Preliminary Recommendations for Effective Outreach and Engagement in the Down Syndrome Community

Background
An INCLUDE workshop in September 2019 on “Planning a Virtual Cohort for Down Syndrome Across the Life Span” led to the creation of a working group focused on Community Engagement.

The group’s task order was:
1. Identifying barriers and opportunities for care provider involvement in research.
2. Identifying strategies to aid care providers wishing to serve as conduits for research opportunities for individuals with Down syndrome and their families.
3. Describing potential benefits researchers can provide to the community to improve care and create collaborative relationships.

Community Outreach Engagement Working Group
INCLUDEx will investigate conditions that affect individuals with DS and without DS, such as Alzheimer’s disease (AD), autism, cataracts, celiac disease, congenital heart disease, diabetes.

INCLUDEx Objectives
1. Conduct targeted, high-risk, high-reward basic science studies on chromosome 21.
2. Assemble a study population of individuals with DS.
3. Include individuals with DS in existing and future clinical trials.

1. Conduct targeted, high-risk, high-reward basic science studies on chromosome 21.
   • Study animal models of DS
   • Explore the effects of multiple genes with a trisomic imbalance for chromosome 21 simultaneously
   • Identify pathways that may be most responsive to new therapies.
2. Assemble a study population of individuals with DS.
   • Add to or expand existing DS cohorts with omics data
   • Develop shared databases using common data elements
   • Build on the DS-Connect Registry
   • Develop effective community engagement strategies
3. Include individuals with DS in existing and future clinical trials.
   • Bolster recruitment of people with DS in clinical trials for co-occurring conditions
   • Develop new therapies for DS
   • Leverage existing clinical trials infrastructure to explore differences in drug metabolism in those with DS and assist in clinical trial design and training for conducting drug trials in people with DS.
   • Expertise from the DSMG membership will be essential to inform these efforts

See URL: https://www.nih.gov/include-project/include-project-research-plan

Defining the Stakeholders
• Individuals with Down syndrome
• Family members or caregivers
• Healthcare providers (health professional, therapist, teacher, clinician, researcher, clinician researcher, etc.)

4 P’s: Social Marketing Pitch

4 P’s: OUTREACH STRATEGIES FOR EACH STAKEHOLDER

Working group discussions led to initial social marketing strategies for each stakeholder group:

Individual with Down syndrome
• Product: new information that can improve your life and the life of others with DS
• Price: anxiety about what the research will involve; time, transportation
• Place: family members, advocacy groups, educators, trusted allied health providers
• Promotion: This can benefit you in the short term (payment) and long term (learning important new things about DS)

Family member or caregiver
• Product: benefits to research findings, helping others, return of results and resources to families
• Price: location, convenience, risk
• Place: must be in a convenient location to family, a way for young siblings to be occupied during research
• Promotion: increase trust, convenience, low risk, civility and respect, sharing success stories of gains realized from research

We want to close the gap between interest in research and participation in research.

We need more studies that are observative in nature first to improve overall health and quality of life in DS.

Healthcare provider (health professional, therapist, clinician, researcher, clinician researcher etc.)
• Product: New insights about DS to inform practice
• Price: High effort, minimum payoff; Long timeline from recruitment to findings
• Place: Place—DS association websites, Research weekends with DS organizations, Email lists; Flyers; Social media
• Promotion: We’re all in this together; Advanced/transformative methodologies; Serve as a bridge to more advanced treatments

Next Steps
• Create various outreach and promotional strategies and materials using the 4 P’s concept
• Engage the community early on and continuously
• Return of results is very important
• DS-Connect is a powerful online family registry that connects all stakeholders including Individuals with DS, their families or caregivers, and healthcare providers to research opportunities

Goals for DS-Connect®: The Down Syndrome Registry
• Increase the number of participants
• Encourage under-represented minorities for participation
• Use DS-Connect to support cohorts and clinical trials

INCLUDEx will investigate conditions that affect individuals with DS and without DS, such as Alzheimer’s disease (AD), autism, cataracts, celiac disease, congenital heart disease, diabetes.