



Minutes for March 12, 2009

Attendance: Aaron Smith (Wapiyapi), Lance Vierra (Kaden's Kamp), Karla Flook (CureSearch), Rob Breitbarth (Angel Flight West), Tina Williams (Starlight Children's Foundation), Pam Whitaker (Ronald McDonald House), Joan Slaughter (Morgan Adams Foundation), Rachelle Montanaro (Morgan Adams Foundation), Stephanie Seebaum (Tanner Seebaum Foundation), Vicky Sternicki (Heroes Forever), Audrey Loveland (Heroes Forever), Julie O'Connell (Kyle O'Connell Foundation), Natalie Vona, Sandy Steffes (McKaila J. Steffes Foundation), Jan Harrison (Teen with a Dream), Tammy Krause (Gabby Krause Foundation), Anne Milmoie (Roundup River Ranch), Kory Hayes (Gold Ribbon Families). Call in: Gigi McMillan (CBTF), Adele Gelfand (Brent's Place), Dana Baccardi (There With Care), Katrina Brohman (Just In Time Neuroblastoma Fdn).

a. Introductions & Guests: Joan Slaughter facilitated the meeting and began with introductions. Everyone who attended introduced himself or herself and gave a brief update about their organization. Joan introduced two guests: Natalie Vona, Ph.D. and Gigi McMillan, from the Children's Brain Tumor Foundation. Natalie Vona works in private practice with children who have or have had medical illnesses. Gigi was on the conference call. She visited Denver and met with some of the C4 group in February.

b. Membership/Committee List: Joan circulated a membership roster, asking everyone to check his or her name, address, and contact information for accuracy. She also asked that everyone list the committee they volunteered for.

c. 30 second "commercial" by any member/organization present:

Rob Breitbarth of Angel Flight West gave us some information regarding his organization. He said Angel West could fly anyone for compassionate need, including the family of a patient. They would like a week's notice if possible. Typically they can fly 3 passengers plus the pilot. They can also fly people who are on the oxygen canisters even though many commercial airlines cannot do that. Angel Flight West can transport for a distance of 1000 miles.

Joan Slaughter had a question for the two foundations provide families with financial assistance. She asked how they go about that process? Julie O'Connell (Kyle O'Connell Foundation) said families in treatment, needing financial assistance, need to fill out a form and have their doctor or social worker contact Julie. Sandy Steffes (McKaila J. Steffes Foundation) said they also have a form. They are set up through Presbyterian St. Luke's and help families that are currently on treatment. She said they would look at situation for families that are off treatment.

d. Rotation of "in depth: Presentation (5 minutes), organization by organization: We decided this would be a good idea and it will be introduced next month. Joan said we will go by the Membership List and whoever is first on the list can start. We will also take a few minutes to share resources or interests or events that are going on.

e. Our Own C-4 Committee Reports:

General info: Joan said she would circulate the link as soon as the web site is ready.

Membership: Dana Bacardi said she has received only a few "one sheets." She asked everyone to get them to her by April 1. She will let Joan know whose information she is still missing. Dana said they have a volunteer that will be helping her put everything together. The membership will be categorized on the website by type, the same way it will be categorized in the printed directory. The

directory will be used as an inside directory but ultimately the goal is to use it as a resource directory for hospitals, social workers, and outreach (community) workers.

Website: Martha was not able to attend so her report was unavailable.

f. C3 – Pediatric Task Force committees: C4 members sit as a resource in the various adult cancer task force committees. We are the Pediatric Task Force.

1. Executive Committee – Tammy Krause: meeting is next week.
2. General Committee – Lynn: absent from our meeting, no report.
3. Breast Cancer – TBD
4. Health Disparities – Lynn: absent from our meeting, no report.
5. Quality of Life and Palliative Care – Aaron: This meeting is usually conducted with a conference call. The group is going to divide into four sub-committees: 1.) Newly diagnosed; 2.) Cancer Survivors in treatment; 3.) Cancer Survivors post treatment - which would focus on the concept of continuum of care for cancer survivors; 4.) Family, friends, etc. Aaron asked the group for their opinion regarding which sub committee would best fit our needs. The group was unanimous in their opinion that he should participate in the Cancer Survivors Post Treatment group.
6. Skin Cancer – Katrina: was absent, no report
7. Advocacy and Policy – Katrina/ Julie Weber (TBD): no report.
8. Hospital Board Representatives – TBD
9. Ovarian Cancer: Jan Harrison said she would check on this committee
10. Cancer plan chapter – Joan: Joan sent everyone an outline of the Pediatric cancer plan chapter. She invited everyone to go through the outline and make general comments and email her their feedback. The deadline for those comments is **March 22**. Then the subcommittee will each take a section and write the draft for that section. The drafts will be opened up to feedback, reviewed, and edited. The next step will be to send them to a physician panel and solicit their guidance.

g. OLD BUSINESS

How are committees working – contact points, etc.: Since most committees had not met, Joan asked that all committees make appoint of getting together prior to the next meeting.

Good Standing Practices sheet - -do we want to develop? Joan explained the idea of a member organization in good standing could put the C4 logo and the C4 link on their web site. It was agreed that this would be a good idea to explore. The suggestion was that the “good standing” membership requirements should be basic. Tammy asked if we needed to come up with a mission statement. It was suggested that we draw our mission statement from the 4 objectives that we discussed our first meeting. Sandy Steffes said the Membership Committee could do the mission statement. Tammy said the membership committee should check the C3 website for their mission statement and we might be able to work with they are using. Joan said that she thought serving on one of the committees should be one of the criteria used for being a “member in good standing.” The committee will

also look at dues. Aaron Smith will send Sandy Steffes a copy of the MOU (Memorandum of Understanding) that was used in the past.

Speakers – Review and discuss further as needed & nominations: We decided to table this idea and look at it again in 6 months.

Update on CBTF meeting – Stephanie Seebaum & Gigi McMillan: CBTF is specifically a pediatric brain tumor organization. Gigi said she really enjoyed meeting with several members of the C4 organization when she was in Denver last month. She said that CBTF brings support to pediatric neurology team at the hospitals. She said they also have training for parents who wish to serve as mentors to newly diagnosed childhood cancer families and that they would be happy to share that information and training with any of us. In fact, Jenny is working on getting a training for the Denver area. The CBTF will do a phone training if they have 7 interested people and will do an in-person training if they have 10 interested people. She said they could also work with us in the Denver area to bring seminars or conferences in since they have a lot of resources and would share the models that have worked for them. Gigi said she was impressed by the ability of the different childhood cancer groups to work and collaborate together instead of just fostering competition with one another.

h. NEW BUSINESS:

Event Calendar – let’s get them all listed and then Martha can put them on the website, too,

With an “update” function: There were posters around the room with each poster representing

a month. Everyone sent around and listed their events on the appropriate month. These will be

listed on the web site. We will send out a reminder email once a month asking everyone to check

the web site calendar. Adele Gelfand from Brent’s Place announced they are having a grand

opening next Thursday evening, March 19 at 5:30 and invited everyone to attend.

Question regarding how to handle general inquiries that come into C4 via the Peds Task Force – new projects where people want to do a community service thing benefitting kids with cancer, etc.

Press Release announcing C4/ Peds task force: There will be a press release coming out about

us. Joan will circulate the release to the group by email so everyone can see it before it is released to the media.

RESUME SHARING: When we get ‘em can we post via the website to a wiki: It was agreed

that sharing and posting of resumes would be a good idea.

Possible additional committees/ website pages:

National Orgs list – for resources that can be utilized in CO and Surrounding States

Orgs list – start small, but relevant: Kori Hayes and Aaron Smith will check on both of these and report back. Natalie Vona suggested they check Dana Farber’s web site, which has an extensive resource list.

Preferred Vendors' list – not so aptly named, but shall we begin to build a resource

list of practitioners, service providers who are NOT NPO's, but who work with./ for patients/ families of kids with cancer (to wit, therapists, grief counselors, etc?):

We

won't do this due to liability issues. Natalie Vona did tell us she was building her own resource list and would welcome suggestions from any of us if we felt comfortable sharing with her.

Meeting was adjourned!

**PLEASE NOTE FUTURE MEETING DATES: May 14th, July 9th, September 10th, November 12th
All meetings will be held at the Daniel's Fund. 11am – 11:30am social; 11:30am – 1:00pm meeting time!**