

Consortium on Law and Values In Health, Environment & the Life Sciences 2010-11 Consortium/JDP Member Proposal Cover Page

Applicant Information

Applicant Name	<u>Bonnie S. LeRoy</u>	Email	<u>leroy001@umn.edu</u>
Project Title	<u>Every Picture Tells a Story: Effects of Photographic Images on Perceptions and Attitudes About Genetic Conditions</u>		
Depart./Center	<u>Institute of Human Genetics</u>		
Dept./Center Head's Name	<u>Brian VanNess, PhD</u>	Dept./Center Head's email	<u>vanne001@umn.edu</u>
Dean's Name	<u>Aaron Friedman, MD</u>	Dean's email	<u>alfried@umn.edu</u>
How did you hear about this funding opportunity? From RFP sent via e-mail.			

Funding

Amount of funding requested: \$18,511.00
Explain how these funds will help the Consortium member or JDP partner program further their work on the societal implications of the life sciences. Indicate if more than one Consortium/JDP partner program is involved.]

The long range objective of this project is to enhance the quality and effectiveness of genetic service provision by physicians and genetic counselors through development of a novel medical resource. Current reference texts available to practitioners rely on stark clinical images to illustrate features of genetic conditions. We propose the creation of a reference text that will contain professional photographs depicting patients in their daily lives and accompanying patient/family stories. Funding from the Consortium for this project will allow us to collect the empirical data needed to secure additional funds from a private foundation for the development of a reference text.

Approvals

Check all appropriate approvals required for your proposal. Approvals must be obtained prior to receipt of funding. If you have applied for approval but have not yet received it, indicate that approval is pending.

IRB Yes No Application pending

IACUC Yes No Application pending

Other Yes No Application pending

Checklist

- The proposal is 2000 words or less excluding budget, biographies, references & citations.
- The proposal includes a work plan with a timeline using months or quarters to identify work to be done and completion dates.
- The budget form is complete including the funds sought for this project, other pending applications for this project, and the amount/source of matching or other funds.
- Faculty descriptions and roles on the project are included.
- A biographical sketch for each investigator or project leader (limited to one page per investigator or leader) is included.
- Approval (via email) from the administrator with fiscal responsibility for the department, program, or center is included.
- All necessary approvals are pending or received.

Budget for Consortium and JDP Member Proposals

Every Picture Tells a Story: Effects of Photographic Images on Perceptions and Attitudes About Genetic Conditions

Instructions provided below.		Requested funding	Matching/other funding		
	Personnel costs	Description & justification Salary = ___hrs x ___ hrly wage	Amount	Amount	Source
1	Research Assistant through GCD	10 hrs/week X \$17.08/hr for 2 semesters	\$14,000		
2	Statistical Consultation	\$50/hr for 20 hours total	\$1,000		
3	5 expert consultants to judge selection of photographs to be included	\$ 50/ person total	\$250		
4	Personnel				
5	Personnel Subtotal		\$15,250.00	\$0.00	\$0.00
6	\$25 gift cards for the 20 students who participate in the follow up	20 students X \$25 Gift Cards = \$500	\$500		
7	Supplies & Services: Production costs for 200 surveys (\$1361); transcription	Identify and explain use: Production of survey booklets for the 1st year medical students with	\$2,761		
8	Equipment	Identify and explain use.			
9	Travel				
10	Subtotal research supplies, equipment, travel, other		\$2,761.00	\$0.00	\$0.00
11	TOTAL BUDGET		\$18,511.00	\$0.00	\$0.00

1. Stipend justification. You must justify the amount of stipend you are requesting by identifying the number of hours you plan to work on the project and the hourly wage used for research assistants in your department. Include fringe benefits.
- 2-4. Identify all other personnel to be paid from this grant including interpreters, travel guides, etc. and justify their salary by identifying the number of hours they will work and the hourly wage. What is the hourly wage based on?
6. For colloquia, identify the number of speakers and the amount of honoraria you will provide.
7. Supplies and services. List out all supplies and their estimated costs. Explain in line 7 or in the body of your proposal what the supplies will be used for.
8. Equipment costs are allowable only if the justification clearly shows that the equipment is necessary for the project. Include explanation of what will happen to equipment at completion of project.
9. Travel costs must include a description of the purpose of the travel, start and stop dates of travel, transportation costs, housing costs, and allowable per diem (use University rates found at [http:// travel/umn.edu](http://travel/umn.edu)).

Title: Every Picture Tells a Story: Effects of Photographic Images on Perceptions and Attitudes about Genetic Conditions

WORK PLAN:

The long range objective of this project is to enhance the quality and effectiveness of genetic service provision by physicians and genetic counselors through development of a medical resource containing realistic, balanced information about common genetic conditions. We envision this resource to be in the format of a reference text for use by physicians and genetic counselors who talk to patients and families dealing with common genetic conditions.

This proposal requests support for the first phase of this project – generation of empirical evidence concerning the effects of photographic images of genetic disease and disability on perceptions and attitudes of the future providers of the majority of genetic healthcare services (medical students and genetic counseling students). To achieve this goal we will conduct a study in which we survey first year medical students at the University of Minnesota and first and second year genetic counseling students enrolled in graduate programs accredited by the American Board of Genetic Counseling (ABGC). Participants will read descriptions of two common genetic conditions. Through random assignment to experimental groups, one-third will receive only the descriptions; one-third will receive the descriptions and clinical photographs of a child with each condition; and one-third will receive the descriptions and professional photographs of a child with each condition showing the child participating in a common daily situation such as running at the camera or playing with a toy. Participants will respond to questions assessing their perceptions of the severity and burden of each genetic condition and the child's quality of life, as well as their attitudes about the parents' options (e.g., termination of an affected pregnancy, future reproductive decisions). We will assess differences in their responses as a function of experimental group and student specialty. We will conduct follow up interviews with 10 medical students and 10 genetic counseling students to obtain in-depth explanations of their survey responses. We are targeting medical students and genetic counseling students as they will be the healthcare professionals talking to patients and families about the impact of having a child with or being diagnosed as having a genetic condition.

PROJECT NATURE AND IMPORTANCE:

Visual imagery is a powerful source of information, affecting an individual's perceptions, attitudes, and behaviors. Visual images are a common component of healthcare. For instance, "Recorded photographic images of medical conditions aid health care providers in their study of disease etiology, course, and treatment effects." (Sutton et al., 2006, p. 260). Moreover, photographs often are used in the clinic setting to inform patients about the course and effects of medical conditions. Currently, clinical texts serve as reference books for providers when they discuss genetic conditions with patients and their family members. For instance, one widely used medical reference book is: *Smith's Recognizable Patterns of Human Malformation*^{6th} ed. (Jones, 2006). The publisher describes this book as "...the source to consult for guidance on diagnosis, prognosis, plan management, and genetic counseling... On opposing pages are several descriptive photographs and line

drawings of either an individual with the abnormality or specific features of the abnormality.” This book “provides over 1,450 photographs and illustrations to depict each malformation—many from the personal collections of Drs. Smith and Jones....” This reference text is one of the most commonly used resources by physicians and genetic counselors when talking to patients and families. The photographs contained in this and other reference books graphically portray genetic conditions in sterile medical settings. Although technically accurate, these photographs fail to “tell the whole story.” Missing are professional photographs that realistically portray a patient in her/his daily life.

In this project we will study the effects of different photographic images of genetic disease and disability on the perceptions and attitudes of future providers of healthcare services (medical students, genetic counseling students).

Research in social psychology has examined the effects of photographs of individuals with disabilities on non-disabled persons’ perceptions and attitudes (cf. Fellinghauer, Roth, Bugari, & Reinhardt, 2011; Gething, 1992). For instance Fellinghauer et al. (2011) found that healthcare professionals rated a person photographically portrayed in a wheel chair as less psychosocially adjusted than that same person portrayed sitting in a desk chair. To date only one study provides evidence of the possible effects of visual portrayals of genetic conditions on perceptions in a medical setting. Wexler et al. (2009) surveyed 600 parents who had a family member (age range: 1 yr-55 yrs) with Williams syndrome. They were asked to retrospectively report on positive and negative aspects of receiving their child’s diagnosis from healthcare providers. Negative effects included “being shown photographs in ‘textbooks’.” (p. 628). These data are based exclusively on self-report, rely on memory (in some cases about events that occurred several decades ago), and they represent only parents’ perceptions.

Presently, no published studies have systematically examined the effects of visual portrayals of genetic conditions on healthcare providers’ perceptions of severity and burden of the condition, and their attitudes about the patients’/family members’ options (e.g., termination of an affected pregnancy). An understanding of these effects is important because provider perceptions and attitudes may influence their interactions with patients. For example, they might alter the information they provide, the manner in which they provide it, and/or hold different opinions about patients’ and family members’ options. Furthermore, when healthcare providers show patients and family members photographs of individuals with a genetic condition, the type of photograph shown may significantly affect the patients’ and family members’ perceptions and attitudes and decisions regarding their options.

This proposed project will begin to address the research gap by generating empirical data from a large sample of students in health care professions. The findings will contribute to our long range objective, namely developing a medical reference book containing “real world” photographs of common genetic conditions and accompanying patient/family stories.

Research Design and Methods

We will conduct a mixed methods study in which we survey first year medical students (~N= 200) at the University of Minnesota, and first and second year genetic counseling students (~N=450) from the 33 ABGC accredited genetic counseling programs in North America. Participants will read descriptions of two common genetic conditions. Through random assignment, one-third will receive only the descriptions; one-third will receive the descriptions and clinical photographs of a child with each condition (photographs from a medical genetics textbook, reprinted with permission); and one-third will receive the descriptions and professional photograph of a child with each condition (reprinted with permission from *Positive Exposure*, a non-profit organization that uses photography to explore the experiences of individuals with genetic conditions). The clinical and professional photographs for each genetic condition will be matched on salient variables (patient gender, race, age; full or partial body view), and all will be in color.

Next participants will respond to questions assessing their perceptions of the severity and burden of each genetic condition and the child's quality of life, as well as their attitudes about the parents' options (e.g., termination of an affected pregnancy, future reproductive decisions). Medical students will complete a paper version of the survey. All first year medical students participate in small discussion group sessions ($n=15$) during the medical genetics course. Group leaders are practicing genetic counselors who will be enlisted to assist with administration of the survey during the first 15-20 minutes of these groups. Each student will complete the survey in an individual break-out room in order to avoid being influenced by other participants' reactions. After surveys are completed, the topic could be used to stimulate a discussion. Genetic counseling students will be invited to complete the same survey online. One of three different survey links will be provided randomly to genetic counseling students directing them to one of the three experimental conditions. We will statistically analyze all students' survey responses to assess differences as a function of experimental group (No Photographs, Clinical Photographs, Professional Photographs) and specialty (medical student, genetic counseling student). We hypothesize that participants who view the professional photographs will generally have more favorable perceptions and attitudes than participants who either view the clinical photographs, or no photographs.

Creation of the survey will be informed by a critical review of literature in medicine, genetic counseling, and psychology. Development of the descriptions of the genetic conditions and selection of photographs will be done in consultation with five expert genetic counselor consultants who will receive \$50 each for their efforts. Their input will substantiate the content validity of these stimulus materials.

We will conduct individual, 30-minute, semi-structured interviews with 10 medical students and 10 genetic counseling students to obtain in-depth explanations of their survey responses. Participants will receive \$25 gift cards to compensate them for their time. Development of the interview protocol will be informed by a critical review of

literature in medicine, genetic counseling, and psychology. Interviews will be recorded, transcribed, and coded for major themes.

Future Plans

The data generated from the present project will help to empirically substantiate the need for a medical reference book of this sort. Upon completion of this project, we will:

- (1) extend this study by surveying potential genetic counseling patients and practicing genetic counselors.
- (2) seek funding from private foundations to support the development of a reference book that contains “real world” professional photographs of individuals with common genetic conditions and accompanying patient/family stories. We have identified five foundations which we will target. We will work in consultation with Rick Guidotti from *Positive Exposure*. *Positive Exposure* is a non-profit organization ‘... whose innovative programs challenge the stigma associated with difference, celebrating the richness of human diversity.’ *Positive Exposure* uses professional photography to illustrate the person behind the disease. Rick specializes in genetic conditions and he has thousands of photographs of children and adults with a wide range of disorders.

FUNDING:

We request funding for the following:

1. A research assistant at 25% time to collect the data and assist with the data analysis for the project.
2. Funding for statistical consultation.
3. Honoraria for Genetic Counseling experts to review the descriptions of the genetic conditions and to assist in selecting the photographs used in this study.
4. Funding to produce the printed version of the survey tool.
5. Funding to compensate 20 students for participating in one, 30 minute interview.
6. Transcription services.

BIOGRAPHICAL SKETCH

The research team is uniquely qualified to conduct this work for several reasons. First, they are a cross-disciplinary team consisting of a director of an accredited genetic counseling graduate program and a licensed psychologist. They have collaborated on numerous research and educational projects for the past 20 years. For example, together, they co-authored the only basic helping skills text, DVD and workbook for genetic counselor training and supervision (McCarthy Veach et al., 2003; Nielson et al. 2004); conducted the only published work proposing a model of practice for genetic counseling (McCarthy Veach et al., 2007); and co-edited the only advanced practice teaching text for genetic counseling (LeRoy, et al., 2010). They have conducted grant-supported research - a national study of ethical and professional challenges encountered by primary care providers and genetic counselors when their patients have genetic concerns – resulting in a series of articles (Bower et al., 2002; McCarthy Veach et al., 2001; McCarthy Veach et al., 2002), a monograph, and on-line case-based materials for educating primary care providers about how to recognize and address ethical and professional challenges for patients with genetic concerns (LeRoy et al., 2002).

Principle Investigator, Bonnie LeRoy, MS, CGC is an associate professor in the Dept. of Genetics, Cell Biology and Development, faculty in the Institute of Human Genetics, and Associate Member of the Center for Bioethics. She is past president of the American Board of Genetic Counseling and National Society of Genetic Counselors. Currently she is serving as Editor-in-Chief of the *Journal of Genetic Counseling*.

Co-investigator, Patricia McCarthy Veach, PhD, is a full professor of Educational Psychology, Adjunct Professor in the Dept. of Genetics, Cell Biology and Development, Member of the Academy of Distinguished Teaching Professors at the U of M, and Associate Member of the Center for Bioethics. She is the Assistant Editor of the *Journal of Genetic Counseling*, and she teaches graduate students in genetic counseling.

Contact Information for PI: Department of Genetics, Cell Biology and Development and the Institute of Human Genetics, MMC 485, 420 Delaware St., SE, Minneapolis, MN 55455. Phone: (612) 624-7193; E-mail: leroy001@umn.edu

Every Picture Tells a Story: Effects of Photographic Images on Perceptions and Attitudes about Genetic Conditions

PROPOSED PROJECT TIMELINE

May 2011 – July 2011	Develop survey tool and interview protocol for project. Conduct literature review to inform survey development. Consult with genetic counseling experts on the development of descriptions of the genetic counseling conditions and the selection of photographs to be used in the survey. Obtain permission to reprint selected photographs. Pilot survey tool. Produce printed and online versions of survey.
August 2011	Collect data from 1 st year medical students at the University of Minnesota. The medical students are enrolled in the medical genetics course which begins in August each year. Recruit 10 medical students to participate in interviews and conduct interviews.
September 2011 – December 2011	Collect data from genetic counseling students enrolled in graduate programs accredited by the American Board of Genetic Counseling. All programs have a September start date. Recruit 10 genetic counseling students to participate in interviews and conduct interviews. Transcribe tapes from all interviews with medical and genetic counseling students ($n=20$) and code data from transcriptions.
January 2012 – April 2012	Analyze data from survey. Prepare manuscript for publication in a professional journal.
May 2012- June 2012	Submit proposal to present the study findings at the 2012 National Society of Genetic Counseling annual education conference.

BUDGET

RA	\$14,000.00	A Research Assistant at the minimum hourly amount (\$17.08 per hour including fringe) at 25% appointment will be \$7000 for one semester and we are requesting 2 semesters.
Statistical Consultation	\$1,000.00	We estimate that we will need 20 hours of statistical consultation to analyze the quantitative and qualitative data at \$50/ hour.
Expert Consultants	\$250.00	We will have 5 expert (experienced) genetic counselors assist with selecting the photographs and reviewing the case write ups for the survey. They will be reimbursed \$50 for their time.
Student Participants	\$500.00	Twenty students (10 medical students and 10 genetic counseling students) will participate in 30 minute interviews for the qualitative component of the study. They will each receive a \$25 gift card for their time.
Survey Production	\$1,361.00	We have a bid from Kinko's to produce 200 copies of the survey for use in the medical school genetics course. The survey will include 4 photographs and written copy. The bid is attached to this proposal.
Tape Transcription	\$1,400.00	We estimate that we will have 10 hours of tape. Transcription cost is \$35.00 per hour (based on 4 hrs. transcribing time per 1 hr. of tape).

TOTAL REQUESTED: \$18, 511.00

MATCHING FUNDS

The members of the research team will provide 5% in kind effort for 2011-2012 academic year to develop the survey tool and interview protocol, supervise the collection of data, analyze the survey and interview data, and prepare a manuscript for publication. The investigators will submit the findings for presentation at the 2012 National Society of Genetic Counselors annual education conference. Each investigator will use professional development funds to cover travel costs and other expenses related to the presentation of

the project at the NSGC meeting in 2012. In addition, the investigators will use the findings from the project to prepare a proposal for funding the development and publication of resource text for use by genetic counseling and physician practitioners who work with families with genetic disease.

INSTITUTIONAL REVIEW

Institutional Review Board approval for the proposed research is pending.

REFERENCES

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Consortium on Law and Values in Health, Environment the Life Sciences
Budget for Consortium and JDP Member Proposals

Every Picture Tells a Story: Effects of Photographic Images on Perceptions and Attitudes About Genetic Conditions

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