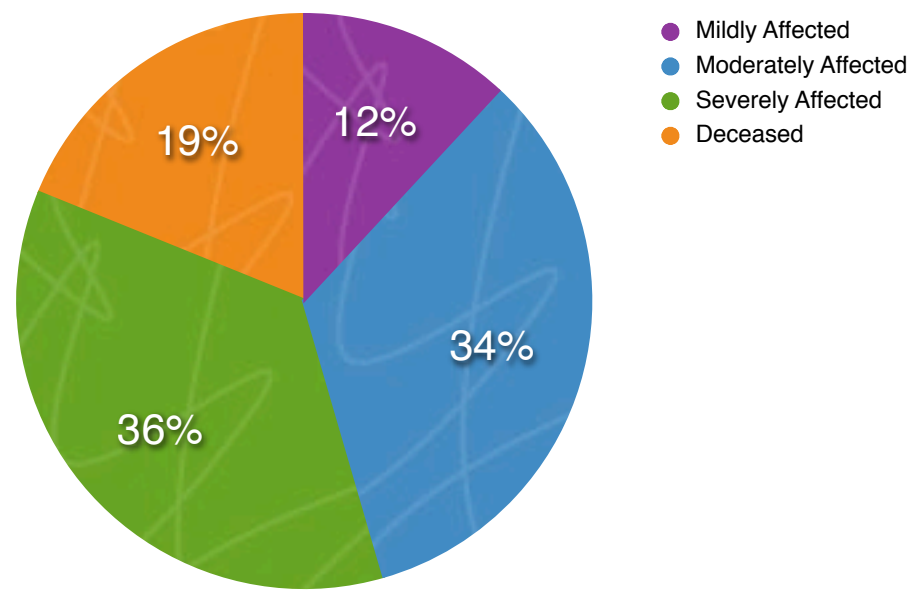
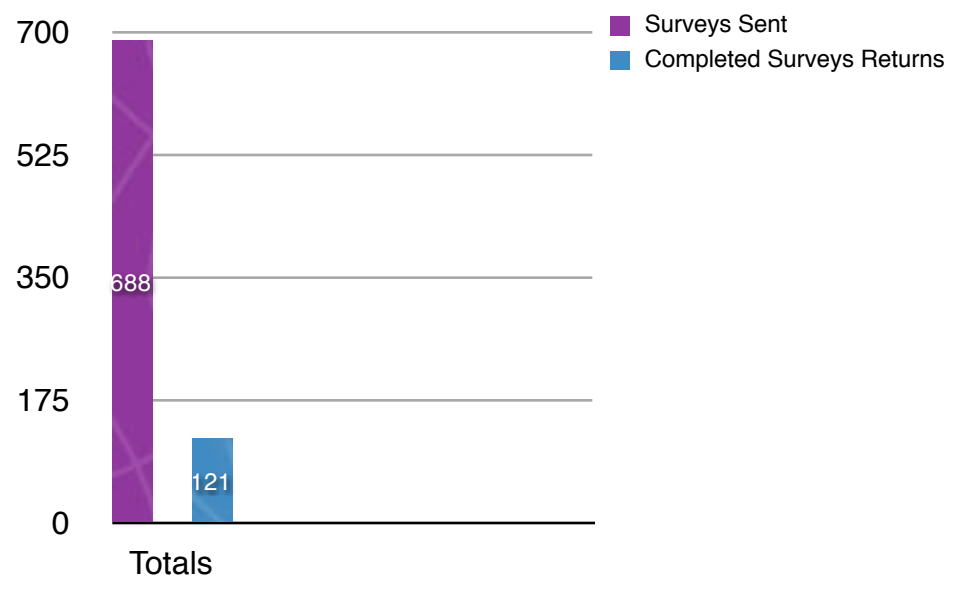
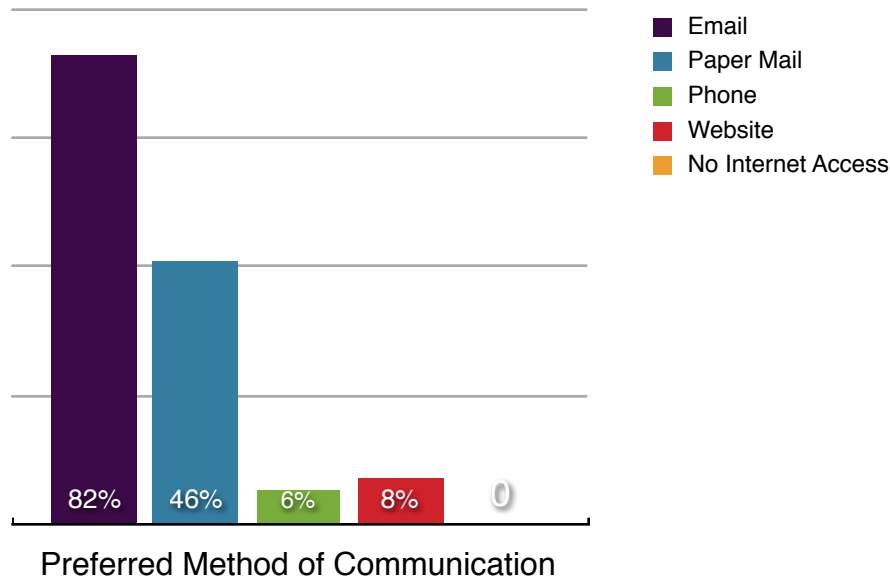


2010 Membership Survey
Education & Publicity Committee
Kimberly Frye, Ph.D.

This year the Education & Publicity Committee conducted a survey of the membership to explore satisfaction with communication, family support programs and publications available to the membership. Participation in this survey was made available to all members of the National MPS Society in the summer of 2010. Responses were collected through an online survey website. Members without internet access were mailed a paper copy. Participation was optional and all ideas and feedback was encouraged. This was an anonymous survey designed to provide members the freedom to communicate honestly. What follows is a summary of the results of this survey. Six hundred eighty eight members were invited to participate and 121 members completed the survey.

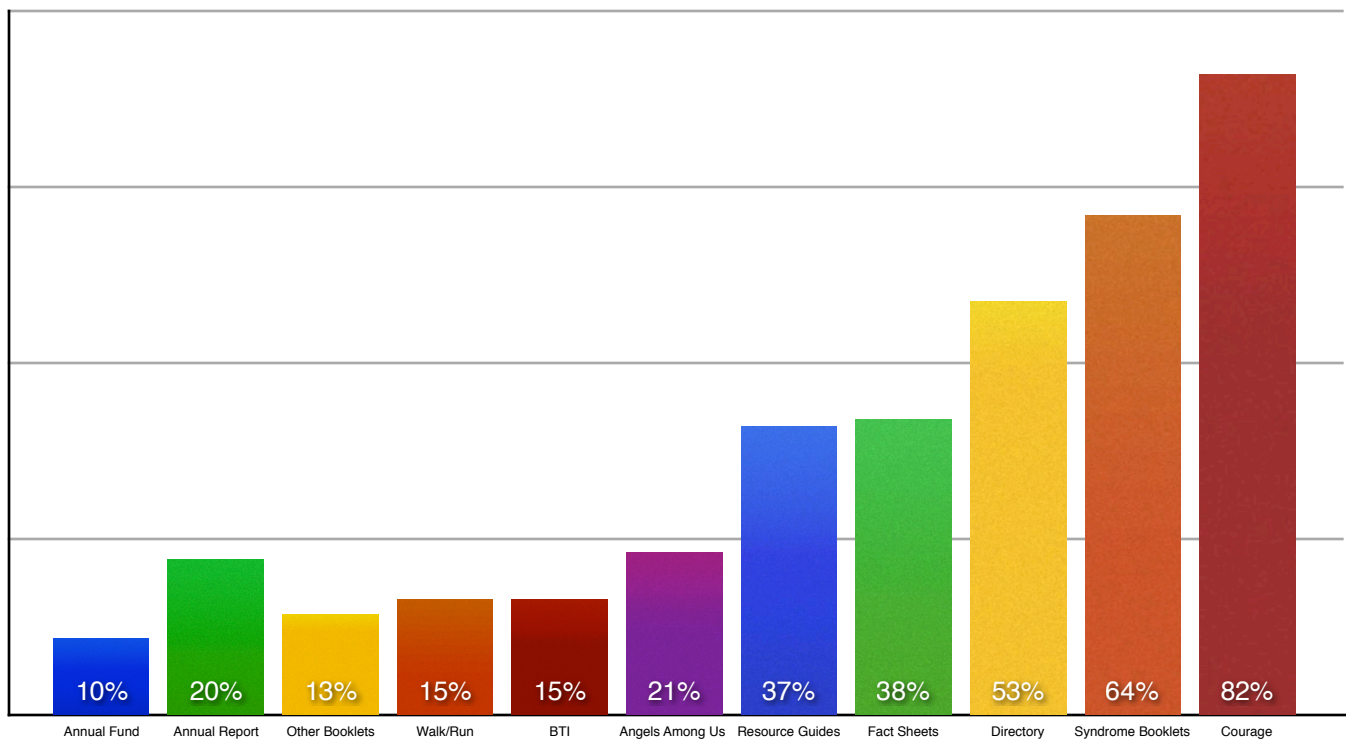


As we modify ourselves to adapt best to current trends it is important to understand exactly how our members access the society and what preferences our membership have with regard to communication.

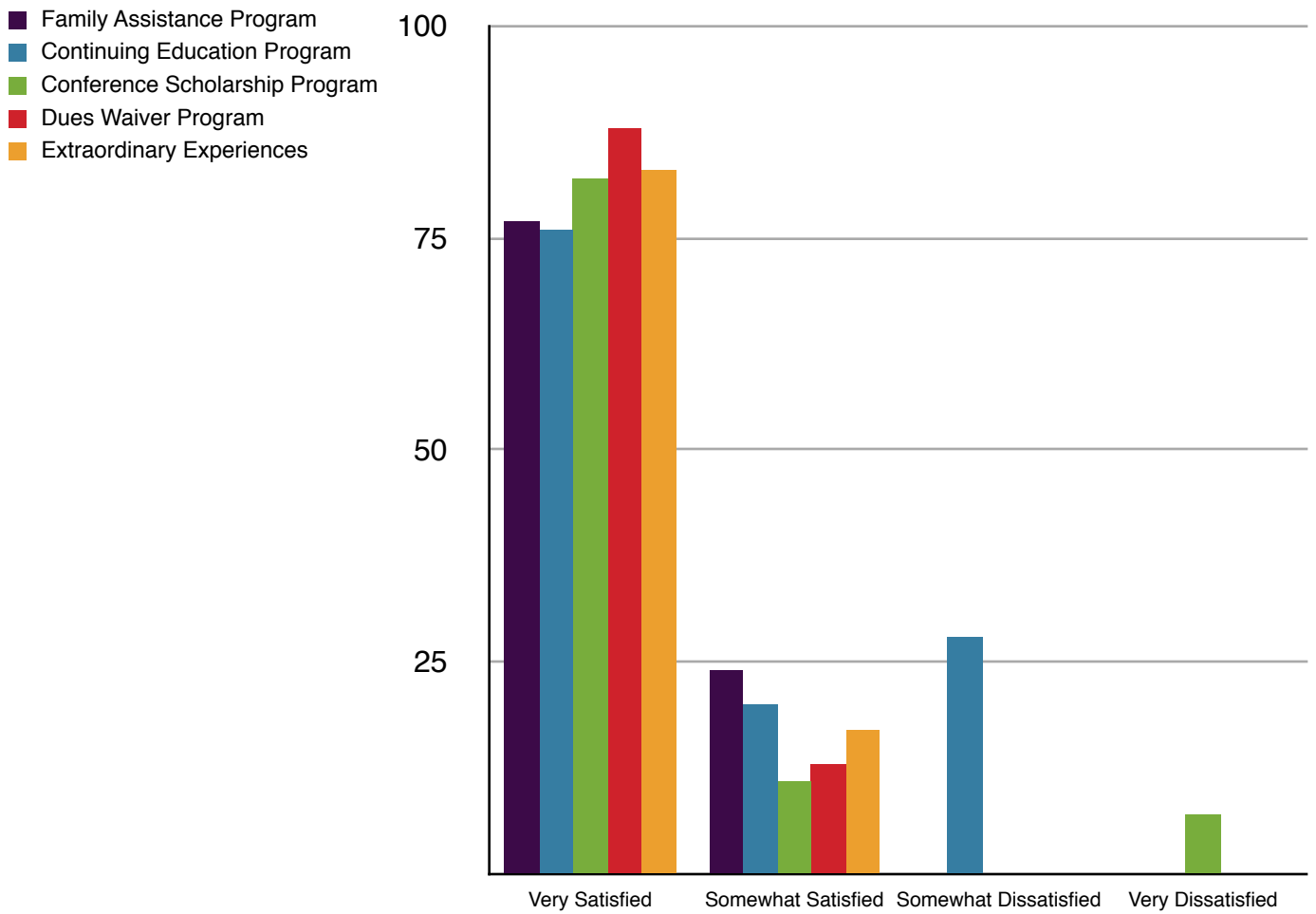


It was of great importance to understand what publications our membership find helpful and supportive. While some publications are more costly to produce than others (Courage vs. Fact Sheets) the intended purpose is educate families, provide support and facilitate collaboration with others. These results are presented in the chart below.

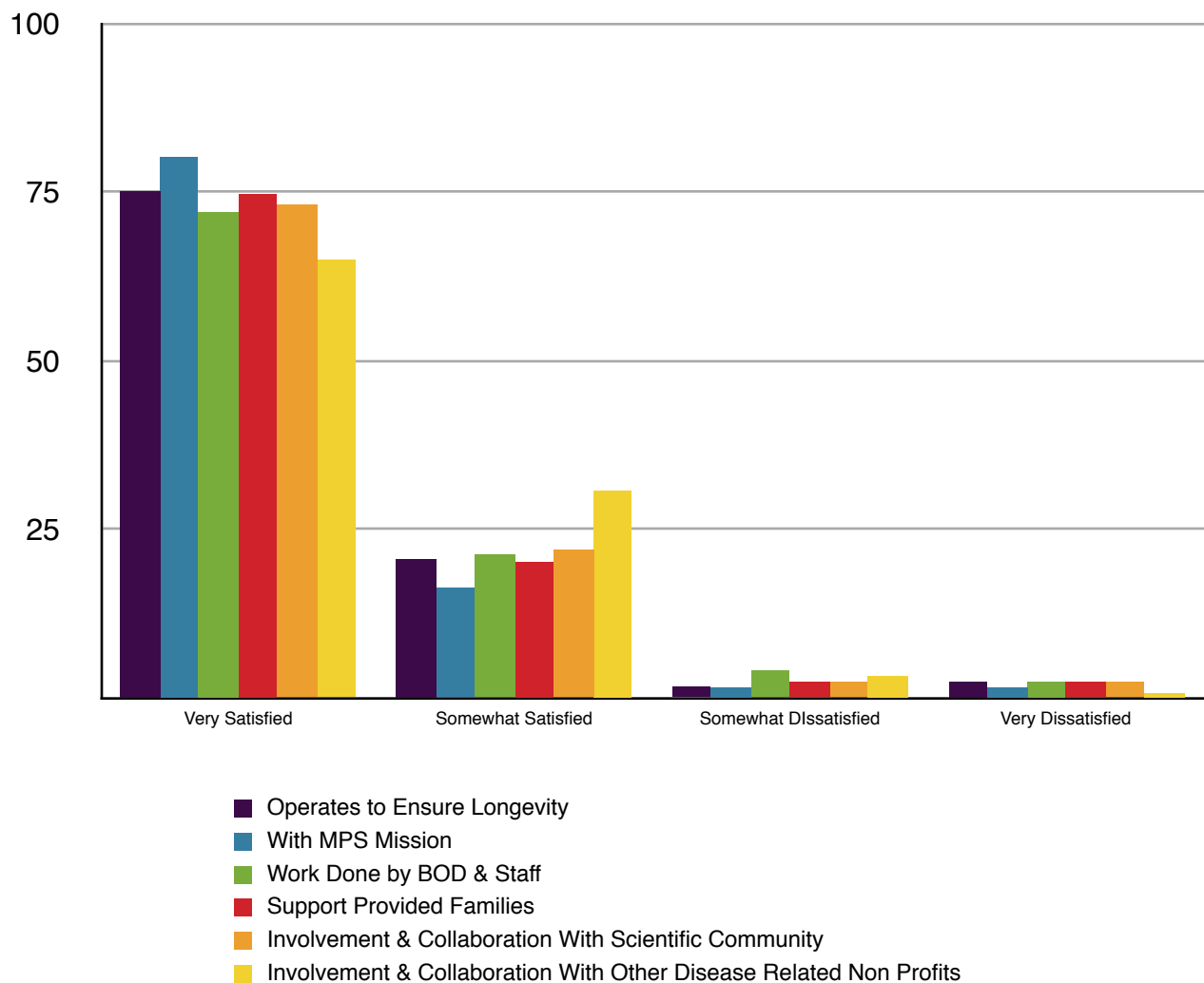
Publications Found Most Helpful



Many of our programs have been developed and designed to provide support to families. The results are presented in the chart below.



The survey included several questions exploring membership satisfaction with the work done by both the staff and the Board of Directors. These results are presented in the chart below.



This survey was anonymous to ensure that all who participated could respond honestly without concern for repercussion. It was our *hope* to hear *all* concerns. Below is a list of concerns communicated in this survey. These results have been reviewed and discussed by the Education & Publicity Committee, at the most recent board of directors meeting and at the general membership meeting at the annual family conference held at Knott's Berry Farm.

Expressed Concern	Committee/Board Discussion and Action(s)	Discussion at Annual General Membership Meeting
Board of Directors needs to change more	Issue of term limits has been discussed in the past and discussions continue.	The idea of term limits was raised as something to consider.
Appearance of selectivity based on skills and profession	Ongoing discussion. From time to time the Board has needed a member with a skill to effectively uphold to duties required of the Board as stated in the mission and bylaws.	Various members agreed that there are times where this is necessary but did not feel that it was done in a self serving manner.
The new Governance Committee has taken my rights away	Discussions ongoing. Governance has provided membership with specific goals and objectives in Courage and during general membership meetings at AGM Disney & Knott's.	Members discussed how difficult change can be and the existence of Governance Committee's in both public and private sectors. Members discussed the need for Governance.
Too many professionals on Board	At present the professionals on the Board of Directors include one MD, one Ph.D., two CPA's, and two entrepreneurs.	Discussed that board composition is representative of members who run for the board.
Staff do not have MPS children	At present we have one staff that does have an adult child with an MPS or related disease.	Discussed the need for this for staff effectiveness and the fact that we have a staff member with an affected adult child.
Board of directors needs to be more outgoing at conferences - too cliquy	This was heard, discussed and acted on during our Knott's Conference. Conference evaluations will be examined.	Discussion similar to stated discussion among committee and board.
Too much money going to families for items needed when other programs exist to fund items	This is an ongoing discussion among the family support committee. Access to certain programs varies from state to state. The Education & Publicity Committee is working toward creating a resource for families.	Discussion similar to stated discussion among committee and board.
Society is not beneficial to all MPS families.	This was heard but difficult to discuss. It was unclear as to what is not beneficial. There is great interest in development if needs are not being met.	This was heard but difficult to discuss. It was unclear as to what is not beneficial. There is great interest in development if needs are not being met.

Expressed Concern	Committee/Board Discussion and Action(s)	Discussion at Annual General Membership Meeting
No board members with severely affected children	Discussed and a review of the makeup of the current board reveals that many of the board have children who are severely affected by MPS.	Members discussed the lack of evidence to support this comment.

This survey provided other valuable information as well. We learned that members want booklets or fact sheets on topics not yet available in our library. However we also learned that members were unaware of certain topics that already have a fact sheet or a booklet. Perhaps this speaks to a need for this committee to arrange or organize available materials differently. We learned that our members want to hear from us more. This was a pleasant surprise. More email, more contact, more communication was overwhelmingly okay with the members who completed this survey. The Education & Publicity Committee would like to extend a word of thanks to every member who took the time to complete this survey. The information you shared with us provides important direction and assurance. It also helps us see where we need to go, how we need to grow and what we can do better. Thank you.