



## A Shared Vision: Collaboration, Community Outreach, and Informatics

The Clinical and Translational Science Awards (CTSA) Program and the Rare Diseases Clinical Research Network, highlighted in this edition of the magazine, share three features that are key to their success: collaboration, community outreach, and clinical research informatics.

The grantees of these programs have pledged to leverage their expertise and resources with researchers, physicians, industry, advocacy groups, their communities, and beyond. Success will lie, in part, on their abilities to share an inclusive and far-reaching vision with both the research community and the public. Clinical research informatics will make the vision a reality, with networks that link the various groups together and help them attain their ultimate goal of improving human health.

The CTSA, working as a consortium, will train and advance a cadre of multi- and interdisciplinary investigators, collaborating to translate discoveries made in the laboratory into improved therapies for patients. Through these collaborations—with basic, translational, and clinical investigators—a new discipline of clinical and translational science will be formed. At the same time, the CTSA researchers plan to expand their efforts with minority and medically underserved communities, and make broad connections across schools, institutions, and regions. Their strategic partnerships also will include the U.S. Department of Veterans Affairs, the Food and Drug Administration, and private health care organizations.

Woven into the CTSA plans are robust informatics programs that are the cornerstone of communication with the CTSA consortium and with collaborating organizations. Interoperability, security, workflow, usability, and standards are essential areas of focus. A national CTSA Informatics Steering Committee will serve as a forum for discussion and agreement on standards, best practices, and solutions.

In much the same way, the Rare Diseases Clinical Research Network is focused on a collaborative and coordinated system of investigators and patient support organizations committed to the study of rare diseases. Collaborations extend to sites in England, Japan, and Brazil. The research sites work in partnership with leaders in technology to enhance communication and sharing of resources for both investigators and patient support groups. A Data and Technology Coordinating Center provides innovative tools to collect and manage geographically distributed clinical research data on diverse diseases using standardized data elements. Researchers, physicians, and patient support groups benefit from this ability to coordinate and disseminate information.

Patients, researchers, institutions, and industry organizations will add value to the CTSA Consortium and the Rare Diseases Clinical Research Network. Bringing these many diverse participants together will depend on their willingness to collaborate, reach out to communities, and employ technologies that make communication possible.

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