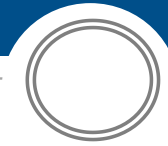


# *Integrity and Medical Innovation*



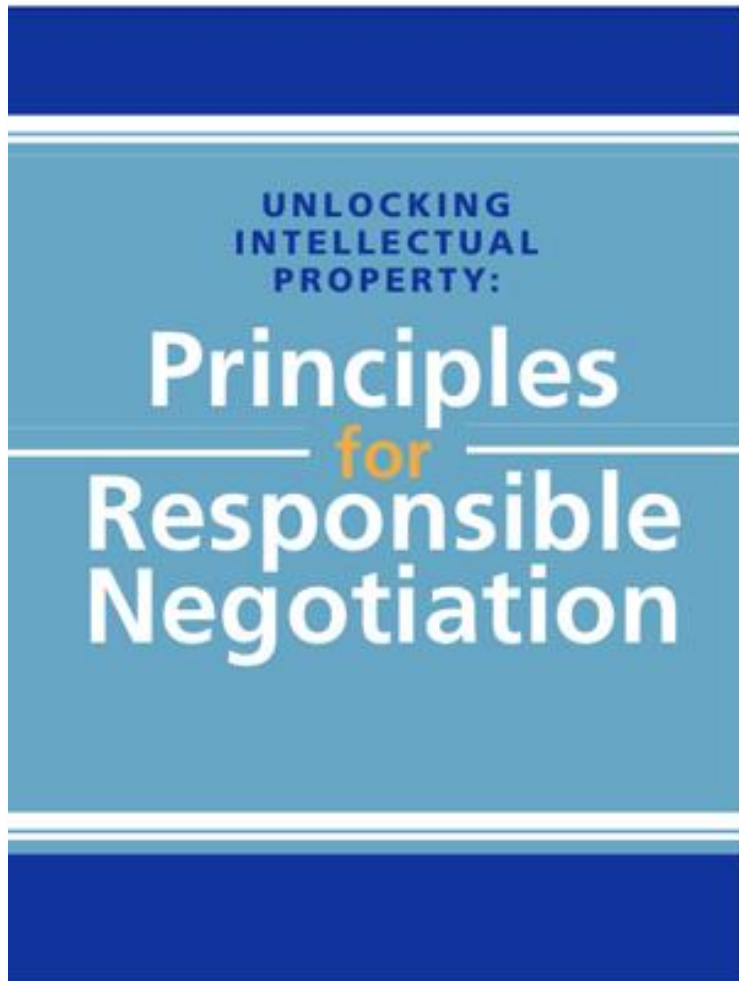
*Institute of Medicine*  
*Roundtable on Translating Genomic-Based Research for Health*

**Margaret Anderson**  
**Executive Director, *FasterCures***  
**June 5, 2013**

***FasterCures***  
A CENTER OF THE MILKEN INSTITUTE

# Unlocking Intellectual Property

*Overly restrictive licensing and unrealistic expectations can **deter innovation** or **improvement** by controlling the exchange of information and materials for research or the **ability to improve** the patented product.*



- *FasterCures* convened a small IP expert panel to develop a set of guiding principles and points to consider that can serve as a useful tool for all parties in biomedical research, in particular nonprofit disease groups and philanthropists negotiating IP with academic, industrial, and other nonprofit partners.
- The principles are intended to provide guidance for organizations new to IP negotiation as well as to serve as a set of useful values for more experienced organizations.

# Honest Brokers for Cures



“We are not your grandmother’s charity. We survey the scientific and clinical landscape ourselves, develop an agenda to strategically deploy out dollars, and then work to ensure we are making the smartest use of our money.”

- *FasterCures* dissects the new business model that has emerged from the shared sense of urgency and frustration stemming from these patient-driven foundations, also known as venture philanthropy groups.
- Provides a glimpse into how these entrepreneurial groups have ramped up their in-house expertise, and how they've tackled the science where it needs the most effort and resources, from basic to clinical research, and everywhere in between.

## CENTRAL STATION

A platform for venture philanthropy in medical research

FasterCures

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## Now available: TRAIN INVENTORY



half a billion dollars

The amount that TRAIN organizations provide in medical research grants in one year, according to the most recent available financial data



and TRAIN organizations are worth



2.2 billion

At least



one-third of TRAIN groups have supported one or more clinical trials



49%

of these groups incorporate advocacy efforts into their strategies for fighting disease

84%

partner with biotechnology or pharmaceutical companies

This free, Web-based index includes downloadable profiles of all 56 of The Research Acceleration and Innovation Network participating organizations.

### TRAIN Central Station Features

#### TRAIN E-News

CFIDS Association provides overview of drug development landscape

Parkinson's biomarker initiative reaches recruitment milestone

#### Blog

5/29: Medical research investment: an opportunity for bipartisanship?

5/24: One parent's mission to end pediatric rare disease

#### Discussion Group

Asking funded investigators to deposit their raw data

Recommendations for consultants who will perform a disease landscape analysis for a foundation to help identify strategic opportunities



### WHAT'S NEW AT TRAIN



#### EVENTS

Save the date for Partnering for Cures, Nov. 3-5 in New York

Register now for June 19 Webinar on LLS' Therapy Acceleration Program



#### CASE STUDIES

Multiple Myeloma Research Foundation

Myelin Repair Foundation



#### TOOLS AND RESOURCES

Inventory of Disease Research Foundations

Honest Brokers for Cures: How Venture Philanthropy Groups are Changing Biomedical Research

Measuring and Improving Impact: A Toolkit for Nonprofit Funders of Medical Research



#### CURRENT NEWS

The Burrill Report: New Initiative Takes on Multiple Sclerosis with Big Data

### INNOVATOR SPOTLIGHT

FOUNDATION  
FIGHTING  
BLINDNESS

Q&A with William Schmidt, CEO

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### NEW! DEAL-MAKING RESOURCES

FasterCures is pleased to present a new cache of tools, publications, resources, and slides addressing the challenges of cross-sector dealmaking, contributed by TRAIN organizations in 2012. If you have a resource, internal or external, that you would like to contribute or recommend to the community, please send it to us at [train@fastercures.org](mailto:train@fastercures.org).

#### tools

#### Collaboration

##### CHDI Agreement Templates

Collection of 13 templates for research agreements with academic institutions, service agreements with CROs, material transfer agreements, and compound testing agreements

Source: CHDI Management

##### Fox Foundation Agreement Templates

Collection of six pre-clinical and clinical contract templates, along with a confidential disclosure agreement

Source: Michael J. Fox Foundation for Parkinson's Research

##### NCATS Collaboration Agreement

Template for agreement to collaborate on a research project that is neither a funding agreement nor a CRADA

Source: National Center for Advancing Translational Sciences

##### Chordoma Foundation Grant Award Letter

Terms and conditions of grant award from Chordoma Foundation

Source: Chordoma Foundation

##### ALCFI Master Collaboration Agreement

Master agreement between Addario Lung Cancer Medical Institute and the 15 academic institutions that are part of its consortium

Source: Addario Lung Cancer Medical Institute

##### Company-Nonprofit Material Transfer Agreement

Template agreement for sharing company proprietary materials with a nonprofit institution for research

Source: Karyopharm, Inc.

##### Memorandum of Understanding for The Learning Collaborative

Details each party's roles and responsibilities within The Learning Collaborative, a government-academic-nonprofit research and development collaboration

Source: National Center for Advancing Translational Sciences



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