

Final Progress Report for Research Projects Funded by Health Research Grants

Instructions: Please complete all of the items as instructed. Do not delete instructions. Do not leave any items blank; responses must be provided for all items. If your response to an item is “None”, please specify “None” as your response. “Not applicable” is not an acceptable response for any of the items. There is no limit to the length of your response to any question. Responses should be single-spaced, no smaller than 12-point type. The report **must be completed using MS Word**. Submitted reports must be Word documents; they should not be converted to pdf format. Questions? Contact Health Research Program staff at 717-783-2548.

1. **Grantee Institution:** Philadelphia College of Osteopathic Medicine
2. **Reporting Period (start and end date of grant award period):** 1/1/2010 – 12/31/13
3. **Grant Contact Person (First Name, M.I., Last Name, Degrees):** Jane Z. Dumsha, Ph.D., CHES
4. **Grant Contact Person’s Telephone Number:** 215-871-6783
5. **Grant SAP Number:** 4100050905
6. **Project Number and Title of Research Project:** 1 - Psychological Functioning, Coping, and Factors Affecting Quality of Life in Persons with Long QT Syndrome.
7. **Start and End Date of Research Project:** 1/1/2010 – 12/31/13
8. **Name of Principal Investigator for the Research Project:** Stephanie H. Felgoise, PhD
9. **Research Project Expenses.**

9(A) Please provide the total amount of health research grant funds spent on this project for the entire duration of the grant, including indirect costs and any interest earned that was spent:

\$ 25,546.00

9(B) Provide the last names (include first initial if multiple individuals with the same last name are listed) of **all** persons who worked on this research project and were supported with health research funds. Include position titles (Principal Investigator, Graduate Assistant, Post-doctoral Fellow, etc.), percent of effort on project and total health research funds expended for the position. For multiple year projects, if percent of effort varied from year to year, report in the % of Effort column the effort by year 1, 2, 3, etc. of the project (x% Yr 1; z% Yr 2-3).

Last Name, First Name	Position Title	Institution	% of Effort on Project	Cost
Lawrence, Katherine	Graduate Research Assistant (Yr 1) Coordinator (Yr 2, 3, 4)	PCOM	20%, Yrs 1-4	\$1,000
Waldron, Elizabeth	Graduate Research Assistant	PCOM	20%, Yr 1, 2, 3, 4	\$1,000
Monk, Maggie	Graduate Research Assistant	PCOM	10%, Yr 1-4	\$500
Gentis, Karen	Graduate Research Assistant	PCOM	10%, Yr 2, 3, 4	\$500

9(C) Provide the names of **all** persons who worked on this research project, but who *were not* supported with health research funds. Include position titles (Research Assistant, Administrative Assistant, etc.) and percent of effort on project. For multiple year projects, if percent of effort varied from year to year, report in the % of Effort column the effort by year 1, 2, 3, etc. of the project (x% Yr 1; z% Yr 2-3).

Last Name, First Name	Position Title	% of Effort on Project
Felgoise, Stephanie	Principal Investigator	20%
Tress, Carmella	Graduate Research Coordinator (Yr 1), Assistant (Yr 2, 3)	20%, Yr 1, 5% Yrs 2, 3
Feinberg, Betsy	Graduate Research Assistant	5%, Yr 1
Zaccheo, Vincenzo	Graduate Research Assistant	5%, Yrs 1-4
Devins, Morgan	Graduate Research Assistant	2.5%, Year 1
Koskinen, Hillary	Graduate Research Assistant	2.5% Year 1
Muench, Alexandra	Graduate Research Assistant	2.5%, Year 4
Velez, Marisol	Graduate Research Assistant	2.5%, Year 4
Arnold, Mariah	Graduate Research Assistant	2.5%, Year 4
Gallagher, Thea	Graduate Research Assistant	2.5%
Brecher, Robert	Graduate Research Assistant	10%, Years 1, 2

Vetter, Victoria L.	Collaborator/Consultant	consultation
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9(D) Provide a list of **all** scientific equipment purchased as part of this research grant, a short description of the value (benefit) derived by the institution from this equipment, and the cost of the equipment.

Type of Scientific Equipment	Value Derived	Cost
None		

10. Co-funding of Research Project during Health Research Grant Award Period. Did this research project receive funding from any other source during the project period when it was supported by the health research grant?

Yes No

If yes, please indicate the source and amount of other funds:

The PCOM Department of Psychology provided funding for graduate research assistants.

11. Leveraging of Additional Funds

11(A) As a result of the health research funds provided for this research project, were you able to apply for and/or obtain funding from other sources to continue or expand the research?

Yes No

If yes, please list the applications submitted (column A), the funding agency (National Institutes of Health—NIH, or other source in column B), the month and year when the application was submitted (column C), and the amount of funds requested (column D). If you have received a notice that the grant will be funded, please indicate the amount of funds to be awarded (column E). If the grant was not funded, insert “not funded” in column E.

Do not include funding from your own institution or from CURE (tobacco settlement funds). Do not include grants submitted prior to the start date of the grant as shown in Question 2. If you list grants submitted within 1-6 months of the start date of this grant, add a statement below the table indicating how the data/results from this project were used to secure that grant.

A. Title of research project on grant application	B. Funding agency (check those that apply)	C. Month and Year Submitted	D. Amount of funds requested:	E. Amount of funds to be awarded:

None	<input type="checkbox"/> NIH <input type="checkbox"/> Other federal (specify: _____) <input type="checkbox"/> Nonfederal source (specify: _____)		\$	\$
	<input type="checkbox"/> NIH <input type="checkbox"/> Other federal (specify: _____) <input type="checkbox"/> Nonfederal source (specify: _____)		\$	\$

11(B) Are you planning to apply for additional funding in the future to continue or expand the research?

Yes _____ X _____ No _____

If yes, please describe your plans:

Data from this project has established mental health concerns and needs of persons with Long QT Syndrome (LQTS) that warrant further investigation with a larger sample size. To accomplish this goal, multisite collaboration is needed. Contacts have been made with other lead investigators in the LQTS field (as described in item 16, below), and funding will be sought for a large-scale observational study from the American Heart Association and smaller foundations and associations. The CURE funding and this project helped to identify specific target variables and areas for expansion of the research.

12. Future of Research Project. What are the future plans for this research project?

Specifically, the areas of Post Traumatic Stress Disorder, anxiety, quality of life, and social problem solving are psychological variables that will be targeted and investigated in a larger sample in future research. Adherence to medical recommendations will also be studied systematically. Dissatisfaction with emergency room care warrants advocacy and education for persons with LQTS, and will be pursued first by gathering more data from a larger sample, and then by developing educational materials to increase better consumerism by LQTS patients. Future research will attempt to recruit participants from a registry of genetically confirmed patients and will aim to increase racial and ethnic diversity in U.S. participants for a large scale observational study. Cross-cultural international research may also be a goal of future work, as Internet and social media options have shown to be viable means of recruitment. It is the future goal to introduce and advocate for mental health

screening of all LQTS patients during routine cardiology, diagnosis, and emergency care.

13. New Investigator Training and Development. Did students participate in project supported internships or graduate or post-graduate training for at least one semester or one summer?

Yes _____ x _____ No _____

If yes, how many students? Please specify in the tables below:

	Undergraduate	Masters	Pre-doc	Post-doc
Male				
Female			3	
Unknown				
Total			3	

	Undergraduate	Masters	Pre-doc	Post-doc
Hispanic				
Non-Hispanic			3	
Unknown				
Total			3	

	Undergraduate	Masters	Pre-doc	Post-doc
White			3	
Black				
Asian				
Other				
Unknown				
Total			3	

14. Recruitment of Out-of-State Researchers. Did you bring researchers into Pennsylvania to carry out this research project?

Yes _____ No _____

If yes, please list the name and degree of each researcher and his/her previous affiliation:

15. Impact on Research Capacity and Quality. Did the health research project enhance the quality and/or capacity of research at your institution?

Yes _____ No _____

If yes, describe how improvements in infrastructure, the addition of new investigators, and other resources have led to more and better research.

This project facilitated development of dissertation research projects in the Doctor of Psychology in Clinical Psychology program and created research opportunities for master's and doctoral students.

16. Collaboration, business and community involvement.

16(A) Did the health research funds lead to collaboration with research partners outside of your institution (e.g., entire university, entire hospital system)?

Yes _____ _____ No _____

If yes, please describe the collaborations:

Three well-known physicians specializing in LQTS research have gained knowledge of the research supported by this grant and intend to collaborate in the expansion of this project. Dr. Arthur Moss of University of Rochester committed to collaboration on a large-scale observational study via the LQTS Registry at University of Rochester. Dr. Irfan Asif from University of Tennessee agreed to collaborate in the submission of an American Heart Association grant for the observational study expansion. Dr. Victoria Vetter has continued her involvement in the LQTS research project and recruitment of her patients at the Children's Hospital of Philadelphia cardiology center. Lastly, National Research Corporation has donated the use of their empirically validated emergency room satisfaction survey to facilitate the research online.

16(B) Did the research project result in commercial development of any research products?

Yes _____ No _____

If yes, please describe commercial development activities that resulted from the research project:

16(C) Did the research lead to new involvement with the community?

Yes _____x_____ No _____

If yes, please describe involvement with community groups that resulted from the research project:

Research assistants have raised LQTS and sudden cardiac arrest (SCA) awareness on PCOM's campus by staffing tables with educational materials. Collaborations to raise awareness and advocacy efforts for persons with LQTS have begun with the Pediatric Medicine club on campus. The PI and research assistants helped raise money at the Plymouth Little League baseball field to purchase an automated external defibrillator for the seven baseball and softball fields. Recent involvement with Simon's Fund in Philadelphia has also begun, and the CEO of Simon's fund has visited campus to encourage advocacy for LQTS and heart screenings. Dr. Victoria Vetter has provided guest lectures at PCOM to educate professionals and health professionals students about cardiac rhythm disorders, such as LQTS. As a result of the research sponsored by this grant and related research, the PI has become a member of the medical advisory board of Parent Heart Watch and is consulting with the youth group "Connected by Hearts" that is developing through Parent Heart Watch. She has also been invited to the advisory board for the SADS Channelopathy registry.

17. Progress in Achieving Research Goals, Objectives and Aims.

List the project goals, objectives and specific aims (as contained in the grant agreement). Summarize the progress made in achieving these goals, objectives and aims for the period that the project was funded (i.e., from project start date through end date). Indicate whether or not each goal/objective/aim was achieved; if something was not achieved, note the reasons why. Describe the methods used. If changes were made to the research goals/objectives/aims, methods, design or timeline since the original grant application was submitted, please describe the changes. Provide detailed results of the project. Include evidence of the data that was generated and analyzed, and provide tables, graphs, and figures of the data. List published abstracts, poster presentations and scientific meeting presentations at the end of the summary of progress; peer-reviewed publications should be listed under item 20.

This response should be a DETAILED report of the methods and findings. It is not sufficient to state that the work was completed. Insufficient information may result in an unfavorable performance review, which may jeopardize future funding. If research findings are pending publication you must still include enough detail for the expert peer reviewers to evaluate the progress during the course of the project.

Health research grants funded under the Tobacco Settlement Act will be evaluated via a

performance review by an expert panel of researchers and clinicians who will assess project work using this Final Progress Report, all project Annual Reports and the project's strategic plan. After the final performance review of each project is complete, approximately 12-16 months after the end of the grant, this Final Progress Report, as well as the Final Performance Review Report containing the comments of the expert review panel, and the grantee's written response to the Final Performance Review Report, will be posted on the CURE Web site.

There is no limit to the length of your response. Responses must be single-spaced below, no smaller than 12-point type. If you cut and paste text from a publication, be sure symbols print properly, e.g., the Greek symbol for alpha (α) and beta (β) should not print as boxes (\square) and include the appropriate citation(s). DO NOT DELETE THESE INSTRUCTIONS.

Purpose:

This project was designed to identify and address the psychosocial needs of persons with Long QT Syndrome (LQTS) and distressed subsets of this population. Presently, little is known about the experience of anxiety, depression, quality of life or methods of coping in this population, despite the large numbers of people living with this life-threatening condition, significant lifelong medical treatments and restrictions on activity and diet, and the experience of cardiac arrest and revival in many of these patients. Information gained may inform medical and allied health professionals about the psychosocial aspects of living with LQTS. New knowledge will eventually be used to develop clinical resources, interventions, and services for delivery on the Internet and in medical inpatient and outpatient settings, and in the short-term, findings will support the need for larger scale research in this area.

The purpose of this project was achieved.

Objective:

To examine the psychological morbidity, coping skills, quality of life (QOL) and factors affecting QOL in adults with LQTS. *This objective was met.*

Specific Aims:

Specific Aim 1: To describe the psychological morbidity of a sample of adults with LQTS to identify areas of risk or need for intervention for this population.

Specific Aim 2: To examine if social problem solving skills (SPS) relate to psychological morbidity and health-related locus of control (HRLC), as it does in other medical populations, such that social problem solving skills may be a potential route of intervention for coping and adjustment to living with LQTS.

Specific Aim 3: To determine the QOL maintained by adults with LQTS and the relationship among QOL, HRLC, LQTS history, and compliance with medical recommendations.

Specific Aim 4: To examine LQTS patients' satisfaction with health care, as frequent users of primary care, cardiology, and emergency room services, and its relationship to LQTS history, SPS, and HRLC.

Specific Aim 5: To examine the relationship of religiosity and spirituality to QOL, psychological morbidity, LQTS history, and HRLC in adults with LQTS.

Specific Aim 6: To examine if there are differences between LQTS persons with and without

AICDs in psychological morbidity, QOL, HRLC, and religiosity/spirituality.

Specific Aim 7: To examine symptoms and expression of post traumatic stress disorder, generalized anxiety, and panic disorder in persons with LQTS who have experienced an LQTS-related loss, or an aborted SCA, or shocks from an ICD.

Summary of progress made to achieve specific aims:

The objectives and aims were achieved and significant areas of mental health needs for persons with LQTS were identified, along with an understanding of quality of life, coping skills, and factors affecting persons with LQTS. Based on the limited sample size, the findings may not be generalizable to all persons with LQTS, but the results substantiate the hypothesis that at least the subset of the LQTS population who participated in the study have poorer psychological health, lower quality of life, low satisfaction in emergency rooms, and high incidence of post traumatic stress disorder in persons who experienced cardiac events or had implantable devices, compared to norm scores of adults without LQTS.

Specific Aim 3 was partially accomplished. However, the measure used to evaluate compliance with medical recommendations may not be specific enough to LQTS to comment on LQTS-specific compliance. As a result, a future study is being designed. Specific Aim 6 was partially accomplished because data was collected on these variables, with meaningful results. However, the subset of the LQTS respondents who had implantable devices resulted in underpowered analyses, and must be interpreted cautiously. Specific Aim 7 was partially accomplished. Grief was not fully explored, due to the smaller sample size. However, the findings regarding PTSD are significant and dictate further study of the phenomena revealed by this project.

Research Design and Methods:

Inclusion/Exclusion Criteria:

The original proposal aimed to recruit 147 participants to meet power requirements for multiple regression analyses with 10 variables. The study did not meet the recruitment goal in years 1 and 2, despite major recruitment efforts. Therefore, usable data from 64 participants was collected.

Persons were included in the study if they met the following criteria:

- (a) 18 years or older.
- (b) Can read and write English sufficiently to complete the questionnaires.
- (c) Diagnosis of LQTS.

Persons were excluded from the study under the following circumstances:

- (a) Younger than 18 years of age.
- (b) Cardiac arrhythmia disorders other than LQTS.
- (c) Inability to read and complete questionnaires.

Procedure: Self-report data was collected and a cross-sectional observational design was employed via two different data collection methods for two arms of the study.

- 1) Recruitment of participants 18 years and older with LQTS was conducted via LQTS user group message boards, Facebook LQTS pages, informational websites focused on cardiac arrhythmias and sudden cardiac arrests, paid and unpaid posts on Craigslist, and university-based Web pages directing interested persons to a research phone line or email address (lqtstudies@pcom.edu) to request questionnaire packets via mail. Participants were given \$10 gift cards for time compensation once they sent an email stating they completed and mailed their data packets. Questionnaires were completed anonymously; completed packets were mailed separately from an email indicating completion (honor system) and the prompt for gift card compensation. Participants who requested packets and did not email that they completed questionnaires were sent reminders within two weeks of the original contact. All participants received a list of mental health websites and referral sources with the questionnaires. Data was managed by maintaining a log of the number of packets sent and the date when they were mailed and received.
- 2) Participants who sought medical services in an emergency room (ER) in the past year were recruited to participate in the research study by the same means listed above. However, questionnaires specific to ER, QOL, SPS, and personal information for those who sought care in the ER were completed online on a website, SurveyMonkey, that maintained the questions and allowed data to be downloaded into SPSS, Inc. software. Completers then followed the procedure above and emailed the research team at lqtstudies@pcom.edu to request gift card compensation. This additional method was added in the fourth year of the study to increase the sample size for the project specific to Aims 1, 2, 3, 4.

Definition and Measurement of Key Variables

All measures selected for this study (a) are commonly used with primary care patients or medical patients with chronic medical conditions (i.e., AICD, arrhythmias, cancer, heart failure), (b) have published acceptable psychometric data, (c) are age-appropriate, and (d) have also been used with nonpsychiatric (“normal”) adult populations. With the exception of the SPSI-R and the SCL-90, all measures are available free of charge.

- a. **Quality of Life.** Quality of life is operationally defined by the World Health Organization (WHO) as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (http://www.who.int/mental_health/media/en/76.pdf, p. 5 of 18). This definition focuses on individuals’ global perception of QOL, rather than their health-status or QOL directly affected by their health condition. QOL was measured by three measures in this study. The first was the 26-item **World Health Organization Quality of Life-Abbreviated Form (WHOQOL-BREF)**, (World Health Organization, 1997) a standard measure of QOL assessing four domains: psychological, physical, social relationships, and environment. The **McGill Quality of Life Single-Item Scale (MQOL-SIS)** was used, which consists of a single question in which patients rate their QOL over the preceding two days on a 0-10 scale. It has been modified for this study to reflect participants’ past week to be consistent with other measures being used. This is the first question of the MQOL (Cohen et al., 2005), and is being used as a measure of the patient’s own view of his

- or her QOL (Moons, Van Deyk, Budts, & DeGeest, 2004). It appears as the first question on the Personal Information Questionnaire. Lastly, the **Satisfaction with Life Scale (SWLS)**, a 5-item Likert-type questionnaire, measures general satisfaction with life, a closely related concept to QOL.
- b. **Psychological Morbidity.** Psychological morbidity is defined as expression of dysfunctional, disordered, or maladaptive psychological symptoms consistent with criteria set forth by the Diagnostic and Statistic Manual-IV (American Psychiatric Association, 1994). Assessment of this construct was limited to nine dimensions of psychological morbidity as defined by the **Symptom Distress Checklist-Revised (SCL-90-R)** (Derogatis, 1973), and the Global Severity of Index scale and Positive Symptom Distress Index. The nine dimensions include: Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Hostility, Depression, Phobic Anxiety, Anxiety, Paranoid Ideation, and Psychoticism. A combination of items also yields a post-traumatic stress screening score. The **PTSD Checklist-Civilian Version** (Ruggiero, Del Ben, Scotti, & Rabalais, 2003) is a 17-item measure of self-reported PTSD with Likert-type scales used to endorse the level of distress experienced within the past 30 days. This measure was completed by individuals who endorsed having had previous AICD shocks, aborted cardiac arrests, seizures, fainting, or witnessing a cardiac arrest or aborted arrest of a significant other.
- c. **Coping.** Coping is defined as a rational and systematic way of attempting to reduce, minimize, or control problems and related stress associated with such problems by way of changing the nature of a situation, one's reaction to it, or both (D'Zurilla & Nezu, 1999). In this project, the **Social Problem-Solving Inventory-Revised-Short Form for Research (SPSI-R-SF)**, a 25-item measure using a Likert-type scale, was used to measure social problem solving as a means of coping according to 5 subscales: negative problem orientation, positive problem orientation, rational problem-solving skills, avoidant style, and impulsive/careless style of coping. Additionally, the **BMMRS** (Brief Multidimensional Measure of Religiousness/Spirituality; Fetzer, 2003), a 38-item multidimensional measure of religiosity, was used to examine spirituality as a form of coping across 11 indices. The **Idler Index of Religiosity (IIR; Idler, 1987)**, a four-item measure, was used to measure public and private religiosity.
- d. **Patient Satisfaction With Healthcare.** Satisfaction with healthcare is based on subjective patient experiences and specific aspects of medical health care quality and access (Ware et al., 1983). Patient satisfaction has been shown to relate to compliance with medical treatment and overall health outcomes (DiMatteo & Hayes, 1980). This construct was measured by the **Patient Satisfaction Questionnaire-II** (Ware, Snyder, Wright, & Davies, 1984), which contains 55 Likert-type items that result in 18 subscales and 8 global scales. **Emergency Room Satisfaction** was measured by a standardized adult satisfaction survey developed and validated by NRC Picker, Inc., and used nationally for evaluation of major medical center emergency room services. Permission was granted for the use of the measure in this study. The measure evaluates the following dimensions: Access to Care, Continuity

- and Transition, Coordination of Care, Emotional Support, Information and Education, Involvement of Friends and Family, Patient Safety, Physical Comfort, and Respect for Patient Preferences. This measure was added after the initial proposal for the grant-funded study was submitted based on input from experts in the satisfaction survey field.
- e. **Health Locus of Control.** Health locus of control describes a person's beliefs about his/her health and how it is or is not determined by his/her own behavior, behavior by others, and by chance. Perceived control over health status has been shown to relate to compliance and decreased levels of distress. The **Multidimensional Health Locus of Control (MHLC)** is an 18-item measure of Internal Health Locus of Control, Powerful Others Health Locus of Control, and Chance Health Locus of Control. Given the unpredictable nature of LQTS related events, MHLC is important to measure, as patients' sense of control may be related to compliance behaviors. If patients perceive their LQTS events as random, they may have less belief in the need to comply with medical treatment. Conversely, if they have not had LQTS-related events, they may have less belief in their physicians' recommendations.
 - f. **Health Adherence Behavior Inventory (HABIT).** This measure was originated by R. A. DiTomasso in 1997 as a 50-item true-false questionnaire and validated for use in primary care settings (Parke, 2004). The statements measure real-life "habits" of people that are intended to reflect individuals' general health behaviors and adherence to medical recommendations. Statements include, "I try to avoid being around people who are smoking near me," "I eat my meals while doing other things," "I don't chew tobacco."
 - g. **Life Experiences.** Positive and negative life events are known to affect social, occupational, and individual functioning, as described by the DSM-IV Psychosocial Stressors scale. The **Life Experiences Survey (LES)** measures positive and negative events an individual may have experienced over the past year, and the individual's perceived positive or negative impact the event has had during the indicated timeframe. Inclusion of this measure in the current project helped to understand results of the psychological morbidity measure, PTSD measure, and QOL by providing a broader picture of the individuals' lives beyond living with LQTS. Life experiences can serve as a covariate, if significant events are reported in a majority of the population.
 - h. **Personal Information Questionnaire.** This questionnaire was designed to gather information about individuals' diagnoses of, experience with, and treatment of LQTS, their LQTS-related family history, behavioral compliance with LQTS treatment recommendations, demographic and socioeconomic information. Information gleaned from this questionnaire was used for descriptive purposes.

Statistical Analyses:

Data Screening. Data was screened for missing responses. Double scoring and spot-checking of data entry by research assistants and the PI was utilized to minimize errors in

data management. Ten percent of the data was randomly selected for accuracy verification by the principal investigator on a quarterly basis.

Descriptive Data Analysis.

Participants completing questionnaires via pencil-paper, and consisting of the majority of participants, included 13 males, 29 females, ranging in ages from 19-69 (X=36.67, SD=13.07). The type of LQTS reported by participants included: LQTS1 (n=18), LQTS2 (n=10), LQTS3 (n=2), unidentified gene (n=5), and other (n=4); 3 did not respond. These statistics suggest the sample reflects the primary types of LQTS seen in the population. Participants reported beginning treatment for LQTS at the ages of 7-62 (X=25.95, SD= 14.4), and the age of diagnosis coincided with these ages. Of those reporting an LQTS related event, the average number of events was 3 (range 1-5, N=41). 59.5% of the sample had neither a pacemaker nor an implantable cardioverter defibrillator (ICD); 3 had pacemakers; 4 had ICDs; 10 had ICD/pacemakers. Seven of the total respondents had received a shock to correct arrhythmia from their ICD at some time, and 8 persons had sought services in the ER in the past 6 months; 47.6% of respondents had sought mental health treatment (n=20). The sample had some racial diversity (2 Asian, 7 Black, 31 White, 2 multiracial persons), according to self-identification. Religious group affiliation was reported as 78.8% Christian, 2.4% Jewish, 9.5% Atheist, and 9.5% other. Participants resided in 21 U.S. states.

Of the 21 adults who completed the ER arm of the study via SurveyMonkey, ages ranged from 19-63 (x=49.15, SD=15.07), and 9 reported having genetically confirmed LQTS (6 LQTS1, 2 LQTS2, 1 LQTS3), 1 borderline LQTS, and the remainder reported “other.” Four of the 21 reportedly had ICDs, and mental health concerns of anxiety, depression, psychosis, and “other mental health disorder” were reported by 5 respondents. Five of 12 who replied to the question indicated they have sought mental health support at some point in time.

Results.

Specific Aim 1: 38 participants completed the SCL-90-R. Raw scores were transformed to area T-scores, per the manual’s directions. Transformation was done using norm scores from 974 “nonpatients” or community residents not known to have mental health problems. This sample was appropriate based on review of their reported characteristics, and because there has been no evidence establishing LQTS persons as having mental health difficulties. Findings revealed that the LQTS sample had mean scores one standard deviation above the normative sample on all of the subscales (Somatization, Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobia, Psychoticism), except Paranoid Ideation, and including the Global Severity Index, Positive Symptom Distress Index, and the Positive Symptom Total. Greatest relative inflation was seen on Depression subscale, Psychoticism subscale, Somatization Subscale, and Interpersonal Sensitivity Subscale. (See Table 1a).

Table 1a. Descriptives of Symptoms Checklist 90 Revised (SCL-90-R)

Scale	N	Minimum	Maximum	Mean	Std. Deviation
Somatization	38	35	80	62.76	11.831

Obsessive-Compulsive	38	37	80	61.32	13.759
Interpersonal Sensitivity	38	39	80	62.66	14.081
Depression	38	34	80	64.03	11.698
Anxiety	38	37	80	60.18	14.476
Hostility	38	41	80	60.05	13.23
Phobia	38	41	80	61.42	12.017
Paranoid Ideation	38	40	80	56.92	15.027
Psychoticism	38	44	80	63.76	13.439
Global Severity Index	38	5	80	62.47	16.064
Positive Symptom Distress Index	37	48	80	61.65	9.801
Positive Symptom Total	38	30	79	62.47	12.721

Specific Aim 2: The Social Problem-Solving Skills-Revised (SPSI-R) measures 5 domains of this construct, and the first sample of LQTS adults performed comparably to “normal” adults on all subscales. Raw scores are converted to standard scores, with a mean of 100 and a standard deviation of 15 (see Table 2a). The second sample of LQTS participants who had been to the ER in the past year showed maladaptive problem solving skills, compared to norm scores (see Table 2b). It is possible that individuals with poorer problem solving skills tend to use emergency room services more than those who have more effective problem solving skills, although this comparison was not directly made. The Multidimensional Health Locus of Control (MHLC) measures different aspects of this construct, and greater scores mean higher sense of these aspects of control. The possible range of scores for the Internal, Chance, and Powerful Others scales is 6-36; Doctors and Other People range is 3-18. Compared to the “normal” sample provided by Wallston, Wallston, and DeVellis (1978), persons with LQTS had slightly lower mean scores on the Internal Locus of Control Scale, higher scores on the Chance scale, and about the same scores on the Powerful Others score (see Table 2a). Their sense of control by doctors seems relatively lower, although there is limited guidance in how to interpret these findings. Further investigation is needed. MHLOC Internal was not significantly correlated with any of the SPSI-R subscales, suggesting that ability to problem solve rationally, or beliefs about problems in daily living, is not related to a sense of control. This is different than with other medical populations. Perception of control being due to Chance was correlated with SPSI-NPO ($r = .365, p = .024, N=38$), suggesting a negative view of problems, and feeling one has little ability to solve problems in daily living is related to the belief that health is related to chance. Powerful Others, and MHLOC Doctors were also not significantly related to social problem-solving dimensions. This finding was not expected, and suggests that persons with LQTS do not

have an overinflated sense of lack of control, or internal control, and may not relate to their problem solving abilities, which seem average, overall.

Table 2a. Descriptives of Social Problem Solving Inventory-Revised (SPSI-R) and Multidimensional Health Locus of Control (MHLOC) for Sample 1

Scale	N	Minimum	Maximum	Mean	Std. Deviation
SPSI Positive Problem Orientation	38	54	131	98.45	18.657
SPSI Negative Problem Orientation	38	74	154	100.79	19.749
SPSI Rational Problem Solving	38	56	136	100.24	17.548
SPSI Impulsivity Carelessness Style	38	73	158	100.63	20.345
SPSI Avoidant Style	38	78	138	100.76	15.762
SPSI Total	38	62	136	100.87	16.545
MHLOC Internal	42	10	35	24.76	5.268
MHLOC Chance	42	12	32	19.17	4.690
MHLOC Powerful Others	42	13	36	20.90	4.172
MHLOC Doctors	42	6	18	9.90	2.593
MHLOC Other People	42	6	18	11.29	2.578

Table 2b. Descriptives of Social Problem Solving Inventory-Revised (SPSI-R) for the 2nd Sample of Long QT Syndrome (LQTS) Participants

Scale	N	Minimum	Maximum	Mean	Std. Deviation
SPSI Negative Problem Orientation	15	93	146	117.13	16.92
SPSI Rational Problem	10	101	136	117.3	10.11

Solving					
SPSI Impulsivity-Carelessness	10	109	157	130.2	16.55
SPSI Avoidant Style Standard Score	10	105	153	127.4	15.34
SPSI Positive Problem Orientation	12	100	131	120	9.52

As has been seen typically with individuals with psychological morbidity, SPS were found to be significantly correlated with most subscales of the SCL-90R (see Table 2c). These findings suggest that improving social problem solving skills may improve psychological functioning, or that those with poorer psychological functioning may be less effective in their problem solving abilities and may have a more negative view toward problems in daily living and their self-efficacy to handle daily problems. MHLOC was not tested as a mediator, since there were no significant relationships noted between MHLOC and SPSIR.

Table 2c. Correlations between Social Problem Solving Inventory-Revised (SPSI-R) and Symptoms Checklist 90 Revised (SCL-90R) Measures

Scale	PPO	NPO	RPS	ICS	AS	SPSI Total
SCL90R Somatization	.091	.571**	.205	.577**	.537**	-.428**
SCL90R Obsessive-Compulsive	.060	.633**	.208	.658**	.571**	-.478**
SCL90R Interpersonal Sensitivity	.088	.453*	.075	.496*	.499*	-.351
SCL90R Depression	.036	.567**	.106	.619**	.599**	-.481*
SCL90R Anxiety	-.041	.655**	.110	.666**	.697**	-.560**
SCL90R Hostility	.001	.629**	.073	.684**	.638**	-.516**
SCL90R Phobia	-.160	.436*	.150	.355	.477**	-.366
SCL90R Paranoid Ideation	.064	.526**	.014	.599**	.595**	-.434*
SCL90R Psychoticism	.182	.590**	.226	.624**	.626**	-.428*

SCL90R Global Severity Index	.158	.575**	.215	.608**	.577**	-.406
SCL90R Positive Symptom Distress Index	-.078	.482**	-.031	.437*	.370	-.358

*p<.01, **p<.001

NPO= Negative Problem Orientation, RPS= Rational Problem Solving, ICS= Impulsivity/Carelessness Style, AS= Avoidance Style, PPO= Positive Problem Orientation: N=37 for all correlations, except N=36 for correlations with the SCL-90-R Positive Symptom Index.

Specific Aim 3: Persons with LQTS reported poor quality of life, according to the WHOQOL-BREF, and in comparison to normative scores based on an Australian population that was deemed the closest in cultural characteristics among the normative data available in the literature (Hawthorne, Herrman, & Murphy, 2006). Overall, persons with LQTS reported significantly poorer QOL across domains and age groups. Table 3a shows the average WHOQOL-BREF scores from the LQTS sample 1. Persons with LQTS in the 20-29 age group, and 50-59 age group showed the greatest difficulty in Psychological Functioning (Domain 1; data not presented below), although an ANOVA comparing age groups across domains suggested females showed differences in Social Functioning and Physical Functioning and not in Psychological Functioning and Environmental Functioning (See Table 3b). Males showed no differences across age groups on any of the four domains (See Table 3c); however, both of these ANOVAs are likely underpowered to detect significant differences.

Table 3a. World Health Organization Quality of Life (WHOQOL-BREF) and Satisfaction with Life Scores (SWLS) for Persons with Long QT Syndrome (LQTS) in Sample 1 (N=42).

Scale	Mean	Median	Mode	Std. Deviation	Minimum	Maximum
WHOQOL1	56.05	56.00	38	18.575	19	94
WHOQOL2	57.60	56.00	56	18.751	6	88
WHOQOL3	55.79	56.00	56	20.569	25	100
WHOQOL4	63.19	63.00	50	17.690	25	100
SWLS	20.45	22.00	22	7.229	8	32

Table 3b. ANOVA Comparing Age Groups Across Domains of Quality of Life by the World

Health Organization Quality of Life (WHOQOL) in Females with Long QT Syndrome (LQTS)

Scale	Sum of Squares	df	Mean Squares	F	Significant
WHOQOL 1					
Between Groups	2925.758	4	731.440	2.324	.086
Within Groups	7552.104	24	314.67		
Total	10477.862	28			
WHOQOL2					
Between Groups	1989.962	4	497.490	1.226	.326
Within Groups	9737.832	24	405.743		
Total	11727.793	28			
WHOQOL3					
Between Groups	3488.063	4	872.016	3.201	.031
Within Groups	6537.247	24	272.385		
Total	10025.310	28			
WHOQOL4					
Between Groups	1523.885	4	380.971	1.223	.327
Within Groups	7473.288	24	311.387		
Total	8997.172	28			

Table 3c. ANOVA Comparing Age Groups Across Domains of Quality of Life by the World Health Organization Quality of life (WHOQOL) Measure in Males with Long QT Syndrome (LQTS)

Scale	Sum of Squares	df	Mean Squares	F	Sig.
WHOQOL 1					
Between Groups	695.333	4	17.833	.468	.758
Within Groups	2972.667	8	371.583		
Total	3668.000	12			
WHOQOL 2					
Between Groups	1356.103	4	339.026	2.038	.182
Within Groups	1330.667	8	166.333		
Total	2686.769	12			
WHOQOL 3					
Between Groups	1259.026	4	314.756	.415	.793
Within Groups	6062.667	8	757.833		
Total	7321.692	12			
WHOQOL 4					

Between Groups	1084.256	4	271.064	1.236	.369
Within Groups	1754.667	8	219.333		
Total	2838.923	12			

Specific Aim 4: Patient experiences in the Emergency Department are predominantly negative, according to NRC Adult Satisfaction Survey and (Personal Information Questionnaire) PIQ measures (see Table 4a, 4b, and 4c). The sample size was too small to analyze the ER satisfaction data in relation to SPS for this sample. As data collection continues, data will be analyzed for a future project.

Table 4a. Adult Patient Satisfaction with Emergency Department, NRC Adult Satisfaction Survey from Sample 2 of Long QT Syndrome (LQTS) Persons.

Dimensions	Positive	N
Access to Care	22%	13
Continuity and Transition	15%	13
Coordination of Care	15%	13
Emotional Support	21%	13
Information and Education	27%	12
Involvement of Family and Friends	20%	10
Patient Safety	0%	4
Physical Comfort	0%	7
Respect for Patient Preferences	22%	10

Table 4b. Questions from the Personal Information Questionnaire (PIQ) about Emergency Room Experiences from Sample 2 Long QT Syndrome (LQTS) Persons.

Question	Scale				
Was the Emergency Department physician...	(1) Not at all	2	(3) Neutral	4	(5) Very Much So
friendly?	0.00%	0.0%	26.7%	13.3%	3.30%
generally knowledgeable?	0.00%	3.30%	23.30%	13.30%	3.30%
knowledgeable about LQTS?	6.70%	20.00%	6.70%	6.70%	3.30%
helpful in treating LQTS?	13.30%	13.30%	6.70%	6.70%	3.30%

Table 4c. Personal Information Questionnaire Results from Sample 2 of Long QT Syndrome (LQTS) Persons

Question	Scale				
Did your Emergency Department physician...	(1) Not at all	2	(3) Neutral	4	(5) Very Much So

respond to your presenting symptoms?	3.30%	16.70%	13.30%	6.70%	3.30%
clearly explain what you should do at home?	3.30%	20%	10%	6.70%	3.30%
answer all of your questions	3.30%	16.70%	13.30%	6.70%	3.30%
answer all of your questions about LQTS?	13.30%	6.70%	13.30%	10.00%	0.00%
encourage you to talk about your worries?	13.30%	3.30%	23.30%	3.30%	0.00%
ask for your opinion about treatment?	20.00%	3.30%	16.70%	3.30%	0.00%
spend enough time talking to you?	0.00%	16.70%	16.70%	3.30%	6.70%
treat you with respect?	0.00%	0.00%	26.70%	10.00%	6.70%
listen to you?	0.00%	6.70%	20.00%	10.00%	6.70%
explain your condition?	6.70%	10.00%	20.00%	3.30%	3.30%
involve you in the decision-making process?	10.00%	3.30%	13.30%	10.00%	3.30%
give you a sense of control over your medical care?	13.30%	3.30%	16.70%	10.00%	0.00%
address your tests properly?	6.70%	6.70%	16.70%	6.70%	3.30%

Specific Aim 5:

In comparison to “healthy” adults who are caregivers of Amyotrophic Lateral Sclerosis (ALS) patients (Chakraborty, 2007; $X=98$, $SD=25.87$), the LQTS sample reported lower overall spirituality, according to their BMMRS Total Score ($X=94.95$, $SD=26.60$). The possible range of scores on the BMMRS is 36 to 176, with highest scores indicating a tendency to be more religious and spiritual. Pearson Product Moment correlations revealed no significant correlations between psychological morbidity and spirituality, according to the SCL-90-R and BMMRS scales, with one exception Interpersonal sensitivity (SCL-90R) and BMMRS Religious History scales were correlated ($r=.365$, $p = .026$, $N=37$). However, this correlation does not appear to have obvious clinical meaning. As such, spirituality does not seem to be related to psychological morbidity or well-being, and will be further explored in the future regarding relevance to coping with LQTS, with a larger sample size. Some subscales of Spirituality were correlated with WHOQOL-Domain 1 (Psychological Functioning), which warrants additional analyses and considerations for the future. However, since there was no relationship with spirituality and psychological well-being, commentary on these variables are not reported.

Specific Aim 6: Persons with LQTS and ICDs and/or pacemakers typically are thought to be at greater risk for cardiac arrest, have a significant family history of arrest, or have arrested prior to device placement. The small sample size suggests caution in interpretation of the one-way ANOVA is warranted. However, significant differences between groups exist when comparing persons with a pacemaker, an ICD, both, or neither, across the four domains of WHOQOL-BREF. See Table 6a. Analyses showed differences in Domain 2 (Physical Functioning) between those with pacemakers and those with ICDs (Scheffe, $p=.035$; Bonferroni, $p = .023$), but the sample size within each group was small and the test was underpowered, so caution is recommended in interpreting the results. Given the small sample sizes of persons with implantable devices, the additional proposed analyses are deferred until more data is collected in the future.

Table 6a. Differences in World Health Organization Quality of Life (WHOQOL-BREF) Domains between Sample 1 of Long QT Syndrome LQTS Persons with Pacemakers, ICDs, Both, or No Implantable Device (N=41).

Scale	Sum of Squares	df	Mean Squares	F	Significant
WHOQOL 1					
Between Groups	1693.315	3	564.438	1.722	.179
Within Groups	12452.590	28	327.700		
Total	14145.905	41			
WHOQOL 2					
Between Groups	3001.792	3	1000.597	3.331	.029

Within Groups	11414.327	38	300.377		
Total	14416.119	41			
WHOQOL 3					
Between Groups	492.565	3	164.188	.370	.775
Within Groups	16854.507	38	443.540		
Total	17347.071	41			
WHOQOL 4					
Between Groups	756.100	3	252.033	.793	.505
Within Groups	12074.377	38	317.747		
Total	12830.476	41			
Satisfaction with Life Scale (SWLS)					
Between Groups	193.948	3	64.649	1.261	.302
Within Groups	1948.457	38	51.275		
Total	2142.405	41			

Specific Aim 7: 35 of 42 adults who participated in study experienced at least 1 LQTS related cardiac event. 27 had complete data (71.4% female; mean age=36; avg. cardiac events=3.5). 40% met criteria for PTSD, according to the Posttraumatic Checklist (PCL) (See Table 7a). Responses on the PCL scales were evaluated for relationship to SPS. Findings showed that PPO was not significantly related to PTSD symptoms. NPO was significantly correlated with many PTSD symptoms, including Emotional Reaction ($r=.488, p=.01$), Avoidance of Activities ($r=.431, p=.025$), Emotional Numbing ($r=.527, p=.005$), and Irritability ($r=.531, p=.004$). While the sample was small, negative problem orientation addresses one's view of problems in daily living, one's sense of control over problems and ability to handle them. It is commonly a target for treatment intervention, and therefore, this relationship is deemed worthy of further research exploration. The current study may be the first to identify LQTS patients reporting PTSD symptoms, and certainly warrants more attention. variables.

Table 7a. PCL Checklist completed by Sample 1 of LQTS Participants (N=30).

Scale	N	Minimum	Maximum	Mean	Std. Deviation
PCL Q1	30	1.00	5.00	2.7333	1.33735
PCL Q2	30	1.00	5.00	2.5000	1.52564
PCL Q3	30	1.00	5.00	2.3000	1.46570
PCL Q4	30	1.00	5.00	2.7000	1.36836

PCL Q5	30	1.00	5.00	2.5000	1.47975
PCL Q6	30	1.00	5.00	2.7667	1.35655
PCL Q7	30	1.00	5.00	2.6000	1.54474
PCL Q8	30	1.00	5.00	1.9000	1.37339
PCL Q9	30	1.00	5.00	2.2667	1.33735
PCL Q10	30	1.00	5.00	2.7000	1.39333
PCL Q11	30	1.00	5.00	2.0000	1.31306
PCL Q12	30	1.00	5.00	2.7667	1.54659
PCL Q13	30	1.00	5.00	2.8000	1.60602
PCL Q14	30	1.00	5.00	2.7333	1.33735
PCL Q15	30	1.00	5.00	2.4667	1.27937
PCL Q16	30	1.00	5.00	2.4667	1.25212
PCL Q17	30	1.00	5.00	2.2333	1.33089
PCL PTSD Diagnosed	30	0	1	.40	.498
PCL Total Score	30	20	81	42.43	18.122

Limits to data procedures (measures, recruitment, selection) and alternative approaches.

Collecting data via online recruitment poses potential threats of selection biases due to voluntary status of participants, inability to verify LQTS diagnosis, risk for overrepresentation of persons from one family lineage, likelihood of capturing persons who have computer access and knowledge of computer use that may differentiate them from persons with LQTS without those privileges. However, the ability to reach a large portion of the population makes this data collection method seem most appropriate for a study aiming to collect pilot data for higher-constraint studies in the future. Measures used in this study are not previously validated or normed on the LQTS population; however, many have been used with other congenital heart disease patients, normal samples, and people with other chronic disorders. There is not an identifiable control group to be used in this study, as there are no bases for selecting what an appropriate control group would be. It is possible that the time required for completion of measures may be a deterrent from participation; however, the principal investigator had success with this methodology in a QOL study of persons with irritable bowel syndrome in 2005-2006 (Davis, 2008; Heckert, 2008; McCleary, 2007),

which suggests this method is viable.

The previous data yielded accepted poster presentations at the following conferences:

Felgoise, S. H., Corvi, K., & Waldron, E. A. (2014). Social Problem-Solving Orientation and PTSD Symptoms in Adults with LQTS Who Experienced Cardiac Events. Poster accepted to Society for Behavioral Medicine, Philadelphia, PA.

Felgoise, S. H., Lawrence, K., & Vetter, V. L. (2013). LQTS Patients' Satisfaction with Emergency Department Care. Poster presentation at the Association for Behavioral and Cognitive Therapies Annual Conference, Nashville, TN.

The previous data yielded a submitted abstract for a poster presentation at the following conference:

Felgoise, S. H. & Corvi, K. (2014). Caregivers' Satisfaction with Emergency Room Care for Children with LQTS. Poster submitted to Society for Behavioral Medicine, Philadelphia, PA.

18. Extent of Clinical Activities Initiated and Completed. Items 18(A) and 18(B) should be completed for all research projects. If the project was restricted to secondary analysis of clinical data or data analysis of clinical research, then responses to 18(A) and 18(B) should be "No."

18(A) Did you initiate a study that involved the testing of treatment, prevention or diagnostic procedures on human subjects?

_____ Yes
___x___ No

18(B) Did you complete a study that involved the testing of treatment, prevention or diagnostic procedures on human subjects?

_____ Yes
___x___ No

If "Yes" to either 18(A) or 18(B), items 18(C) – (F) must also be completed. (Do NOT complete 18(C-F) if 18(A) and 18(B) are both "No.")

18(C) How many hospital and health care professionals were involved in the research project?

_____ Number of hospital and health care professionals involved in the research project

18(D) How many subjects were included in the study compared to targeted goals?

_____ Number of subjects originally targeted to be included in the study
_____ Number of subjects enrolled in the study

Note: Studies that fall dramatically short on recruitment are encouraged to provide the details of their recruitment efforts in Item 17, Progress in Achieving Research Goals, Objectives and Aims. For example, the number of eligible subjects approached, the number that refused to participate and the reasons for refusal. Without this information it is difficult to discern whether eligibility criteria were too restrictive or the study simply did not appeal to subjects.

18(E) How many subjects were enrolled in the study by gender, ethnicity and race?

Gender:

Males
 Females
 Unknown

Ethnicity:

Latinos or Hispanics
 Not Latinos or Hispanics
 Unknown

Race:

American Indian or Alaska Native
 Asian
 Blacks or African American
 Native Hawaiian or Other Pacific Islander
 White
 Other, specify: _____
 Unknown

18(F) Where was the research study conducted? (List the county where the research study was conducted. If the treatment, prevention and diagnostic tests were offered in more than one county, list all of the counties where the research study was conducted.)

19. Human Embryonic Stem Cell Research. Item 19(A) should be completed for all research projects. If the research project involved human embryonic stem cells, items 19(B) and 19(C) must also be completed.

19(A) Did this project involve, in any capacity, human embryonic stem cells?

Yes
 No

19(B) Were these stem cell lines NIH-approved lines that were derived outside of Pennsylvania?

Yes

_____ No

19(C) Please describe how this project involved human embryonic stem cells:

20. Articles Submitted to Peer-Reviewed Publications.

20(A) Identify all publications that resulted from the research performed during the funding period and that have been submitted to peer-reviewed publications. Do not list journal abstracts or presentations at professional meetings; abstract and meeting presentations should be listed at the end of item 17. **Include only those publications that acknowledge the Pennsylvania Department of Health as a funding source** (as required in the grant agreement). List the title of the journal article, the authors, the name of the peer-reviewed publication, the month and year when it was submitted, and the status of publication (submitted for publication, accepted for publication or published.). Submit an electronic copy of each publication or paper submitted for publication, listed in the table, in a PDF version 5.0.5 (or greater) format, 1,200 dpi. Filenames for each publication should include the number of the research project, the last name of the PI, and an abbreviated title of the publication. For example, if you submit two publications for Smith (PI for Project 01), one publication for Zhang (PI for Project 03), and one publication for Bates (PI for Project 04), the filenames would be:

- Project 01 – Smith – Three cases of isolated
- Project 01 – Smith – Investigation of NEB1 deletions
- Project 03 – Zhang – Molecular profiling of aromatase
- Project 04 – Bates – Neonatal intensive care

If the publication is not available electronically, provide 5 paper copies of the publication.

Note: The grant agreement requires that recipients acknowledge the Pennsylvania Department of Health funding in all publications. Please ensure that all publications listed acknowledge the Department of Health funding. If a publication does not acknowledge the funding from the Commonwealth, do not list the publication.

Manuscripts are in preparation stage and will be submitted to Emergency Medicine journals, cardiology, genetic counseling, and multidisciplinary journals such as Anals of Behavioral Medicine. A summary of results with acknowledgements to Dept of Health will also be posted to the SADS.org website.

Title of Journal Article:	Authors:	Name of Peer-reviewed Publication:	Month and Year Submitted:	Publication Status (check appropriate box below):
1. None				<input type="checkbox"/> Submitted <input type="checkbox"/> Accepted <input type="checkbox"/> Published

2.			<input type="checkbox"/> Submitted <input type="checkbox"/> Accepted <input type="checkbox"/> Published
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20(B) Based on this project, are you planning to submit articles to peer-reviewed publications in the future?

Yes X No _____

If yes, please describe your plans:

Although the exact journals for submission have not been selected, it is planned to submit in the Summer of 2014 the results from the Emergency Room study, adult sample, in a journal such as one of the following: *Emergency Medicine Journal, Annals of Emergency Medicine, Journal of Emergency Medicine, The American Journal of Emergency Medicine, Emergency Medicine, or the International Journal of Emergency Medicine*. The journal will be selected based on identification of the journal most interested in psychosocial aspects, and one that may have published data on arrhythmia disorders in the past. If additional data collection permits separate analysis of parents of children who presented to the ER, a second publication may also be submitted. The data from the Internet-Based Study will be submitted to a journal such as *Heart Rhythm, or the Journal of Interventional Cardiac Electrophysiology, Cardiac Electrophysiology, Circulation: Arrhythmia and Electrophysiology*.

21. Changes in Outcome, Impact and Effectiveness Attributable to the Research Project.

Describe the outcome, impact, and effectiveness of the research project by summarizing its impact on the incidence of disease, death from disease, stage of disease at time of diagnosis, or other relevant measures of outcome, impact or effectiveness of the research project. If there were no changes, insert “None”; do not use “Not applicable.” Responses must be single-spaced below, and no smaller than 12-point type. DO NOT DELETE THESE INSTRUCTIONS. There is no limit to the length of your response.

None

22. Major Discoveries, New Drugs, and New Approaches for Prevention Diagnosis and Treatment.

Describe major discoveries, new drugs, and new approaches for prevention, diagnosis and treatment that are attributable to the completed research project. If there were no major discoveries, drugs or approaches, insert “None”; do not use “Not applicable.” Responses must be single-spaced below, and no smaller than 12-point type. DO NOT DELETE THESE INSTRUCTIONS. There is no limit to the length of your response.

Major discoveries include the first known exploration of mental health symptoms and aspects of quality of life for adults living with Long QT Syndrome. The incidence of PTSD symptoms in this population is striking, and secondary prevention could be instituted for persons with LQTS. Furthermore, findings establish the mental health needs of persons with

LQTS, such that a larger study providing greater generalizability is indicated.

23. Inventions, Patents and Commercial Development Opportunities.

23(A) Were any inventions, which may be patentable or otherwise protectable under Title 35 of the United States Code, conceived or first actually reduced to practice in the performance of work under this health research grant? Yes _____ No X

If “Yes” to 23(A), complete items a – g below for each invention. (Do NOT complete items a - g if 23(A) is “No.”)

- a. Title of Invention:
- b. Name of Inventor(s):
- c. Technical Description of Invention (describe nature, purpose, operation and physical, chemical, biological or electrical characteristics of the invention):
- d. Was a patent filed for the invention conceived or first actually reduced to practice in the performance of work under this health research grant?
Yes _____ No _____

If yes, indicate date patent was filed:

- e. Was a patent issued for the invention conceived or first actually reduced to practice in the performance of work under this health research grant?
Yes _____ No _____
If yes, indicate number of patent, title and date issued:
Patent number:
Title of patent:
Date issued:

- f. Were any licenses granted for the patent obtained as a result of work performed under this health research grant? Yes _____ No _____

If yes, how many licenses were granted? _____

- g. Were any commercial development activities taken to develop the invention into a commercial product or service for manufacture or sale? Yes ___ No ___

If yes, describe the commercial development activities:

23(B) Based on the results of this project, are you planning to file for any licenses or patents, or undertake any commercial development opportunities in the future?

Yes _____ No

If yes, please describe your plans:

24. Key Investigator Qualifications. Briefly describe the education, research interests and experience and professional commitments of the Principal Investigator and all other key investigators. In place of narrative you may insert the NIH biosketch form here; however, please limit each biosketch to 1-2 pages. *For Nonformula grants only – include information for only those key investigators whose biosketches were not included in the original grant application.*

CoA Abbreviated Curriculum Vita

Name: Stephanie Felgoise

Highest Degree Earned: Ph.D. Psy.D. Ed.D. Other:

Date of Degree: May 1998

Substantive Area of Degree Clinical Psychology

Institution Awarding Degree: Hahnemann University

APA or CPA Accredited Doctoral Program: No: Yes:

Psychology Internship Completed: No: ___ Yes: Year: 1997-8

Name of Program: Robert Wood Johnson Medical School/University Behavioral Healthcare

Type of Setting: Medical School and Community Mental Health

APA/CPA Accredited Internship: No: Yes:

Psychology Postdoctoral Residency Completed: No: ___ Yes: Year: 1998-1999

Name of Program: Hahnemann University and Hospital

Type of Setting: Academic and Hospital

APA/CPA Accredited Postdoctoral Residency: No: Yes:

Area of Emphasis: Clinical Health Psychology and Research

Psychology Licensure: No: Yes: State/Provinces: PA

ABPP Diplomate: No: ___ Yes: Specialty: Clinical Psychology

Currently listed in National Register and/or Candian Register? No: Yes:

Primary Professional appointment:

Position title: Vice-Chair & Associate Professor; Director, PsyD Program in Clinical Psychology; Department of

Psychology, Philadelphia College of Osteopathic Medicine

Type of Setting: Academic

Academic Position, Rank, Tenure-Status, Year of Appointment to Program under Review:

Promoted to Professor as of July 1, 2009; Have tenure since 2005; Appointed to Department/Program as Assistant Professor in July 1999.

Describe Clinical/Services Delivery Position or Responsibilities in current position:

Program Director. Course instructor for 6- 9 credits/year. Dissertation advisement, Chair. Academic advisement. Program committee work (i.e., Research, Curriculum. SPEC).

Supervisor for 1 hour/week for practicum or internship student in the Center for Brief Therapy, PCOM. College responsibilities to serve on committees as designated by the Dean. Currently Chair, Academic Budget & Planning Committee; Member, Graduate Programs Curriculum Committee and Graduate Programs Admissions Committee; Rep-at-Large, Executive Faculty; Member, Center for Chronic Disease of Aging grant review committee. Study Group of Faculty, Chair, Committee on Accreditation by Middle States, Aug 2012-present. Center for Chronic Disorders of Aging, PCOM, Grant Application Reviewer, Sept 2007 – present. Faculty Senate, Chair, PCOM, Sept 2011-2012.

Professional Memberships (last 7 years):

Committee Member, Sudden Arrhythmia Death Syndrome International Registry of Channelopathies or SIRCh, October 2013-present. Sudden Arrhythmia Death Syndrome Foundation. Conference Committee Member, Society of Pediatric Psychology (Div 41, APA) Annual Conference 2014. Philadelphia, PA, March. Scientific Board Member, Parent Heart Watch, (2012-present).

American Board of Professional Psychology; American Psychological Association (Div 12, 38, 54); Association for the Advancement of Behavior Therapy: Nominations and Elections Committee, Chair (2005-2007); Membership Committee, Chair (2000-2004); Member, Special Interest Group, Behavioral Medicine (2002-present); Philadelphia Behavior Therapy Association (Board of Directors, 1997-present); Sigma Xi Research Society, PCOM Chapter, application pending; Society for Behavioral Medicine

Professional Honors & Recognition:

Associate Editor, *Journal of Clinical Psychology (Wiley Publications)* – 2010-present. Editorial Board Member/Consulting Editor, *Journal of Consulting and Clinical Psychology (APA)* – 2010- Present. Editorial Board Member/Consulting Editor, *Professional Psychology: Research and Practice, (APA)* - 2012-present. Ad Hoc Reviewer, *Research and Education in Professional Practice (APA)* – 2007 –present. Presenter, Education Leadership Conference, APA (2010). Fellow, Academy of Clinical Psychology (2003); Diplomate in Clinical Psychology, American Board of Professional Psychology (June 2003); Associate Convenor, World Congress of Behavioral and Cognitive Therapies (2001); Award Recipient, Who's Who in American Colleges and Universities (1998)

Selected Peer-Reviewed Presentations in Last Six Years (due to space limitations):

Felgoise, S. H., Walsh, S., Bremer, B. A., Stephens, H. E., Rodriguez, J., & Simmons, Z. (Nov, 2008). Validation Of A Shorter ALS-specific Quality Of Life Instrument: The ALSSQOL-R. Presented at the 19th International Symposium on ALS / MND.

Felgoise SH, Rodriguez JL, Bremer BA, Walsh SM, Stephens HE, Horowitz MD, Simmons Z. Validation of the ALS specific quality of life-revised measure (ALSSQOL-R). (December, 2007). Presented at the 18th International Symposium on ALS/MND, Toronto, Ontario, Canada.

Stephens HE, Green B, Bremer B, Felgoise S, Walsh S, Simmons Z. A pilot study to evaluate the reliability of administering the ALS-specific quality of life instrument-revised (ALSSQOL-R) in a self-administered format vs. interview based format. *Amyotroph Lateral Scler* 2007;8:103-104.

Duff, J., **Felgoise, S. H.,** & DiTomasso, R. A. (Nov, 2007). *Oral Communication Ability & Quality of Life in Persons with Amyotrophic Lateral Sclerosis*. Presented to the

Association for Behavioral and Cognitive Therapies, Philadelphia, PA.

Horowitz, M., **Felgoise, S. H.**, Golden, B., & Simmons, Z. (Nov, 2007). *Does Social Problem-Solving Moderate the Relationship Between Physical Functioning and Depression in ALS Patients?* Presented to the Association for Behavioral and Cognitive Therapies, Philadelphia, PA.

Stephens, H. E., **Felgoise, S. H.**, Bremer, B. A., Walsh, S. M., & Simmons, Z. (March, 2007). *An ALS-specific tool to measure quality of life.* Presented at the Regional Symposium on Health Care and Quality of Life, Penn State Harrisburg.

Davis, T., **Felgoise, S. H.**, McCleary, J., & Heckert, T. (Nov, 2006). *Illness Perception Among Female Irritable Bowel Syndrome Patients across Levels of Care (Work-in-Progress).* Presented to the Association for Behavioral and Cognitive Therapies, Chicago, IL.

Heckert, T., **Felgoise, S. H.**, McCleary, J., Davis, T., & Rodriguez, J. (Nov, 2006). *The Role of Anxiety Sensitivity in IBS Patients' Quality of Life (Work-in-Progress).*

Presented to the Association for Behavioral and Cognitive Therapies, Chicago, IL.

Chakraborty, B. H., **Felgoise, S. H.**, Golden, B. A., & Simmons, Z. (Nov, 2005). *Resiliency Factors: Predictors of Quality of Life and Psychological Hardiness in Spousal Caregivers of Patients with Amyotrophic Lateral Sclerosis.* Presented to the Association for Behavioral and Cognitive Therapies, Washington, D. C.

Felgoise, S. H., Chakraborty, B., Bond, E., Bremer, B. A., Walsh, S., & Simmons, Z. (Nov, 2005). *Psychological Well-Being and Morbidity in Persons with Amyotrophic Lateral Sclerosis: Data from Two Samples.* Presented to the Association for Behavioral and Cognitive Therapies, Washington, D. C.

Simmons, Z., **Felgoise, S. H.**, Bremer, B. A., Walsh, S. M., Bromberg, M. B., David, W., Forshew, D. A., Herman-Patterson, T. D., Lai El, McCluskey, L. (2004). *Development and Validation of an ALS-specific quality of life instrument.* *ALS* 2004; 5(suppl 2):140.

Bremer, B. A., Simone, A. L. Walsh, S. Simmons, Z. & **Felgoise, S. H.** (March, 2004). *Religion and quality of life with amyotrophic lateral sclerosis.* Presented to the 2nd Annual Mid-Winter Research Conference on Religion and Spirituality, Columbia, MD.

Selected Publications in Last Six Years (due to space limitations):

Journal Articles:

Zamietra, K., Lehman, E. B., **Felgoise, S. H.**, Walsh, S. M., Stephens, H. E., & Simmons, Z. (2012). Non-invasive ventilation and gastrostomy may not impact overall quality of life in patients with ALS. *Amyotrophic Lateral Sclerosis*, 13; 55–58.

Cupp, J. Simmons, S., Berg, A., **Felgoise, S.**, Walsh, S. & Stephens, H. (2011). Psychological health in patients with ALS is maintained as physical function declines. *Amyotrophic Lateral Sclerosis*, 12; 290–296.

Felgoise, S. H., Chakraborty, B. H., Bond, E., Rodriguez, J., Bremer, B. A., Walsh, S. M., Lai, E. C., McCluskey, L. & Simmons, Z. (2010). Psychological morbidity in ALS: The importance of psychological assessment beyond depression alone. *Amyotrophic Lateral Sclerosis*, 11, 351-358.

Murphy, V. , **Felgoise, S. H.**, Walsh, S., & Simmons, Z. (2009). Problem solving Skills Predict Quality of Life and Psychological Morbidity in ALS Caregivers. *Amyotrophic Lateral Sclerosis*, 10(3): 147-53.

Felgoise, S. H., Stewart, J. L., Bremer, B. A., Walsh, S. M., Bromberg, M. B., & Simmons,

Z. The SEIQoL-DW for assessing quality of life in ALS: strengths and limitations. (2009) *Amyotrophic Lateral Sclerosis*, 10(5-6): 456-62.

Felgoise, S. H., Stewart, J. L., Bremer, B. A., Walsh, S. M., Bromberg, M. B., & Simmons, Z. The SEIQoL-DW for assessing quality of life in ALS: strengths and limitations. (*In press; Accepted for publication 7/9/2008*) *Amyotrophic Lateral Sclerosis*.

Murphy, V., **Felgoise, S. H.**, Walsh, S., & Simmons, Z. (*Accepted for Publication 9/2008*). Problem solving Skills Predict Quality of Life and Psychological Morbidity in ALS Caregivers. *Amyotrophic Lateral Sclerosis*.

Simmons, Z, **Felgoise, S.H.**, Bremer, B.A., Walsh, S.M., Hufford, D.J., Bromberg, M.B., David, W, Forshew, D.A., Heiman-Patterson, T.D., Lai, E.C., McCluskey, L. (2006). The ALSSQOL: Balancing physical and non-physical factors in assessing quality of life in ALS. *Neurology*, 67, 1659-1664.

Bremer, B. A., Simone, A.L., Walsh, S., Simmons, Z., & **Felgoise, S. H.** (2004). Factors supporting quality of life over time for individuals with Amyotrophic Lateral Sclerosis: The role of positive self-perception and religiosity. *Annals of Behavioral Medicine*, 28(2), 119-125.

Nezu, A. M., Nezu, C. M., **Felgoise, S. H.**, McClure, K. S., & Houts, P. S. (2003). Project Genesis: Assessing the efficacy of problem-solving therapy for distressed adult cancer patients. *Journal of Consulting and Clinical Psychology*, 71(6), 1036-1048.

Walsh, S., Bremer, B. A., **Felgoise, S. H.**, & Simmons, Z. (2003). Religiousness is related to quality of life in patients with ALS. *Neurology*, 60, 1527-1529.

Books and book chapters:

Freeman, A. & **Felgoise, S. H.**, & Davis, D. (2008). *Clinical Psychology: Integration of Science and Practice*. New York: Wiley.

Freeman, A. (Ed. In Chief), **Felgoise, S. H.**, Nezu, A. M., Nezu, C. M., & Reineke, M. (Eds.). (2005). *Encyclopedia of Cognitive and Behavior Therapies*, New York: Kluwer.

Felgoise, S. H. (2005). History of Behavioral Medicine. In A. Freeman et al., (Eds). *Encyclopedia of Cognitive and Behavior Therapies*, pp. 209-214. New York: Kluwer.

Felgoise, S. H., & Golden, B. A. (2005). Clinical Health Psychology. In A. Freeman et al., (Eds). *Encyclopedia of Cognitive and Behavior Therapies*, pp. 114-117. New York: Kluwer.

Felgoise, S. H., & Kricher, H. (2005). Terminal Illness. In A. Freeman et al., (Eds). *Encyclopedia of Cognitive and Behavior Therapies*, pp., 401-405. New York: Kluwer.

Felgoise, S. H., & Olex, K. (2005). Caregivers of medically ill patients. In A. Freeman et al., (Eds). *Encyclopedia of Cognitive and Behavior Therapies*, pp. 94-98. New York: Kluwer.

Funded Research Grants or Training Contracts in Last Seven Years:

Principal Investigator, Psychological Functioning, Coping, and Factors Affecting Quality of Life in

Persons with Long QT Syndrome. **Funded by the Department of Pennsylvania Health, Tobacco Settlement Act, Act 2001-77 (approximately \$26,000; 2010-2013).**

Principal Investigator, QOL, Coping, and Psychological Well-Being in Children with LQTS and Their Primary Caregivers. **Funded by Center for Chronic Disorders of Aging (\$11,250; 2007-2010).**

Principal Investigator, Phase II development of an ALS-Specific Quality of Life measure

for persons with Amyotrophic Lateral Sclerosis. **Funded by Christopher Reeve Paralysis Foundation (\$10,000, Aug 2004)**

Paid Reviewer/Consultant, Competitive renewal for grant application on Social Problem-solving for Caregivers of TBI

patients. PI: Timothy Elliott, Ph.D. CDC-sponsored Injury Control Research Center (ICRC), University of

Alabama at Birmingham. Russ Fine, Ph.D., MSPH, Director, UAB Injury Control Research Center.

Co-Investigator, “Developing a Disease-Specific Tool to Assess Quality of Life in Amyotrophic

Lateral Sclerosis”; **Funded by ALSA, \$28,080**, (Oct 2001 – Feb 2003). Penn State Hershey Medical Center, Neurology Department. PI: Zachary Simmons, M.D.