

MSGRCC Consumer Advocacy Workgroup
Meeting Summary, Mid-Year

MSGRCC Mid-year Workgroup Meeting – Consumer Advocacy
Friday, February 5th, 2010
8:00am to 1:00pm

Attendees: Joe Martinec, Dorey Nez, Billie Jo Petersen, Yolanda Sandoval, Rod Slaght (participated via Skype), Brad Thompson, Lori Wise

Staff: Celia Kaye, Joyce Hooker, Amanda Conway, Liza Creel

Welcome and Introductions

Joe Martinec, workgroup co-chair, welcomed the group and asked for introductions.

Update from Meetings Attendees

American College of Medical Genetics Annual Meeting, March 2009 – Lori Wise

- Very enjoyable meeting, especially the sessions focusing on consumer advocacy and power.
- Interesting update on alternative medication and drugs.
- Counselors at conference were talking about PHI (Personal Health Information) and privacy concerns. There is a perception that these issues actually create barriers to science and clinical care.
- Other update from Lori:
 - Genzyme currently has one plant shut down due to contamination. This has resulted in a supply shortage of drugs for genetic disorders. This brings up the issue of having only a single supplier of supplements and medications on which peoples lives depend. There is little or no back up in these cases.
 - Action Item: Single provider/supplier issue needs to be addressed nationally.

Genetic Alliance Annual Meeting, July 2009 – Rod Slaght

- Underlining message of the meeting was empowerment.
- Discussed privacy concerns related to patient information. It was suggested that using a code name or number for security could eliminate many of the privacy issues being raised.
- Discussion:
 - There are interesting differences between the viewpoints of ACMG and Genetic Alliance.
 - Because there is not linkage of NBS to birth certificates, there is not a way to tell how many patients have not been tested. There has never been 100% of the population on file.
 - Navajo families find the privacy issues difficult because they do not understand them, especially those raised by the IRB. They don't know the process and aren't often asked to participate.
 - It is all about balancing risks and rewards.

National PKU Conference – Joe Martinec

- This was an excellent conference. The only conference of its kind that the PKU community has been able to organize.

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- They presented on new products and technologies and gave awards to Hero's of PKU.
- Issue – PKU has several treatment options, supplements and education compared to other disorders.
- Many of the young adults were very excited about sharing transition stories.
- MSGRCC should have a transition panel with young adults during the annual meeting. There are so many issues that could be addresses, including navigating the health care system, dealing with insurance changes, parent perspectives, etc.

Update on Medical Home Training Project – Brad Thompson

- This project works to build communities while implementing the medical home model. Family service programs are often missing the personal connection. Brad is training parents to serve a unique role within the clinical setting. They provide new patients with a face to face opportunity to talk with another parent. This immediate connection is invaluable at a time when there are many unknowns. As these connections are made, community will be created. All in the room agreed that this was an excellent idea and would have been very helpful when their children were diagnosed.

Future Trainings

- March 25 & 26 – Omaha, Nebraska
- June, 2010 – Utah
- August, 2010 – Round Rock, Texas (school-based training)
- Action Item: Dorey and Yolanda will attend one of Brad's training sessions (probably in UT). Then the team can develop a grant to get training system going in the Navajo community.

Recruitment

Joyce Hooker informed the group that Susan Duffy is no longer able to be on the advisory committee or a member for the workgroup due to health reasons. She asked anyone who knows a person from Montana who may be interested in participating to please let staff know.

Brad Thompson will also ask Tammy Amosson if she knows anyone from Nevada who can participate.

Joyce mentioned that the national transitioning workgroup has a difficult time getting a consumer member that can participate during the weekdays. They have monthly calls at 11am MST on the last Wednesday of the month. Lori Wise said that she could participate and will be on the February call.

Update on Genetic Alliance Projects

Celia Kaye gave an overview of the Newborn Screening Clearinghouse and Congenital Conditions projects awarded to the Genetic Alliance (GA). Press releases explaining each project can be found here [INSERT LINKS]. Celia mentioned that the MSGRCC needs to have a mechanism for review and feedback of products for the Clearinghouse to ensure the consumer voice from the Mountain States Region is represented. The workgroup members agreed that they would review products and materials on behalf of the Mountain States as needed. There was discussion about how to deliver a message that technology is good but it will not reach

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everyone. They agreed to continue reminding those at a national level of the importance of still serving those not well connected technologically.

Review Final White Paper on Recruitment

Joyce Hooker gave some history on the white paper. The concept of the paper began with a discussion at a national meeting where one of the leaders said that there should be more Native Americans present. There was minimal consideration of the cultural barriers that prevent successful recruitment of minority populations. Joyce brought the issue back to the Consumer Advocacy Workgroup who decided to develop a white paper on recruitment of minorities, specifically Native Americans. The workgroup provided the framework and themes for the white paper.

Liza Creel reviewed the recommendations from the white paper and the group approved finalization of the paper with the following edits:

- The term Native Americans is incorrect. Include in a preface that input from the workgroup indicates that naming matters. For purposes of this paper, the term referencing the Navajo population – The People - will be used. To lump all of the native tribes to one term is insensitive. We have to be culturally sensitive even in different cultures.
- Change the title to “The Life Rope: Engagement of Diverse Population for Recruitment and Representation in Genetics”
- Section 1: Recommendation #3
 - Add examples of reservation dogs.
 - Add non medical examples (i.e. corn cross pollination) that introduce pride for the community.
- There may not be a word for what is being discussed (i.e. DNA as “life rope” or cancer as “the wound that will not heal”) and the paper should reflect this ambiguity.
- Section 2 - This is not a step by step process. It should all be done at the same time. Note this in the document.
- Section 2: Recommendation #2 - Make it clear that the professional should be straightforward and upfront about what is not understood.
- Section 3: Expand on how community based programs will help establish credibility.

Liza will make the changes and return the final copy to the group. Next steps include:

- Present on the white paper during a PI call.
- Get on the agenda during a meeting of the SACHDNC education and training subcommittee meeting.
- Publish the paper. Staff will brainstorm on journals and other periodicals.

MSGRCC Website Update

Joyce Hooker updated the group on the following activities related to the MSGRCC website.

- Currently transferring information from the MSGF’s website to the MSGRCC website. These materials were grant funded in the previous cycle and are the property of the MSGRCC who will keep the materials current.
- Working to redesign the website and populate existing pages.

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- Other needs identified:
 - Update the mission statement on the front page.
 - Have consumer members help populate resources page with useful information.
 - State health departments and treatment centers need to have the MSGRCC link under their resource page. MSGRCC should work to make this happen
 - Add hit counter on each page so we can see where people visit most.
 - Add maps that demonstrate how underserved the region actually is.

Next Steps

1. Update & finalize the white paper
2. Connect Yolanda and Dorey with Brad so they can attend his UT parent training
3. Develop a transition panel for the Annual Meeting
4. Distribute NBS Clearinghouse documents (as available) to workgroup for their review
5. Update website and marketing materials
6. Continue working to recruit new members
7. Consumer Workgroup will get involved with Telemedicine Workgroup on their marketing materials directed toward potential consumers of telemedicine services.
8. Annual Meeting – July 13-15th, 2010

The meeting was adjourned.