BIOGRAPHICAL SKETCH

NAME Sharon Fontaine Terry	**POSITION TITLE** 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 & Space Sciences

A. Positions and Honors

Honors

2005 Honorary Doctorate for community engagement, Iona College
2007 1st Annual Patient Service Award, UNC Institute for Pharmacogenomics and Individualized Therapy
2009 Inaugural Disruptive Woman in Health Care
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 for Platform for Engaging Everyone Responsibly (PEER)
2013 Ashoka Changemakers First Prize for PEER
2013 Forbes Best Business Model for Transforming Health Systems for PEER
2013 FDA Hero for the 30th Anniversary of the Orphan Drug Act
2014 Women of Impact, Robert Wood Johnson Foundation
2015 Robert Wood Johnson Foundation Pioneer Award
2016 National Associate, National Research Council
2016 Health 2.0 Activist Award
2016 TedMed Talk (>1M views) and TED Radio Hour

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

1978- 1983	Experiential educator and retreat director, Self Enrichment Experience
1980-present	President, Schola Ministries
1983-1986	Chaplain, Northwest Connecticut Youth Ministries
1986-1988	Campus Minister, Assumption College, Worcester MA
1988-2000	Pastoral Minister, Our Lady of Sorrows Catholic Church, Sharon MA
1990-2000	President, Massachusetts Home Learning Association
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
2016-present	Board Member, Interface Health Society, Canada
2016-present	Board Member, The International Policy Interoperability and Data Access Clearinghouse (IPAC)
2016-present	Board Member, Vivli, Center for Global Clinical Research Data
2016-present	Advisor, UCSF-Stanford CERSI External Advisory Board
2016-present	Member, Advisory Board, Genome Medical
2017-present	Board Member, Mindstrong

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
2009-2015	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	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
2014-2017	Member, Acting Chair, PubMed Central Advisory Committee, National Institutes of Health
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, Council member, and Engagement Committee 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, National Academy of Sciences, Engineering, and Medicine Committee on Human Gene Editing: Scientific, Medical, and Ethical Considerations
2015-present	Board Member, Strategic Advisory Board for the Global Alliance for Genomes and Health
2015-present	Member, Precision Medicine Initiative Cohort Program Advisory Panel
2016-present	Member, Blue Ribbon Panel's Working Group on Enhanced Data Sharing, Cancer Moonshot, White House

2016-present Member, Forum on Regenerative Medicine, Medicine Division of the National Academies of Science, Engineering, and Medicine
2016-present Member, Cures Acceleration Network Review Board, National Center for Accelerating Translation Science, NIH
2016-present Member, Advisory Board, LawSeq project
2017-present Member, Advisory Board, Mindstrong

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
2016-present Chief Patient Advisor, Clinical and Translational Science
2016-present Patient Engagement Editor, Genetic Testing and Biomarkers

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*, 2000 Dec.
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. Pseudoxanthoma elasticum (PXE). In: *GeneClinics: Clinical Genetic Information Resource* [database online]. Copyright, University of Washington, Seattle. 2001 June. 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. PMCID: PMC1226061
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, et al; 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. PMCID: PMC2271136

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. PMCID: PMC1867419
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. PMCID: PMC2597973
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. doi: 10.1111/j.1748-720X.2008.00266.x. PMID: 18547191. PMCID: PMC2575242
36. **Terry, SF**. Genetic testing. *Genet Test*. 2008 Jun;12(2):175-6. doi: 10.1089/gte.2008.1500. 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. doi: 10.1159/000133306. 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. doi: 10.2217/17410541.6.2.171
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. doi: 10.1016/j.jdermsci.2009.02.008. 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. doi: 10.1097/GIM.0b013e3181a551cc. 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. doi:10.1097/GIM.0b013e3181b13a6c. PMID: 19617843. PMCID: PMC2936269
42. Haga SB, **Terry SF**. Ensuring the safe use of genomic medicine in children. *Clin Pediatr (Phila)*. 2009 Sep;48(7):703-8. doi: 10.1177/0009922809335736. 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. doi: 10.1038/clpt.2009.146. 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. doi: 10.1097/GIM.0b013e3181c00a96. 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. doi: 10.1097/GIM.0b013e3181d2af04. 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. doi: 10.1089/adt.2010.0802.rt. PMID: 20307201
47. **Terry SF**. Accelerate medical breakthroughs by ending disease earmarks. *Nat Rev Genet.* 2010 May;11(5):310. doi: 10.1038/nrg2782. PMID: 20414986
48. **Terry SF**. Genetic Testing Registry Benefits. *Genetic engineering & biotechnology news: GEN* 2010 May;30(9)

49. 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. doi: 10.1089/bio.2010.0007. PMID: 24845940
50. 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. doi: 10.1097/GIM.0b013e318ef6079. PMID: 20808230. PMCID: PMC4277882
51. **Terry SF**, Krokosky A. Rare conditions: where do primary care and genetic diseases intersect? *JAAPA*. 2010 Nov;23(11):63-4. PMID: 21086896
52. **Terry SF**, Terry PF. Power to the people: participant ownership of clinical trial data. *Sci Transl Med*. 2011 Feb 9;3(69):69cm3. doi: 10.1126/scitranslmed.3001857. PMID: 21307299
53. **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. doi: 10.2217/pme.11.1
54. 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. doi: 10.10.16/j.jaad.2010.03.030. PMID: 21397982. PMCID: PMC3078966
55. 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. doi: 10.1353/cpr.2011.0016. PMID: 21623013
56. 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. doi: 10.1097/GIM.0b013e3182147639. PMID: 21602691
57. 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. doi: 10.1002/ajmg.a.34067. PMID: 21671388; PMCID PMC3121926
58. 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. doi: 10.1016/j.jaad.2010.05.023. PMID: 21496949
59. 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. doi: 10.1016/j.ymgme.2011.07.005. PMID: 21835664. PMCID: PMC3171614

60. 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 Dec;881(12):378-79. doi:10.1038/nrg3011-c2. PMID: 22025002
61. 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. doi:10.1038/gim.2011.5. PMID: 22237434
62. 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. doi: 10.1007/s10897-011-9392-7. PMID: 21830165
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43. Lambertson K, **Terry SF**. Free the data**.** *Genet Test Mol Biomarkers.* 2014 Jan;18(1):1-2. doi: 10.1089/gtmb.2014.1551. PMID: 24401097
44. **Terry SF**. A call for participatory oversight. *Genet Test Mol Biomarkers*. 2014 Feb;18(2):71-2. doi: 10.1089/gtmb.2014.1552. PMID: 24506510
45. **Terry SF**. Sharing your thoughts about sharing clinical trial data. *Genet Test Mol Biomarkers.* 2014 Apr;18(4):221-2. doi: 10.1089/gtmb.2014.1553. PMID: 24689892
46. Mukherjee S, **Terry SF**. Companions: tests and drug for better healthcare. *Genet Test Mol Biomarkers.* 2014 May;18(5):287-8. doi: 10.1089/gtmb.2014.1554. PMID: 24786598
47. **Terry SF**. The global alliance for genomics & health. *Genet Test Mol Biomarkers.* 2014 Jun;18(6):375-6. doi: 10.1089/gtmb.2014.1555. 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. doi: 10.1089/gtmb.2014.1556. 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. doi: 10.1089/gtmb.2014.1557. PMID: 25089910
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53. **Terry SF**. Obama's Precision Medicine Initiative. *Genet Test Mol Biomarkers*. 2015 Mar;19(3):113-4. doi: 10.1089/gtmb.2015.1563. PMID: 25751403. PMCID: PMC4361161
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63. Baker DB, Kaye J, **Terry SF**. Governance through privacy, fairness, and respect for individuals. *EGEMS (Wash DC)*. 2016 Mar 31;4(2):1207. Doi:10.13063/2327-9214.1207. PMID 27141520. PMCID: PMC4827784
64. **Terry SF**. The day the president of the United States said "That data is mine". *Genet Test Mol Biomarkers*. 2016 Apr;20(4):165-6. doi: 10.1089/gtmb.2016.29013.sjt. PMID:27003240
65. **Terry SF**. New Institute of Medicine report on molecular biomarkers. *Genet Test Mol Biomarkers*. 2016 May;20(5):221-2. doi: 10.1089/gtmb.2016.29014.sjt. PMID: 27077401
66. **Terry SF**. Bipartisan genetic research privacy protection act introduced. *Genet Test Mol Biomarkers.* 2016 June, 20(6): 274-275. doi:10.1089/gtmb.2016.29016.sjt. PMID: 27249160
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69. Oyama S**, Terry SF**. Epigenetics and racial health inequities. *Genet Test Mol Biomarkers.* 2016 Sep;20(9):483-4. doi: 10.1089/gtmb.2016.29021.sjt. PMID: 27636025
70. Johnson-King B, **Terry SF**. Future of microbiomes through the National Microbiome Initiative. *Genet Test Mol Biomarkers*. 2016 Oct;20(10):561-562. PMID: 27749134
71. Gates A, **Terry SF**, Bonhomme N. Expanded carrier screening and its implication on genetic testing protocols. *Genet Test Mol Biomarkers*. 2016 Nov;20(11):643-644. PMID: 27831818
72. Lambertson KF, **Terry SF**. Data sharing as the new norm: what about the people part? *Genet Test Mol Biomarkers*. 2017 Feb;21(2):63-65. doi: 10.1089/gtmb.2017.29026.sjt. PMID: 28207325
73. **Terry SF**. Turning toward participants in biobanking. *Genet Test Mol Biomarkers*. 2017 Mar;21(3):132-133. doi: 10.1089/gtmb.2017.29029.sjt. PMID: 28306400
74. Mena C, **Terry SF**. A new day dawns for direct-to-consumer marketing. *Genet Test Mol Biomarkers.* 2017 May;21(5):273-274. doi: 10.1089/gtmb.2017.29031.sjt. PMID: 28498774

75. **Terry SF**. An evidence framework for genetic testing. *Genet Test Mol Biomarkers.* 2017 Jul;21(7):407-408. doi: 10.1089/gtmb.2017.29032.sjt. PMID: 28715288
76. **Terry SF**. Research for the people by the people. *Genet Test Mol Biomarkers*. 2017 Sep;21(9):521-522. PMID: 28915083
77. **Terry SF**. The International Rare Diseases Research Consortium announces new vision and goals. *Genet Test Mol Biomarkers*. 10/2017; 21(10):578-579. doi: 10.1089/gtmb.2017.29035.sjt. PMID: 29045173
78. **Terry SF**. A crack in the wall of competition: will compassion prevail? *Genet Test Mol Biomarkers*. 2017 Nov;21(11):635-636. doi: 10.1089/gtmb.2017.29037.sjt. PMID: 29154720
79. Wurst T., **Terry SF.** Beyond recommendation: requiring returning findings to research participants. *Genet Test Mol Biomarkers*. 2018 Mar;22(3):141-142. doi: 10.1089/gtmb.2018.0052. PMID: 29565740

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. *Genetics and Life Insurance: Medical Underwriting and Social Policy*. Cambridge, Massachusetts. The MIT Press, 2004.
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; 2001July 2; Pretoria, South Africa.

2001 Genomics, patents and patient rights – redefining the boundaries between private and public. American Society of Sociologists Annual Meeting; 2001 August 18-21; Anaheim, CA.

2001 Third party issues and informed consent. Forum of Third Party Rights and Informed Consent, Virginia Commonwealth University; 2001 March; Richmond, VA.

2003 Intellectual property and benefit sharing – a consumer perspective. Commercializing the Genome, University of Pennsylvania; 2003 March 3; Philadelphia, PA.

2003 Many needs, one voice. The XIX International Congress of Genetics; Murdoch Childrens Research Institute, Human Genetics and Global Health; 2003 July 8; Melbourne, Australia.
2003 BioBanks. NHGRI; 2003 September 3; Bethesda, MD.
2004 Advocacy through biobanks accelerates research. ISMRD Family Conference; 2004 April 3; Rockville, MD.
2004 The role of patient advocacy in LSDs. The Educational Initiative for Lysosomal Storage Disorders; 2004 May 1; San Francisco, CA.
2004 Genetic discrimination. Legislative update: what can we do? North American Brain Tumor Coalition; 2004 May 3; Washington, DC.
2004 Advocacy in rare disease research. New Zealand Organization for Rare Disorders. Partnership for Progress Conference; 2004 May 28; New Zealand.
2004 Starting an advocacy group. World Congress on Chromosome Abnormalities; 2004 June 29; San Antonio, TX.
2004 Consumer concerns: DNA-based technologies and newborn screening. The Hastings Center and March of Dimes; 2004 September 1; Washington, DC.
2004 From here to genome and back again: personal stories, genetics ad populations. Iona College; 2004 September 28; New Rochelle, NY.
2004 Mapping human dimensions of genetic variation. Iona College; 2004 October 2; New Rochelle, NY.
2004 Results of the PXE epidemiological study. PXE Research Meeting; 2004 October 14-15; Bethesda, MD.
2004 Consumer issues in pharmacogenetics. American Society of Human Genetics; 2004 October 26-30; Toronto, Canada.
2005 Accelerating rare disease research: advocacy organizations are essential. ICORD; 2005 February 16; Stockholm, Sweden.
2005 Clinical trial registries. International Pharmaceutical Compliance Summit; 2005 April 1; Philadelphia, PA.
2005 Genetic Alliance as a model coalition. BioVision; 2005 April 14; Lyon, France.
2005 The inside view. NIH, National Library of Medicine, History of Medicine Division; 2005 May 16; Bethesda, MD.
2005 Advocacy owned and managed sample collections. DNA, Health, and Social Justice: A Community Forum on Genetics, University of Washington; 2005 May 21; Seattle, WA.
2005 Advocates move research. Brazilian Annual Clinical Genetics Meeting; 2005 June 9; Curitiba, Brazil.
2005 Patient and advocate perspective: an evolution of influences. Cambridge Healthtech Institute, 2nd Annual Summit on Targeted Therapeutics; 2005 June 13; Washington, DC.
2005 Targeted therapeutics: Consumer Concerns. 2nd Annual Summit on Targeted Therapeutics; 2005 June 13; Washington, DC.
2005 Consumer perspective on clinical trial registries. Institute of Medicine; 2005 June 27; Washington, DC.
2005 State of the Genetic Alliance. Genetic Alliance Annual Meeting; 2005 July 29; Washington, DC.

2005 Women in advocacy. Association for Politics and the Life Science Annual Meeting; 2005 September 1; Washington, DC.
2005 Public attitudes towards genetics: consumer survey. Personalized Medicine Coalition; 2005 September 7; Washington, DC.
2005 Research repositories: why they make a difference. The Society of Reproductive Medicine Annual Meeting; 2005 October 16; Montreal, Canada.
2005 Advocacy at its best: forging the research agenda. Duke University Institute for Genomic Sciences and Policy Seminar; 2005 October 17; Durham, NC.
2005 Assessing the value and impact of information. A consumer perspective. American Society of Human Genetics Annual Meeting. Social Issues Sessions; 2005 October 23; Salt Lake City, UT.
2005 Genetic information nondiscrimination – where we need to go. Duke University Freshman FOCUS program lecture; 2005 October 17; Durham, NC.
2005 Impact and value of information for consumers. American Society of Human Genetics Annual Meeting; 2005 October 26; Salt Lake City, UT.
2006 Providers' knowledge of genetics: A Survey of 5,915 Individuals and Families with Genetic Conditions. NCHPEG Annual Meeting; 2006 February 2; Bethesda, MD.
2006 Advocacy in genetics: coordinating research. McKusick-Nathans Institute of Genetic Medicine Seminar; 2006 March 2; Baltimore, MD.
2006 Advocacy organizations and the regulation of genetic tests. Genetics and Public Policy Center Consumer Workshop; 2006 March 13; Washington, DC.
2006 Consumer interests in the delivery of genetic services. American College of Medical Genetics; 2006 March 24; San Diego, CA.
2006 Organizing genetic advocacy. Sarah Lawrence Health Advocate Annual Conference Keynote; 2006 March 31; New York, NY.
2006 Advocacy in China. People's Liberation Army Hospital; 2006 August 14; Beijing, China.
2006 A research participant perspective. American Society of Human Genetics; 2006 October 10; New Orleans, LA.
2006 Alliances for advocacy. Association of Chinese Geneticists in America, American Society of Human Genetics; 2006 October 11; New Orleans, LA.
2006 Genetic testing: from family history to complex genetic testing. New England Regional Genetics Group Annual Meeting Keynote; 2006 December 1; Durham, NH.
2006 Rare disease trial and drug data disclosure and transparency. Rare Disease Leadership Summit; 2006 December 7; Washington, DC.
2007 Making every voice count: public consultation on genetics, environment, and health. Genetics and Public Policy Center; 2007 January 8; Washington, DC.
2007 Access to credible genetics resources (ATCG) network. National Coalition for Health Professional Education in Genetics (NCHPEG) Annual Meeting; 2007 February 2; Bethesda, MD
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; 2007 February 2; Washington, DC.
2007 Draft guidance for industry. Clinical Laboratories, and FDA Staff on In Vitro Diagnostic Multivariate Index Assays; 2007 February 8; Washington, DC.

2007 Special policy issues. Centers of Excellence in ELSI Research Principal Investigator's Meeting Plenary Presentation; 2007 February 22; Washington, DC.

2007 Collaboration, education and test translation (CETT). Project Meeting Plenary Session; 2007 March 5; Washington, DC.

2007 Collaboration across communities: how do you make research community-specific and universally-relevant? Poster session presented at: American College of Medical Genetics Annual Meeting; 2007 March 22; Nashville, TN.

2007 Consumers of new knowledge in the genomic/proteomic age. American Association of Medical Colleges; 2007 April 17; Washington, DC.

2007 The laboratory connection: patient, providers, policymakers. The American Clinical Laboratory Association Annual Meeting Plenary Session; 2007 April 20; Washington, DC.

2007 Models for collaborative research: accelerating translation. University of Maryland Genetics Program Lecture; 2007 April 25; College Park, MD.

2007 If not a symphony, then at least harmony. Association of Public Health Laboratories, Newborn Screening National Meeting Keynote; 2007 May 7; Minneapolis, MN.

2007 Testimony regarding the genetic information nondiscrimination act. Energy and Commerce Subcommittee Hearing; 2007 May 8; Washington, DC.

2007 Genetic testing: from family history to complex genetic testing. Connecticut State Department of Public Health Annual Genomics Meeting; 2007 May 10; West Hartford, CT.

2007 Consumer empowerment and advocacy. Sickle Cell Quality Care Conference Plenary Presentation; 2007 May 11; New Haven, CT.

2007 Individualized therapy: consider the patient. University of North Carolina Institute Symposium Address; 2007 May 18; Chapel Hill, NC.

2007 Perspectives of patient advocates and normal controls. 2nd Annual Chapel Hill Drug Conference. Pharmacogenetics and Individualized Therapy; 2007 June 7; Washington, DC.

2007 Secondary uses of health data. National Committee on Vital and Health Statistics ad hoc Work Group on Secondary Uses of Health Data; 2007 September 2; Washington, DC.

2007 Eyes on the prize: truth telling about genetic testing. Genetic Testing Summit; 2007 September 12; Washington, DC.

2007 A consumer perspective on newborn screening. Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children; 2007 September 18; Washington, DC.

2007 Consumer perspective on personalized medicine. Forum on Drug Discovery, Development, and Translation; 2007 October 15; Washington, DC.

2007 Access to credible genetics resources networks. Quality information. Social Issues Session Platform, American Society of Human Genetics; 2007 October 24; San Diego, CA.

2007 Eyes on the prize report. Secretary's Advisory Committee on Genetics, Health and Society; 2007 December 12; Washington, DC.

2008 Personalized medicine: transforming health. President's Council on Science and Technology; 2008 January 8; Washington, DC.

2008 Molecular diagnostics and the changing landscape: from development through reimbursement considerations and implications. AdvaMed Annual Meeting; 2008 February 8; Washington, DC.
2008 Genetic Alliance BioBank: enabling translational medicine. International Society of Biological and Environmental Repositories; 2008 April 8; Bethesda, MD.
2008 DC celebrating 25 years of the Orphan Drug Act. Patient/public perspective. FDA's Meeting on the ODA; 2008 May 18; Washington, DC.
2008 Transforming translation: from family history to biobanks. International Congress on Rare Disorders Annual Meeting; 2008 May 21; Washington, DC.
2008 Translational research: disruptive consumer innovation. House of Lords; 2008 June 6; London, United Kingdom.
2008 Regulation of genetic testing. Biotechnology Industry Organization Annual Meeting; 2008 June 18; San Diego, CA.
2008 Models for translational research. Institute of Medicine, Translational Medicine Roundtable; 2008 June 23; Washington, DC.
2008 Companion diagnostics as disruptive innovation. Molecular Diagnostics Advisory Board Meeting; 2008 September 4; Chicago, IL.
2008 Genetic Information Nondiscrimination Act: an overview. National Coalition of Health Professional Education in Genetics Annual Meeting; 2008 September 4; Bethesda, MD.
2008 Consuming genomic information from the firehouse. Genetics of Common Disease Meeting, Broad Institute; 2008 September 8; Cambridge, MA.
2008 Personalized medicine: disruptive innovation. Biotechnology Industry Organization; 2008 September 9; Washington, DC.
2008 Has genetic testing reached a tipping point for labs? Lab Institute 2008; 2008 September 19; Washington, DC.
2008 Venture philanthropy strategies: communications. IOM Roundtable: Neuroscience Forum; 2008 October 3; Irvine, CA.
2008 Why disease advocacy organizations make excellent curators of locus-specific variation. Human Variome Meeting; 2008 November 10; Philadelphia, PA.
2008 Dynamic informed consent: an end to worrying about privacy. Association of Clinical Research Organizations; 2008 November 13; Washington, DC.
2008 Genetic Information Nondiscrimination Act: Onramp to personal healthcare. The Fourth Annual Symposium on Predictive Health. Human Health: Molecules to Mankind Meeting; 2008 December 15; Atlanta, GA.
2008 Consumer perspective on personal genomics. Personal Genomics Meeting; 2008 December 17; Bethesda, MD.
2009 Genetic Alliance Registry and BioBank. Helmsley Type 1 Diabetes Registry Meeting; 2009 January 7; New York, NY.
2009 Pruebas genetics: la era de los genomas personales. Nature Genetics; 2009 January 29; Madrid, Spain.
2009 Access to information for patients. ICORD, Instituto Superiore di Sanita; 2009 February 24; Rome, Italy.
2009 Genetic services in the information age. National Society of Genetic Counselors; 2009 April 17; Washington, DC.

2009 Participants at the center: accelerating the pathway from research to health. Beyond Eureka, Donaghue Foundation Keynote; 2009 April 28; Hartford, CT.
2009 Personalized medicine, planning for the future: you, biomarkers, and your rights; Looking Beyond Science. AAAS/FDLI; 2009 June 2; Washington, DC.
2009 Public policy and GINA. Consumer Genetics Show; 2009 June 8; Boston, MA.
2009 Public policy and GINA. Consumer Genetics Conference; 2009 June 10; Boston, MA.
2009 Community centered family health history. NIH State-of-the-Science Consensus Conference; 2009 August 24; Bethesda, MD.
2009 Empower one, strengthen all. Annual Prader-Willi Research Foundation Conference; 2009 September 13; Washington, DC.
2009 GINA: The long road to singing. American Society of Human Genetics Annual Meeting; 2009 October 21; Waikiki, HI.
2009 Landscape analysis of biobanks and registries as a tool to enhance translational research systems. Poster presented at: 59th Annual Meeting of the American Society of Human Genetics; October 20-24, 2009; Honolulu, HI.
2009 Resource repository: revolutionizing access to information. Poster presented at: 59th Annual Meeting of the American Society of Human Genetics; 2009 October 20-24; Honolulu, HI.
2009 Drug development for rare and neglected diseases. Poster presented at: 59th Annual Meeting of the American Society of Human Genetics; 2009 October 20-24; Honolulu, HI.
2009 Access to credible genetics resources: what does that mean for my practice? Poster presented at: National Society of Genetic Counselors Annual Educational Conference; 2009 November 12-15; Atlanta, GA.
2009 Addressing issues of privacy and discrimination: needs of genetic counselors. Poster presented at: National Society of Genetic Counselors Annual Education Conference; 2009 November 12-15; Atlanta, GA.
2009 Therapeutic development for rare diseases. IOM Committee on Accelerating Rare Disease Research and Orphan Product Development; 2009 November 23; Washington, DC.
2010 Drinking from the firehouse: are consumers ready? Molecular Medicine Tri-Conference; 2010 February 5; San Francisco, CA.
2010 Alternative and/or novel models of consent. Perspectives on data sharing and informed consent in genomic research; 2010 March 11; Houston, TX.
2010 Linking information. ICORD; 2010 March 20, Rome, Italy.
2010 Disease advocacy organizations may accelerate research through registries and biobanks. Poster presented at: 2010 ACMG Annual Clinical Genetics Meeting; 2010 March 24-28; Albuquerque, NM.
2010 How disease-advocacy groups participate in clinical research: results from a national survey of organizations for genetic disorders. Poster presented at: 2010 ACMG Annual Clinical Genetics Meeting; 2010 March 24-28; Albuquerque, NM.
2010 Newborn screening clearinghouse: access to relevant information for all. American College of Medical Genetics Annual Clinical Genetics Meeting; 2010 March 26; Albuquerque, NM.

2010 Openness as process and product. Sage Commons Congress; 2010 April 24; San Francisco, CA.

2010 Newborn screening clearinghouse: access to relevant information for all. Association of Public Health Laboratories; 2010 May 2; Orlando, FL.

2010 The coming revolution in prenatal genetic testing? Patient/Consumer/Public Perspective, Maternal Serum Cell-free Fetal DNA Testing, Stanford University; 2010 May 7; Stanford, CA.

2010 Disease advocacy organization-initiated biorepositories and registries– an exploratory survey. ISBER 2010 Annual Meeting; 2010 May 14; Rotterdam, The Netherlands.

2010 Balancing issues from the patient/parent perspective. Challenges and opportunities in using newborn screening samples for translational research. Institute of Medicine; 2010 May 24; Washington, DC.

2010 Increased coordination between discovery science and regulatory science. NIH-FDA Leadership Council; 2010 June 2; White Oak, MD.

2010 Health and innovation. La Conférence de Montréal/Forum Économique International Des Amériques (pre G8-G20); 2010 June 10; Montreal, Canada.

2010 Requisites for successful precompetitive collaboration in drug development. Institute of Medicine; 2010 July 22; Washington, DC.

2010 Should we feedback individual results to participants. International Data Sharing Conference, University of Oxford; 2010 September 22; Oxford, UK.

2010 Identifiability in the era of genome-scale research: perspective of participants. American Society of Human Genetics Annual Meeting; 2010 November 3; Washington, DC.

2010 Access for all to emerging technologies. Patient/Consumer perspective. American Public Health Association; 2010 November 9; Denver, CO.

2010 The public wants to know: a recent survey of women about attitudes on newborn screening. World Congress on Disabilities; 2010 November 19; Dallas, TX.

2010 Responsible genetic testing: what do we need? 4th National Conference on Genomics and Public Health; 2010 December 9; Bethesda, MD.

2011 Residual NBS samples & transparency. Advocacy and Public Policy Meeting; 2011 January 20; Salt Lake City, UT.

2011 Resources and tools for rare disease research and services. NIH; 2001 February 28; Bethesda, MD.

2011 Resources and tools for rare disease research and services. The World Orphan Drug Congress USA; 2011 March 1; Washington DC.

2011 Translational research. Plenary presentation at: Genetic Diseases in Children; 2011 March 8; New York, NY.

2011 Registries, biobanks, consent and IRBs. International Rare Disease Research Consortium; 2011 April 4; Washington, DC.

2011 Effective strategies for ensuring patients are equal partners in research. Australia's Inaugural National Rare Diseases Symposium; 2011 April 20; Fremantle, Western Australia.

2011 Rare and neglected diseases: the time is now! Gold Lab 2nd Annual Symposium; 2011 May 14; Boulder, CO.

2011 The full monty: what exposing your genome means in 2011. Consumer Genetics Show; 2011 June 7; Boston, MA.

2011 Genomics, medicine and ordinary people. Genome BC Board Meeting; 2011 June 9; Vancouver, Canada.

2011 Capitalizing the value proposition in systems level transformation in health and disease. The Indus Entrepreneurs; 2011 June 14; Alexandria, VA.

2011 Diagnosis and treatment: hi tech, novel solutions. Ashoka International Forum; 2011 June 21; Paris, France.

2011 Everyone a changemaker. Knight Foundation; 2011 June 28; Washington, DC.

2011 Public views on the importance of diagnostic innovation. Biotechnology Industry Organization (BIO); 2011 June 30; Washington, DC.

2011 Newborn screening: of the people and by the people. CDC Grand Rounds; 2011 August 18; Atlanta, GA.

2011 Bits and bytes: participant data sharing and data mining. FasterCures Webinar; 2011 September 16.

2011 Patient and family perspectives in genomic medicine. Genetics, Primary Care and Emerging Nations, American Society of Human Genetics; 2011 October 7; Montreal, Canada.

2011 The way forward. Keynote presentation: Genome Canada's Strategic Planning; 2011 October 7; Montreal, Canada.

2011 Treasure trove or Baby DNA database? International Congress on Human Genetics; 2011 October 14; Montreal, Canada.

2011 Not just a seat at the table: participants building the research agenda. International Conference on Patient-centric Initiatives; 2011 October 28; Rome, Italy.

2011 Navigating the ecosystem of translational science (NETS). Ashoka Globalizer; 2011 November 7; Vienna, Austria.

2011 Not only a seat at the table: participants planning the menu. 56th Annual Meeting of the Japan Society for Human Genetics; 2011 November 11; Tokyo, Japan.

2011 Families and patients at the center. University of Tokyo, 56th Annual Meeting of the Japan Society for Human Genetics; 2011 November 13; Tokyo, Japan.

2011 The role of the disease advocacy community in rare disease research and information development and dissemination to the public. National Academy of Sciences, U.S.-Russia Scientific Forum; 2011 November 16; Moscow, Russia.

2011 Collaborative innovation: the international ambitions of the International Rare Disease Research Consortium. World Orphan Drug Congress; 2011 November 29; Geneva, Switzerland.

2011 The ultimate data capture: creating a global registry of patient registries. World Orphan Drug Congress; 2011 November 30; Geneva, Switzerland.

2012 Beyond the clinic: personalized medicine integrated into personal health. Personalized Medicine World Congress; 2012 January 23; Palo Alto, CA.

2012 Citizen science: what happens when the public engages in science? AAAS Annual Meeting; 2012 February 17; Vancouver, Canada.

2012 Creating a team of teams. Rare Disease Day Keynote at: National Institutes of Health; 2012 February 29; Bethesda, MD.

2012 Empowering the public to participate in translational research. Food & Drug Administration; 2012 April 3; Silver Spring, MD.
2012 State of the science and patient support in pseudoxanthoma elasticum (PXE). Netherlands Cancer Institute; 2012 May 3; Amsterdam, The Netherlands.
2012 Informing reproductive choice? Prenatal genetic testing in the 21st century: disease advocacy organizations' perspective. Stanford Center on Law and the Biosciences and the Stanford Center for Integration of Research in Genetics and Ethics; 2012 May 29; Stanford, CA.
2012 Advocacy and biobanking. National Institute of Mental Health Alliance Meeting; 2012 July 13; Bethesda, MD.
2012 Citizen science: what happens when the public engages in health? Luminary Series, Scientia Advisors; 2012 August 13; Boston, MA.
2012 Taking research forward: role of patient and health advocacy organizations. 7th European Elastin Conference, University of Ghent; 2012 September 4; Ghent, Belgium.
2012 PXE International works for you. PXE Patient Conference; 2012 September 5; Ghent, Belgium.
2012 Team of teams, Orphan Drug Development. Orphan Drug Congress; 2012 October 17; Barcelona, Spain.
2012 Clinical Data Sharing Workshop; Chair, Institute of Medicine; 2012 October 24-25; Washington, DC.
2012 Advocacy and registries for all: time for China? 4 city tour; 2012 November 8-16; Shanghai, Xi'an, Beijing and Hebei, China.
2012 Reclaiming health: power to the people. National Institute of Mental Health Director's Innovation Speakers Series; 2012 November 29; Bethesda, MD.
2013 Data sharing. Keynote: New England Journal of Medicine Editorial Board Annual Meeting; 2013 February 8; Boston, MA.
2013 Vision for the future. International Pachyonychia Congenita Conference; 2013 February 13; Park City, UT.
2013 Registries for all diseases. Rare Disease Day, National Institutes of Health; 2013 March 1; Bethesda, MD.
2013 Registries for all diseases, building new patient-centered research networks. Faster Cures; 2013 March 20; Webinar.
2013 The next generation of problem solvers. Biovision; 2013 March 24; Lyon, France.
2013 The haystack is made of needles: a global view of rare diseases. International Rare Diseases Research Consortium; 2013 April 16; Dublin, Ireland.
2013 The haystack is made of needles. Genetics Environments and Traits Conference of the Personal Genome Project, Harvard University; 2013 April 23; Boston, MA.
2013 Reg4All. Registries for all diseases. RAD Lab, University of California; 2013 April 30; Berkeley, CA.
2013 Building the We. TEDx; 2013 June 9; Rosalyn, VA.
2013 Power to the people: individuals move personalized medicine. Personalized Medicine World Conference; 2013 June 30; Hertzelia, Israel.
2013 New models in citizen science. NCI Consent Forum; 2013 September 4; Rockville, MD.

2013 PEER: Platform for Engaging Everyone Responsibly in biomedical research. Sanofi Pasteur National Meeting; 2013 September 17; Swiftwater, PA.
2013 Building partnerships in research: participants at the center. Medicine 2.0; 2013 September 24; London, United Kingdom.
2013 What does Genetic Alliance Registry and BioBank offer? ABCC6-Budapest Meeting; 2013 September 27; Budapest, Hungary.
2013 Platform for Engaging Everyone Responsibly. Syapse; 2013 October 7; Palo Alto, CA.
2013 Epidemiology, registries, biobanks and more. Shandong Academy of Medical Sciences; 2013 October 16; Shandong, China.
2013 Science and advocacy (or Without mud there is no lotus). Trinity Washington University; 2013 October 30; Washington, DC.
2013 Platform for Engaging Everyone Responsibly. PRIM&R; 2013 November 6; Boston, MA.
2013 Empowering an engaged public, personalized medicine: is it our future? Women in Science; 2013 November 7; Ridgefield, CT.
2013 Taking control: ethical challenges for participant-centered and participant-led research. PRIM&R; 2013 November 8; Boston, MA.
2013 Mendelian diseases as a potential new domain. PhenX Steering Committee; 2013 November 18-19; Boston, MA.
2013 Platform for Engaging Everyone Responsibly in biomedical research (PEER). Institute of Medicine; 2013 December 4; Washington, DC.
2013 Platform for Engaging Everyone Responsibly in biomedical research. National Human Genome Research Institute; 2013 December 16; Bethesda, MD.
2014 Participant engagement: tools to meet people where they are. PCORnet: Community Engaged Network for All (PPRN 18); 2014 February 21; Washington, DC.
2014 Patients' perspectives on human participant engagement in cancer research. National Cancer Policy Forum Workshop, Institute of Medicine; 2014 February 24; Washington, DC.
2014 The human in human genome. 8th Wellcome Trust Genomic Disorders Conference; 2014 March 6; Cambridge, United Kingdom.
2014 Participant engagement. Broad Institute's Medical and Population Genetics Program; 2014 March 20; Boston, MA.
2014 Platform for Engaging Everyone Responsibly (PEER). Quality Improvement Special Interest Group Forum, American College of Medical Genetics; 2014 March 25; Nashville, TN.
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; 2014 April 10; Washington, DC.
2014 Discovering clinical trial cohorts: tools to meet people where they are. DIEX Research; 2014 April 11; Webinar.
2014 Engaging consumers in research. National Partnership for Women & Families; 2014 April 15; Webinar.
2014 Patient engagement: is it time to marry? Regeneron; 2014 April 23; Bridgewater, NJ.
2014 Building the WE (or Without mud there is no lotus). Postbac Poster Day, National Institutes of Health; 2014 May 1; Washington, DC.

2014 Participant engagement: from little data to big data. Charité Entrepreneurship Summit 2014; 2014 May 6; Berlin, Germany.
2014 Platform for Engaging Everyone Responsibly. FDA; 2014 May 19; Silver Spring, MD.
2014 Dynamic and granular consent is needed. PCORnet; 2014 May 23; Washington, DC.
2014 Pregnancy registry. National Institute of Child Health and Human Development; 2014 June 30; Bethesda, MD.
2014 The ethics and regulatory landscape: is a massive public campaign needed? The NIH Collaboratory; 2014 July 17; Webinar.
2014 Platform for Engaging Everyone Responsibly (PEER). Granular and Dynamic Consent, National Institutes of Health; 2014 July 21; Bethesda, MD.
2014 CENA: Community Engaged Network for All. PCORnet; 2014 July 24; Webinar.
2014 PPRN: Community Engaged Network for All (CENA). Board of Governors Meeting; 2014 September 15; Washington, DC.
2014 Meeting your enrollment targets: effective strategies to engage research participants. Patient-Centered Outcomes Research Institute; 2014 September 19; Washington, DC.
2014 Empowering the public to participate in research. Achieving Excellence in Clinical Research; 2014 September 19; Oak Brook, IL.
2014 Harnessing social networking to empower engagement. 64th Annual Meeting of the American Society of Human Genetics; 2014 October 22; San Diego, CA.
2014 Role of the advocacy organization in rare disease research. 2nd Annual International Rare Disease Research Consortium Conference; 2014 November 7; Shenzhen, China.
2014 Participant involvement: USA. 2nd Annual International Rare Disease Research Consortium Conference; 2014 November 8; Shenzhen, China.
2014 (Women) Health advocates as citizen scientists. Rosalind Franklin Society Annual Meeting; 2014 December 16; Washington, DC.
2015 Engaging participants. National Center for Advancing Translational Sciences; 2015 January 27; Bethesda, MD.
2015 The role of participants in transforming development of interventions. Alzheimer's Disease Research Summit 2015; 2015 February 10; Bethesda, MD.
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; 2015 February 11-12; Bethesda, MD.
2015 New ways of engaging research participants and novel consent models. National Institutes of Health Precision Medicine Initiative; 2015 February 26; White Oak, MD.
2015 Role of the advocacy organization in rare disease research. Telethon XVIII Scientific Convention; 2015 March 7; Riva del Garda, Italy.
2015 Genetic Alliance's unique role as a network. American College of Medical Genetics Annual Clinical Genetics Meeting; 2015 March 25; Salt Lake City, UT.
2015 PCORI: patient powered research networks. Real World Data for Clinical Research: A PCORnet Workshop; 2015 March 30; Washington, DC.
2015 Data for health, Platform for Engaging Everyone Responsibly. Robert Wood Johnson Foundation (RWJF); 2015 April 2; Washington, DC.
2015 PCORI: patient powered research networks. Clinical Research Forum 2015 Annual Meeting; 2015 April 17; Washington, DC.

2015 Why PMI? NIH Workshop: “Precision Medicine Initiative.”; 2015 April 28; Bethesda, MD.
2015 Precision medicine and PPRNs: participant power in 2015. Center for Medical Technology Policy; 2015 April 30; Baltimore, MD.
2015 PEER: Platform for Engaging Everyone Responsibly. Arthritis Foundation Registry Workshop: Improving Health Outcomes for People with Arthritis; 2015 May 13-14; Atlanta, GA.
2015 What little can do for BIG (DATA); BIG DATA in Biomedicine; Stanford University; 2015 May 20; Stanford, CA.
2015 Fostering patient involvement in international research: Getting more patient representation at the International Rare Diseases Research Consortium. International Rare Diseases Research Consortium (IRDIRC); Rare Disease International Inaugural Meeting; 2015 May 28; Madrid, Spain.
2015 Platform for Engaging Everyone Responsibly (PEER). Granular and Dynamic Consent, 2015 Health Privacy Summit, Georgetown University; 2015 June 2; Washington, DC.
2015 Illuminating bottlenecks through experience. IOM GaugeRx Mapping, Institute of Medicine; 2015 June 23; Washington, DC.
2015 Engaging research participants & novel consent models. California Initiative to Advance Precision Medicine, University of California; 2015 June 29; San Francisco, CA.
2015 Participatory research. PXE Research Meeting; 2015 September 7; Budapest, Hungary.
2015 Participant engagement. Ethical Aspects of Participant-Centered Research Initiatives, Foundation Brocher & COST CHIPME; 2015 September 30; Geneva, Switzerland.
2015 Participant engagement. Sleep Research Network Annual Meeting; 2015 October 13; Bethesda, MD.
2015 Engaging patients as co-designers in research care delivery re-design. Kaiser Permanente Center for Effectiveness & Safety Research; 2015 October 27; Denver, CO.
2015 PCORI: a validated and recognized approach for creating patient reported outcomes. EURORDIS Industry Meeting; 2015 October 28; Barcelona, Spain.
2015 Advocacy organizations and emerging technologies. International Summit on Gene Editing; 2015 December 1; Washington, DC.
2015 PCORnet PPRNs. PCORI Board of Governors Meeting; 2015 December 7; Washington, DC.
2016 Partners in research. Rare Disease Day, National Institutes of Health; 2016 February 29; Bethesda, MD.
2016 Participants’ expectations: sharing data. Global Alliance for Genomics and Health; 2016 April 3; Kyoto, Japan.
2016 If you are not at the table, you are on the menu. International Congress on Human Genetics; 2016 April 6; Kyoto, Japan.
2016 Framing the scientific and policy opportunities. NHGRI Workshop Aggregate Data: Balancing Risks and Opportunities; 2016 May 19; Washington, DC.
2016 Opening keynote lecture. 15th National Life Sciences & Technology Week; IATI Biomed 2016 Conference; 2016 May 24-26; Tel Aviv, Israel.
2016 Global policy in genetic research. Merck Genetics and Pharmacogenomics (GpGx) seminar; 2016 June 2; Boston, MA.

2016 Ignite presentation for the Cancer Moonshot Summit, Howard University, 2016 June 29; Washington, DC.
2016 If you are not at the table, you are on the menu; Advancing the Science of Community Engaged Research; AAMC; 2016 August 25; Washington, DC.
2016 PCORnet: people powered outcomes research. NIAMS Advisory Council Open Session; NIH, 2016 September 13; Washington, DC.
2016 The future of clinical trials. AHCJ's Fellowship on Comparative Effectiveness Research, PCORI; 2016 September 14; Washington, DC.
2016 PCORnet building trustworthiness. Grand Rounds: A Shared Forum of the NIH HCS Collaboratory and PCORnet; 2016 September 16; Webinar.
2016 Participant-driven research: If we are not on the table, we are on the menu; Cincinnati Children's Hospital; 2016 October 6; Covington, KY.
2016 Introducing the Platform for Engaging Everyone Responsibly; RWJF's Pioneer working to build a Culture of Health; 2016 October 14; New York, NY.
2016 Hope and caution: The public's perception of gene editing; American Society of Human Genetics Annual Meeting; 2016 October 21; Vancouver, BC.
2016 PCORnet. People-Powered Outcomes Research; Rare diseases in PCORnet; PCORI; 2016 October 27; Washington, DC.
2016 Designing research platforms to serve patient populations; Big Data and Precision Medicine Conference; 2016 November 2; Washington, DC.
2016 Engagement on steroids: Why people matter?; National Bone Marrow Donor Program; 2016 November 11; Minneapolis, MN.
2016 What if we love without fear?; TEDMED; 2016 December 2; Palm Springs, CA.
2017 Participants' expectations: sharing data; PMWC Silicon Valley; 2017 January 24; Mountain View, CA.
2017 Participants in clinical and translational science; CTS – Driving patient-centered translational medicine; 2017 January 25; Webinar.
2017 If we are not at the table, we are on the menu!; Industry Pharmacogenomics Working Group (IPWG); 2017 February 14; Webinar.
2017 Participant-Driven Research: If we are not at the table, we are on the menu; NIH Rare Disease Day; 2017 February 27; Bethesda, MD.
2017 Creating an Uber model for rare disease drug discovery: putting people in the driver's seat; Rare Diseases Symposium; 2017 March 1; Chapel Hill, NC.
2017 Evolving role of patients and providers; Pfizer's YBM Strategic Planning Session; 2017 March 2; Orlando, FL.
2017 Patients as innovation partners; Annual Bipartisan Congressional Health Policy Retreat; 2017 March 3; Warrenton, VA.
2017 If we are not at the table, we are on the menu; Vital Signs; The University of Austin, Dell Medical School; 2017 April 25; Austin, TX.
2017 Participant-driven research: If we are not at the table, we are on the menu; Takeda Translational Medicine Symposium; 2017 May 3; Cambridge, MA.
2017 The end of patients?; NESTA The Future of People Powered Health Conference; 2017 May 9; London, UK.

2017 Trustworthiness; Learning from Patient Experience: New Frontiers in People-Powered Research Symposium, The Broad Institute; 2017 May 13; Cambridge, MA.
2017 Jane Engelberg Memorial Fellowship (JEMF) Research Plenary Session; NSGC Annual Conference; 2017 September 15; Columbus, OH
2017 Changing research in genomics, cancer and personalized medicine for better outcomes; Interface Summit, Future Health: Real. Virtual. Augmented; 2017 October 17; Vancouver, Canada.
2017 Don Rix distinguished keynote speaker; Genome BC; 2017 October 19; Vancouver, Canada.
2018 Genomic literacy; Illumina Global Channel Partner Summit Meeting – TRIBE; 2018 March 1; San Diego, CA.
2018 Engaging individuals, families and communities to transform health; Genetic Medicine Workshop, Chan Zuckerberg Initiative; 2018 March 27-28; San Francisco, CA.

C. Research Support ($34 M)

Patient-Centered Outcomes Research Institute 2000-53 (PI: Terry, SF) 03/01/2016 – 10/31/2018
Coordinating Center for Network, Commons, Engagement and PPRN in PCORnet. • 3 Years • $4,722,062
Coordinate and provide technical assistance to PCORnet, specifically network, engagement, commons and patient powered research networks (PPRNs).

Patient-Centered Outcomes Research Institute 1306-04899 (PI: Terry, SF) 09/30/2015 – 09/29/2018
Community Engaged Network for All (CENA) • 3 Years • $1,840,382
Patient Powered Research Network, PCORnet, continuing to expand registries for 11 disease advocacy organizations and conducting research on several conditions.
Sub-Award: Healthy Mind Healthy You: A Dose-Finding Study of Mindfulness • 08/01/16-07/31/19 • $378,215

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

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.

1R13AR070643-01 (PI: Terry, SF) 09/01/2016 – 08/31/2017 • NIH/NIAMS
PXE International Research Meeting 2016 • 1 year • $20,000
This meeting reviewed progress in diagnostics, research and treatments in PXE, generated robust discussion around biomarker identification and potential clinical trials.

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.

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, commons and patient powered research networks (PPRNs).

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.

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.

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.

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
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
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.