

Summary
September 23, 2010 Meeting
Genetic Advisory Committee to the Oregon Health Services Commission and
Division of Medical Assistance Programs

- I. Meeting Participants
 - A. Advisory Committee members: Sudge Budden, Karen Kovak, Carolyn Sue Richards, Kerry Silvey, Robert Wilden, Jonathan Zonana,
 - B. Health Services Commission (HSC) staff: Darren Coffman, Ariel Smits
 - C. DMAP staff: Wally Shaffer
- II. Purpose for convening the group: to provide expert advice to the Health Services Commission (in establishing guidance for DMAP and the OHP managed care plans) about what changes, if any, should be made to the HSC Guideline D1, Non-prenatal Genetic Testing Guideline.
- III. Discussion Topics
 - A. What changes if any should be made to the current specific guidelines for developmental delay in children? Specifically, should microarray technologies be covered?
 - 1. The group reached consensus that section III be changed from relating only to genetic testing for infants and children with developmental delay, to relating to genetics evaluation and genetic testing of individuals with intellectual disability, autism spectrum disorder, and multiple congenital anomalies.
 - 2. That III.A. be changed so say that cytogenetic microarrays (also called “Array CGH” or “molecular karyotyping”) be covered without a visit or consultation with a specialist and that in most cases cytogenetic microarrays should be the first tier test. Fragile X and chromosome studies for this population should be covered according to the Non-Prenatal Genetic Testing Algorithm.
 - B. Should genetic testing for MODY be covered?
 - 1. The committee agreed for the purposes of genetic counseling, the Non-Prenatal Genetic Testing Algorithm should be used to decide whether to cover the test.
 - 2. The committee members present recommended that experts in pharmacogenetics and endocrinologists be consulted for a recommendation about whether to cover genetic testing for MODY for the purpose of guiding treatment.
 - C. Should genetic testing for neurofibromatosis be covered?
 - 1. The committee reached consensus that coverage for genetic testing for neurofibromatosis continue to be decided using the Non-Prenatal Genetic Testing Algorithm, and recommended against establishing a specific guideline about genetic testing for neurofibromatosis.
 - D. Should changes be made to the HSC guidelines related to genetic testing for cancer?
 - 1. The committee members present recommended that a group consisting of oncologists and genetics specialists who are regularly involved in cancer genetics services be convened to address potential changes to the HSC cancer genetics testing guidelines.
 - 2. Suggestions for group: Kate Morris (oncologist & surgeon), Kathryn Murray (genetic counselor), Nancy Ledbetter (advanced practice nurse in genetics), Sue

Richards (OHSU DNA lab director), Jone Sampson (physician geneticist at Knight Cancer Institute).

- E. Should changes be made to the Genetic Testing algorithm?
 - 1. Two changes were recommended:
 - a) Change the branch “Results will change course of tx or surveillance?” to “Results may provide prognosis or change course of tx or surveillance?”
 - b) Add footnote: “***Examples include: recurrence risks for client, client's parents, or client's siblings”
- F. Does the group have any other recommendations relating to other genetic tests?
 - 1. No.

IV. Next steps

- A. After the meeting, Ariel Smits, Darren Coffman, and Kerry Silvey discussed whether to convene a group to make recommendations related to cancer genetics evaluation and testing. Due to Health Services Commission staffing shortages and a high work load on other issues, Darren and Ariel elected not to convene this group for at least six months.
- B. Health Services Commission staff consider whether to convene an advisory group relating to cancer genetics evaluation and testing in six months time.
- C. Kerry Silvey to draft recommendations for the issues decided by the group today and circulate to the committee for review and comment.
- D. Kerry Silvey write a summary of the meeting.