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Teeuw, M.E.

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References

- Ahmed S, Green JM, Hewison J. 2006. Attitudes towards prenatal diagnosis and termination of pregnancy for thalassaemia in pregnant Pakistani women in the North of England. *Prenat Diagn* 26:248-257.
- Ait-Idir D, Khilan A, Djerdjouri B, El-Shanti H. 2011. Spectrum of mutations and carrier frequency of familial Mediterranean fever gene in the Algerian population. *Rheumatology*, ker328.
- Aksoy M. 1985. Hemoglobinopathies in Turkey. *Hemoglobin* 9:209-216.
- Alkuraya F. 2013. Impact of new genomic tools on the practice of clinical genetics in consanguineous populations: the Saudi experience. *Clin Genet* 84:203-208.
- Asscher L. 2010. De ontsluiting van de stad. Bert Bakker.
- Atkin K, Ahmad WI, Anionwu EN. 1998. Screening and counselling for sickle cell disorders and thalassaemia: the experience of parents and health professionals. *Soc Sci Med* 47:1639-1651.
- Atkin K, Ahmed S, Hewison J, Green JM. 2008. Decision-making and ante-natal screening for sickle cell and thalassaemia disorders. *Current Sociology* 56:77-98.
- Baars MJ, Henneman L, Ten Kate LP. 2005. Deficiency of knowledge of genetics and genetic tests among general practitioners, gynecologists, and pediatricians: a global problem. *Genet Med* 7:605-610.
- Bamshad MJ, Ng SB, Bigham AW, Tabor HK, Emond MJ, Nickerson DA, Shendure J. 2011. Exome sequencing as a tool for Mendelian disease gene discovery. *Nat Rev Genet* 12:745-755.
- Bartels A, Loukili G. 2012. Testing isn't the problem: Views of Muslim theologians, spiritual counsellors, Imams and physicians on preconceptional testing. *Medische Antropologie* 24:321-332.
- Basaran N, Cenani A, Sayli BS, Ozkinay C, Artan S, Seven H, Basaran A, Dincer S. 1992. Consanguineous marriages among parents of Down patients. *Clin Genet* 42:13-15.
- Bekker H, Modell M, Denniss G, Silver A, Mathew C, Bobrow M, Marteau T. 1993. Uptake of cystic fibrosis testing in primary care: supply push or demand pull? *BMJ* 306:1584-1586.
- Bell CJ, Dinwiddie DL, Miller NA, Hateley SL, Ganusova EE, Mudge J, Langley RJ, Zhang L, Lee CC, Schilkey FD, Sheth V, Woodward JE, Peckham HE, Schroth GP, Kim RW, Kingsmore SF. 2011. Carrier testing for severe childhood recessive diseases by next-generation sequencing. *Sci Transl Med* 3:65ra4.
- Belmahi L, Sefiani A, Fouveau C, Feingold J, Delpech M, Grateau G, Dode C. 2006. Prevalence and distribution of MEFV mutations among Arabs from the Maghreb patients suffering from familial Mediterranean fever. *C R Biol* 329:71-74.
- Belmahi L, Cherkaoui I, Hama I, Sefiani A. 2012. MEFV mutations in Moroccan patients suffering from familial Mediterranean Fever. *Rheumatol Int* 32:981-984.
- Ben-Chetrit E, Levy M. 1998. Familial Mediterranean fever. *Lancet* 351:659-664.
- Bennett RL, Hudgins L, Smith CO, Motulsky AG. 1999. Inconsistencies in genetic counseling and screening for consanguineous couples and their offspring: the need for practice guidelines. *Genet Med* 1:286-292.
- Bennett RL, Motulsky AG, Bittles A, Hudgins L, Uhrich S, Doyle DL, Silvey K, Scott CR, Cheng E, McGillivray B. 2002. Genetic counseling and screening of consanguineous couples and their offspring: Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling* 11:97-119.
- Biernacki P, Waldorf D. 1981. Snowball sampling: problems and techniques of chain referral sampling. *Sociological Methods & Research* 10:141-163.
- Bishop M, Metcalfe S, Gaff C. 2008. The missing element: consanguinity as a component of genetic risk assessment. *Genet Med* 10:612-620.
- Bittles A. 2001. Consanguinity and its relevance to clinical genetics. *Clin Genet* 60:89-98.
- Bittles AH. 1994. The role and significance of consanguinity as a demographic variable. *Popul Dev Rev* 20:584.
- Bittles AH. 2009. Commentary: The background and outcomes of the first-cousin marriage controversy in Great Britain. *Int J Epidemiol* 38:1453-1458.

- Bittles AH, Black ML. 2010a. Evolution in health and medicine Sackler colloquium: Consanguinity, human evolution, and complex diseases. *Proc Natl Acad Sci U S A* 107 Suppl 1:1779-1786.
- Bittles AH, Black ML. 2010b. The impact of consanguinity on neonatal and infant health. *Early Hum Dev* 86:737-741.
- Bittles AH. 2005. Endogamy, consanguinity and community disease profiles. *Community Genet* 8:17-20.
- Bittles AH, Egerbladh I. 2006. Consanguinity, fertility and early mortality in Sweden during the 18th and 19th centuries. [<http://www.ichg2006.com/session/372.htm>].
- Bittles AH. 2012. A population genetics perspective on consanguinity. *Consanguinity in Context*: Cambridge University Press. p 74-92.
- Bowling A. 2009. Research methods in health: investigating health and health services. Open University Press.
- Bredenoord AL, de Vries MC, van Delden JJ. 2013. Next-generation sequencing: does the next generation still have a right to an open future? *Nat Rev Genet* 14:306.
- Carothers AD, Rudan I, Kolcic I, Polasek O, Hayward C, Wright AF, Campbell H, Teague P, Hastie ND, Weber JL. 2006. Estimating human inbreeding coefficients: comparison of genealogical and marker heterozygosity approaches. *Ann Hum Genet* 70:666-676.
- Carr IM, Markham SA, Pena SD. 2011. Estimating the degree of identity by descent in consanguineous couples. *Hum Mutat* 32:1350-1358.
- Chaabouni HB, Ksantini M, M'rad R, Kharrat M, Chaabouni M, Maazoul F, Bahloul Z, Ben Jemaa L, Ben Moussa F, Ben Chaabane T, Mrad S, Toutou I, Smaoui N. 2007. MEFV mutations in Tunisian patients suffering from familial Mediterranean fever. *Seminars in Arthritis and Rheumatism* 36:397-401.
- Condit CM. 2010. Public attitudes and beliefs about genetics. *Annu Rev Genomics Hum Genet* 11:339-359.
- Cooper DN, Ball EV, Mort M. 2010. Chromosomal distribution of disease genes in the human genome. *Genet Test Mol Biomarkers* 14:441-446.
- Curtis D, Vine AE. 2010. Yin Yang haplotypes revisited - long, disparate haplotypes observed in European populations in regions of increased homozygosity. *Human Heredity* 69:184-192.
- Darr A. 1997. Consanguineous marriage and genetics: a positive relationship. In: Clarke A, Parsons E, editors. *Culture, kinship and genes, towards cross-cultural genetics*. Cardiff: MacMillan Press. p 83-97.
- Daar AS, al Khitamy AB. 2001. Bioethics for clinicians: 21. Islamic bioethics. *CMAJ* 164:60-63.
- Darr A, Small N, Ahmad WI, Atkin K, Corry P, Benson J, Morton R, Modell B. 2013. Examining the family-centred approach to genetic testing and counselling among UK Pakistanis: a community perspective. *J Community Genet* 4:49-57.
- Dixon-Salazar TJ, Silhavy JL, Udpa N, Schroth J, Bielas S, Schaffer AE, Olvera J, Bafna V, Zaki MS, Abdel-Salam GH. 2012. Exome sequencing can improve diagnosis and alter patient management. *Science translational medicine* 4:138ra78.
- Elwyn G, Gray J, Clarke A. 2000. Shared decision making and non-directiveness in genetic counselling. *J Med Genet* 37:135-138.
- Emami A, Mazaheri M. 2007. Difficulties in recruiting participants for a research study on immigrant dementia caregiver. *Journal of Immigrant & Refugee Studies* 5:103-108.
- Facione NC. 1993. The Triandis model for the study of health and illness behavior: A social behavior theory with sensitivity to diversity. *Adv Nurs Sci* 15:49-58.
- Fost N. 1992. Ethical implications of screening asymptomatic individuals. *FASEB J* 6:2813-2817.
- Fromer M, Moran JL, Chambert K, Banks E, Bergen SE, Ruderfer DM, Handsaker RE, McCarroll SA, O'Donovan MC, Owen MJ, Kirov G, Sullivan PF, Hultman CM, Sklar P, Purcell SM. 2012. Discovery and statistical genotyping of copy-number variation from whole-exome sequencing depth. *Am J Hum Genet* 91:597-607.
- Gialluisi A, Pippucci T, Anikster Y, Ozbek U, Medlej-Hashim M, Megarbane A, Romeo G. 2012. Estimating the allele frequency of autosomal recessive disorders through mutational records and consanguinity: the Homozygosity Index (HI). *Ann Hum Genet* 76:159-167.
- Gialluisi A, Incollu S, Pippucci T, Lepori MB, Zappu A, Loudianos G, Romeo G. 2013. The homozygosity index (HI) approach reveals high allele frequency for Wilson disease in the Sardinian population. *Eur J Hum Genet* 21:1308-1311.

- Gibson J, Morton NE, Collins A. 2006. Extended tracts of homozygosity in outbred human populations. *Hum Mol Genet* 15:789-795.
- Gilissen C, Hoischen A, Brunner HG, Veltman JA. 2012. Disease gene identification strategies for exome sequencing. *Eur J Hum Genet* 20:490-497.
- Gitsels-van der Wal JT, Mannien J, Ghaly MM, Verhoeven PS, Hutton EK, Reinders HS. 2014a. The role of religion in decision-making on antenatal screening of congenital anomalies: a qualitative study amongst Muslim Turkish origin immigrants. *Midwifery* 30:297-302.
- Gitsels-van der Wal JT, Mannien J, Gitsels LA, Reinders HS, Verhoeven PS, Ghaly MM, Klomp T, Hutton EK. 2014b. Prenatal screening for congenital anomalies: exploring midwives' perceptions of counseling clients with religious backgrounds. *BMC Pregnancy Childbirth* 14:237.
- Giordano PC, Dihal AA, Hartevelde CL. 2005. Estimating the attitude of immigrants toward primary prevention of the hemoglobinopathies. *Prenat Diagn* 25:885-893.
- Hamamy H. 2012. Consanguineous marriages : Preconception consultation in primary health care settings. *J Community Genet* 3:185-192.
- Hamamy H, Antonarakis SE, Cavalli-Sforza LL, Temtamy S, Romeo G, Kate LP, Bennett RL, Shaw A, Megarbane A, Van Duijn CM, Bathija H, Fokstuen S, Engel E, Zlotogora J, Dermitzakis E, Bottani A, Dahoun S, Morris MA, Arsenault S, Aglan MS, Ajaz M, Alkalamchi A, Alnaqeb D, Alwasayah MK, Anwer N, Awwad R, Bonnefin M, Corry P, Gwanmesia L, Karbani GA, Mostafavi M, Pippucci T, Ranza-Boscardin E, Reversade B, Sharif SM, Teeuw ME, Bittles AH. 2011. Consanguineous marriages, pearls and perils: Geneva International Consanguinity Workshop Report. *Genet Med* 13:841-847.
- Health Council of the Netherlands. Preconception Care: a good beginning 2007. Den Haag: Gezondheidsraad.
- Henneman L, Timmermans DR, van der Wal G. 2004. Public experiences, knowledge and expectations about medical genetics and the use of genetic information. *Community Genet* 7:33-43.
- Hewison J, Green JM, Ahmed S, Cuckle HS, Hirst J, Hucknall C, Thornton JG. 2007. Attitudes to prenatal testing and termination of pregnancy for fetal abnormality: a comparison of white and Pakistani women in the UK. *Prenat Diagn* 27:419-430.
- Houwink EJ, Van Luijk SJ, Henneman L, Van der Vleuten C, Dinant G.J., Cornel MC. 2011. Genetic educational needs and the role of genetics in primary care: a focus group study with multiple perspectives. *BMC Fam Pract* 12:5.
- Human Genetics Commission. 2011. Increasing options, informing choice: a report on preconception genetic testing and screening.
- IBM Corp. 2011. IBM SPSS Statistics for Windows, Version 20.0. Armonk, NY: IBM Corp.
- Ibrahim S, Sidani S. 2013. Strategies to recruit minority persons: a systematic review. *J Immigrant Minority Health*:1-7.
- Inhorn MC. 2006. Making Muslim babies: IVF and gamete donation in Sunni versus Shi'a Islam. *Cult Med Psychiatry* 30:427-450.
- Jaber L, Romano O, Halpern GJ, Livne I, Green M, Shohat T. 2005. Awareness about problems associated with consanguineous marriages: Survey among Israeli Arab adolescents. *Journal of Adolescent Health* 36:530.
- James RD, Yu JH, Henrikson NB, Bowen DJ, Fullerton SM. 2008. Strategies and stakeholders: minority recruitment in cancer genetics research. *Community Genet* 11:241-249.
- De Jong A. 2005. KNOV-standpunt preconceptiezorg [KNOV standpoint preconception care].
- De Jong-Potjer LC, Beentjes M, Bogchelman M, Jaspas AHJ, Van Asselt KM. 2011. NHG-standaard preconceptiezorg [The Dutch College of General Practitioners guideline preconception care]. *Huisarts Wet* 54:310-312.
- Jonker M, van der Vaart A. 2014. On the correction of the asymptotic distribution of the likelihood ratio statistic if nuisance parameters are estimated based on an external source. *Int J Biostat.* 10(2):123-142.
- Kingsmore SF, Lantos JD, Dinwiddie DL, Miller NA, Soden SE, Farrow EG, Saunders CJ. 2012. Next-generation community genetics for low- and middle-income countries. *Genome Med* 4:25.
- Kirin M, McQuillan R, Franklin CS, Campbell H, McKeigue PM, Wilson JF. 2010. Genomic runs of homozygosity record population history and consanguinity. *PLoS One* 5:e13996.

- Kisioglu AN, Ormeci AR, Uskun E, Ozturk M, Ongel K. 2010. Effects of a formal training programme on consanguineous marriages on high school students' knowledge and attitudes: an interventional study from Turkey. *J Biosoc Sci* 42:161-176.
- De Koning M, Storms O, Bartels E. (2014). Legal "ban" on transnational cousin-marriages: citizen debate in the Netherlands. *Transnational Social Review*, 4(2-3), 226-241.
- Koochmeshgi J, Bagheri A, Hosseini-Mazinani SM. 2002. Incidence of phenylketonuria in Iran estimated from consanguineous marriages. *J Inherit Metab Dis* 25:80-81.
- Lakeman P, Plass AM, Henneman L, Bezemer PD, Cornel MC, Ten Kate LP. 2008. Three-month follow-up of Western and non-Western participants in a study on preconceptional ancestry-based carrier couple screening for cystic fibrosis and hemoglobinopathies in the Netherlands. *Genet Med* 10:820-830.
- Leutenegger AL, Prum B, Genin E, Verny C, Lemaître A, Clerget-Darpoux F, Thompson EA. 2003. Estimation of the inbreeding coefficient through use of genomic data. *Am J Hum Genet* 73:516-523.
- Levenson D. 2010. New test could make carrier screening more accessible. *Am J Med Genet A* 152A:vii-iii.
- Li CC. 1955. *Population Genetics*. Chicago: University of Chicago Press.
- Liu F, Elefante S, Van Duijn CM, Aulchenko YS. 2006. Ignoring distant genealogic loops leads to false-positives in homozygosity mapping. *Annals of Human Genetics* 70:965-970.
- Livneh A, Langevitz P, Zemer D, Zaks N, Kees S, Lidar T, Migdal A, Padeh S, Pras M. 1997. Criteria for the diagnosis of familial mediterranean fever. *Arthritis & Rheumatism* 40:1879-1885.
- Locock L, Kai J. 2008. Parents' experiences of universal screening for haemoglobin disorders: implications for practice in a new genetics era. *Br J Gen Pract* 58:161-168.
- Mahowald MB, Verp MS, Anderson RR. 1998. Genetic counseling: clinical and ethical challenges. *Annu Rev Genet* 32:547-59.
- Makrythanasis P, Hamamy H, Antonarakis SE, Mauron A, Hurst SA. 2014. Analysis of the Born in Bradford birth cohort. *Lancet* 383:123.
- Manichaikul A, Mychaleckyj JC, Rich SS, Daly K, Sale MI, Chen WM. 2010. Robust relationship inference in genome-wide association studies. *Bioinformatics* 26:2867-2873.
- Markel H. 1992. The stigma of disease: implications of genetic screening. *Am J Med* 93:209-215.
- Marteau TM, Dundas R, Axworthy D. 1997. Long-term cognitive and emotional impact of genetic testing for carriers of cystic fibrosis: the effects of test result and gender. *Health Psychol* 16:51-62.
- McQuillan R, Leutenegger AL, Abdel-Rahman R, Franklin CS, Pericic M, Barac-Lauc L, Smolej-Narancic N, Janicijevic B, Polasek O, Tenesa A, MacLeod AK, Farrington SM, Rudan P, Hayward C, Vitart V, Rudan I, Wild SH, Dunlop MG, Wright AF, Campbell H, Wilson JF. 2008. Runs of homozygosity in European populations. *The American Journal of Human Genetics* 83:359-372.
- Modell B, Darr A. 2002. Science and society: genetic counselling and customary consanguineous marriage. *Nat Rev Genet* 3:225-229.
- Modell B, Darlison M. 2008. Global epidemiology of haemoglobin disorders and derived service indicators. *Bull World Health Organ* 86:480-487.
- Mohammadi N, Jones T, Evans D. 2008. Participant recruitment from minority religious groups: the case of the Islamic population in South Australia. *International Nursing Review* 55:393-398.
- Muralidharan K, Wilson RB, Ogino S, Nagan N, Curtis C, Schrijver I. 2011. Population carrier screening for spinal muscular atrophy a position statement of the association for molecular pathology. *J Mol Diagn* 13:3-6.
- Newman JE, Sorenson JR, DeVellis BM, Chevront B. 2002. Gender differences in psychosocial reactions to cystic fibrosis carrier testing. *Am J Med Genet* 113:151-157.
- Ormond KE, Wheeler MT, Hudgins L, Klein TE, Butte AJ, Altman RB, Ashley EA, Greely HT. 2010. Challenges in the clinical application of whole-genome sequencing. *Lancet* 375:1749-1751.
- Petukhova L, Shimomura Y, Wajid M, Gorroochurn P, Hodge SE, Christiano AM. 2009. The effect of inbreeding on the distribution of compound heterozygotes: a lesson from Lipase H mutations in autosomal recessive woolly hair/hypotrichosis. *Hum Hered* 68:117-130.
- Poppelaars FA, Cornel MC, Ten Kate LP. 2004. Current practice and future interest of GPs and prospective parents in pre-conception care in The Netherlands. *Fam Pract* 21:307-309.

- Purcell S, Neale B, Todd-Brown K, Thomas L, Ferreira MA, Bender D, Maller J, Sklar P, de Bakker PI, Daly MJ, Sham PC. 2007. PLINK: a tool set for whole-genome association and population-based linkage analyses. *Am J Hum Genet* 81:559-575.
- Qureshi N. 1997. The relevance of cultural understanding to clinical genetic practice. In: Clarke A, Parsons E, editors. *Culture, Kinship and Genes. Towards Cross Cultural Genetics*. Basingstoke: MacMillan. p 111-119.
- Qureshi N, Modell B, Modell M. 2004. Raising the profile of genetics in primary care. *Nat Rev Genet* 5:783-790.
- Rawaf S, De MJ, Starfield B. 2008. From Alma-Ata to Almaty: a new start for primary health care. *Lancet* 372:1365-1367.
- Raz AE, Atar M, Rodnay M, Shoham-Vardi I, Carmi R. 2003. Between acculturation and ambivalence: knowledge of genetics and attitudes towards genetic testing in a consanguineous bedouin community. *Community Genet* 6:88-95.
- Reich DE, Lander ES. 2001. On the allelic spectrum of human disease. *Trends Genet* 17:502-510.
- Reniers G. 2010. Post-immigration survival of traditional marriage patterns: consanguineous marriage among Turkish and Moroccan immigrants in Belgium. *Gent: Department of Population Studies, University of Gent*.
- Ridder M. 2014. *Family, Health & Genetics. Training community health workers to discuss cousin marriage and genetic risk with migrant women in the Netherlands (master thesis)*.
- Rigter T, Henneman L, Kristoffersson U, Hall A, Yntema HG, Borry P, Tonnie H, Waisfisz Q, Elting MW, Dondorp WJ, Cornel MC. 2013. Reflecting on earlier experiences with unsolicited findings: points to consider for next-generation sequencing and informed consent in diagnostics. *Hum Mutat* 34:1322-1328.
- Romeo G, Bianco M, Devoto M, Menozzi P, Mastella G, Giunta AM, Micalizzi C, Antonelli M, Battistini A, Santamaria F. 1985. Incidence in Italy, genetic heterogeneity, and segregation analysis of cystic fibrosis. *Am J Hum Genet* 37:338-349.
- Ropers HH. 2012. On the future of genetic risk assessment. *J Community Genet* 3:229-236.
- Salway S, Ali P, Ratcliffe G, Bibi S. 2012. Understandings related to consanguineous marriage and genetic risk: Findings from a community level consultation exercise in Sheffield and Rotherham. NIHR CLAHRC for South Yorkshire.
- Sandridge AL, Takeddin J, Al-Kaabi E, Frances Y. 2010. Consanguinity in Qatar: knowledge, attitude and practice in a population born between 1946 and 1991. *J Biosoc Sci* 42:59-82.
- Schulpen TW, van Steenberghe JE, van Driel HF. 2001. Influences of ethnicity on perinatal and child mortality in the Netherlands. *Arch Dis Child* 84:222-226.
- Schulpen TWJ. 2002. Valse Voorlichting [False Information]. *Medisch Contact* 57:1436.
- Sedehi M, Keshtkar AA, Ghalipour MJ. 2012. The knowledge and the attitude of youth couples on/towards consanguineous marriages in the north of Iran. *JCDR* 6:1233-1236.
- Serour GI. 2008. Islamic perspectives in human reproduction. *Reprod Biomed Online* 17 Suppl 3:34-38.
- Shaw A, Hurst JA. 2008. "What is this genetics, anyway?" Understandings of genetics, illness causality and inheritance among British Pakistani users of genetic services. *J Genet Couns* 17:373-383.
- Sheridan E, Wright J, Small N, Corry PC, Oddie S, Whibley C, Petherick ES, Malik T, Pawson N, McKinney PA, Parslow RC. 2013. Risk factors for congenital anomaly in a multiethnic birth cohort: an analysis of the Born in Bradford study. *Lancet* 382:1350-1359.
- Shields AE, Burke W, Levy DE. 2008. Differential use of available genetic tests among primary care physicians in the United States: results of a national survey. *Genet Med* 10:404-414.
- Shohat M, Halpern GJ. 2011. Familial Mediterranean fever. A review. *Genet Med* 13:487-498.
- Stevens EL, Baugher JD, Shirley MD, Frelin LP, Pevsner J. 2012. Unexpected relationships and inbreeding in HapMap phase III populations. *PLoS One* 7:e49575.
- Stoffman N, Magal N, Shohat T, Lotan R, Koman S, Oron A, Danon Y, Halpern GJ, Lifshitz Y, Shohat M. 2000. Higher than expected carrier rates for familial Mediterranean fever in various Jewish ethnic groups. *Eur J Hum Genet* 8:307-310.

- Storms O, Bartels E. 2015. Changing patterns of partner choice? Cousin marriages among migrant groups in the Netherlands. In: Cousin marriages. Between tradition, genetic risk and cultural change. Shaw A, Raz AE, editors. Berghahn books: Oxford and New York.
- Stronks K, Ravelli ACJ, Reijneveld SA. 2001. Immigrants in the Netherlands: Equal access for equal needs? *Journal of Epidemiology and Community Health* 55:701-707.
- Stuurgroep Zwangerschap en Geboorte. 2009. Een goed begin. Veilige zorg rond zwangerschap en geboorte.
- Talan D, van Elderen T, Hoogeboom J. 2012. Ongelijk verdeeld: migranten vragen minder én ander klinisch genetisch advies [Unequally divided: migrants request less as well as different clinical genetic advice]. *Medisch Contact*:1828-1829.
- Teeuw ME, Hagelaar A, Ten Kate LP, Cornel MC, Henneman L. 2012. Challenges in the care for consanguineous couples: an exploratory interview study among general practitioners and midwives. *BMC Fam Pract* 13:105.
- Teeuw ME, Henneman L, Bochdanovits Z, Heutink P, Kuik DJ, Cornel MC, Ten Kate LP. 2010. Do consanguineous parents of a child affected by an autosomal recessive disease have more DNA identical-by-descent than similarly-related parents with healthy offspring? Design of a case-control study. *BMC Med Genet* 11:113.
- Teeuw ME, Loukili G, Bartels EA, Ten Kate LP, Cornel MC, Henneman L. 2014. Consanguineous marriage and reproductive risk: attitudes and understanding of ethnic groups practising consanguinity in Western society. *Eur J Hum Genet* 22:452-457.
- Ten Kate L, Teeuw M, Henneman L, Cornel M. 2010. Autosomal recessive disease in children of consanguineous parents: inferences from the proportion of compound heterozygotes. *J Community Genet* 1:37-40.
- Ten Kate LP. 2012. Genetic risk. *J Community Genet* 3:159-166.
- Ten Kate LP, Scheffer H, Cornel MC, Van Lookeren Campagne JG. 1991. Consanguinity sans reproche. *Hum Genet* 86:295-296.
- Ten Kate LP, Teeuw ME, Henneman L, Cornel MC. 2014. Consanguinity and endogamy in the Netherlands: demographic and medical genetic aspects. *Hum Hered* 77:161-166.
- Touitou I. 2001. The spectrum of Familial Mediterranean Fever (FMF) mutations. *Eur J Hum Genet* 9:473-483.
- Triandis HC. 1970. *Interpersonal behaviour*. Monterey: Brooks/Cole.
- Tunca M, Akar S, Hawkins PN, Booth SE, Sengul B, Yavuzsen TU, Oktem S, Soyuturk M, Akkoc N, Booth DR. 2002. The significance of paired MEFV mutations in individuals without symptoms of familial Mediterranean fever. *Eur J Hum Genet* 10:786-789.
- Unesco. 1997. *The Universal Declaration on the Human Genome and Human Rights*. www.unesco.org.
- Van Elderen T, Mutlu D, Karstanje J, Passchier J, Tibben A, Duivenvoorden HJ. 2010. Turkish female immigrants' intentions to participate in preconception carrier screening for hemoglobinopathies in the Netherlands: an empirical study. *Public Health Genomics* 13:415-423.
- Van der Vaart A. 1998. *Asymptotic Statistics*. Cambridge: Cambridge University Press.
- Van der Zee B, de Beaufort I, Temel S, de Wert G, Denktas S, Steegers E. 2011. Preconception care: an essential preventive strategy to improve children's and women's health. *J Public Health Policy* 32:367-379.
- Waelput AJM, Achterberg PW. 2007. *Desire to have children in consanguineous parents: risks and genetic counseling*. Bilthoven: RIVM, National Institute for Public Health and Environment.
- Wang J. 2002. An Estimator for Pairwise Relatedness Using Molecular Markers. *Genetics* 160:1203-1215.
- Wang J. 2011. Coancestry: a program for simulating, estimating and analysing relatedness and inbreeding coefficients. *Molecular Ecology Resources* 11:141-145.
- Welkenhuyzen M, Evers-Kiebooms G, Decruyenaere M, Van den Berghe H. 1996. Unrealistic optimism and genetic risk. *Psychology & Health* 11:479-492.
- De Wert G, Dondorp W, Knoppers B. 2012. Preconception care and genetic risk: ethical issues. *Journal of community genetics* 3:221-228.
- Wienke S, Brown K, Farmer M, Strange C. 2014. Expanded carrier screening panels-does bigger mean better? *J Community Genet* 5:191-198.

- Wildschut HJ. 2000. NVOG Indicatie prenatale diagnostiek [NVOG indication prenatal diagnostics].
- Wolf NI, Salomons GS, Rodenburg RJ, Pouwels PJ, Schieving JH, Derks TG, Fock JM, Rump P, van Beek DM, van der Knaap MS, Waisfisz Q. 2014. Mutations in RARS cause hypomyelination. *Ann Neurol* 76: 134-139.
- Woods CG, Cox J, Springell K, Hampshire DJ, Mohamed MD, McKibbin M, Stern R, Raymond FL, Sandford R, Malik Sharif S, Karbani G, Ahmed M, Bond J, Clayton D, Inglehearn CF. 2006. Quantification of homozygosity in consanguineous individuals with autosomal recessive disease. *The American Journal of Human Genetics* 78:889-896.
- Wright S. 1922. Coefficients of inbreeding and relationship. *The American Naturalist* 56:330-338.
- Yilmaz E, Ozen S, Balci B, Duzova A, Topaloglu R, Besbas N, Saatci U, Bakkaloglu A, Ozguc M. 2001. Mutation frequency of Familial Mediterranean Fever and evidence for a high carrier rate in the Turkish population. *Eur J Hum Genet* 9:553-555.
- Zoubak S, Clay O, Bernardi G. 1996. The gene distribution of the human genome. *Gene* 174:95-102.

