

NCATS Day 2018: Engaging Patients and Communities for Smarter Science

Sept. 28, 2018

Natcher Conference Center • Room F1/F2

Poster List**1. Collaboration Between All Stakeholders: Accelerating to Treatments***By Monica Weldon, Bridge the Gap — SYNGAP Education and Research Foundation*

This presentation explains the benefits of collaboration with a vested group of rare disease experts and the patients and/or organizations that support their research. It is important that the patient organization understand both the rare disorder research landscape and the emerging standards for clinical care. This level of understanding will facilitate the construction of programs that fulfill both scientific and patient needs. This synchronization of research priorities with foundation programs will help drive and accelerate the process of finding answers to many questions, especially if the organization is in translational science and drug discovery. The foundation found that maintaining an open dialogue with the scientific advisory board and outside interested researchers can directly reshape the landscape of the rare disease space while setting standards for clinical care and possible therapeutic solutions.

2. Community Voices: An Innovative Program to Create and Sustain Successful Community-Academic Partnerships*By Linda Ko, Fred Hutchinson Cancer Research Center*

Community Voices involves a multi-step community-academic matching program focused on:

- Bringing to the forefront community research ideas to academic research teams;
- Creating a community-academic match based on shared research interests, research experience and commitment to community-engaged research; and
- Embedding a training curriculum on the science of community engagement and team science to facilitate effective team functioning.

A tracking system and surveys are used to evaluate:

- Partnership satisfaction and team functioning;
- Productivity on conference presentations, publications and grant writing;
- Team sustainability to undertake multiple projects; and
- Creation of new tools, programs and policies, including their adoption at local, regional and national levels.

3. Development of a CTSA Stakeholder Advisory Board: Lessons and Strategies*By Kimberly Dukes, University of Iowa Institute of Clinical and Translational Science (ICTS)*

The ICTS shares lessons and strategies learned during the initial development of its Stakeholder Advisory Board, which includes community organization leaders, patient navigators, public health professionals and clinicians. Stakeholders offer feedback on the direction of the ICTS and its cores, advisory board best practices, and specific research projects (e.g., preeclampsia research recruitment, an older-adult registry, an autism-research smartphone application for



pregnant women and new mothers). The ICTS offers team science training to all board members.

4. Patient Engagement: An Emerging Definition, Key Concepts and Resources

By Julien Rashid, FasterCures

Pulling from FasterCures and other organizations and collaborators' work, this poster presentation will collate emerging definitions, key concepts and resources for patient engagement. The content will complement Dr. Cynthia Grossman's morning presentation and will point to useful references for patient-engagement best practices and considerations. Some of these resources will be distributed as collateral printed reports.

5. NCATS Toolkit for Patient-Focused Therapy Development

By Eric Sid, Office of Rare Diseases Research, National Center for Advancing Translational Sciences (NCATS), NIH

The NCATS Toolkit for Patient-Focused Therapy Development provides a collection of online resources that can help patient groups advance through the process of therapy development and provide the tools that they need to advance medical research. As a living, online resource containing tools for and by patient groups, as well as other reliable sources of information, the Toolkit includes information such as how to:

- Establish a patient registry and natural history study database;
- Advance patient-focused discovery and pre-clinical research and development;
- Work with NIH and the Food and Drug Administration; and
- Assist with post-market surveillance.

This poster will provide a first-year update on the Toolkit, a patient-initiated project to provide a collection of online resources to engage in translational research. Learn more at <https://ncats.nih.gov/toolkit>.

6. Genetic and Rare Diseases (GARD) Information Center

By Janine Lewis, GARD Information Specialist, Office of Rare Diseases Research, NCATS, NIH

NCATS collaborates with the National Human Genome Research Institute (NHGRI) to support GARD, an information center designed to provide comprehensive information about rare and genetic diseases to patients, their families, health care providers, researchers and the public. The online GARD database, in English and Spanish, provides accurate, up-to-date information about ongoing research, symptoms, treatment options and other details. GARD information specialists are also available to discuss questions by phone in English and in Spanish. Sources for GARD and other hard-to-find information include the National Library of Medicine, scientific conferences, support groups, and clinical trials and research. Learn more at <https://ncats.nih.gov/gard>.

7. Duke CTSI Sparks Program

By Pamela Maxson, Duke Clinical and Translational Science Institute (CTSI), Duke University

The Duke CTSI Sparks program provides a platform for the cross-pollination of ideas. The premise is simple: Bring together researchers, community groups and/or members, patients and other stakeholders who work on the same health issue but from different approaches. During the poster presentation, staff will "spark" new and innovative ideas for community-engaged research projects that can inform proposals submitted to various funders, ranging from private foundations to governmental funding opportunities. Benefits of the Sparks program include:

- Building trust and transparency across stakeholders;

- Bringing partners together at the beginning of the research process; and
- Forging new relationships that are then poised to leverage future funding opportunities.

Poster staff will provide an example of a Sparks session that led to pilot funding through the Duke Clinical and Translational Science Award.

8. AlzScience: A Case Study in Science Blogging

By Maya Gosztyla, NCATS, NIH

Alzheimer's disease affects an estimated 5.7 million Americans, including one in three people over the age of 85. As a neuroscience undergraduate conducting research on Alzheimer's disease, Maya Gosztyla frequently encountered confusion among non-scientists about what caused the disease, how to reduce the risk and what possible treatments were emerging in clinical trials. To address this need for accurate and understandable information on Alzheimer's disease, she started a science blog called AlzScience (alzscience.wordpress.com). She used this platform to translate scientific articles into non-technical language and to discuss common misconceptions related to dementia and brain health. The site's following has grown considerably in the three years since its inception, with most articles reaching 500 to 1,000 views within two weeks of publication. This year, AlzScience won a first-place Science Seeker Award in the category of Health, Medicine, and Brain Science. This poster will chronicle her journey with AlzScience as well as showcasing recent efforts to teach other students and early-career researchers about science communication through a guest authorship program. She will also outline some practical tips for getting started with science blogging, with an emphasis on reaching middle-aged and elderly readers.