Partnership-based Practical Strategies for Participant Recruitment and Informed Participation

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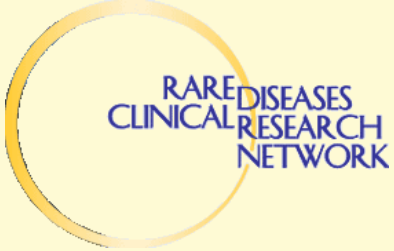
Strategies to Share

- Recruitment Registries On-line tools
- Integrating UCEDD & IDDRC approaches
- Partnering with community organizations
- Fragile X Registry: A case study & replication manual
- Effective communication strategies for finding, enrolling and retaining participants with disabilities
- Working with self-advocacy organizations to improve credibility, maximize participation, and respectful consent practices, as well as
- Tools for working with IRBs/Ethics Committees
- Consenting persons with disabilities

Context

- Family-centered research and registries are national issues of interest.
  - National Institutes of Health
  - Centers for Disease Control
  - Rare Diseases Network
- Recruitment is an emerging art/science



What is a "registry" and what decisions are involved?

- Volunteers? Research projects?
- Contact info? Descriptive?
- "Vetted?" Self-enrollment?
- Who "owns" the families?
- How will it be maintained?
- Local, Regional or National?
- Competing or Collaborating?

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National Institutes of Health Rare Diseases Clinical Research Network

Purpose of Prader-Willi Syndrome (PWS) Research Studies

We study the "whole person" with PWS–their strengths as well as problems– and how these features relate to:

- Genetics (the various subtypes of PWS)
- Families (both strengths and concerns of families)
- Neurochemicals (that regulate mood and appetite)
- Aging (changes from childhood through old age)
- Successful living (with food, work, daily living, leisure)

With this information, we will develop behavioral and dietary interventions that lead to positive outcomes for persons with PWS and their families.

What Is Involved

- We invite individuals with PWS, ages 4 years and up to come for a day of study activities to the Vanderbilt Kennedy Center in Nashville, Tennessee. Parents or staff care providers should also come.
- We may ask participants to come back 3 times over 5-years, to track changes in that person's life.
- We provide a comprehensive behavioral and developmental evaluation with a report for each participant.
- We will cover costs of transportation, lodging, and meals for the participant and a caregiver. We offer compensation for your time and effort.

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Principle Investigator: Elisabeth Dykens, Ph.D.
Professor of Psychology and Human Development
Associate Director, Vanderbilt Kennedy Center
Director, Vanderbilt Kennedy Center
for Excellence in Developmental Disabilities

Prader-Willi Syndrome

Prader-Willi syndrome (PWS) is a genetic disorder of the 15th chromosome. It is associated with severe overeating, obesity, and behavior problems, including compulsive behaviors such as hoarding, skin picking, and intolerance to change in routines. Many people with PWS also have unusual strengths in their abilities to solve jigsaw and word search puzzles, and in their personalities.

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FOR RESEARCH ON HUMAN DEVELOPMENT

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Telling Our Story: Life with Angelman syndrome

We want to follow

- people with Angelman syndrome
- from birth to 60 years old
- over 5 years.

We will **ask** questions about your family, and the health and well-being of your family member with Angelman syndrome.

You will **get** yearly evaluations of your family member, with reports, at no cost.

Contact:
angelmanstudies@vanderbilt.edu
(615) 322-8093

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Study conducted by Elisabeth Dykens, PhD, Terry Jo Bichell, RN, CNM, MPH, Greg Barnes, MD, PhD, Kevin Haas, MD, Evon Lee, PhD, Tyler Reimschisel, MD, Juliann Paolicchi, MD and Saska Peters, PhD sponsored by NIH Rare Disease Clinical Network.

Affiliations with: Angelman Syndrome Foundation
Prader-Willi Syndrome Association, USA
Williams Syndrome Association

Recruitment Strategies

- Network
- Plan with participants in mind
- Think like a volunteer
- Simplify!!!

Network Recruitment

Network

	Nicole
	Lynnette
	COMPLETE!

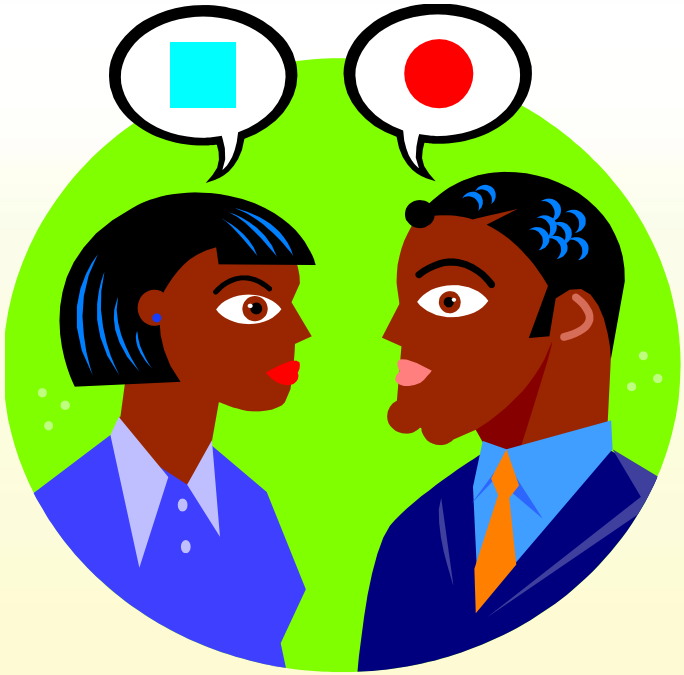
Recruitment Plans

1. On-campus:
    a. Contacts:
        i. Susan Gray School
            1. flyers in racks
            2. In-service: Fall 2006
            3. Michelle about home-visitors
            4. SGS parent newsletter item? (AUG?)
        ii. Center for Child Development
            1. Dissemination committee approval??
            2. Provide to Dr. Lisa Craft for Infant toddler clinic
            3. Acrylic flyer display in waiting room
            4. Stickee for take home (cost?)
        iii. Down Syndrome Clinic
            1. Melissa Webb --Sent pdf flyer to DS children
            2. Left flyers with her
        iv. Pediatric Acute Care Clinic—DOT 6th floor
            1. Acrylic flyer display +stickies in waiting room
        v. VBWC
            1. Acrylic flyer display in waiting room+ stickies
            2. Identify SLPs who work with this age:
            3. Meet with team DELAY until 10/07
            4. Take flyers to them DELAY until 10/07
        vi. VKC collaborators:
            1. More than Words project—Nick Bennett
            2. PSEP (at 1st inquiry) DELAY until 10/07
            3. Typically developing research teams DELAY until 10/07
        vii. VUMC broadcast email with Lynnette's help (hold until 9/07) DELAY until 10/07
        viii. Newsletters
            1. Discovery--Jan
            2. VCH news release (Jan Rosemergy on dissemination plan) (hold until 9/07)

2. Studyfinder:
    a. Text
    b. Flyer in PDF
    c. Approval
    d. Copies of flyers to Lynnette

3. Community efforts:
    a. City Paper—check on rates DELAY
    b. Parent Support groups:
        i. Newsletters and email lists
            1. NAAEYC
                a. Flyers at workshops
                b. conference presentation (changed mind)

Plan with participants in mind



- Who are they?
- What do they **need** that we can offer?
- Would **they** be willing to do **that**?

Think like a volunteer

- What's my **motivation**?
  - Altruism
  - Hope
  - Money

- What **information** do I need to make the decision to call?
- What do they **know** about what we are asking them to do, and what will we **need to explain** in more detail?

Messages

1. Messages addressing **awareness, fear, trust**
   - **WE CARE ABOUT <u>YOU</u>**

2. Messages addressing **benefits**
   - **<u>YOU</u> BENEFIT FROM VOLUNTEERING**

3. Messages specific to **minorities**
   - **WE WANT TO PARTNER WITH <u>YOU</u>**

4. Messages reporting on **results**
   - **<u>YOU</u> HELPED US GET RESULTS**

SIMPLIFY!

- Language
- Information
- Visuals

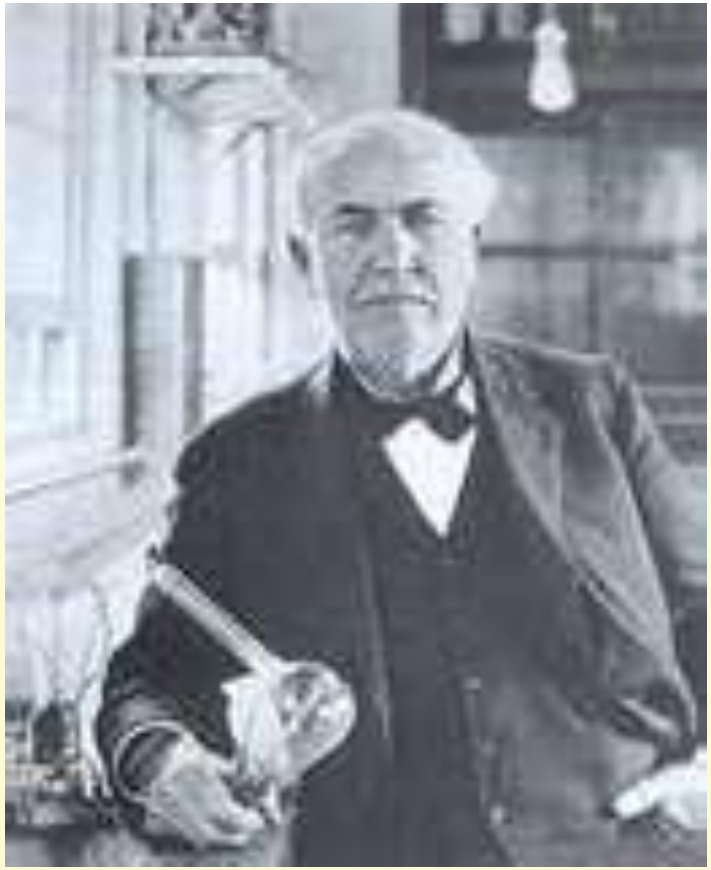
Obstacles to volunteering?

1. Lack of awareness/understanding
2. Fear of side effects, pain
3. Lack of trust (Tuskegee)
4. Time & inconvenience
5. Cost of travel, parking, childcare
6. Culturally inappropriate materials
7. Family pressures

Obstacles in blue can be best overcome with the help of community partners.

Recruitment Pitfalls

Study Design
Point of view
Motivation
Language problems
Money



Finding all the ways it doesn't work

StudyFinder - Participate in Research Studies

Much of the research completed at the Vanderbilt Kennedy Center is made possible by the generous contributions of time by people and families from the community who participate in research studies.

Services and Compensation

Many of these studies offer compensation for participating either through monetary exchange or by providing services that you would otherwise have to pay for.

Search the diagnosis to find a study

Researchers look for participants that meet specific criteria.

Do you, a friend or a family member possibly fit under any of the following categories?

- ADHD (4)

Let us find studies for you through Research Family Partners!

Research Family Partners is a program that helps families connect with Vanderbilt Kennedy Center research studies in which they may be interested in taking part.

We contact you when a study fits!

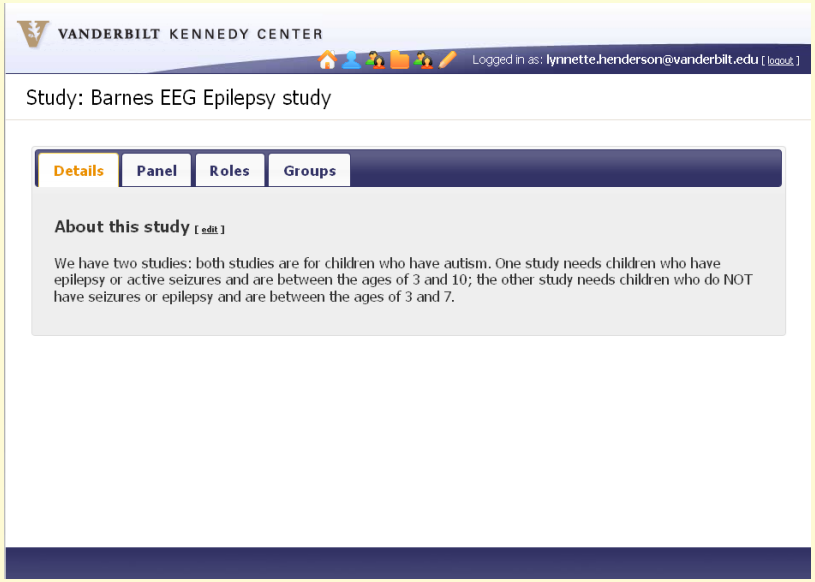
Go online to sign your family up for studies–

Your participation can help shape our research!

www.kc.vanderbilt.edu/RFP

RFP

- Registry with ~2400 people
- Contact information and preference
- Individual descriptors and Family connections
- Source for eager volunteers
- Promoted at events



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ResearchMatch.org

researchmatch

[ALREADY REGISTERED? LOGIN]

ABOUT VOLUNTEERS NETWORK CONTACT

[main menu]

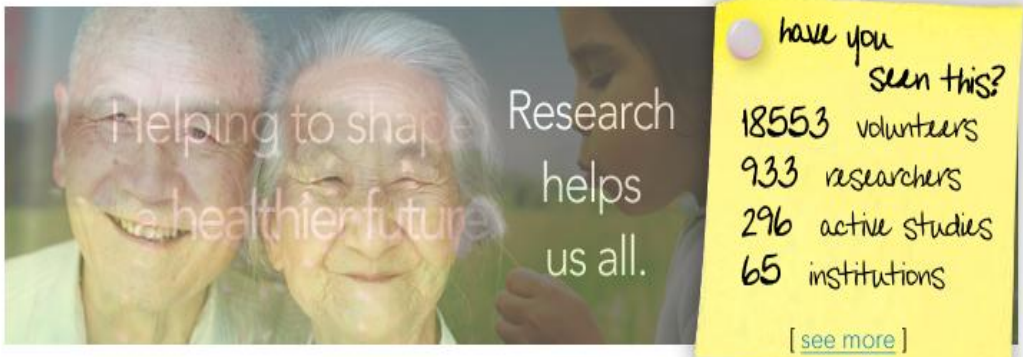
REGISTER NOW
RESEARCHER INTEREST FORM
VOLUNTEER FAQ
RESEARCHER FAQ
TELL A FRIEND

Interested in a specific medical condition?

SEARCH

Please enter your city:

Please enter your state:



have you seen this?
18553 volunteers
933 researchers
296 active studies
65 institutions
[see more]

what is researchmatch?
It is a registry of volunteers willing to learn more about research studies. Research needs both volunteers and researchers. ResearchMatch helps bring these two groups together in a secure and convenient way. [more]

how do I get involved?
Signing up is free and anyone can join. Learn more about ResearchMatch and join the registry today!

REGISTER NOW!

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ResearchMatch Partners with NetWellness
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Family-Friendly Research Approach

You are the smiling face of the Vanderbilt Kennedy Center.

You are the caring hands of the Kennedy Center.

You are a valuable resource to families and to the Kennedy Center.

- Confidentiality in Research Tip Sheet
- Conducting Family-Friendly Research Tip Sheet