The Research Enterprise: Driven by the Individual’s Passion to Find Answers to Health-Related Questions

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Philippine Nurses Association of America
38th National Convention – July 23-30, 2017
Disclosure of Conflict of Interest

• None
### Objectives

By the end of this presentation, the audience will be able to:

1. Describe the journey of pursuing a research-focused doctorate.
2. Discuss the milestones of research in cystic fibrosis.
3. Highlight research conducted by Filipino nurse scientists.
Objective 1

First, I will describe the journey of pursuing a research-focused doctorate.
<table>
<thead>
<tr>
<th><strong>PhD</strong></th>
<th><strong>DNP</strong></th>
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</table>
| - Research career  
- Developing nursing knowledge  
- Leadership experience in area of sustained research funding  
- Access to research settings and resources  
- Outcome: Development of new knowledge and scholarly products | - Practice career  
- Improving patient care outcomes  
- Leadership experience in role and population practice  
- Access to diverse practice settings  
- Outcome: Healthcare improvement via practice and policy change |

PhD vs. DNP
PhD vs. DNP

2015-2016:
• Students enrolled in DNP programs increased from 21,995 to 22,289
• DNP graduates increased from 4,100 to 4,855

Since DNP movement began in 2004:
• Enrollment in PhD programs has increased by 53.8%.
### PhD

**Program of Study: 74 total credits**

<table>
<thead>
<tr>
<th>Course Number</th>
<th>Course Name</th>
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<tr>
<td>NUR 751Q**</td>
<td>Philosophical Foundations of Science</td>
</tr>
<tr>
<td>NUR 753Q</td>
<td>Nursing as a Scientific Discipline</td>
</tr>
<tr>
<td>NRM 750Q**</td>
<td>Foundations of Quantitative Research</td>
</tr>
<tr>
<td>NUR 755Q**</td>
<td>Critical Analyses of Theories, Models and Frameworks</td>
</tr>
<tr>
<td>NRM 780Q**</td>
<td>Application of Research Design Principles I</td>
</tr>
<tr>
<td>NRM 798QL</td>
<td>Research Immersion</td>
</tr>
<tr>
<td>NRM 752Q**</td>
<td>Responsible Conduct of Research</td>
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<tr>
<td>NST 778Q**</td>
<td>Data Management</td>
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<tr>
<td>NUR 742Q**</td>
<td>Writing a Career Development Grant Proposal</td>
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<td>Substantive Core</td>
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<td>NUR 760Q</td>
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<tr>
<td>NRM 781Q**</td>
<td>Quantitative Measurement</td>
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<tr>
<td>NST 779Q**</td>
<td>Statistical Modeling 1 Linear Models</td>
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<td>NRM 782Q**</td>
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<td>NUR 758Q**</td>
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<td>NRM 783Q**</td>
<td>Foundations of Qualitative Research</td>
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<tr>
<td>NST 780Q**</td>
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<tr>
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<td>Dissertation</td>
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<tr>
<td>NUR 799Q</td>
<td>Dissertation</td>
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</table>
What do you do with a PhD?

- Focus on research
- Academic faculty
- Become primary investigator on research grants
- Academic leadership positions
- Directors of research in health systems
- Conduct research that influences practice
Common PhD Job Titles

Chief Nurse Researcher

Director of Nursing Research

Associate Professor

Research Position with Government Organizations ex: CDC
- Takes 8 semesters and is a part-time program

<table>
<thead>
<tr>
<th>Course Code</th>
<th>Course Title</th>
<th>Credits</th>
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<tbody>
<tr>
<td>NUR 700</td>
<td>Clinical Data Management and Analysis</td>
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<tr>
<td>NUR 701</td>
<td>Writing for Publication</td>
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<td>NUR 729</td>
<td>Evidence Based Practice Design and Translation</td>
<td>3</td>
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<tr>
<td>NUR 731</td>
<td>Philosophical, Theoretical, and Conceptual Foundations for Advanced Practice Nursing</td>
<td>3</td>
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<td>NUR 743</td>
<td>Evidence-Based Practice Strategies</td>
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<td>NUR 735</td>
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<td>NUR 733</td>
<td>Informatics for Advanced Practice Nursing</td>
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<td>NUR 737</td>
<td>Interdisciplinary Leadership and Role</td>
<td>3</td>
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<td>NUR 740</td>
<td>Development for Practice Excellence</td>
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<tr>
<td>NUR 742</td>
<td>Health Policy &amp; Politics: Implications in Health Care</td>
<td>3</td>
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<td>NUR 745</td>
<td>Program Evaluation Methods</td>
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<td>NUR 738</td>
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<td>NUR 739</td>
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<td>NUR 739</td>
<td>Scholarly Project</td>
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<tr>
<td>NUR 739</td>
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<td></td>
<td><strong>Total</strong></td>
<td><strong>43 credits</strong></td>
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What do you do with a DNP?

- Focus on nursing practice
- Formulate and interpret evidence-based practice
- Health policy development
- Advanced clinical practice
- Information technology
- Educator
- Director of clinical nursing at health facilities
- Use research to advance nursing practice
Common DNP Job Titles

- Vice president for Nursing and Clinical Services
- Program Director
- Vice President for Patient Care
- Chief Executive Officer
- Health Officer
- Commissioner of Health
- Quality Improvement Director
Need for Filipino Nurses

Demographic Survey of Filipino American Nurses:
- 3.7% had a masters in healthcare
- 12.3% had an MSN
- 0.6% had a PhD or EdD
Passion Behind Doctoral Degree

**Vision:**
To best engage the needs of students and society

**Passion:**
Help future students and colleagues develop their vision to be engaged as public intellectuals in their research and teaching

**Action:**
Commit to action and chance of failing publicly to ensure accountability
Passion Behind Doctoral Degree

• We learn from our failures and will eventually succeed
• We must have courage to take risks
• If the work we do matters, we will be determined to do it successfully
• Faculty encourage mentees to develop passion for their work that sustains a lifelong commitment
# Common Struggles of a PhD Student

## Application process:
- References
- Writing sample
- Identifying potential research interest and mentor

## Role transition:
- Expert clinician to novice student
- Learning to think critically
- Changes worldview
- Socialization into academia and research
- Work/life balance
Common Struggles of a PhD Student

- **Financial implications**

  **Full time student**
  - Cannot work full time
  - Pay for 9 credit hours (~ $5,000 per semester)
  - Takes approximately 3-4 years

  **Part time student**
  - Can work full time
  - Pay for 6 credit hours (~ $2,500 per semester)
  - Takes approximately 5-6 years
Lessons Learned as PhD Student

Resilience

Perseverance

Learn to adapt to "scientific writing"

Ability to take constructive criticism
What is Tenure and Tenure Track?

**Tenure:**
- Provides elevated level of job security
- Enhanced level of protection for academic freedom

**Tenure Track:**
- Probationary period lasting ~ 5-7 years.
- Scholarship, service, and teaching are evaluated by an oversight committee.
- Promotion is voted on by the committee.
Common Struggles of New Tenure-Track Assistant Professor

• What does tenure track entail?
  – Meeting the mission of the university and school of nursing:
    • Education
    • Scholarship
    • Service
  – Grant funding to support research
  – Achieving work-life balance
  – Being a professional
Second, we will discuss the milestones of research in cystic fibrosis.
Cystic Fibrosis: Background

- **1989**: CF gene discovered by Tsui, Riordan, Collins, and their colleagues.
- Survival:
  - **1990**: 31.9 years
  - **Now**: 49.7 years
Cystic Fibrosis: Overview

- Autosomal recessive
- Abnormal chloride transport across cell membranes
- Thickened secretions
- Creates extensive treatment regimen
Underlying Problem with CFTR

- Video depicts CFTR working properly vs. CFTR in cystic fibrosis.
Overview

CYSTIC FIBROSIS (CF)

*Treatment*
- Diet: ↑ Cal, ↑ Protein
- Pulmonary Therapy
  - Chest Physiotherapy
  - Postural Drainage
- Breathing Exercises
- Aerosol Therapy

*Meds*
- Antibiotics
- Supplemental Vitamins
- Aerosol Bronchodilators
- Mucolytics
- Pancreatic Enzymes

*Symptoms*
- Fatigue
- Chronic Cough
- Recurrent URI's
- Thick, Sticky Mucus
- Chronic Hypoxia:
  - Clubbing, Barrel Chest
  - ↓ Absorption of Vitamins and Enzymes
- Abdominal Distention
- ↓ Digestive Enzymes
  - Rectal Prolapse
  - Fatty, Stinky Stools (Steatorrhea)
  - Meconium Ileus in Newborn

©2007 Nursing Education Consultantes, Inc.
• **Airway clearance:** Chest physiotherapy (manual or vest).

• **Inhaled medications:** given via nebulizer.

• **Pancreatic enzymes:** taken with every meal to improve absorption

• **2015:** CFTR modulators to correct function of defective protein created by the CF gene.
Complications

- Chronic sinusitis
- Nasal polyps
- Repeated lower respiratory tract infection
- Bronchiectasis
- Abnormal sweat secretions (high sodium and chloride)
- Liver disease
- Portal hypertension
- Gallstones
- Pancreatic insufficiency
- Diabetes
- Finger clubbing
- Distal intestinal obstruction syndrome
- Osteoporosis
- Steatorrhoea
- Male infertility
- Arthropathy/arthritis
- Arthropathy/arthritis

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SCHOOL OF NURSING
Knowledge that will change your world
Day in the Life

- [Link](https://youtu.be/qmzvCnt5cHA)

Knowledge that will change your world
Cystic Fibrosis Milestones

- **1962**: Median survival age reaches 10 years
- **1989**: CF gene discovered
- **1993**: Pulmozyme approved to thin mucus in lungs
- **1997**: Tobramycin approved that reduces hospital stays and improves lung function
- **2002**: Azithromycin improves lung health
- **2003**: 3-D structure of CFTR protein discovered
Cystic Fibrosis Milestones

**2006:** Ivacaftor enters clinical trials and targets CFTR protein

**2012:** FDA approves Kalydeco for G551D mutation to treat underlying cause of CF

**2015:** FDA approves Orkambi for double F508del mutation

**2016:** Cystic Fibrosis Foundation maintains a pipeline of potential therapies to target CF in hopes for a cure
Emergent Issues in CF Research

• Treatments for rare mutations that will not benefit from first-generation CFTR modulators
  – Cystic Fibrosis Foundation launched new Nonsense and Rare Mutations Therapeutics Initiative
  – UAB and Southern Research are using a screening process to find therapies for these genetic mutations
Emergent Issues in CF Research

• **Addressing mental health**
  
  – People with CF and their parents are 2-3 times more likely than the general population to have depression, anxiety or both
  
  – CFF developed the first practice guidelines for depression and anxiety in 2015
  
  – Data on follow-up will be in the 2016 CFF annual report

“There is no health without mental health”
- Cystic Fibrosis Foundation
Emergent Issues in CF Research

• Fertility and pregnancy in women with CF
  – Number of CF women who became pregnant has doubled in the last 20 years.
  – In a recent study, 32.8% of women understood how CF affects fertility
  – Life expectancy now in the 40’s
  – Education and pregnancy planning with care team is imperative.
Emergent Issues in CF Research

- **Lung Transplantation**
  - Can extend and improve life
  - Requires extensive evaluation
  - More than 50% live at least 5 years post-transplant
  - Risks:
    - Rejection
    - Infections
    - Cancer
    - Side effects of immunosuppressive drugs
<table>
<thead>
<tr>
<th>Category</th>
<th>Status</th>
<th>Clinical Trials</th>
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<td><strong>Restore CFTR Function</strong></td>
<td>2 drugs already reached patients</td>
<td>7 phase 2</td>
</tr>
<tr>
<td></td>
<td>7 in phase 2 clinical trials</td>
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<tr>
<td></td>
<td>2 in phase 1 clinical trials</td>
<td></td>
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<tr>
<td><strong>Mucociliary Clearance</strong></td>
<td>2 drugs already reached patients</td>
<td>1 phase 3</td>
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<tr>
<td></td>
<td>1 in phase 3 clinical trials</td>
<td></td>
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<tr>
<td></td>
<td>4 in phase 2 clinical trials</td>
<td></td>
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<tr>
<td></td>
<td>1 in phase 1 clinical trials</td>
<td></td>
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<tr>
<td><strong>Anti-inflammatory</strong></td>
<td>1 drug already reached patients</td>
<td>3 phase 2</td>
</tr>
<tr>
<td></td>
<td>3 in phase 2 clinical trials</td>
<td></td>
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<tr>
<td></td>
<td>1 in phase 1 clinical trials</td>
<td></td>
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<tr>
<td><strong>Anti-Infective</strong></td>
<td>4 drugs already reached patients</td>
<td>4 phase 2</td>
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<td></td>
<td>4 in phase 2 clinical trials</td>
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<td></td>
<td>1 in phase 1 clinical trials</td>
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<tr>
<td><strong>Nutritional-GI</strong></td>
<td>3 drugs already reached patients</td>
<td>1 phase 3</td>
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<td></td>
<td>1 in phase 2 clinical trials</td>
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FEMALE FERTILITY IN THE AGE OF NEW CFTR-MODULATING DRUGS

BACKGROUND: With advances in research, genetic testing, therapeutics, and comprehensive care, people with CF are living into adulthood and engaging in developmental milestones including parenthood. The CF Foundation’s Patient Registry indicates that the number of CF women who became pregnant has doubled in the last 20 years. As new CFTR-modulating drugs are approved, the number of pregnancies will likely continue to increase. Specifically, the combination drug ivacaftor/lumacaftor targets the underlying cause of CF for people with homozygous F508del mutation (double DF508), and has shown to improve patient’s FEV1 and sweat chloride concentration; however, its impact on fertility has not been studied. This study aims to explore the perceptions of women of childbearing age with double DF508 on fertility changes secondary to the drug.

METHODS: A semi-structured, audiotaped interview was conducted with ten women ages 25-34 with double DF508, FEV1 ≥40%, and proficient in English. Interview transcripts were reviewed, coded, and analyzed using Braun and Clarke’s approach for thematic analysis.

RESULTS: Three main themes emerged that described the participants’ perceptions on fertility, reproductive health, and the potential impact of ivacaftor/lumacaftor: (1) “Positive, negative, and unknown effects of ivacaftor/lumacaftor”; (2) “Need for comprehensive reproductive and sexual health education and counseling by the CF care team”; and (3) “Wanting to have a child despite knowing or suspecting impaired fertility”. Half of the participants were on ivacaftor/lumacaftor, and described positive effects, i.e., lung clearance, increased energy, and improved quality of life. Several identified negative effects, i.e., loose stools and chest tightness. The majority shared concerns about the drug’s unknown fetal effects. All of the participants believe that the drug has the potential to affect fertility, mainly by making cervical mucus less viscous, thus allowing for easier sperm transport. One participant directly linked her pregnancy to the drug after taking it for two weeks. Secondly, participants described how there was no uniformity in how reproductive and sexual health information was disseminated, and reported a desire for more collaboration with their CF care team when discussing pregnancy plans. Lastly, all of the participants wished to have at least one child despite knowing or suspecting that they may have problems conceiving secondary to CF. Two participants shared that being on ivacaftor/lumacaftor made it possible for them to make plans for the future, which include being mothers.

CONCLUSIONS: This study illustrated that women of childbearing age with double DF508 want to become mothers even with potentially impaired fertility. While there is currently no clear evidence that show ivacaftor/lumacaftor improves fertility, these women are hopeful that targeted therapeutics will make their dream of motherhood a reality. They are also aware of the drug’s effects and concerned about its unknown effects on the fetus. They desire comprehensive clinical care that includes discussions about fertility and reproductive health with their CF care team. Several implications for practice, education, and research are gleaned from this study.
Title: Knowledge of Fertility Among Women of Childbearing Age with Cystic Fibrosis Homozygous F508del Mutation

Background: People with cystic fibrosis (CF) now live full adult lives, potentially including parenthood. Although many affected women have impaired fertility secondary to CF, the number of women with CF who became pregnant has doubled in the last 20 years. New targeted medications for some CF mutations may result in further increase in pregnancies. While the cause of male infertility in CF is widely accepted, impaired female fertility is less well understood. Literature shows that many women with CF are unaware of possible effects on fertility.

Aims: To explore knowledge of fertility and CF’s impact on reproduction and fertility in women of childbearing age with homozygous F508del mutation (DDF508).

Methods: Subjects included 10 adult English proficient women with DDF508 and forced expiratory volume in 1 second ≥40%, and a non-CF comparison group. Three questionnaires were administered: demographics form, Knowledge of Fertility (KF) scale, and Knowledge of Impact of CF on Reproduction and Fertility (KICFRF) questionnaire (administered to the CF group only).

Results: Fifteen subjects were Caucasian, five were African American, and 18 were college graduates. Twelve subjects were married, and 14 (2 with CF) were pregnant at least once. On the KF scale, subjects in both the CF (N=7) and non-CF group (N=8) reported a lot of knowledge about the impact of age on fertility. Approximately half of the subjects in both groups reported only some knowledge about the effect of smoking on fertility. Similarly, around half reported a lot of knowledge about the impact of weight. Seven subjects in the CF group and eight in the non-CF group reported little knowledge about the infertility workup. On the KICFRF questionnaire, all ten CF subjects reported that they knew CF can affect fertility, and seven reported a lot of knowledge on the role of cervical mucus on fertility. Half of the CF group did not correctly identify the genetic transmission of CF.

Conclusion: Women with DDF508 are knowledgeable about general fertility concepts and how CF affects fertility. Areas of less knowledge (i.e., infertility work-up, effect of smoking and weight, and genetic transmission) require future research to inform educational interventions.
Fertility and Reproductive Health Implications of Targeted Therapeutics for Cystic Fibrosis

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Abstract

Aims: To explore knowledge of fertility and knowledge of the impact of cystic fibrosis (CF) on reproduction and fertility among women of childbearing age with homozygous F508del mutation, and explore these women's perceptions on fertility changes secondary to lumacaftor/ivacaftor.

Methods: This pilot had a sample of 20 women. Ten women with CF, ages 19-35 with homozygous F508del mutation, stable lung function, and English proficient were included, as well as a non-CF comparison group. Three questionnaires were administered: demographics form, Knowledge of Fertility (KF), and Knowledge of Impact of CF on Reproduction and Fertility (KCFRFR). A semi-structured interview was conducted with the CF group. Interview transcripts were coded and analyzed using thematic analysis.

Results: On the KF scale, participants in both groups reported a lot of knowledge about the age of menopause. Seven participants in the CF group and eight in the non-CF group reported little knowledge about the infertility work up. On the KCFRFR, seven reported a lot of knowledge on the role of cervical mucus viscosity on fertility. Only three reported a lot of knowledge on the role of cervical mucus pH. Half of the CF group correctly identified CF's genetic transmission. Three main themes emerged from the qualitative data: (1) Positive, negative, and unknown effects of lumacaftor/ivacaftor, (2) “Hoping comprehensive reproductive and sexual health education and accompanying the CF care team,” and (3) “Wanting to have a child knowing or suspecting impaired fertility.”

Discussion: Women with CF are knowledgeable about general fertility concepts. Areas of less knowledge (i.e., infertility work-up, genetic transmission, and role of cervical mucus pH) require further research. They desire comprehensive clinical care that includes discussions about fertility and reproductive health. They want to become mothers and are hopeful that targeted therapeutics will make their dream of motherhood a reality.
Lastly, I will highlight research conducted by Filipino nurse scientists.
Filipino Nurse Scientists

Marlon Garzo Saria, PhD, RN, AOCNS®, FAAN

Karen Meneses, PhD, RN, FAAN

Joseph D. Tariman, PhD, RN, ANP-BC, FAAN
• **Research Interest:**
  – Effect of cancer and cancer-related toxicities on patient outcomes
  – Impact of caregiver burden on caregiver well-being outcomes, patient health outcomes, and healthcare utilization outcomes

• **Why this area?**
  – Oncology nurse
  – Works with a Physician Scientist

“I want to help patients and families as they live every day of their lives with cancer.”
Marlon Garzo Saria, PhD, RN, AOCNS®, FAAN

Top 5 professional achievements

- PhD
- Getting commissioned as air force officer
- Induction as Fellow of American Academy of Nursing
- Secretary of Oncology Nursing Society
- Associate Editor for Clinical Journal of Oncology Nursing

"Getting my PhD showed me that perseverance trumps talent."
Advice about pursuing a graduate degree:

- Just do it
- Life always has demands that will be a reason not to go back to school
- If you want it, you should do it

“Walls are there to keep those who do not really want what is on the inside out.”

Marlon Garzo Saria, PhD, RN, AOCNS®, FAAN
Karen Meneseses, PhD, RN, FAAN

• Research Interest:
  – Breast cancer survivorship-disparities research
  – Grew from clinical practice with cancer survivors

“I have been a nurse since dinosaurs roamed the earth”
• **Top professional achievements:**
  – Distinguished Faculty Lecturer
  – Mara Mogensen Memorial Lectureship

• **Advice about pursuing a graduate degree:**
  – Just do it.

“Filipino nurses are the best!”
Joseph D. Tariman, PhD, RN, ANP-BC, FAAN

• **Research Interest:**
  – Shared decision making
  – Multiple myeloma therapies
  – Side effects management

• **Why this area?**
  – Nurse practitioner for 15 years specializing in myeloma
  – Led research team of myeloma program at Northwestern University
Joseph D. Tariman, PhD, RN, ANP-BC, FAAN

- **Top professional achievements:**
  - **2013:** Speaker at PNAA annual conference
  - **Chair:** Annual Myeloma Nursing Conference for 7 consecutive years
  - **2013:** Plenary speaker for International Myeloma Nursing conference

- **Advice about pursuing a graduate degree:**

  “Stop hesitating! Enroll in grad school.”
Dare to dream, dare to dream
All our brothers and sisters
breathing free
Unafraid, our hopes unswayed
*Til the story of CF is history
• [http://www.aacn.nche.edu/dnp/ContrastGrid.pdf](http://www.aacn.nche.edu/dnp/ContrastGrid.pdf)
• [https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/](https://www.cff.org/What-is-CF/About-Cystic-Fibrosis/)
• [https://www.cff.org/Research/About-Our-Research/Research-Milestones/](https://www.cff.org/Research/About-Our-Research/Research-Milestones/)
• [https://www.cff.org/trials/pipeline](https://www.cff.org/trials/pipeline)
• [http://www.aacn.nche.edu/dnp/dnp-tool-kit-section-1](http://www.aacn.nche.edu/dnp/dnp-tool-kit-section-1)