; if possible, meet in person.
4. Adapt and restructure the MAB as needed based on organizational growth and/or the strategic plan.

DEFINING THE ROLE OF THE MAB CHAIRPERSON:

The Chairperson plays a key role in the MAB. The Chairperson must ensure that the MAB functions properly, that there is full participation during meetings, that all relevant matters are discussed, and that effective decisions are made and carried out.

1. The Chairperson is a leader and primary point of contact for the MAB.
2. The Chairperson can play a critical role in managing the tasks and responsibilities of sub-committees.
3. The Chairperson can be nominated and elected by the MAB or by the Board of Directors – this depends upon your organizational infrastructure and preference.

TIPS FOR ONGOING COMMUNICATIONS WITH YOUR MAB:

1. Get acquainted with your MAB members' assistants. Many of your MAB members will be busy and may not be able to reply directly to all communications. Send meaningful, short messages.
2. Give and take feedback from the MAB to identify strengths and areas for improvement.
3. If your MAB is large, setup a Google group or email list to track threads of conversation.
4. Appreciate your Board. Their knowledge and expertise are priceless to the stability and credibility of the overall organization. Consider profiling individual MAB members in newsletters, on social media and through other outlets to acknowledge their contributions.