

## Brain Injury Alliance of SD

### Meeting Notes from 9/20/12

In attendance: Mary Ohman, Denise Johnson , Ron Sasso, Karen Brokenleg, Mary Tommeraasen, Justine Ashokar (Skype)

Unavailable: Lori Sletten, Teresa

### Notes from meeting by Mary Tommeraasen

Karen, Mary O., and Denise started by bringing up the fact that our group is not going anywhere and it was agreed that we should do something. Denise mentioned that she had attended a new TBI workgroup in Sioux Falls recently which included doctors and teachers who knew nothing about what was being done in our area already. Denise suggested we get the word out to schools about TBI and explain what is available to educate in this area. Justine said she would attend the group when they meet again in December.

Justine mentioned counting the number of people with TBI in SD and that she could take the lead with this. Karen stated the hospitals were mainly doing this, but there was no mandate so they tried to get the main hospital in the state to do it in a consistent way with a consistent definition. They all do this (or maybe some do), but it is not consistent and open to their own interpretation of what is to be recorded.

Mary O. mentioned the survey that was on our website, but found it was not as successful as hoped. We did not know the numbers.

Ron mentioned he was working with someone on this and Justine will get involved with that person.

Prevention of TBI and goals for recognizing and dealing with concussions was discussed. Having schools educate through an in-service might be good. Justine will work on it and take it from there. Karen stated that a couple does this at O'Gorman in Sioux Falls in the Driver's Ed. class, but the public high schools were not interested. She also stated that in 1990 the Denver Rocky Mountain Brain Injury group blanketed the schools with information and nothing happened. Denise mentioned that the larger schools now have trainers on the field. Denise also thought that at the Dec. meeting of the workgroup mentioned above there would be more people in attendance, and so more resources should be available to them. It might be a good time to add the prevention piece.

Mary O. liked that Justine was willing to do a PowerPoint presentation to take to some schools and then eventually more schools could be presented this information. She felt it would be important that the presentation be done for both students and teachers so they could both understand the information. Justine thought they COULD have the PowerPoint as Mary asked, but Karen thought we would prefer to be there to present it. Perhaps it could be linked to our webpage??

Karen mentioned that more people in the Sioux Falls support group are interested in the Brain Injury Alliance of SD, but they need to know more information if they are to join. Justine stated the phone number is wrong. It should read 605-389-0334. Karen also stated she would make the changes on our brochure so that when they tear off the piece to join the group, they still have our names on the brochure. Currently, that is the part that gets torn off and mailed in. Denise stated we also need the

updates for people. Mary O. stated we need to provide resources and it says we do training. Justine agreed that the PowerPoint will be one thing to provide. Ron added that we are doing some training and that we are providing some support to the conference this year. Mary O. stated that Ron Hoops had provided her with past stuff and she needed notes from the meetings she has missed lately. Denise thought we could have yearly trainings and do more educating and then go back and do them again. Perhaps they could be on our web site, also. Ron mentioned they had recently done this when the Center for Disabilities had the workgroup, which included schools and doctors. It will be held again December 13<sup>th</sup> and Karen, Justine, Denise, and Ron will be there. Others may also plan to attend.

Justine discussed offering services to families at the hospitals. It has not worked well in the past as hospitals were not open to the idea, and families were not ready to accept or understand the information. Denise and Karen agreed. Ron stated that the families have been through so much and the hospital in Rapid City has not done much. He visits with them at Community Transitions later and families are so thankful at that point. They have stated that it was the most information they have been provided.

Denise mentioned March is Brain Injury Awareness month. We could send information to the schools to let them know what we could offer and see if we get feedback. Mary O. wondered if there was such a thing as "state classifieds" where we could write something up for them. Justine wondered if we could put something in the papers and Ron thought perhaps the editorial. We could write a longer piece of what we do, but would need to know that piece first!

Karen will plan to contact Pam Homan, the Sioux Falls Superintendent of Schools, once the PowerPoint presentation is completed. We could expand our monthly meeting letter so that we could include information regarding how we can help, what we could do/offer to help others. Maybe individuals would be willing to provide their stories for the letter.

Mary O. brought up the fact that funding is a problem. Karen stated Mary O. donated \$75 from her family so currently there was \$3000.32. Ron stated that money had been contributed for the Brain Injury conference in the past. We contributed \$300 as a sponsor. No scholarships were used this time for the conference. Karen could write out a \$300 check today. Once the 501c3 is in place, then we can get ways to raise money. Karen stated the Rock-a-Betty's could raise money, as they did so at Pizza Ranch recently and got tips. Denise stated her group raised money at Jazz Fest recently. Mary O. felt we need people behind us. Ron felt we have people and just need them to sign up with no money involved. Karen and Mary O. agreed people can donate money, but no dues are necessary. Karen's home address will be the address used to send donations.

Karen agreed to redo the brochure by Dec. 13<sup>th</sup>. The workgroup meeting is from 9-11:30. It is a Thursday. Justine agreed to have the PowerPoint ready by that date. Mary O. will plan to have a good handle on the 501c3 by then. We will hold our meeting that same day at 1:00. Denise will try to get us a room at SD Achieve for the meeting. Denise will send a letter to all members of the Brain Injury Alliance 15 days prior to the Dec. 13<sup>th</sup> meeting. Karen will send Denise the list of addresses to do so. We should be able to send information to the schools following this meeting.

Justine mentioned she had received a letter from a man in Canada who was recruiting family/caregivers for research. Students in Canada are conducting the research and individuals could participate. Karen mentioned our Sioux Falls support group will include a panel of family members in the fall. Information regarding the research efforts could be shared then.

We agreed that school presentations could begin in March, if possible, as we will have met as a team to discuss how the information may be utilized.

Ron wondered if someone would be willing to take over as Vice President.

Karen mentioned a Dr. Christopher Davidson in Sioux Falls wanted to be a member. Karen would contact him by October 15<sup>th</sup>.

Justine would like an article in the newspaper by Dec. 13<sup>th</sup>.

Mary O. discussed the long process of applying for the 501c3. It contained 20 pages on the IRS form. She thought she might be able to answer what she knows and then scan it to all of us on the board. She would explain what we still need and we could talk about it further at the Dec. 13<sup>th</sup> meeting.

Mary O. has a form letter for the annual meeting and will get it to Denise by 11/1/12. Denise thought we could use the money her group raised at Jazz Fest for the mailing cost.

Justine mentioned we are one of 2 states without a TBI grant or waiver. Karen wondered how to write the grant. Justine felt she needed numbers of individuals with TBI's first and then we could look at writing a grant. The information for writing grants is on the Internet under TBI grants. Justine stated she would email us the link to the grant websites.

Denise thought volunteer groups can be organized later. We do need more board members, though. She provided more information about the workgroup that met in August at the Center for Disabilities. It was called Bridging the Gap of Services for People with Brain Injuries. Fifteen people were in attendance. They will be meeting quarterly. Denise will send a letter to the people who attended to let them know we will be having our Brain Injury Alliance meeting following theirs on Dec. 13<sup>th</sup>. She will see if anyone is interested and if they have any ideas of individuals who have sustained a brain injury who might be interested in serving on our board.

Denise reported SD Achieve has females needing the 1:1 services similar to the males in her program. They are poor at making decisions and there are 3 of them at this time. She is working on funding for a locked facility for them and is also working to move some of the guys to more independent settings.

Mary O. will contact Shelly Pfaff for any ideas of interested individuals to be on the board.

The meeting was adjourned for attendance at the Brain Injury Alliance conference.