

Patrick F Terry

Chairman
Gray Group Ventures

March 18, 2014

Terminology Matters

- <u>We</u> (Advocates) decline the term 'patient' as a surrogate for the more empowering consideration of 'participant'.
- Participants here are individuals <u>engaged in an activity</u> related to their health.
- Individuals diagnosed with chronic and inherited conditions describe themselves only as <u>patients</u> in the clinical care setting, during which they often feel <u>powerless</u>.
- Language is important in the <u>culture shift</u> that must take place to ensure people are at the center of population health and <u>emerging health literacy</u>.

My Conflicts of Interest

Co-founder:

Coalition for 21st Century Medicine, Washington DC
European Personalized Medicine Association, Luxembourg
Genetic Alliance BioBank, Gaithersburg MD
Genomic Health, Inc., Redwood City CA [NASDAQ: GHDX]
GRAND Therapeutics, Inc., Bethesda MD
International Genetic Alliance, The Hague Netherlands
National Assoc. of Healthcare Reimbursement, Carmel IN
Personalized Medicine Coalition, Washington DC
Technic Solutions, LLC (Acquired by Scientia Advisors)

Advisor:

BioMarkers & Diagnostics Journal
GenomeCANADA
Journal of Translational Medicine - Open Source Journal
Massachusetts Life Science Center, Boston MA
Private Access, Inc. Irvine CA
Registries for All, Washington DC
InVitae, San Francisco CA
EspeRare Foundation, Geneva CH

Board of Directors:

GRAND Therapeutics, Inc. Bethesda MD MeMed Diagnostics, Inc. Haifa Israel Sirius Genomics, Inc. Vancouver BC

Chairman & President:

PXE International, Washington DC Gray Group Ventures. Bethesda MD

Father of Two Adult Children with a Rare Disease

<u>Current & Past Advisor to Hundreds</u> <u>of Life Science Organizations</u>

Many For-Profit and Not-for-Profit Biotechnology, Life Science, Research Foundations, Institutions, Universities, Governmental Bodies, Trade Associations, Patient Groups, Public Policy Groups, Thinktanks, and Health Care Delivery Companies:

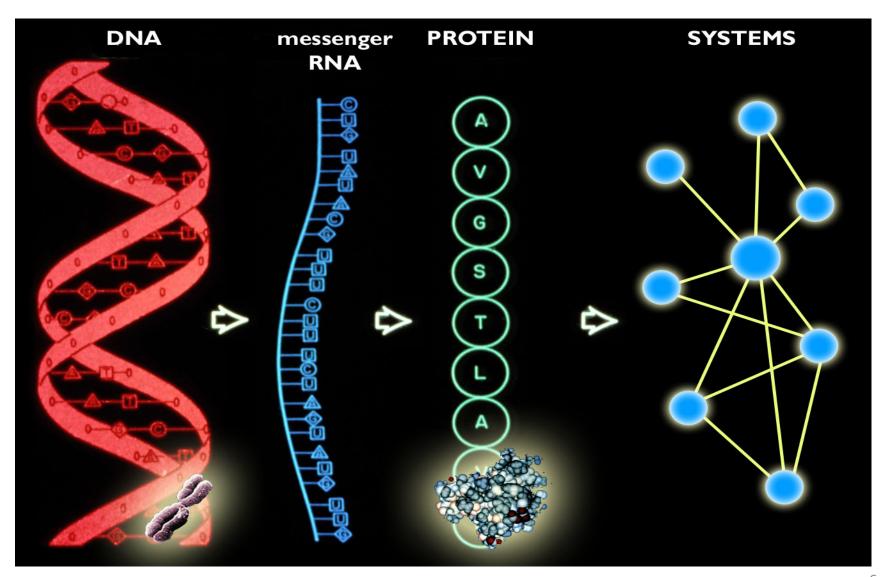
Located In: US, Canada, Mexico, Chile, Brazil, Europe, Mid-East, Israel, Japan, China, South Africa, and India.

My Children



The Genome

The Genome: Parts, Info, & Assembly





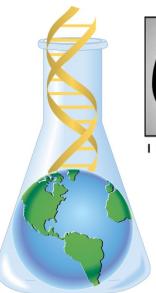






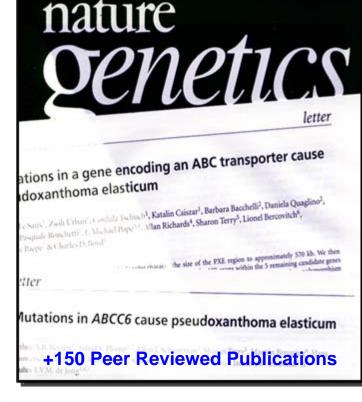
Patient Driven Enterprise in the Genomic Age

www.pxe.org





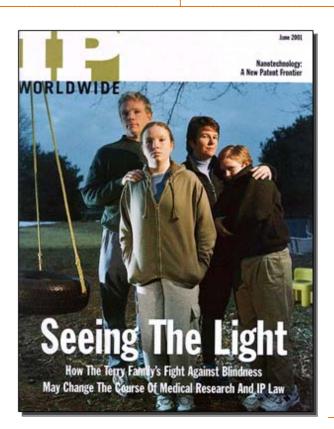
Gene(s) Discovery



BioBank

Testing

Clinical
Diagnostic
Test
Development
via FDA &
CLIA
Regulatory
Strategies



Human Clinical Trials

www.pxe.org

Diagnostic & Therapeutics

Saving
Vision &
Lives

Patenting & Licensing

Licensing & Intellectual Property Management

The Actionable Genome

Significant Diagnostic Utility of Human Health & Disease

The Clinical Cancer Genome



- ✓ Established Clinically Actionable Diagnostics ← Provided as LDT Panel
- ✓ Translational Research as Clinical Service
- Over Time...

 Transition of More

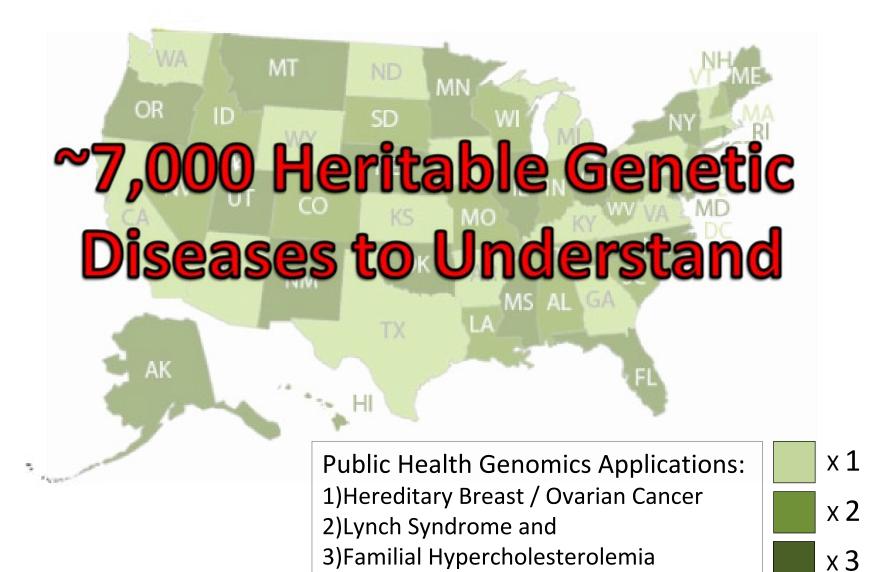
 Content, More Quickly
- ✓ Established "Payor Coverage Thresholds"
- ✓ Mechanism-of-Action Marker for Approved Therapies in Other Indications
- ✓ Masked Data Indeterminate Results Incidental Findings
- **✓** Emerging Realtime Actionable Content **←** Self Reported ?
- ✓ Active Discovery Trials (Population Trial Enrollment) ← Observational ?
- ✓ Alternations of Unknown Significance ← Target Cohort Development?

Recent Public Policy

Policy Affecting Implementation of Genomic Medicine

- □ In 2013, several branches of the US government enhanced implementation of genomic applications through significant policy and legislative activities while curtailing premature use of such technologies. These included:
 - Supreme Court ruling on gene patents;
 - FDA authorization of the first, next-gen DNA sequencer;
 - FDA's increased regulatory activity over the direct-toconsumer genetic testing;
 - Affordable Care Act provisions for coverage of some genetic counseling and testing;
 - Progress in implementation of genomics objectives in the Healthy People 2020 initiative .

Public Health Genetics



My Vision of Health Care

I suggest that the future of **Population**

Health is the **Effective Mass-Customization** of **Targeted Approaches** to **Health Maintenance**

- Purposeful Pursuit Away from Sick Care Delivery
- To Include Accessible Genetic Information
- •Engaged Participatory Health Care At Scale
- Health Care Subject to True Market Forces and Consumer
 Demand Dynamics
- Problems will Always Arise when Patients and Care are Viewed
 Only as ICD and CPT Codes / Transactional Context
- Health Status Must be Deemed Valuable and Incentivized

The Science of Delivery

- 1) Traditional Health Care Delivery
- 2) Patient Advocacy as We Know It Today
- •The Art and Science of Delivering Improvements in health care services, as we have assembled them today, or even through the proposed reform movement will NOT Scale, become Effective, Efficient, or Sustainable. So as a result;
- •Alternative Models and Novel Partnerships will be necessary to succeed in population health.

The Inescapable Truth

Population Health Management require healthcare providers to care more effectively, efficiently, and safely for more people - despite shrinking reimbursements, ever increasing informational complexity, and escalating costs.

Emerging Active Participants

New entrants will become increasingly important in population health management

Stratified Medicine / Precision Medicine / Personalized Medicine Stakeholders

RESEARCH TOOLS

PRODUCT DEVELOPMENT **REG. APPROVAL 8** REIMBURSEMENT

HEALTHCARE DELIVERY

HOSPITALS



PATIENTS

PM Research

- Genetics/PGx
- Genomics
- Proteomics
- Metabolomics





DIAGNOSTIC COMPANIES





3rd PARTY **PAYORS**



PHYSICIANS



NEXT GEN SEQUENCING COMPANIES



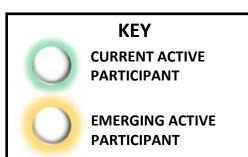
GENOME MANAGEMENT COMPANIES



PHARMACY BENEFIT **MANAGERS**



HEALTH IT COMPANIES



My Presentation

- My Perspective on Population Health
- Value of Consumer Health Literacy
- The Need for <u>US</u> to Work on Behalf of the <u>WE</u> and Improved Health for All

Thank You!

