

If you are not at the table, you are on the menu

Advancing the Science of Community Engaged Research

August 25

Association of American Medical Colleges

Washington, DC

Sharon F. Terry



Genetic Alliance

President & CEO



**Elizabeth and Ian diagnosed with
pseudoxanthoma elasticum (PXE) 1994**





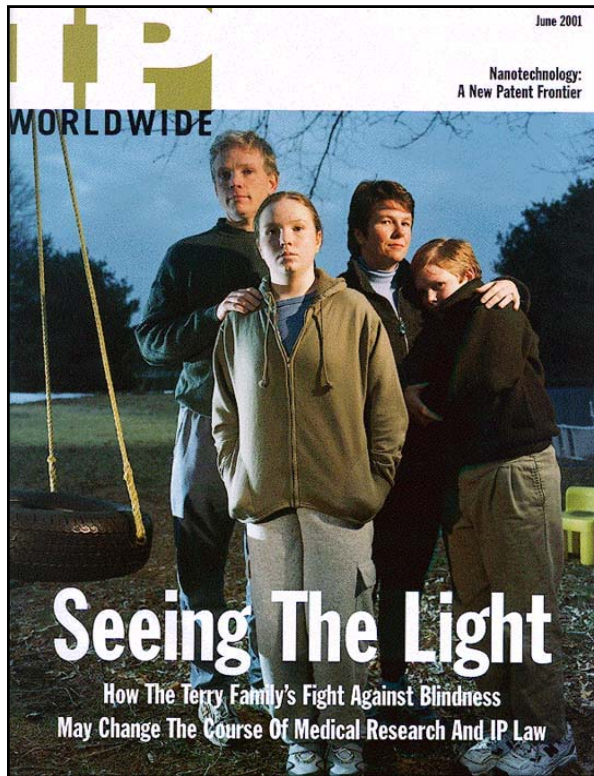
PXE
international

**Gene
Discovery**

BioBank

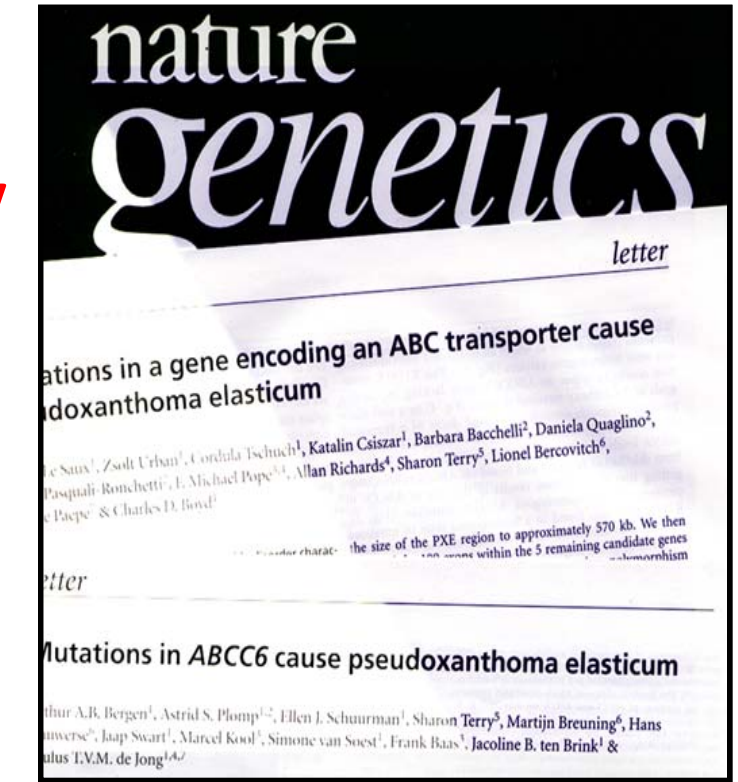
Testing

Clinical
Diagnostic
Test
Development
via FDA & CLIA
Regulatory
Strategies



Patenting

Licensing & Intellectual Property Management



**Human
Clinical
Trials**

**Drug
Screening &
Development
Approaches**

Therapeutics

- Small Molecules
- Nonsense mutants

Engaging Communities and Participants

- Partners
 - Not patients, co-investigators
 - Not 'at the table', planning the meal
- Frictionless
 - In communities, with community leaders
 - Where we live and play, in our pathway
- Relevance/Value/Benefit
 - Our questions, meet needs
 - Results are visible and tangible
 - Solve my problems while you solve yours
- Beyond advocates and advocacy to affinity

Watch our language

“When we LET patients...

- Engage
- Participate
- Partner

If this is real, then we are not LETTING patients come in or be part, we ARE partners, no need for permission...

Discover Shared and
Divergent Values

Not consent, engagement

Engagement, including Fair
Information Practices

Evolving PROCESS



The goal of PCORI's National Patient-Centered Clinical Research Network Program is to improve the nation's capacity to conduct CER efficiently, by creating a large, highly representative national patient-centered clinical research network to conduct clinical outcomes research.

The vision is to support a learning US healthcare system, which would allow for large-scale research to be conducted with advanced accuracy and efficiency.

\$1.26 Billion



PCORnet: “The National Patient-Centered Clinical Research Network”



- 1000 researchers, traditional and lay
- 33 funded entities covering all 50 states
- Focus on patient-centered outcomes research
- No “one size fits all”



- Community Engaged Network for All (CENA)
- 10 disease-specific advocacy organizations, UCSF, UCD
- From hepatitis (affects millions) to Alström syndrome (affects a several hundred)

Users are assisted by highly intuitive, non-coercive “guides”

Select a guide : For New User ▼

Set your privacy preferences manually, or select a guide who has studied the options and made suggestions for persons with high, medium and low concerns about privacy. Select a guide who you know, or whose experience or perspectives you value.

Stephen Mack
President, JSRDF. Parent of 10-year old daughter with Joubert syndrome

Stephen's daughter, Isabelle, was diagnosed in 2004 when she was just three days old. He currently serves as President of JSRDF, which he will hold through 2015. Prior to this, he served for two years as the organization's president-elect, and seve

... More >>

What's this?

Select Stephen as your guide

To enable ease and an extraordinary range of granularity

Each guide suggests his or her ideas as a possible starting point

Participants use privacy settings to specify who can, and cannot, find and/or export their de-identified and/or personal contact data, and for what purpose


For multiple categories of uses, and specified usage rights

Participants may choose to Allow, Deny, or Ask Me (wait for more information) before deciding

Deny
(Deny is not used in this individual's choices)

Privacy settings for Matt's profile.

Select Matt's preferred privacy settings...

 Stephen suggested settings for persons with: **Moderate concerns about privacy**

1. Choose a level of concern about privacy that more closely reflects your views.
2. To accept Stephen's suggested privacy settings shown below, click 'Accept and continue'.
3. If not, either click 'Customize' to refine these settings, or 'Go Back' to choose a different guide.

<< Go Back Customize Accept and continue >>

Who can access your data and for what purpose...
Click any column or row name for more information

	Find/Analyze except for name and contact details (click for details)	Export/Link except for name and contact details> (click for details)	Get Contact find, view, use and export contact details (click for details)
JSRDF			
Joubert Syndrome & Related Disorders Foundation (JSRDF)	✔ Allow	✔ Allow	⚠ Ask Me
Researchers recommended by JSRDF	✔ Allow	✔ Allow	⚠ Ask Me
Other Researchers			
Researchers addressing your condition	✔ Allow	✔ Allow	⚠ Ask Me
All researchers	✔ Allow	⚠ Ask Me	⚠ Ask Me
Data Analysis Platforms			
PCORnet: Patient-Centered Outcomes Research Network	✔ Allow	⚠ Ask Me	✔ Allow
Newly-Released Data Analysis Platforms	⚠ Ask Me	⚠ Ask Me	NA

<< Go Back Customize Accept and continue >>



- Crowdsourcing Research to Diverse Stakeholders
 - Welcome all perspectives: “Research is stronger when all voices are heard and valued”



Primary Condition of Interest *

Please select one condition that is most relevant to you. You will still be able to participate in discussions and opportunities associated with other conditions.

- Select a value -

Reason I am Interested *

Select all that apply.

I have this condition

My family member or someone I take care of has this condition

I am a healthcare provider

I am a scientist/researcher

Other

My Signature Line

This description will appear next to your name or pseudonym when you post comments on Mosaic. If you would like to change this signature line, please replace the text below with a brief phrase that describes your involvement in Mosaic. For example "Relative of a child with Joubert Syndrome".

- Build trust
- Respect privacy
- Support open discussions
- MOSAIC
 - Website open to public
 - Registration required to post comments
 - Select identity settings

Include Public/Participants in All Stages of Clinical Research

- Participant perspective to study design
 - Protocol Review
 - IRB service
 - Data safety monitoring boards
- Informed decision making
- Reasonable compliance - AIDS Community examples
- Enhanced community education
- Better cohort accrual - Herceptin example
- Improve participant retention
- Advance public trust in research

Culture Challenge

- Non-paternal (maternal)-istic
- Share investigation, partners
- Set the passion of people on fire, it will fuel the cultural transformation – not just enrollment for you study
- Support engagement
- Build a trustworthy environment, don't ask people to trust you
- Face our fears – this will be weird at first
- Participants/partners accountable too
- Transparency – make mistakes, apologize, move on





Contact Information



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PeerPlatform.org