



HS-USA, Inc.
7362 High Hill Drive
Brighton, MI 48116-9143

Minutes of HS-USA, Inc. 5th Annual Board Meeting

June 16, 2007 – Philadelphia, Pennsylvania

Sheraton Suites Philadelphia Airport Hotel

1) Call to Order

Meeting was called to order by President Paige at 11:22 a.m. EDT

2) Roll Call of the Board of Trustees

Members Present: Costin, Edwards, Kemmerer, Kennedy, Paige, Solarski

Members Absent: Hunter

Staff Present: Hall

3) Approval of Minutes of 4th Annual Meeting (2006)

Motion by Kennedy, supported by Edwards, to approve the minutes.

Roll call vote: motion approved unanimously

4) Approval of Agenda

Motion by Edwards, supported by Solarski, to approve the Agenda

Roll call vote: motion approved unanimously

5) Treasurer's Report

Kennedy submitted Midterm Report for 2007, indicating need for improved fundraising efforts.

Motion by Edwards, supported by Paige, to approve Report.

Roll call vote: motion approved unanimously

6) Committee Reports

- a) Crisis/ Helpline Report –Almost 4,000 calls logged in 2006. October and July were the busiest months, while February was the month with the least amount of calls. Suggestion was made to research Vonage as a possible new provider for phone service.

7) Old Business

- a) Grant Writing Committee – Paige reported that HS-USA is now registered with the required agencies, including Grants.gov, which will allow access to government funded grants. Kemmerer was key in recruiting Megan from Congressman Dent's office to point the committee in the proper direction. Volunteers to work on this committee included Dr. Kimberly Black, Lori Aul, Patti Kemmerer and Sandra Payne.
- b) Membership Committee – Discussion held regarding need for membership: legitimacy vs. income. Fee structure and benefits of membership would need to be decided. Bylaws will need to be amended to allow for change in the structure of the organization. Recommendation to use law schools' public law externship programs for legal advice and pro bono assistance.
- c) Petition Committee – Determination that online documents are not valid tools for petitioning government offices. Requires evaluation as to information necessary for validation of petition. Again, law schools may be valuable resources for assistance in this regard. Document may be useful as an avenue for membership recruitment. Solarski uses petition signatures to disseminate information about HS-USA as well as local and regional support groups. Volunteers are needed.
- d) Funding – Discussion regarding need for stronger fundraising efforts, together with more grant writing proposals. Hidradenitis is beginning to generate interest in the medical and pharmaceutical communities, and HS-USA must move quickly.

8) New Business

- a) Need for new treasurer – Kennedy indicated a desire to step down as treasurer. Volunteers requested. Board will discuss possible replacements.
- b) Necessity for Annual Conference – Discussion regarding requirements of IRS for annual meeting; discussion regarding change of bylaws to allow for flexibility with the month of conference and annual meeting; discussion regarding asking for HS community input as to the best month via a survey.

Motion by Paige, supported by Solarski, to change the bylaws regarding flexibility in the month of the conference and annual meeting.

Roll call vote: motion approved unanimously

- c) Documentary: Discussion regarding role of HS-USA in the production and future possible distribution of video. Denise Boucher needs to clarify her goals, intentions and expectations. HS-USA needs to state a position regarding the inclusion of its conference in this endeavor, and whether its events and functions should be utilized to further those goals.
- d) Improvement of Communication: HS-USA Board of Trustees needs to renew and follow the original schedule of monthly conference call meetings, and will research www.freeconference.com as a possible call center, in addition to the method provided by Donaldson.

- e) Public awareness / accurate count: Discussion regarding utilizing a Member Directory (either with or without membership fee structure) to assist with getting a more accurate count of HS sufferers in the U.S.
 - f) Medical Advisory Board v. Panel: Dr. Talbott will be invited to become a member along with Dr. Lee and Dr. Haeffner. Kennedy will touch base with Dr. Haeffner. Leaders in the HS community who would like to invite a physician to the MAB should discuss same with a Trustee, and if appropriate, the Secretary can send a formal invitation to the physician. The programs of HS-USA need to be more clearly defined so the expectations of the physicians can be related.
 - g) Finding a spokesman: Board will pursue relationship with Mr. White. Discussion of pro bono legal advice being sought to define this relationship. Members of the HS community are encouraged to continue their letter writing and email campaigns to various celebrities, and to seek out friends and family members involved in the Screen Actors Guild, or any entertainment industry or organization. Discussion regarding local cable stations and college students providing assistance with Public Service Announcements.
 - h) Webmaster – seeking experienced assistant. Also, discussion regarding separate section for physicians and/or area for physicians to post on website.
- 9) Call to Public (for additional comments or announcements)
Kennedy announced the positive IRS ruling on the continuation of the 501(c)(3) status of HS-USA, Inc. as a public charity. No other comments.

10) Roundtable Evaluation and Review of Actions

Discussion held later in day. Consensus is that this meeting was successful, although a longer period of time needs to be allotted for this meeting. Discussions need to be kept on topic and timely.

11) Adjournment

Motion by Kennedy, supported by Paige, to adjourn

Roll call vote unanimously approved. Meeting was adjourned at 1:30 pm. EDT.