

AUCD-MCHB LEND Genetics Grant Progress Reports

Report Type: GC 12-month progress report
Start Date: 01/01/2006
End Date: 06/30/2006

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SUMMARY

From January 1, 2006-June 30, 2006, recipients of the AUCD-MCHB LEND Genetics grants have together supported 64 (15 long term, 10 intermediate and 39 short term) LEND genetic counseling trainees through the grants. All three programs describe a significantly increased ability to include training on genetics for all LEND trainees.

Of the 64 genetic counseling grant-supported trainees enrolled in the three programs, 14 identified themselves as non-Caucasian, 3 as Hispanic, 4 as male, 4 as having a disability or family member with a disability and 4 as being from a rural or remote location. Together the three grantees are providing 42 hours of required genetics training to non-genetics LEND trainees, 38 hours of required genetic clinics for non-genetics LEND trainees, and 321 hours of optional genetics activities are available to non-genetics LEND trainees.

To address the grant's goal of increasing the diversity of practicing genetic counselors, grantees have partnered with their University's Office of Academic Diversity, neighboring Universities or Colleges, their local school districts, student organizations and national underrepresented minority undergraduate groups to recruit a diverse pool of genetics trainees for the 2006-2007 school year.

Products and leadership opportunities are being created through this grant. One grantee is in the process of creating a web-based/CD-ROM learning module on genetic awareness which will be available to the entire LEND network and other MCHB interdisciplinary leadership training programs. Due to a grantee's efforts, a Special Interest Group on disabilities is being created within the National Society of Genetic Counselors (NSGC). An eight-week summer college internship in genetic counseling and disabilities is being implemented by one grantee. One grantee is using a second year genetic counseling student to develop and implement the genetics curriculum in LEND. All three programs and the AUCD National Office have collaborated to create a poster abstract about the Genetics Grants; the poster was accepted for the National Consortium for Health Professionals Education in Genetics (NCHPEG) Annual Meeting in February 2006.

Benefits of the grant to other LEND trainees focus on the interdisciplinary nature of the program. Grantees note in their reports that "the genetic counseling trainees are learning about the roles of other disciplines in the interdisciplinary process and the other trainees and staff are learning and beginning to appreciate what genetic counselors have to offer," and "...the trainees learn from one another by sharing their disciplinary perspective and demonstrating their clinical skills and knowledge of the field."

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## AUCD- MCHB LEND Genetics Grant Progress Report: 12-month summary

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|--------------------------------------------------------------------------------------------|
| <b>Project Title:</b> LEND Supplemental Grant Application for Genetics Counseling Training |
| <b>Grantee:</b> Rose F. Kennedy Center                                                     |
| <b>Primary Investigator:</b> Herbert J. Cohen                                              |
| <b>Report Type:</b> GC 12-month progress report                                            |
| <b>Start Date:</b> 01/01/2006                                                              |
| <b>End Date:</b> 06/30/2006                                                                |

### I. ACCOMPLISHMENTS

The project has accomplished almost all of the goals and objectives stated in the grant application.

In brief, a collaborative effort was developed involving the University Center for Excellence in Developmental Disability Education, Research and Service (UCEDD) and the Kennedy Center's Children's Evaluation and Rehabilitation Center (CERC), the UCEDD's principal clinical affiliate, the Sarah Lawrence College's (SLC) Genetic Counselor Training Program and Montefiore Medical Center's Children's Hospital (CHAM) and its Reproductive Genetics Program. The new grant-supported program was initiated in August, 2005 when 3 long-term LEND trainees in the SLC program were interviewed and selected. They entered the program in September, 2005 and completed it at the end of May, 2006. In addition, 10 intermediate trainees received some clinical training at CHAM and in the Reproductive Genetics Program. An additional 33 1<sup>st</sup> and 2<sup>nd</sup> year SLC students participated in three courses offered by the LEND project faculty. The LT and intermediate term trainees also attend these courses. This course material was supplemented by lectures and seminars for all 1<sup>st</sup> and 2<sup>nd</sup> year SLC students provided by Dr. H. Cohen, the UCEDD/CERC Director, and Dr. Maris Rosenberg, Director of Medical Training in the CERC/UCEDD. In addition, courses or seminars were offered by Dr. Robert Marion and Dr. Susan Gross who are other key faculty participating in this project.

Since the current LEND GC trainees have participated in ID team activities along with other LEND trainees, it has added a new dimension to the team activities. The GC trainees developed complete genetic profiles on selected clients, acted as liaisons to the Genetics Clinic at CHAM, and offered genetic counseling. The GC trainees learned about the roles of other disciplines in the ID process and the other trainees and staff learned and began to appreciate what GCs have to offer.

# AUCD- MCHB LEND Genetics Grant Progress Report: 12-month summary

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|--------------------------------------------------------------------------------|
| <b>Project Title:</b> SYNERGY: Va-LEND and Genetic Counseling Working Together |
| <b>Grantee:</b> Partnership for People with Disabilities                       |
| <b>Primary Investigator:</b> Joann Bodurtha                                    |
| <b>Report Type</b> GC 12-month progress report                                 |
| <b>Start Date</b> 01/01/2006                                                   |
| <b>End Date</b> 06/30/2006                                                     |

## I. ACCOMPLISHMENTS

Our accomplishments are outlined according to our project goals below.

### 1. Interdisciplinary Leadership Training

#### *1.1: Integrated genetic content into the LEND curriculum:*

This was accomplished with a review and inventory of the genetic content in the LEND curriculum and implemented through our teaching in the 2005-2006 academic year, including the Leadership Seminars, Childhood Neurodevelopmental Disabilities Course and Teamwork Course.

#### *1.2: Enhance the VCU Genetic Counseling (GC) Program with leadership training:*

For the first year of the grant two (non-LEND) GC students elected to enroll in the LEND leadership seminars, in addition to 3 GC long-term LEND trainees. In future years this will be required for all GC students regardless of their LEND affiliation.

#### *1.3: Develop 3 web-based or CDROM learning modules for network distribution:*

The first learning module is on genetic awareness, and is a leadership project for one of our long-term LEND GC students. The module is currently in development through collaboration with our GC trainee and faculty in SYNERGY/LEND and Instructional Development, VCU School of Medicine.

### 2. Trainees and Recruitment

#### *2.1: Recruit, accept, and support 2 GC students in the Va-LEND program:*

In the past academic year we enrolled 3 long-term LEND trainees from the VCU GC Program. Two of these graduate students received tuition assistance and a stipend from the SYNERGY grant and the third received funding from the LEND grant. In addition we enrolled two short term GC trainees who took the leadership seminar series. The tuition for the seminars was supported through SYNERGY.

*2.2: Expand the Multicultural Advisory Committee:*

A Multicultural Advisory Committee for Va-LEND was expanded through the SYNERGY grant in the fall 2005. New members include faculty from Virginia Union University and Virginia State University, two historically Black colleges and universities in our area, the Director of the Health Careers Opportunity Program (HCOP) at VCU, the Director of Multicultural Affairs at VCU, and two genetic counseling consultants who are part of the SYNERGY grant. A meeting was held November 14, 2005. Our second meeting was on July 27, 2006. In March and April 2006 a subcommittee of the Multicultural Advisory Committee met to review summer internship applications and to interview the candidates.

*2.3: Implement a Summer College Internship Program in GC and disabilities:*

We received a total of eight applications from undergraduate students at Virginia State University and Virginia Union University in March 2006. An admissions committee composed of members of our Multicultural Advisory Committee reviewed the applications and interviewed the top four candidates. Two students were selected for eight week internships for the period of May 22 – July 14, 2006. The interns participated in GC clinics and administrative work, rotated through LEND clinics, and met with LEND faculty in audiology, nursing, nutrition, physical therapy, occupational therapy, speech and language pathology, psychology, and special education. They participated in a LEND faculty retreat on workforce diversity. The interns attended care coordination meetings, visited a state hospital for individuals with mental retardation, and met with an adult with Down syndrome at her job in the community. They met weekly for a lunchtime discussion with GC/LEND faculty and GC graduate students. They completed reading and discussed problems in Skirton and Patch's text, Genetics for Healthcare Professionals during the internship. In addition the interns kept a journal of observations and topics of interest. The journals are reviewed every 2-3 weeks. They prepared a paper and presentation on a selected topic of interest. GC graduate students have served as mentors for the projects.

3. Dissemination

*3.1: Present findings at national meetings:*

A collaborative poster was presented at the February 2006 National Consortium for Health Professional Education in Genetics (NCHPEG) meeting. Collaborators included our colleagues at AUCD, the Rose Kennedy Center, and the Waisman Center. A proposal for a poster on our genetic awareness learning module has been submitted to AUCD for the annual meeting in October 2006. The proposal is provided in Attachment E.

*3.2: Establish LEND discussion forum:*

A draft document of a Genetic Awareness Checklist was disseminated through the LEND network in January 2006. At least two programs indicated they would use it in their training programs. In addition, the

Director of the Genetics Program in the Missouri Department of Health is collaborating with Dr. Bodurtha to modify and use the checklist throughout public health programs in Missouri. A LEND genetic counseling trainee will be working on the development and evaluation of the genetic awareness module in collaboration with LEND directors.

*3.3: Provide leadership to form a Disabilities Special Interest Group (SIG) in the National Society of Genetic Counselors (NSGC):*

The Disabilities SIG has been formed through the NSGC and is in the process of adding new members.

*3.4: Disseminate SYNERGY learning modules:*

Currently we are finishing Module 1 on genetic awareness. We have discussed a dissemination plan through the LEND network and other MCHB funded leadership training programs. We will implement the dissemination plan after we complete the module.

The addition of GC trainees in Va-LEND has been very beneficial for the other trainees. All the trainees work together on teams in clinics and on class projects. Whenever possible we have made an effort to make sure that a GC trainee is on each team. As in many interdisciplinary experiences the trainees learn from one another by sharing their disciplinary perspective and demonstrating their clinical skills and knowledge of the field. In clinical settings and in case study discussions other LEND trainees are learning the importance of taking a family history, to think in terms of genetic traits and patterns of inheritance, and to know when and how to make a referral to a Genetics Clinic. In addition there are natural exchanges across disciplines when two students sit next to one another in class or other activities. There are many opportunities for students to learn from one another. For example: one GC student who graduated from VCU and LEND in May 2006, developed her leadership and masters project in collaboration with the Virginia Deaf-Blind Project due to a contact she made with the program director who was another LEND trainee in special education.

## AUCD- MCHB LEND Genetics Grant Progress Report: 12-month summary

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|-------------------------------------------------------------|
| <b>Project Title:</b> Wisconsin MCH LEND Genetic Counseling |
| <b>Grantee:</b> Waisman Center                              |
| <b>Primary Investigator:</b> Lewis Levitt                   |
| <b>Report Type</b> GC 12-month progress report              |
| <b>Start Date</b> 01/01/2006                                |
| <b>End Date</b> 06/30/2006                                  |

### I. ACCOMPLISHMENTS

Goal 1: All (5) first year Genetic Counseling (GC) students completed the two semester MCH LEND program. The second year GC student increased her leadership skills by developing 6 online case discussions that could be utilized by the LEND trainees. The possibility of LEND training was included in the recruitment materials for the incoming GC graduate students

Goal 2: All MCH LEND trainees participated in 6 on-line case based discussions designed to enhance their understanding of the clinical, social, psychological and systems implications of genetic services. The children who served as the basis for the discussions had diagnoses which included: Deafness, Cystic Fibrosis, Sickle Cell Anemia, Neurofibromatosis, and Duchene Muscular Dystrophy. The topics of Newborn and Population Screening were also discussed; issues that were raised by trainees included patient autonomy, equal access to resources, cultural sensitivity and fiscal responsibility. Two of the non-GC students observed Genetic clinic assessments or counseling sessions.

Goal 3: Letters were sent to UW System student groups (Indian Student Association, AHANA Pre-Health Organization, La Mujer Latina, Hmong American Student Association, Multicultural Student Center, Asian Pacific American Council) describing minority recruitment efforts with offers to speak with their members to increase awareness of genetic counseling career opportunities. The GC Training Program Admissions Committee reviewed applications for student enrollment for Fall 2006. There were no US citizen applicants who self-identified as something other than white-non Hispanic. The Director of the GC Training Program joined the Diversity Special Interest Group within the National Society of Genetic

Counselors and offered to be involved with the minority recruitment event to be held at the annual education conference in November 2006. The MCH LEND GC Project Assistant and the GC Training Program Director participated in a career panel discussion on May 4, 2006 to the Advanced Genetics class on the UW-Madison campus.

The non-GC trainees reported that having the additional genetic content and having the GC trainees participate in the LEND Program was helpful. Four of the 5 GC trainees, along with 5 other LEND trainees and 9 trainees from a Department of Education ID training program, participated in an intensive 3 week summer cultural immersion experience. They reported immense benefit from spending time learning from children and adults on an American Indian reservation and in inner city day care programs. One of the GC students used the cultural competence experiences gained through LEND for her leadership project and plans to expand upon this topic for her masters thesis project. A psychology doctoral LEND trainee used the genetic knowledge she gained through LEND to focus on genetics research and research on learning abilities in children with Noonan syndrome. She plans to expand upon this topic for her doctoral dissertation.