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COMPREHENSIVE CANCER CENTER

ESTOY CONTIGO
Compartiendo el Camino

PATIENT CARE
RESEARCH
EDUCATION
COMMUNITY

Real Life Example: Nueva Vida Intervention

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NCI
A Comprehensive Cancer Center Designated by the National Cancer Institute

http://lombardi.georgetown.edu
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Outline

1. Community-Academic Partnership: Nueva Vida Intervention
2. Engagement through Communities: Short and Long-term Benefits
3. Lessons Learned to Maximize Community-Academic Partnerships



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Evolution of 'Engaged' Partnership

- Community-Based Organization: Nueva Vida
 - Successful program to address needs and improve quality of life of Latina Survivors and Caregivers
 - Trusted relationship with Latino families
- Academic Partner: Georgetown
 - Successful prior research with Latina breast cancer survivors
 - Significant interest in intervention research and engaging patients and families



Engaging Community-Based Organizations in Research

- Understand common goals
 - Improving quality of life
- Allow relationships to grow
 - First met in 2009
 - Submitted proposal in 2012
- Recognize expertise of community-based organizations from project inception



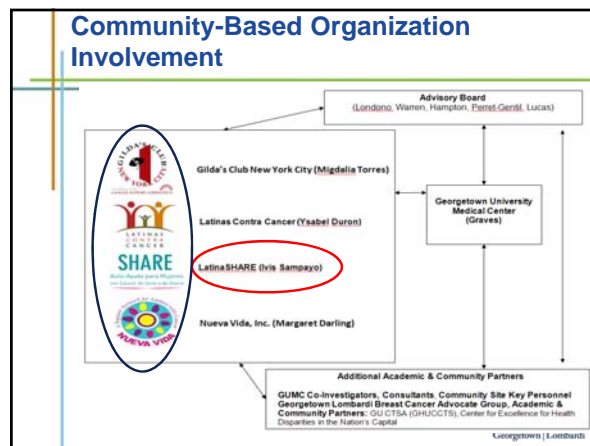
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Team: Leveraging Connections

- Built upon existing relationships
 - SHARE (NY, NY)
 - Gilda's Club New York City (NY)
 - Latinas Contra Cancer (CA)
- Recognize community expertise and input throughout process
 - Team, Design & Implementation
 - Engagement & Dissemination




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Proposal and Design Logistics

- Patient and Community partners involved in:
 - Formulating research questions & study design
 - Identifying eligibility criteria of participants
 - Making decisions about comparators and interventionists
 - Participating in and monitoring conduct of project
 - Helping to plan dissemination of results
 - Establishing reciprocal relationships, co-learning, trust, transparency
- Outcomes
 - Outcomes of common interest to patient partners, community organizations and research team
- Lead Time Critical
 - Biosketches, Review of documents, Budget



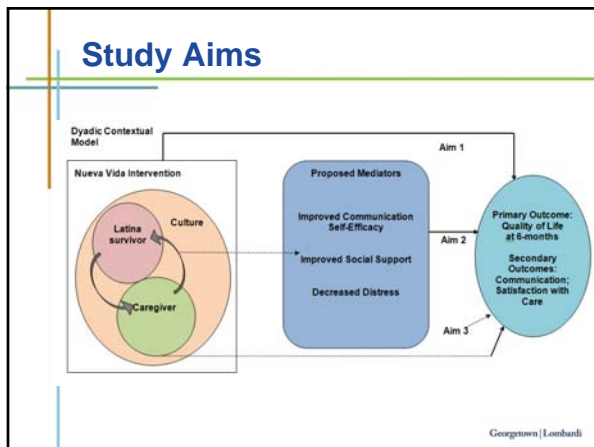
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Nueva Vida Intervention




- Comparison (randomized controlled trial) between
 - Nueva Vida Intervention
 - Usual Services
- Focus to improve quality of life among Latina breast cancer survivors as well as their caregivers

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Nueva Vida Intervention



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Implementation: "Research Democracy"

Impact of Cancer on Family (Introduction)*

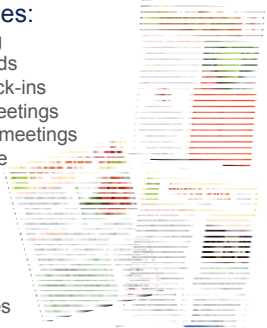
- 8 "talleres" (workshops)
 - 2 per month
 - 5 core topics
 - 3 topics: "Research Democracy"



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Engagement & Dissemination: Equal Input

- Engagement Strategies:
 - Phone calls, scheduling
 - Birthday cards, postcards
 - Twice monthly site check-ins
 - Monthly team phone meetings
 - Annual in person team meetings
 - "Think aloud" technique
 - Polls / Surveys
- Dissemination:
 - Community Meetings
 - Newsletters
 - Webinars
 - Post-Intervention Parties



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Benefits of Partnerships

- Short-term:
 - Greater relevance
 - More likely to address true needs
 - Increased awareness of a community's:
 - Strengths / Expertise
 - Services / Resources
 - Greater proposal appeal
- Long-term:
 - Increased capacity
 - Greater likelihood for dissemination / impact
 - Expanded (and strengthened) collaborative relationships




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Challenges to Partnerships

- Implementation subtleties / less “internal validity”?
 - Greater external validity / real-world research
 - Rich diversity in patients and caregivers
- Ready to listen carefully and share decisions?
 - Recognize greater salience to patients, family & community
 - Provide infrastructure support and training as needed
 - Plan on additional effort that may be needed for reaching some participants (e.g., caregivers)



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Lessons Learned: Researcher

- Recognize value of community-based organizations in generating, partnering and sustaining research.
 - Be receptive to what is already being done by patients or in the community.
 - Keep needs of patients and families as a priority.
- Use a democratic approach to decision-making.
- Set a culture of open communication.




Lessons Learned: Researcher

- Spend time educating team members about the study process.
- Offer training that meets partners' needs.
- Be prepared for a potentially higher administrative burden.
- Be flexible.




Lessons Learned & Taught: Community

- Appreciate the time and focus needed for research, including IRB.
- Practice patience (we want answers yesterday, but research provides important information).
- Stay involved in the entire process (not just learning the results).



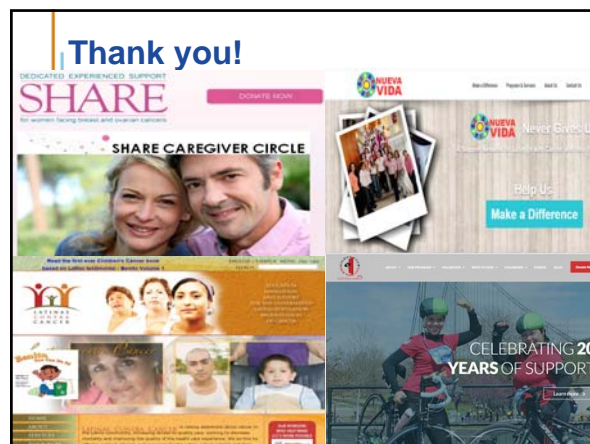
Lessons Learned & Taught: Community

- Learn how to bring topics, ideas back to the team (relevant on both sides)
- Remind all involved to keep in mind the ‘whole picture’ and ‘whole patient.’
- Be willing to listen, even if something seems ‘minute.’



Lessons Learned & Taught: Community

- Appreciate that research truly helps move things forward.
- Experience increased joy to see how the researchers 'get it.'
- Create a community so that all perspectives are elicited and respected.

<p>Georgetown University: Roxanne Jensen Jeanne Mandelblatt Vanessa Sheppard Stacey Kaltman George Luta Christina Rush Adriana Serrano Tania Lobo Neha Rajpal Maxie Blasini Charlene Kuo</p>	<p>SHARE: Ivis Febus Sampayo (PI) Jennie Santiago Olympia Cepado-Coto</p> <p>Gilda's Club NYC: Migdalia Torres (PI) Carolina Hoires Awilda Torres Lily Safani</p> <p>Latinas Contra Cancer: Ysabel Duron (PI) Angela Chiprez Teresa Ipong Garcia Martha Brewer Claudia Colindres</p> 	<p>Consultants: Lina Jandorf Maria Gloria Elliott Barry Jacobs Anna Napoles</p> <p>Advisory Board Members: Roberto Londono Robert Warren Regina Hampton Monique Perret-Gentil Wanda Lucas</p> <p>Other Partners: Lombardi Breast Cancer Patient Advocacy Committee</p> <p>Data Safety Monitoring: Alfiee Breland-Nobel Filipa Lynce Georreen Newland Florencia Gonzalez</p>
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- Additional slides for questions

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Research Plan Decisions

- Participant Eligibility (decision = broad)
- Design / Methods
 - Many phone calls to discuss:
 - Usual Care (decision = typical services offered)
 - Intervention (decision = compromise delivery schedule)
 - Interventionist Qualifications (decision = broad)
- Outcomes
 - Outcomes of common interest to patient partners, community organizations and research team

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