Sharon F Terry

List of Publications by Year
in descending order

120 papers	6,489 citations	94433 37 h-index	66911 78 g-index
131 all docs	131 docs citations	131 times ranked	7496 citing authors

#	Article	IF	Citations
1	Genetic heterogeneity of heritable ectopic mineralization disorders in a large international cohort. Genetics in Medicine, 2022, 24, 75-86.	2.4	5
2	Oral supplementation of inorganic pyrophosphate in pseudoxanthoma elasticum. Experimental Dermatology, 2022, 31, 548-555.	2.9	11
3	Comment on â€œClinical practice guidelines for pseudoxanthoma elasticum (2017)â€: The importance of mutation analysis. Journal of Dermatology, 2022, 49, .	1.2	0
4	ENPP1 variants in patients with GACI and PXE expand the clinical and genetic heterogeneity of heritable disorders of ectopic calcification. PLoS Genetics, 2022, 18, e1010192.	3.5	13
5	Web-Based Mindfulness-Based Interventions for Well-being: Randomized Comparative Effectiveness Trial. Journal of Medical Internet Research, 2022, 24, e35620.	4.3	2
6	Data Sharing Goals for Nonprofit Funders of Clinical Trials. Journal of Participatory Medicine, 2021, 13, e23011.	1.3	2
7	Voices of biotech leaders. Nature Biotechnology, 2021, 39, 654-660.	17.5	1
8	Ascertaining Nonfatal Endpoints in Clinical Trials: Central Adjudication Versus Patient Insurance Claims. Therapeutic Innovation and Regulatory Science, 2021, 55, 1250-1257.	1.6	0
9	Toward better governance of human genomic data. Nature Genetics, 2021, 53, 2-8.	21.4	31
10	The Human Face of ABCC6. FEBS Letters, 2020, 594, 4151-4157.	2.8	5
11	Reactions to the National Academies/Royal Society Report onHeritable Human Genome Editing. CRISPR Journal, 2020, 3, 332-349.	2.9	15
12	Time for NIH to lead on data sharing. Science, 2020, 367, 1308-1309.	12.6	42
13	Reply to: â€œComment on â€˜Magnesium supplementation in the treatment of pseudoxanthoma elasticum: Is magnesium oxide the best choice?'â€: Journal of the American Academy of Dermatology, 2019, 81, e137.	1.2	1
14	Adopt a moratorium on heritable genome editing. Nature, 2019, 567, 165-168.	27.8	314
15	Database shares that transform research subjects into partners. Nature Biotechnology, 2019, 37, 1112-1115.	17.5	11
16	Magnesium supplementation in the treatment of pseudoxanthoma elasticum: A randomized trial. Journal of the American Academy of Dermatology, 2019, 81, 263-265.	1.2	15
17	Plain-language medical vocabulary for precision diagnosis. Nature Genetics, 2018, 50, 474-476.	21.4	28
18	Application of a Dynamic Map for Learning, Communicating, Navigating, and Improving Therapeutic Development. Clinical and Translational Science, 2018, 11, 166-174.	3.1	27

#	Article	IF	Citations
19	A dynamic map for learning, communicating, navigating and improving therapeutic development. Nature Reviews Drug Discovery, 2018, 17, 150-150.	46.4	43
20	Leveraging electronic health records for clinical research. American Heart Journal, 2018, 202, 13-19.	2.7	36
21	Including all voices in international data-sharing governance. Human Genomics, 2018, 12, 13.	2.9	50
22	PhenX measures for phenotyping rare genetic conditions. Genetics in Medicine, 2017, 19, 834-837.	2.4	2
23	Data Sharing as the New Norm: What About the People Part?. Genetic Testing and Molecular Biomarkers, 2017, 21, 63-65.	0.7	0
24	Turning Toward Participants in Biobanking. Genetic Testing and Molecular Biomarkers, 2017, 21, 132-133.	0.7	2
25	Insights into Pathomechanisms and Treatment Development in Heritable Ectopic Mineralization Disorders: Summary of the PXE International BiennialÂResearch Symposiumâ€”2016. Journal of Investigative Dermatology, 2017, 137, 790-795.	0.7	36
26	The study is open: Participants are now recruiting investigators. Science Translational Medicine, 2017, 9, .	12.4	21
27	Creating a data resource: what will it take to build a medical information commons?. Genome Medicine, 2017, 9, 84.	8.2	36
28	ABCC6 and Pseudoxanthoma Elasticum: The Face of a Rare Disease from Genetics to Advocacy. International Journal of Molecular Sciences, 2017, 18, 1488.	4.1	16
29	Research for the People by the People. Genetic Testing and Molecular Biomarkers, 2017, 21, 521-522.	0.7	1
30	Privacy, Fairness, and Respect for Individuals. EGEMS (Washington, DC), 2017, 4, 7.	2.0	22
31	Realizing Our Potential in Biobanking: Disease Advocacy Organizations Enliven Translational Research. Biopreservation and Biobanking, 2016, 14, 314-318.	1.0	4
32	Clinical trial result reporting: Time to move into the 21st century. Clinical Trials, 2016, 13, 597-598.	1.6	0
33	Data Acquisition, Curation, and Use for a Continuously Learning Health System. JAMA - Journal of the American Medical Association, 2016, 316, 1669.	7.4	48
34	Toward clinical genomics in everyday medicine: perspectives and recommendations. Expert Review of Molecular Diagnostics, 2016, 16, 521-532.	3.1	58
35	Life as a numerator: Putting the person in personal genomics. Applied & Translational Genomics, 2016, 8, 40-41.	2.1	7
36	Research Progress in Pseudoxanthoma Elasticum andÂRelated Ectopic Mineralization Disorders. Journal of Investigative Dermatology, 2016, 136, 550-556.	0.7	30

#	Article	IF	Citations
37	Participant-Driven Matchmaking in the Genomic Era. Human Mutation, 2015, 36, 965-973.	2.5	28
38	Copy number variation in the <scp>ATP</scp>â€binding cassette transporter <scp>ABCC6</scp> gene and <scp>ABCC6</scp> pseudogenes in patients with pseudoxanthoma elasticum. Molecular Genetics & Genomic Medicine, 2015, 3, 233-237.	1.2	6
39	Benefits and Risks of Sharing Genomic Information. Genetic Testing and Molecular Biomarkers, 2015, 19, 648-649.	0.7	7
40	Hearing voices: FDA seeks advice from patients. Science Translational Medicine, 2015, 7, 313ed12.	12.4	5
41	Mitochondrial Disease Sequence Data Resource (MSeqDR): A global grass-roots consortium to facilitate deposition, curation, annotation, and integrated analysis of genomic data for the mitochondrial disease clinical and research communities. Molecular Genetics and Metabolism, 2015, 114, 388-396.	1.1	76
42	Linking Personal Health Data to Genomic Research. Genetic Testing and Molecular Biomarkers, 2015, 19, 1-2.	0.7	4
43	Obama's Precision Medicine Initiative. Genetic Testing and Molecular Biomarkers, 2015, 19, 113-114.	0.7	60
44	The Matchmaker Exchange: A Platform for Rare Disease Gene Discovery. Human Mutation, 2015, 36, 915-921.	2.5	390
45	The effects of bisphosphonates on ectopic soft tissue mineralization caused by mutations in the ABCC6 gene. Cell Cycle, 2015, 14, 1082-1089.	2.6	57
46	Evidence synthesis and guideline development in genomic medicine: current status and future prospects. Genetics in Medicine, 2015, 17, 63-67.	2.4	16
47	A Call for Participatory Oversight. Genetic Testing and Molecular Biomarkers, 2014, 18, 71-72.	0.7	2
48	Pseudoxanthoma elasticum: diagnostic features, classification and treatment options. Expert Opinion on Orphan Drugs, 2014, 2, 567-577.	0.8	69
49	Nothing About Us Without Us: Guidelines for Genetic Testing. Genetic Testing and Molecular Biomarkers, 2013, 17, 357-358.	0.7	5
50	Don't Just Invite Us to the Table: Authentic Community Engagement. Genetic Testing and Molecular Biomarkers, 2013, 17, 443-445.	0.7	10
51	The Haystack Is Made of Needles. Genetic Testing and Molecular Biomarkers, 2013, 17, 175-177.	0.7	22
52	Screening criteria: the need to deal with new developments and ethical issues in newborn metabolic screening. Journal of Community Genetics, 2013, 4, 59-67.	1.2	18
53	Warfarin Accelerates Ectopic Mineralization in Abcc6â^'/â^' Mice. American Journal of Pathology, 2013, 182, 1139-1150.	3.8	21
54	Assessing NIHâ€™s Big Idea. Science Translational Medicine, 2013, 5, 196ed11.	12.4	4

#	Article	IF	Citations
55	Response to the Commentary â€œSignificance of Patient Registries for Dermatological Disorderâ€• Journal of Investigative Dermatology, 2013, 133, 1361.	0.7	0
56	An End to the Myth: There Is No Drug Development Pipeline. Science Translational Medicine, 2013, 5, 171cm1.	12.4	38
57	Reforming Biobank Consent Policy: A Necessary Move Away from Broad Consent Toward Dynamic Consent. Genetic Testing and Molecular Biomarkers, 2013, 17, 855-856.	0.7	46
58	Ethics and Genomic Incidental Findings. Science, 2013, 340, 1047-1048.	12.6	160
59	Disease advocacy organizations catalyze translational research. Frontiers in Genetics, 2013, 4, 101.	2.3	12
60	Reporting Actionable Research Results: Shared Secrets Can Save Lives. Science Translational Medicine, 2012, 4, 143cm8.	12.4	10
61	The impact of false-positive newborn screening results on families: a qualitative study. Genetics in Medicine, 2012, 14, 76-80.	2.4	78
62	How disease advocacy organizations participate in clinical research: a survey of genetic organizations. Genetics in Medicine, 2012, 14, 223-228.	2.4	67
63	Precision Medicine: Generating Real-World Evidence for Companion Diagnostics. Genetic Testing and Molecular Biomarkers, 2012, 16, 75-76.	0.7	3
64	From patients to partners: participant-centric initiatives in biomedical research. Nature Reviews Genetics, 2012, 13, 371-376.	16.3	250
65	Regulating Genetic Tests: Issues That Guide Policy Decisions. Genetic Testing and Molecular Biomarkers, 2012, 16, 1-2.	0.7	5
66	Community Engagement about Genetic Variation Research. Population Health Management, 2012, 15, 78-89.	1.7	10
67	Managing incidental findings and research results in genomic research involving biobanks and archived data sets. Genetics in Medicine, 2012, 14, 361-384.	2.4	418
68	Iona College Community Centered Family Health History Project: Lessons Learned from Student Focus Groups. Journal of Genetic Counseling, 2012, 21, 127-135.	1.6	7
69	Biobanking Challenges and Informatics Opportunities. Computers in Health Care, 2012, , 221-231.	0.3	2
70	Genetic Alliance Registry and BioBank: a novel disease advocacy-driven research solution. Personalized Medicine, 2011, 8, 207-213.	1.5	19
71	Acquired pseudoxanthoma elasticum presenting after liver transplantation. Journal of the American Academy of Dermatology, 2011, 64, 873-878.	1.2	17
72	A randomized controlled trial of oral phosphate binders in the treatment of pseudoxanthoma elasticum. Journal of the American Academy of Dermatology, 2011, 65, 341-348.	1.2	30

#	Article	IF	Citations
73	Response to 'Mutation (variation) databases and registries: a rationale for coordination of efforts': an IRDiRC perspective. Nature Reviews Genetics, 2011, 12, 881-881.	16.3	9
74	Pseudoxanthoma elasticum: Progress in diagnostics and research towards treatment. American Journal of Medical Genetics, Part A, 2011, 155, 1517-1526.	1.2	65
75	Committee report: Considerations and recommendations for national guidance regarding the retention and use of residual dried blood spot specimens after newborn screening. Genetics in Medicine, 2011, 13, 621-624.	2.4	72
76	From Bench to Practice to Population Health Impact: Barriers to Realizing the Public Health and Clinical Promise of Basic Scientific Discovery. Genetic Testing and Molecular Biomarkers, 2011, 15, 191-192.	0.7	6
77	Engaging Research Participants and Building Trust. Genetic Testing and Molecular Biomarkers, 2011, 15, 839-840.	0.7	13
78	Risky Business: The Need for Hypothesis-Generating Research. Genetic Testing and Molecular Biomarkers, 2011, 15, 577-578.	0.7	1
79	Power to the People : Participant Ownership of Clinical Trial Data. Science Translational Medicine, 2011, 3, 69cm3.	12.4	51
80	Understanding Geneâ€“Environment Interactions. Genetic Testing and Molecular Biomarkers, 2011, 15, 371-372.	0.7	1
81	Accelerate medical breakthroughs by ending disease earmarks. Nature Reviews Genetics, 2010, 11, 310-311.	16.3	6
82	FDA and CLIA Oversight of Advanced Diagnostics and Biomarker Tests. Genetic Testing and Molecular Biomarkers, 2010, 14, 285-287.	0.7	2
83	Standards for Personalized Medicine. Genetic Testing and Molecular Biomarkers, 2010, 14, 155-156.	0.7	1
84	Assay, Preclinical, and Clinical Brick Walls and Opportunities for System Change Through GRANDRx. Assay and Drug Development Technologies, 2010, 8, 128-134.	1.2	0
85	Landscape Analysis of Registries and Biobanks: A Tool for Disease Advocacy Organizations to Enhance Translational Research Systems. Biopreservation and Biobanking, 2010, 8, 115-117.	1.0	3
86	Committee report: Method for evaluating conditions nominated for population-based screening of newborns and children. Genetics in Medicine, 2010, 12, 153-159.	2.4	78
87	Carrier testing for spinal muscular atrophy. Genetics in Medicine, 2010, 12, 621-622.	2.4	29
88	What Are the Biggest Challenges and Opportunities for Biorepositories in the Next Three to Five Years?. Biopreservation and Biobanking, 2010, 8, 81-88.	1.0	19
89	Genetic Testing and Biomarkers in the New Decade. Genetic Testing and Molecular Biomarkers, 2010, 14, 1-2.	0.7	4
90	Genetic Information Nondiscrimination Act Insurance Protections Issued. Genetic Testing and Molecular Biomarkers, 2009, 13, 709-710.	0.7	4

#	Article	IF	Citations
91	The Genomic Applications in Practice and Prevention Network. Genetics in Medicine, 2009, 11, 488-494.	2.4	57
92	Pseudoxanthoma elasticum: Wide phenotypic variation in homozygotes and no signs in heterozygotes for the c.3775delT mutation in ABCC6. Genetics in Medicine, 2009, 11, 852-858.	2.4	30
93	Ensuring the Safe Use of Genomic Medicine in Children. Clinical Pediatrics, 2009, 48, 703-708.	0.8	7
94	Spectrum of genetic variation at the ABCC6 locus in South Africans: Pseudoxanthoma elasticum patients and healthy individuals. Journal of Dermatological Science, 2009, 54, 198-204.	1.9	10
95	What do leaders of disease-specific advocacy organizations know about pharmacogenomics and biomarkers, anyway?. Personalized Medicine, 2009, 6, 171-181.	1.5	1
96	The Scientific Foundation for Personal Genomics: Recommendations from a National Institutes of Healthâ€“Centers for Disease Control and Prevention Multidisciplinary Workshop. Genetics in Medicine, 2009, 11, 559-567.	2.4	207
97	Pseudoxanthoma elasticum: genetic diagnostic markers. Expert Opinion on Medical Diagnostics, 2008, 2, 63-79.	1.6	24
98	Mutation detection in the ABCC6 gene and genotype phenotype analysis in a large international case series affected by pseudoxanthoma elasticum. Journal of Medical Genetics, 2007, 44, 621-628.	3.2	161
99	Providers' knowledge of genetics: A survey of 5915 individuals and families with genetic conditions. Genetics in Medicine, 2007, 9, 259-267.	2.4	70
100	Development of a Rapid, Reliable Genetic Test for Pseudoxanthoma Elasticum. Journal of Molecular Diagnostics, 2007, 9, 105-112.	2.8	16
101	Advocacy groups as research organizations: the PXE International example. Nature Reviews Genetics, 2007, 8, 157-164.	16.3	151
102	Pseudoxanthoma Elasticum-Like Phenotype with Cutis Laxa and Multiple Coagulation Factor Deficiency Represents a Separate Genetic Entity. Journal of Investigative Dermatology, 2007, 127, 581-587.	0.7	168
103	Testicular Microlithiasis in Association with Pseudoxanthoma Elasticum. Radiology, 2005, 237, 550-554.	7.3	26
104	In the public interest: Open access. College and Research Libraries News, 2005, 66, 522-525.	0.1	1
105	Ethical issues in identifying and recruiting participants for familial genetic research. American Journal of Medical Genetics Part A, 2004, 130A, 424-431.	2.4	55
106	Participation by clinical geneticists in genetic advocacy groups. American Journal of Medical Genetics Part A, 2003, 119A, 89-92.	2.4	10
107	Re: yellowish papules on flexural areas in a child. Pediatric Dermatology, 2003, 20, 543-545.	0.9	1
108	Mammographic findings in pseudoxanthoma elasticum. Journal of the American Academy of Dermatology, 2003, 48, 359-366.	1.2	23

#	Article	IF	Citations
109	Learning Genetics. Health Affairs, 2003, 22, 166-171.	5.2	12
110	Extracutaneous Ultrastructural Alterations in Pseudoxanthoma Elasticum. Ultrastructural Pathology, 2003, 27, 375-384.	0.9	77
111	Extracutaneous ultrastructural alterations in pseudoxanthoma elasticum. Ultrastructural Pathology, 2003, 27, 375-84.	0.9	29
112	Before It's Too Late--Addressing Fear of Genetic Information. Science, 2002, 297, 196-197.	12.6	46
113	Evidence for a founder effect for pseudoxanthoma elasticum in the Afrikaner population of South Africa. Human Genetics, 2002, 111, 331-338.	3.8	35
114	A Spectrum of ABCC6 Mutations Is Responsible for Pseudoxanthoma Elasticum. American Journal of Human Genetics, 2001, 69, 749-764.	6.2	442
115	A consumer perspective on informed consent and third-party issues. Journal of Continuing Education in the Health Professions, 2001, 21, 256-264.	1.3	1
116	Researching the biology of PXE: Partnering in the process. American Journal of Medical Genetics Part A, 2001, 106, 177-184.	2.4	43
117	Mutations in a gene encoding an ABC transporter cause pseudoxanthoma elasticum. Nature Genetics, 2000, 25, 223-227.	21.4	512
118	Mutations in ABCC6 cause pseudoxanthoma elasticum. Nature Genetics, 2000, 25, 228-231.	21.4	804
119	Pseudoxanthoma Elasticum Maps to an 820-kb Region of the p13.1 Region of Chromosome 16. Genomics, 1999, 62, 1-10.	2.9	61
120	Current trends in biobanking for rare diseases: a review. Journal of Biorepository Science for Applied Medicine, 0, , 49.	0.2	16