

Hemophilia Foundation of Minnesota/Dakotas
HFMD Board Retreat, Ramada-MOA, Bloomington, MN
Meeting Minutes
November 18, 2006

Meeting was called to order at 9:07 a.m.

Present: Aaron Reeves, Bob Stone, Dan Tinklenberg, Sharold Friedrich, Judith Campbell, Brenda Neubauer, Jim Langworthy, Bill Kallberg, Liz Myers, Steph Miller, John Schulte, Jim Brown, and Nancy Golden.

Staff: Jim Paist, Executive Director, and Pam Cella, Office Manager.

Minutes: The Board reviewed the September 19, 2006 minutes. Sharold Friedrich made a motion to approve the minutes as written and Bill Kallberg seconded. Motion carried.

Financials: August: The total assets for checking and savings were \$251,126.47. Year to date income is \$302,289 and expenses are \$244,962.

September: At the end of September, our checking and savings amount to \$258,405 and our year to date income sits at \$324,461.

October: Total assets for checking and savings are at \$234,548.89. Year to date income is \$333,943. Jim Paist reported that looking beyond the camp and golf expenses which has already occurred, HFMD is not expecting any major expenses.

This year, we had 58 campers. That number was down somewhat as Courage North sent a letter to families asking for payment. The HFMD and the HTC agreed that in no way will families suffering hardships not be able to send their children to camp.

Bill Kallberg asked if we could give a P&L for our two major events, the golf and gala. The Golf Tournament income is Account 3800 and the Gala income is shown under Account 3900. This year, the Gala raised \$113,504. Expenses however, are spread throughout this P&L statement. Account 5200, Banquet/Food, shows \$66,687 and this is an accumulation of banquet costs for programs i.e.; the gala, retreats, annual meeting, golf tournament, etc. Therefore, Jim suggested that we provide the Board with individual P&L's after each event.

Jim Paist also reported that our Poinsettia Fundraiser will be held in late November and early December and this is our third fundraiser for the year.

A motion was made by Bill Kallberg to approve the August, September and October financials. John Schulte seconded the motion. Motion Carried.

2007 Budget: Jim Paist reported that the proposed budget for 2007 is \$366,500 and is similar to the approved 2006 budget was \$355,700. We were pretty much on track with our budgets over the past two to three years of income and expenses. We have had some fluctuation in certain areas. Increases such as employee health insurance will go up 13 percent as well as decreases such as Community Health Charities (CHC). Monies we have received from CHC are down from the past two years due to shifting of funds however, we should be receiving an additional check before year end.

Jim Paist explained how CHC operates. We are one of a 26 member organization with a common thread of health care illnesses within Minnesota i.e.: the Children's Hospital, the Alzheimer's Association, the American Lung Association, and the Minneapolis Heart Institute just to name a few. Normally, distribution is based on employee designations to these various groups, via payroll deductions. However, most of our money comes from the general pool because historically, we have not had many employees designate to HFMD. One way that we can increase our CHC funding is by recruiting new businesses to sign up with CHC. So if anyone on the Board knows a business that would be interested in signing up, HFMD would gain 50 percent of the monies that would be allocated to the general fund for the first year. Jim will arrange to have a member of CHCM make a presentation at our next Board meeting. Nancy Golden mentioned that medical groups could be important groups to contact and Jim will look into this.

Along with financial donations received, each member organization has to donate a specific number of volunteer hours to CHC. Because of our size, we need to donate 40 hours per year and our balance this year stands at 21 hours. We have recruited Steph Miller to help and if anyone else is interested in volunteering, please send Jim an e-mail. Aaron asked what companies were already involved in CHC so duplication of businesses doesn't occur. It's a long list, so Jim will look into obtaining that information and distribute to Board members. We have CHC brochures in the office and will send them to all Board Members.

On the Income Side; Last year we projected \$27,500 for Account 2500. However, this year we have reduced that income to \$10,000. Grants are sent out from HFMD to various foundations whose criteria we meet. Historically, we have been turned down by most foundations as they do not give much funding for health care. Another component is letting people know about The Hemophilia Foundation and establishing awareness of who we are and what we do.

Line 3900, Gala Income, was budgeted at \$101,500 but we brought in \$117,500 last year. For the 2007 budget, we estimated the income at \$105,000.

Line 4000, Charms/fundraiser, didn't bring in anything additional this year. We bought these charms for \$2.00 and sold then for \$10.00 previously. We need to start selling these at our various events, retreats, etc.

Line 4100, Advertising Income, is income raised through advertising in the Veinline. The budgeted amount for 2007 has been scaled down to reflect the income that we did receive. Jim said it would be no problem.

On the Expense Side; Account 5200, Banquet/Food & Lodging, received a 6 percent increase. Judith Campbell asked if we could separate the events and list the actual expense.

Account 5400, Brochure Expense, will incur nothing in 2007 since the reproduction of a new HFMD Brochure will be incurred this year.

Account 6300, Emergency Assistance Expense, was increased a couple of months ago as the Board took action to adjust the 2006 budget to reflect an increase in assistance to families.

Account 6600, Insurance, will remain level for 2007.

Account 6900, Employee Benefits, was increased due to a 13.5 percent adjustment for 2007 health insurance cost increases. HFMD pays 100 percent of health care premium for Jim Paist and 50 percent for Pam Cella.

Account 7700, Payroll, was reduced to show a more actual figure.

Account 8600, Scholarship, was raised as in 2006 we allocated \$15,000 to students for their post high school education.

Account 8900, Temp Staff, was left in for additional staffing during the year.

Jim further explained Account 9850, CHC Growth Fund, is for purchase of two growth shares for \$3,000. Last year, these purchases were a line item under expenses. That was changed by the Board so that the income from this investment would be reflected on the balance sheet. But the purchase of these funds has a separate line item which is not part of our overall expenses since this comes from our investments.

Aaron asked if anyone had anything specific to discuss about the 2007 budget because now is the time to delve into it. Aaron then asked for a motion to approve the 2007 budget. Bill Kallberg made a motion to approve the 2007 budget and Bob Stone seconded. With no opposition, motion carried.

Board Manual:

Governance/Page 1/HFMD Board Responsibilities/Item 5: This states that each Board member to have the ability to raise at least \$1,000 for the chapter per year and to donate 20 hours to the chapter. Jim Paist raised questions about this implied requirement. Do we want to change the language, delete it, or leave as is? Aaron realizes that each individual is different as well as year by year so we do need some flexibility. We could leave it and view this as a goal for the Board. It does only say “asks”, and not expected. Jim mentioned that opportunities arise that include donating items to the Gala or Golf Tournament is an additional way to help. Everyone does their part by raising funds for HFMD from family or friends, donating time by attending Board meetings, retreats, or attending NHF events. Nancy Golden, on behalf the Hearts of Hope Gala for 2007, asked Board members if they could both attend the gala and donate one item for the Silent Auction. She also encouraged Board presence at the Gala. After a lengthy discussion, it was agreed upon that the HFMD office will track all donations for Board members. The Board agreed to leave the language as is. Therefore, no Board action is required.

Governance/Page 2/HFMD Board Responsibilities/Item 8: This states that HFMD Board will fund member and family up to \$1,000. Currently, NHF trips are open to Board members and those that haven't gone will get priority. And \$1,500 does reflect the current budgetary amount. A motion was made by Bob Stone to state that HFMD Board will fund a voting member and family up to \$1,500 to attend at least one Annual NHF or

WHF meeting during their two year tenure with the Board. Dan Tinklenberg seconded the motion. Motion Carried.

Governance/Page 3/Board of Directors/BYLaw 8: Jim Paist stated this reads that every Board member needs to be elected by our members and not by our fellow Board members. The way we operated at last year's Annual Meeting is that John Schulte, Liz Myers, and Steph Miller were elected by the Board of Directors. This is for clarification so that our language and policy are the same. Voting members are given a ballot at our Annual Meeting and asked to nominate and vote for individuals who will serve on the Board of Directors. Ballot boxes are furnished and tabulated by HFMD staff. Bill Kallberg has requested that a formal process for voting be adopted at our Annual Meeting. Our BYLAWS state no proxy voting. However prior to the Annual Meeting, we can send out ballots to voting members asking for Board nominations. Aaron asked if everyone was satisfied with the verbiage of this section to leave as is. Board members were in agreement.

Operating Policies/Conflict of Interest: Jim Paist read the Conflict of Interest Policy to clarify language as it reflects to our current committees by eliminating Advisory Committees. Brenda Neubauer made a motion to remove any reference to Advisory Committee language in the Conflict of Interest Policy and Steph Miller seconded. Motion Carried

Operating Policies/Confidentiality Policy: The third paragraph of the HFMD Confidentiality Policy Mailing List was deleted due to the HFMD Board of Directors taking action in 2005.

Industry Contributions: Bob Stone reported that last year, the Board of Directors approved having representatives from Pharmaceutical companies attend a retreat and that went well. Last year, Dr. Kobrinsky requested Pharmaceutical companies only and the cost of \$500 was charged as an exhibitor fee. This year, we discussed having both Pharmaceutical and Home Health Care exhibit at our Dakota's Retreat. We checked with the two HTC's in North Dakota and South Dakota and it was agreed upon by the committee to have industry exhibit only with no participation in any of the activities/events. Both Dr. Kobrinsky and Dr. Stout were in agreement with this.

Jim asked if we need to take Board action to approve or amend the official policy that we are in support of having Pharmacy and Home Health Care in the Dakotas. As this reads now, the Board will decide when industry will be invited and it is on a case by case basis. So, if we leave the language as is, then exhibiting is covered. However, Bob and Jim both wanted to have approval to have industry exhibit in the Dakotas. Aaron stated that we should leave the policy as is. Aaron feels that the issue of industry at the Dakotas Retreat should be brought up under Old and New Business. However, on behalf of Dakotas, the HTC's and their retreats coming up in 2007, we will allow industry to exhibit and take this on a case by case basis. Bob Stone made a motion to allow industry to exhibit in the 2007 Dakotas Retreat. Brenda Neubauer seconded and with no opposition, motion carried.

In item #1, Jim stated that the **non exclusive basis** policy should be reviewed to see if we are going to offer exclusively sponsored portions for events i.e.; Key Note Speaker at our

Annual Meeting. Jim asked if HFMD wants more consistency and clarity in their policy? At the current time, we are not consistent. Jim Paist stated that industry would like clarity on this issue since we are all over the board on this and we are looking for a level playing field for all participants.

After a lengthy discussion, Aaron suggested that we hold our policy in place until we get clarification from the HTC's and the Industry Relations Committee. Jim Brown reported that the next Industry Relations Committee Meeting will not be until February. However, Jim Brown and Nancy Golden will contact all IR representatives and ask for their recommendations and report back to the HFMD Board meeting in January. Jim Langworthy suggested putting together a task force with industry, HTC's and board/consumers to review this issue as this topic could drive programming within the community. At this time, John Schulte recommended suspending item #1 and #2. Bill Kallberg made a motion to waive Industry Contributions #1, and #2 until our Annual Meeting in 2007. Brenda Neubauer seconded. Motion Carried.

Patient Assistance: Jim Paist suggested changing the mileage reimbursement from 22 cents to 15 cents per mile for families under the Patient Assistance Guidelines since requests are more frequent and is becoming a significant budgetary expense. Dan Tinklenberg made a motion to reimburse at 15 cents per mile and Bob Stone seconded. Brenda Neubauer said 15 cents per mile is offensive. She said that would not cover the wear and tear on vehicles. Jim Paist asked if our intent is to pay for gas, or to pay beyond the cost of gas? Bob Stone advised that we need to set limits on mileage reimbursement since this was a big expense for the Dakotas Retreat. Brenda suggested stepping up our fundraising or increase exhibitor fees to accommodate this expense. Jim Paist said we paid over \$2,000 just for mileage reimbursements with Medora. Judith mentioned medical rate reimbursement is 14 cents per mile and the business rate is 48.5 cents per mile. However, we do not reimburse at the IRS rate for families. Aaron asked what would be agreeable since we want families to attend our events and help with the crunch! John Schulte suggested that 15 cents does cover gas. Brenda recommended 25 cents per mile as it would also cover wear and tear of the vehicle. Dan Tinklenberg said it was o.k. to pay a little more if it does change the budget. Aaron stated that we can adjust the budget if need be. Dan Tinklenberg amended his first motion to increase the mileage to 25 cents per mile. Bob Stone seconded. Motion carried.

Bob Stone made a motion to change the verbiage in the last paragraph and delete the reference to Executive Committee and replace it with Board of Directors. In addition, the last line refers to proof of payment. This should read proof of purchase. Sharold Friedrich seconded. With no opposition, Motion Carried.

Travel Reimbursement Policies: Item 2A-1: Aaron made a motion to clarify the verbiage to read: Proof of airline ticket purchase. Bill Kallberg seconded. Motion Carried.

Item 1-C: Bill Kallberg made a motion to change the daily meals and miscellaneous expenses to not to exceed \$45 per day. It was previously \$30 per day. Bob Stone seconded. Motion Carried.

Goals for 2007 & Strategic Planning (3-5 yr): Aaron stated that these both run together. Jim Paist presented a power point presentation showing the accomplishments of HFMD over the past year. Attached is the HFMD Strategic Plan and this was tabled for the next HFMD Board of Directors meeting, along with Goals for 2007.

Presentation by NHF: Jim Paist introduced our guests from NHF, Dr. Alan Kinniburgh and Glenn Mones. Alan stressed the importance of having goals for an organization and it is great to see this presentation and strategic plan for taking charge. “We would like to hear your concerns and issues that you feel may be inhibiting as we work together. My goal is to try to link up the organization and gain from each chapter and national. The reason I took over an organization that was in trouble was because of the strength and dedication that people have within this community. The Board of Trustees has felt that we need two options to pull our chapters together. They are to merge with the National Organization or form a tight alliance where we can speak with one voice. Alan recapped the two options. 1) Merger – is giving up your 501(c)(3). Once a chapter releases their 501(c)(3) and it goes dormant, they need to file a Form 990 short form. 2) Agree to a charter or alliance where each chapter would be uniformly branded and named. Find a formula to share the expenses and revenues i.e. fundraisers. The charter is a template and an alliance agreement is a 1-2 year contract. Each chapter would negotiate what they are interested in. The NHF Board felt that these two options fit the vast majority of chapters with NHF”.

Moving forward, the charter still needs to be defined and a committee has been established. From HFMD, Aaron Reeves and Bill Kallberg are on this committee. This committee will work on standards for chapters because people need to be served within the community and this is something that we need to do. Some chapters may need to link up with other chapters. These things need to be worked on at the national level. The managerial links still need to be defined but one will be Chapter Resources. We will move ahead to develop a level of standards.

Glenn Mones stated that this is a plan that has been proposed and many details need to be filled out yet. The plan, first of all, needs to be adopted and passed by the chapters. Secondly, the plan includes both options. Glenn stated that when NHF envisioned what a chapter should be, HFMD came the closest. HFMD is really a model on how a chapter can work successfully. The one thing that the NHF Board didn't want was to leave the structure as it is today as the identity and resources from various chapters are all over the place.

Q: Brenda Neubauer asked how the committee chose people to be on the committee.

A. Alan stated that we needed a broad representation. It was important to have members of this chapter on that committee to give it strength.

Q. Brenda asked what benefits would there be in a merger?

A. Alan stated that there are things that are done in this chapter that are done very well but could be done more efficiently. Such as greater participation in programs, fundraising with larger companies that would attract more money involved. HFMD has already tapped into Glenn and the public policy arena. If you have more people and more knowledge and a national brand, you could possibly raise more money. Let's take the money we raise and spend it on mission and helping people.

Q. Jim Paist asked if NHF could talk about the contractual model because that is likely what we would be more interested in. **A.** Glenn explained the contractual model and a merger can both work. It takes a lot more work and money to make the contractual model work as compared to the merger. A contractual agreement is more specific i.e., with name, etc. as compared to a charter which is a general agreement. When building a contractual model, always remember the goal when going through the process. However, a set of standards for a contractual model has not yet been set. Since HFMD is a very productive chapter, Alan stated that we are way above any set of standards.

Q. Bob Stone asked if our finances will go to NHF?

A. Allen clarified that with an alliance agreement, you have your own set of books but agree to show books to each other and devise a way to share revenue when doing things together. To develop a brand, we do need a signature fundraising event.

Alan and Glen both agreed that there is so much still up in the air but we all need a standard name, standard branding.

340B Coalition Presentation: Jim introduced Mark Plencner, R.Ph., from the Fargo HTC, Roger Maris Cancer Center. Mark discussed a new, non-profit, HTC pharmacy purchasing alliance whose purpose is to purchase blood-clotting factor products in efforts to lower costs for choice of products. This new approach comes from a newly organized group called The Hemophilia Alliance Group Purchasing Organization (HAGPO). Their goals include:

- Helping support physician/patient choice of products
- Pool purchasing power of federally funded HTC's
- Manage the cost of care over the full range of therapeutic options
- Improve product availability by becoming a large, contracted purchaser of factor
- Help ensure the continued existence and excellent of HTC's nationwide

Old/New Business: Aaron reported on Jim's annual review and after meeting with Jim and obtaining feedback from Board members, Aaron recommended a six percent increase in his salary. Bob Stone made a motion to give Jim the six percent increase and Sharold Friedrich seconded the motion. Motion Carried.

A motion was made to adjourn by Bob Stone and seconded by Dan Tinklenberg. Motion carried. Meeting was adjourned at 3:03 p.m. Our next Board meeting will be held January 16th at 7:00 p.m. in the lower level HFMD conference room. Our conference call in number will be 1-866-246-6862 and the pass code is 1022011#.

Respectfully submitted,

Pam Cella
HFMD Office Manager
hemophiliafound@visi.com

