BIOGRAPHICAL SKETCH

NAME	**POSITION TITLE**		
Sharon Fontaine Terry	President and CEO, Genetic Alliance		
EDUCATION/TRAINING			
INSTITUTION and LOCATION	**DEGREE**	**YEAR(s)**	**FIELD of STUDY**
Assumption College, Worcester, MA	MA	1983	Religious Studies
State University of NY at Stony Brook	BA	1979	Earth and Space Sciences

A. Positions and Honors

Honors

2005 Honorary Doctorate, Iona College
2007 1st Annual Patient Service Award, UNC Institute for Pharmacogenomics and Individualized Therapy
2009 Elected Ashoka Fellow
2010 Research!America's 2011 Paul G. Rogers Distinguished Organization Advocacy Award
2011 Clinical Research Forum's Public Advocacy Award
2012 Spirit of Empowerment Advocacy Award, Facing Our Risk of Cancer Empowered
2012 Honorary Professorship, Hebei United University, Tangshan, China
2012 Collaborate|Activate Innovation Challenge First Prize Award
2013 Ashoka Changemakers First Prize
2013 Forbes Best Business Model for Transforming Health Systems

Academic Appointments

1986-1988 Campus Minister, Instructor, Assumption College, Worcester, MA

Memberships - Professional Organizations

Member, American Association for the Advancement of Science
Member, American College of Medical Genetics
Member, American Society of Human Genetics
Member, Association for Research in Vision and Ophthalmology
Member, Coalition of Skin Diseases
Member, Society of Investigative Dermatology
Charter Member, American Society of Matrix Biology

Positions Held - Organizations

1995-present Founding CEO, PXE International, Inc.
1998-2001 Vice President for Consumers, Genetic Alliance
1999-present President, Coalition of Heritable Disorders of Connective Tissue
2000-2010 Professional Advisory Board Member, Aneurysm Outreach Inc.
2001-present Member, Professional Advisory Board, Autosomal Recessive Polycystic Kidney Disease Alliance
2002-2005 Board Member, American Society of Matrix Biology
2002-2010 Board Member, The Biotechnology Institute
2002-present Member, Scientific Council, PXE France
2002-present President, Genetic Alliance
2003-2006 Member, National Institute of Arthritis Musculoskeletal and Skin Diseases Council, NIH, DHHS
2003-present Founding President, Genetic Alliance Registry and BioBank Board of Directors
2004-2009 Board Member, DNA Direct
2004-2010 Member, Genetic Services Research Advisory Board
2004-present Board Member, International Genetic Alliance
2004-present CEO, Genetic Alliance
2005-2007 Board Member, Personalized Medicine Coalition
2005-2009 Board Member, Colorectal Cancer Coalition
2006-present Board Member, Coalition for 21st Century Medicine

2007-2013 Board Member, National Coalition of Health Professional Education in Genetics
2008-2011 Board Member, Center for Information & Study on Clinical Research Participation (CISCRP)
2011-present Member, Institute of Medicine Board on Health Sciences Policy
2013-present President, EspeRare Foundation, Geneva, Switzerland

Positions Held - Committees

1997-2002 Consumer representative, Women's Dermatology Committee, American Academy of Dermatology
1997-2002 Representative to the Research Council, American Academy of Dermatology
1997-2002 Member, Ad-hoc Committee for Consumer Issues, The American Society of Human Genetics
2000-2003 Appointed Member, Ad Hoc Committee of Experts on IRBs and Informed Consent, HHS Secretary's Advisory Council on Genetic Testing
2000-2004 Appointed Member, Ethical, Legal and Social Issues Research Advisors, NIH
2000-2004 Member, Advisory Committee on Informed Consent, Centers for Disease Control
2002-2006 Appointed Member, Advisory Board, Genetics and Public Policy Center, Johns Hopkins University
2003-2006 Appointed Member, The Society of Investigative Dermatology Government Liaison Committee
2004-2008 Advisory Board Member, Center for Information & Study on Clinical Research Participation
2004-2010 Member, Office of Rare Diseases, NIH and CDC Rare Diseases Testing Working Group
2005-2009 Member, Cellular, Tissue, and Gene Therapies Advisory Committee, FDA
2005-2013 Liaison, National Advisory Council for Human Genome Research
2006-2008 Workgroup Member, Genetic Testing for Rare Diseases in an International Perspective
2006-present Expert advisor, Cellular, Tissue, and Gene Therapies Advisory Committee, FDA
2007-2009 Chairperson, Social Issues Committee, American Society of Human Genetics
2007-2011 Member, Google Health Advisory Board
2007-2012 Liaison, Advisory Committee on Heritable Disorders in Newborn and Children
2007-2012 Member, Institute of Medicine Roundtable on Translating Genomic-Based Research for Health
2008-2009 Member, Institute of Medicine Planning Committee, Workshop on the Systems Evaluation of Genome-Based Health Care
2009-2011 Member, Advocates in Research Training Planning Team, National Cancer Institute, NIH
2009-present Member, Health and Human Services Office of the National Coordinator Health Information Technology Standards Committee
2009-present Member, Rosalind Franklin Society Advisory Board
2010 Member, Institute of Medicine Planning Committee, Workshop on Evidence Generation for Genomic Diagnostic Test Development
2010 Member, Institute of Medicine Planning Committee, Workshop: Establishing Precompetitive Collaborations to Stimulate Genomics Driven Drug Development
2010-present Executive Committee member, International Rare Disease Research Consortium
2011 Member, Institute of Medicine Committee on the Use of Chimpanzees in Biomedical and Behavioral Research
2011-2012 Member, Institute of Medicine Committee Review of the California Institute of Regenerative Medicine (CIRM)
2011-2012 Member, Institute of Medicine Planning Committee, Workshop on New Paradigms in Drug Discovery: How Genomic Data Are Being Used to Revolutionize the Drug Discovery and Development Process
2012 Co-chair and Chair, Institute of Medicine Workshop on Sharing Clinical Research Data
2012-2013 Co-chair, Institute of Medicine Planning Committee, Workshop on Improving the Efficiency and Effectiveness of Genomic Science Translation
2012-2013 Vice-chair, Institute of Medicine Committee Review of the Clinical and Translational Science Awards Program at the National Center for Advancing Translational Sciences (NCATS)
2012-present Co-chair, Institute of Medicine Roundtable on Translating Genomic-Based Research for Health
2013 Chair, Institute of Medicine Workshop, Assuring Integrity while Facilitating Innovation in Medical Research
2013 Member, Regulatory Expert Working Group of the Global Alliance
2013 Member, Scientific Advisory Board, Fondazione Telethon

2013 Member, Institute of Medicine Planning Committee, Workshop on Genomics-Enabled Drug Repurposing and Repositioning
2013-2014 Member, Institute of Medicine Independent Review and Assessment of the Activities of the NIH Recombinant DNA Advisory Committee
2013-2014 Member, Institute of Medicine Planning Committee, Workshop on Data Harmonization for Patient-Centered Clinical Research
2013-2015 Member, Institute of Medicine Committee on Strategies for Responsible Sharing of Clinical Trial Data
2013-present Scientific advisor, BabySeq, Genome Sequence-Based Screening for Childhood Risk and Newborn Illness
2013-present Steering Committee member, PhenX: Consensus Measures for Phenotypes and eXposures
2013-present Member, Genome Advisory Board
2014 Member, Institute of Medicine Planning Committee, Workshop on Ethical Review and Oversight Issues in Research Involving Standard of Care Interventions
2014-present Scientific advisor, MEDSeq, Integration of Whole Genome Sequencing into Clinical Medicine
2014-present Executive Committee member, Steering Committee member, and Governance Task Force Co-Chair, PCORnet, Patient-Centered Outcomes Research Institute
2014-present Executive Committee member, Accelerating Medicines Partnership
2015-present Member, Institute of Medicine Committee on Public Health Approaches to Reduce Vision Impairment and Promote Eye Health
2015-present Member, Institute of Medicine Committee on Gene Editing
2015-present Board Member, Strategic Advisory Board for the Global Alliance for Genomes and Health
2015-present Precision Medicine Iinitiative Cohort Program Advisory Panel

Positions Held – Editorial Boards
2011-present Genetic Testing and Biomarkers
2013-present The Journal of Rare Disorders
2013-present Genome
2014-present Drug Repurposing, Rescue and Repositioning
2014-present Rapid Science

B. Selected Peer-Reviewed Publications and Presentations

Journal Articles
1. Uitto J, Boyd C, Lebwohl M, Moshell A, Rosenbloom J, and **Terry SF**. International centennial meeting on pseudoxanthoma elasticum: progress in PXE research. *J Invest Dermatol*. 1998 May;110(5):840-2. PMID: 9579557
2. Le Saux O, Urban Z, Göring HHH, Csiszar K, Pope FM, Richards A, Pasquali-Ronchetti I, **Terry SF**, Bercovitch LG, Lebwohl MG, Breuning MH, van den Berg P, Kornet L, Doggett N, Ott J, de Jong PTVM, Bergen AAB, Boyd CD. Pseudoxanthoma elasticum maps to an 820 kb region of the p13.1 region of chromosome 16. *Genomics.* 1999 Nov 15;62(1):1-10. PMID: 10585762
3. Le Saux O, Urban Z, Tschuch C, Csiszar K, Bacchelli B, Quaglino D, Pasquali-Ronchetti I, Pope FM, Richards A, **Terry SF**, Bercovitch L, de Paepe A, Boyd CD. Mutations in a gene encoding an ABC transporter cause pseudoxanthoma elasticum. *Nat Genet.* 2000 Jun;25(2):223-7. PMID: 10835642
4. Bergen AA, Plomp AS, Schuurman EJ, **Terry SF**, Breuning M, Dauwerse H, Swart J, Kool M, van Soest S, Baas F, ten Brink JB, de Jong PT. Mutations in ABCC6 cause pseudoxanthoma elasticum. *Nat Genet.* 2000 Jun;25(2):228-31. PMID: 10835643
5. **Terry SF**, Davidson ME. Meeting the Needs of Affected Individuals in the New Genetics Age. *Exceptional Parent*, December 2000.
6. **Terry SF**, Davidson ME. Empowering the Public to be Informed Consumers of Genetic Technologies and Services. *Community Genet.* 2000 Dec;3(3):148-50. PMID: 11831266
7. **Terry SF**, Bercovitch L, Boyd C (June 2001) Pseudoxanthoma elasticum (PXE). In: *GeneClinics: Clinical Genetic Information Resource* [database online]. Copyright, University of Washington, Seattle. Available at http://www.geneclinics.org. PMID: 20301292

8. Gheduzzi D, Taparelli F, Quaglino D Jr, Di Rico C, Bercovitch L, **Terry SF**, Singer DB, Pasquali-Ronchetti I. The placenta in pseudoxanthoma elasticum: clinical, structural and immunochemical study. *Placenta*. 2001Jul;22(6):580-90. PMID: 11440547
9. **Terry SF**, Boyd C. Researching the biology of PXE: partnering in the process. *Am J Med Genet.* 2001 Fall;106(3):177-84. PMID: 11778977
10. Terry PF, **Terry SF**. A consumer perspective on informed consent and third-party issues. *J Contin Educ Health Prof*. 2001 Fall;21(4):256-64. PMID: 11803770
11. Le Saux O, Beck K, Sachsinger C, Silvestri C, Treiber C, Göring HH, Johnson EW, De Paepe A, Pope FM, Pasquali-Ronchetti I, Bercovitch L, Marais AS, Viljoen DL, **Terry SF**, Boyd CD. A spectrum of abcc6 mutations is responsible for pseudoxanthoma elasticum. *Am J Hum Genet*. 2001 Oct;69(4):749-64. PMID: 11536079
12. Beskow LM, Burke W, Merz JF, Barr PA, **Terry SF**, Penchaszadeh VB, Gostin LO, Gwinn M, Khoury MJ. Informed consent for population-based research involving genetics. *JAMA*. 2001 Nov 14;286(18):2315-21. PMID: 11710898
13. Rothenberg KH, **Terry SF.** Human genetics. Before it's too late--addressing fear of genetic information. *Science*. 2002 Jul 12;297(5579):196-7. PMID: 12114610
14. **Terry SF**. Pharmacogenetic challenges. *Health Aff (Millwood).* 2002 Sep-Oct;21(5):307; discussion 307-8. PMID: 12224905
15. Le Saux O, Beck K, Sachsinger C, Treiber C, Göring HH, Curry K, Johnson EW, Bercovitch L, Marais AS, **Terry SF**, Viljoen DL, Boyd CD. Evidence for a founder effect for pseudoxanthoma elasticum in the Afrikaner population of South Africa. *Hum Genet.* 2002 Oct;111(4-5):331-8. PMID: 12384774
16. Bercovitch L, Schepps B, Koelliker S, Magro C, **Terry SF**, Lebwohl M. Mammographic findings in pseudoxanthoma elasticum. *J Am Acad Dermatol*. 2003 Mar;48(3):359-66. PMID: 12637915
17. Uhlmann WR, Bennett R, Botkin JR, Botstein D, Boughman JA, Chakravarti A, Clayton EW, Kahn J, Koenig B, Murray TH, Olson MV, Rowley J, **Terry SF**, Valle D. Planning the genome institute's future. *Science*. 2003 Mar 7;299(5612):1515; author reply 1515. PMID: 12624247
18. Collins FS, Green ED, Guttmacher AE, Guyer MS; US National Human Genome Research Institute. A vision for the future of genomics research. *Nature*. 2003 Apr 24;422(6934):835-47. PMID: 12695777
19. Lin AE, **Terry SF**, Lerner B, Anderson R, Irons M. Participation by clinical geneticists in genetic advocacy groups. *Am J Med Genet A*. 2003 May 15;119A(1):89-92. PMID: 12707968
20. **Terry SF**, Burke W. Banning pens and pads misses the main point. *Am J Bioeth*. 2003 Summer;3(3):63-5. PMID: 14594500
21. **Terry SF**. Learning genetics. *Health Aff (Millwood).* 2003 Sep-Oct;22(5):166-71. PMID: 14515892
22. Bercovitch L, Robinson-Bostom L, **Terry SF,** Pasquali-Ronchetti I, Harrist T. Re: yellowish papules on flexural areas in a child. *Pediatr Dermatol*. 2003 Nov-Dec;20(6):543-5; author reply 545. PMID: 14651582
23. Gheduzzi D, Sammarco R, Quaglino D, Bercovitch L, **Terry SF**, Taylor W, Ronchetti IP. Excutaneous ultrastructural alternations in pseudoxanthoma elasticum. *Ultrastruct Pathol.* 2003 Nov-Dec;27(6):375-84. PMID: 14660276
24. The International HapMap Consortium (**Terry, SF**, member, Populations group). Integrating ethics and science in the International HapMap Project. *Nat Rev Genet*. 2004 Jun;5(6):467-75. PMID: 15153999
25. Beskow LM, Botkin JR, Daly M, Juengst ET, Lehmann LS, Merz JF, Pentz R, Press NA, Ross LF, Sugarman J, Susswein LR, **Terry SF**, Austin MA, Burke W. Ethical issues in identifying and recruiting participants for familial genetic research. *Am J Med Genet A.* 2004 Nov 1;130A(4):424-31. PMID: 15455364
26. Bercovitch L, LeRoux T, **Terry SF**, Weinstock MA. Pregnancy and obstetrical outcomes in pseudoxanthoma elasticum. *Br J Dermatol*. 2004 Nov;151(5):1011-8. PMID: 15541079
27. Bercovitch RS, Januario JA, **Terry SF**, Boekelheide K, Podis AD, Dupuy DE, Bercovitch LG. Testicular microlithiasis in association with pseudoxanthoma elasticum. *Radiology.* 2005 Nov;237(2):550-4. PMID: 16244264
28. **Terry SF**, Terry PF. A consumer perspective on forensic DNA banking. *J Law Med Ethics.* 2006 Summer;34(2):408-14. PMID: 16789963
29. **Terry SF**, Terry PF, Rauen K, Uitto J, Bercovitch L. Advocacy groups as research organizations: the PXE International example. *Nat Rev Genet.* 2007 Feb;8(2):157-64. PMID: 17230202
30. Shi Y, **Terry SF**, Terry PF, Bercovitch LG, Gerard GF. Development of a rapid, reliable genetic test for pseudoxanthoma elasticum. *J Mol Diagn.* 2007 Feb;9(1):105-12. PMID: 17251343

31. Vanakker OM, Martin L, Gheduzzi D, Leroy BP, Loeys BL, Guerci VI, Matthys D, **Terry SF**, Coucke PJ, Pasquali-Ronchetti I, De Paepe A. Pseudoxanthoma elasticum-like phenotype with cutis laxa and multiple coagulation factor deficiency represents a separate genetic entity. *J Invest Dermatol.* 2007 Mar;127(3):581-7. PMID: 17110937
32. Herrick EK, Fogel CE, Christensen K, **Terry SF,** McInerney JD. Providers' knowledge of genetics: a survey of 5,915 Individuals and families with genetic conditions. *Genet Med.* 2007 May;9(5):259-67. PMID: 17505202
33. Pfendner EG, Vanakker O, **Terry SF**, Vourthis S, McAndrew PE, McClain MR, Fratta S, Marais AS, Hariri S, Coucke PJ, Ramsay M, Viljoen D, Terry PF, De Paepe A, Uitto J, Bercovitch LG. Mutation detection in the ABCC6 gene and genotype-phenotype analysis in a large international case series affected by pseudoxanthoma elasticum. *J Med Genet.* 2007 Oct;44(10):621-8. PMID: 17617515
34. Vanakker OM, Leroy BP, Coucke P, Bercovitch LG, Uitto J, Viljoen D, **Terry SF**, Van Acker P, Matthys D, Loeys B, De Paepe A. Novel clinico-molecular insights in pseudoxanthoma elasticum provide an efficient molecular screening method and a comprehensive diagnostic flowchart. *Hum Mutat.* 2008 Jan;29(1):205. PMID: 18157818
35. Wolf SM, Lawrenz FP, Nelson CA, Kahn JP, Cho MK, Clayton EW, Fletcher JG, Georgieff MK, Hammerschmidt D, Hudson K, Illes J, Kapur V, Keane MA, Koenig BA, Leroy BS, McFarland EG, Paradise J, Parker LS, **Terry SF**, Van Ness B, Wilfond BS. Managing incidental findings in human subjects research: analysis and recommendations. *J Law Med Ethics*. 2008 Summer;36(2):219-48, 211. PMID: 18547191
36. **Terry, SF**. Genetic testing. *Genet Test*. 2008 Jun;12(2):175-6. PMID: 18554161
37. Petruccio C, Mills Shaw KR, Boughman J, Fernandez C, Harlow I, Kruesi M, Kyler P, Lloyd-Puryear MA, O'Leary J, Skillman A, **Terry SF**, McKain F. Healthy choices through family history: a community approach to family history awareness. *Community Genet.* 2008;11(6):343-51. PMID: 18690002
38. **Terry, SF**. What do leaders of disease-specific advocacy organizations know about pharmacogenomics and biomarkers, anyway? *Future Medicine.* 2009;6(2):171-81.
39. Ramsay M, Greenberg T, Lombard Z, Labrum R, Lubbe S, Aron S, Marais AS, **Terry SF**, Bercovitch L, Viljoen D. Spectrum of genetic variation at the ABCC6 locus in South Africans: Pseudoxanthoma elasticum patients and healthy individuals. *J Dermatol Sci.* 2009 Jun;54(3):198-204. PMID: 19339160
40. Khoury MJ, Feero WG, Reyes M, Citrin T, Freedman A, Leonard D, Burke W, Coates R, Croyle R, Edwards K, Kardia S, McBride C, Manolio T, Randhawa G, Rasooly R, St Pierre J, **Terry SF**; GAPPNet Planning Group. The genomic applications in practice and prevention network. *Genet Med.* 2009 Jul;11(7):488-94. PMID: 19471162
41. Khoury MJ, McBride CM, Schully SD, Ioannidis JP, Feero WG, Janssens AC, Gwinn M, Simons-Morton DG, Bernhardt JM, Cargill M, Chanock SJ, Church GM, Coates RJ, Collins FS, Croyle RT, Davis BR, Downing GJ, Duross A, Friedman S, Gail MH, Ginsburg GS, Green RC, Greene MH, Greenland P, Gulcher JR, Hsu A, Hudson KL, Kardia SL, Kimmel PL, Lauer MS, Miller AM, Offit K, Ransohoff DF, Roberts JS, Rasooly RS, Stefansson K, **Terry SF**, Teutsch SM, Trepanier A, Wanke KL, Witte JS, Xu J. The Scientific Foundation for personal genomics: recommendations from a National Institutes of Health-Centers for Disease Control and Prevention multidisciplinary workshop. *Genet Med.* 2009 Aug;11(8):559-67. PMID: 19617843
42. Haga SB, **Terry SF**. Ensuring the safe use of genomic medicine in children. *Clin Pediatr (Phila)*. 2009 Sep;48(7):703-8. PMID: 19448129
43. Dressler LG, **Terry SF.** How will GINA influence participation in pharmacogenomics research and clinical testing? *Clin Pharmacol Ther*. 2009 Nov;86(5):472-5. PMID: 19844223
44. Plomp AS, Bergen AA, Florijn RJ, **Terry SF**, Toonstra J, van Dijk MR, de Jong PT. Pseudoxanthoma elasticum: Wide phenotypic variation in homozygotes and no signs in heterozygotes for the c.3775delT mutation in ABCC6. *Genet Med.* 2009 Dec;11(12):852-8. PMID: 19904211
45. Calonge N, Green NS, Rinaldo P, Lloyd-Puryear M, Dougherty D, Boyle C, Watson M, Trotter T, **Terry SF**, Howell RR. Committee report: Method for evaluating conditions nominated for population-based screening of newborns and children. *Genet Med.* 2010 Mar;12(3):153-9. PMID: 20154628
46. **Terry SF**, Austin C, Inglese J, Meeker D, Terry PF. Assay, preclinical, and clinical brick walls and opportunities for system change through GRANDRx. *Assay Drug Dev Technol*. 2010 Apr;8(2):128-34. PMID: 20307201
47. **Terry SF**. Accelerate medical breakthroughs by ending disease earmarks. *Nat Rev Genet.* 2010 May;11(5):310. PMID: 20414986

48. Horn EJ, Bialick J, **Terry SF**. Landscape analysis of registries and biobanks – a tool for disease advocacy organizations to enhance translational research systems. *Biopreserv Biobank.* 2010 Jun;8(2):115-7. PMID: 24845940
49. Gitlin JM, Fischbeck K, Crawford TO, Cwik V, Fleischman A, Gonye K, Heine D, Hobby K, Kaufmann P, Keiles S, MacKenzie A, Musci T, Prior T, Lloyd-Puryear M, Sugarman EA, **Terry SF**, Urv T, Wang C, Watson M, Yaron Y, Frosst P, Howell RR. Carrier testing for spinal muscular atrophy. *Genet Med*. 2010 Oct;12(10):621-2. PMID: 20808230
50. **Terry SF**, Krokosky A. Rare conditions: where do primary care and genetic diseases intersect? *JAAPA*. 2010 Nov;23(11):63-4. PMID: 21086896
51. **Terry SF**, Terry PF. Power to the people: participant ownership of clinical trial data. *Sci Transl Med*. 2011 Feb 9;3(69):69cm3. PMID: 21307299
52. **Terry SF**, Horn EJ, Scott J, and Terry PF. Genetic Alliance Registry and BioBank: a novel disease advocacy-driven research solution. *Personalized Medicine*. 2011 Mar;8(2):207-13.
53. Bercovitch L, Martin L, Chassaing N, Hefferon TW, Bessis D, Vanakker O, **Terry SF**. Acquired pseudoxanthoma elasticum presenting after liver transplantation. *J Am Acad Dermatol*. 2011 May;64(5):873-8. PMID: 21397982
54. O'Leary J, Edelson V, Gardner N, **Terry SF**, et al. Community-centered family health history: a customized approach to increased health communication and awareness. *Prog Community Health Partnersh*. 2011 Summer;5(2):113-22. PMID: 21623013
55. Therrell BL Jr, Hannon WH, Bailey DB Jr, Goldman EB, Monaco J, Norgaard-Pedersen B, **Terry SF**, Johnson A, Howell RR. Committee Report: Considerations and recommendations for national guidance regarding the retention and use of residual dried blood spot specimens after newborn screening. *Genet Med*. 2011 Jul;13(7):621-4. PMID: 21602691
56. Uitto J, Bercovitch L, **Terry SF**, Terry PF. Pseudoxanthoma elasticum: progress in diagnostics and research towards treatment: Summary of the 2010 PXE International Research Meeting. *Am J Med Genet A.* 2011 Jul;155A(7):1517-26. PMID: 21671388
57. Yoo JY, Blum RR, Singer GK, Stern DK, Emanuel PO, Fuchs W, Phelps RG, **Terry SF,** and Lebwohl MG. A randomized controlled trial of oral phosphate binders in the treatment of pseudoxanthoma elasticum. *J Am Acad Dermatol*. 2011 Aug;65(2):341-8. PMID: 21496949
58. Oster-Granite ML, Parisi MA, Abbeduto L, Berlin DS, Bodine C, Bynum D, Capone G, Collier E, Hall D, Kaeser L, Kaufmann P, Krischer J, Livingston M, McCabe LL, Pace J, Pfenninger K, Rasmussen SA, Reeves RH, Rubinstein Y, Sherman S, **Terry SF**, Siewhitten M, Williams S, McCabe ER, Maddox YT. Down syndrome: national conference on patient registries, research databases, and biobanks. *Mol Genet Metab.* 2011 Sep-Oct;104(1-2):13-22. PMID: 21835664
59. Ayme S, **Terry SF**, Groft S. Response to 'Mutation (variation) databases and registries: a rationale for coordination of efforts': an IRDiRC perspective. *Nat Rev Genet.* 2011 Oct 25.
60. Schmidt JL, Castellanos-Brown K, Childress S, Bonhomme N, Oktay JS, **Terry SF**, Kyler P, Davidoff A, Greene C. The impact of false-positive newborn screening results on families: a qualitative study. *Genet Med*. 2012 Jan;14(1):76-80. PMID: 22237434
61. Moore PJ, Gratzer W, Lieber C, Edelson V, O'Leary J, **Terry SF**. Iona College community centered family health history project: lessons learned from student focus groups. *J Genet Couns*. 2012 Feb;21(1):127-35. PMID: 21830165
62. Landy DC, Brinich MA, Colten ME, Horn EJ, **Terry SF**, Sharp RR. How disease advocacy organizations participate in clinical research: a survey of genetic organizations. *Genet Med.* 2012 Feb;14(2):223-8. PMID: 22261756
63. **Terry SF**, Christensen KD, Metosky S, Rudofsky G, Deignan KP, Martinez H, Johnson-Moore P, Citrin T. Community engagement about genetic variation research. *Popul Health Manag*. 2012 Apr;15(2):78-89. PMID: 21815821
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65. Kaye J, Curren L, Anderson N, Edwards K, Fullerton SM, Kanellopoulou N, Lund D, Macarthur DG, Mascalzoni D, Shepherd J, Taylor PL, **Terry SF**, Winter SF. From patients to partners: participant-centric initiatives in biomedical research. *Nat Rev Genet*. 2012 Apr 3;13(5):371-6. PMID: 22473380
66. Hunter LE, Hopfer C, **Terry SF**, Coors ME. Reporting actionable research results: shared secrets can save lives. *Sci Transl Med.* 2012 Jul 18;4(143):143cm8. PMID: 22814848.
67. Forman J, Coyle F, Levy-Fisch J, Roberts P, **Terry SF**, Legge M. Screening criteria: the need to deal with new developments and ethical issues in newborn metabolic screening. *J Community Genet*. 2013 Jan;4(1):59-67. PMID: 23055099
68. Baxter K, Horn E, Gal-Edd N, Zonno K, O'Leary J, Terry PF, **Terry SF**. An end to the myth: there is no drug development pipeline. *Sci Transl Med*. 2013 Feb 6;5(171):171cm1. PMID: 23390245
69. Li Q, Guo H, Chou D, Harrington DJ, Shurgers LJ, **Terry SF**, Uitto J. Warfarin accelerates ectopic mineralization in abcc6(-/-) mice: clinical relevance to pseudoxanthoma elasticum. *Am J Pathol*. 2013 Apr;182(4):1139-50. PMID: 23415960
70. McGuire AL, Joffe S, Koenig BA, Biesecker BB, McCullough LB, Blumenthal-Barby JS, Caulfield T, **Terry SF**, Green RC. Point-counterpoint. Ethics and Genomic Incidental Findings. *Science.* 2013 May 16;340(6136):1047-8. PMID: 23686340
71. Uitto J, Váradi A, Bercovitch L, Terry PF, **Terry SF**. Pseudoxanthoma Elasticum: Progress in Research Toward Treatment: Summary of the 2012 PXE International Research Meeting. *J Invest Dermatol*. 2013 Jun;133(6):1444-9. PMID: 23673496
72. **Terry SF.** Disease advocacy organizations catalyze translational research. *Front Genet*. 2013 Jun 4;4:101. PMID: 23761807
73. **Terry SF**, Leshner AI. Assessing NIH's Big Idea. *Sci Transl Med*. 2013 Jul 31;5(196):196ed11. PMID: 23903753
74. Uitto J, Jiang Q, Varadi A, Bercovitch LG, **Terry SF**. Pseudoxanthoma elasticum: Diagnostic features, classification, and treatment options. *Expert Opin Orphan Drugs*. 2014 Jun 1;2(6):567-77. PMID: 25383264
75. Graham CE, Molster C, Baynam GS, Bushby K, Hansson M, Kole A, Mora M, Monaco L, Bellgard M, Carpentieri D, Posada M, Riess O, Rubinstein YR, Schaefer F, Taruscio D, **Terry SF**, Zatloukal K, Knoppers B, Lochmüller H, Dawkins HJS. Current trends in biobanking for rare diseases: a review. *Journal of Biorepository Science for Applied Medicine*. 2014 Nov 21;2:49-61.
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Perspectives

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39. **Terry SF.** Let's try it: me for you. *Genet Test Mol Biomarkers*. 2013 Jul;17(7):513-4. PMID: 23819845
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41. Saulsberry K, and **Terry SF**. The need to build trust: a perspective on disparities in genetic testing. *Genet Test Mol Biomarkers*. 2013 Sep;17(9):647-8. PMID: 24000888
42. Stein DT, **Terry SF**. Reforming biobank consent policy: a necessary move away from broad consent toward dynamic consent. *Genet Test Mol Biomarkers*. 2013 Dec;17(12):855-6. PMID: 24283583
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46. Mukherjee S, **Terry SF**. Companions: tests and drug for better healthcare. *Genet Test Mol Biomarkers.* 2014 May;18(5):287-8. PMID: 24786598
47. **Terry SF**. The global alliance for genomics & health. *Genet Test Mol Biomarkers.* 2014 Jun;18(6):375-6. PMID: 24896853
48. Gerdes M, **Terry SF**. Five principles: returning genetic testing results to research participants. *Genet Test Mol Biomarkers.* 2014 Jul;18(7):453-4. PMID: 25014338
49. Rangi SK, **Terry SF**. Genetic testing and native peoples: the call for community-based participatory research. *Genet Test Mol Biomarkers.* 2014 Aug;18(8):531-2. PMID: 25089910

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51. Pathak B, **Terry SF**. FDA's framework for regulatory oversight of LDTs. *Genet Test Mol Biomarkers*. 2014 Dec;18(12):785-6. PMID: 25469801
52. Li AM, **Terry SF**. Linking personal health data to genomic research. *Genet Test Mol Biomarkers*. 2015 Jan;19(1):1-2. PMID: 25549296
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56. Schulz R, **Terry SF**. The science, applications, and ethical concerns surrounding low copy number DNA analysis. *Genet Test Mol Biomarkers*. 2015 Jun;19(6):281-2. PMID: 26053787.
57. Ellis K, **Terry SF**. Dangerous Liaisons: Connecting CRISPR/Cas9 to Clinical Science. *Genet Test Mol Biomarkers*. 2015 Aug;19(8):409-10. PMID: 26225797.
58. Caldwell L, **Terry SF**. 21st-Century Healthcare Policy and the Regulation of Laboratory-Developed Tests. *Genet Test Mol Biomarkers*. 2015 Sep;19(9):467-8. PMID: 26368293.
59. Lutins E, **Terry SF**. NIST RM 8398: Standardizing Discoveries. Genet Test Mol Biomarkers. 2015 Nov;19(11):589-590. PMID: 26502080.

Book Chapters

1. "Advocacy Groups and the New Genetics", co-authored with Alan Stockdale, in *The Double-Edged Helix: Social Implications for Genetics in a Diverse Society*, published by Johns Hopkins University Press, 2002.
2. "Consumer Perspectives on Life Insurance", co-authored with Wendy Uhlmann in Rothstein, M.A.ed. (2004). *Genetics and Life Insurance: Medical Underwriting and Social Policy*. Cambridge, Massachusetts. The MIT Press.
3. "Genetic Information Nondiscrimination Act", in *Genetics and Genomics for Nursing*, editors: Carole A Kenner and Judith A. Lewis, published by Prentice Hall, October 12, 2012.
4. "The global drug development process: What are the implications for rare diseases and where must we go?", with Jayson Swanson, in *Rare Diseases: Challenges and Opportunities for Social Entrepreneurs*, published by Greenleaf Press, 2013.
5. "Without Mud there is no Lotus", in *The Reluctant Innovator*, editor: Kenneth Banks. December 13, 2013.
6. "Disease Advocacy Organizations", with Caroline Kant, in *Orphan Drugs and Rare Diseases*, published by the Royal Society of Chemistry, UK. February 2014.

Papers Presented

2001 Empowering families in the genetics era: a case study, Annual Congress, South African Sociological Association, Pretoria, South Africa, July 2, 2001
2001 Genomics, patents and patient rights – redefining the boundaries between private and public, American Society of Sociologists Annual Meeting, Anaheim CA, August 18-21, 2001
2001 Third Party Issues and Informed Consent, Forum of Third Party Rights and Informed Consent, Virginia Commonwealth University, Richmond VA
2003 Intellectual Property and Benefit Sharing – a consumer perspective, Commercializing the Genome, University of Pennsylvania, Philadelphia PA
2004 Results of the PXE Epidemiological Study, PXE Research Meeting, Bethesda MD, October 14-15, 2004
2004 Consumer Issues in Pharmacogenetics, American Society of Human Genetics, Toronto, Canada, October 26-30, 2004
2005 Clinical Trial Registries, International Pharmaceutical Compliance Summit, Philadelphia PA, April 1, 2005
2005 Genetic Alliance as a Model Coalition, BioVision, Lyon, France, April 14, 2005
2005 Advocacy Owned and Managed Sample Collections, DNA, Health, and Social Justice: A Community Forum on Genetics, University of Washington, Seattle WA, May 21, 2005
2005 Advocates Move Research, Brazilian Annual Clinical Genetics Meeting, Curitiba, Brazil, June 9, 2005

2005 Targeted Therapeutics: Consumer Concerns, 2nd Annual Summit on Targeted Therapeutics, Washington DC, June 13, 2005
2005 Consumer Perspective on Clinical Trial Registries, Institute of Medicine, Washington DC, June 27, 2005
2005 State of the Genetic Alliance, Genetic Alliance Annual Meeting, Washington DC, July 29, 2005
2005 Women in Advocacy, Association for Politics and the Life Science Annual Meeting, Washington DC, September 1, 2005
2005 Public Attitudes Towards Genetics: Consumer Survey, Personalized Medicine Coalition, Washington DC, September 7, 2005
2005 Research Repositories: Why They Make a Difference, The Society of Reproductive Medicine Annual Meeting, Montreal, Canada, October 16, 2005
2005 Advocacy at its Best: Forging the Research Agenda, Duke University Institute for Genomic Sciences and Policy Seminar, October 17, 2005
2005 Genetic Information Nondiscrimination – Where We Need to Go, Duke University Freshman FOCUS program lecture, Durham NC, October 17, 2005
2005 Impact and Value of Information for Consumers, American Society of Human Genetics Annual Meeting, Salt Lake City UT, October 26, 2005
2006 Providers' Knowledge of Genetics: A Survey of 5,915 Individuals and Families with Genetic Conditions, NCHPEG Annual Meeting, Bethesda MD, February 2, 2006
2006 Advocacy in Genetics: Coordinating Research, McKusick-Nathans Institute of Genetic Medicine Seminar, Baltimore MD, March 2, 2006
2006 Advocacy Organizations and the Regulation of Genetic Tests, Genetics and Public Policy Center Consumer Workshop, Washington DC, March 13, 2006
2006 Consumer Interests in the Delivery of Genetic Services, American College of Medical Genetics, San Diego CA, March 24, 2006
2006 Organizing Genetic Advocacy, Sarah Lawrence Health Advocate Annual Conference Keynote, New York NY, March 31, 2006
2006 Advocacy in China, People's Liberation Army Hospital, Beijing, China, August 14, 2006
2006 A Research Participant Perspective, American Society of Human Genetics, New Orleans LA, October 10, 2006
2006 Alliances for Advocacy, Association of Chinese Geneticists in America, American Society of Human Genetics, New Orleans LA, October 11, 2006
2006 Genetic Testing: from Family History to Complex Genetic Testing, New England Regional Genetics Group Annual Meeting Keynote, Durham NH, December 1, 2006
2006 Rare Disease Trial and Drug Data Disclosure and Transparency, Rare Disease Leadership Summit, Washington DC, December 7, 2006
2007 Making Every Voice Count: Public Consultation on Genetics, Environment, and Health, Genetics and Public Policy Center. Washington DC, January 8, 2007
2007 Access To Credible Genetics Resources (ATCG) Network, National Coalition for Health Professional Education in Genetics (NCHPEG) Annual Meeting, Bethesda MD, February 2, 2007
2007 Models for Collaborative Research: The View from the Patient, Health Resources and Services Administration (HRSA)/American College of Medical Genetics (ACMG) Meeting on Rare Diseases Plenary Session, Washington DC, February 2, 2007
2007 Draft Guidance for Industry, Clinical Laboratories, and FDA Staff on In Vitro Diagnostic Multivariate Index Assays, Washington DC, February 8, 2007
2007 Special Policy Issues, Centers of Excellence in ELSI Research Principle Investigator's Meeting Plenary Presentation, Washington DC, February 22, 2007
2007 Collaboration, Education and Test Translation (CETT) Project Meeting Plenary Session, Washington DC, March 5, 2007
2007 American College of Medical Genetics Annual Meeting Poster Session, Nashville TN, March 22, 2007
2007 Consumers of New Knowledge in the Genomic/Proteomic Age, American Association of Medical Colleges, Washington DC, April 17, 2007
2007 The Laboratory Connection: Patient, Providers, Policymakers, The American Clinical Laboratory Association Annual Meeting Plenary Session, Washington DC, April 20, 2007

2007 Models for Collaborative Research: Accelerating Translation, University of Maryland Genetics Program Lecture, College Park MD, April 25, 2007
2007 If Not a Symphony, Then at Least Harmony, Association of Public Health Laboratories, Newborn Screening National Meeting Keynote, Minneapolis MN, May 7, 2007
2007 Testimony regarding the Genetic Information Nondiscrimination Act, Energy and Commerce Subcommittee Hearing, Washington DC, May 8, 2007
2007 Genetic Testing: From Family History to Complex Genetic Testing, Connecticut State Department of Public Health Annual Genomics Meeting, West Hartford CT, May 10, 2007
2007 Consumer Empowerment and Advocacy, Sickle Cell Quality Care Conference Plenary Presentation, New Haven CT, May 11, 2007
2007 Individualized Therapy: Consider the Patient, University of North Carolina Institute Symposium Address, Chapel Hill NC, May 18, 2007
2007 Perspectives of Patient Advocates and Normal Controls, Institute of Medicine Board of Directors Meeting, Washington DC, June 7, 2007
2007 Secondary Uses of Health Data, National Committee on Vital and Health Statistics ad hoc Work Group on Secondary Uses of Health Data, Washington DC, September 2, 2007
2007 Eyes on the Prize: Truth Telling about Genetic Testing, Genetic Testing Summit, Washington DC, September 12, 2007
2007 A Consumer Perspective on Newborn Screening, Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children, September 18, 2007
2007 Consumer Perspective on Personalized Medicine, Forum on Drug Discovery, Development, and Translation, Washington DC, October 15, 2007
2007 Access to Credible Information, Social Issues Session Platform, American Society of Human Genetics, San Diego CA, October 24, 2007
2007 Eyes on the Prize Report, Secretary's Advisory Committee on Genetics, Health and Society, Washington DC, December 12, 2007
2008 Personalized Medicine: Transforming Health, President's Council on Science and Technology, Washington DC, January 8, 2008
2008 Molecular Diagnostics and the Changing Landscape: From Development through Reimbursement Considerations and Implications, AdvaMed Annual Meeting, Washington DC, February 8, 2008
2008 Genetic Alliance BioBank: Enabling Translational Medicine, International Society of Biological and Environmental Repositories, Bethesda MD, April 8, 2008
2008 Celebrating 25 years of the Orphan Drug Act, FDA's Meeting on the ODA, Washington DC, May 18, 2008
2008 Transforming Translation: From Family History to Biobanks, International Congress on Rare Disorders Annual Meeting, Washington DC, May 21, 2008
2008 Translational Research: Disruptive Consumer Innovation, House of Lords, United Kingdom, June 6, 2008
2008 Regulation of Genetic Testing, Biotechnology Industry Organization Annual Meeting, San Diego CA, June 18, 2008
2008 Models for Translational Research, Institute of Medicine, Translational Medicine Roundtable, Washington DC, June 23, 2008
2008 Companion Diagnostics as Disruptive Innovation, Molecular Diagnostics Advisory Board Meeting, Chicago IL, September 4, 2008
2008 Genetic Information Nondiscrimination Act: an overview, National Coalition of Health Professional Education in Genetics Annual Meeting, Bethesda MD, September 4, 2008
2008 Consuming Genomic Information from the Firehouse, Genetics of Common Disease Meeting, Broad Institute, Cambridge MA, September 8, 2008
2008 Personalized Medicine: Disruptive Innovation, Biotechnology Industry Organization, Washington DC, September 9, 2008
2008 Has Genetic Testing Reached a Tipping Point for Labs? Lab Institute 2008, Washington DC, September 19, 2008
2008 Investing IN the Money: Venture Philanthropy, IOM Roundtable: Neuroscience Forum, Irvine CA, October 3, 2008

2008 Why Disease Advocacy Organizations make Excellent Curators of Locus-specific Variation, Human Variome Meeting, Philadelphia PA, November 10, 2008
2008 Dynamic Informed Consent: an end to worrying about privacy, Association of Clinical Research Organizations, Washington DC, November 13, 2008
2008 Genetic Information Nondiscrimination Act: Onramp to personal healthcare, Human Health: Molecules to Mankind Meeting, Atlanta GA, December 15, 2008
2008 Consumer Perspective on Personal Genomics, Personal Genomics Meeting, Bethesda MD, December 17, 2008
2009 Pruebas Genetics: La Era de los Genomas Personales, Nature Genetics, Madrid, Spain, January 29, 2009
2009 Access to Information for Patients, ICORD, Rome, Italy, February 24, 2009
2009 Participants at the center: Accelerating the pathway from research to health, Beyond Eureka, Donaghue Foundation Keynote, Hartford CT, April 28, 2009
2009 Personalized Medicine, Planning for the Future: You, BioMarkers, and Your Rights; Looking Beyond Science, AAAS/FDLI, Washington DC, June 2, 2009
2009 Public Policy and GINA, Consumer Genetics Show, Boston MA, June 8, 2009
2009 Community Centered Family Health History, NIH State-of-the-Science Consensus Conference, Bethesda MD, August 24, 2009
2009 Empower One, Strengthen All, Annual Prader-Willi Research Foundation Conference, September 13, 2009
2009 Landscape analysis of biobanks and registries as a tool to enhance translational research systems (Poster), 59th Annual Meeting of the American Society of Human Genetics, Honolulu HI, October 20-24, 2009
2009 Resource Repository: Revolutionizing Access to Information (Poster), 59th Annual Meeting of the American Society of Human Genetics, Honolulu HI, October 20-24, 2009
2009 Drug development for rare and neglected diseases (Poster), 59th Annual Meeting of the American Society of Human Genetics, Honolulu HI, October 20-24, 2009
2009 Access to Credible Genetics Resources: What does that mean for my practice? (Poster), National Society of Genetic Counselors Annual Educational Conference, Atlanta GA, November 12-15, 2009
2009 Addressing issues of privacy and discrimination: needs of genetic counselors (Poster), National Society of Genetic Counselors Annual Education Conference, Atlanta GA, November 12-15, 2009
2009 Therapeutic Development for Rare Diseases, IOM Committee on Accelerating Rare Disease Research and Orphan Product Development, Washington DC, November 23, 2009
2010 Disease advocacy organizations may accelerate research through registries and biobanks (Poster), 2010 ACMG Annual Clinical Genetics Meeting, Albuquerque NM, March 24-28, 2010
2010 How disease-advocacy groups participate in clinical research: results from a national survey of organizations for genetic disorders (Poster), 2010 ACMG Annual Clinical Genetics Meeting, Albuquerque NM, March 24-28, 2010
2010 Newborn Screening Clearinghouse: Access to Relevant Information for All, American College of Medical Genetics Annual Clinical Genetics Meeting, Albuquerque NM, March 26, 2010
2010 Openness as Process and Product, Sage Commons Congress, San Francisco CA, April 24, 2010
2010 Newborn Screening Clearinghouse: Access to Relevant Information for All, Association of Public Health Laboratories, Orlando FL, May 2, 2010
2010 Newborn Screening Clearinghouse, Association of Public Health Laboratories, Information and Data Collection for Newborn Screening: A National Approach, Orlando FL, May 6, 2010
2010 The Coming Revolution in Prenatal Genetic Testing? Patient/Consumer/Public Perspective, Maternal Serum Cell-free Fetal DNA Testing, Stanford University, Stanford CA, May 7, 2010
2010 Disease advocacy organization-initiated biorepositories and registries– an exploratory survey, ISBER 2010 Annual Meeting, Rotterdam, The Netherlands, May 14, 2010
2010 Challenges and Opportunities in Using Newborn Screening Samples for Translational Research, Institute of Medicine, Washington DC, May 24, 2010
2010 Increased Coordination between Discovery Science and Regulatory Science, NIH-FDA Leadership Council, White Oak MD, June 2, 2010
2010 Health and Innovation, La Conférence de Montréal/Forum Économique International Des Amériques (pre G8-G20), Montreal, Canada, June 10, 2010

2010 Requisites for Successful Precompetitive Collaboration in Drug Development, Institute of Medicine, Washington DC, July 22, 2010
2010 Should We Feedback Individual Results to Participants, International Data Sharing Conference, University of Oxford, Oxford UK, September 22, 2010
2010 Identifiability in the Era of Genome-Scale Research: Perspective of Participants, American Society of Human Genetics Annual Meeting, Washington DC, November 3, 2010
2011 Translational Research, Plenary Presentation, Genetic Diseases in Children, New York NY, March 8, 2011
2011 Registries, BioBanks, Consent and IRBs, International Rare Disease Research Consortium, Washington DC, April 4, 2011
2011 Effective Strategies for Ensuring Patients are Equal Partners in Research, Fremantle, Western Australia, April 20, 2011
2011 Rare and Neglected Diseases: The Time is Now, Gold Lab 2nd Symposium, Boulder CO, May 14, 2011
2011 The Full Monty: What Exposing Your Genome Means in 2011, Consumer Genetics Show, Boston MA, June 7, 2011
2011 Genomics, Medicine and Ordinary People, Genome BC Board meeting, Vancouver, Canada, June 9, 2011
2011 Consumers' Place in Translational Research, The Indus Entrepreneurs, Alexandria VA, June 14, 2011
2011 Diagnosis and Treatment: Hi Tech, Novel Solutions, Ashoka International Forum, Paris, France, June 21, 2011
2011 Everyone a Changemaker, Knight Foundation, Washington DC, June 28, 2011
2011 Public Views on the Importance of Diagnostic Innovation, Biotechnology Industry Organization (BIO), Washington DC, June 30, 2011
2011 Newborn Screening: Of the People and By the People, CDC Grand Rounds, Atlanta GA, August 18, 2011
2011 Patient and Family Perspectives in Genomic Medicine, Genetics, Primary Care and Emerging Nations, American Society of Human Genetics, Montreal, Canada, October 7, 2011
2011 The Way Forward, Keynote presentation for Genome Canada's Strategic Planning, Montreal, Canada, October 7, 2011
2011 Treasure Trove or DNA Database: NBS Bloodspots, International Congress on Human Genetics, Montreal, Canada, October 14, 2011
2011 Not Just a Seat at the Table: Participants Building the Research Agenda, International Conference on Patient-centric Initiatives, Rome, Italy, October 28, 2011
2011 Navigating the Ecosystem of Translational Science, Ashoka Globalizer, Vienna, Austria, November 7, 2011
2011 Not Just a Seat at the Table: Planning the Menu, Japan Society for Human Genetics, Tokyo, Japan, November 11, 2011
2011 Families and Patients at the Center, University of Tokyo, Japan, November 13, 2011
2011 US Advocates in Research and Services, National Academy of Sciences, Moscow, Russia, November 16, 2011
2011 Keynote Address, World Orphan Drug Congress, Vienna, Austria, November 29, 2011
2012 Keynote, Beyond the Clinic: Personalized Medicine Integrated into Personal Health, Personalized Medicine World Congress, Palo Alto CA, January 23, 2012
2012 Citizen Science: What Happens When the Public Engages in Science?, AAAS Annual Meeting, Vancouver, Canada, February 17, 2012
2012 Creating a Team of Teams, Rare Disease Day Keynote, National Institutes of Health, Bethesda MD, February 29, 2012
2012 Empowering the Public to Participate in Translational Research, Food & Drug Administration, Silver Spring MD, April 3, 2012
2012 State of the Science and Patient Support in Pseudoxanthoma elasticum (PXE), Netherlands Cancer Institute, Amsterdam, The Netherlands, May 3, 2012
2012 Informing Reproductive Choice – Prenatal Genetic Testing in the 21st Century, Stanford Center on Law and the Biosciences and the Stanford Center for Integration of Research in Genetics and Ethics, Stanford CA, May 29, 2012

2012 Advocacy and Biobanking, National Institute of Mental Health Alliance Meeting, Bethesda MD, July 13, 2012
2012 Citizen Science, Luminary Series, Scientia Advisors, Boston MA, August 13, 2012
2012 Taking Research Forward: Role of Patient and Health Advocacy Organizations, 7th European Elastin Conference, University of Ghent, Belgium, September 4, 2012
2012 PXE International Works for You, PXE Patient Conference, Ghent, Belgium, September 5, 2012
2012 Team of Teams, Orphan Drug Development, Orphan Drug Congress, Barcelona, Spain, October 17, 2012
2012 Clinical Data Sharing Workshop, Chair, Institute of Medicine, Washington DC, October 24-25, 2012
2012 Advocacy and Registries for All: Time for China?, 4 city tour, Shanghai, Xi'an, Beijing and Hebei, November 8-16, 2012
2012 Reclaiming Health: Power to the People, National Institute of Mental Health Director's Innovation Speakers Series, Bethesda MD, November 29, 2012
2013 Data Sharing, New England Journal of Medicine Editorial Board Annual Meeting Keynote, Boston MA, February 8, 2013
2013 Vision for the Future, International Pachyonychia Congenita Conference, Park City UT, February 13, 2013
2013 Registries for All Diseases. Rare Disease Day, National Institutes of Health, Bethesda MD, March 1, 2013
2013 Registries for All Diseases, Building New Patient-Centered Research Networks, Webinar, Faster Cures, March 20, 2013
2013 The Next Generation of Problem Solvers, Biovision, Lyon, France, March 24, 2013
2013 The Haystack Is Made of Needles: A Global View of Rare Diseases. International Rare Diseases Research Consortium, Dublin, Ireland, April 16, 2013
2013 The Haystack Is Made of Needles, Genetics Environments and Traits Conference of the Personal Genome Project, Harvard University, Boston MA, April 23, 2013
2013 Registry Solution for Big Data, RAD Lab, University of California Berkeley CA, April 30, 2013
2013 Building the We, TEDx, Rosalyn VA, June 9, 2013
2013 The Haystack Is Made of Needles, Personalized Medicine World Conference, Hertzelia, Israel, June 30, 2013
2013 New Models in Citizen Science, NCI Consent Forum, Rockville MD, September 4, 2013
2013 Partnerships with Participants, Medicine 2.0, London, United Kingdom, September 24, 2013
2013 What Does Genetic Alliance Registry and BioBank Offer?, ABCC6-Budapest Meeting, Budapest, Hungary, September 27, 2013
2013 Platform for Engaging Everyone Responsibly, Syapse, Palo Alto CA, October 7, 2013
2013 Epidemiology, Registries, Biobanks and More, Shandong Academy of Medical Sciences, Shandong, China, October 16, 2013
2013 Science and Advocacy (or Without Mud there is No Lotus), Trinity Washington University, Washington DC, October 30, 2013
2013 Platform for Engaging Everyone Responsibly, PRIM&R, Boston MA, November 6, 2013
2013 Empowering an Engaged Public, Personalized Medicine: Is it our future?, Women in Science, Ridgefield CT, November 7, 2013
2013 Platform for Engaging Everyone Responsibly (PEER), PRIM&R, Boston MA, November 8, 2013
2013 Taking Control: Ethical Challenges for Participant-Centered and Participant-Led Research, PRIM&R, Boston MA, November 8, 2013
2013 PhenX Steering Committee Potential Domain Mendelian Diseases, Boston MA, November 18-19, 2013
2013 Platform for Engaging Everyone Responsibly in Biomedical Research (PEER), Institute of Medicine, Washington DC, December 4, 2013
2013 Platform for Engaging Everyone Responsibly in Biomedical Research, National Human Genome Research Institute, Bethesda MD, December 16, 2013
2014 Participant Engagement: Tools to Meet People Where They Are, PCORnet: Community Engaged Network for All (PPRN 18), Washington DC, February 21, 2014
2014 Patients' Perspectives on Human Participant Engagement in Cancer Research, National Cancer Policy Forum Workshop, Institute of Medicine, Washington DC, February 24, 2014

2014 The Human in Human Genome, 8th Wellcome Trust Genomic Disorders Conference, Cambridge, United Kingdom, March 6, 2014
2014 Participant Engagement, Broad Institute's Medical and Population Genetics Program, Boston MA, March 20, 2014
2014 Platform for Engaging Everyone Responsibly (PEER), Quality Improvement Special Interest Group Forum, American College of Medical Genetics, Nashville TN, March 25, 2014
2014 Why Networking with Patients and their Advocates is Critical to your Future Research Funding or Get Your Work Done Cheaper and Easier, Clinical Research Forum, Washington, DC, April 10, 2014
2014 Discovering Clinical Trial Cohorts: Tools to Meet People Where They Are, DIEX Research, Webinar, April 11, 2014
2014 Engaging Consumers in Research, Webinar for National Partnership for Women & Families, April 15, 2014
2014 Patient Engagement: Is it time to marry?, Regeneron, Bridgewater NJ, April 23, 2014
2014 Building the WE (or Without Mud there is No Lotus), Postbac Poster Day, National Institutes of Health, Washington DC, May 1, 2014
2014 Participant engagement: from Little Data to Big Data, Charité Entrepreneurship Summit 2014, Berlin, Germany, May 6, 2014
2014 Platform for Engaging Everyone Responsibly, FDA, Silver Spring MD, May 19, 2014
2014 Dynamic and Granular Consent is Needed, PCORnet, Washington DC, May 23, 2014
2014 Pregnancy Registry, National Institute of Child Health and Human Development, Bethesda MD, June 30, 2014.
2014 The Ethics and Regulatory Landscape: Is a Massive Public Campaign Needed?, Webinar for the NIH Collaboratory, July 17, 2014
2014 Platform for Engaging Everyone Responsibly (PEER), Granular and Dynamic Consent, National Institutes of Health, Bethesda MD, July 21, 2014
2014 CENA: Community Engaged Network for All, Webinar for PCORnet, July 24, 2014
2014 PPRN: Community Engaged Network for All (CENA), Board of Governors Meeting, Washington DC, September 15, 2014
2014 Meeting Your Enrollment Targets: Effective Strategies to Engage Research Participants, Patient-Centered Outcomes Research Institute, Washington DC, September 19, 2014
2014 Empowering the Public to Participate in Research, Achieving Excellence in Clinical Research, Oak Brook IL, September 19, 2014
2014 Harnessing Social Networking to Empower Engagement, 64th Annual Meeting of the American Society of Human Genetics, San Diego CA, October 22, 2014
2014 The Role of Disease Advocacy Organizations in Rare Disease Research, 2nd Annual International Rare Disease Research Consortium Conference, Shenzhen, China, November 7, 2014.
2014 Advances in Research as a Result of Disease Advocacy Organizations in the USA, 2nd Annual International Rare Disease Research Consortium Conference, Shenzhen, China, November, 8, 2014.
2014 Health Advocates as Citizen Scientists, Rosalind Franklin Society Annual Meeting, Washington DC, December 16, 2014
2015 Engaging Participants, National Center for Advancing Translational Sciences, Bethesda MD, January 27, 2015
2015 The Role of Participants in Transforming Development of Interventions, Alzheimer's Disease Research Summit 2015, Bethesda MD, February 10, 2015
2015 New ways of engaging research participants and novel consent models, Building a Large U.S. Cohort for Precision Medicine Research, National Institutes of Health, Bethesda MD, February 11-12, 2015
2015 New Ways of Engaging Research Participants & Novel Consent Models, Food and Drug Adminstration, White Oak, MD, February 26, 2015
2015 Role of the advocacy organization in rare disease research, Telethon XVIII Scientific Convention, Riva del Garda, Italy, March 7, 2015
2015 Genetic Alliance's Unique Role as a Network, American College of Medical Genetics Annual Meeting, Salt Lake City UT, March 25, 2015
2015 PCORI: Patient Powered Research Networks, Real World Data for Clinical Research: A PCORnet Workshop, Washington DC, March 30, 2015

2015 Data for Health, Platform for Engaging Everyone Responsibly, Robert Wood Johnson Foundation (RWJF), Washington DC, April 2, 2015
2015 PCORI: Patient Powered Research Networks, Clinical Research Forum 2015 Annual Meeting, Washington DC, April 17, 2015
2015 Why PMI?, NIH Workshop: Precision Medicine Initiative, Bethesda MD, April 28, 2015
2015 Precision Medicine and PPRNs: Participant Power in 2015, Center for Medical Technology Policy, Baltimore MD, April 30, 2015
2015 PEER: Platform for Engaging Everyone Responsibly, Arthritis Foundation Registry Workshop: Improving Health Outcomes for People with Arthritis, Atlanta GA, May 13-14, 2015
2015 What Little can do for BIG, BIG DATA in biomedicine, Stanford University, Stanford CA, May 20, 2015
2015 International Rare Diseases Research Consortium, Fostering patient involvement in international research: Getting more patient representation at the International Rare Diseases Research Consortium (IRDIRC), Madrid Spain, May 28, 2015
2015 Platform for Engaging Everyone Responsibly (PEER), Granular and Dynamic Consent, 2015 Health Privacy Summit, Georgetown University, Washington DC, June 2, 2015
2015 Illuminating Bottlenecks through Experience, IOM GaugeRx Mapping, Institute of Medicine, Washington DC, June 23, 2015
2015 Engaging Research Participants & Novel Consent Models, California Initiative to Advance Precision Medicine, University of California, San Francisco CA, June 29, 2015
2015 Participatory Research, PXE Research Meeting, Budapest, Hungary, September 7, 2015
2015 Participant Engagement, Ethical Aspects of Participant-Centered Research Initiatives, Foundation Brocher & COST CHIPME, Geneva, Switzerland September 30, 2015
2015 Participant Engagement, Sleep Research Network Annual Meeting, Bethesda MD, October 13, 2015
2015 Engaging Patients as Co-Designers in Research Care Delivery Re-Design, Kaiser Permanente: Center for Effectiveness & Safety Research, Denver CO, October 27, 2015
2015 PCORI: A Validated and Recognized Approach for Creating Patient Reported Outcomes, EURORDIS Industry Meeting, Barcelona Spain, October 28, 2015

C. Research Support ($28.4 M)

Patient-Centered Outcomes Research Institute 1306-04899 (PI: Terry, SF) 09/30/2015 – 09/29/2018
Community Engaged Network for All (CENA) • 3 Years • $1,682,000
Patient Powered Research Network, PCORnet, continuing to expand registries for 11 disease advocacy organizations and conducting research on several conditions.

Patient-Centered Outcomes Research Institute 2000-52 (PI: Terry, SF) 01/01/2015 – 09/30/2015
Coordinating Center for Patient Powered Research Networks in PCORnet. • 9 Months • $386,000
Extension – 9/30/2015 – 2/29/2016• 5 Months • $523,963
Coordinate and provide technical assistance to PCORnet, specifically network, engagement, and patient powered research networks (PPRNs).

Patient-Centered Outcomes Research Institute EA-236-PXE (PI: Terry, SF) 05/15/2015 – 4/30/2016
Discovering What Matters Most • 1 year • $247,477
Conduct a pseudoxanthoma elasticum (PXE) conference to develop process whereby disease advocacy organizations can learn what methods work to elicit and prioritize research questions from individuals living with diseases.

Robert Wood Johnson Foundation Pioneer Award 71636 (PI: Terry, SF) 12/01/2014 – 11/30/2015
Breaking Down the Silos of Institutional Control of Data: Participants at the Center Take Control • 1 Year • $500,000
This grant will allow the Platform to Engage Everyone Responsibly to be used by any organization or community easily and efficiently.

HHSN276201400649P (PI: Terry, SF) 09/19/2014 – 09/18/2017 • NLM/National Institutes of Health

Professional Support Services to Support Genetics Home Reference • 3 years • $105,732
This contract provides three years of outreach and management of dozens of disease advocacy organizations to update the specific disease entries in Genetic Home Reference.

American College of Medical Genetics (PI: Terry, SF) 06/01/2012 – 05/31/2015
Consumer engagement in genetics and the regional collaboratives • 3 years • $1,500,000
This grant provides support for consumer engagement in genetics, particularly around emerging technologies and decision-making.

9 U36MC16509 (PI: Terry, SF) 09/01/2009 - 08/31/2018 • HRSA/Genetic Services Branch
Quality Assessment of the Newborn Screening System • 9 years • $3,750,000
This grant provides five years of funding to establish the Newborn Screening Clearinghouse and associated resource and data collection tools.

Completed

Illumina Unrestricted Grant (PI: Terry, SF) 08/01/2015 – 10/01/2015
Application of PEER to Genomes • 60 days • $500,000
Create a PEER system for individuals who have been sequenced, focusing on diagnosed (people with mitochondrial disease), early adopters (the Illumina Understanding Your Genome program), and the more typically 'public' (people who have donated blood to the San Diego Blood Bank). Study the effectiveness of PEER in all instances.

Pharmaceutical Research and Manufacturers of America (PI: Terry, SF) 02/01/2015 – 10/01/2015
Enhancing data collection for PDUFA V: Patient Focused Drug Development for the FDA • 8 months • $163,000
Built Platform for Engaging Everyone Responsibly registries for obesity and studied the science of patient preference in partnership with DCRI. Collaboration with Center for Device and Radiologic Health.

Patient-Centered Outcomes Research Institute 1306-04899 (PI: Terry, SF) 03/01/2014 – 09/30/2015
Community Engaged Network for All (CENA) • 18 months • $1,000,000
Patient Powered Research Network, PCORnet, enabling registries for 10 disease advocacy organizations, common and rare, in which individuals determine their data sharing, privacy and access settings.

Pharmaceutical Research and Manufacturers of America (PI: Terry, SF) 10/01/2013 – 02/01/2014
Enhancing data collection for PDUFA V: Patient Focused Drug Development for the FDA • 4 months • $240,000
Built Platform for Engaging Everyone Responsibly registries for three conditions (sickle cell disease, inflammatory bowel disease, and idiopathic pulmonary fibrosis) to assess their perspectives on risk and benefit in drug development.

Sanofi Collaborate Innovate Competition (PI: Terry, SF) January 2013
Registries for All • $325,000
Cross platform registry for all diseases, using gamification and granular data sharing and privacy preference technology.

HHSN276201100698 (PI: Terry, SF) 09/19/2011 – 09/18/2014 • NLM/National Institutes of Health
Professional Support Services to Support Genetics Home Reference • 1 year, 2 years of options • $149,050
This contract provided three years of outreach and management of dozens of disease advocacy organizations to update the specific disease entries in Genetic Home Reference. NLM opted to extend it the two additional years.

HHSH250201000035C (PI: Terry, SF) 10/01/2010 – 09/29/2012 • HRSA
Family Health History Tool Community-based Dissemination and Integration in HRSA-funded Health Centers • 2 years • $793,467

Developed the family health history tool in six community-based health centers.

R13 AR060159-01 (PI: Terry, SF) 09/01/2010 – 08/31/2011 • NIH/NIAMS
Pseudoxanthoma Elasticum (PXE) Research Meeting • 1 year • $49,999
This meeting reviewed progress in genetics, cellular and molecular biology, catalyzed the current research through knowledge and tools of related research, provided the foundation for a comprehensive research plan, and determined best practices for clinical care of individuals affected by PXE.

3R13AR060159-01S1 (PI: Terry, SF) 07/15/2010 – 06/30/2011 (Who awarded this grant?)
Pseudoxanthoma Elasticum Research 2010 Conference • 1 year • $50,000
To accelerate an understanding of the pathogenesis of pseudoxanthoma elasticum (PXE), to form a consensus on the diagnostic criteria, and to create a research plan.

2R13HG005190-02 (PI: Terry, SF) 06/22/2010 – 06/22/2012 (Who awarded this grant?)
Conference Support for Genetic Alliance Annual Conference • 2 years • $140,000
Research workshop within conference to accelerate translational research.

4 U35MC16451-02 (PI: Terry, SF) 09/01/2009 – 08/31/2011 • HRSA/Genetic Services Branch
Translating Research into Medical Services • 4 years • $3,280,000
This grant provided two of the awarded four years of funding to focus on clinical care consensus guidelines and resources for congenital conditions. Grant was prematurely terminated because of budget cuts to HRSA.

2 R13HG005190-02 (PI: Terry, SF) 07/09/2009 – 06/30/2011 • NIH/NHGRI
Conference Support for Genetic Alliance • 2 years - $240,000
This grant was for conference support for "Discovering Openness in Health Systems," the 2009 Genetic Alliance Annual Conference. Over the course of three days, symposia, workshops, and panel discussions focused on critical issues in translational research.

5 U33MC07945-05 (PI: Terry, SF) 06/01/2007 – 05/31/2012 • HRSA/Genetic Services Branch
National Consumer Center for Genetic Resources & Services • 5 years • $2,900,000
This grant enabled development of a central infrastructure, providing information and education for consumers regarding genetics.

3 U33MC07951-03 (PI: Terry, SF) 06/01/2007 – 05/31/2010 • HRSA/Genetic Services Branch
Screening for Heritable Disorders in Children: Efficacy from a Family/Consumer Perspective • 3 years • $750,000
This project ascertained issues to inform the development of models to educate parents, create systems of informed decision-making, and provide data to policymakers to determine what tests should be offered.

3 U33MC07952-03 (PI: Terry, SF) 06/01/2007 – 05/31/2010 • HRSA/Genetic Services Branch
Screening for Heritable Disorders in Children: Efficacy from a Family/Consumer Perspective • 3 years • $1,500,000
This project used a mixed method and iterative strategy of unstructured interviews, focus groups and structured interviews to understand the experience of families and professionals with respect to false+ screens and carrier identification in newborn screening.

3 U33MC00214-05-03 (PI: Terry, SF) 06/01/2006 – 05/31/2009 • HRSA/Genetic Services Branch
Community Centered Family Health History • 3 years • $1,800,000
This project coordinated the efforts of more than 22 communities and created a customizable guide to gathering family health history. The result was a downloadable, and printable, guide with culturally sensitive components such as stories, pictures, and methods.

6 U10CCU525036-06 (PI: Terry, SF) 10/01/2005 – 09/30/2011 • Centers for Disease Control and Prevention
Access to Credible Genetics Resources Network • 6 years • $4,250,000

This project defined evidence-based information, best clinical practices and core competencies, using two conditions as the focus: Duchenne Becker Muscular Dystrophy and Fragile X Syndrome. Infrastructure and processes were established that are used for other single gene disorders. Materials for patients and providers were produced and nationally disseminated broadly in multiple forms.

R13 AR051859-01 (PI: Terry, SF) 10/01/2004 – 09/30/2005 • NIH/NIAMS
Pseudoxanthoma Elasticum Research Meeting • 1 year • $49,999
This meeting reviewed progress in genetics, cellular and molecular biology, catalyzed the current research through knowledge and tools of related research, provided the foundation for a comprehensive research plan and determined best practices for clinical care of individuals affected by PXE.

5 U33MC00214-04-05 (PI: Terry, SF) 06/01/2002 – 05/30/2007 • HRSA/Genetic Services Branch
Genetic Services and Resources Center • 5 years • $2,000,000
This project connected all of the major HHS information and resource grants, built a central repository, convened an accessible forum, and created a family history coalition, with focus on underserved and underrepresented communities.