



Region4
Genetics Collaborative

AGENDA

Genetic Expertise Workgroup
Telemeeting Agenda
Friday, April 3rd, 2009 11am CT/12pm ET

Toll-free - 1/866/489-0573; at the prompt, enter *4545164*

Roll Call & Introductions

- Review of Agenda

May 1st Workgroup Face-to-Face Meeting in Chicago

- Logistics
- Recruiting Physicians
- Review meeting agenda

Review of Genetic Access Survey

- Provide update on Access Survey for Families

Other Announcements:

Next meeting is May 1st in Chicago

Adjourn 12:30 p.m. Central, 1:30 p.m. Eastern

Genetic Expertise Workgroup Telemeeting Notes
Friday, March 6th, 2009

Upcoming Genetic Access Survey:

- Region 4 is partnering with the Michigan's Birth Defects Registry and Children's Special Health Care Services programs to survey families of children with heritable conditions in Michigan. The survey will assess families' knowledge of and perceived need for clinical genetic services. Region 4 will provide incentives to parents to complete the survey. The survey will be sent to a sample of families in Michigan.
- Other states are invited to talk with us about conducting the survey in their state. Illinois and Ohio expressed an interest and we will talk with them further about this opportunity. Carry-forward funds must be used before May 31st so we need to move quickly.
- Incentive for families to complete the survey will be a raffle--this has worked successfully in the past in Michigan.
- Region 4 parent partners will be reviewing the survey at a telemeeting on March 13th. After all changes have been made we will be moving quickly to get the survey distributed.
- The workgroup discussed suggestions for changes in survey including lowering the reading level of the survey, translating it into Spanish and other languages prominent in each state, clarifying what "genetic services" are so that families understand the question (it was decided this would be best done in a cover letter to families), look at questions 10 and 11 and decide if both are needed/differences between the two
- There is not question that asks all respondents about their perceived need for genetic services such as, "Do you feel that you could benefit from clinical genetic services or do you feel you have access to clinical genetic services?" This question is asked at the end of the survey but at that point not everyone is asked.
- Workgroup hoped to have MI be the pilot for the survey then move to other states, but noted time limitations as well to use carry-forward funds
- Carrie Langbo, Clinical Services Coordinator in MI and developer of the survey was present on today's call and will be working on the group's suggestions for the survey

Upcoming Workgroup Face-to-Face Meeting on May 1st in Chicago:

- The meeting will be held in Chicago, most likely near the O'Hare Airport on Friday, May 1st. We are actively recruiting primary care providers/pediatricians to attend the meeting and talk with us about access to genetic services (especially those in rural areas) and telemedicine. Sarah has heard from MN and KY but needs names of providers from the other five states. Please forward those names asap to Sarah and she will contact them.
- Group discussed inviting physician assistants as well in case they have more contact/better idea of access for families
- Sarah will contact AAFP (Frederick Chen, Chair of Genomics Subcommittee) for help in distributing announcement about the meeting to primary care providers
- Group discussed time on meeting and suggested 10:00am to 4:00pm so that people can fly in and out in one day.
- Group discussed agenda topics and goals for the meeting such as:
 - Hearing from primary care providers about the process of identifying children with metabolic conditions and how they interact with genetic centers, what works and doesn't work. Also, same questions about children with complex diagnoses and known diagnoses.

- Has there been a difference because of the fewer number of genetic counselors who feel comfortable doing a metabolic diagnosis—has there been a difference in getting this service? Do they have concerns about the future of this service?
- What do the primary care physicians perceive as the role of the geneticists and counselors in their practice?
- Need a clear agenda and clear goals. Goals include deciding what we want out of this meeting, identifying three major concerns to approach and where is our group going? Starting with what is the charge from this grant by brainstorming/having a conversation with this grant narrative then in the afternoon discussing our goals and plans and a time frame
- We will also be studying the access survey's results and looking at past studies that can inform us about questions that we need to ask, WI survey will be a good place to start looking at questions to ask PCPs.
- The workgroup feels that this needs to be a facilitated discussion with PCP run by a moderator
- Sarah will draft an agenda in partnership with the Region 4 staff and email it to workgroup before the next workgroup meeting on April 3rd. It will be discussed at the April 3rd meeting and a packet will then be sent to all participants for the May 1st meeting.
- Meeting location and time will be announced soon.

NEXT MEETING IS FRIDAY, APRIL 3rd 11:00-1:30 CENTRAL, 12:00 – 1:30 EASTERN

Notes by Sarah Wedepohl



Genetic Expertise Workgroup Meeting Friday, May 1, 2009 10:00am to 4:00pm CT

Chicago O'Hare Hilton

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- Introduction of workgroup members and guests
 - Review of agenda
 - Goals and objectives for this meeting including:
 - Promoting links between genetic specialists and rural health service and communication systems
 - Exploring practice models to assist the limited number of genetic specialists in maximizing use of their time
 - Gain more knowledge of families' accessibility of genetic services especially in rural areas
-

Goals and objectives for the workgroup as we move forward including:

- Reviewing and discussing the charge from this grant
 - Identifying three major concerns to approach and better define the direction of the workgroup
 - Attaching timelines to the goals
-

Facilitated discussion with workgroup members and primary care physicians

Explore primary care physicians' need for genetics information and expertise when providing a medical home for children with heritable disorders.

- Hear from primary care providers about the process of identifying children with metabolic conditions and how they interact with genetic centers, what works and doesn't work. Also, same questions about children with complex diagnoses and known diagnoses.
 - Ask about any differences in access to services because of the fewer number of genetic counselors who feel comfortable doing a metabolic diagnosis—has there been a difference in getting this service? Do they have concerns about the future of this service?
 - What do the primary care physicians perceive as the role of the geneticists and counselors in their practice?
 - Also use questions from Wisconsin survey as discussion questions (see next page)
-

- Review and discuss survey results from Michigan that examined families' access to genetic services.
 - Review and discuss efforts in and outside of our region to use telemedicine to increase access to genetic services
-

Next steps

Where do we go from here?

Draft discussion questions for Primary Care Providers (based on survey questions from Wisconsin):

- In your practice, do you routinely take a family history? When? What does it usually include?
- Have you ever referred a patient to another facility or physician for genetic counseling or consultation?
- Who do you utilize for genetic counseling/consultation? How far away is the counselor located?
- Are you aware of genetic outreach services which visit your area regularly? If yes, how far away are they located? How often are they available?
- Approximately how many genetics consultations have you obtained in the past 12 months?
- Give some examples of the types of conditions or situations in which you would refer for genetic services?
- How many patients on your current caseload have a clinically significant genetic condition?
- Do you have needs for genetic services that are not currently available to you? Please explain...
- If you have ever ordered genetic testing, where did you order it from/send it to? If the test results were abnormal did you discuss them with the patient? Did you refer for genetic consultation?
- Are you or your patients concerned that genetic information could be used to discriminate against people (insurability and/or employability)? If so, have you ever experienced this kind of discrimination in your practice?
- What do you think are the benefits of a genetics consultation? The disadvantages, if any?
- Do you think that the impact of genetics in your medical practice will become more significant in the future than it is now?
- Do you use any resources to update your medical knowledge regarding genetics (e.g., medical conferences, review courses, satellite teleconferences, journals/newsletters, TV, newspaper, Internet, etc.)?
- What types of genetic information would you be interested in learning more about?

Clinical Genetic Services: A View from Michigan's Children's Special Health Care Services' (CSHCS) Families

March, 2009

Thank you for doing this survey. Your answers will let us learn what you think about clinical genetic services. Please look at the **Michigan Genetic Counseling Services** brochure. It was sent to you with this survey. It will tell you about clinical genetic services.

If you have questions, please call the Michigan Birth Defects Referral and Follow-up Program at **1-866-852-1247**.

1. Please list your child's CSHCS covered diagnosis: _____
(Please list any other conditions or diagnoses): _____
2. What type of health insurance does your child have? *(Please check all that apply)*
- CSHCS Private Insurance Medicaid Medicare Other
3. What have you been told about your child's diagnosis? *(Please check all that apply)*
- | | |
|---|---|
| <input type="checkbox"/> Cause or reason for it | <input type="checkbox"/> Name of it |
| <input type="checkbox"/> Current research (results &/or opportunity to participate) | <input type="checkbox"/> Problems it may cause |
| <input type="checkbox"/> Effect on daily living | <input type="checkbox"/> Resources/services (financial, educational, support) |
| <input type="checkbox"/> Genetics of it | <input type="checkbox"/> Special treatment centers |
| <input type="checkbox"/> Genetic testing | |
| <input type="checkbox"/> How to treat it | |
4. Have you been told if your child's condition is genetic?
- Yes *(If yes, answer a., b., c.)* No
- a. If yes, were you told facts that you could understand?
- Yes No
- b. If yes, were your questions all answered?
- Yes No *(If no, please circle the answers listed in #3 you would have wanted.)*
- c. If yes, who gave you genetic facts about your child's diagnosis? *(Please check all that apply)*
- | | |
|---|---|
| <input type="checkbox"/> Family doctor/Pediatrician | <input type="checkbox"/> Office or Clinic Nurse |
| <input type="checkbox"/> Geneticist or Genetic Counselor | <input type="checkbox"/> Parent Support Group |
| <input type="checkbox"/> Medical Specialist (please list type): _____ | <input type="checkbox"/> Public Health Nurse |
| <input type="checkbox"/> Nurse Practitioner | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> No one, I found it on my own | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> No one, I have not been given any facts | |
5. Have you been told about clinical genetic services?
- Yes No Unsure

6. How did you learn about clinical genetic services? (Check all that apply):
- | | |
|---|---|
| <input type="checkbox"/> Family doctor/Pediatrician | <input type="checkbox"/> Office or Clinic Nurse |
| <input type="checkbox"/> Geneticist or Genetic Counselor | <input type="checkbox"/> Parent Support Group |
| <input type="checkbox"/> Medical Specialist (please list type): _____ | <input type="checkbox"/> Public Health Nurse |
| <input type="checkbox"/> Nurse Practitioner | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> No one, I found it on my own | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> No one, I have not received any information | |

7. Do you understand what clinical genetic services are?
- Yes No Unsure

8. In your own words, please write how you feel clinical genetic services would or would not help you:

9. Has genetic testing (e.g. chromosome studies, DNA testing) been ordered for your child?
- Yes No Unsure

If yes, please check who ordered the genetic test. (Check all that apply):

- | | |
|--|---|
| <input type="checkbox"/> Family doctor/Pediatrician | <input type="checkbox"/> Medical Specialist (please list type): _____ |
| <input type="checkbox"/> Geneticist or Genetic Counselor | <input type="checkbox"/> Nurse Practitioner |
| <input type="checkbox"/> Other: _____ | |

10. How far would you be willing to drive so that your child can be seen in a genetics clinic?

- Less than 20 miles 20-50 miles 50-100 miles Over 100 miles

I would not be willing to travel any miles because:

- ___ No transportation ___ No child care ___ No time-off work ___ They would not help us

___ Other: _____

11. How far have you driven for other special medical care for your child? (Example: heart or brain specialists)

- I have not gone Less than 20 miles 20-50 miles 50-100 miles Over 100 miles

12. What would be the best way for your child **to be seen** by a geneticist or genetic counselor?

(Please rank up to 5 choices. 1 is your best choice down to 5 for your worst choice.)

- ___ At a multi-disciplinary clinic visit (Many of my child's specialty doctors are seen in one visit)
- ___ By telemedicine (While in a doctor's office, I speak by video and telephone with the genetic specialist)
- ___ Scheduled to happen on the same day as another specialty care visit for my child
- ___ In a genetics outreach clinic in my town or within 50 miles of my town
- ___ In a genetics clinic at a large medical center
- ___ I do not want clinical genetic services for my child
- ___ Other: _____

Clinical Genetic Services: A View from Michigan's Children's Special Health Care Services' (CSHCS) Families *cont.*

13. How would you like to learn more about the possible genetics of your child's diagnosis?
(Please rank up to 5 choices. 1 is your best choice down to 5 for your worst choice)

- ___ Meetings for parents at different times of the year in Michigan
- ___ Spoken by my child's doctor or specialist
- ___ Written Fact sheets or brochures
- ___ I do not want to learn more about the possible genetics of my child's diagnosis
- ___ Other: _____

14. Have you ever taken your child to a genetics clinic?

- Yes, (Please go to a. and b.) No, (Please go to c.)

a. Please check your feelings about the clinical genetics visit:

- Very satisfied Somewhat satisfied Satisfied Unsatisfied

b. Do you feel you learned helpful new facts about your child's diagnosis at the genetics clinic?

- Yes. What was the most helpful part? _____

- No. What could have been done differently to better meet your needs? _____

c. If you have **NEVER** been to a genetics clinic, please tell us why:

(Please check all that apply. Rank those checked from 1 up to 9. 1 is the main reason for never going):

- | | |
|--|---|
| <input type="checkbox"/> ___ Can't afford it | <input type="checkbox"/> ___ Embarrassed to attend them |
| <input type="checkbox"/> ___ Did not know about them | <input type="checkbox"/> ___ Too nervous to attend them |
| <input type="checkbox"/> ___ Do not feel a need for them | <input type="checkbox"/> ___ Wouldn't attend if over 100 miles away |
| <input type="checkbox"/> ___ Do not understand the value of them | <input type="checkbox"/> ___ Wouldn't attend if found in large city |
| <input type="checkbox"/> ___ Other _____ | |

15. Please use the space below or on the back of this page. Tell us about any other feelings you have regarding clinical genetic services:



Please take a moment to finish the questions on the next page.

Parent/Guardian Information

16. Is it important for you to know *(Please check all that apply)*:

- The chance for future children to have the same condition
- The chance for your other children to have the same condition
- The chance for your children to have a child of their own with the same condition
- The chance for other family members to have the same condition

17. What is your gender?

- Female
- Male

18. What ethnicity or race do you identify with?

- White or Caucasian
- American Indian or Alaskan Native
- Arab or Middle Eastern American
- Asian/Southeast Asian or Pacific Islander
- Black or African American
- Latino or Hispanic
- Multiracial (parent from more than one of the above racial groups or at least one parent is multiracial)
- Other _____

19. What is the year you were born? _____

20. What is your highest level of school?

- Grade school
- High school diploma
- College degree
- Some high school
- Some college
- Graduate degree

21. Please circle which **Region** you live in. Counties are listed so you can find your region. Please just circle the **Region**. Thank you.

<p>Region 1 Macomb St. Clair Wayne</p> <p>Region 2 Oakland</p> <p>Region 3 Jackson Lenawee Livingston Monroe Washtenaw</p> <p>Region 4 Allegan Barry Berrien Branch Calhoun Cass Hillsdale Kalamazoo St. Joseph Van Buren</p>	<p>Region 5 Ionia Kent Lake Mason Mecosta Montcalm Muskegon Newaygo Oceana Osceola Ottawa</p> <p>Region 6 Clinton Eaton Gratiot Ingham Shiawassee</p> <p>Region 7 Genessee Lapeer</p>	<p>Region 8 Arenac Bay Clare Huron Gladwin Iosco Isabella Midland Ogemaw Roscommon Saginaw Sanilac Tuscola</p> <p>Region 9 Alcona Alpena Antrim Benzie Charlevoix Cheboygan Crawford Grand Traverse Emmet Kalkaska Leelenau</p>	<p>Region 9 cont. Manistee Missaukee Montmorency Oscoda Otsego Presque Isle Wexford</p> <p>Region 10 Alger Baraga Chippewa Delta Dickinson Gogebic Houghton Iron Keewenaw Luce Mackinac Marquette Menominee Ontonagon</p>
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