Hemophilia Advisory Committee
Conference Call
May 18, 2009
7:00 p.m. – 9:00 p.m.

Minutes

The regular meeting of the Iowa Hemophilia Advisory Committee was held via conference call.

Members Present

Steven Lentz, MD
Andrew Meyer
Karla Watkinson
Tami Bullock
Michael Lammer
Carol Has
Angela Burke Boston*
Kimberly Noble Piper*
Sally Nadolsky*

Members Absent

Kari Atkinson**
Dave Postel

Others Present

Nancy Patrilla (rep for Kari)
Stacy Cowen
Elizabeth Stoltz
Brice Oakley

*ex-officio
**excused

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<thead>
<tr>
<th>Topics</th>
<th>Discussion/Action</th>
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<td>Call to order</td>
<td>▪ Andrew Meyer called the meeting to order at 7:04 p.m.</td>
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<td>▪ Members and guests introduced themselves.</td>
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<td>Announcements</td>
<td>▪ Budget – funding cuts discussed. Piper will ask the Asst. AG for an opinion if no appropriation, does the HAC continue?</td>
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<td>▪ Brice Oakley will discuss with contacts in legislature and governor's office.</td>
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<td>▪ Piper will speak with the Division Director about IDPH support, if not funded.</td>
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<td>Bylaws</td>
<td>▪ Motion to approve bylaws as amended was made by Bullock; second by Nadolsky.</td>
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<td>▪ Roll call vote – approved.</td>
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<td>IowaCare</td>
<td>▪ Recommendation to provide factor to outpatients</td>
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<td>▪ Will draft a letter to IowaCare regarding the need to provide factor to outpatients, rather than through inpatient admission requirement</td>
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<td>▪ Members will also send a letter to Jennifer Vermeer (head of Medicaid) re: BMC not having factor available, necessitating travel to Iowa City.</td>
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<td>August Meeting with HoI</td>
<td>▪ Saturday August 22nd. HAC will make a presentation right after the main speaker, explaining what its mission. Goal will be to solicit issues and questions from the chapter that the HAC should address. Meyer will develop a presentation.</td>
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<td>Changing Disability determination from 1960s to current language</td>
<td>▪ Needs to be addressed at the federal level, as is federal statute, rather than state.</td>
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<td>▪ Lammer will contact the National Hemophilia Foundation (NHF) re: advocacy for this change</td>
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| **Plan of Action** | ▪ Pre-existing condition insurance issues (NHF addressing possible legislation addressing lifetime caps). Lammer will speak to the NHF representative about how to weigh in.  
▪ Gaps in health care coverage – i.e., college grad before job/benefits. Boston reminds group that legislation extends coverage to full-time students, and age 25 unmarried Iowa resident. Noted that this is the age population that is meeting their lifetime caps – so legislation is even more important.  
▪ Thrombophilia issues – need to get good information out there, no good sources of information like hemophilia has. No Iowa organization yet, but one in MN. Bullock will forward contact information from the MN group. Reimbursement for non-standard anticoagulant therapy (i.e., low-molecular weight thinners).  
▪ Will work with the insurance division (Angela Burke Boston) to address insurance issues and who to work with to manage the issues (caps, no coverage) and what options are available.  
▪ Elizabeth Stoltz states Baxter provides a hotline for individuals who may have hardships in paying for therapies |
| **2010 meeting dates** | ▪ Motion to approve 2010 schedule made by Lentz, second by Bullock.  
▪ Roll call vote - approved |
| **Next meeting agenda items** | ▪ Issues from chapter members  
▪ Budget/appropriations follow-up.  
▪ Future of HAC |
| **Adjourn** | ▪ Motion to adjourn by Hans, second by Meyer.  
▪ Roll call vote– meeting adjourned.  
▪ Meeting adjourned at 8:13 p.m. |