



## **CONSUMER ADVOCACY WORKGROUP MEETING SUMMARY**

THURSDAY, JULY 16, 2009

8AM – 11AM

DENVER, CO

CO-CHAIRS: JOE MARTINEC AND ROD SLAGHT

### **Welcome and Introductions**

Joe Martinec welcomed the group and asked for introductions.

### **Discussion on Recruitment White Paper**

MSGRCC staff summarized the current draft of the recruitment white paper and posed several questions to the workgroup members.

1. What is the primary goal of this recruitment paper – to involve more Native American individuals in the MSGRCC or to encourage Native American people to accept non-Native American providers?
2. What is missing in the white paper?

There was consensus that the primary goal of the white paper was to recruit members into the MSGRCC. A secondary outcome of increased involvement of any minority population is their ability to participate in other MSGRCC activities that promote more culturally appropriate care and a better understand of genetics in their community.

Suggestions for missing components of the white paper included:

- Identify the long term vision of the MSGRCC and why the Native American population is an important contributor.
- Describing the holistic approach that Native American people use when managing their health. This is especially important when talking about the relationship with providers.
- Outlining the role of a consumer member more specifically so individuals know exactly what their commitment entails. This should include their responsibilities for educating others in their state about MSGRCC activities.
- Outline community engagement strategies to encourage self selection into this group. This includes outlining how the consumer's participation helps them.
- Talk about new ways of defining community (not just by geographic proximity) and identify strategies for communicating information to these communities, many of which may not have resources like the Internet.

## **Meeting Directory Update**

Liza Creel presented the final version of the Professional Meeting Directory for workgroup approval. The group approved the directory for publication with only a few formatting changes including adding MSGRCC contact information and a last updated date.

## **Recruitment Strategy**

The workgroup members discussed a number of specific strategies that the MSGRCC could use to recruit new consumer members into the workgroup. Those proposed included:

- Identify your actual pool of advocates, then identify who is not currently participating.
- Tap into other advocacy groups including Sickle Cell, Cystic Fibrosis and other religious organizations.
- Have every current member identify at least one person to recruit.
- Talk to provider members about recruiting consumers and their families.
- Appeal to peoples individual gifts and what they can contribute to and take from the MSGRCC.

One particular discussion focused on if MSGRCC recruitment activities should include families with “normal” children. Several members felt that these families would be difficult to recruit because there is little motivation to participate. Two alternatives were presented: encouraging participation of normal siblings or that MSGRCC staff serve as the normal population.

## **Genetic Alliance Update**

Jim Bialick, the Genetic Alliance (GA) representative to MSGRCC, gave a presentation on new Genetic Alliance resources available to families and communities. His overview included summaries of these web resources:

- [www.resourcerepository.org](http://www.resourcerepository.org)
- [www.trustortrash.org](http://www.trustortrash.org)
- [www.geneticalliance.org](http://www.geneticalliance.org)
- [www.doesitruninthefamily.org](http://www.doesitruninthefamily.org)

Jim also summarized Gas new resource for state newborn screening programs and providers. This tool allows nbs programs and provider to customize a booklet of information on newborn screening in their particular state.

## **Next Steps and Closing Remarks**

Joe thanked all participants for attending the meeting and contributing to the conversation. MSGRCC staff told the group that the white paper would be updated and sent out for final edits and comments.

The meeting was adjourned.