



**The
Mastocytosis
Society**

The Mastocytosis Society Board Meeting Minutes August 1, 2006

Meeting called to order at 8:22 pm via teleconference.

ATTENDEES:

Rita Barlow, Chair (co chairing meeting)
Valerie Slee, Co-Chair (co-chairing meeting)
Regina Rentz, Treasurer
Len Levenda, Special Events Chair
Cindra Carey, Support Group Chair
Rita Barlow and Valerie Slee, co-chairing meeting

ABSENT:

Susan Manchester, Corresponding Secretary, partial medical leave of absence.

▶ ACTIONS:

- Motion made to approve July minutes, seconded and passed.
- Motion made to include a book signing by Dr. Akin and other MAB doctors who wrote chapters in his book, for the annual meeting. Seconded and passed unanimously.
- Motion made to approve ballots as presented to us by Wanda, and to approve the names of the candidates listed. Seconded and passed unanimously.

▶ OLD BUSINESS:

- Discussion about grant money applied for in 2006, with Valerie Slee and/or Jim Boyle, and received. We discussed using this grant money, as specified under some of the grants, to cover conference expenses for the annual meeting, the AAAAI, etc.
 - Motion made that Valerie to contact each company, and ask how they want to be credited in the program and at the Annual Meeting, seconded
Those grants include the following:
 - Dey Pharmaceuticals: makers of Epi-pen; \$5,000 specified educational grant for the purpose of financing some of the annual meeting expenses.
 - Critical Therapeutics: makers of Zyflo (zileuton); \$4000,00 unspecified educational grant;



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- **Azur Pharmaceuticals:** makers of Gastrocrom (oral cromolyn sodium); \$3,000 unspecified educational grant to help with annual meeting expenses.
 - **Genentech Pharmaceuticals:** makers of Xolair; \$5,000 educational grant to help with any meeting or conference expenses.
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- **Scholarship money:** We have been notified of intent to donate \$1500.00 for our scholarship fund. **Motion made and passed to disburse all grant money for the reason it was donated.**
 - Discussion took place about moderating both the new online support group, set up by Cindra Carey, as well as the new website bulletin board designed early this summer by Karen Curtiss.
Motion was made and passed for Cindra to contact Karen about activating the first part of the bulletin board, called "Questions for the Board".
 - **Bylaws:** once the member advisory bylaw review committee presents its recommendations, they will be made available by email, fax, or snail mail to anyone that requests them, as previously decided. The board will review them and decide what to accept, with input submitted from all members taken into consideration.
 - **A motion was made and passed unanimously to postpone the final bylaw review due to the election and annual meeting demands, to be sure not to rush through this very important process. No timeline was decided upon, pending further discussion into this very important matter.**
 - **Motion was made and passed for Len to put the articles, provided by the speakers and the MAB to the Research Advisory Board, on to a CD.**
 - **Motion was made and passed to change the bylaws to include a provision that if the majority of votes are not received, then a candidate may win the election by plurality vote.** (This was done because there are so many candidates for election, and it simplifies things so that the five candidates (*this year*, for five open positions; this may change depending on open positions year to year who receive the most votes win)
 - **Motion was made for Wanda, Cecile and Emily to look into new items to be sold for the annual meeting, especially sweatshirts and baseball caps, seconded and passed.**



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- Emily asked for a way to set up a bank account for her fall EBay fundraiser. Motion made and passed to set up a separate bank account just for this purpose.
- Member Advisory Committee:

Rita had proposed this type of committee earlier this year, and discussion was tabled until now. The committee would be comprised of support group leaders, a caregiver, and one board member. The role of the committee would be to give us input and advice when needed, with all final decisions made by the board after considering that input and advice.
A motion was made and passed to table this discussion until September or later, because we do not have the time to start a new initiative right now while dealing with the election and the annual meeting.
- Discussion took place about the grant money expressly applied for, and received directly for the purpose of helping with board and MAB travel and meal expenses (\$2000.00 of a \$5000.00 grant from Dey Pharma). Motion was made to use the money expressly applied for, and received directly for this purpose to pay for meals that include the board, MAB, and speakers and also to offer money to any board member that needs it to attend the annual meeting. This money was applied for to avoid having to allocate existing TMS funds for this reason. **Motion seconded and passed unanimously.**
- Private funds from one of the board members and spouse will be donated to TMS to cover meeting registration fees for an anonymous recipient. In addition, anyone that needs financial help to attend the annual meeting will be urged to submit a scholarship form, as there will be money available, as discussed earlier.
- **Motion made and passed unanimously to continue to seek advice from the Maryland Association of Non-profit Organizations attorney's office in dealing with election matters.**
- Discussion took place about having an ineligible list that would contain the names of members who are not eligible to stand as a candidate for election in the future. This list would include anyone who was not a member in good standing with dues paid, and anyone that had to be removed from a director or committee chair position for any serious reason, in accordance with the bylaws. This discussion will be continued when we convene to discuss the bylaw revisions with advice from Deb Jung and Peter Berns of the MD Association of Non-Profit Organizations.

Motion was made, seconded and passed to adjourn at 10:25 pm.