

To All Oregon Genetics Services Providers:

I am writing to report two exciting pieces of news and to **ask for your assistance** in an effort to assess current availability and utilization of genetic services in Oregon.

The first piece of news is that the Oregon Health Division (OHD) and the Child Development and Rehabilitation Center (CDRC) at OHSU (with technical assistance and support from PacNoRGG) have been awarded a state genetics planning grant by the Maternal and Child Health Bureau of the federal Health Resources and Services Administration for a period of two years. The grant funds, which began June 1, 2000, will be used to support staff, including a Genetics Community Planner, and to develop a statewide public health genetics plan. The overall goal of the project is to improve the health and well-being of children and families affected by genetic conditions and other special health needs through the core functions of public health. Input from diverse community stakeholders including genetics services providers and consumers is crucial to the success of this project.

The second piece of good news is that Pat Himes, genetic counselor at OHSU in Portland, has accepted the position of State Genetics Services Coordinator (a joint position with the OHD and CDRC). Pat will begin work in early September. Pat has extensive experience in clinical genetics services, and she is prepared to facilitate collaboration between genetics providers, policy makers, consumers, payers & others.

A first step in developing a state genetics plan is to inventory Oregon's current genetics services. We hope to collect information about the types of services your group provides and some summary demographic information about the clients you serve, including an estimate of the number of clients you serve on an annual basis. We do not seek any information about individual clients. The Health Division will use the collected information to evaluate what additional services are needed in the state.

Attached to this message is a brief list of questions. We hope to have this list distributed to the appropriate clinical contact person by August 17. The list is intended as a guide to help the contact person collect the desired information, and we will follow up this e-mail with a brief telephone interview during the week of August 24.

Please take a moment to respond to this e-mail by filling in the following contact information:

Are you the appropriate contact person for your group? Yes ___ No ___
If you are not the appropriate contact person, who would be?
Name _____ Phone _____
e-mail _____ Fax _____
What is the best time and day to reach you by telephone during the week of
August 21-25? _____

Thank you for your time. With your help, we will be able to compile a complete inventory of genetics services, which will in turn allow us to create a state public health genetics plan that will meet the needs of Oregonians. We look forward to collaborating with you on other components of this project as well. Please contact us at the numbers below for questions, concerns, or other input.

Sincerely,

Kiley Ariail
OHD Genetics Intern
phone: (503)-872-6747
fax: (503)-731-4091
e-mail: kiley.ariaail@state.or.us

Astrid M. Newell, MD
CCFH Medical Consultant/
Acting Genetics Program Coordinator
phone: (503) 731-4021 ext. 287
fax: (503) 731-4091
e-mail: astrid.marie.newell@state.or.us