

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)*
- Cause or reason for it     Name of it  
 Current research (results &/or opportunity to participate)     Problems it may cause  
 Effect on daily living     Resources/services (financial, educational, support)  
 Genetics of it     Special treatment centers  
 Genetic testing  
 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)*
- Family doctor/Pediatrician     Office or Clinic Nurse  
 Geneticist or Genetic Counselor     Parent Support Group  
 Medical Specialist (please list type): \_\_\_\_\_     Public Health Nurse  
 Nurse Practitioner     Social Worker  
 No one, I found it on my own     Other: \_\_\_\_\_  
 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:

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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:

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