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	Mutations in ABCC6 cause pseudoxanthoma elasticum. Nature Genetics, 2000, 25, 228-231.	21.4	804
2	Mutations in a gene encoding an ABC transporter cause pseudoxanthoma elasticum. Nature Genetics, 2000, 25, 223-227.	21.4	512
3	A Spectrum of ABCC6 Mutations Is Responsible for Pseudoxanthoma Elasticum. American Journal of Human Genetics, 2001, 69, 749-764.	6.2	442
4	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
5	The Matchmaker Exchange: A Platform for Rare Disease Gene Discovery. Human Mutation, 2015, 36, 915-921.	2.5	390
6	Adopt a moratorium on heritable genome editing. Nature, 2019, 567, 165-168.	27.8	314
7	From patients to partners: participant-centric initiatives in biomedical research. Nature Reviews Genetics, 2012, 13, 371-376.	16.3	250
8	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
9	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
10	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
11	Ethics and Genomic Incidental Findings. Science, 2013, 340, 1047-1048.	12.6	160
12	Advocacy groups as research organizations: the PXE International example. Nature Reviews Genetics, 2007, 8, 157-164.	16.3	151
13	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
14	The impact of false-positive newborn screening results on families: a qualitative study. Genetics in Medicine, 2012, 14, 76-80.	2.4	78
15	Extracutaneous Ultrastructural Alterations in Pseudoxanthoma Elasticum. Ultrastructural Pathology, 2003, 27, 375-384.	0.9	77
16	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
17	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
18	Providers' knowledge of genetics: A survey of 5915 individuals and families with genetic conditions. Genetics in Medicine, 2007, 9, 259-267.	2.4	70

#	Article	IF	Citations
19	Pseudoxanthoma elasticum: diagnostic features, classification and treatment options. Expert Opinion on Orphan Drugs, 2014, 2, 567-577.	0.8	69
20	How disease advocacy organizations participate in clinical research: a survey of genetic organizations. Genetics in Medicine, 2012, 14, 223-228.	2.4	67
21	Pseudoxanthoma elasticum: Progress in diagnostics and research towards treatment. American Journal of Medical Genetics, Part A, 2011, 155, 1517-1526.	1.2	65
22	Pseudoxanthoma Elasticum Maps to an 820-kb Region of the p13.1 Region of Chromosome 16. Genomics, 1999, 62, 1-10.	2.9	61
23	Obama's Precision Medicine Initiative. Genetic Testing and Molecular Biomarkers, 2015, 19, 113-114.	0.7	60
24	Toward clinical genomics in everyday medicine: perspectives and recommendations. Expert Review of Molecular Diagnostics, 2016, 16, 521-532.	3.1	58
25	The Genomic Applications in Practice and Prevention Network. Genetics in Medicine, 2009, 11, 488-494.	2.4	57
26	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
27	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
28	Power to the People : Participant Ownership of Clinical Trial Data. Science Translational Medicine, 2011, 3, 69cm3.	12.4	51
29	Including all voices in international data-sharing governance. Human Genomics, 2018, 12, 13.	2.9	50
30	Data Acquisition, Curation, and Use for a Continuously Learning Health System. JAMA - Journal of the American Medical Association, 2016, 316, 1669.	7.4	48
31	Before It's Too Late--Addressing Fear of Genetic Information. Science, 2002, 297, 196-197.	12.6	46
32	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
33	Researching the biology of PXE: Partnering in the process. American Journal of Medical Genetics Part A, 2001, 106, 177-184.	2.4	43
34	A dynamic map for learning, communicating, navigating and improving therapeutic development. Nature Reviews Drug Discovery, 2018, 17, 150-150.	46.4	43
35	Time for NIH to lead on data sharing. Science, 2020, 367, 1308-1309.	12.6	42
36	An End to the Myth: There Is No Drug Development Pipeline. Science Translational Medicine, 2013, 5, 171cm1.	12.4	38

#	Article	IF	Citations
37	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
38	Creating a data resource: what will it take to build a medical information commons?. Genome Medicine, 2017, 9, 84.	8.2	36
39	Leveraging electronic health records for clinical research. American Heart Journal, 2018, 202, 13-19.	2.7	36
40	Evidence for a founder effect for pseudoxanthoma elasticum in the Afrikaner population of South Africa. Human Genetics, 2002, 111, 331-338.	3.8	35
41	Toward better governance of human genomic data. Nature Genetics, 2021, 53, 2-8.	21.4	31
42	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
43	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
44	Research Progress in Pseudoxanthoma Elasticum andÂRelated Ectopic Mineralization Disorders. Journal of Investigative Dermatology, 2016, 136, 550-556.	0.7	30
45	Carrier testing for spinal muscular atrophy. Genetics in Medicine, 2010, 12, 621-622.	2.4	29
46	Extracutaneous ultrastructural alterations in pseudoxanthoma elasticum. Ultrastructural Pathology, 2003, 27, 375-84.	0.9	29
47	Participant-Driven Matchmaking in the Genomic Era. Human Mutation, 2015, 36, 965-973.	2.5	28
48	Plain-language medical vocabulary for precision diagnosis. Nature Genetics, 2018, 50, 474-476.	21.4	28
49	Application of a Dynamic Map for Learning, Communicating, Navigating, and Improving Therapeutic Development. Clinical and Translational Science, 2018, 11, 166-174.	3.1	27
50	Testicular Microlithiasis in Association with Pseudoxanthoma Elasticum. Radiology, 2005, 237, 550-554.	7.3	26
51	Pseudoxanthoma elasticum: genetic diagnostic markers. Expert Opinion on Medical Diagnostics, 2008, 2, 63-79.	1.6	24
52	Mammographic findings in pseudoxanthoma elasticum. Journal of the American Academy of Dermatology, 2003, 48, 359-366.	1.2	23
53	The Haystack Is Made of Needles. Genetic Testing and Molecular Biomarkers, 2013, 17, 175-177.	0.7	22
54	Privacy, Fairness, and Respect for Individuals. EGEMS (Washington, DC), 2017, 4, 7.	2.0	22

#	Article	IF	Citations
55	Warfarin Accelerates Ectopic Mineralization in Abcc6â^'/â^' Mice. American Journal of Pathology, 2013, 182, 1139-1150.	3.8	21
56	The study is open: Participants are now recruiting investigators. Science Translational Medicine, 2017, 9, .	12.4	21
57	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
58	Genetic Alliance Registry and BioBank: a novel disease advocacy-driven research solution. Personalized Medicine, 2011, 8, 207-213.	1.5	19
59	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
60	Acquired pseudoxanthoma elasticum presenting after liver transplantation. Journal of the American Academy of Dermatology, 2011, 64, 873-878.	1.2	17
61	Development of a Rapid, Reliable Genetic Test for Pseudoxanthoma Elasticum. Journal of Molecular Diagnostics, 2007, 9, 105-112.	2.8	16
62	Current trends in biobanking for rare diseases: a review. Journal of Biorepository Science for Applied Medicine, 0, , 49.	0.2	16
63	Evidence synthesis and guideline development in genomic medicine: current status and future prospects. Genetics in Medicine, 2015, 17, 63-67.	2.4	16
64	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
65	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
66	Reactions to the National Academies/Royal Society Report onHeritable Human Genome Editing. CRISPR Journal, 2020, 3, 332-349.	2.9	15
67	Engaging Research Participants and Building Trust. Genetic Testing and Molecular Biomarkers, 2011, 15, 839-840.	0.7	13
68	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
69	Learning Genetics. Health Affairs, 2003, 22, 166-171.	5.2	12
70	Disease advocacy organizations catalyze translational research. Frontiers in Genetics, 2013, 4, 101.	2.3	12
71	Database shares that transform research subjects into partners. Nature Biotechnology, 2019, 37, 1112-1115.	17.5	11
72	Oral supplementation of inorganic pyrophosphate in pseudoxanthoma elasticum. Experimental Dermatology, 2022, 31, 548-555.	2.9	11

#	Article	IF	Citations
73	Participation by clinical geneticists in genetic advocacy groups. American Journal of Medical Genetics Part A, 2003, 119A, 89-92.	2.4	10
74	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
75	Reporting Actionable Research Results: Shared Secrets Can Save Lives. Science Translational Medicine, 2012, 4, 143cm8.	12.4	10
76	Community Engagement about Genetic Variation Research. Population Health Management, 2012, 15, 78-89.	1.7	10
77	Don't Just Invite Us to the Table: Authentic Community Engagement. Genetic Testing and Molecular Biomarkers, 2013, 17, 443-445.	0.7	10
78	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
79	Ensuring the Safe Use of Genomic Medicine in Children. Clinical Pediatrics, 2009, 48, 703-708.	0.8	7
80	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
81	Benefits and Risks of Sharing Genomic Information. Genetic Testing and Molecular Biomarkers, 2015, 19, 648-649.	0.7	7
82	Life as a numerator: Putting the person in personal genomics. Applied & Translational Genomics, 2016, 8, 40-41.	2.1	7
83	Accelerate medical breakthroughs by ending disease earmarks. Nature Reviews Genetics, 2010, 11, 310-311.	16.3	6
84	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
85	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
86	Regulating Genetic Tests: Issues That Guide Policy Decisions. Genetic Testing and Molecular Biomarkers, 2012, 16, 1-2.	0.7	5
87	Nothing About Us Without Us: Guidelines for Genetic Testing. Genetic Testing and Molecular Biomarkers, 2013, 17, 357-358.	0.7	5
88	Hearing voices: FDA seeks advice from patients. Science Translational Medicine, 2015, 7, 313ed12.	12.4	5
89	The Human Face of ABCC6. FEBS Letters, 2020, 594, 4151-4157.	2.8	5
90	Genetic heterogeneity of heritable ectopic mineralization disorders in a large international cohort. Genetics in Medicine, 2022, 24, 75-86.	2.4	5

#	Article	IF	Citations
91	Genetic Information Nondiscrimination Act Insurance Protections Issued. Genetic Testing and Molecular Biomarkers, 2009, 13, 709-710.	0.7	4
92	Genetic Testing and Biomarkers in the New Decade. Genetic Testing and Molecular Biomarkers, 2010, 14, 1-2.	0.7	4
93	Assessing NIHâ€™s Big Idea. Science Translational Medicine, 2013, 5, 196ed11.	12.4	4
94	Linking Personal Health Data to Genomic Research. Genetic Testing and Molecular Biomarkers, 2015, 19, 1-2.	0.7	4
95	Realizing Our Potential in Biobanking: Disease Advocacy Organizations Enliven Translational Research. Biopreservation and Biobanking, 2016, 14, 314-318.	1.0	4
96	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
97	Precision Medicine: Generating Real-World Evidence for Companion Diagnostics. Genetic Testing and Molecular Biomarkers, 2012, 16, 75-76.	0.7	3
98	FDA and CLIA Oversight of Advanced Diagnostics and Biomarker Tests. Genetic Testing and Molecular Biomarkers, 2010, 14, 285-287.	0.7	2
99	A Call for Participatory Oversight. Genetic Testing and Molecular Biomarkers, 2014, 18, 71-72.	0.7	2
100	PhenX measures for phenotyping rare genetic conditions. Genetics in Medicine, 2017, 19, 834-837.	2.4	2
101	Turning Toward Participants in Biobanking. Genetic Testing and Molecular Biomarkers, 2017, 21, 132-133.	0.7	2
102	Data Sharing Goals for Nonprofit Funders of Clinical Trials. Journal of Participatory Medicine, 2021, 13, e23011.	1.3	2
103	Biobanking Challenges and Informatics Opportunities. Computers in Health Care, 2012, , 221-231.	0.3	2
104	Web-Based Mindfulness-Based Interventions for Well-being: Randomized Comparative Effectiveness Trial. Journal of Medical Internet Research, 2022, 24, e35620.	4.3	2
105	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
106	Re: yellowish papules on flexural areas in a child. Pediatric Dermatology, 2003, 20, 543-545.	0.9	1
107	What do leaders of disease-specific advocacy organizations know about pharmacogenomics and biomarkers, anyway?. Personalized Medicine, 2009, 6, 171-181.	1.5	1
108	Standards for Personalized Medicine. Genetic Testing and Molecular Biomarkers, 2010, 14, 155-156.	0.7	1

#	Article	IF	Citations
109	Risky Business: The Need for Hypothesis-Generating Research. Genetic Testing and Molecular Biomarkers, 2011, 15, 577-578.	0.7	1
110	Understanding Geneâ€“Environment Interactions. Genetic Testing and Molecular Biomarkers, 2011, 15, 371-372.	0.7	1
111	Research for the People by the People. Genetic Testing and Molecular Biomarkers, 2017, 21, 521-522.	0.7	1
112	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
113	Voices of biotech leaders. Nature Biotechnology, 2021, 39, 654-660.	17.5	1
114	In the public interest: Open access. College and Research Libraries News, 2005, 66, 522-525.	0.1	1
115	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
116	Response to the Commentary â€œSignificance of Patient Registries for Dermatological Disorderâ€• Journal of Investigative Dermatology, 2013, 133, 1361.	0.7	0
117	Clinical trial result reporting: Time to move into the 21st century. Clinical Trials, 2016, 13, 597-598.	1.6	0
118	Data Sharing as the New Norm: What About the People Part?. Genetic Testing and Molecular Biomarkers, 2017, 21, 63-65.	0.7	0
119	Ascertaining Nonfatal Endpoints in Clinical Trials: Central Adjudication Versus Patient Insurance Claims. Therapeutic Innovation and Regulatory Science, 2021, 55, 1250-1257.	1.6	0
120	Comment on â€œClinical practice guidelines for pseudoxanthoma elasticum (2017)â€• The importance of mutation analysis. Journal of Dermatology, 2022, 49, .	1.2	0