

Genetics in the LEND

Leadership Education in Neurodevelopment and Related Disabilities (LEND) at the Center on Human Development and Disability; University of Washington

The University of Washington has a strong and diverse genetics-training program in medicine; it does not have a genetics counselor-training program. Therefore, the LEND has incorporated genetics training for all interdisciplinary trainees and community providers utilizing a variety of strategies.

1. What strategies have you used to infuse genetics information into your training Program?

A. Clinical training opportunities

Medical students, developmental pediatrics residents and Fellows, and genetics Fellows all have the option of a rotation in the PKU/ Biochemical Genetics Clinics. The rotation ranges from one month to six months and includes didactic and case focused conferences. These trainees review a specified disorder and present the molecular and clinical genetics, diagnostics, treatment, and prognosis at the pre-clinic conference. The interdisciplinary team, which guides this work, consists of geneticist, genetic counselor, and nutritionist.

LEND nutrition trainees participate in the PKU/Biochemical Genetics clinic for two quarters and focus on the impact of the disorder on family life and long-term intervention. These trainees often choose some aspect of their work as a Leadership project, which often leads to the Master's thesis project.

Nursing, psychology and social work trainees have the option of clinical work and special projects.

B. Didactic training

All MCHB LEND, PPC, MCH, and Dental trainees invited to these didactic seminar series.

The LEND Core Seminar series provides a session on genetics. The session is taught by a genetic counselor (CGC) who works with the 'General Genetics' clinical program at CHDD and emphasizes modes of inheritance and genetic testing.

The Nutrition and Biochemical Genetics Seminar is a three-quarter series that focuses, in detail, on the identification and treatment of the metabolic disorders seen in the PKU/Biochemical Genetics Clinics which are primarily the disorders identified by expanded newborn screening in Washington. The series is co-taught by a genetic counselor and the team nutritionists. Each disorder-specific session focuses on mode of inheritance, newborn screening, diagnostic testing, medical and nutritional parameters of treatment, and a discussion of prenatal testing.

All trainees are encouraged to utilize the web-based 'Genetics and Your Practice' modules.

C. Other opportunities

Washington has an active and focused statewide Genetics Providers Group; trainees may choose to participate in this activity as an observer or with a project.

Clinical websites are used to provide genetics information to trainees, for example, the PKU Clinic website at <http://www.depts.washington.edu/pku> and GeneClinics at <http://geneclinics.org>

2. What funding/resources did you use to support these activities?

Collaborative efforts have led to the development of the clinical and didactic curricula described above, for example, collaboration between LEND faculty, the Washington Office of Newborn Screening and the Department of Pediatrics. Small grants have supported some development efforts. However, without a LEND discipline leader in genetics, the genetics material in the curriculum is a 'bit diffuse' and trainees are not explicitly directed in participation or mastery of the material.

3. What relationships were developed or expanded?

Relationships with the Office of Newborn Screening, the Pediatric Genetics Fellowship program, the Pediatric Residency program, the Regional Genetics program, the Pediatric Pulmonary Center, the Maternal and Child Health program, the Pediatric Dentistry Fellowship and the Washington Genetics Providers Group have all supported clinical rotations and curricula development in a variety of ways.

4. What lessons have you learned and what would you suggest for the future?

Overt funding is necessary if rapidly changing genetics concepts are to be incorporated into LEND programs and meet the changing educational requirements of the health care providers of the future. This funding could support the faculty and the development of educational strategies that take advantage of technology.

We would propose an interdisciplinary training curriculum with two prongs of genetics activities: 1) enhancing the role of genetic counselors on the clinical teams, and 2) increasing the knowledge of all LEND trainees about genetics and genetic counseling.

More specifically- 1)'genetics' is ever more complicated; CGC expertise as integral LEND faculty is important; 2) informed genetics faculty could support families as they struggle with family-decisions, for example, the next step after prenatal diagnosis of Down syndrome; 3) all issues related to follow-up of genetics screening require genetics knowledge and skills, partnership with critical disciplines, and knowledge of systems change; 4) increased precision in treatment of genetic conditions requires an interdisciplinary approach and a long-term intervention approach, for example, the PKU Clinic prototype with pediatric, adolescent transition, reproductive, and adult specialties.