
LEND-Genetics Planning Meeting Report

**December 13, 2006
Washington, DC**

Prepared by:

Ann W. Cox, PhD, RN, FAAN

February 2007

Executive Summary

LEND-Genetics Planning Meeting

December 13, 2006

PURPOSE

The purpose of this first in an anticipated series of genetics planning meetings was two-fold:

1. to share what has been accomplished to enhance genetic content and learning opportunities for genetic counseling and other trainees across the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) programs, and
2. to identify ways to build a sustainable genetic component within all LEND programs, with application to other Maternal and Child Health Bureau (MCHB) training programs.

FORMAT

A diverse group of individuals were invited to present and to participate in the discussion during this one-day meeting. Included were representatives from (a) the three LEND programs that received additional funding for genetic initiatives, (b) other examples of LEND programs with genetic or genetic counseling training components, (c) the Research, Training and Education Division and the Genetics Branch of the Maternal and Child Health Bureau (MCHB), (d) the Association of University Centers on Disabilities (AUCD), and (e) other national genetic organizations. Reports from the programs were given and discussed with particular emphasis on what can be applied across the network. Structured small and large group discussions addressed questions related to resources required within the LEND network to address the need for a viable genetic component and to extend beyond LEND to other federal, state, and local partners.

FINDINGS

1. Programs are challenged by rapidly increasing knowledge and competency in genetics at a time when there are workforce shortages in medical genetics and genetic counseling.
2. LEND programs, generally, are incorporating genetics information within their training programs, although the degree and methods vary.
3. Interdisciplinary education and leadership training for genetic counselors is important, although not included in most genetic counseling programs.
4. Genetic and genetic counseling faculty and trainees are important contributors to LEND interdisciplinary training programs, yet core LEND

- funding is inadequate to add faculty or to recruit diverse genetic counseling trainees.
5. Additionally, recruitment of diverse genetic counseling trainees into LEND programs is difficult due to the limited pool of diverse genetic counseling trainees from which to recruit.
 6. Through the special awards, the LEND/Genetics Special Projects have been able to support genetic counseling faculty time, to fund genetic counseling students in the LEND program, and to develop training materials in genetics that have benefited all LEND trainees.
 7. Some excellent tools and materials have been developed by the programs that need to be shared among all training programs.
 8. The National Institutes of Health (NIH) and the Centers for Disease Control (CDC) are interested in diffusing genetic knowledge and awareness, although professional training has not been their mandate.
 9. Funding for newborn screening and interest in training and education in genetics has emerged within Congress. Advocates for expanded services and research for single diagnoses recently have been effective in securing additional funding, although training has not been a part of the requests.

RECOMMENDATIONS

A list of potential activities/strategies were developed, yet were not prioritized. Some of those that were seen as possible starting points included the following:

- ❖ Use the AUCD website as a vehicle for the dissemination of information and materials to others within the LEND network. Explore the needs of other training programs.
- ❖ Connect with others such as the regional newborn screening centers and state Title V agencies for trainee learning opportunities and to assist with staff training.
- ❖ Use existing LEND trainee stipends flexibly to support genetic counseling trainees.
- ❖ Create/expand distance learning modules that are available to all training programs. Avoid “recreating the wheel”.
- ❖ Explore innovative mechanisms for participation of genetic counseling trainees in LEND.

The above were identified as activities that could be started without significant additional funding. Other strategies would require additional funding and include creative approaches for funding genetic counseling students, faculty, and combined research. Some broader policy initiatives included partnering with other governmental and advocacy agencies with similar, yet more narrowly

defined constituencies; creating a broad resource support center that would provide technical assistance across the training programs; and developing joint pipeline outreach initiatives for careers in disabilities and with an emphasis on increasing diversity of the workforce.

NEXT STEPS

- ◆ Continue the dialogue beginning with a follow-up meeting of this group to develop a specific plan and action steps.
- ◆ Develop a map indicating the current sources of training support for genetic counseling and the availability of funding by source.
- ◆ Identify the steps needed to move from “zero dollars” in support of genetics within LEND to adequate funding.
- ◆ Bring other key people to the table (other MCHB training program representatives, NIH, CDC, other genetic organizations, and genetics leaders) for a future meeting.
- ◆ Address the issue of training within the missions of agencies/organizations that typically do not emphasize training (NIH, CDC, etc.).
- ◆ Continue to pursue pipeline activities geared toward increasing diversity within all LEND disciplines in addition to genetic counseling.

LEND Genetics Planning Meeting

December 13, 2006

Phoenix Park Hotel

Washington, DC

Facilitator: Ann Cox, PhD, RN

Purpose

This meeting was the first in an anticipated series of meetings. The meeting was convened to share approaches from within the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) network to enhance genetics and genetic counseling content and trainee experiences. Over the past year and one-half, three LEND programs were selected to receive approximately \$ 50,000 each, yearly for three years, to develop and implement strategies to increase genetics content within their LEND programs and to support inclusion of genetic counseling trainees, particularly those from under-represented groups. These three programs presented their accomplishments and future plans. Other presentations were made by selected LEND programs. By bringing together these programs, the purpose was to share what has been accomplished to enhance genetic content and learning opportunities for genetic counseling and all LEND trainees and to identify ways to build a sustainable genetic component within all LEND programs. It is anticipated that what is learned can be broadly applied to other Maternal-Child Health Bureau (MCHB) training programs.

Attendees

(A complete participant list can be found in Appendix A of this document and is accessible at www.aucd.org, click LEND, click genetics)

Marion T. Baer, PhD, RD	Judith Benkendorf, MS, CGC
Daniel Bier, MPA	Joann Bodurtha, MD, MPH
Darla Cohen	Herbert Cohen, MD
Ann W. Cox, PhD, FAAN	Christopher DeGraw, MD, MPH
Karen Edwards, MD, MPH	Cindy Ellis, MD
Erynn Gordon	Anne Heintzelman
George Jesien, PhD	Laura Kavanagh, MPP
Audrey Koertvelyessy, MSN, MA, FNP	Penny Kyler, MA, OTR
Michelle Lloyd-Puryear, MD	Marie Mann, MD, MPH
Sheryl Mathis	Roz Parish, MSN
Crystal Pariseau, MSSW	CAPT. Nanette H. Pepper
Madhavi Reddy, MSPH	Casey Reiser
G. Bradley Schaefer, MD, FAAP, FACMG	Jill Shuger, MS
Denise Sofka, MPH, RD	Martha Thomas
Lann Thompson, EdD, MSSW	Christine M. Trahms, MS, RD
Lauren Vanner Nicely, GENETIC COUNSELING	

Agenda

(A copy of the full agenda can be found in Appendix A of this document and is accessible at www.aucd.org, click LEND, click genetics)

The agenda for the meeting was developed by a planning committee consisting of Ann Cox, Crystal Pariseau, George Jesien, Laura Kavanagh, Penny Kyler, Madhavi Reddy, and Denise Sofka. The agenda and supplemental information were sent to participants prior to the meeting. The programs were requested to prepare written comments that addressed specific questions of interest to the planning committee. These reports are included in Appendix C. Both small and large group discussions were planned to assist in moving the group toward synthesis of priorities and initial implementation steps.

Introductions and Welcome

Following a review of the Agenda and introductions, the facilitator, Ann Cox, underscored the purposes of the meeting: to identify ways to expand genetic content within LEND programs and to provide leadership learning experiences for Genetic Counseling trainees. Presentations highlighted programs that have embedded genetic content; attempted to recruit genetic counseling trainees from diverse backgrounds for leadership education opportunities; and partnered with other universities, programs, and key stakeholders to bridge the genetics and LEND communities. Welcoming comments from a few of the primary architects of the LEND/genetics initiative were given.

Laura Kavanagh, MPP, Chief, MCHB Training Branch, acknowledged the people who worked 4 years ago to infuse genetics back into the training programs. The Medical Genetics Program began in the 1960s and because of financial issues was dropped as a priority. Because of the work of Joann Bodurtha, Michelle Lloyd-Puryear, Marie Mann, and Denise Sofka creative funding mechanisms were found to support some efforts to bring genetic counseling training and LEND back together. The group was encouraged to think about how genetics could be infused into training beyond LEND.

Michelle Lloyd-Puryear, MD, Chief, Genetics Branch, credited the inspiration and conceptualization of this new initiative to the faculty from the Virginia LEND program. There is a chance now with the new legislation introduced by Sen. Obama (IL) to revisit this issue. Senator Obama is going to reintroduce this particular piece of legislation to include education and training. Because of the budgetary continuing resolution, no one knows the level of funding tied to this legislation.

George Jesien, PhD., Executive Director, Association of University Centers on Disabilities (AUCD) saw this meeting as an opportunity to reflect, compile experiences, hear about lessons learned, and identify the challenges that need to

be addressed to propel this group into the future. In 2005 there were three grants of \$ 50,000 per year (for three years) competitively available to LEND programs to demonstrate approaches that would bring genetic counseling and LEND training together. Seventeen (17) applications were received. Out of 35 LEND programs, half were interested enough to set aside what they were doing and to submit a proposal. This was the most popular response to any funding proposal the AUCD network has had. It is hoped that the cost effectiveness of this approach is considered today. While the program is costly, there may be alternatives to augment it so that more LEND programs can be involved. He praised the idea of bringing the grantees to today's meeting and challenged the grantees to exert leadership aimed at generating new ideas.

The Genetics group is at the beginning of a fast-moving field. The National Institutes of Health (NIH) recently sponsored a Mid-East and North African conference on genetic screening. State programs are evolving. With science changing at a tremendous pace, implications for everyone's work will be great. Mechanisms need to be found to identify the science. The 2008 legislation eliminates earmarks; this will be a fairly lean year through the fall of 2008.

Overview of the LEND/Genetics Special Projects

The three special LEND projects addressed the following questions in their presentations:

- Of your original plan, what have you been able to accomplish?
- What resources were developed and used?
- How have you addressed your trainee diversity goal?
- What has been the return on investment (ROI)?
- What lessons have you learned along the way?
- What would you recommend for the future?

Copies of the complete PowerPoint presentations made by these three programs and the AUCD-MCHB LEND Genetics Grant Progress Reports can be found in Appendix B of this report and are accessible at www.aucd.org, click LEND, click genetics.

Herb Cohen, MD, Rose Kennedy Center, NY

Accomplishments. Dr. Cohen reviewed the nature of the collaborative project emphasizing the following accomplishments:

1. UCEDD/Children's Evaluation and Rehabilitation Center (CERC), Sarah Lawrence College, Genetic Counseling MS Program (SLC), Children's Hospital at Montefiore (CHAM), and Albert Einstein College of Medicine, Reproductive Genetics Program (AECOM) formed the collaborative relationships necessary to implement this project.

2. Genetic Counseling LEND Interdisciplinary Fellows participate in the following training components along with the other long-term LEND trainees:
 - Interdisciplinary Clinical Team Experience at CERC
 - Core Lecture Series on DD
 - Genetic Counseling Experience at CERC and CHAM
 - Research Project
3. CERC faculty provide training at SLC to all genetic counseling students. Topics include pediatric genetic syndromes and reproductive genetics. Other DD and Health Policy lectures are provided.
4. The results from the first 18 months of this training include:
 - Five full genetic counseling LEND fellows enrolled
 - Ten intermediate trainees from genetic counseling (clinical placement)
 - Sixty-one genetic counseling students in courses and seminars (short-term)
 - All LEND trainees receive increased exposure to genetic content and role of the genetic counselor
 - Genetic counseling fellows receive exposure to interdisciplinary leadership training and understand roles of other disciplines.
 - Research involvement of trainees in genetics-related topics expands.
5. This compares favorably to the original plan.

Resources developed and used.

- Increased availability of genetic counseling services at the Rose Kennedy Center
- Expanded emphasis on diagnosis and managing genetic disorders

Diversity of Genetic Counseling Trainees

- Complicated in that the Sarah Lawrence Genetic Counseling Program has few students from minority groups.
- Has one student with a hearing impairment for which the lectures have been accommodated.
- Stipend may not be enough to attract the few eligible diverse students due to competing priorities.

Return on Investment (ROI)

- Additional Interdisciplinary Training Activities, benefiting all LEND trainees.

- Expanded interdisciplinary and leadership training for five genetic counseling fellows.
- Training program has been modified based on genetic counseling trainee feedback.
- Three first year fellows are working in the field, one at another UCEDD/LEND program.
- Expansion to include another genetic counseling program in the region.

Lessons Learned

- Need to begin recruitment of trainees earlier by marketing the program to 1st year Sarah Lawrence genetic counseling students.
- More structure and hands-on activities are needed.

Recommendations for the Future

- Incorporate genetic counseling as a discipline within the LEND program.
- Increase funding in the core LEND grant to support genetic counseling trainees.
- Follow-up to see how trainees are using their experience.

Casey Reiser, Anne Heintzelmann, Dan Bier, Waisman Center LEND Program, Madison, WI

Accomplishments

1. Over half of the funding was used for direct trainee expenses, including LEND Genetics Trainee Stipends (5) and tuition reimbursement and travel expenses for one genetic counseling 2nd year trainee who serves as the project assistant.
2. A Genetics Discipline Training coordinator was hired at .25 FTE.
3. Genetic content within the LEND curriculum was expanded. Six on-line genetics case based discussions were designed and implemented. Genetic clinic and counseling sessions were available for non-genetics trainees.
4. Leadership and Policy content from the LEND curriculum became a component of LEND genetics.

Resources Developed

- Six genetic case based discussions, using [Learn@UW](#) for online discussions, were developed and used.

- DVDs of these discussions are available for non-genetic trainees.

Diversity

- Recruitment letters sent through UW system student groups
- No diverse students were admitted to the genetic counseling training program.
- Genetic counseling training program director joined the diversity special interest group of the National Society of Genetic Counselors.
- University of Washington diversity contacts were expanded.
- Five genetic counseling trainees participated in an intensive summer cultural immersion experience with other LEND trainees.

Return on Investment

- National Coalition for Health Professional Education in Genetics (NCHPEG) competencies are part of the overall LEND curriculum.
- Genetic Counseling trainees perceive themselves as part of the interdisciplinary team, and LEND trainees and faculty view the genetic counselor as an integral member of the interdisciplinary team.
- Influence of the genetics curriculum enhancements on the research activities of a Psychology LEND trainee's dissertation.
- LEND genetic trainee scholarship an outgrowth of the LEND Leadership project.
- Speech-Language Pathology LEND trainee reported higher performance on National Board Exam, in part attributed to genetic content.

Lessons Learned

- Genetic counseling trainees must be part of the interdisciplinary clinical experiences in which all LEND trainees participate.
- Must fully integrate LEND genetic counseling trainees into Wisconsin LEND curriculum.
- New content can be integrated without overwhelming trainees or faculty.
- Enhanced potential for genetics influence on future research of non-genetics disciplines.

Recommendations for the Future

- Maintain and expand continued commitment to LEND genetics.
- Make trainee stipend money available.
- Support for Faculty Discipline Training Coordinator important.

Joann Bodurtha, MD, SYNERGY, Virginia LEND, Richmond, VA

The goals of SYNERGY are to (1) integrate genetics into LEND training, (2) train genetic counseling students in interdisciplinary leadership excellence, (3) increase genetic awareness through checklists and modules, (4) enhance diversity in genetic counseling.

Accomplishments

1. Genetic awareness checklist developed and distributed to all LEND programs.
2. All Virginia LEND students have some genetics training.
3. One of three web-based learning modules (genetic awareness) has been developed and is awaiting IRB approval for evaluation; two others (family history and newborn screening) are in development.
4. All genetic counseling students take the LEND leadership seminar series.
5. National Society for Genetic Counselors' Disabilities Special Interest Group established.
6. Multicultural Advisory Committee established and functioning well.
7. Two-three genetic counseling students/year enrolled as long-term LEND trainees.
8. Two Historically Black Colleges and University (HBCU) undergraduate students selected as interns and completed summer internship.
9. SYNERGY presented at Association of Maternal-Child Health Programs (AMCHP), AUCD, and NCHPEG meetings.

Resources Developed and Used

- Genetic awareness checklist developed and disseminated.
- HBCU summer internship planned and implemented with focused recruitment strategies.
- Autism clinic genetic screening tool and family history tool developed and used with the Virginia Department of Health, March of Dimes funding for State Genetics Education Plan.

Diversity

- Partnered in LEND recruitment with HBCU (Virginia Union University, Virginia State University).
- LEND faculty have given lectures at HBCUs.
- Partnered with other diversity Life Science and summer initiatives at Virginia Commonwealth University (VCU) to introduce all LEND disciplines.
- Drafted organizational cultural competency plan.
- Formed Multicultural Advisory Committee.

Return on Investment

- One HBCU intern presented at National meeting, both are ongoing advocates at their schools for the LEND program and summer internship.
- Five long term LEND genetic counseling trainees are considering pediatric genetic counseling careers.
- Genetic counseling students connected with HBCUs.
- Genetic counseling faculty dollars and support important to PhD Chair, school leadership.
- Module development estimated 1/10th the cost of doing them commercially. Modules and checklist made available for use across LEND network.

Lessons Learned

When the glass is half empty:

- No dollars, no diversity
- No extramural NIH funding available, no diversity
- No outside dollars/overhead available, no institutional support.
- No insurance, no genetic testing accessible.

When the glass is half full:

“Effective leadership unfolds from the common good.” DePaola

Recommendations for the Future

- Partnerships across all training programs, performance measure.
- Create a genetic counseling research network
- Consider extramural training grants through National Human Genome Research Institute
- Recommend use of genetic awareness checklist
- Include genetic counseling/LEND training in autism funding portfolio.
- Secure funding to continue stipends for genetic counselors in LEND programs.
- Maintain funding for a genetics faculty for LEND programs.
- Consider lifespan partnering on projects.

Large Group Discussion and Summation

Currently, everyone has some genetic content in their LEND programs. Genetics and neuroscience is the future direction that is being infused into the training programs. However, funding is critical to sustain the momentum. Funding opportunities need to be sought to further enhance the LEND Interdisciplinary training with genetic content and practitioners. This is an evolving process for roles to be developed and worked into the teams. Faculties are learning more from watching the trainees with the genetic counselor as part of the team.

The diversity goal in each of these projects has been the most difficult to achieve. That is because the genetic counseling programs with which the LEND programs are partnering do not attract a diverse student group (and this is the trend nationwide). There are many reasons for this, one of which includes lack of funding. We need to expand the pipeline dollars for minority recruitment.

The genetic awareness checklist, developed by SYNERGY, was praised for the family focus of the first four items.

Other LEND Program Genetic Efforts

Other LEND programs in the network with genetic training components were invited to participate in this meeting. Each responding program was asked to prepare a written report of their genetic counseling/LEND activities and was given a brief amount of time to present. Each program was asked to respond to the following four questions:

- What strategies have you used to infuse genetics information into your training program?
- What funding/resources did you use to support these activities?
- What relationships were developed or expanded?
- What lessons have you learned and what would you suggest for the future?

Copies of the written reports from these six programs (University of Southern California LEND, University of Washington LEND, Nebraska LEND, Westchester LEND, Indiana LEND, Cincinnati LEND) can be found in Appendix C of this document and are accessible at www.aucd.org, click on LEND, click genetics.

The following points were made during these six presentations.

1. Genetics content was being offered in these LEND programs and there was an expressed need and desire to further expand this content.
2. Genetic counseling students are available to most of these programs but typically not as long term leadership trainees. Unless stipends are

- available, genetic counseling students receive a “less” than full LEND training experience.
3. Some of these programs have genetic faculty on staff, few have genetic counseling faculty.
 4. If stipends are available to genetic counseling trainees, it typically comes from the core LEND funding. This means that the same number of funded trainee slots are spread among a larger group of disciplines.
 5. Genetic Counseling faculty involvement in the LEND program was often voluntary because of limited funds via the core LEND grants. Both genetics faculty and genetic counseling faculty are needed to develop and to sustain an integrated genetics component within LEND.
 6. All programs have developed collaborative relationships among departments within their universities and centers or with departments in affiliated universities (especially genetic counseling programs) to accomplish their goals around integration of genetic content and experiences.
 7. These programs continue to expand content and experiences for LEND trainees in genetics, even without funding. What they are less able to do is to hire faculty in genetics/genetic counseling for their LEND programs to coordinate this expansion and recruitment of trainees or to competitively recruit genetic counseling trainees.
 8. A common theme was that the programs have been able to advance their efforts by coming up with creative ideas to increase funding to advance the LEND Programs.

Update on New Issues, Efforts, Resources, Diversity Recruitment, and Retention in the Field of Genetics

Three individuals were invited to give an overview of what is happening nationally around these issues. Joseph McInerney, Director, National Coalition for Health Professional Education in Genetics, refers participants to the NCHPEG website @ www.nchpeg.org for presentation materials and other useful information.

Judith Benkendorf, MS, CGC, Project Manager, American College of Medical Genetics.

(A copy of Ms. Benkendorf's PowerPoints is available in Appendix D of this document and is accessible at www.aucd.org , click on LEND, click genetics).

Judith Benkendorf presented a review of activities related to genetics and genetic counseling around workforce issues and diversity, from multiple organizations including the American College of Medical Geneticists (ACMG), the American Board of Medical Genetics (ABMG), the National Society of Genetic Counselors (NSGC), and the National Coordinating Center (NCC) for Genetics and Newborn

Screening Regional Collaborative Groups. Findings from recent surveys regarding workforce issues related to medical genetic and genetic counseling personnel underscore several trends including:

- Genetic advances will impact the healthcare for people and families with neurodevelopmental disabilities.
- The genetics workforce situation is critical, requiring coordinated, multi-pronged approaches (1 board certified MD clinical geneticist for every 301,900 Americans; 1 genetic counselor for every 166,900 Americans. Data from August 2005 survey)
- The lack of workforce diversity needs to be addressed. (According to 2003 data, 13% of board certified medical geneticist belong to minority groups. In a more recent survey (2006), 91% of genetic counselors are Caucasian and 94% are women)
- Both the ACMG and NSGC are engaged in activities directed toward increasing the workforce and advancing diversity.
- The Regional Centers are a venue for LEND trainees to gain experience in public health genetics, and they provide a vehicle for dissemination of LEND materials and messages.

Penny Kyler, MA, OTR, MCHB, Genetic Services Branch, HRSA/MCHB

Penny Kyler reviewed a number of resources that were supported with MCHB funding and are appropriate resources to support training. An array of low health literacy materials have been developed and disseminated and some materials are in both English and Spanish. Several DVDs and CDs are available including a DVD template of newborn screening material, AAFP DVD – Annual Clinical Focus on Genomics 2005, and a CD – Medical Home Family Stories; Genetics and Common Disorders: Implications for Primary Care and Public Health Providers. The following sites can be used to access many of these resources:

www.geneticalliance.org (A Guide to Family Health History)

www.genes-r-us.uthscsa.edu (Newborn Screening Tests and promotional flyers in multiple languages)

<http://www.genetists.org/> (click on Genetics Tools)

<https://familyhistory.hhs.gov/> - Family Health Portrait profile online

Discussion and Comments from Session

The issue of payment for genetic counseling services was raised. In response, the vast majority of genetic counselors are working in hospital settings and universities. With the growth of genetic counselors, less traditional settings such as labs, private practice, public health, and health maintenance organizations

have emerged as work settings. The following table summarizes work sites identified from a recent survey conducted by the National Association of Genetic Counselors (2006).

Table 5. Primary Employment Setting

	N	%
<i>University Medical Center</i>	474	38%
<i>Private Hospital/Medical Facility</i>	252	20%
<i>Public Hospital/Medical Facility</i>	134	11%
<i>Diagnostic Laboratory</i>	95	8%
<i>Physician's Private Practice</i>	58	5%
<i>Health Maintenance Organization</i>	43	3%
<i>University/Non-Medical Center</i>	39	3%
<i>Other</i>	38	3%
<i>Federal/ State/County Office</i>	27	2%
<i>Self-Employed/Private Practice</i>	12	0.9%
<i>Research Development/Biotechnology Company</i>	10	0.8%
<i>Pharmaceutical Company</i>	7	0.6%
<i>Outreach/Satellite/Field Clinic</i>	4	0.3%
<i>Internet/Website Company</i>	2	0.2%
<i>Bioinformatics Company/Health Advocacy Organization</i>	1	0.1%

Very few geneticists work in a private setting. Salaries are not based on counseling services. Previously, training grants, medical procedures, and diagnostic laboratories and procedures paid for genetic services. Medical clinical geneticists have to generate their income, thus time for training is limited. Residency slots are available, and are variably funded. While most are funded, they are hard to fill. Some Title V grant money is used to develop infrastructure. Resources are in different parts of the system. This challenges all to be creative in locating roles within existing programs and diminishes the likelihood of genetic services operating as independent programs.

Work Group Assignments

A number of excellent strategies to address the goal of integration of genetics and genetic counseling with the LEND programs were discussed. A review of the workforce issues from a national perspective as well as the availability of national resources was presented. For the afternoon, the participants broke into four smaller work groups. Given that it is not known whether there will be continued funding for genetics within LEND, the groups discussed the following:

- (1) Discuss and place those activities that have been or could be fruitful to enhancing genetic information and experiences within the LEND programs into one of three categories:

- activities that can be done if no additional funding is earmarked for genetics in LEND,
 - activities that can be done by a program if a supplement of up to \$ 50,000 is available, and
 - activities that require substantial increases or additional funding sources can be found.
- (2) Prioritize the activities in each category from most attainable to least attainable.
- (3) Then determine whose priority is it (MCHB, AUCD/network, LEND program-level), and who are appropriate partners?

(Copies of this assignment and recording format can be found in Appendix E of this document)

The information discussed and gleaned is organized by category on the following tables.

Activities we can do if <u>no</u> additional funding sources is earmarked for genetics in LEND:	
1: Organize existing materials, post on AUCD web, disseminate	A: who? MCHB,AUCD B: partners? LEND programs, NCHPEG
2: Maintain/expand current level of genetics content	A: who? LEND programs B: partners? AUCD,MCHB,Genetics Br, PPC, SPH LEAH,
3: Connect with regional NBS centers and partner with them in training	A: who? LEND programs, genetic counseling programs B: partners? NCC/RCC, MCHB, Genetics Br
4: Cultivate relationship with genetic counseling faculty	A: who? LEND programs B: partners? Genetic counseling programs, Genetics Br, NSGC MCHB, NCC/RCC
5: Use existing LEND stipends flexibly	A: who? LEND programs B: partners? MCHB
6: Exchange among LEND mentor/mentee/clinical exposure with some student sharing among LEND programs	A: who? LEND programs B: partners? Genetic counseling programs, regional centers, State/local genetics programs
7: Work with existing pipeline initiatives, multicultural committees	A: who? B: partners?
8: Advocate for needs broadly and at multiple levels	A: who? B: partners?
9. Encourage the use of Title V Block Grant money for genetic counseling and other training	A: who? MCHB, genetic counseling programs B: partners? State Title V, UCEDD/LEND

10. Add genetic and LEND competency questions to national accreditation requirement for schools of medicine	A: who? B: partners?
11. Add family-centeredness/family focus to all genetic counseling training	A: who? B: partners?
12. Make the guidance clear that genetic counselors are considered "official, approved" LEND trainees	A: who? MCHB B: partners? Genetic counseling programs LEND, NSGC
13. Provide regular updates to network on GENETIC COUNSELING and LEND initiatives	A: who? MCHB/AUCD B: partners? Special Projects, Planning Group
14. Develop a performance measure that embraces genetics within LEND	A: who? MCHB, Genetics Branch B: partners? LEND Programs, genetic counseling programs

Activities we can do if a supplement of up to \$50,000, in addition to current funds earmarked for genetics in LEND, is available:

1: Hire faculty to serve as genetic counseling coordinator for LEND programs	A: who? LEND B: partners? Genetic counseling programs, faculty
2: Earmark part of faculty time to work with minority granting institutions or in pipeline-type activities aimed at recruiting	A: who? LEND, genetic counseling programs B: partners?
3: Award stipend money for long-term genetic counseling trainees on par with amount allocated for other LEND disciplines	A: who? LEND B: partners? Genetic counseling programs, MCHB, other funders
4: Create unconventional mechanisms for participation in LEND (part through distance learning, part on site)	A: who? LEND B: partners?
5: Creation or expansion of distance learning modules that are available to all programs	A: who? Funded programs, LEND B: partners? Genetic counseling programs, MCHB, AUCD
6: Advocate for a student loan repayment program for GenLEND trainees with mechanisms for loan forgiveness if working in underserved area	A: who? NSGC, genetic counseling programs B: partners? LEND, Genetics Br., MCHB, AUCD
7: Include LEND trainees in National Health Service Corps	A: who? B: partners?
8: Create collaborative LEND/genetics research program	A: who? B: partners?

9. Develop internships, with genetic counseling mentoring, to increase diversity	A: who? LEND, genetic counseling programs B: partners? HBCU's, other minority institutions
10. Award \$ 500- \$ 1000 to LEND trainees for projects on genetic topics	A: who? LEND, AUCD B: partners? Trainees, faculty
11. Involve LEND trainees (genetic counseling as well) in community membership activities	A: who? B: partners?

Activities we can do if increased funding and additional funding sources are found:	
1: Support genetic counseling/genetics faculty time in clinician/educator role	A: who? LEND B: partners?
2: Develop joint pipeline outreach to high schools re: careers in disabilities (focus on all LEND disciplines and all Bureau of Health Professions training)	A: who? MCHB, Bureau of Health Professions B: partners?
3: Develop a coordinating resource support center (technical assistance) on infusing genetics into LEND-National Center on LEND-etics	A: who? MCHB, Genetics Br. B: partners? AUCD
4: Advocate for all NBS legislation to include interdisciplinary training and workforce development component	A: who? AUCD, National Organizations B: partners? LEND, genetic counseling programs, LEAH, PPC, Schools of Public Health
5: Develop national, high profile Fellowships in genetics and genetic counseling	A: who? B: partners?
6: Develop training consortia across state lines	A: who? B: partners?
7: Explore avenues to advocate for jobs, adequate salary, and reimbursement for genetic counselors	A: who? National Organizations B: partners? Genetic counseling programs, Genetics Branch
8: Develop summer internships for practicing professionals who will complete part of LEND (certificate in leadership)	A: who? LENDs with interest Health departments B: partners? State/local professionals
9. Embrace a translational approach to training (research to practice to policy)	A: who? B: partners? NIH, CDC, AHRQ, MCHB

Large Group Discussion and Consensus

Following the group reports, the larger group was challenged to address the following:

- Collectively select several priorities and develop implementation strategies.
- Identify what needs to be done, who will do it, and what resources are required.
- Decide next steps.

A lively, although abbreviated (due to limited time), discussion followed. Several points were made that will influence the direction that is taken. One participant talked about how advocacy groups and genetic support groups spend their time getting dollars for research, not the translation of information or training. While alliances with these groups is important, the missions are different. Congress is typically approached with a single gene group (autism, fragile X are examples). To leverage additional dollars, a case needs to be made for an interdisciplinary approach, requiring many disciplines. Thus the need is substantial for workforce development through training.

As part of the care infrastructure, genetics is an important component, yet is under-funded (lower reimbursement avenues) and under-staffed. Further, there is a distribution problem in the number and location of genetic counseling programs. For instance, there are only five genetic counseling programs west of the Rockies.

While most LEND programs have incorporated some genetic content within their programs, fewer have genetic clinical experiences. Several strategies were discussed to heighten the visibility of genetics across the network. For example, some group could sponsor a monthly genetic topic (Genetics for the Month) offered as a webcast to the entire MCHB training network. Resources like those that were presented during this meeting could be shared broadly across the Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND), University Centers for Education in Developmental Disabilities (UCEDD), Leadership Education in Adolescent Health (LEAH), Pediatric Pulmonary Centers (PPC), Bureau of Health Professions (BHPr), Schools of Public Health (SPH) programs. Resources will be needed to support the development of infrastructure, research, training, and current structures. Thus, supplemental funding will be needed to add a viable genetics program. And while there is support for reaching beyond the LEND network, it will be critical to identify some coordinating entity that can use technology to disseminate information.

Finally, there is the need to stretch across federal agencies. National Institute for Child Health Development (NICHD) and Centers for Disease Control (CDC) also are invested in newborn screening. A way needs to be found to share and/or develop resources among Federal partners. Perhaps it is time to set a high-level meeting to look at what collectively can be done and to identify partnership responsibilities in this regard.

Next Steps

In conclusion, the LEND-Genetics planning meeting participants suggested the following:

- (1). Continue the dialogue beginning with a follow-up meeting of this group to develop a specific plan and action steps.
- (2). Develop a map indicating the sources of genetic counseling training support and availability funding by source.
- (3). Identify the steps needed to move from “zero dollars” in support of genetics within LEND to adequate funding.
- (4). Bring other key people to the table (other MCHB training program representatives, NIH, CDC, other genetic organizations, and genetics leaders) for a future meeting.
- (5). Address the issue of training within the missions of agencies/organizations that typically do not emphasize training (NIH, CDC, etc.).
- (6). Continue to pursue pipeline activities geared toward increasing diversity within all LEND disciplines in addition to genetic counseling.

Appendices

(Because of the size, the complete appendices are contained in a separate file.
The title of and content included in these appendices is as follows)

Appendix A Participant List
Agenda

Appendix B Presentations from AUCD/Genetics Special Projects
Rose Kennedy Center, NY
Waisman Center, WI
Virginia LEND, VA
Progress Reports – June 2006

Appendix C Reports from Other LEND Programs
University of Southern California, CA
University of Washington, WA
Monroe-Meyer Institute, NE
Westchester Institute for Human Development, NY
Riley Child Development Center, IN
Cincinnati Center for Developmental Disabilities, OH

Appendix D Update on National Issues, Efforts, Recruitment, Diversity, and
Resources
Presentation by Judith Benkendorf, MS, CGC

Appendix E Work Group Assignment and Recording Format

APPENDIX A

Participant List

Agenda

PARTICIPANT LIST

Marion T. Baer, PhD, RD
Project Director, LEND
Pediatrics/USC UCEDD
4650 W. Sunset Blvd., Stop 53
Los Angeles, CA 90027
323-671-3823
mbaer@chla.usc.edu

Judith Benkendorf, MS, CGC
Project Manager
American College of Medical
Genetics
9650 Rockville Pike
Bethesda, MD 20814-3998
301.634.7127 (phone)
301.634.7275 (fax)
jbenkendorf@acmg.net

Daniel Bier, MPA
Waisman Center
U. of Wisconsin-Madison
1500 Highland Ave.
Madison, WI. 53705
608-263-5254
bier@waisman.wisc.edu

Joann Bodurtha, MD, MPH
Virginia Institute for Developmental
Disabilities
Virginia Commonwealth University
1000 East Marshall Street
Richmond, VA. 23298
804-828-0073
bodurtha@hsc.vcu.edu

Darla Cohen
Riley Child Development Center
LEND Family Faculty
702 Barnhill Drive Room 5837
Indianapolis, IN 46205
317-274-8167 office
317-696-3993 cell
darla.cohen@sbcglobal.net

Herbert Cohen, MD
Director, MCH LEND
Rose F. Kennedy Center
Albert Einstein College of Medicine
1410 Pelham Parkway South
Bronx, NY 10461
718-430-8522
hcohen@aecom.yu.edu

Ann W. Cox, PhD, RN, FAAN
3001 Jones Ferry Rd.
Chapel Hill, NC 27516-5587
919-932-5874 (home)
919-360-7755 (cell)
annwcox@bellsouth.net

Christopher DeGraw, MD, MPH
Deputy Director, Division of
Research, Training and Education
MCHB
5600 Fishers Lane, Rm. 18A55
Rockville, MD 20857
301-443-1964
cdegrow@hrsa.gov

Karen Edwards MD MPH
LEND Program Director,
Westchester Institute for Human
Development
Associate Dean for Primary Care
Office of Undergraduate Medical
Education
Munger Suite 600
New York Medical College
Valhalla NY 10595
914-594-4609
KEdwards@wihd.org

Cindy Ellis, M.D.
Associate Professor of Pediatrics
and Psychiatry
Munroe Meyer Institute for Genetics
and Rehabilitation
University of Nebraska Medical
Center
985380 Nebraska Medical Center
Omaha, NE 68198-5380
402-559-4097
cellis@unmc.edu

Erynn Gordon
Children's Research Institute
LEND Program
111 Michigan Avenue NW
Washington DC 20010
202-884-5849

Anne Heintzelmann
Waisman Center
U. of Wisconsin- Madison
1500 Highland Ave.
Madison, WI. 53705
608-263-9915
heintzelman@waisman.wisc.edu

George Jesien, Ph.D.
Executive Director
Association of University Centers on
Disabilities (AUCD)
1010 Wayne Avenue, Suite 920
Silver Spring, MD 20910
301-588-8252
301-588-2842 (fax)
gjesien@aucd.org
www.aucd.org

Laura Kavanagh, MPP
Chief, Training Branch, DRTE
DHHS/HRSA/MCHB
5600 Fishers Lane, Room 18A-55
Rockville, MD 20857
301-443-2254
lkavanagh@hrsa.gov

Audrey Koertvelyessy, MSN, MA,
FNP
Division of Research Training and
Education
Maternal and Child Health Bureau
Health Resources and Services
Administration
5600 Fishers Lane, Room 18A-55
Rockville, MD 20857
301- 443-0392
akoertvelyessy@hrsa.gov

Penny Kyler, MA, OTR
Genetic Services Branch
MCHB/HRSA
5600 Fishers Lane
Rockville, MD 20857
301-443-6829
301-443-8604 (fax)
PKyler@hrsa.gov

Michele A. Lloyd-Puryear, M.D.,
Ph.D.
Chief, Genetic Services Branch
Division of Services for Children with
Special Health Needs
Maternal and Child Health Bureau
5600 Fishers Lane. Rm. 18-A-19
Rockville, MD 20857
301-443-8604-fax
301-443-1080-phone
MPuryear@hrsa.gov

Marie Mann, MD, MPH
Genetics Services Branch
MCHB/HRSA
5600 Fishers Lane, Rm. 18A19
Rockville, MD 20857
301-443-1080
mmann@hrsa.gov

Sheryl Mathis
MCH Training Resource Center
Health Systems Research
1200 18th St. NW
Washington DC 20036
202-828-5100
SMathis@hsrnet.com

Joseph McInerney, Director
NCHPEG
2360 W. Joppa Rd. Suite 320
Lutherville, MD 21093
410-583-0600
jdmcinerney1@comcast.net.

Crystal Pariseau, MSSW
LEND Coordinator
Association of University Centers on
Disabilities (AUCD)
1010 Wayne Avenue, Suite 920
Silver Spring, MD 20910
301-588-8252
301-588-2842 (fax)
cpariseau@aucd.org
www.aucd.org

Roz Parrish, MSN
MCH LEND Associate
Director/Training Director
Cincinnati Children's Hospital
Medical Center Division of
Developmental and Behavioral
Pediatrics
MLC 4002
3333 Burnet Avenue
Cincinnati, OH 45229-3039
513-636-4619
513-636-0107 (fax)
Roz.Parrish@cchmc.org

CAPT Nanette H. Pepper
5600 Fishers Lane 18A-55
Rockville, MD 20857
301 443-6445
npepper@hrsa.gov

Madhavi Reddy, MSPH
Public Health Analyst
Division of Research, Training and
Education
HRSA/MCHB
Parklawn Building/Room 18A-55
5600 Fishers Lane
Rockville, MD 20857
301-443-0754 Office
301-443-4842 Fax
mreddy@hrsa.gov

Casey Reiser
Waisman Center
U. of Wisconsin- Madison
1500 Highland Ave.
Madison, WI. 53705
608-262-9722
reiser@waisman.wisc.edu

G. Bradley Schaefer, MD, FAAP,
FACMG
University of Nebraska Medical
Center
Omaha Scottish Rite, Masonic
Professor of Child Health
Associate Director, Munroe - Meyer
Institute for Genetics and
Rehabilitation
Associate Chairman for Faculty
Development, Department of
Pediatrics
985430 Nebraska Medical Center
Omaha, NE 68198-5430
402-559-6800
402-559-6688 (fax)
gbschaef@unmc.edu

Jill Shuger, MS
Project Officer
Genetics Services Branch
MCHB/HRSA
5600 Fishers Lane, Rm. 18A19
Rockville, MD 20857
301-443-3247
jshuger@hrsa.gov

Denise Sofka, MPH, RD
Public Health Analyst
DHHS/HRSA/MCHB/DRTE
5600 Fishers Lane, Rm. 18A55
Rockville, MD 29857
301-443-0344
dsofka@hrsa.gov

Martha Thomas
VCU LEND
1000 East Marshall Street
Richmond, VA 23298
804-828-0073
thomasmh@vcu.edu

Lann Thompson, EdD, MSSW
Associate Director
Riley Child Development Center
Indiana University
702 Barnhill Drive
Indianapolis, IN 46202
317-274-8167
laethomp@iupui.edu

Cristine M Trahms, MS, RD
PKU/Biochemical Genetics Clinics
Center of Human Development and
Disability (CHDD), Box 357920
University of Washington
Seattle, WA 98195
206-598-3025
206-598-1915 (fax)
ctrahms@u.washington.edu

Lauren Vanner Nicely, GC
VCU LEND
1000 East Marshall Street
Richmond, VA 23298
804-828-0073
lvanner@vcu.edu

AGENDA

LEND GENETICS PLANNING MEETING

December 13, 2006
Phoenix Park Hotel
520 N. Capitol Street, NW
Washington, DC
Facilitator: Ann Cox

8:30am Continental Breakfast

9:00am Welcome and Introductions

George Jesien, EdD, AUCD;
Michele Puryear, MD, Genetic Services Branch, MCHB;
Laura Kavanagh, MPP, Training Branch, MCHB

9:30am Overview of LEND Genetics Special Projects
Herb Cohen, MD, Albert Einstein College of Medicine
Daniel Bier, MPA, Waisman Center, U. of Wisconsin
Joann Bodurtha, MD, Virginia Commonwealth University

Points to address:

- Of your original plan, what have you been able to accomplish?
- What resources were developed and used?
- How have you addressed your trainee diversity goal?
- What has been the ROI - Return on Investment?
- What lessons have you learned along the way?
- What would you recommend for the future?

10:30am Break

10:45am Describe Other LEND Genetic Efforts (5 minute presentations)

Marion Taylor Baer, PhD, USC, Children's Hospital Los Angeles
Chris Trahms, MS, RD, U. of Washington
Bradley Schaeffer, MD, University of Nebraska
Karen Edwards, MD, New York Medical College, Valhalla
Lann Thompson, EdD, MSSW, Indiana University
Roz Parrish, MSN, University of Cincinnati

Summaries may include responses to the following questions:

- What strategies have you used to infuse genetics information into your training program?
- What funding/resources did you use to support these activities?
- What relationships were developed or expanded?
- What lessons have you learned and what would you suggest for the future?

11:30am Update on New Issues, Efforts, Resources, Diversity
Recruitment and Retention in the Field of Genetics
Judith Benkendorf, MS, CGC, American College of Medical Genetics
Joseph D. McInerney, Director, National Coalition for Health
Professional Education in Genetics
Penny Kyler, MA, OTR, MCHB

12:15pm Lunch

1:00 – 1:30pm Large group discussion

- Given the experiences shared from the morning sessions, how do we use these to make a greater impact across the LEND network?
- With whom can we partner to extend the training benefit beyond the LEND network?

1:30 – 2:30pm Small group focused discussion
Thinking about our experiences within the LEND network and not knowing whether there will be continued funding how can we plan to (1) maintain and expand our work in genetics within LEND and (2) extend it within the other MCHB training programs.

Current activities will be listed under one of three categories:

- Activities that can be done if no additional funding is earmarked for genetics in LEND;
- Activities that can be done if a supplement of up to \$50,000, in addition to current funds earmarked for genetics in LEND, is available; and
- Activities that require substantial increases or additional funding sources can be found.

Prioritize the activities in each category from most attainable to least attainable.

Then determine:

- Whose priority is it? (MCHB, AUCD/network, LEND program-level)
- Who are appropriate partners?

2:30 – 2:45pm

Break

2:45 – 3:45pm

Group reports and large group discussion

We will discuss the work of each of the four groups and:

- Collectively select several priorities and develop implementation strategies;
- Identify what needs to be done, who will do it, and what resources are required; and
- Decide our next steps.

3:45- 4:00pm

Wrap up

APPENDIX B

Presentation from AUCD/Genetics Special Projects

Rose F. Kennedy Center, NY
Waisman Center, WI
Virginia LEND, VA

Progress Reports – June 2006

ROSE F. KENNEDY CENTER UCEDD

ID Training in Genetic Counseling

Collaborative Project

UCEDD/Children's Evaluation and Rehabilitation Center
(CERC)

Sarah Lawrence College's (SLC) Genetic Counseling
Training Program (M.S.)

Children's Hospital at Montefiore (CHAM)

AECOM Reproductive Genetics Program

Genetic Counselor LEND ID Fellows

ID Clinical Team Experience at CERC

Core Lecture Series on DD

Genetic Counseling Experience at
CERC and CHAM

Research Project

CERC has 8 ID Units

Pediatric Rehab Unit (C.P., Spina Bifida, etc.)

* Infant Toddler Team (EI Unit) – Many cases of ASDs

Infant Preschool Unit (Language Disorders, Dev. Delays, MR, Autism)

* School Age Unit (LDs, ADHDs)

* Communication Disorders Group (Hearing Impairments)

Adolescent Unit (LDs, with Comorbidities)

Developmental and Family Services Unit (HIV-Affected)

Adult Literacy Program (LDs, Dyslexia)

* Denotes major units for GC Students

Special Units or Clinics

- Special Care Dentistry
- Early Childhood Center
- Nutritional Counseling
- Psychoeducational Services
- ENT, EYE, Orthopedic,
Neurology & Genetic
Consultation

CERC

- Serves about 7,500 clients/patients each year.
- 90% children and adolescents, 10% Adults
- Serves the entire range of DDs
- Over 80% from minority groups.

Other Components of Training

Faculty Offer – 2 courses at SLC

- 1) Pediatric Genetic Syndromes
- 2) Reproductive Genetics

Supplemental Lectures from UCEDD
staff on DDs and Health Policy Issues

Results Thus Far

1st and 2nd year – total of 5 full LEND Fellows

About 10 others each year in AECOM/MMC

Clinical placements

61 students in the courses and seminars.

Other LEND trainees exposure to GC Trainee
and vice versa

Research

Involvement in a major projects about the Genetics of Hearing Impairment, a study of children before and after cochlear implants, and one of families with autism.

Comparison to Original Plans

Provided LT Training to 5 GC Trainees
(Goal = 6)

Provide Intermediate Training to 20 Trainees
– No numerical goal initially.

Expose all S.L.C. students to DD issues – all exposed.

Exposed most other UCEDD ID Trainees to
GC Trainees – Accomplished

All LT GC trainees had ID team exposures

All LT GC trainees involved in a Research
project.

Collaborative Efforts are working well.

Resources Developed

1. Increased availability of GC services at our Center.
2. Expanded emphasis on diagnosis and managing genetic disorders.

Diversity

Not easily achieved, since the SLC program has few students from minority groups, one student with hearing impairment –
Accommodations arranged.

Stipend may not be enough to attract the few eligible minority students (competing priorities).

Return on Investment

Certainly added a new ID training activity. Have modified program based on feedback to improve the training for GC students (more hands-on activities, more diverse team experiences).

All 3 of last year's graduates are working in the field; one is at a UCEDD/LEND program in Nebraska.

Now collaborating with another UCEDD GC training program in our region.

Lessons Learned

Needed to provide more structure, more hands on activity – not just observation.

Start recruitment of trainees earlier by plugging the program to 1st year SLC students.

Recommendations for the Future

Incorporate in the future as a permanent part of LEND Activities with increased funding part of the Core Grant.

Follow up to see how trainees are using their experience.

Wisconsin LEND Genetics

Casey Reiser

Training Coordinator, LEND Genetics

Anne Heintzeman

Discipline Training Coordinator, LEND

Dan Bier

Associate Director, UCEDD

Goal 1

- To increase the number of genetic counselors who are prepared to demonstrate leadership in serving individuals with neurodevelopmental disabilities and their families and in affecting relevant public health policy

Goal 2

- To increase the awareness, knowledge and skills regarding genetics and genetic counseling among LEND trainees from non-genetic disciplines.

Goal 3

- To develop and implement strategies for recruiting genetic counseling students from diverse ethnic, racial and cultural backgrounds.

How are the dollars used?

- Direct Trainee Expenses: \$27,000
 - LEND Genetics Trainee Stipends
 - Project Assistant – 2nd year LEND GN trainee
 - Tuition remission and travel expenses
- Personnel: \$18,797
 - LEND Genetics Discipline Training Coordinator (25% + fringe)
- Indirect Costs: \$1,503
 - (8% on non-trainee expenses)

Accomplishments

- Enhanced genetics content within MCH LEND curriculum
- Leadership and Policy content of MCH LEND a component of LEND Genetics

Resources Developed and Used

- Use of Learn@UW for on-line Genetics case discussions

Diversity Goal

- University Office of Diversity contacts
 - Assistant Dean of Diversity Resources
 - Office of Academic Diversity and Development
 - UW System student groups
- On-going efforts at the national level
- Expect to see benefits from these efforts in the future

Return on Investment

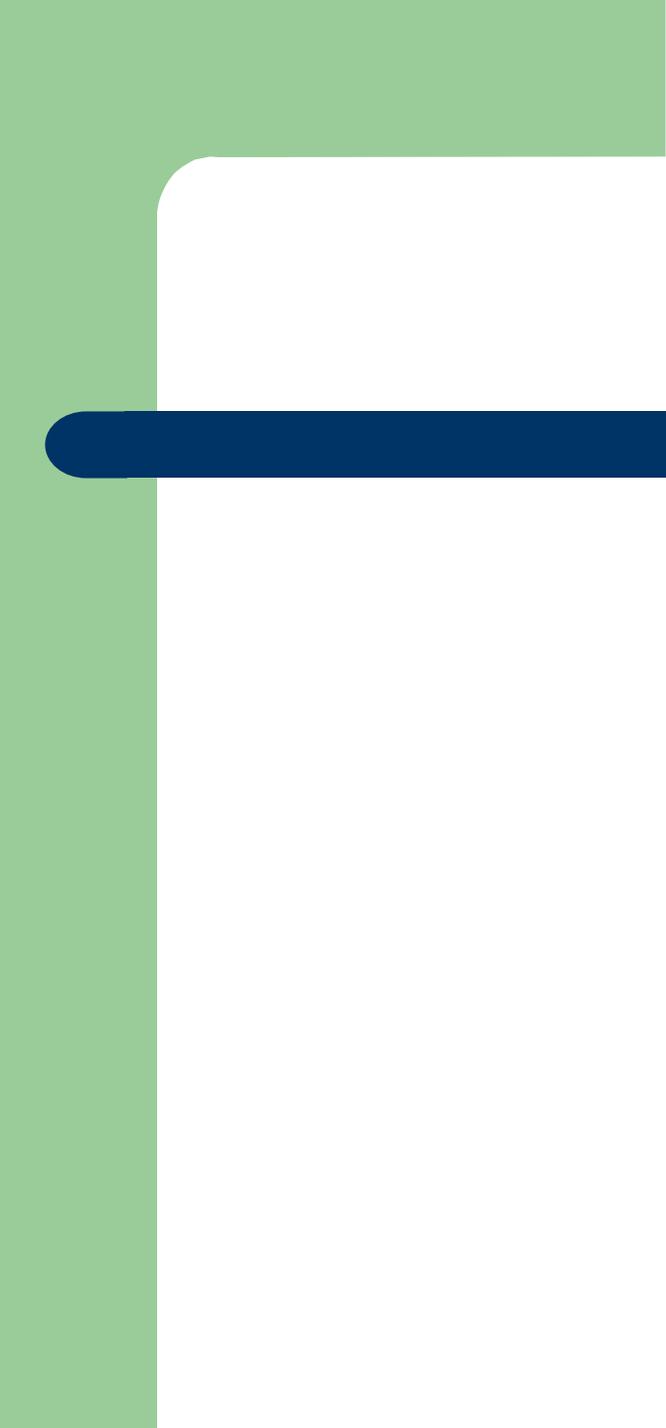
- NCHPEG Competencies part of overall LEND curriculum
- LEND Genetics trainee travel scholarship an outgrowth of LEND Leadership project
- Reported higher performance on national board exam for SLP LEND trainee
- Genetic Counseling trainees perceive themselves as part of the ID Team, and LEND trainees and faculty view genetics as an integral member of the ID Team
- Influence of Genetics curriculum on the research activities of Psychology LEND trainee extending into the trainees dissertation

Lessons Learned

- Fully integrate LEND GC trainees into WI LEND Curriculum
- New content can be integrated without overwhelming trainees/faculty
- GC trainees must be part of the ID Clinical experiences that all LEND trainees participate in
- Enhanced potential for genetics influence on future research of non-genetics disciplines

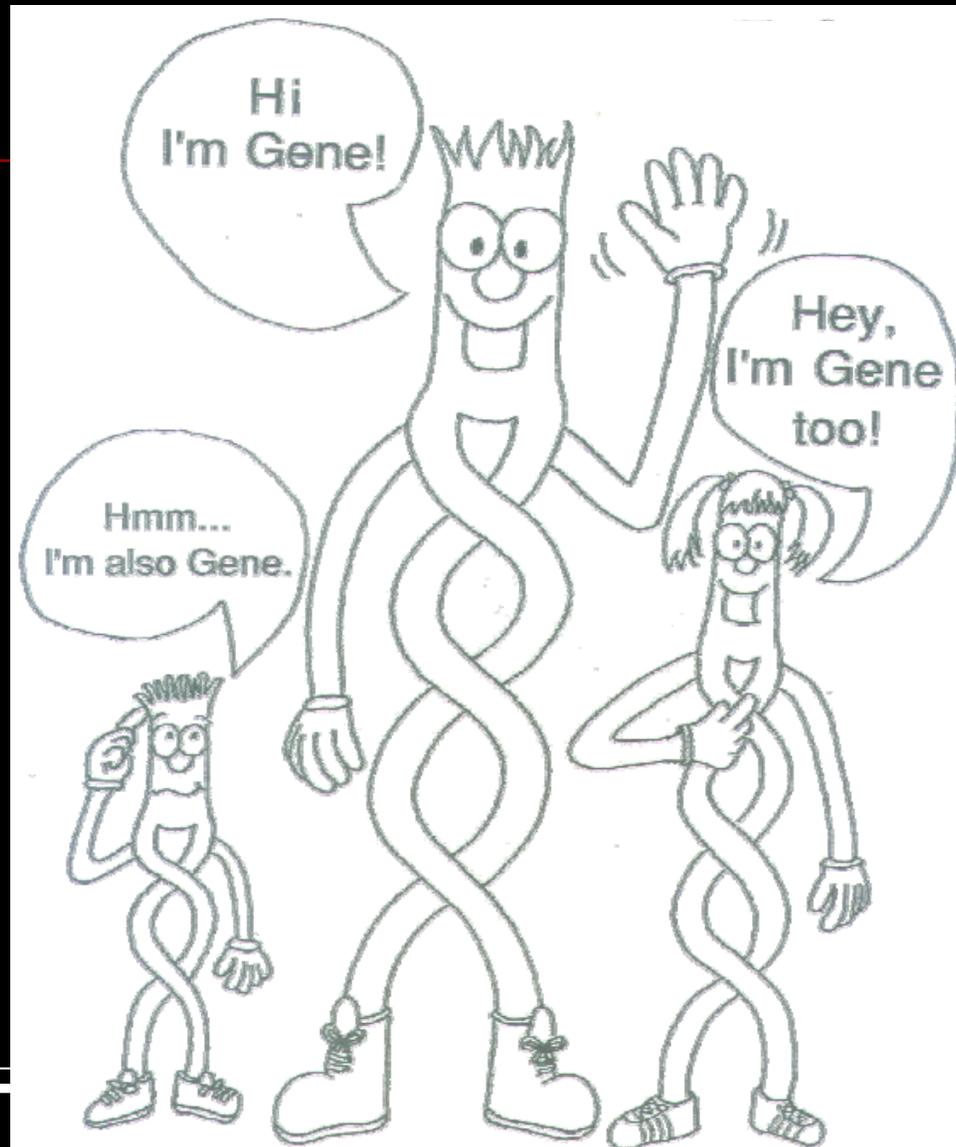
Future Recommendations

- Continued commitment to LEND Genetics
 - Maintain and Expand
- Make trainee stipend money available
- Support for Faculty Discipline Training Coordinator important





The Gene Team



SYNERGY

Our DNA goes back to the Ice Age.
What are we doing with it now and in the days to come?

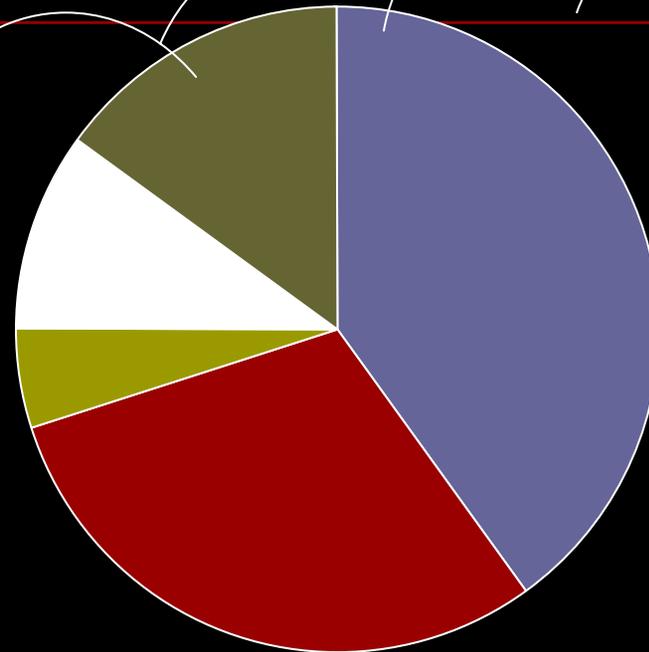
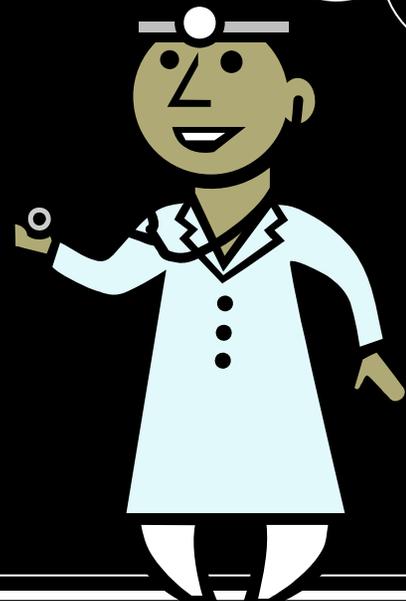


Joann Bodurtha MD MPH
VaLEND, Virginia Commonwealth University

A few genetic messages

- Take folic acid to prevent NTDs
- Insure NBS to promote early intervention
- Know your family history, it could save your life
- Health and illness both influenced by interplay of genes, environment, and nurture
- Practitioners, and definitely leaders, need to be genetically aware and literate
- Sorry, it is complicated

Genetics is >30% of Health!



- Behavior
- Genetics
- Environment
- Healthcare
- Social Circumstances

The Platinum Rule

- Do unto others as you would have them do unto you, but remember they might make different choices
- Recognize the new Paternalism in excluding genetic considerations
 - hype, exhaustion cycles
 - mankind doesn't rotate around DNA but it is a part of reality (Galileo, Darwin, OJ ...)
 - skeletons in closet, learning new ways

SYNERGY

- Integrate genetics into LEND training
- Train genetic counseling students in interdisciplinary leadership excellence
- Increase genetic awareness – checklist and modules
- Enhance diversity – Multicultural Advisory Committee and HBCU internships

What has been accomplished thus far from original plan?

- Genetic awareness checklist distributed to all LEND programs
- All VaLEND students have some genetics training
- 1st (Genetic awareness) module awaiting IRB approval for evaluation, 2 others (Fam hx and NBS) in development
- All GC students take LEND leadership seminar
- 2-3 GC students/yr enrolled as long-term trainees
- NSGC Disabilities SIG established
- Multicultural Advisory Committee functioning effectively
- 2 HBCU interns complete summer internship
- Synergy presented at AMCHP, AUCD, NCHPEG

Meghan Strenk presents poster & learning module at AUCD meeting October 2006



What resources have you developed and used?

- Genetic awareness checklist
- HBCU summer internship plan/implementation with recruitment strategies
- Prior/ongoing – autism clinic genetic screening tool, family history tool with VDH, MOD funding for state genetics education plan

How have you addressed your trainee diversity goal?

- Partnered in LEND recruitment with HBCU
- Given talks at HBCU
- Partnered with other diversity Life Sciences and summer initiatives at VCU to introduce all LEND disciplines
- Drafted organizational cultural competency plan

What has been the return on investment?

- Cost analysis – How do the costs compare?
- Cost- minimization analysis – Which costs less to get the same results?
- Cost-effectiveness analysis – Which costs less per unit of outcome?
- Cost-utility analysis? - Which do people prefer?
- Cost-benefit analysis? – Which will save the most money?
- In commercial sector - the income that an investment provides in a year.

- (Schwalberg, Gavin, Scarato 1998
<http://www.mchb.hrsa.gov/assets/applets/econ-mch1.pdf>)

What has been the return on investment?

- One HBCU intern presented at national meeting, both are ongoing advocates at their schools
- 5 GC students considering pediatric GC careers
- GC students connect with HBCU
- GC faculty \$ support important to PhD chair, school leadership
- Module cost estimated 1/10 of doing commercially

Teleace Gary presents at Annual Biomedical Research Conference for Minority Students, November 2006



What lessons have you learned along the way?

- When glass half empty –
 - No dollars, no diversity
 - No extramural NIH training funding available, no diversity
 - No outside dollars/overhead available, no institutional support
 - No insurance, no genetic testing accessible

When glass half full -

- “Effective leadership unfolds from the common good.” DePaola
- “There is nothing more difficult to take in hand, more perilous to conduct, or uncertain in its success, than to take the lead in the introduction of a new order of things.” Machiavelli

What would you recommend for the future?

- Genetic awareness checklist (antennae?, computerized decision support tools?, Genability concept like readability indices?, family history by Hallmark?, soap operas? Science and children's museum partnerships? etc.)
- Balance in autism funding portfolio to include genetic counseling/LEND training (N.B. >10% of 53 current clinical trials explicitly include genetics/specific syndromes, >80% involve pharmacogenomics)
- Consideration of extramural training grants through NHGRI
- Partnerships across all training programs, performance measure?
- GC research network
- Genetic Information Service, like CIS
- Lifespan partnering on projects (e.g. fragile X and adult tremor/ataxia)

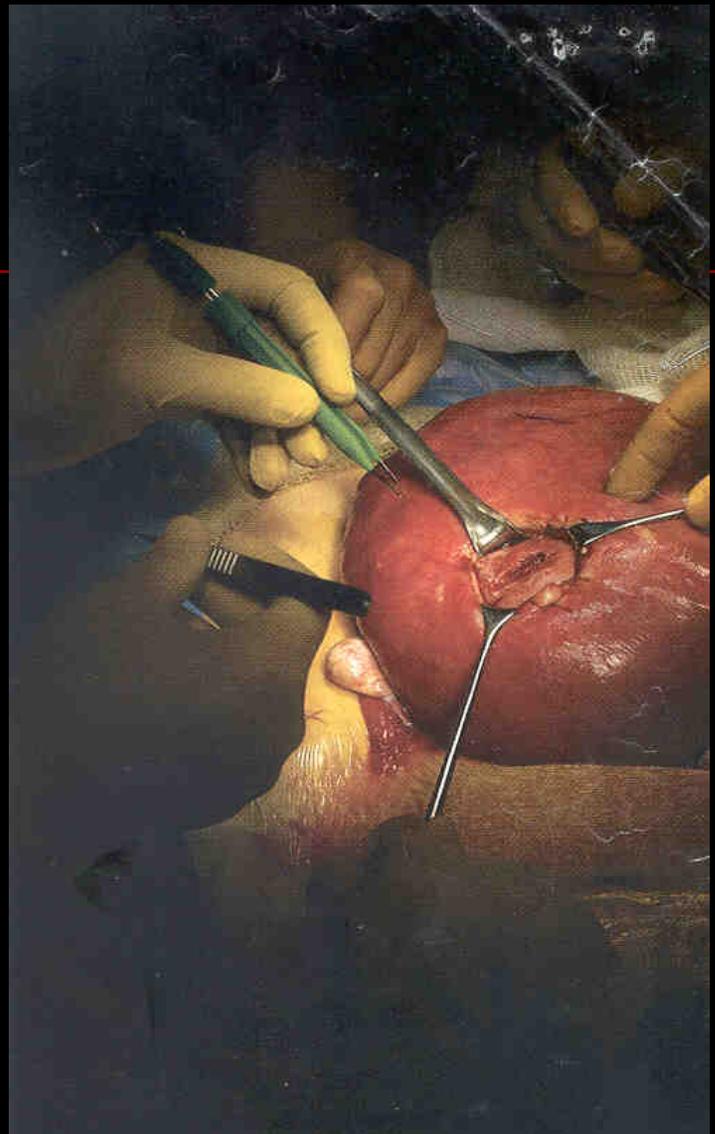
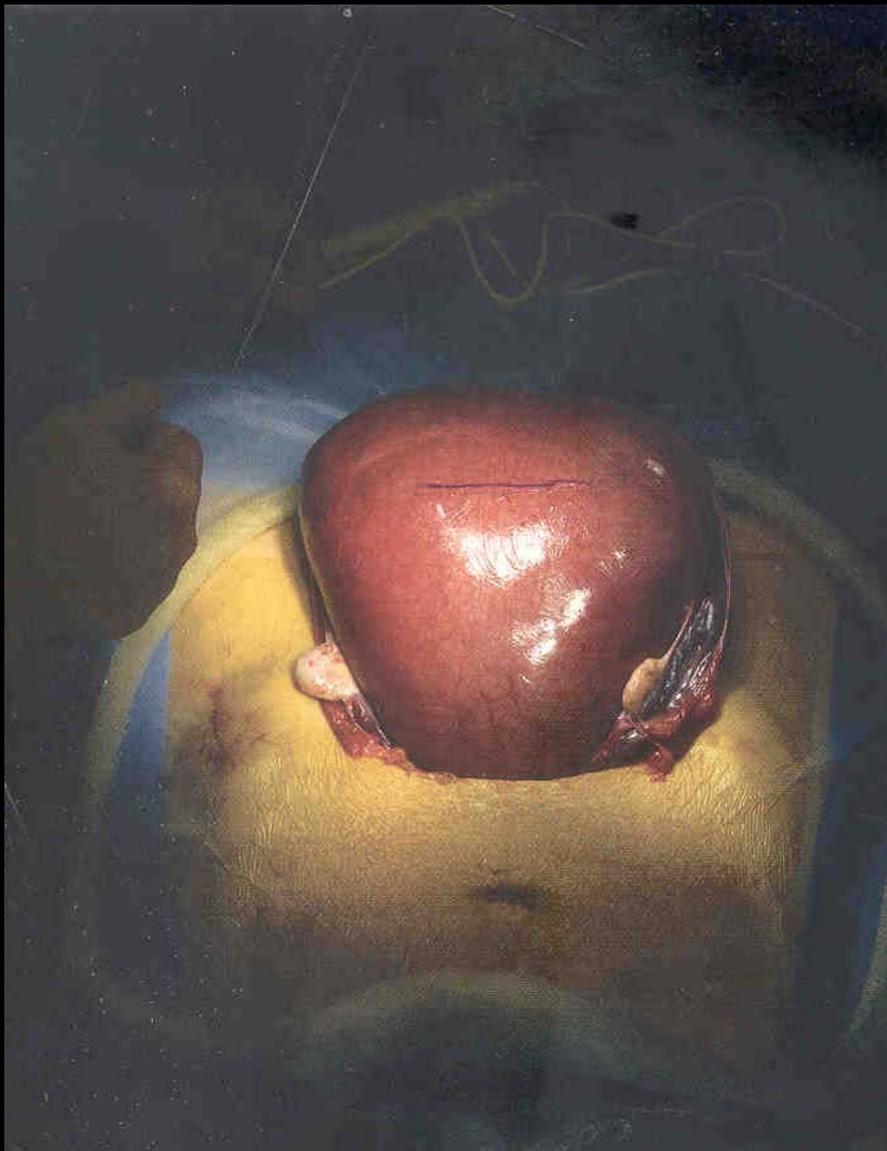


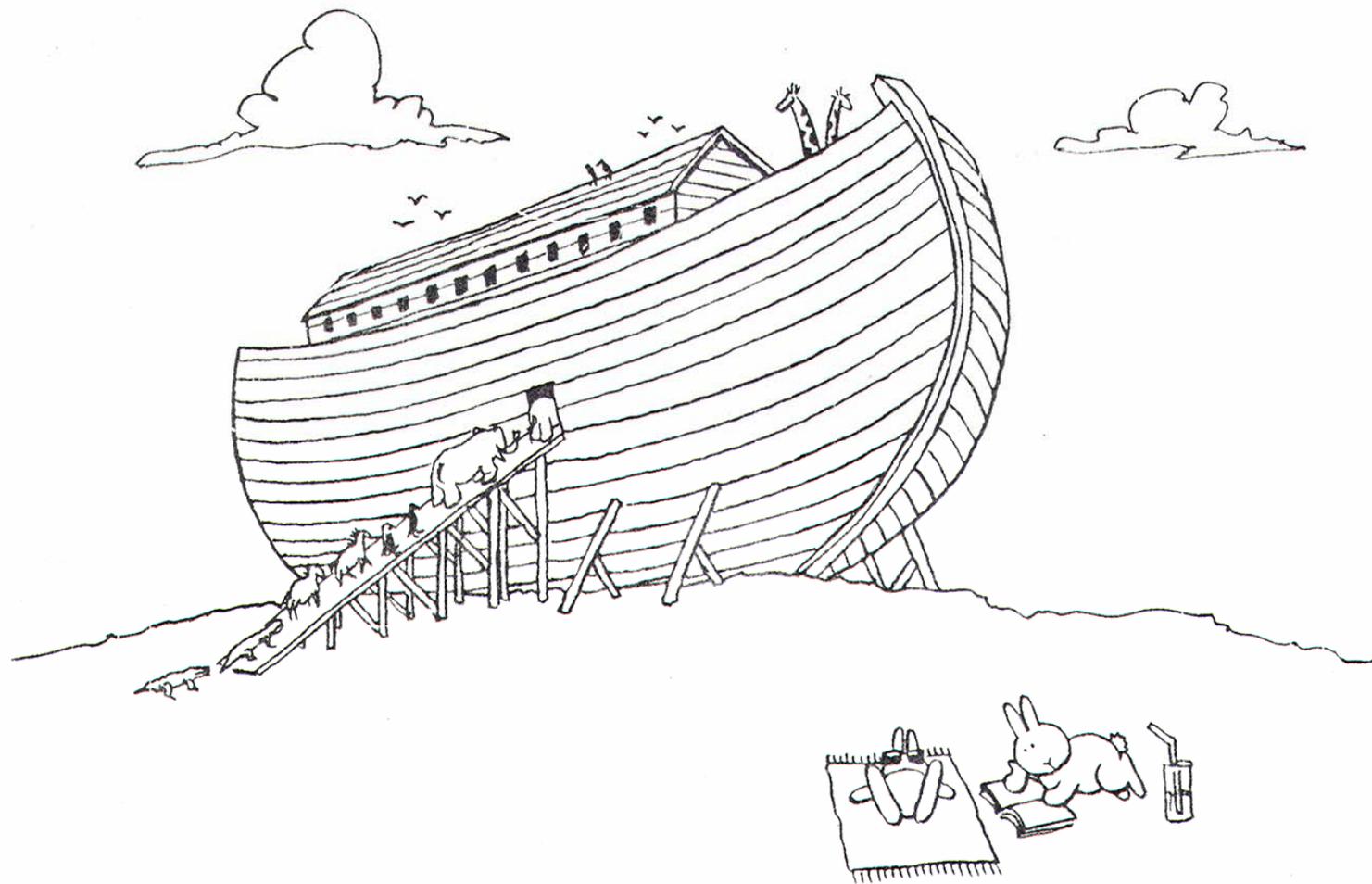
◀ **Bubble Blower**

Turn yard work into yard fun! Blow bubbles... or use as a kid-size leaf blower. Bubble solution included. Ages 3-up. 139058

Fisher-Price

14⁹⁹





DRAFT 12/2006
Virginia LEND/SYNERGY
Cultural Competence Plan

Value Statement/Philosophy

The faculty and staff of Va-LEND and SYNERGY are committed to training health care professionals and related disciplines who demonstrate cultural competence and have the tools to work within communities to address health disparities. We believe that cultural competence is an integral component of family centered care. We demonstrate our belief in the value of diversity by:

- Preparing trainees to work in culturally and linguistically diverse settings;
- Accommodating students with special learning needs;
- Promoting a diverse student and faculty community;
- Supporting intellectual curiosity;
- Modeling and promoting social justice and equal access to service delivery;
- Promoting activities to address health care disparities

(adapted from VCU School of Education Values Statement (1/2005))

Definition of Diversity

Our diversity goals and objectives address the need to increase faculty and trainees from underrepresented groups within our training program and within the workforce of health care, special education and related disciplines. Within Va-LEND and SYNERGY underrepresented groups include groups based on race, ethnicity, gender, and disability status.

Recruitment and Retention

Va-LEND has an objective to increase the percentage of long-term leadership trainees/fellows from typically under-represented groups from 16% to a minimum of 20% on average by 2009.

One of the stated purposes of the SYNERGY grant is to prepare a diverse workforce of genetic counselors capable of teaming with other health care professionals to provide leadership in serving children with special health care needs and disabilities.

Our recruitment plan includes the following strategies:

- Establishing a Multicultural Advisory Committee to provide guidance.
- Collaborating with Historically Black Universities, Virginia State University and Virginia Union University to recruit undergraduate students for an 8-week summer internship program in genetic counseling and disabilities (SYNERGY)
- Conducting a faculty retreat on minority recruitment and diversity workforce issues (6/2006)
- Providing guest lectures at Historically Black Colleges and Universities (Norfolk State University, Virginia State University, Virginia Union University)
- Developing recruitment materials for parents/family members of children with disabilities to apply to our program
- Providing outreach to teachers, therapists and administrators within Richmond Public Schools for collaboration and for recruitment of trainees/fellows

Training Competencies for Cultural Competence and Family Centered Care

Cultural competence is an integral component of family centered care. We have developed a curriculum with didactic and practicum experiences to address this competency.

The following list describes the outcomes for LEND trainees fulfilling this competency:

- Demonstrates respect for values & preferences
- Demonstrates awareness of own cultural attitudes, values, & beliefs
- Demonstrates value of diversity
- Establishes effective interpersonal relationships with child & family
- Supports family as they access services

- Includes family in team meetings
- Supports family choices & shows respect for culturally different approaches
- Provides technical assistance to ensure success.
- Identifies cultural differences/similarities in communication styles, child-rearing practices, & attitude toward children with disabilities
- Exercises leadership, reflecting on cultural diversity
- Adopts evaluation approaches to needs

Educational Activities in the LEND Curriculum:

The following learning activities are provided through Va-LEND to teach/experience the values of cultural competence and family centered care:

Teamwork Course:

- ◆ Participate in discussion with parent panel
- ◆ Apply knowledge to case studies with diverse cultural issues

Leadership Seminar:

- ◆ Learn strategies that empower families
- ◆ Discuss family centered care with family faculty and guest speakers
- ◆ Examine personal/professional practices
- ◆ Complete cultural competence check list
- ◆ Complete cultural & clinical encounters exercises
- ◆ Discuss leadership issues related to health disparities

Childhood Neurodevelopmental Disabilities Course:

- ◆ Discuss medical home principles
- ◆ Apply person-first language & practices
- ◆ Apply knowledge to case studies with diverse cultural issues

Research:

- ◆ Examine/discuss national CSHCN data for family satisfaction & access to care
- ◆ Discuss issues related to health disparities

Family Mentorship:

- ◆ Experience family views & practices
- ◆ Writes family mentorship journal

Clinical & Community-based Practicum:

- ◆ Experience a variety of families & backgrounds in clinical rotations
- ◆ Identify family strengths & concerns in assessments and reports
- ◆ Apply skills to clinical situations

Monitoring and Evaluation

Monitoring and oversight for minority recruitment and cultural competence training is provided by the management team, the faculty, and the Multicultural Advisory Committee. The goals and objectives of the Va-LEND and SYNERGY grants are evaluated annually and discussed in the annual progress reports submitted to the MCHB and the Association of University Centers on Disabilities, respectively.

As a Maternal and Child Health Training Program, Va-LEND is responsible for attending to MCHB Training Performance Measures. Performance Measure 9 addresses trainee diversity. For this measure, data is collected on the percentage of long-term LEND trainees who are from underrepresented groups. MCHB Performance Measure 11 addresses cultural competency training. Annually programs report on the degree to which cultural competency is included in the LEND training curricula.

DRAFT 12/2006

Is a Career Helping Children with Genetic Conditions for You?

Summer Internship in Genetics and Disabilities

at Virginia Commonwealth University in Collaboration with Virginia State University and Virginia Union University



DATES: Summer, 8 weeks: May 21 - July 13, 2007

Would you like to learn about

- + Genetic counseling?
- + Helping children with developmental disabilities?
- + Careers on a health care team?

If so, the Summer Internship in Genetics and Disabilities may be just for you. During the internship you will:

- + Gain hands-on experience in helping people with genetic conditions and developmental disabilities by working with medical professionals
- + Become part of the health care team in weekly genetics and other health care clinics (for example, Autism, Hemophilia, Dental, etc.)
- + Develop leadership skills
- + Work with your own graduate student mentor
- + Attend and take part in discussion forums
- + Learn to take a multicultural family history
- + Keep a journal related to your experiences
- + Develop and give a presentation on a specific project at the end of your internship
- + Receive guidance on admissions processes for health career programs
- + Join other students and interns in the Health Careers Opportunities Program
- + Attend special workshops on study skills, test taking, time management, & medical terminology

THIS INTERNSHIP WITH ALSO GIVE YOU MANY BENEFITS:

- + You will receive career training in genetic counseling and developmental disabilities from national experts in the field.
- + You will become a student leader in genetics and developmental disabilities, and may be asked to work with the LEND team to get other students interested in the program and in health care careers.
- + You will be paid a stipend of \$2500.
- + You will be better prepared to apply to health care training programs, and to work with many types of health professionals in the future.

YOU ARE ELIGIBLE FOR THE SUMMER INTERNSHIP IF:

- + You are currently a student who is enrolled in Virginia State University or Virginia Union University as a freshman, sophomore, or junior;
- + You are excited about pursuing a career in genetic counseling or helping children with disabilities;
- + You are in good academic standing; and,
- + You are recommended by a college or university advisor who knows you well.

Contacts:

- VSU:** Regina Knight-Mason, Ph.D. (524-6867, or RKnight@vsu.edu)
VUU: Anthony Madu, Ph.D. (257-5614, or AMadu@vuu.edu)
VCU: Joann Bodurtha, MD, MPH (828-9632, ext 112, or Bodurtha@vcu.edu)
Lauren Vanner-Nicely, MS, CGC (828-9632, ext. 135, lvanner@vcu.edu)
Janet Willis, MPH, RD (828-0073, jwillis@vcu.edu)

Key Elements of Genetic Awareness – Checklist to Facilitate the Development of Genetically Aware Policies, Practices, and Research

A genetically aware service setting, educational activity, or research plan recognizes the contribution of genetic factors to health and disease, and their interaction with environmental factors. A genetically aware professional demonstrates basic knowledge of the role genomics plays in the development of diseases, identifies his/her own genomic expertise, and makes appropriate referrals to those with more expertise (CDC competencies, NCHPEG competencies for health professionals). Genetically aware health care builds upon the medical home concept and integrates the concepts of family-centered, culturally and linguistically competent care. These indicators dovetail with the consumer indicators of quality genetic services developed by the Genetic Alliance.

SCORE: ALWAYS (A) , SOMETIMES (S), NEVER (N)

YOUR SCORE	CHECKLIST ITEMS
	Recognizes that genetic information is part of all health information
	Collaborates with families and communities in addressing genetic awareness
	Encourages families to discuss and document family health history with consideration of confidentiality and the psychosocial impact at all life stages
	Shares unbiased and complete information geared to the consumers' needs and culture with families on an ongoing basis
	Links families to consumer-oriented resources, community-based supports, and genetic research information
	Recognizes and honors the contribution of genetic factors to diversity
	Incorporates current genetic information in educational initiatives
	Establishes a mechanism of referral for more in-depth genetic counseling and consultation
	Recognizes the potential impact of differing genetic susceptibilities on research design, outcomes, and guideline development
	Works to address issues of ethical, legal, and social concern, including privacy, access, cost, fairness, and discrimination

AUCD-MCHB LEND Genetics Grant Progress Reports

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

Contents:

SUMMARY	2
Grantee: Rose F. Kennedy Center.....	3
Grantee: Partnership for People with Disabilities.....	4
Grantee: Waisman Center	7



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."

~~~

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

|                                                                                            |
|--------------------------------------------------------------------------------------------|
| <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

|                                                                                |
|--------------------------------------------------------------------------------|
| <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

|                                                             |
|-------------------------------------------------------------|
| <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.

# **APPENDIX C**

## **Reports from Other LEND Programs**

University of Southern California, CA

University of Washington, WA

Monroe-Meyer Institute, NE

Westchester Institute for Human Development, NY

Riley Child Development Center, IN

Cincinnati Center for Developmental Disabilities, OH

**Genetic Counseling in the USC LEND Program  
Collaboration with the Genetic Counseling Program at California State University  
Northridge (CSUN)**

**Status as of December, 2006**

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

- **Historic:**
  - Month-long USC LEND module on Genetic Disorders (March)
    - Content
      - Overview of genetic disorders
      - Case-study of a child with a genetic disorder in the month-long scenario-based learning module
      - Policy issues: newborn screening; role of genetics counseling; legislative issues (Policy Group)
      - Systems issues: Genetically Handicapped Person's Program: CA Childrens Medical Services
    - Presentors
      - Linda Randolph, MD, Director, Medical Genetics Program, CHLA
      - Catherine Mosely, MS, RD, Metabolic Nutritionist, Medical Genetics Program, CHLA
      - Genetic counselors, MGP
      - Fiona Field, MS, CGC, CSUN Genetic Counseling Program
  - Participation (rotation) of genetic counseling students from California State University, Northridge (CSUN) in Medical Genetics Clinics at CHLA
  - Participation of USC LEND nutrition trainees in CHLA Medical Genetics Clinics
- **New in 2006-2007 – (result of proposal development):**
  - Participation as a long-term LEND fellow (2006-08) of Fiona Field, MS, CGC, Associate Director, CSUN Genetic Counseling Program.
  - Addition of genetic profiling to the scenario-based learning module on genetic disorders
  - Recruitment to the USC LEND Advisory Board of Aida Metzenberg, PhD, CGC, Director of the Genetic Counseling Program and Professor of Biology at CSUN .
- **Future:**
  - Fiona Field, Associate Director of the CSUN Genetic Counseling Program will become a part-time USC LEND faculty member.
  - CSUN genetic counseling students included as LEND trainees, beginning in 2007. Attempt to increase the numbers of those

students representing ethnic minorities using LEND stipend support.

- Potential recruitment of Kim Cobb Powell, PhD, RD (former USC nutrition intern, USC LEND trainee, and UNC SPH doctoral trainee; current AUCD fellow at CDC CBDDD) as a faculty member to bridge the USC LEND Program (Nutrition faculty) and the CHLA Medical Genetics Clinics (PKU/Metabolic Clinic Director). This would enhance our potential for both clinical training and research in genetics.
- Potential for LEND trainees in other disciplines to participate in Medical Genetics clinics (Pediatric; Prenatal Diagnosis Center)
- Ms. Field sits on the Board of the National Society of Genetic Counselors representing Region VI (West), and, as such could help promote awareness of LENDs and the existence of the new SIG on developmental disabilities.

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

No supplementary funding, so far. We offered Ms. Field a LEND stipend, but this year her time as a fellow is being contributed by the Genetic Counseling Program at CSUN. We plan to use our current resources to provide part-time faculty support for her and stipend support for genetic counseling trainees next year if our joint recruitment is successful.

## **3. What relationships were developed or expanded?**

Fiona Field, our current fellow, has been “thrilled” with her training and has utilized the information she has gained to help train her graduate students in genetic counseling on the many aspects surrounding developmental disabilities. Because of her LEND participation, she is better able to clearly define and explain resources that are available to families of children with special needs - both here in California and on a national level. She is also much more equipped to explain and address policy issues with regard to helping these families, and to point her students in the correct direction for resources.

Lastly, inspired by her USC LEND training thus far, Ms. Field has created a working relationship with the “Family Focus” Resource Center at CSUN to have her graduate students work with individuals and families with special needs throughout their training at CSUN.

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

- The importance of genetics/genomics as a wave of the future and the need to make training in genetics a priority – for all LEND programs
- The need for genetic counselors to be trained in the area of special health care needs/developmental disabilities in order to better serve their clients
- The need for genetic counselors is increasing as the number of screening tests available for various genetic conditions is increasing

- The importance of increasing the numbers of representatives of ethnic minorities trained to provide culturally-competent genetic counseling to currently underserved groups

**SUMMARY OF PROPOSAL, 2005**

|                                                                                                                                                   | <b>Person(s) responsible</b>                 | <b>Process Evaluation</b>                                                                                                                                                                                                                                                                              | <b>Outcome Evaluation</b>                                                                                                                                                                                                                                      |
|---------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Objective 1:</b> To train at least 4 CSUN students/year, for a total of 8 or more.                                                             | Field, Baer                                  | <ul style="list-style-type: none"> <li>• Year 1: two each 1<sup>st</sup> and 2<sup>nd</sup> year students are identified</li> <li>• Years 2&amp;3: two 1<sup>st</sup> yr students identified</li> <li>• Trainee supervision occurs monthly</li> </ul>                                                  | <ul style="list-style-type: none"> <li>• Tuition is paid for 4 students per year</li> <li>• Trainee stipends are paid for 2 students/year to complete LEND</li> <li>• Trainees completing LEND demonstrate competencies, receiving LEND certificate</li> </ul> |
| <b>Objective 2:</b> To recruit genetics counseling trainees from diverse backgrounds, including Spanish-speaking students, by Fall 2005.          | Field, Metzenberg, Harris                    | <ul style="list-style-type: none"> <li>• Year 1 - minority recruitment efforts are developed and implemented</li> <li>• Years 1-3: program is promoted to minority students</li> </ul>                                                                                                                 | <ul style="list-style-type: none"> <li>• At least ½ of the students receiving tuition and stipend support speak Spanish</li> <li>• trainees represent ethno-cultural populations served in Los Angeles</li> </ul>                                              |
| <b>Objective 3:</b> To enhance the current LEND program by incorporating content related to genetic counseling into the curriculum by Fall, 2005. | Field, Powers, Pierson, Randolph             | <ul style="list-style-type: none"> <li>• Years 1-3: LEND genetic counseling faculty participates in all LEND activities</li> <li>• Trainees from different disciplines visit the genetics clinics at CHLA</li> <li>• LEND core curriculum includes additional content on genetic counseling</li> </ul> | <ul style="list-style-type: none"> <li>• LEND faculty present training model at AUCD meeting</li> <li>• LEND trainees demonstrate knowledge and application of the field of genetic counseling</li> </ul>                                                      |
| <b>Objective 4:</b> To create a genetics counseling module as an adjunct to the LEND curriculum over the 3 years of the grant period.             | Field, Powers, Pierson, Metzenberg, trainees | <ul style="list-style-type: none"> <li>• Year 1: needs assessment is conducted re: content and format for learning module</li> <li>• Year 2: module development and piloting timelines are met</li> <li>• Year 3: learning module is refined and disseminated</li> </ul>                               | <ul style="list-style-type: none"> <li>• Needs assessment results are available end of Year 1</li> <li>• Module is piloted in Year 2 with 10 LEND trainees</li> <li>• Module is available through CSUN and UCEDD websites</li> </ul>                           |

Aida Metzenberg, M.A., Ph.D., C.G.C.  
 Director, Genetic Counseling Program  
 Professor  
 Department of Biology  
 California State University, Northridge  
 18111 Nordhoff Street  
 Northridge, CA 91330-8303  
<http://www.csun.edu/~hcbio033/>  
 e-mail: aida.metzenberg@csun.edu  
 Voice: (818) 677-3355

Fiona M. Field, M.S., C.G.C.  
 Associate Director, Genetic Counseling

# Genetics in the LEND

Cristine M Trahms, MS, RD

Department of Pediatrics,

Center on Human Development  
and Disability

University of Washington, Seattle

# Genetics in the LEND:

## Our Strengths:

- The University of Washington has a strong and diverse genetics-training program in medicine
- The LEND has incorporated genetics training for all interdisciplinary trainees utilizing a variety of strategies.

# Genetics in the LEND: Our Strategies

## *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 interdisciplinary team, which guides this work, consists of geneticist, genetic counselor, and nutritionist.

# Genetics in the LEND: Our Strategies

## *A. Clinical training opportunities*

LEND nutrition trainees participate in the PKU/Biochemical Genetics clinic. They often choose some aspect of their work as a Leadership project, which often leads to the Master's thesis project.

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

# Genetics in the LEND: Our Strategies

## *B. Didactic Training*

All MCHB trainees- 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).

# Genetics in the LEND: Our Strategies

## *B. Didactic training*

The 3 quarter “Nutrition and Biochemical Genetics Seminar” is co-taught by a genetic counselor and the team nutritionists.

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

# Genetics in the LEND: Our Strategies

## *C. Other opportunities*

Trainees may chose to participate in the state-wide Genetics Providers Group

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>

# Genetics in the LEND: Funding/Resources to Support Activities

Collaborative efforts have led to the development of the clinical and didactic curricula.

Collaborators: LEND faculty, WA Office of Newborn Screening, Dept of Pediatrics.

Maximizing genetics training requires a focused discipline leader

# Genetics in the LEND: Relationships Developed

## Relationships:

Office of Newborn Screening

Pediatric Genetics Fellowship program  
Pediatric Residency program

Regional Genetics program

Pediatric Pulmonary Center

Maternal and Child Health program

Pediatric Dentistry Fellowship

Washington Genetics Providers Group

All supported clinical rotations and curricula  
development in a variety of ways.

# Genetics in the LEND: Lessons and Suggestions

Funding is needed if -

genetics concepts are to be incorporated into programs & be visible, viable, & meet the educational requirements of the health care providers.

Proposal: An interdisciplinary training curriculum 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.

# Genetics in the LEND: Lessons and Suggestions

- 1) 'genetics' is complicated; CGC expertise as integral LEND faculty is important;
- 2) genetics faculty could support families as they struggle with family-decisions;
- 3) issues related to follow-up of genetics screening require knowledge & skills, partnership, & knowledge of systems change;
- 4) increased precision in treatment of genetic conditions requires an interdisciplinary approach & long-term intervention approach

## 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.

## **Nebraska LEND Project**

### **ORGANIZATION AND ADMINISTRATION**

#### University of Nebraska System and Medical Center

The University of Nebraska is Nebraska's only public university. Founded in 1869, its land-grant heritage forms the foundation for the University's contributions to the educational, economic, and cultural fiber of Nebraska. It is one of only two major universities in the state and the only university which offers a comprehensive program of education, service, and research in all of the major academic and professional disciplines.

The Nebraska Medical Center is a comprehensive educational institution that is critical to the education of health care providers for the State of Nebraska and much of the surrounding region. Many of its programs (transplantation, genetics, and cancer) are nationally and internationally recognized. The UNMC is the only publicly tax-supported health sciences program in the state. UNMC has an enrollment of over 2,700 students and over 1,000 faculty members. It is composed of eight major units: The Colleges of Medicine, Dentistry, Nursing, Pharmacy and Graduate Studies; the School of Allied Health Professions; The Eugene C. Eppley Institute for Research in Cancer and Allied Diseases; and the Munroe-Meyer Institute for Genetics and Rehabilitation. [Appendix 2A]

#### Munroe-Meyer Institute

The Munroe-Meyer Institute (MMI) for Genetics and Rehabilitation is one of 35 Leadership Education in Neurodevelopmental Disabilities (LEND) programs funded by the Maternal and Child Health Bureau for over 25 years to provide comprehensive interdisciplinary leadership training. MMI is also one of 61 University Centers of Excellence in Developmental Disabilities Education, Research and Service (UCEDD) funded by the Administration on Developmental Disabilities for administrative support of its effort to meet the needs of persons with disabilities. MMI is an interdisciplinary program with specialists in eighteen health and rehabilitation related fields (nursing, nutrition, psychology, public health, social work, developmental pediatrics, clinical genetics, molecular genetics, endocrinology/diabetes, dentistry, physical therapy, occupational therapy, education and child development, speech-language pathology, audiology, recreation therapy, health policy, orthotics and prosthetics (Brace Place) and health administration).

The mission of Munroe-Meyer Institute is to improve the quality of life for persons with disabilities and for their families. The Institute's extensive services, interdisciplinary education, research, technical assistance, and outreach programs have evolved with the support and guidance of consumers with the aim of promoting independence, full inclusion, and productivity of persons with disabilities to empower those individuals to exert greater control over their everyday lives. The Institute provides interdisciplinary, family-centered services and supports for individuals with disabilities. These services include the development of new and innovative ways to promote inclusion of the

individual in the community.

The Institute educates individuals and practitioners through interdisciplinary educational experiences conducted at the University of Nebraska Medical Center (UNMC), in the community, and through outreach training and on-site technical assistance in rural communities across Nebraska and the Upper Midwest. Education of students and practicing professionals is of utmost importance to the mission of MMI so that these individuals can use their skills to meet the needs of rural and urban consumers and their families.

MMI is a multifaceted organization with the two major areas of emphasis: genetics and rehabilitation. Pertinent to this grant are two major MMI programs - the Nebraska LEND Project and the Hattie B. Munroe Center for Human Genetics.

**The Nebraska LEND Project : Interdisciplinary Leadership Training Program**  
The Interdisciplinary Leadership Training Program (ILTP) is currently under the co-direction of Cynthia R. Ellis, M.D., who is an Associate Professor of Pediatrics and Psychiatry and Director of MMI's Department of Developmental Medicine and G. Bradley Schaefer, M.D., who is a Professor of Pediatrics and Director of MMI's Department of Genetic Medicine. The program is completely integrated into the total teaching program of the Institute. Both Dr. Ellis and Dr. Schaefer have extensive clinical, research, and educational experience with children with neurodevelopmental disabilities, serve as the Director of a primary discipline, and are members of the Institute's core coordinator's group. As Project Directors, they assure that all programmatic aspects of the ILTP are fully integrated into the activities of MMI. In addition, each of the relevant health discipline directors for the Institute is responsible for carrying out their portions of the Project's training objectives. In the MMI administrative structure, each discipline director is responsible for all services and training within that respective discipline. This ensures integration of the teaching and service components which is essential for training based on supervised practicum experience. Overall coordination of Institute activities is provided by the Deputy Director, J. Michael Leibowitz, Ph.D., with the support of core coordinators, the LEND Directors and the MMI Family/Consumer Coordinator. Interdisciplinary Research activities are coordinated by Wayne Stuber, Ph.D., Clinical Services by Ms. Marsha Sullivan, Education by Ms. Pat Gromak, and Technical Assistance/Outreach by Joe Evans, Ph.D.

#### The Hattie B. Munroe Center for Human Genetics

The Hattie B. Munroe Center for Human Genetics is a comprehensive, full service clinical genetics program. The Center for Human Genetics (CHG) is coordinated by Dr. Bruce Buehler (director) and Dr. Brad Schaefer (associate director). Administratively the center is organized into three sections:

Clinical Genetics (section chief - Dr. Brad Schaefer). This section provides direct medical care and counseling services for patients with congenital anomalies (birth defects), genetic disorders, and related disabilities. The staff of the Clinical Genetics

sections represents one of the largest, most comprehensive providers of clinical genetics care in the country. They currently staff over 30 multidisciplinary clinics throughout the state of Nebraska and South Dakota. Many of these clinics are the only such clinic of their kind in a 10 state region or in the nation. Many of these clinics have an international referral base. The staff also provides a tremendous amount of statewide continuing education for medical personnel and lay persons throughout the state.

Cytogenetics (section chief Dr. Warren Sanger) The Hattie B. Munroe Center, Human Genetics Laboratories provides cytogenetic and molecular cytogenetic diagnostic services for physicians and residents from within the Nebraska as well as from surrounding states. These diagnostic services include diagnosis for prenatal abnormalities, birth defects, and cancer diagnosis as well as disease monitoring. The laboratory and staff provide services from physicians and hospitals in Nebraska and adjacent states. In addition to the service activities of this laboratory, the staff provides education for medical students, nurses, graduate students, and post-doctoral students. This laboratory is also involved in various collaborative research projects with other departments and other institutions

Molecular Genetics (section chief, Dr. Shelley Smith) The Hattie B. Munroe Center for Human Molecular Genetics conducts extensive research into the origin of multiple human genetic conditions. The faculty and staff have particularly strong expertise in neurosensory disorders, neurogenetic disorders, developmental biology and metabolic abnormalities

#### Mid- America Genetics Education Consortium

The Mid-America Genetic Education Consortium (MAGEC) is a recently funded four state (Nebraska, Oklahoma, Arkansas and Kansas) collaborative for training genetic counselors. This program is the answer to a persistent shortage of genetic counselors throughout the central region of the United States. The MAGEC masters program is not only innovative in the utilization of multi-institutional collaborations for a genetic counseling program, but it is also innovative due to its core use of distance education methodologies. Genetic counseling masters programs typically have two significant components which includes the coursework and the clinical experience. Traditionally, the coursework for genetic counseling programs have been implemented by using a conventional classroom setting. MAGEC will apply Distance Education methodologies to the coursework facet of the Masters in Genetic Counseling program.

The MAGEC genetic counseling program has many direct and indirect impacts. The current 27 American Board of Genetic Counseling accredited programs average approximately 150 graduates annually. The potential graduation of 16 students annually by MAGEC will increase the national number of genetic counseling graduates by more than 10%. From a more local perspective, each state has an increased likelihood of recruiting and retaining genetic counselors. This is due to several reasons. Not only do the previously stated explanations apply, but in addition, more individuals from the region would consider attending a program that is regionally available. These same individuals are also more likely to work somewhere within the MAGEC states,

contributing to the availability of regional genetics services.

Administratively, the MAGEC project is based out of the University of Arkansas with Ms. Becky Butler, an Arkansas Genetic Counselor, as the Principal Investigator. Salient to this grant proposal, Dr. Brad Schaefer, the Co-director of the Nebraska LEND project is also the Medical Director for MAGEC. Dr. Schaefer's dual roles will undoubtedly allow for much easier coordination of the Genetic Counseling and LEND programs as proposed in this grant submission.

## PROGRAM SETTING

### Current Genetic Resources

The section of Clinical Genetics at MMI is a large active group of genetic health care professionals. The section is directed by Dr. Brad Schaefer. The section currently has four (4) MD Clinical Geneticists, two (2) PhD Medical Geneticists, seven (7) genetic counselors, and two (2) metabolic geneticists. All members of the section participate in a wide variety of disciplinary and interdisciplinary clinics throughout the region. General genetics clinics are conducted by all four clinical geneticists on site at MMI. The Clinical Genetics staff members participate in over 20 distinct interdisciplinary clinics at MMI and other hospitals within Omaha [Appendix 3]. Outreach clinical genetic services are conducted across the total expanse of Nebraska (Scottsbluff, Kearney and Winnebago) and central / western South Dakota (Rapid City, Pierre). Most recently, telemedicine consultative services have begun. The full range of MMI clinical genetic services is available to Nebraska and parts of South Dakota by telemedicine connections. In total, clinical genetics services are provided to over 4000 patients / families per year.

The seven genetic counselors at UNMC are organized by areas of specialty / expertise. Two genetic counselors staff and support pediatric genetic clinics; two, prenatal services; one, cancer genetics; one, genetics and ethics, and one counselor directs the Title V funded Teratogen Information System (TIS). The TIS is a comprehensive network that provides regional consultation for health care providers, local clinical services (including Fetal Alcohol Syndrome clinics), and national consultation to other Teratogen projects.

All clinical genetics faculty and staff actively participate in genetics education. Educational offerings are provided to students and residents at the University, health care professionals across the state, and lay persons/ support groups. In total, clinical genetics personnel at MMI provided over 3,500 hours of training in clinical genetics and over 2,400 individuals participated in Continuing Education activities provided by clinical genetics faculty over the last fiscal year.

### Genetic Resources in the Nebraska LEND Project

A distinct advantage of the Nebraska LEND Project is that clinical genetics is intimately woven into every aspect of MMI activities. This is facilitated by the fact the Director of MMI, Dr. Bruce Buehler, is himself a clinical geneticist. Dr. Buehler was the Nebraska LEND director for 10 years prior to becoming the Chairman of Pediatrics. As noted above, Dr. Schaefer has been the director / co-director of the Nebraska LEND Project

for the last 8 years. He too is a clinical geneticist, and the director of the MMI section of Clinical Genetics (and the direct supervisor of the genetic counselors). He is also the Medical Director of the Mid-America Genetics Education Consortium genetic counseling training program. Thus, in every conceivable permutation, clinical genetics and interdisciplinary activities for persons with disabilities are inseparable at MMI. This ensures that all of the 'current genetic resources' noted in the section above are part of the Nebraska LEND Project.

#### Current Genetics Faculty in the Nebraska LEND Project

The current Genetics Faculty formally participating in the Nebraska LEND Project include Dr. Brad Schaefer (LEND Co-director and clinical geneticist) and Ms. Becky Anderson who is the bioethicist faculty person for the Nebraska LEND Project. Ms. Anderson is both a lawyer and a board-certified genetic counselor.

#### Current use of Genetic Counselors in the Nebraska LEND Project

MMI genetic counselors currently contribute to the Nebraska LEND project in a variety of ways: 1) One of the genetic counselors is a representative to the MMI Interdisciplinary Education Committee 2) Genetic counselors share in the coordination of 3rd year medical students during a mandatory week at MMI during their pediatric rotation. The genetic counselor acts as a mentor for the medical student demonstrating the role of non-physician clinical services and principles of interdisciplinary care. 3) Genetic counselors provide didactic lectures for LEND trainees, and 4) Genetic counselors participate in most of the interdisciplinary clinics noted above.

## Information about genetics and LEND in Nebraska

### 1) Strategies for delivering genetics information into training program?

- A genetic counselor is a representative to the MMI Interdisciplinary Education Committee
- Genetics topics in Core curriculum (etiology and genetics of MR, autism, CP, etc.)
- Genetics courses available for LEND trainees
- We offer 31 different interdisciplinary clinics that are coordinated and/or staffed by clinical genetics personnel . All clinics are accessible to LEND trainees
- Genetic counseling as a non-physician MMI discipline
- Weekly genetics case conference - elective attendance by LEND students

### 2) What funding sources do you use to support these activities?

- No LEND dollars specifically. Dr. Schaefer receives a small amount of salary support as Co-PI on LEND
- Clinical genetics staff volunteer time on LEND activities.
- Clinical genetics program funded by clinical revenues, grants, contracts, and foundation dollars

### 3) What relationships were developed or expanded?

- None specifically

### 4) Lessons learned?

- Almost everyone is interested in genetics
- Genetics is central to most aspects of clinical medicine. This is especially true in neurodevelopmental disabilities
- Medical genetics and genetic counseling should be a core discipline in a LEND program

### 5) Suggestions for future?

- Continue to find ways to further integrate genetics into LEND programs
- Resource sharing is vital

**Leadership Education in Neurodevelopmental and related Disabilities Training Program**  
at  
**Westchester Institute for Human Development (WIHD) and**  
**The School of Public Health**  
**at New York Medical College**  
and the  
**Joan H. Marks Graduate Program in Human Genetics**  
**at Sarah Lawrence College (SLC)**

**Incorporating Genetics into the LEND Program at WIHD**

- Choice of genetics topic for one LEND interdisciplinary research team projects per year
  - See posters concerning two such projects
- Sarah Lawrence College (SLC) Human Genetics Program Director presents LEND sessions on genetics topics
  - See “Participatory Care” case handout as one example
- Genetics considerations included in case discussions re interdisciplinary approach
  - See “A child with language delay” handout as an example
- Genetic counseling included as one of the LEND disciplines during “Disciplinary Presentation” series
  - See “Guidelines for Disciplinary Presentations”
- Sarah Lawrence Program Director is a panelist or co-discussant for interdisciplinary case discussion and disciplinary presentations during several LEND sessions and attends, with one or more other SLC faculty, the end-of-year LEND poster session at WIHD
- Three SLC genetic counseling students have been included in the WIHD LEND group since 2004, assuring that genetics issues arise and can be addressed to some extent during group discussions, even when a genetics faculty member is not present

**Incorporating LEND curriculum into training of genetic counselors**

- SLC students in LEND program write thesis based on, or as an outgrowth of, participation in WIHD LEND research teams
  - See three cover pages and abstracts from such theses
- LEND faculty serve as thesis advisors for SLC graduate students who are LEND trainees
- LEND program director is a member of SLC’s thesis project planning group
- LEND faculty/staff give presentations at SLC

**Summary of SLC-WIHD LEND collaboration in research training:**

- See handout of poster presented at AUCD meeting 11-06

Karen Edwards MD MPH  
LEND Program Director  
Westchester Institute for Human Development  
Cedarwood Hall Room 332  
Valhalla NY 10595  
914-493-8175  
kedwards@wihd.org

Caroline Lieber, MS, CGC  
Director, Joan H. Marks Graduate Program in Human Genetics  
Sarah Lawrence College  
Bronxville NY 10708  
914-395-2371  
clieber@slc.edu

## **Participatory Care in Genetic Counseling: Case Discussion**

Caroline Lieber MS, CGC  
Director, Human Genetics Program, Sarah Lawrence College  
Erin Carter, Ushtavaity Davar, Alice Hawkins, LEND fellows

1/06 Presentation to LEND Trainees  
Westchester Institute for Human Development

The goals of this session are:

- 1) To use a multidisciplinary process to discuss the approach to a child presenting with certain history and physical examination findings which suggest a genetic or congenital etiology
- 2) During small group discussion, consider the cultural, family, economic, and social factors which must be addressed to best serve this child and her family
- 3) For trainees to gain insight into the approach used by genetic counselors to evaluate and counsel individuals referred to them.

A seven year old Hispanic female is referred to the genetics service for evaluation because of certain findings on history and physical examination. In brief: She is at the 75<sup>th</sup> percentile for height and weight, and her head circumference is at the 50<sup>th</sup> percentile. She has several café-au-lait spots on her torso, her hair is two different textures (soft over most of her head, but very coarse around a hair whorl on the right crown of her head). The right side of her face is larger than the left side. Developmentally, she is not keeping up with her classmates. The pediatrician who referred her is concerned that these findings might be consistent with a neurocutaneous disorder.

The genetic counselor seeing the child and her mother has learned that the child's family is from Colombia, South America, and they speak very little English. The father is not present at the meeting, as he is working. The child's health care is covered by a Medicaid managed care plan.

**LEND Program at WIHD  
September 2006**

**A child with language delay**

Ms. B. is concerned that her two and a half year old son, L.B., is not speaking as much as his eight year old brother was speaking at 2 ½. In fact, L.B. can say only five or ten words, all of them familiar nouns. He can understand simple household commands. His mother notes that he often does not pay attention when people speak to him. She also notices that he does not seem as “coordinated” as his older brother was at this age and that he hasn’t gotten as far as she would expect in feeding himself. She is concerned enough that she made an appointment to take her son to his pediatrician.

The pediatrician agrees that L.B.’s language is delayed. Other important information shared by Ms. B is that her child has a habit of flapping his hands and biting his hands. Family history is significant for mother’s 40 year old brother having moderate cognitive disability (first noted at age three).

The pediatrician recommends a referral to Early Intervention (EI) and Ms. B agrees. The pediatrician also notes in the chart that in light of family history and the developmental and behavioral findings, the child should be referred to genetics / genetic counseling at a future date. She decides to wait until the child comes for a return visit after the EI core evaluation to discuss this recommendation with Ms. B.

Ms. B calls the Westchester County Department of Health EI office. An initial service coordinator (who is a social worker) is selected. The initial service coordinator contacts the parent, discusses concerns, and then suggests options for a core evaluation. They arrange to have the psychologist and speech/language pathologist do a core evaluation in the home.

A few weeks later, the pediatrician asks Ms. B to return for follow-up and discusses with her the recommendation that the child be evaluated by genetic counseling/medical genetics. The child is then seen by genetics/genetic counselor for evaluation.

As part of the Individualized Family Service Plan, the family is referred to a social worker for parenting training and to an occupational therapist because of “low tone” detected by the EI core evaluators and because of the history of feeding difficulties.

**The LEND Training Program**  
at  
**Westchester Institute for Human Development and  
the School of Public Health at New York Medical College**

**Guidelines for Disciplinary Presentations  
2006-2007**

In September, we discussed the interdisciplinary approach to evaluation of a child with language delay in order to begin to understand the role of various disciplines in this process. The **Disciplinary Presentations** provide an opportunity to share with LEND trainees from other disciplines more detail about how you work with children who have or are at risk for having developmental disabilities and their families.

With other LEND trainees from your discipline, and in consultation with faculty from your discipline, prepare a twenty minute presentation ( do not use Powerpoint) which helps LEND trainees from other disciplines to understand your discipline and how you work with children and adolescents with, or at risk for, developmental disabilities and their families. Please limit your discussion to your discipline's work with children and adolescents.

**On October 12**, presentations will be made by the Occupational Therapy, Speech/Language Pathology, Psychology, and Psychiatry groups. **On October 19**, presentations will be made by the Social Work, Genetic Counseling, and Family Specialist groups (Family Specialist group should meet with Barbara Levitz before starting this assignment since there are special guidelines for your group).

Each team member should present a portion of the team's presentation.

Each team's presentation should include these elements:

- 1) Briefly state the educational and NYS licensure requirements (if any) for your discipline.
- 2) List the settings in which your discipline does clinical practice and is most likely to encounter children and adolescents with disabilities (or at risk for disabilities). For each setting, describe the most common reasons for them to come to your attention.
- 3) Briefly describe (in terms which can be understood by someone who is not from your own discipline!) standard elements of an evaluation by a member of your discipline of a child or adolescent with, or at risk for, developmental disability. Describe how family members would be involved in the evaluation.
- 4) State the professional organization which students in your discipline typically join and briefly state the benefits to students of joining the organization. Indicate

whether there is a regional or local chapter of the group which accepts students as members.

5) Ask if your colleagues from the other LEND disciplines have questions about what you have presented.

These resources may be helpful to you in preparing your presentation:

### **Annotated listing of LEND disciplines provided in the LEND Manual**

#### **Professional organization websites:**

American Speech-Language Hearing Association  
<http://www.asha.org>

American Psychological Association  
<http://www.apa.org>

National Society of Genetic Counselors  
<http://www.nsgc.org>

National Association of Social Workers  
<http://www.naswdc.org>

American Occupational Therapy Association  
<http://www.aota.org/>

The American Academy of Child and Adolescent Psychiatry  
<http://www.aacap.org/index.wv>

#### **New York State Education Department: Office of the Professions (Includes detailed information concerning NYS licensing requirements):**

<http://www.op.nysed.gov/proflist.htm>

#### **Several references available in the LEND office at WIHD:**

Guralnick, Interdisciplinary Clinical Assessment of Young Children with Developmental Disabilities. Brooks, 2000.

Vargas and Prelock, eds. Caring for Children with Neurodevelopmental Disabilities and their Families. LEA, Inc., 2004.

**LEND GENETICS PLANNING MEETING  
December 13, 2006, Washington, DC**

**Riley Child Development Center- Indiana LEND  
James Whitcomb Riley Hospital for Children  
Indiana University School of Medicine-Pediatrics  
Indianapolis, Indiana**

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

- a) Selected clinical training/teaching cases by specific syndrome
- b) Case review/problem case presentations, e.g., ethical dilemmas
- c) Core seminar/symposia topics on medical genetics syndromes and issues
- d) Trainee rotations through Medical Genetics Clinics, Metabolism Clinics and Specialty Clinics, e.g., Down, Fragile X, Williams, Prader-Willi and Lowe Syndromes
- e) Family as faculty seminar presentations
- f) Trainee involvement in specific genetic research projects

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

- a) Generated revenues from clinic fees
- b) In kind support and donated faculty time from Indiana University Department of Medical Genetics and Pediatric Section of Metabolism and Nutrition
- c) Small MCH block grant initiatives from Indiana Department of Health
- d) MCH LEND core grant funds

**3. What relationships were developed or expanded?**

The RCDC has developed and expanded collaborative working relationships with the Indiana University Department of Medical Genetics, the Pediatric Section of Metabolism and Nutrition and the Indiana State Department of Health-Division of Maternal and Child Health. The Department of Medical Genetics and the Metabolism and Genetics Section both have a designated core faculty member on the LEND Interdisciplinary Training Team. Trainee rotations are supported and encouraged across the RCDC LEND clinics, the Medical Genetics Clinics and the Metabolism and Nutrition Clinics. The Indiana Department of Health, Division of Maternal and Child Health has a designated representative on the RCDC LEND Advisory Committee and who provides information on state genetic initiatives and issues.

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

Knowledge and technological advances in molecular and medical genetics are expanding at a very rapid rate. Specialty and long term training in these new and emerging areas must increase to keep pace with practice demand but additional LEND funding support is needed particularly for long term trainee stipends. Many good training modules on medical genetics have been developed but need to be more broadly delivered to LEND trainees via online/distance learning formats. With the advent of the human genome pedagogy must also maintain a focus on the inherent moral, legal and ethical dilemmas.

## Genetic Counseling

### **MCH LEND Program Division of Developmental & Behavioral Pediatrics Cincinnati Children's Hospital Medical Center/ University of Cincinnati**

#### **Background:**

Collaboration related to genetic counseling began in the early 1980's when the Cincinnati Children's Medical Center (CCHMC) Division of Human Genetics and the LEND began jointly funding a position to: 1) develop medical genetics education within the Division of Human Genetics and the LEND; 2) establish the Division of Human Genetics as a training site for University of Cincinnati (UC) graduate level genetic counseling students; and 3) develop a genetics option within the LEND for UC College of Nursing master's level nursing students. This collaborative endeavor resulted in selected nursing trainees receiving genetic counseling experiences (short-, intermediate- and long-term) within the LEND and CCHMC pediatric residents receiving didactic content on genetic counseling during their one month LEND rotation.

In the early 1990's, the College of Nursing shifted focus from preparation of master's level clinical specialists to the preparation of nurse practitioners. This resulted in the LEND genetic counseling option for nursing trainees to be no longer feasible due to limited time in the curriculum for elective experiences. A rotation in developmental pediatrics also became a required part of the pediatric resident curriculum in the 1990's which increased the number of pediatric residents rotating through the LEND to the extent that it was no longer possible to provide didactic content on genetic counseling on an individual basis for all the rotating residents.

Simultaneously during the 1990's, the UC/CCHMC Division of Human Genetics Graduate Genetic Counseling Program grew rapidly and the initial jointly funded position evolved into the position of Program Director of the Graduate Genetic Counseling Program. The LEND has continued to partially fund the position to provide student supervision for at least eight (8) first year and eight (8) second year genetic counseling trainees per year within the LEND and the Division of Human Genetics. During the 2005-2006, a second year genetic counseling student was stipended with an unused trainee stipend from another discipline to participate in the full LEND Interdisciplinary Leadership Core Curriculum. The involvement of the a genetic counseling student in the Core Curriculum activities, along with trainees from other disciplines, was felt to greatly enrich the both the knowledge gained by other trainees and the genetic counseling trainee.

#### **Currently:**

All first year genetic counseling trainees participate in an alternative course format for the LEND three academic quarter Interdisciplinary Core Course. This format allows them to enroll for one quarter of the course, but complete the requirements over the academic year by attending at least 10 Interdisciplinary Core Sessions of their choice. The academic requirements maximum credits per quarter has never permitted them to be able to take all three quarters of the course for credit.

In the past, the trainees attended all of the Fall Quarter sessions but felt that some of the were not as pertinent to their interests as ones held during other quarters.

All second year genetic counseling trainees have half-day experiences in the LEND/Division of Developmental and Behavioral Pediatrics' Down syndrome, Autism Spectrum Disorders, Spina Bifida, and Cerebral Palsy Clinics.

When the LEND application was submitted for 7/1/2006 – 6/30/2011, a stipend for a second year genetic counseling trainee to continue to participate in the full LEND Interdisciplinary Leadership Core Curriculum each year, along with the trainees in other disciplines. This occurred, however, at the lost of a stipend in a discipline that traditionally had stipends for two trainees.

The LEND partially funds the Director of Human Genetics Graduate to be the LEND Genetic Counseling Faculty member. As such, she provides student supervision for at least eight (8) first year and eight (8) second year genetic counseling trainees per year, including the stipended LEND genetic counseling trainee, within the LEND and the Division of Human Genetics. She also participates in the LEND Interdisciplinary Leadership Core Curriculum, along with other LEND faculty, in an orientation session on overview of disciplinary training, Interdisciplinary Training Case Discussions, and Trainee Team meetings. Under her supervision, the LEND genetic counseling trainee presents the LEND Interdisciplinary Core Course session on genetic counseling.

The LEND Director serves on the Genetic Counseling Program Advisory Committee and as a faculty member of the program. LEND/Division of Developmental and Behavioral Pediatrics faculty provide lectures as part of the Program's "Topics in Medical Genetics" Course and serve on graduate genetic counseling trainees' theses committees.

### **Exploring:**

- 1) To give trainees in other disciplines a fuller sense of genetic counselors do and to expand the genetic related content they receive, requiring all other trainees who participate in the LEND Interdisciplinary Core Curriculum to attend the Genetic Counseling Program's Case Conference. This is a peer-review conference during which three in-depth cases are present by the genetic counseling trainees.
- 2) Requiring that the LEND trainees in other disciplines attend a designated number of session of the Topics in Genetics course offered through the UC College of Allied Health. To date, schedule conflicts have been a problem.
- 3) A joint Genetic Clinic between our Division and the Division of Human Genetics to decrease duplication in services. This clinic would also provide additional experiences for the genetic counseling trainees, LEND trainees in other disciplines and pediatric residents who are required to do a month rotation through the our Division.

### **For Additional Information Contact:**

Roz Parrish, LEND Associate LEND Director/Training Director  
[roz.parrish@cchmc.org](mailto:roz.parrish@cchmc.org)

# **APPENDIX D**

## **Update on National Issues, Efforts, Recruitment, Diversity, and Resources**

Presentation by Judith Benkendorf, MS, CGC

# **So Many Updates in a Little Bit of Time!**

**Judith L. Benkendorf, MS, CGC  
Project Manager  
American College of Medical Genetics  
LEND Genetics Planning Meeting  
December 13, 2006**

# The ACMG, NCC, Genetics Workforce Study, and NSGC Diversity Interest Group Meet LEND Genetics





# Introducing the Medical Genetics Workforce (1)

- **Genetic counselors**

- 1,811 board certified (as of August 2005)
- 1 genetic counselor for every 166,900 Americans
  - *Assuming all are alive and practicing in USA*

- **ABMG certified geneticists**

- 1,520 active in US (estimated)
- 995 MD; 525 PhD
  - *~1 BC MD clinical geneticist for every 301,900 Americans; 3.5 per million population*
- Royal College of Physicians estimates 1 FTE/250,000 population.
  - Based on current population, 300,377,103, US needs 1200 FTE MDs.

- **Nurses in genetics**

- 300 ISONG members

- **Laboratory technologists and others**



# Introducing the Medical Genetics Workforce (2)

## *The Genetic Counselor Workforce:*

- NSGC has conducted biennial Professional Status Surveys (PSS) since 1986
- Most recently completed survey - 2006
  - 1245 surveys returned (response rate 68%)
- **91% Caucasian (was 94% in 2004); 94% women (2004)**
- Age: 71% < 40 years
- 38% have  $\leq$  5 years experience in the field
- 27 US programs graduate ~200 new counselors/year



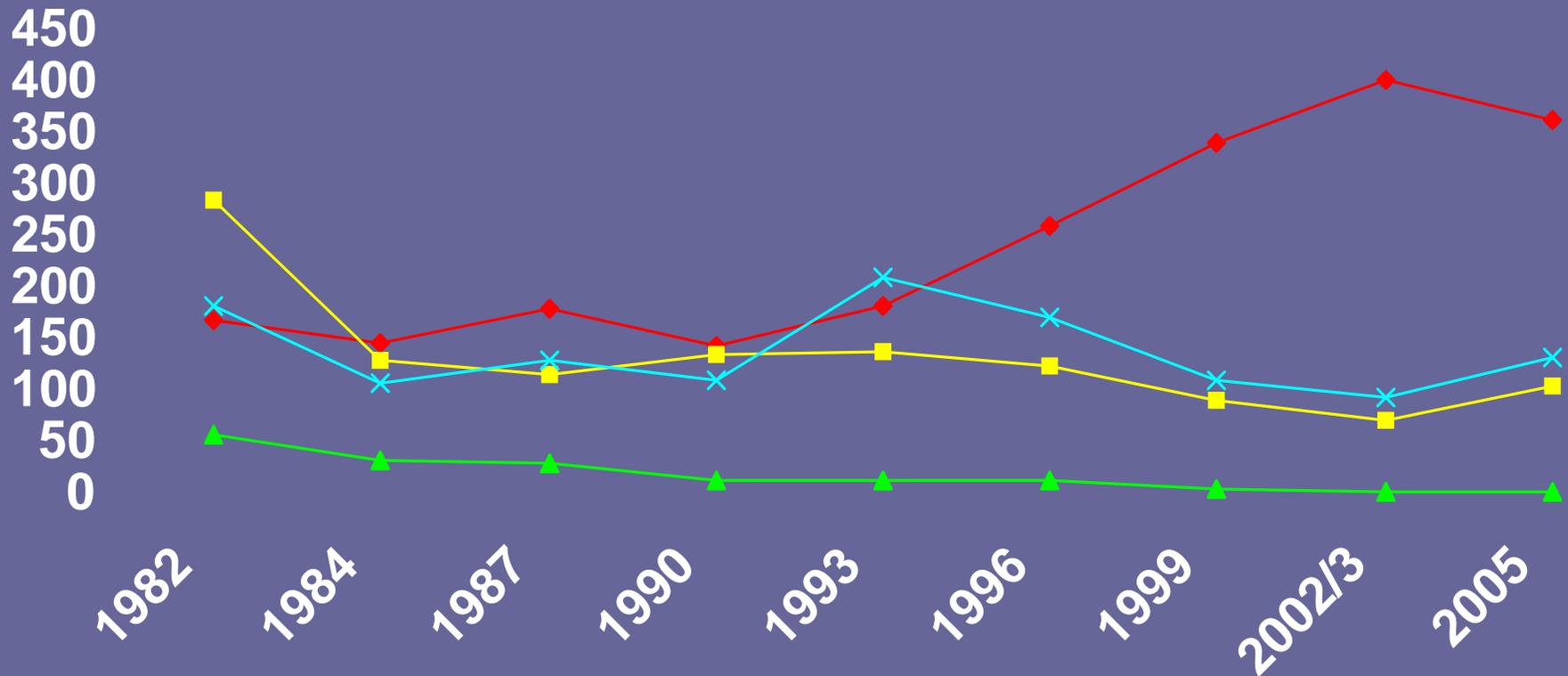
# Introducing the Medical Genetics Workforce (3)

## *ABMG Medical Genetics Workforce (2003 data):*

- 50% are women; mean age 52 years
- **13% belong to minority groups**
  - 9% Asian; 2% Hispanic; 1% Black; 1% Other
- Highly educated: 23% of MDs also had PhD
- MDs have prior GME:
  - 71% Pediatrics, 11% Internal Medicine
  - 10% Ob/Gyn, 6% Pathology
- Laboratory geneticists by specialty:
  - 13% Biochemical, 19% Molecular, 29% Cytogenetics

# Genetics Certification Trends

## 1982 - 2005



◆ Genetic Counselors

■ MD Clinical Geneticists

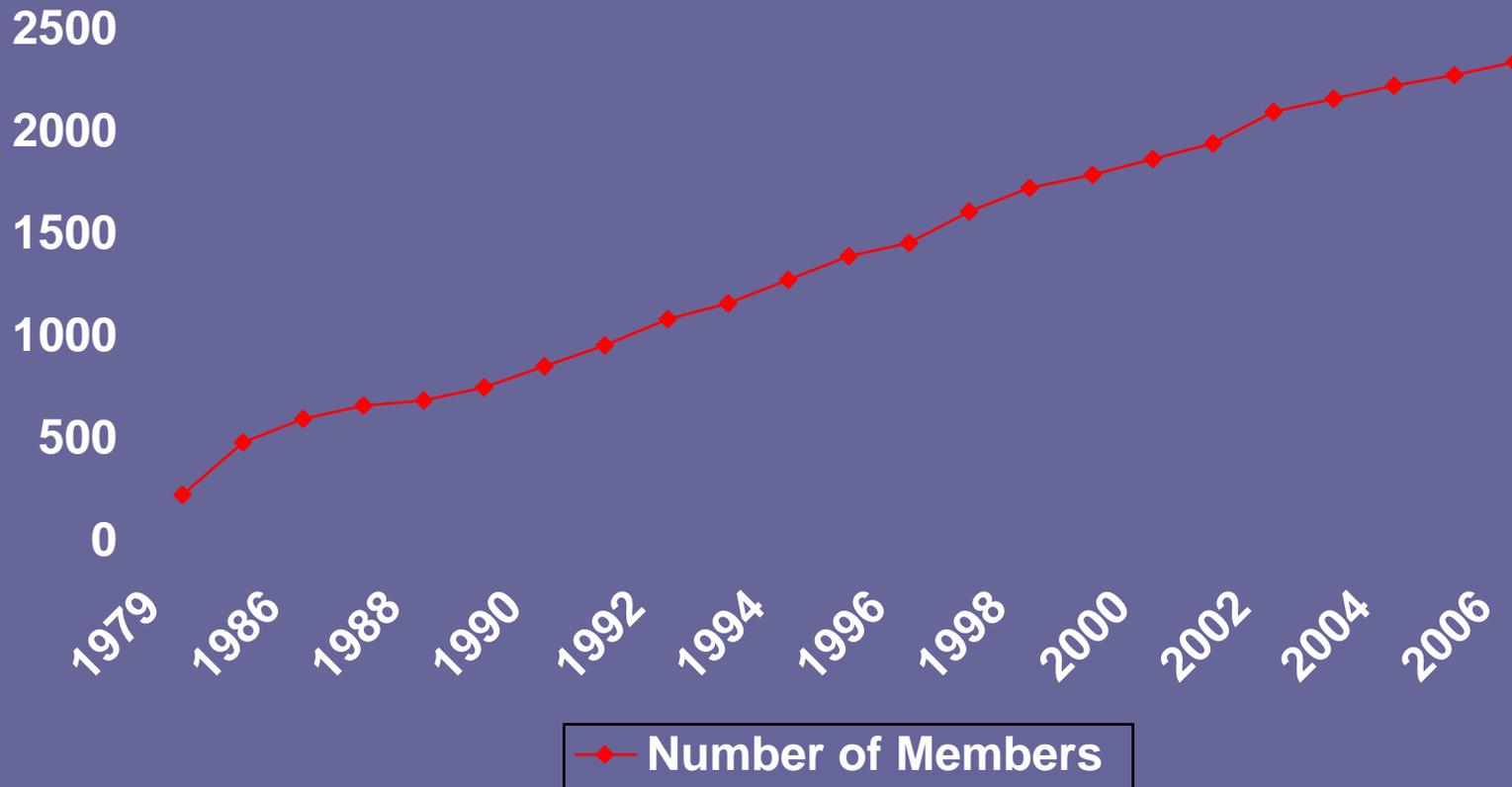
▲ PhD Medical Geneticists

× Laboratory Geneticists

# NSCG Membership

(2334 members; 2024 full members)

*November 2006*





# Genetics Workforce Study Conclusions

## *The medical genetics workforce situation is critical!*

- Current clinical services workforce not expected to meet patient care needs in next 5-15 years.
- Serious mismatch exists between expansion of knowledge and workforce size.
- Young physicians not entering field; competition expected to increase with emerging national physician shortage.
- Many states and parts of US have inadequate supply of MD clinical geneticists to meet demand.
- Issues of how MD geneticists work also a factor.



# Medical Geneticist Recruitment Activities (1)

- ACMG sponsored two summit meetings at The Banbury Center to discuss MD geneticist workforce issues:
  - October 2004, focus on recruitment issues
    - *Genetics in Medicine, July 2005*
  - February 2006, defined Scope of Practice
    - *White paper forthcoming*
  - Next step, define residency curriculum to align training to scope of practice



# Medical Geneticist Recruitment Activities (2)

- ***On-going organization-based activities:***
  - **ACMG:** GME brochure; white paper; sessions at annual meeting for residency program directors; 1 industry-sponsored fellowship in Clinical Biochemical Genetics
  - **APHMG:** Building network of residency program and medical school course directors
  - **ABMG:** Developing joint training programs; re-vamping general genetics exam; broadening emphasis of medical genetics exam
  - **RRC:** Reviewing and revising curricular requirements; consider alternative pathways
  - **ASHG:** Developing K-college genetics education; inviting MD/PhD students to Annual Meeting



# NSGC Diversity Interest Group (1)

## *Mission Statement:*

"The Diversity Subcommittee is committed to **promoting cultural diversity in the genetic counseling profession by increasing the number of minority genetic counselors** and by providing cultural competency education to genetic counselors of all backgrounds."

– Nancy Steinberg Warren, MS, CGC, *Chair*  
*University of Cincinnati*



# NSGC Diversity Interest Group (2)

## *Current Activities Include:*

- Recruitment brochure (early 2007)
- Recruitment slide show for high school and college students, designed to attract under-represented minority students. Emphasis on:
  - Giving back to the community
  - Working with families
  - Reducing health disparities
  - Diverse career paths and rewards
  - What to do if interested



The  
National Coordinating Center  
(NCC) for the Genetics and  
Newborn Screening Regional  
Collaborative (RC) Groups

[www.nccrcg.org](http://www.nccrcg.org)

A cooperative agreement between  
GSB/MCHB/HRSA and ACMG



# ***A collaborative effort to bring high quality genetics and NBS services to the public...***

*...through shared information, activities, tools and resources*

## **The Regions**

- Enhance coordination of efforts in the states
- Address gaps in services and promote access in states and communities
- Build infrastructure
- Strengthen capacity
- Develop “best practices” that meet local needs
- Identify issues best addressed nationally

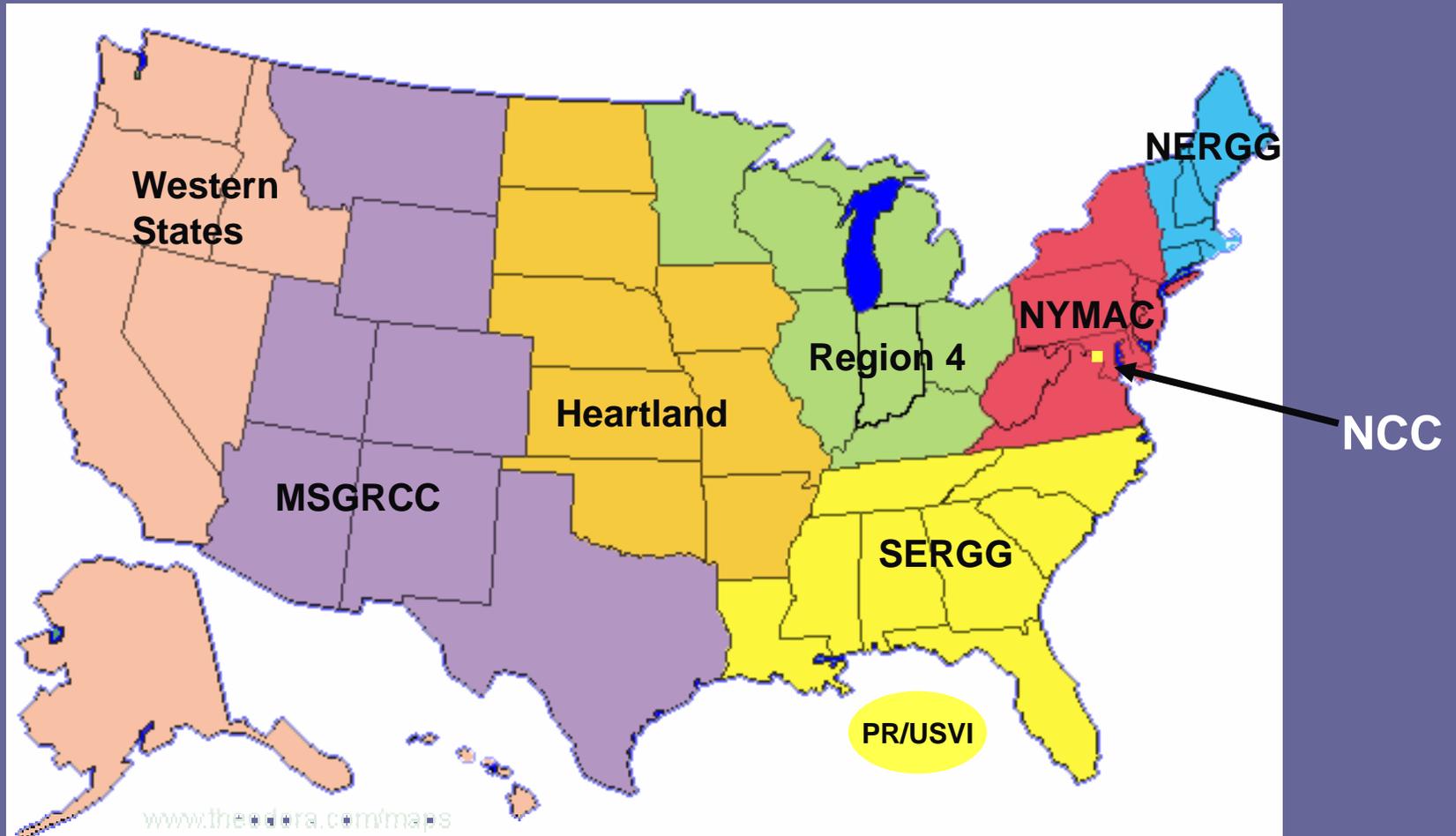
## **The NCC**

Supports the regions by:

- Focusing on issues specific to utilization of genetic and NBS services at all levels
- Facilitating communication and collaboration between RCs and nationally
  - Workgroup coordination; relationships with stakeholder organizations
- Translating “best practices” and RC activities into national efforts
- Providing guidance and technical resources
  - Minimizing duplication of efforts and optimizing shared expertise
- Connecting PCPs (Medical Home), public health and medical genetics specialists



# The 7 Regional Genetics and NBS Collaborative Groups





# Workgroups and Activities (1)

- Telegenetics Workgroup: Capacity development
- NBS Emergency Preparedness Workgroup
- Infrastructure Development: Genetic service delivery
  - Developing and mapping (using GIS) a national network of genetic service providers
    - Services to be categorized (lab, clinical, special populations, etc.); subspecialty/organ/disease clinics included



## Workgroups and Activities (2)

- Data Collection and Related Projects
  - Building the Business Case will involve collection of outcomes data
    - Integration with Quality of Genetic Services Project
  - NBS data collection projects
    - Tracking NBS pilot studies
    - Genetics patient registry
    - Organizing metabolic centers around follow-up



# Workgroups and Activities (3)

- Management Guidelines
  - NBS ACT(ion) Sheets and Diagnostic Algorithms
    - For all conditions in uniform panel
    - Approved by ACMG Board of Directors
    - Distributed to NBS labs and programs
      - To accompany all “screen positive” lab reports
    - Distributed to RCs to coordinate use with local and regional plans
  - NBS ACT Sheets currently being written for non-S hemoglobin alleles
    - Beyond SCD and the thalassemyias



# Workgroups and Activities (4)

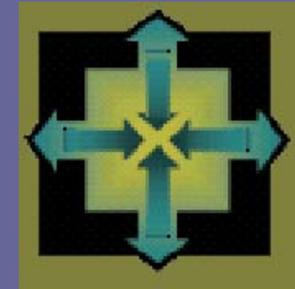
- NB Hearing Screening ACT Sheet being adapted into a brochure for parents of “screen positive” infants
  - Tailored to low-literate populations
  - Emphasis on genetic workup as part of etiologic diagnosis
- Supplemental grant to NCC to develop similar primary care guidance for genetic testing
  - To be disseminated by genetics laboratories in the US with “positive” test results
  - Fragile X, CF and hemoglobinopathy testing as models
- Model management guidelines for primary care providers around transition to adult care
  - Pilot project using hemoglobinopathies
  - Information to be collected on dissemination methods (pediatricians versus adult medicine)

# So what does all this have to do with LEND Genetics?



- The genetics workforce situation is critical, requiring coordinated, multi-pronged solutions.
- The lack of workforce diversity needs to be addressed.
- Common Ground: The NCC addresses issues related to access to quality genetics and NBS services (viewing services as a continuum), and decreasing health disparities, at the level of individuals, families, communities and nationally.
- Genetic advances will impact the healthcare for people and families with neurodevelopmental disabilities.
  - NBS for developmental disabilities debate continues
- The RCs are a venue for LEND trainees to gain experience in public health genetics, and they provide a vehicle for dissemination of LEND materials and messages.

# May this be our first of many more meetings!



# **APPENDIX E**

## **Work Group Assignment and Recording Format**

## Small Groups

On the following pages:

1: take the list of genetics activities generated from the morning discussions and separate into the following areas:

|                                                                                 |                                                                                                                                   |                                                                                    |
|---------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------|
| Activities we can do if no additional funding is earmarked for genetics in LEND | Activities we can do if a supplement of up to \$50,000, in addition to current funds earmarked for genetics in LEND, is available | Activities we can do if increased funding and additional funding sources are found |
|---------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------|

2: prioritize the activities within each of those possible funding scenarios

3: For each priority area, determine:

A: Whose priority area is it? i.e.: MCHB? AUCD/network? LEND program-level?

B: Who are appropriate partners?

**Activities we can do if no additional funding is earmarked for genetics in LEND:**

|    |              |
|----|--------------|
| 1: | A: who?      |
|    | B: partners? |
| 2: | A: who?      |
|    | B: partners? |
| 3: | A: who?      |
|    | B: partners? |
| 4: | A: who?      |
|    | B: partners? |

**Activities we can do if a supplement of up to \$50,000, in addition to current funds earmarked for genetics in LEND, is available:**

|    |              |
|----|--------------|
| 1: | A: who?      |
|    | B: partners? |
| 2: | A: who?      |
|    | B: partners? |
| 3: | A: who?      |
|    | B: partners? |
| 4: | A: who?      |
|    | B: partners? |

**Activities we can do if increased funding and additional funding sources are found:**

|    |              |
|----|--------------|
| 1: | A: who?      |
|    | B: partners? |
| 2: | A: who?      |
|    | B: partners? |
| 3: | A: who?      |
|    | B: partners? |
| 4: | A: who?      |
|    | B: partners? |