

PROJECT REPORT

Mountain States Genetics Collaborative Center Small Grant Program

Name of Principal Investigator(s) (PI): Dr. Vijay Tonk, Professor of Pediatrics, Texas Tech University

Name of Project Director(s): Dr. Golder Wilson, Clinical Professor of Pediatrics, Texas Tech University and KinderGenome pediatric genetics practice, Dallas TX phone (214-797-0031) email (TheGgnome@aol.com)

Project Name: GENE-ARM: GEnetic Nursing Network for Access, Referral, and Management: A West Texas/Dallas area pilot project

Project Goal(s): Initiate a pilot project to inform and empower nurses to recognize, refer, and guide management of genetic disease. The project will include 1) Design of brochures for nurse genetic education and registration 2) Design of conferences and manuals for area nurse education 3) Revision of conference programs based on nurse suggestions 4) Assessment of project effectiveness by tallying nurse registration, conference attendance, and referrals 5) delivery of final project report so the GENE-ARM module can be adapted for other MSGCC regions

Summary of progress with reference to grant objectives:

1. Establish a GEN-ARM website and central email/phone contact with the nursing consultant in Lubbock.

We have established a central email/phone contact through Sherry Letalien and Golder Wilson at TTUHSC Lubbock. We did not obtain cooperation in establishing a website in Lubbock; we would suggest each state or region create a small nursing network website with links to MSGCC.

2. Design a brochure in consultation with MSGN personnel and nurse consultants to alert nurses in various specialties to key genetic issues and solicit their participation in the GEN-ARM network.

A brochure has been designed emphasizing nursing recognition of key genetic case presentations, contact numbers for questions, genetics resources, and nursing courses in genetics (including International Society of Nurses in Genetics—ISONG). We now propose to include the brochure on the GEN-ARM CD and proceed by recruiting nursing genetic coordinators at regional hospitals and agencies

3. Mail brochures with nurse registration forms to all primary care nurses in the west Texas area (extending from Amarillo to El Paso, Lubbock to Midland/Odessa and Abilene).

Approximately 100 brochures were distributed to nurses without a single registration. We have therefore concluded that mailing or distributing genetics brochures to general nurses will not be effective and have decided to modify our approach by locating nurse facilitators at major hospitals or centers who have some interest in genetics. These facilitators will be encouraged to attain or maintain some proficiency in genetics through use of the GEN-ARM CD, give in-service presentations, and distribute the CD or brochures to nurse attendees.

4. The Lubbock nursing consultant will establish and maintain a database of nurse registrants for mailings (seminar announcements and project-ending survey), tracking of calls or referrals, and assembly of a directory of nurses interested in genetics.

An unforeseen problem with the grant is that a partial salary for a nurse coordinator is not sufficient to hire a nurse with some training/interest in genetics. Nurse Letalien is doing some coordination but has many outpatient clinic duties that preclude undergoing genetics training and doing outreach. We have not had any responses to our GEN-ARM brochures, so we have not established a database.

5. Design a standard conference program and manual with input from MSGN administrators and GEN-ARM nurse consultants (including nurse Spahis from ISONG)

A draft GEN-ARM CD includes a brochure for interesting nurses in genetics, a nursing genetics primer that begins with practical nursing genetic presentations in the key fields of pediatrics, OB, and adult medicine, a follow-up text with details on basic genetics and applications in these various nursing fields, power-point presentations in each fields, and review questions/examinations in each field. Key strategies in the primer, presentations, and examinations are to begin with a simple case, then illustrate the genetic principles in order to demystify genetics. The CD also includes a listing of genetic resources for nurses. The CD will be modified by MSGCC representatives in each region/state according to their ideas and local resources.

6. Organize two conferences in each urban area (Amarillo, Lubbock, El Paso, Midland/Odessa, and Abilene—10 conferences total), the first 5 conferences at about 5-7 months after grant initiation, the second 5 at about 11-13 months after grant initiation. It is anticipated the second group of conferences may be altered based on feedback from the first.

We have not been able to organize a conference specific for nurses, but have given several presentations in Dallas through Nurse Joanna Spahis and a talk at the annual postgraduate medical conference in Lubbock by Dr. Wilson. We now recognize it will be necessary to convince nursing schools to adopt genetics lectures and courses, then proceed to CNU presentations by nursing genetic coordinators.

7. The project director and nurse consultants will present at conferences. Pre- and post-conference questionnaires will ascertain nursing genetic knowledge and solicit suggestions on program content and promotion of nursing genetic services.

Since nursing presentations have been minimal, the questionnaires are replaced by the review examinations in each nursing field on the CD-ROM.

8. A final project report will be assembled containing data on the number of nurse registrants, conference attendance, phone/email queries, and referrals plus brochure and manuals that can be used to adapt the GEN-ARM program to other MSNG and US regions.

A GEN-ARM CD has been developed and edited by collaborating nurses and is submitted as the final product of our grant. The CD is essentially a tool-kit to allow self-study of genetics or presentation of genetics in-services or courses by nurse genetics coordinators. The CD contains a brochure, primer, 60-question examinations in each area of nursing genetics (pediatrics, obstetrics, adult medicine), slide presentations, and a genetic resource directory. The brochure, first chapter of the primer, and slide presentations all start with sample case presentations to emphasize a practical, clinical approach to genetics.

Future Plans

We hope the GEN-ARM CD will be adapted by individual states and regions within the Mountain States Genetics Collaborative Center area to suit their own objectives and needs. The brochure, primer, resource directory, and slide presentations can be modified to reflect local emphasis and resources. This CD should

serve the purpose of information exchange and genetic literacy for nurses, and thus for the large number of patients they serve.

We plan to further edit the CD using our nurse collaborators in West Texas (Texas Tech University area) and Dallas-Fort Worth and to distribute it to agencies and hospitals. We will distribute the CD through professional talks by Drs. Tonk and Wilson, nurses Karr, Myers, and Spahis. We will also make the CD available to geneticists and genetic centers in these areas so they can modify it and make it an information exchange and resource for their practices.

Summary of expenditures:

Since part-time funding of the primary nurse in Lubbock was not used, and those presentations given were done pro bono, we have \$10397.79 of the first payment that was not spent. This money could be used for copying and distribution of the CD-ROM by MSGCC and/or the principal investigators. We await instructions on the return/re-allocation of these moneys:

Item	Total amount requested	First year budget based on initial payment of \$15,000	Amount actually spent
Partial salary primary nursing consultant in Lubbock	12,000	6400	0
Travel/supplies/development of materials (Dr Tonk and Texas Tech, Lubbock)	5000	2670	2527.04
Travel/supplies/development of materials (Dr. Wilson)	3000	1600	1545.17
Travel/supplies/development of materials (Nurses Karr and Myers, Amarillo)	1500	800	0
Travel/supplies/development of materials (Nurse El Paso)	750	400	0
Travel/supplies/development of materials (Nurse Spahis, Dallas)	1500	800	0
Printing/Xeroxing costs	3000	1600	500
Mailing costs	1500	800	100
Totals	28250	15070	4672.21
Amount first payment not spent as of 4-07			10397.79