

NMF Mid-Atlantic Chapter Board Meeting

May 14, 2011 - Saturday

Our meeting was in Arlington, hosted at home by Faye Morford. Our President Amy Speck lead us off once people had arrived and gotten a chance to say hellos and eat. Amy circulated an agenda. Rob and Kelly Berklite began our discussion of the second annual golf fundraiser. In attendance: Catherine George, Jeanne Heller-George, Cindy Amdur-Clark, Fred Clark, Rob Berklite, Kelly Berklite, Jessica Berklite, Amy Speck, Daniel Speck, Lisa Rüber, Caryn Kauffman, Faye Morford, Caroline Brozak, Mary Ahearn. Guests: Cheryl Folmer and son.

GOLF

2011 Golf fundraiser, September 9 Friday. Friday after Labor Day.

- Headed by Rob & Kelly Berklite.

Cheryl Folmer, VA licensed real estate agent, has been generous to be our main sponsor.

Contact information: cherylfolmer@cox.net or 703.338.2520

- 2, up to 4 Redskins!
- return location at South Riding VA
- \$110 per play. (nearly same cost as 2010 \$120)
 - target of roughly 80 players
 - we yielded 50% profit on \$120
 - couple's rate possibility

2010 brought in approx. \$7,500

• Food. Catered by South Riding, or delivered by outside vendor? No onsite cooking by independent/outside companies allowed.

- going outside may conserve funds and make a preferable, nicer meal
- from in-house grill is convenient

Golf club will need a head count thirty days out, with some flexibility. Last year some add-ons weren't an issue within a few days.

Fosters was all set to do food last year until restrictions prevented them. Cooking on premises possible? Liability? Outback. Sweetwater Tavern or other from Great American Restaurants group, Rio Grande, Chevy's, Famous Dave's

Alternative activities for non-golfers- Ladies "Tea Time" Manicurist donating services and a hair stylist. Childrens' activity.

- \$10 to \$15, or different levels for however much services received

Tables and registration:

Display Table of two Super Bowl rings (from Redskins' win XXVI 1992?)

- Tickets to a Redskins game, desirable seats.
- Signed footballs.
- Golf night.
- Spa package at Lansdowne, Ritz Carrolton, or Gaylord National.
- "Mystery" Gift card. Envelope of random surprises.

Baskets and gift bags:

- Golf Galaxy, local golf boutique, was generous last year. Items, donations, solicitations, gift cards.
- VA Gold Cup in The Plains, Virginia and other wineries in the area – Can they offer a basket? Donate a weekend or tasting.
- Corporate giving programs, proposals. Letterhead, business cards.
- Contact our participants, and sponsors from 2010

Gift bags for all participants. Snack. Water. Water bottles? Coupons and cards. Cheez-Its were a hit.

Can we find a doctor to be a Marfan ambassador, Hospital to be a knowledgable entity on site?

Other possible projects:

- Raffle tickets for a car. Would a raffle would be less sticky with red tape given insurance, and taxes for a donated car?
- Silent Auction for a Super Bowl, tickets, air, hotel.

Lessons from 2010:

- Set up a website -First Giving -Active -through NMF at Marfan.org, and/or use dedicated donation option of NMF website, listing the event.
- Have sponsorship forms
- Waivers for players - what do we need them to waive? Assume risk and responsibility for participation?
- Have a designated table only for registration. Other tables to peruse baskets and goodies. We'll spread out. Registration was crowded and under manned. Set raffle table away so people get a look at the goods.
- Have a locking money box. (Cindy and Fred may have one available)
- Officers and board not eligible for wins 50/50 raffle. (Decision voted at meeting by members)
- Plan for budget 2012 needs.
- Gift cards are best as widely available national chain businesses accessible to everyone. Relevant gift cards. Walmart. Target. Whole Foods. Giant. PF Chiangs. Cheesecake Factory. Apple iTunes.
- Suggestion was made for a box to collect gift cards donated back from recipients who are out of the area and cannot use the gift cards.

NMF tax id available for ease of giving for businesses upon request. Best not printed on cards. We'll go by headquarter's guidance.

Insurance agents interested in giving? Corporate level giving has high test for proposals. Getting connections is key groundwork.

Auction item. Silent auction – Super Bowl FOUR airline hotel and tickets to the Super Bowl with TWO winning Redskins.

Real Estate donations commission percentage. 10 to 15 percent of referred work.
Refinances, titles.. work done through Cheryl and her partners also donating 10-15%
(toward the Super Bowl silent auction) Locations flexible as long as referral comes back to Cheryl. VA MD DC PA WV NC OH

Refer business to her. Generate interest over Redskins. Any business contacts or coming business helps. Doesn't add to cost, just generates \$. If goal isn't met we pull it.

Publicity & media:

Reach out to Gavin Lundberg. Barbara Heller, board member. Patricia Estrada (sister died of Marfan Syndrome/works at Supreme Court), Francis Collins, head of NIH (though, as government employee might have conflicts.) Ryan Clagg (former NMF employee who now works for Washington Center), Washington Center academic donations

Create Facebook "event" page. Catherine George. Also, create a page for our NMF chapter

Media - contact as we get closer, soon. Advertising. Papers- approach Centreville Times, NOVA Journal, Washington City Paper, Washington Post Express, Examiner. Blogs. TV. CBS is NFL broadcaster. Fox5 morning show with Holly Morris. Radio. Sports radio. WJFK, WTOP, DC101. 92.5 Winchester VA

VOLUNTEER FAIRFAX. Jeanne Heller George

Volunteers and help if needed

An organization that coordinates non profits and volunteers. We have already registered with VF. Emily Davis-contact with our timeline for needs.

High school students working on community service hours. Day-of work, promotional, inventory data. – Amy will generate a volunteer hours form to be signed and certificate.

Interns for experience with a non profit. Form letter and groomed language. Marketing interns to help us promote event, assist with reaching media

OUTREACH to EXTENDED STAY FAMILIES " Cindy Amdur and Libby Sparks
"Heartfelt Taste of Home"

Support and outreach to temporarily relocated people receiving medical care in our area. Meals. Food basket. Donated gift cards.

Libby Sparks in cardiology, and a contact in Sponseller's office. Pulmonary and orthopedic issues have longer care than cardio. Dr. Columbani, Pediatric surgeon. Hopkins and Fairfax are the local relevant care centers for Marfan. People coming for planned surgery. Assist as someone to sit in place? Also, how much contact is appropriate? We can make ourselves available but not intrude during a private moment.

Budgeting. Care box/basket/package. Balloons, bears for children. Stickers, or bubbles which could be good pulmonary exercise.

What are the families' needs? Create a contact card for responses or notes. Options for vegetarian kosher halal. Transportation, food, toy, social visithow can we help? Offering warmth, comfort, recognition. Hospitality package. Socks, in-kind donations, bath & body works. Soft tp.

Goal is the outreach and recognition. Makes the impression. Budget for the demo year. 1k to 2k. Might have one family a month volunteer to provide dinner and make a run to the caregiver. Parking coupons! Booklet of parking vouchers. Lisa remembers how big a deal it was to handle parking. Johns Hopkins University Hospital, Fairfax Hospital, Washington Hospital Center

Rotating schedule for our end by month. Enclose a list of family friendly restaurants. Baltimore, sights, National Aquarium, Fort McHenry, Maryland science center.

A map of Baltimore and it's nicer neighborhoods. An item and a Visa or AmEx cash card.
Costs could get high quickly. Magazine or bear. Do kids want to enclose a poem or drawing?

BUDGET: Caryn Kauffman.

- new budget is being prepared. Fiscal 2012 starts 1st July.

Projected revenue 8,000-10,000

Costs for Golf. Programs - developed by Jeanne last year. Flyers. Brochure. PWC printed them free last year but that won't be available this year. Quantity 100. 1k

FUTURE FUNDRAISING ACTIVITIES:

candy sales, walk/run

Daniel and Amy Speck, Dog walk 2012.

Amy Speck, Heart and Soul concert 2013

FUNDRAISING: raffle iPad iPod

Enquire for availability slots in marathons. A walk or run, "Heart + Sole" or "Miles for Marfans" 5K 10K - National is working on a marathon, coordinated marathon. More information about this after the National conference.

Postage: One mailing per year can be handled by Port Washington. 1200 people in database. For golf we'd need to do July or very early August. Include as much as possible in our mailing. Send it up to national before they head to Portland.

CHAPTER BROCHURE Amy Speck

Develop a brochure to introduce and inform of our work. Include our outreach program to caregivers. Hope to have this done for the conference in Portland.

DATABASE Contacts: address the list and update contacts- calls to board members, donors. We'll try to reach people in our area and see who is warm and receptive.

BANNER. Mid Atlantic NMF chapter. We will always have for events. Roughly \$100 own from 200. Jeanne Heller George

Caryn Kaufman -

Provide a letter insert for conference attendees from our area. Make our presence known and reach out. Possibly gain new recruits.

Outing day to arboretum. Social event, accessible. Springtime 2012

Budget supplies, red folders, print jobs and miscellaneous expenses.

FALL MEETING post golf tourney.

Support meeting and talk. We'll be more casual and social. October/November. Carolyn Levering might join us so we can work with her schedule.

PEDIATRIC AWARENESS Campaign:

Realize there is a need to provide a presence. Surprising how many hospital pediatric departments and cardiology offices do not have NMF materials present. Looking for a way to accomplish this.

SUMMER KIDS Activity:

View that this seems improbable at this time was shared. People are active and going in different directions during summer. Currently only 3 children attended this meeting, so we do not have enough active younger participants to establish an event at this time.

Meeting Minutes submitted by Catherine George, Secretary and Amy Speck, President.