

## Midwest Advocacy Project (MAP) Project Information

The Brain Injury Association of Wisconsin invites you to participate in this advocacy project. Becoming a successful advocate is an important way to improve services for individuals with traumatic brain injury (TBI), their family members, and significant others. The Brain Injury Association of Wisconsin is partnering with the Mayo Clinic TBI Model System in a research study to identify how to best teach advocacy to people touched by TBI to improve their health and that of their communities. This groundbreaking study is expected to advance the science of TBI research. The plan is to have 300 people from Minnesota, Iowa, and Wisconsin take part over 5 years.

As with all Mayo Clinic research studies, there are criteria interested participants have to meet in order to participate. Criteria for this study are:

- Have sustained a TBI at least one year ago, or be the family member or significant other of this person
- Have sustained a moderate to severe TBI as assessed by the Mayo TBI Model System researchers, or be the family or significant of this person
- Be at least 18 years old
- Be able to participate in a group meeting, that is, demonstrate physical, cognitive, communication, and behavioral skills conducive to participating with others in a group process for several hours at a time

If you agree to be in this research study:

- 1) You will be put in one of two MAP groups by chance (as in the flip of a coin). Two groups of up to 15 participants each will meet for four consecutive months (August through November), on a Saturday, for approximately 6 hours, at a training site arranged by the TBI Model System.
- 2) Prior to beginning the first group you will do several things. First, you will meet with a Mayo Clinic researcher who will complete the consent process. Then, you will fill out six short questionnaires, expected to take about 20 minutes altogether. These questionnaires were selected in order for us to learn about your current advocacy activities, perceived control, perception of environmental barriers, and quality of and satisfaction with life. Finally, you will complete two behavioral assessments of either self or system advocacy skills (examples will be provided):
  - a. Self advocacy – write a 1-2 page letter to a provider and participate in a videotaped 2-3 minute mock interview with a provider on an issue that is personally relevant to you or your family

**OR**

  - b. Systems advocacy – write a 1-2 page letter to a legislator and participate in a videotaped 2-3 minute mock interview with a legislator on a system of care issue or an issue pertinent to entire groups/communities
- 3) You will then begin participating in the series of four MAP group meetings with others interested in advocacy training and improving TBI services. Mayo Clinic TBI Model System and BIA staff will serve as facilitators of each group over the course of the four Saturday meetings.

- 4) At the conclusion of the final meeting you will again fill out the six short questionnaires and repeat the two behavioral assessments of either self or system advocacy skills.
- 5) Following completion of your final group and until the MAP study concludes on September 30, 2012, you will be contacted on a quarterly basis by a Mayo Clinic TBI Model System researcher by mail to inquire about what advocacy related activities you have participated in since completion of training. Examples of advocacy activities we are interested in tracking will be provided in a checklist format and will include things like “contacted my state senator”, “hosted a legislative home visit”, or “arranged for media coverage of a TBI related issue”.

This research study is voluntary. You may stop participating at any time during the study. You may decide not to participate. If so, none of your current care either at Mayo Clinic or the Brain Injury Association within your state will be affected in any way.

Travel expenses including one night in a hotel (standard hotel room) and mileage up to \$200 maximum per session will be covered for those residing 60 or more miles from the training site. All participants will receive a research stipend of \$100 upon completion of the four sessions. If participants miss one session but still complete the needed assessments, this stipend may be reduced. If participants miss two or more sessions, they will not qualify for any stipend and will be considered to have withdrawn. If you withdraw from the study, we will continue to contact you on a quarterly basis by mail to inquire about what advocacy related activities you have participated in since you withdrew.

Take time to think about participating in this study. Please contact us again at Brain Injury Association of Wisconsin at 1-262-790-9660 or 1-800-882-9282 for additional information and/or an application. Upon receipt of your application, which will be reviewed by Mayo Clinic researchers and staff at the BIA, you will be notified if you are eligible to participate and specific training dates and times will be reviewed with you.

Thank you for your interest in this important TBI research study. We hope you will consider joining with others eager to gain better advocacy skills and know-how.