

July 1, 2019

CURRICULUM VITAE

Name: Joanna Helen Fanos, Ph.D.

Institutions: Assistant Affiliate Faculty
Institute on Disability, College of Health and Human Services,
University of New Hampshire
10 West Edge Drive, Suite 101
Durham, New Hampshire 03824

Lecturer Emerita, Department of Psychology
San Jose State University, San Jose, California 95192

Place of Birth: Lake Ronkonkoma, New York

Education Barnard College, Columbia University, New York, New York
B.A., History of Art

Harvard University, Cambridge, Massachusetts (Summer)

British Institute, Florence, Italy (Spring Semester)

California State University, Hayward, Department of Psychology
(GPA 4.0)

University of California, San Francisco (Ph.D., 1987)
Human Development & Aging, Department of Psychiatry (GPA 4.0)

Institutional Appointments/Affiliations

1987-1992 Research Psychologist, Pediatric Pulmonology Center, Children's
Hospital Medical Center, Oakland, California

1991-1992 Research Psychologist, Children's Hospital Oakland Research Institute, &
Division of Medical Genetics

1992-1993 Visiting Scientist, Children's Hospital Research Institute,
Children's Hospital Medical Center, Oakland, California

1992- 2004 Senior Scientist, California Pacific Medical Center Research
Institute & Department of Pediatrics, Medicine & Psychiatry
San Francisco, California 94115

Jan-Dec 1995 **NIH**, Visiting Investigator, Medical Genetics Branch,
National Human Genome Research Institute, Bethesda, Maryland

2002-2009	Founder and Director, Sibling Center, Department of Pediatrics, California Pacific Medical Center, San Francisco, California
2004-2014	Faculty, Hood Center for Children & Families, Geisel School of Medicine at Dartmouth, Lebanon, NH
2004 -2014	Research Assistant Professor, Department of Pediatrics, Geisel School of Medicine at Dartmouth, Hanover, NH
2008 –2012	Visiting Faculty, Stanford Center for Biomedical Ethics, Stanford University, Stanford, CA
2012-2019	Affiliate Faculty, Stanford Center for Biomedical Ethics, Stanford University, Stanford, CA
2015-2017	Clinical Scientist, Children’s Hospital Oakland Research Institute/ University of California San Francisco Benioff Children’s Hospitals
2017- present	Assistant Affiliate Faculty, Institute on Disability College of Health and Human Services University of New Hampshire, Durham, New Hampshire

Teaching Appointments

1990 Fall	Lecturer, The Wright Institute, Berkeley, California
1991 Spring	Lecturer, University of California, Berkeley Extension Division Berkeley, California
1991 Spring	University of California, Santa Cruz Department of Psychology Santa Cruz, California
1991-2018	Lecturer, Department of Psychology, San Jose State University, San Jose, California
1999-2011	Lecturer, Department of Psychology, California State University East Bay, California
2003 June	Visiting Faculty, Geisel School of Medicine at Dartmouth, Department of Pediatrics, Lebanon, New Hampshire
2005-2006	Adjunct Assistant Professor, Department of Psychological and Brain Sciences, Dartmouth College
2009 and 2016	Lecturer, Department of Biology, California State University, Stanislaus, California. Qualitative Research Methods/Genetic Counseling Program

2019--present Lecturer Emerita, Department of Psychology, San Jose State University,
San Jose, CA

Honors and Awards

School of Science Award, California State University, Hayward, California (June, 1980).

Qualifying Exams for Advancement to Candidacy for the Ph.D., University of California, San Francisco, Human Development & Aging Program, Pass with Distinction

Langley Porter Psychiatric Institute-UCSF Alumni-Faculty Association Interdisciplinary Achievement Award (June 1987).

Herrick Hospital Research Award, Continuing Education Committee, Department of Psychiatry, Herrick Hospital, Berkeley, California (January 1989).

Research Award, Northern California Affiliate, Association for the Care of Children's Health (April 1989).

Who's Who in Science and Engineering 2006-2007.

San Jose State University Foundation, Award Incentive, June 1, 2013.

Outstanding Faculty, selected by the Student-Athlete Advisory Committee, San Jose State University, November, 2014.

Graduate Fellowships

National Institute on Aging Fellowship, University of California, San Francisco, 1980-81.

Graduate Opportunity Fellowship, University of California, San Francisco, 1982-83 (also awarded 1980-81).

Chancellor's Fellowship Award for Excellence in Research, The University of California, San Francisco, 1985-86.

Post-Doctoral Fellowship

"Impact on Pediatricians of Caring for Seriously Ill Children." Postdoctoral Fellowship, American Cancer Society, California Division, July 1991 through August 1992. Bertram Lubin, M.D., Children's Hospital Oakland Research Institute.

Grants and Funding

Mary Singleton Sigourney Award for Psychoanalytic Research, University of California, San Francisco, Department of Psychiatry, "Developmental Consequences of Early Sibling Loss to Cystic Fibrosis" (Joanna Fanos, Principal Investigator, Funding January 1984-87).

William T. Grant Foundation, Officer's Discretionary Award, Developmental Consequences of Early Sibling Loss to Cystic Fibrosis" (Joanna Fanos, Principal Investigator, Funding January 1984-86).

Children's Hospital Medical Foundation, Children's Hospital of Northern California, Oakland, California, January 1985.

Earle C. Anthony Travel Fund, The University of California, San Francisco, 1985.

East Bay Neonatology Foundation, Children's Hospital of Northern California, Oakland, California, October 1987 through June 1988.

San Jose State University Foundation, Department of Psychology, May 1992-May 1993, Impact on Pediatricians of Caring for Seriously Ill Children (Joanna Fanos, Principal Investigator).

NIH, Ethical, Legal, Social Implications Program, National Center for Human Genome Research. "Perception of Carrier Status by Cystic Fibrosis Siblings." Joanna Fanos, Principal Investigator, John Johnson, M.D., Co-Investigator, October 1991 through August 1995 (R01HG00639).

Scientist Support Award, "Perception of Carrier Status by Cystic Fibrosis Siblings." Joanna Fanos, PI. September 1 through December 31, 1994.

NIH, National Center for Human Genome Research, Visiting Investigator Award, Medical Genetics Branch (January 9, 1995 through January 8, 1996).

NIH, National Center for Human Genome Research, Medical Genetics Branch, Intramural, "Perception of Carrier Status in A-T Families" (January 9, 1996 through January 8, 1998, J Fanos PI).

San Jose State University Award, January -June 1997 (Perception of Carrier Status in A-T Families), J Fanos PI)

NIH, National Human Genome Research Institute, Genetics and Molecular Biology Branch, Intramural, "Perception of Carrier Status in Families with X-Linked Severe Combined Immune Deficiency" (January 1998 through August 8, 1999, J Fanos PI).

Pathogenesis (pharmaceutical company). Funds for transcription for pilot study on Impact of Transition Programs on Adults with Cystic Fibrosis.

The Impact of Having a Sibling or Parent with Familial Amyotrophic Lateral Sclerosis (ALS). (Joanna Fanos PI). Funded by the Forbes-Norris MDA/ALS Center, CPMC, Jan-June 2000. Specific Aims: 1) assess the psychosocial impact of having a parent who has ALS; 2) assess levels of understanding of medical aspects and genetics of ALS; and 3) explore interest in pre-symptomatic testing in Familial ALS.

California Pacific Medical Center Foundation. Aims are to identify and research leading Silicon Valley tech companies for targeted corporate funding programs. June 1, 2000 -Aug. 31, 2000.

Impact of Transition Programs on Adults with Cystic Fibrosis. Cystic Fibrosis Foundation, July 1, 2000-December 31, 2002. (Joanna Fanos, Principal Investigator). 80 adults with CF and their physicians were interviewed to obtain information in regard to the following Specific Aims: 1) to identify problems with transition at a clinic level; and 2) to identify problems with transition at a patient level; 3) to identify problems with transition at a physician level.

Impact on Siblings of Individuals Affected by Alpha-1 Antitrypsin Deficiency. Alpha-1 Foundation. (July 1, 2002 – December 31, 2003). Joanna Fanos, Ph.D., Principal Investigator.

Axcan Scandipharm. Funds for transcription of oral history of Harry Shwachman, M.D. April 1, 2003.

Hope in Patients with Amyotrophic Lateral Sclerosis (ALS). (Deborah Gelinas, MD, PI, JFanos Co-PI). Funded by the Forbes-Norris MDA/ALS Center, CPMC, July 1, 2003-September 9, 2004.

Prenatal Testing for Fragile-X (Tom Musci, M.D., PI, J Fanos, Co-PI). California Pacific Medical Center Foundation. July 1, 2003-June 30, 2005.

Dartmouth Medical School, Department of Pediatrics, funding from September 2004 through June 2007.

Long-term Impact of Surviving a Sibling in the Intensive Care Nursery. Hearst Foundation (J Fanos, PI, William Edwards, M.D., Co-PI). July 1, 2005-June 30, 2008.

New England Regional Genetics & Newborn Screening Collaborative (HRSA). John Moeschler, PI (Subcontract from University of New Hampshire). Long-term Follow-up. June 1, 2007-May 31, 2008.

Psychosocial Impact of Pre-symptomatic testing for FALS. Subcontract to Fanos from Department of Neurology, Emory University. July 1, 2008 - June 31, 2009.

New England Regional Genetics & Newborn Screening Collaborative (HRSA). John Moeschler PI, Monica McClain Co-PI (University of New Hampshire). Fanos serves as Consultant on ELSI-related issues. September 1, 2008-May 31, 2012.

New England Regional Genetics & Newborn Screening (HRSA), Priority II. Anne Comeau, PI (Subcontract from University of Massachusetts). Long-term Follow-up. June 1, 2007-May 31, 2012.

NIH-ELSI Conference funds provided by NIH P50 HG003389 to Stanford Center for Biomedical Ethics (April 13, 2011).

USMC Educator's Workshop in San Diego, CA (Camp Pendleton) July 18-22, 2011.
Travel/per diem funds provided by the United States Marine Corps.

A Regional Approach to Critical Congenital Heart Disease Newborn Screening Implementation. New England Regional Genetics & Newborn Screening Collaborative (HRSA contract to the University of New Hampshire, Institute on Disability, Monica McClain PI, subcontract to Fanos titled "Parental Response to Diagnosis of Critical Congenital Heart Disease via Newborn Screening". June 1, 2013-May 31, 2014.

American Thoracic Society Annual Meeting. Western Consortium of Cystic Fibrosis Caregivers. January 25-6, 2013. Carmel, CA. Travel funds provided by the Landon Foundation, Ventura, CA.

"Developmental Impact of Growing up with a Sibling with Critical Congenital Heart Disease". June 1, 2014-May 31, 2015. A Regional Approach to Critical Congenital Heart Disease Newborn Screening Implementation. New England Regional Genetics & Newborn Screening Collaborative (HRSA contract to the University of New Hampshire, Institute on Disability, Monica McClain PI, subcontract to Fanos.

Funded Clinical Program:

Sibling Center, California Pacific Medical Center, San Francisco, California. Director: Joanna Fanos, PhD; Medical Director David Tejada, M.D. A preventive clinical program in which families of children and adolescents diagnosed with serious illnesses are offered counseling and support. CPMC Foundation – July 1, 2002-June 30, 2009

Administrative Experience

Publicity Assistant, Committee for Arts and Lectures, University of California, Berkeley. February 1970-August 1971.

Auditorium-Theater Manager, University of California, Berkeley. 1971 through 1983.
Responsible for all front-of-house staff for all productions in all performing arts theaters on the Berkeley campus.

Local Committees

Faculty Executive Committee, University of California, San Francisco Human Development and Aging Program, Student Representative 1982-83.

Faculty Council, University of California, San Francisco, Department of Psychiatry, Graduate Academic Programs Representative, 1983-85.

Behavioral Study Group, Children's Hospital, Oakland, 1988.

Children's Hospital Medical Research Committee, Children's Hospital, Oakland, July 1988-1994.

Research Management Group, Medical Research Institute, California Pacific Medical Center, San Francisco, California, 1992.

Group with Interest in Genetics and Society, California Pacific Medical Center, San Francisco, California (1991-93).

Research Committee, MS Graduate Program in Human Genetics and Genetic Counseling, Stanford University, Palo Alto, CA (2009-present).

National and International Committees

Grant Reviewer, Medical/Scientific Advisory Committee, Canadian Cystic Fibrosis Foundation (November 1985).

NIH, Cystic Fibrosis Studies Consortium, Ethical, Legal and Social Implications Branch, Human Genome Program. October 1991-1993.

NIH Ethics/Genome Ad Hoc Study Section, July 23-24, 1992.

Psycho-Social Research Special Interests Group, The Hospitals for Sick Children, London, England (1992 through 1994)

NIH, Working Group, Informed Consent and Educational Materials for CF Carrier Screening Project (1998-1999).

New Hampshire Endowment for Health Theme Advisory Committee 2006.

Newborn Screening Advisory Committee, University of Utah, 2006-7

Co-Chair, Psychosocial Working Group, Long-term Follow-up of Newborn Screening in New England. 2007-2013.

National Transitions Workgroup, 2010.

Cystic Fibrosis Consortium, 2012.

Additional Research Experience

Participated in an intervention study on depression in a community population, conducted by San Francisco General Hospital, San Francisco, and the Department of Psychology, University of California, Berkeley.

Participated in assessing differences in entry pathways for Caucasian and Asian American patients at Langley Porter Institute, University of California, San Francisco.

Published Articles

1. Fanos, J. "A Life-Span 'Case History': Human Attachment", Unit 24, pp. 567-75. In Krech, Crutchfield, Livson, Wilson & Parducci, Elements of Psychology (4th ed.), New York: Alfred A. Knopf, 1982).
2. Fanos, J. "Siblings Need Your Love Too." In Inspirations, Pediatric Pulmonary Center, Children's Hospital, Oakland, Summer 1988.
3. Interview, "Psychosocial Problems Seen in Surviving Siblings of CF Patients." Cystic Fibrosis Currents, April 1989. McNeilab, Inc. SpringHouse, Pa.
4. Fanos, J. & Nickerson, B. "Long-Term Effects of Sibling Death during Adolescence." Special Issue, D. Balk, Ed., Death and Adolescent Bereavement, Journal of Adolescent Research (1991), 6, pp. 70-82.
5. Fanos, J. & Wiener, L. Tomorrow's Survivors: Siblings of HIV-Infected Children. Journal of Developmental and Behavioral Pediatrics. Special Supplement (15), pp. S43-48, June 1994.
6. Wertz, D., Fanos, J. & Reilly, P. Genetic Testing for Children and Adolescents: Who Decides? JAMA. (1994), 272 (11), pp. 875-881.
7. Wertz, D, Fanos, J. Genetic Testing for Children and Adolescents – Reply. JAMA, (1995), 273 (14): 1090.
8. Wertz, D., Fanos J & Reilly P. Testing Healthy Children and Adolescents: Recommendations for Avoiding Harm. The Genetic Resource (1994), 8 (2), pp. 16-20.
9. Fanos, J. & Johnson, J. Perception of Carrier Testing by Cystic Fibrosis Siblings. American Journal of Human Genetics, 57:431-438, 1995.
10. Fanos, J. & Johnson, J. Barriers to Carrier Testing for Adult Cystic Fibrosis Siblings: The Importance of Not Knowing. Journal of Medical Genetics, 59:85-91, 1995.
11. Fanos, J. Developmental Tasks of Childhood and Adolescence: Implications for Genetic Testing. American Journal of Medical Genetics, 71:22-28,1997.
12. Wilfond BS, Pelias MZ, Knoppers BM, Reilly PR, Wertz DC, Billings P, Fleisher LD, Rowley R, Strom C, Zinberg R, Boyd P, Clayton EW, Fanos J, Markel D, Schneider K. Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents. American Journal of Human Genetics 57 (5): 1233-1241. 1995.
13. Fanos, J & Gatti R. A Mark on the Arm: Myths of Carrier Status in Siblings of Individuals with Ataxia-Telangiectasia. American Journal of Medical Genetics 86:338-346. 1999.

14. Fanos, J. "The Missing Link in Linkage Analysis: The Well Sibling Revisited." Genetic Testing 3:273-278, 1999.
15. Fanos, J. & Mackintosh, M. "Never Again Joy without Sorrow": The Effect on the Parents of a Child with Ataxia-Telangiectasia. American Journal of Medical Genetics 87:413-420, 1999.
16. Fanos, J. "My Crooked Vision": The Well Sib Views Ataxia-Telangiectasia. American Journal of Medical Genetics 87:420-426, 1999.
17. Fanos JH, Puck JM. Family Pictures: The Impact of Growing Up with a Brother with X-Linked Severe Combined Immunodeficiency. American Journal of Medical Genetics 98:57-63, 2001.
18. Fanos, JH. Davis J, Puck JM. Sib Understanding of Genetics and Attitudes Toward Carrier Testing for X-Linked Severe Combined Immunodeficiency. American Journal of Medical Genetics 98:46-56, 2001.
19. Fanos JH, Gelinias D, Miller R: "You Have Shown Me My End: Attitudes Toward Presymptomatic Testing for Familial Amyotrophic Lateral Sclerosis". American Journal of Medical Genetics. Sep 1;129A(3):248-53, 2004.
20. Fanos JH, Strange C: "The Lion, the Witch and the Wardrobe": Impact on Sibs of Individuals with AAT Deficiency. American Journal of Medical Genetics 2004 Oct 15; 130A(3):251-257.
21. Fanos JH, Fahrner K, Jelveh M, King R, Tejada D: The Sibling Center: A pilot program for siblings of children and adolescents with a serious medical condition. Invited Commentary, Journal of Pediatrics 2005;146/6:831-5.
22. Fanos JH, Spangner KA, Musci TJ. Attitudes toward Prenatal Testing and Screening for Fragile X. Genetics in Medicine 2006;8:1-5.
23. Fanos, JH. "Coming through the Fog, Coming over the Moors: The Impact on Pediatric Oncologists of Caring for Seriously Ill Children. J Cancer Educ. 2007;22(2):119-23.
24. Fanos JH. "We Kept our Promises": An Autobiography of Harry Shwachman. American Journal of Medical Genetics, 2008:146A(3):284-93.
25. Fanos JH, Gelinias DF, Foster RS, Postone N, Miller RG. Hope in Palliative Care: From Narcissism to Self-Transcendence in Amyotrophic Lateral Sclerosis. Journal of Palliative Medicine, 2008:11(3), 470-75.
26. Fanos JH, Little GA, Edwards WH. Candles in the Snow: Ritual and Memory for Siblings of Infants who Died in the Intensive Care Nursery. Journal of Pediatrics. 2009; 154(6): 849-53

27. "Meaningful Memories." Dartmouth Medicine. A Magazine for Alumni and Friends of Dartmouth Medical School and Dartmouth Hitchcock Medical Center. Spring 2009. p. 62.
28. Fanos JH, Gronka S, Wu J, Stanislaw C, Andersen PM, Benatar M. Impact of Pre-Symptomatic Genetic Testing for Familial Amyotrophic Lateral Sclerosis. Genetics in Medicine 2011Apr;13(4):342-8.
29. Fanos JH. New "First Families": The Psychosocial Impact of New Genetic Technologies. Genetics in Medicine 2012 Feb;14(2), 189–190.
30. Gong P, Fanos JH, Kory L, Siskind CE, Hanson-Kahn AK. Impact of Huntington Disease Gene-Positive Status on Pre-Symptomatic Young Adults and Recommendations for Genetic Counselors. Journal of Genetic Counseling 2016 Dec;25(6):1188-1197. 22. Epub 2016 Apr 22.
31. Dondanville, D., Hanson-Kahn, A., Kavanaugh, M., Siskind, C., & Fanos, J. "This could be me": Exploring the Impact of Genetic Risk for Huntington's Disease Young Caregivers. Journal of Community Genetics. 2018 Nov 14. doi: 10.1007/s12687-018-0395-z. [Epub ahead of print]

Book

Fanos, J. Sibling Loss (1996). Lawrence Erlbaum & Associates, New Jersey.

Book Chapters

Fanos, J. & Johnson, J. (2001). Genetic Testing and Counseling. In: B. Lask, M. Bluebond-Langner & D. Angst, Psychosocial Aspects of Cystic Fibrosis. Arnold Publishing Company, London.

Fanos J, Wiener L, & Brennan T. Potential Impact of Genetic Information on Childhood Sibling Relationships. In: KP Tercyak, Handbook of Genomics and the Family. Issues in Clinical Child Psychology, 2010, Part 2, 141-161. Springer Publishing.

Published Abstracts

Fanos, J. "Developmental Consequences of Early Sibling Loss to Cystic Fibrosis" Cystic Fibrosis Club Abstracts, Vol. 26, May 1985, p. 175.

Fanos, J. "Developmental Consequences of Early Sibling Loss to Cystic Fibrosis." Abstract, Caregivers Papers, Medical/Scientific Conference, Cystic Fibrosis Foundation, May 1985, p. 67.

Fanos, J. & Johnson, J. "Still Living with Cystic Fibrosis: The Well Sibling Revisited." Sixth Annual North American Cystic Fibrosis Conference, Washington, D.C. October 1992. Pediatric Pulmonology, Supplement 8, September 1992, pp. 228-9. New York: Wiley-Liss.

Fanos, J. "Long-Term Effects of Sibling Loss to Cystic Fibrosis." Abstracts, Research Symposium 1992, California Pacific Medical Center.

Fanos, J. & Johnson, J. "Perception of Carrier Status by CF Siblings." Abstract, Western and Rocky Mountain Psychological Associations 73rd Annual Convention, April 22-25, 1993. New York: Macmillan.

Fanos, JH & Johnson, JP. "Barriers to Carrier Testing for CF Siblings". Supplement, The American Journal of Human Genetics, Abstract #51. (September 1993), Chicago: The University of Chicago Press.

Fanos, JH & Johnson, JP. "Carrier Testing of CF Siblings. Seventh Annual North American Cystic Fibrosis Conference, Dallas, Texas, October 1993. Pediatric Pulmonology, Supplement 9, September 1993, p. 232. New York: Wiley-Liss.

Fanos, JH. & Johnson, JP. "CF Carrier Status: The Importance of Not Knowing." Supplement, The American Journal of Human Genetics Abstract #1711 (September 1994). Chicago: The University of Chicago Press.

Children at Risk: To Test or Not to Test. National Society of Genetic Counselors, October 29, 1995, Minneapolis, MN. Conference Proceedings.

Fanos, JH. & Johnson, JP. Carrier Testing for Adult Cystic Fibrosis Siblings: The Importance of Not Knowing. NIH Consensus Development Conference, Genetic Testing for Cystic Fibrosis. April 14-16, 1997.

Fanos, JH, Gatti, RA, Lederman, HM, Tagle, DA, Winkelstein, JA. Beliefs of Carrier Status by Parents & Siblings of Individuals with A-T. American Journal of Human Genetics, 1997, Abstract # 1272.

Puck, JM, Fanos, JH, Davis, J. (1999). Sibling knowledge and attitudes toward carrier testing for X-linked severe combined immunodeficiency. American Journal of Human Genetics, Abstract #2187.

Fanos JH., Puck JM (1999). Long-term impact on siblings of growing up with a brother with X-linked severe combined immunodeficiency. American Journal of Human Genetics, Abstract # 56.

Genetic Testing of Children and Adolescents: Voices from Affected Families Fanos & Puck, poster). Celebration of a Decade of **ELSI** Research, Natcher Auditorium, January 17, 2001.

Living with Genetic Risk: The Well Sibling Revisited (Fanos, presentation). Celebration of a Decade of **ELSI** Research, Natcher Auditorium, January 17, 2001.

Fanos, JH (2001) Living with Genetic Risk: The Well Sibling Revisited. Journal of Law, Medicine & Ethics (Special Supplement) Vol. 29:2

Fanos JH, Gelinas DF, Miller RG "You have Shown Me My End": Attitudes toward Presymptomatic Testing for FALS. Amyotrophic Lateral Sclerosis & Other Motor Neuron Disorders Vol. 2 (Suppl 2) (September 2001) abstract p. 97.

Fanos, JH: Perception of Transition Programs by Adults with CF and their Pediatric and Adult Pulmonologists. Sixteenth Annual North American Cystic Fibrosis Conference, New Orleans, LA. Pediatric Pulmonology: Supplement 24, 2002, abstract # 481.

Gronka S, Walker M, Wu J, Stanislaw C, Fanos J, Atassi N, Jaffa M, Andersen P, Cudkowicz M, Benatar M. Telemedicine to Facilitate ALS Research. Platform presentation, Session 10B Holistic Care. 21st International Symposium on ALS/MND. Orlando, Fl. Dec 11-13 2010, p. 49.

Fanos National and International Presentations (109 to date)

Methodological Considerations in a Study on Sibling Loss, Seminar on Research Methods, Human Development & Aging Program, University of California, San Francisco, California (October 1984).

Developmental Consequences of Early Sibling Loss: Preliminary Findings. Cystic Fibrosis Clinic, Children's Hospital of Northern California, Oakland, California (December 1984).

Developmental Consequences of Early Sibling Loss to Cystic Fibrosis. Cystic Fibrosis Foundation Annual Medical/Scientific Meeting and 4th Annual Caregivers Conference, Anaheim, California (May 1985).

Long-term Effects of Early Sibling Loss. Resident Teaching Rounds, Children's Hospital of Northern California, Oakland, California (April 1988).

Long-term Effects of Sibling Loss to Cystic Fibrosis. Western Consortium of Cystic Fibrosis Caregivers, Irvine, California (May 1988).

Long-term Effects of Sibling Loss to Cystic Fibrosis. Cystic Fibrosis Center, Phoenix Children's Hospital, Phoenix, Arizona (June 1988).

Long-term Effects of Sibling Loss to Cystic Fibrosis. Tucson Cystic Fibrosis Center, St. Luke's Chest Clinic, Arizona Health Sciences Center, Tucson, Arizona (June 1988).

Long-term Effects of Early Sibling Loss. Psychosocial Program in Pediatric Oncology, The Dana-Farber Cancer Institute, Harvard Medical School, Boston, Massachusetts (June 1988).

Long-term Effects of Sibling Loss to Cystic Fibrosis. Cystic Fibrosis Program, Department of Pediatrics, Harvard Medical School, Children's Hospital, Boston, Massachusetts (August 1988).

Long-term Effects of Sibling Loss to Cystic Fibrosis. Cystic Fibrosis Center, The Floating Hospital for Infants and Children, New England Medical Center, Tufts University, Boston, Massachusetts (August 1988).

Long-term Effects of Sibling Loss. GRAND ROUNDS, Department of Psychiatry, Herrick Hospital, Berkeley, California (April 1989)

Developmental Consequences of Early Sibling Loss. Parent Support Group, Cystic Fibrosis Center, Phoenix Children's Hospital, Phoenix, Arizona (May 1989).

Developmental Consequences of Sibling Loss. GRAND ROUNDS, Pediatric Department, Maricopa Medical Center, Phoenix, Arizona (May 1989).

Survivor Guilt in CF Siblings. Western Consortium of Cystic Fibrosis Caregivers, Oakland, California (May 1989).

Long-term Effects of Sibling Loss. GRAND ROUNDS, Pediatric Department, The University of California, San Francisco School of Medicine, San Francisco, California (May 1989).

Developmental Consequences in Adulthood of Early Sibling Loss. Mills-Peninsula Hospital, Burlingame, California (October 1989).

Effects of Chronic Illness on Siblings. Support Group for Parents of Children with Asthma. Children's Hospital, Oakland (January 1990).

Long-Term Effects of Sibling Loss to Cystic Fibrosis. Division of Neonatology and Pediatric Pulmonology, Children's Hospital of Los Angeles, Los Angeles, California (March 1990).

Long-term Effects of Cystic Fibrosis on Siblings. Parent Support Group, Division of Neonatology and Pediatric Pulmonary, Children's Hospital of Los Angeles, Los Angeles, California (March 1990).

Impact of Loss on Siblings and Caregivers. Adolescent Medicine Unit, Children's Hospital of Los Angeles, Los Angeles, California (March 1990).

Developmental Consequences of Early Sibling Loss. Society of Pediatric Psychology, California/Arizona Regional Conference, San Diego, California (May 1990).

Developmental Consequences of Early Sibling Loss. The Children's Memorial Hospital, McGaw Medical Center, Northwestern University, Chicago, Illinois (October 1990).

Perceived Risk for Carrier Status among CF Siblings. Institute for the Study of Social Change, University of California, Berkeley (February 1991).

Developmental Consequences of Early Sibling Loss. John F. Kennedy University, Orinda, California (February 1991).

Chair, Symposium for Pediatric Psychology, Western Psychological Association, San Francisco, California (April 1991).

NIH, Cystic Fibrosis Studies Consortium, Washington, D.C., October 1991.

Survivor Guilt in Cystic Fibrosis Siblings. Western Psychological Association, San Francisco, California (April 1991).

NIH, Cystic Fibrosis Studies Consortium, Second Meeting, June 1992.

NIH - Department of Energy Meeting, Washington, D.C., September 1992.

The Forgotten Sibling. Impact of a Genetic Illness on the Other Members of the Family. Workshop, Counseling the Newly Diagnosed Patient and Family in the 1990's. Sixth Annual North American Cystic Fibrosis Conference, Washington, D.C. October 1992.

Still Living with CF: The Well Sibling Revisited. Symposium, Living with CF: Individual and Family Perspectives. Sixth Annual North American Cystic Fibrosis Conference, Washington, D.C., October 1992.

Impact on Siblings of HIV-Infected Children and Adolescents. Workshop on Priorities in Psychosocial Research, Pediatric Aids Foundation and National Cancer Institute, **NIH**, New York, New York (February 1993).

Chair, Health Psychology: Clinical and Professional Issues. Paper Session, Western Psychological Association, Phoenix, Arizona (April 1993).

Perception of Carrier Status by CF Siblings. Western Psychological Association, Phoenix, Arizona (April 1993).

NIH, Cystic Fibrosis Studies Consortium Meeting, September, 1993, Washington, D.C.

Barriers to Carrier Testing for CF Siblings. American Society of Human Genetics Meeting, October 1993, New Orleans, Louisiana.

Psychosocial Issues in Cystic Fibrosis. New Jersey Medical School, Newark, New Jersey (November 1993).

Cystic Fibrosis Siblings. Educational Seminar, Cystic Fibrosis Clinic, California Pacific Medical Center, San Francisco, California (December 1993).

Long-Term Effects of Cystic Fibrosis on Well Siblings. GRAND ROUNDS, Department of Psychiatry, California Pacific Medical Center, San Francisco, California (February 1994).

CF Carrier Status: The Importance of Not Knowing. American Society of Human Genetics Annual Meeting, October 1994, Montreal, Quebec.

Carrier Testing in CF-affected Families: The Importance of Not Knowing. Cystic Fibrosis Western Regional Caregivers Conference, March 24, 1995, Newport Beach, CA.

How Family Members React to Genetic Counseling Information. Workshop, CF Western Regional Caregivers Conference, March 24, 1995, Newport Beach, CA.

Carrier Testing in CF-affected Families: The Importance of Not Knowing. **NIH**, National Center for Human Genome Research, May 11, 1995.

Barriers to Cystic Fibrosis Carrier Testing for Adult Siblings (Poster). **NIH**, NCHGR Scientific Retreat, September 12, 1995, Arlie Conference Center, Arlie, Virginia.

A Study of Cystic Fibrosis Carrier Testing in Siblings. American Society of Human Genetics Workshop on Genetic Testing in Children and Adolescents: Ethical, Legal and Social Issues. October 25, 1995, Minneapolis, MN.

Children at Risk: To Test or Not To Test. National Society of Genetic Counselors, October 29, 1995, Minneapolis, MN.

NIH, NCHGR, Workshop on Genetic Testing and Children, September 18, 1996.

NIH, Consensus Development Conference on Genetic Testing for Cystic Fibrosis, Natcher Conference Center, Bethesda, Maryland, April 14-16, 1997.

NIH, Workshop on XSCID, Bethesda, Maryland, April 18-19, 1997.

Pediatric Grand Rounds, California Pacific Medical Center, San Francisco, California, June 6, 1997.

Beliefs of Carrier Status of Parents & Siblings of Individuals with A-T. A-T Research Center, Department of Pathology, University of California, Los Angeles, June 26, 1997.

NIH, Follow-up Workshop, CF Consensus Development Conference, Natcher Conference Center, Bethesda, MD, October 1997.

Beliefs of Carrier Status by Parents & Siblings of Individuals with A-T. American Society of Human Genetics (Poster) Baltimore, MD, October 1997.

Perception of Carrier Status in Families with Severe Combined Immunodeficiency Disorder. Immunologic Genetics Section, Genetics and Molecular and Biology Branch, National Human Genome Research Institute, **NIH**, Bethesda, MD December 10, 1998.

The Forgotten Sibling: Impact of Childhood Chronic Illness on the Family. Genetics Conference, Department of Pediatrics, Division of Medical Genetics, Lucile Packard Children's Health Services at Stanford Medical School, January 22, 1999.

Seminar, Genetic Counseling Program, University of California, Berkeley, California, April 26, 1999.

Attitudes toward Carrier Testing of Siblings of Individuals with X-Linked Severe Combined Immunodeficiency. Immunologic Genetics Section, Genetics and Molecular and Biology Branch, National Human Genome Research Institute, **NIH**, Bethesda, MD July 1999.

Puck, JM, Davis, J, and Fanos, J. Perception of Carrier Status and Carrier Testing of Siblings of Individuals with X-Linked Severe Combined Immunodeficiency. **NHGRI** Annual Scientific Retreat A31, Airlie, VA, 1999 (poster).

Sibling issues in CF-affected families. Cystic Fibrosis Research Inc., San Jose, CA, September 1999.

Interviewing Techniques. Qualitative Methods, National Society of Genetic Counselors, Oakland, CA, October 1999.

Long-term Impact of Growing up with a Brother with XSCID. American Society of Human Genetics, San Francisco, October 1999.

Understanding of Genetics by Siblings of individuals with XSCID [poster]. American Society of Human Genetics, San Francisco, California, October 1999

Genetic Testing of Children and Adolescents: Voices from Affected Families Fanos & Puck, poster). Celebration of a Decade of **ELSI** Research, Natcher Auditorium, January 17, 2001.

Living with Genetic Risk: The Well Sibling Revisited (Fanos, presentation). Celebration of a Decade of **ELSI** Research, **NIH** Natcher Auditorium, January 17, 2001.

Living with Genetic Risk: The Well Sibling Revisited. Bob McCurdy Lecturer, Mountain States Genetics Network, Steamboat Springs, Colorado, July 26, 2001.

Living with Genetic Risk: The Well Sibling Revisited. Dartmouth Medical School, September 13, 2001.

“You Have Shown Me My End: Attitudes toward Presymptomatic Testing for FALS. Fanos JH, Gelinas D, Miller R (poster). 12th International Symposium on ALS/MND Oakland Nov 18-20, 2001.

Pediatric Grand Rounds, California Pacific Medical Center, San Francisco, September 20, 2002.

Cystic Fibrosis Center, California Pacific Medical Center, San Francisco, Perception of Transition Programs by Adults with CF and their Pediatric and Adult Pulmonologists, November 22, 2002.

Department of Pediatrics, In-Service Meeting, California Pacific Medical Center, San Francisco, January 28, 2003. Recommendations from Adults with CF for transitioning from the Pediatric to the Adult Provider.

Cystic Fibrosis Center, Children's Hospital, Oakland, California. Perception of Transition Programs by Adults with CF and their Pediatric and Adult Pulmonologists. March 10, 2003.

The Impact of Childhood Chronic Illness on the Family. Genetic Epidemiology Branch, National Cancer Institute, **NIH**, April 17, 2003.

Sibling Center, Dartmouth Hitchcock Medical Center, Department of Pediatrics, July 2, 2003.

Getting Started on the Path to Funded Research: Qualitative Research Methods and Grant Writing Tips. Joanna Fanos & Alexandra Quittner. The 18th Annual North American Cystic Fibrosis Conference, St. Louis, MO., October 15, 2004.

The Sibling Center: A Pilot Program for Siblings of Children and Adolescents with a Serious Medical Condition. Joanna Fanos & Karen Vogel. The Eighteenth Annual North American Cystic Fibrosis Conference, St. Louis, MO., October 16, 2004.

Siblings of Ill Children: Someone Else for you to Worry About. Conference, Pediatric Residency Program, Dartmouth Medical School. March 14, 2005.

The Sibling Center: A Pilot Program for Siblings of Children and Adolescents with a Serious Medical Condition. **NIH, NHGRI**, Social and Behavioral Sciences Branch, Genetic Counseling Program. April 8, 2005.

Child Health & Development Course: Chronic Illness (with Mark Detzer). Long-term Effects of Growing up with a Sibling with a Serious Medical Condition. Dartmouth Medical School, May 23, 2005

Sibling Center Concept. Children's Hospital at Dartmouth Executive Committee. May 31, 2005.

Long-Term Effects on Siblings of Neonates in the Intensive Care Nursery. Plenary session: Family Support/Twins & Multiples (D/ Paul) and Siblings (J Fanos). The 19th Annual Graven Conference on the Physical and Developmental Environment of the High Risk Infant: Human Factors and Research in the NICU. Jan. 28, 2006. Orlando, Florida.

Family Support Coordinators Meeting, State Building, Concord, New Hampshire, February 21, 2006. Long term impact of growing up with a sibling with a chronic medical condition.

The Sibling Center: A Pilot Program for Siblings of Children with a Serious Medical Condition. Workshop (with K Fahrner, M Jelveh, & R King). California Psychological

Association, 60th Annual Convention. Creating a Better Psychology: Bridging Science, Practice and Community. Palace Hotel, San Francisco, CA March 26, 2006.

Stress and CF Families. Newborn Screening Committee Meeting, Mountain States Genetics Network, Denver, Colorado. July 2006.

Living with Genetic Risk: The Well Sibling Revisited. Clinical Genetics Seminar, Dartmouth Hitchcock Medical Center, Lebanon NH. August 3, 2006.

The Sibling Center: A Pilot Program for Siblings of Children with a Serious Medical Condition. Training Seminar for Psychology Interns, Department of Psychiatry, California Pacific Medical Center, San Francisco, August 31, 2006.

The Forgotten Child: The effects of childhood illness on the well sibling. Area Agency of Greater Nashua, Partners in Health. October 19, 2006.

The Forgotten Child: The effects of childhood illness on the well sibling. Dartmouth Hitchcock Concord. Concord, April 13, 2007.

Psychosocial Impact of newborn screening on children and families. 21st Annual Biologic Basis of Pediatric Practice Symposium. The Lodges, Deer Valley, Utah. September 16, 2007.

Candles in the Snow: Ritual and Memory for Siblings of Infants who Died in the Intensive Care Nursery. Joanna H. Fanos, George A. Little, William H. Edwards. Long-Term Effects on Siblings of Neonates in the Intensive Care Nursery. The 21st Annual Graven Conference on the Physical and Developmental Environment of the High Risk Infant. Feb 1, 2008. Clearwater Beach, Florida.

The Missing Link in Linkage Studies: The Well Sibling Revisited. Stanford Center for Biomedical Ethics, Stanford University, Palo Alto, CA May 14, 2008.

Siblings growing up in family with severe combined immune deficiency. SCID Family Conference, Wintergreen Resort, Wintergreen Virginia July 25-27, 2008.

The Sibling Center: A Pilot Program for Siblings of Children with a Serious Medical Condition. Training Seminar for Psychology Interns, Department of Psychiatry, California Pacific Medical Center, San Francisco, August 27, 2008.

Pre-symptomatic Testing for Amyotrophic Lateral Sclerosis. Symposium, Department of Neurology, Michigan State University. East Lansing, Michigan, September 26, 2008.

Impact of Pre-Symptomatic Testing for Familial Amyotrophic Lateral Sclerosis. Stanford Center for Biomedical Ethics, Stanford University, April 14, 2010.

Impact of Pre-Symptomatic Testing for Familial Amyotrophic Lateral Sclerosis, National Human Genome Research Institute, Medical Genetics Branch, **NIH**, May 5, 2010.

Exploring the ELSI Universe: 2011 Congress (NIH, NHGRI) 2011. Notes from the Front Lines: Psychosocial Follow-up of Newborn Screening. Chapel Hill, North Carolina, April 13, 2011. Session D-6, 10:30 a.m.

Pre-Symptomatic Testing for Familial Amyotrophic Lateral Sclerosis. Clinical Genetics Seminar, Dartmouth-Hitchcock Medical Center, Lebanon, NH, July 7, 2011.

Psychosocial Impact on Parents of a Critical Congenital Health Disease Diagnosis. A Regional Approach to CCHD Newborn Screening Implementation. Fanos J, Landon C, McClain M. Hilton Garden Inn, Portsmouth, NH, April 8, 2015.

“Welcome to Holland”: The Impact on Parents of a Diagnosis of CCHD. The New England Genetics Collaborative Annual Meeting. Fanos J, Landon C, McClain M. Hilton Garden Inn, Portsmouth, NH, April 10, 2015.

Grand Rounds: “A World of Uncertainty”: Impact on Parents of a Diagnosis of Critical Congenital Heart Disease (CCHD). Fanos J, Landon C, Bose A, McClain M. UCSF Benioff Children’s Hospital Oakland, CA, September 15, 2015.

Gong, P., Fanos, J., Korty, L, Siskind, C., and Hanson-Kahn, A. (2015, October). Impact of Huntington's Disease Gene Positive Status on the Lives of Presymptomatic Young Adults and Recommendations for Genetic Counselors. Poster presented at the National Society of Genetic Counselors 34th Annual Education Conference, Pittsburgh, PA.

Dondanville, D., Hanson-Kahn, A., Kavanaugh, M., Siskind, C., & Fanos, J. (2017, June) "This could be me": Exploring the impact of genetic risk for Huntington's disease young caregivers. Poster presented at the Northern California Coalition for Genetic Counselors Conference, San Mateo, CA.
(Stanford Genetic Counseling Program).

Nikam, R., Weil, J., Fanos, J., Sabbadini, M., Youngblom, J. (2017, May). Challenges faced by program administrators when training international genetic counseling students. (2017, May). Poster presented at the Northern California Genetics Exchange, Madera, CA.
(California State University Stanislaus Genetic Counseling Program)

Nikam, R., Weil, J., Fanos, J., Sabbadini, M., Youngblom, J. (2017, June). Challenges faced by program administrators when training international genetic counseling students. Poster presented at the Northern California Coalition of Genetic Counselors Conference, San Mateo, CA.
(California State University Stanislaus Genetic Counseling Program)

Dondanville, D., Hanson-Kahn, A., Kavanaugh, M., Siskind, C., & Fanos, J. (2017, September) "This could be me": Exploring the impact of genetic risk for Huntington's disease young caregivers. Poster presented at the National Society of Genetic Counselors 36th Annual Education Conference, Columbus, OH.
(Stanford Genetic Counseling Program).

Hernandez, M., Fanos, J., Youngblom, J., Howell, R., & Weisiger, K. (2017, November 17). Genetic counselors' experiences with non-paternity in the clinic. 4th Annual UC Davis Human Genomics Symposium, Sacramento, CA.
(California State University Stanislaus Genetic Counseling Program)

Hernandez, M., Fanos, J., Youngblom, J., Howell, R., & Weisiger, K. (2018, May 4). Genetic Counselors' Experiences with Incidental Findings of Non-paternity. **First place**, Health, Nutrition, and Clinical Sciences graduate category at the California State University Systemwide Research Competition (23 campuses).

Hernandez, M., Fanos, J., Youngblom, J., Howell, R., & Weisiger, K. (2018, November 15). Genetic counselors' experiences with misattributed paternity in the clinic. 37th Annual Conference of the National Society of Genetic Counselors. Atlanta, GA.

Fanos, J. The Sibling Center: A Pilot Program for Siblings of Children and Adolescents with a Serious Medical Condition. The Institute on Disability, University of New Hampshire, Durham, New Hampshire. April 19, 2019.

Madeline DeLoria, Kimberly Barr, MS, LCGC, Joanna Fanos, PhD, Jon Weil, PhD, John Turocy, MD, MJ, Janey Yongblom, PhD. Experiences of Women Receiving failed Non-Invasive Prenatal Test (NIPT) Results (2019, May 10). Northern California Genetics Exchange, Genomic Medicine, University of California, Davis, CA.

Schwan, K., Fanos, J., Youngblom, J., Waggoner, R., Weisiger, K., Kiahnmad, J. Newborn screening for X-linked adrenoleukodystrophy: Impact on families and recommendations for healthcare providers. Paper presented at the Northern California Genetics Exchange; 2019 May 10; Sacramento, CA. Platform Presentation.

Clinical Experience

Volunteer, Crisis Unit, Langley Porter Institute, University of California, San Francisco, 1978.

Seminars, San Francisco Psychoanalytic Institute, San Francisco, California, 1978-present

Clinical conferences, Austen Riggs Institute, Stockbridge, Massachusetts, summers of 1980 and 1981.

Clinical Conferences, The Anna Freud Centre, Hampstead, London England, Summer 1987.

Clinical conferences, The Tavistock Clinic, London, England, Summer 1987.

Clinical Internship, Grief Counseling Project, Suicide Prevention and Crisis Intervention Service of Alameda County, Berkeley, California, Fall 1990.

Teaching Experience

Life-span Developmental Psychology. Fall Semester, 1990, The Wright Institute, Berkeley, California (graduate seminar).

Psychological Trauma in Childhood and Adolescence. Spring Semester, 1991, University of California, Berkeley Extension Division

Social Psychology, Department of Psychology, San Jose State University, San Jose, California. Spring Semester 1991

Interpersonal Relationships, Psychology Board of Studies, University of California, Santa Cruz, Santa Cruz, California. Spring Quarter 1991.

Abnormal Psychology, Department of Psychology, San Jose State University, San Jose, California. Summer 1991.

Social Psychology, San Jose State University. Fall Semester 1991 (2 sections).

Social Psychology, San Jose State University. Spring Semester 1992.

Abnormal Psychology, San Jose State University. Summer 1992.

Social Psychology, San Jose State University. Fall Semester 1992.

Social Psychology, San Jose State University. Spring Semester 1993.

Social Psychology, San Jose State University. Summer 1993.

Abnormal Psychology, San Jose State University, Summer 1993.

Social Psychology, San Jose State University. Fall Semester 1993.

Social Psychology, San Jose State University. Spring Semester 1994.

Abnormal Psychology, San Jose State University. Summer 1994

Social Psychology, San Jose State University. Fall Semester 1994

Theory and Method of Counseling and Psychotherapy, Department of Psychology, San Jose State University. Fall Semester 1994.

NIH, National Center for Human Genome Research, Medical Genetics Branch, Seminar on Qualitative Methods, 10 weeks (May through July, 1995)

Social Psychology, San Jose State University. Spring Semester 1996

Personality Psychology, San Jose State University. Fall Semester 1996.

Social Psychology, San Jose State University. Fall Semester 1996

Social Psychology, San Jose State University. Spring Semester 1997.

Abnormal Psychology, San Jose State University, Fall Semester 1997.

Social Psychology, San Jose State University, Spring Semester 1998.

Human Development, San Jose State University, Spring 1998 (Grad clinical students)

Social Psychology, San Jose State University, Summer 1998

Social Psychology, San Jose State University, Fall 1998

Abnormal Psychology, California State University, Hayward, Winter 1999

Human Development, San Jose State University, Spring 1999 (Grad clinical students)

Social Psychology, San Jose State University, Spring 1999

Social Psychology, San Jose State University, Summer 1999

Social Psychology, San Jose State University, Fall 1999

Social Psychology, San Jose State University, Spring 2000

Personality Psychology, San Jose State University, Spring 2000

Human Development, San Jose State University, Spring 2000 (Graduate clinical students)

Social Psychology, San Jose State University, Fall 2000

Human Development, California State University, Hayward, Spring 2001

Social Psychology, San Jose State University, Summer 2001

Social Psychology, San Jose State University, Fall 2001
Social Psychology, San Jose State University, Spring 2002
Theory and Method of Counseling and Psychotherapy, Department of Psychology, San Jose State University. Summer 2002
Social Psychology, San Jose State University, Fall 2002
Social Psychology, San Jose State University, Spring 2003
Dartmouth Medical School, Dartmouth-Hitchcock Medical Center, Department of Pediatrics, Hood Center for Children & Families, Qualitative Research methods, June 2003.
Personality Psychology, San Jose State University, Fall 2003
Social Psychology, San Jose State University, Spring 2004
Interpersonal Relationships, Department of Psychological & Brain Sciences, Dartmouth College, Fall 2005.
Personality Psychology, California State University, East Bay (Hayward), Fall 2007.
Personality Psychology, California State University, East Bay (Hayward), Winter 2008.
Theory and Method of Counseling and Psychotherapy, Department of Psychology, San Jose State University. Spring 2008.
Child Psychology, Department of Psychology, San Jose State University, Spring 2008.
Social Psychology, San Jose State University, Fall 2008 Tues/Thursday 3-4:15 p.m.
Social Psychology, San Jose State University, Fall 2008 Tues eves 6-8:45 p.m.
Personality Psychology, California State University, East Bay (Hayward), Fall 2008.
Social Psychology, California State University, East Bay (Concord), Fall 2008.
Developmental Psychology, California State University, East Bay (Hayward), Winter 2009
Social Psychology, San Jose State University, Spring 2009
Theory and Method of Counseling and Psychotherapy, San Jose State University, Spring 2009
Psychological Trauma in Childhood and Adolescence, San Jose State University, Spring 2009
Developmental Psychology, California State University, East Bay (Hayward), Spring 2009
Developmental Psychology, California State University, East Bay (Concord), Summer 2009
Social Psychology, San Jose State University, Fall 2009
Psychological Trauma in Childhood and Adolescence, San Jose State University, Fall 2009
Developmental Psychology, California State University, East Bay (Hayward), Fall 2009
Research Methodology, Biol 5968, Genetic Counseling MS Program, CSU Stanislaus, Fall 2009
Psychological Trauma in Childhood and Adolescence, San Jose State University, Winter 2010
Psychological Trauma in Childhood and Adolescence, San Jose State University, Spring 2010 (2 sections)
Stress & Coping, California State University, East Bay (Hayward), Spring 2010
Personality Psychology, California State University, East Bay (Hayward), Spring 2010
Psychological Trauma in Childhood and Adolescence, San Jose State University, Fall 2010
Psychology 100W, San Jose State University, Fall 2010 (2 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Spring 2011 (3 sections)
Psychology 100W, San Jose State University, Spring 2011 (2 sections)
Psychology 100W, San Jose State University, Fall 2011 (2 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Fall 2011
Social Psychology, California State University, East Bay (Concord), Fall 2011.
Psychology 100W, San Jose State University, Spring 2012 (2 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Spring 2012 (2 sections)
Psychological Trauma in Childhood and Adolescence, San Jose State University, Summer 2012

Psychology 100W, San Jose State University, Fall 2012 (3 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Fall 2012
Psychology 100W, San Jose State University, Spring 2013 (2 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Spring 2013
(2 sections)
Psychological Trauma in Childhood and Adolescence, San Jose State University, Summer 2013
Psychology 100W, San Jose State University, Fall 2013 (2 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Fall 2013
(2 sections)
Psychology 100W, San Jose State University, Spring 2014 (3 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Spring 2014
(2 sections)
Psychological Trauma in Childhood and Adolescence, San Jose State University, Summer 2014
Psychology 100W, San Jose State University, Fall 2014 (3 sections).
Psychological Trauma in Childhood and Adolescence, San Jose State University, Fall 2014
Psychology 100W, San Jose State University, (2 sections). Spring 2015
Psychological Trauma in Childhood and Adolescence, San Jose State University (2 sections),
Spring 2015
Psychological Trauma in Childhood and Adolescence, San Jose State University, Summer 2015
Psychology 100W, San Jose State University, (2 sections). Fall 2015
Psychological Trauma in Childhood and Adolescence, San Jose State University (2 sections),
Fall 2015
Psychological Trauma in Childhood and Adolescence, San Jose State University (2 sections),
Spring 2016
Psychology 121-C, Advanced Research Methods, Clinical. San Jose State University, Spring
2016.
Psychological Trauma in Childhood and Adolescence, San Jose State University, Summer 2016
Psychology 100W, San Jose State University. Fall 2016
Psychological Trauma in Childhood and Adolescence, San Jose State University (2 sections),
Fall 2016
Psychology 121-C, Advanced Research Methods, Clinical. San Jose State University, Fall 2016.
Psychology 100W, San Jose State University. Spring 2017
Psychological Trauma in Childhood and Adolescence, San Jose State University (2 sections),
Spring 2017
Psychology 121-C, Advanced Research Methods, Clinical. San Jose State University, Spring
2017.
Psychological Trauma in Childhood and Adolescence, San Jose State University, Summer 2017
Psychological Trauma in Childhood and Adolescence, San Jose State University (2 sections),
Fall 2017
Psychology 121-C, Advanced Research Methods, Clinical. San Jose State University, Fall 2017.
Psychology 100W, San Jose State University. Fall 2017
Psychological Trauma in Childhood and Adolescence, San Jose State University (2 sections),
Spring 2018
Psychology 121-C, Advanced Research Methods, Clinical. San Jose State University, Spring
2018.
Psychology 100W, San Jose State University. Spring 2018.
Psychology 190, Psychological Trauma in Childhood and Adolescence, San Jose State
University, Summer 2018.

Additional Professional Activities

Reviewer, Pediatric Aids Foundation Student Intern Award Program

Proposal Reviewer: NIH/NHGRI Intramural Program

Invited Journal Reviewer: American Journal of Critical Care
American Journal of Medical Genetics
American Journal of Human Genetics
Community Genetics
Early Human Development
Genetics in Medicine
Pediatrics
Journal of the American Medical Association (JAMA)
Pediatric Blood and Cancer
Journal of Genetic Counseling
Journal of Palliative Medicine
Prenatal Diagnosis

Book Reviewer: 1) Lawrence Erlbaum & Associates, Mahwah, New Jersey
2) NIH Clinical Center, Brothers and Sisters Together: A Workbook for Siblings of Siblings who are Sick 2006.
3) The Empty Room: Surviving the loss of a brother or sister at any age. Elizabeth DeVita-Radburn. NY: Scribner 2004
4) Sixty-five Roses: A Sister's Memoir. Heather Summerhayes Cariou. McArthur & Co. 2006. Quoted on back cover.
5) Can I Still be Happy: A special book for siblings of children with chronic illness. Colleen Terry & Gordon Gohr. Gohr Creative Services. June 2006.

External Expert Reviewer: The Office of Education and Special Initiatives (OESI), NCI: "When Your Brother or Sister Has Cancer: A Guide for Teens. This publication aims to help teens cope, following the diagnosis of cancer in their brother or sister. NIH Publication No. 05-5733. September 2005

Medical Policy Committee, Blue Shield of California, Carrier Testing for Cystic Fibrosis. October 11, 2000. Reviewed policy recommendations and provided testimony.

Student Supervision

Co-Chair, Master's Thesis Committee, Perceptions of Carrier Status for CF in the General Population, San Jose State University, Department of Psychology (Maggi Mackintosh). Late 1990's.

Faculty Mentor, Schweitzer Program, Dartmouth Medical School. Spring and Fall Terms, 2005 (Daniel J. Kaser)

Faculty Mentor, Presidential Scholar Program, Dartmouth College, Fall 2005 & Winter 2006 Terms, Dartmouth College (Jessica L. Kelly).

Faculty Sponsor, Independent Study, Dartmouth College, Psychological & Brain Sciences Department, Winter & Spring Terms, 2006 (Reed Foster).

Faculty Mentor, Presidential Scholar Program, Dartmouth College, Summer & Fall Terms, 2006 Dartmouth College (Susan Matesanz).

Member, Doctoral dissertation committee, University of Utah (Rebecca Anderson), 2006-07

Faculty Mentor, Presidential Scholar Program, Dartmouth College, Summer Term, 2009 & Winter Term, 2010, Dartmouth College (Hayley Jansson).

Faculty Mentor, Dartmouth Medical School elective (Allisa Curda), Summer and Fall, 2010.

Member, Thesis MS Committee, Stanford University Genetic Counseling Program (Kyla Dunn 2010-2011).

Member, Thesis MS Committee, Stanford University Genetic Counseling Program (Anastasia Richardson 2013- 2014).

Member, Thesis MS Committee, Stanford University Genetic Counseling Program (Ping Gong 2014- 2015).

Impact of Huntington's Disease Gene Positive Status on the Lives of Presymptomatic Young Adults and Recommendations for Genetic Counselors.

Winner, the Jane Engelberg Memorial Fellowship (JEMF), 2016 Student Manuscript Award.

Member, Thesis MS Committee, Stanford University Genetic Counseling Program (Danielle Dondanville 2016-2017).

“This could be me”: Exploring the impact of genetic risk for Huntington's disease young caregivers.

Member, Thesis MS Committee, CSU Stanislaus Genetic Counseling Program (Rachita Nikam 2016-2017)

Challenges faced by program administrators when training international genetic counseling students.

Member, Thesis MS Committee, CSU Stanislaus Genetic Counseling Program (Mara Henandez 2017-2018)

Genetic counselors' experiences with non-paternity in the clinic

Winner, 1st Place first place in the Health, Nutrition, and Clinical Sciences - Graduate category at the California State University Systemwide Research Competition (23 campuses) in Sacramento (May 2018).

Member, Thesis MS Committee, CSU Stanislaus Genetic Counseling Program
Katharina Schwan, MPH, 2018-2019. Newborn screening for X-linked adrenoleukodystrophy: Impact on families and recommendations for healthcare providers.

Member, Thesis MS Committee, CSU Stanislaus Genetic Counseling Program
Madi deLoria, 2018-2019. Experiences of Women Receiving failed Non-Invasive Prenatal Test (NIPT) Results.

Undergraduate Student Research Assistants at SJSU, among others:

Cerda, Janely
Dadashadeh, Sharon
Garcia, Breanna
Garcia, Rebecca
Hull, Katherine
Mackintosh, Maggi
Puente, Katrina
Rueda, Ralph
Shefa, Yalda
Spangord, Kelly
Steffensen-Korges, Pam
Trembley, Zachary
Who, Carmen
Young, Brianna

Media Coverage (Selected)

Protected but Forgotten: Center offers recognition for siblings of ill children.
Profile, San Francisco Chronicle, Health & Fitness Section, E3, Sunday, April 27, 2003.

Program Focuses on Needs of Siblings of Sick Children. Newswise, Journal of Pediatrics. 6/05.
Program Focuses on Needs of Siblings of Sick Children. National Association of Children's Hospitals and Related Institutions. 6/05.

Program Focuses on Needs of Siblings of Sick Children. Dlife: Diabetes News. 6/05.

“Doctor’s Orders: Healthy Kids Need Care Too.” Time Magazine, June 27, 2005

New program focuses on the sometimes neglected needs of siblings.
news.bio-medicine.org/medicine

Siblings Australia Inc, Women’s and Children’s Hospital (listed as web resource 7/05)

“Overlooked Needs of the Sibling of the Sick Child.” She Knows: The Web for Women. 7/05

“The Forgotten Child.” Advance for Nurses, New England edition. September 12, 2005, p. 17.

News of the Day (Pat Fry, President & CEO, Sutter Health. *Time Magazine Recognizes Sutter Health Program*, 9/05)

California Pacific Medical Center Annual Report. "Benoit: 6-Month-Old baby Brother: Advanced surgery treated Benoit's congenital heart problems. The Well Sibling Center treated the side effects of having a sick baby brother." September 2006, pp. 4 & 20.

The Shadow Survivors. Caregivers' Corner, CURE, Fall 2006. A childhood cancer diagnosis often makes well siblings feel like they're battling the disease too. (Jo Cavallo)

Healthy Kids: From our family to yours. California Pacific Medical Center. Caring for Well Siblings of Ill Children. Winter 2007, p. 6

Beyond Medicine: A Community Publication of California Pacific Medical Center. "Benoit, 6-Month-Old baby Brother: Advanced surgery treated Benoit's congenital heart problems. The Well Sibling Center treated the side effects of having a sick baby brother." Winter 2007. Cover photo p. 1-2.

"Parents of young kids taking advantage of photo retouching services," March 22, 2011
http://www.mercurynews.com/bay-area-living-headlines/ci_17646868

The National Post. Siblings of deceased infants may need help coping. April 2, 2009

MedIndia.net. Death of a Child in Neonatal Intensive Care Unit Affects Siblings: Study. April 2, 2009 <http://www.medindia.net/news/Death-of-a-Child-in-Neonatal-Intensive-Care-Unit-Affects-Siblings-Study-49461-1.htm>

Psicozoo. Fratellini in lutto: parliamone April 4, 2009

Student athletes work on sport transition study. Spartan Daily Newspaper, February 19, 2014.