Curriculum Vitae

Frances Jean Rohr

Education

BS	Foods and Nutrition	University of Maine Orono	1976
MS	Nutrition	Tufts University	1981
Dietetic Internship		Frances Stern Nutrition Center Tufts- New England Medical Center	1981

Credentials

Registered Dietitian- Academy of Nutrition and Dietetics (#590514)
Licensed Dietitian – Commonwealth of Massachusetts (#1133)

Professional Experience

Clinical Nutrition Specialist, Children's Hospital, Boston MA 1981- 2019
Met Ed Co, Managing Partner, 2015- present

Consultant, American Academy of Pediatrics Committee on Nutrition 1983-1986
Consultant, National PKU News 2000-2004
Founder, Genetic Metabolic Dietitians International, 2005
Past President, Genetic Metabolic Dietitians International, 2009-2010
Board Member, Genetic Metabolic Dietitians International, 2005-2024
Co-Principal Investigator, Southeast Regional Genetic Network/GMDI Nutrition Guideline Project 2010-present
Nutrition Workgroup Co-Chair, International Guidelines on Long Chain Fatty Acid Oxidation, 2022-present

Books:

Bernstein L E, Rohr F, van Calcar (Eds). Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University, 2nd edition. Springer Publishing. 2022 ISBN 978-3- 319-14620-1

Published Articles:

Rohr F, Burton B, Dee A, Harding CO, Lilienstein J, Lindstrom K, MacLeod E, Rose S, Singh R, van Calcar S, Whitehall K. Evaluating change in diet with pegvaliase treatment in adults with phenylketonuria: Analysis of phase 3 clinical trial data. Mol Genet Metab. 2024 Mar;141(3):108122

Rohr F, Wessel A, Harding CO, Waisbren SE, Viau K, Kritzer A. Reinstitution of pegvaliase therapy during lactation. Mol Genet Metab Rep. 2022 Nov 17;33:10093

Viau K, Wessel A, Martell L, Sacharow S, **Rohr F**. Nutrition status of adults with phenylketonuria treated with pegvaliase. *Mol Genet Metab*. 2021;133(4):345-351

Rohr F, Kritzer A, Harding CO, Viau K, Levy H. Discontinuation of Pegvaliase therapy during maternal PKU pregnancy and postnatal breastfeeding: A case report. Mol Genet Metab Rep. 2020 Mar; 22: 100555.

Hansen J, Hollander S, Drilias N, Van Calcar S, **Rohr F**, Bernstein L. Simplified Diet for nutrition management of phenylketonuria: A survey of U.S. metabolic dietitians. *JIMD Rep*. 2020;53(1):83-89.

Bernstein L, Coughlin CR, Drumm M, Yannicelli S, **Rohr F**. Inconsistencies in the Nutrition Management of Glutaric Aciduria Type 1: An International Survey. *Nutrients*. 2020;12(10):3162. Published 2020 Oct 16. doi:10.3390/nu12103162

Rajabi F, **Rohr F,** Wessel A, Martell L, Dobrowolski SF, Guldberg P, Güttler F, Levy HL. Phenylalanine hydroxylase genotype-phenotype associations in the United States: A single center study.Mol Genet Metab. 2019 Dec;128(4):415-421.

Longo N, Dimmock D, Levy H, Viau K, Bausell H, Bilder DA, Burton B, Gross C, Northrup H, **Rohr F**, Sacharow S, Sanchez-Valle A, Stuy M, Thomas J, Vockley J, Zori R, Harding CO. Evidence- and consensus-based recommendations for the use of pegvaliase in adults with phenylketonuria. Genet Med. 2019 Aug;21(8):1851-1867.

Muntau AC, Adams DJ, Bélanger-Quintana A, Bushueva TV, Cerone R, Chien YH, Chiesa A, Coşkun T, de Las Heras J, Feillet F, Katz R, Lagler F, Piazzon F, **Rohr F**, van Spronsen FJ, Vargas P, Wilcox G, Bhattacharya K. International best practice for the evaluation of responsiveness to sapropterin dihydrochloride in patients with phenylketonuria.
Mol Genet Metab. 2019 May;127(1):1-11.

Jurecki E, Ueda K, Frazier D, **Rohr F,** Thompson A, Hussa C, Obernolte L, Reineking B, Roberts AM, Yannicelli S, Osara Y, Stembridge A, Splett P, Singh RH. Nutrition management guideline for propionic acidemia: An evidence- and consensus-based approach. Mol Genet Metab. 2019 Mar 4.

Burton BK, Jones KB, Cederbaum S, **Rohr F,** Waisbren S, Irwin DE, Kim G, Lilienstein J, Alvarez I, Jurecki E, Levy H. Prevalence of comorbid conditions among adult patients diagnosed with phenylketonuria. Mol Genet Metab. 2018 Nov;125(3):228-234.

Stroup BM, Ney DM, Murali SG, **Rohr F**, Gleason ST, van Calcar SC, Levy HL. Metabolomic Insights into the Nutritional Status of Adults and Adolescents with Phenylketonuria Consuming a Low-Phenylalanine Diet in Combination with Amino Acid and Glycomacropeptide Medical Foods. J Nutr Metab. 2017;2017:6859820.

Stroup BM, Nair N, Murali SG, Broniowska K, **Rohr F**, Levy HL, Ney DM. Metabolomic Markers of Essential Fatty Acids, Carnitine, and Cholesterol Metabolism in Adults and Adolescents with Phenylketonuria. J Nutr. 2018 Feb 1;148(2):194-201.

Bernstein L, Burns C, Sailer-Hammons M, Kurtz A, **Rohr F.** Multiclinic Observations on the Simplified Diet in PKU. J Nutr Metab.;2017:4083293

Stroup BM, Murali SG, Nair N, Sawin EA, **Rohr F**, Levy HL, Ney DM Dietary amino acid intakes associated with a low-phenylalanine diet combined with amino acid medical foods and

glycomacropeptide medical foods and neuropsychological outcomes in subjects with phenylketonuria..Data Brief. 2017 Jun 7;13:377-384.

O'Donnell-Luria AH, Lin AP, Merugumala SK, **Rohr F**, Waisbren SE, Lynch R, Tchekmedyian V, Goldberg AD, Bellinger A, McFaline-Figueroa JR, Simon T, Gershanik EF, Levy BD, Cohen DE, Samuels MA, Berry GT, Frank NY. Brain MRS glutamine as a biomarker to guide therapy of hyperammonemic coma.Mol Genet Metab. 2017 May;121(1):9-15.

Ney DM, Murali SG, Stroup BM, Nair N, Sawin EA, **Rohr F**, Levy HL. Metabolomic changes demonstrate reduced bioavailability of tyrosine and altered metabolism of tryptophan via the kynurenine pathway with ingestion of medical foods in phenylketonuria
Mol Genet Metab. 2017 Jun;121(2):96-103.

Jurecki ER, Cederbaum S, Kopesky J, Perry K, **Rohr F**, Sanchez-Valle A, Viau KS, Sheinin MY, Cohen-Pfeffer JL Adherence to clinic recommendations among patients with phenylketonuria in the United States.Mol Genet Metab. 2017 Mar;120(3):190-197.

Ney DM, Stroup BM, Clayton MK, Murali SG, Rice GM, **Rohr F,** Levy HL. Glycomacropeptide for nutritional management of phenylketonuria: a randomized, controlled, crossover trial.
Am J Clin Nutr. 2016 Aug;104(2):334-45.

Singh RH, Cunningham AC, Mofidi S, Douglas TD, Frazier DM, Hook DG, Jeffers L, McCune H, Moseley KD, Ogata B, Pendyal S, Skrabal J, Splett PL, Stembridge A, Wessel A, **Rohr F**. Updated, web-based nutrition management guideline for PKU: An evidence and consensus based approachMol Genet Metab. 2016 Jun;118(2):72-83.

Cunningham A, Frazier D, Marriage B, Mofidi S, Ogata B, **Rohr F**, Ueda K, Van Calcar S, Yannicelli S. Role of medical food in MMA. Genet Med. 2016 Apr;18(4):413-4

Osara Y, Coakley K, Aisthorpe A, Stembridge A, Quirk M, Splett PL, **Rohr F**, Singh RH. The role of evidence analysts in creating nutrition management guidelines for inherited metabolic disorders.J Eval Clin Pract. 2015 Dec;21(6):1235-43.

Rohr F, Wessel A, Brown M, Charette K, Levy HL. Adherence to tetrahydrobiopterin therapy in patients with phenylketonuria. Mol Genet Metab. 2015 Jan;114(1):25-8.

Frazier DM, Allgeier C, Homer C, Marriage BJ, Ogata B, Rohr F, Splett PL, Stembridge A, Singh RH. Nutrition management guideline for maple syrup urine disease: an evidence- and consensus-based approach. Mol Genet Metab. 2014 Jul;112(3):210-7

Van Calcar SC, Bernstein LE, Rohr FJ, Scaman CH, Yannicelli S, Berry GT A re-evaluation of life-long severe galactose restriction for the nutrition management of classic galactosemia. Mol Genet Metab. 2014 Jul;112(3):191-7.

Camp KM, Parisi MA, Acosta PB, Berry GT, Bilder DA, Blau N, Bodamer OA, Brosco JP, Brown CS, Burlina AB, Burton BK, Chang CS, Coates PM, Cunningham AC, Dobrowolski SF, Ferguson JH, Franklin TD, Frazier DM, Grange DK, Greene CL, Groft SC, Harding CO, Howell RR, Huntington KL,

Hyatt-Knorr HD, Jevaji IP, Levy HL, Lichter-Konecki U, Lindegren ML, Lloyd-Puryear MA, Matalon K, MacDonald A, McPheeters ML, Mitchell JJ, Mofidi S, Moseley KD, Mueller CM, Mulberg AE, Nerurkar LS, Ogata BN, Pariser AR, Prasad S, Pridjian G, Rasmussen SA, Reddy UM, **Rohr FJ**, Singh RH, Sirrs SM, Stremer SE, Tagle DA, Thompson SM, Urv TK, Utz JR, van Spronsen F, Vockley J, Waisbren SE, Weglicki LS, White DA, Whitley CB, Wilfond BS, Yannicelli S, Young JM. Phenylketonuria Scientific Review Conference: state of the science and future research needs.Mol Genet Metab. 2014 Jun;112(2):87-122.

Wessel AE, Mogensen KM, **Rohr F**, Erick M, Neilan EG, Chopra S, Levy HL, Gray KJ, Wilkins-Haug L, Berry GT. Management of a Woman With Maple Syrup Urine Disease During Pregnancy, Delivery, and Lactation. JPEN J Parenter Enteral Nutr. 2014 Mar 11

Van Calcar SC, Bernstein LE, **Rohr FJ**, Yannicelli S, Berry GT, Scaman CH. Galactose content of legumes, caseinates, and some hard cheeses: implications for diet treatment of classic galactosemia.J Agric Food Chem. 2014 Feb 12;62(6):1397-402

Singh RH, **Rohr F,** Frazier D, Cunningham A, Mofidi S, Ogata B, Splett PL, Moseley K, Huntington K, Acosta PB, Vockley J, Van Calcar SC. Recommendations for the nutrition management of phenylalanine hydroxylase deficiency.Genet Med. 2014 Feb;16(2):121-31.

Batey LA, Welt CK, **Rohr F,** Wessel A, Anastasoaie V, Feldman HA, Guo CY, Rubio-Gozalbo E, Berry G, Gordon CM. Skeletal health in adult patients with classic galactosemia. Osteoporos Int. 2012 Apr 19.

Singh RH, **Rohr F,** Splett PL. Bridging evidence and consensus methodology for inherited metabolic disorders: creating nutrition guidelines. J Eval Clin Pract. 2011 Dec 13.

Waisbren SE, Potter NL, Gordon CM, Green RC, Greenstein P, Gubbels CS, Rubio-Gozalbo E, Schomer D, Welt C, Anastasoaie V, D'Anna K, Gentile J, Guo CY, Hecht L, Jackson R, Jansma BM, Li Y, Lip V, Miller DT, Murray M, Power L, Quinn N**, Rohr F,** Shen Y, Skinder-Meredith A, Timmers I, Tunick R, Wessel A, Wu BL, Levy H, Elsas L, Berry GT.The adult galactosemic phenotype.J Inherit Metab Dis. 2012 Mar;35(2):279-86.

Thompson S, **Rohr FJ**. Alternative Therapies in Phenylketonuria. Topics in Clinical Nutrition. 24(4):322-332, October/December 2009

Camp K, **Rohr, FJ**. Advanced Practitioners and What They Do That Is Different: Roles in Genetics Topics in Clinical Nutrition. 24(3):219-230, July/September 2009.

Singh RH, Jurecki E, **Rohr F.** Recommendations for Personalized Dietary Adjustments Based on Patient Response to Tetrahydrobiopterin (BH4) in Phenylketonuria. Topics in Clinical Nutrition 2008; 23(2):149-157.

Rohr F, Munier A, Sullivan D, Bailey I, Gennaccaro M, Levy H, Brereton H, Gleason S, Goss B, Lesperance E, Moseley K, Singh R, Tonyes L, Vespa H, Waisbren S. Resource Mothers Study of Maternal Phenylketonuria: Preliminary Findings. J Inherit Metab Dis. 2004;27(2):145-55.

Brown AS, Fernhoff PM, Waisbren SE, Frazier DM, Singh R, **Rohr F**, Morris JM, Kenneson A, MacDonald P, Gwinn M, Honein M, Rasmussen SA. Barriers to successful dietary control among pregnant women with phenylketonuria. Genet Med. 2002 Mar-Apr;4(2):84-9.

Rohr FJ, Munier AW, Levy HL: Acceptability of a new modular protein substitute for the dietary treatment of phenylketonuria. J Inherit Metab Dis. 2001 Nov;24(6):623-30.

Acosta PB, Yannicelli S, Singh R, Elsas L, Kennedy MJ, Bernstein L, **Rohr F**, Trahms C, Koch R, Breck J. Intake and blood levels of fatty acids in treated patients with phenylketonuria. J Pediatr Gastroenterol Nutr. 2001 Sep;33(3):253-9.

Kalsner LR, **Rohr FJ,** Strauss KA, Korson MS, Levy HL: Tyrosine supplementation in phenylketonuria: diurnal blood tyrosine levels and presumptive brain influx of tyrosine and other large neutral amino acids. J Pediatr. 2001 Sep;139(3):421-7.

Acosta PB, Matalon K, Castiglioni L, **Rohr FJ**, Wenz E, Austin V, Azen C: Intake of major nutrients by women in the Maternal Phenylketonuria (MPKU) Study and effects on plasma phenylalanine concentrations. Am J Clin Nutr. 2001 Apr;73(4):792-6.

Duran GP, **Rohr FJ**, Slonim A, Guttler F, Levy HL: Necessity of complete intake of phenylalanine-free amino acid mixture for metabolic control of phenylketonuria.
J Am Diet Assoc. 1999 Dec; 99(12):1559-63.

Cox GF, Souri M, Aoyama T, Rockenmacher S, Varvogli L, **Rohr F**, Hashimoto T, Korson MS: Reversal of severe hypertrophic cardiomyopathy and excellent neuropsychologic outcome in very-long-chain acyl-coenzyme A dehydrogenase deficiency. J Pediatr. 1998 Aug;133(2):247-53.

Rohr FJ, Lobbregt D, Levy HL: Tyrosine supplementation in the treatment of maternal phenylketonuria. Am J Clin Nutr. 1998 Mar;67(3):473-6.

Waisbren SE, Rokni H, Bailey I, **Rohr F**, Brown T, Warner-Rogers J.: Social factors and the meaning of food in adherence to medical diets: results of a maternal phenylketonuria summer camp. J Inherit Metab Dis. 1997 Mar;20(1):21-7.

Michals K, Acosta PB, Austin V, Castiglioni L, **Rohr F,** Wenz E, Azen C: Nutrition and reproductive outcome in maternal phenylketonuria. Eur J Pediatr. 1996 Jul;155 Suppl 1:S165-8.

North KN, Korson MS, Gopal YR, **Rohr FJ**, Brazelton TB, Waisbren SE, Warman ML: Neonatal-onset propionic acidemia: neurologic and developmental profiles, and implications for management. J Pediatr. 1995 Jun;126(6):916-22.

Yannicelli S, **Rohr F**, Warman ML. Nutrition support for glutaric acidemia type I.
J Am Diet Assoc. 1994 Feb;94(2):183-8

Koch R, Wenz E, Azen C, Friedman EG, Levy H, **Rohr F**, Rouse B, Castiglioni L, Matalon R, Michals-Matalon K, et al: The effect of nutrient intake on pregnancy outcome in maternal phenylketonuria. Ann N Y Acad Sci. 1993 Mar 15;678:348-9.

Doherty LB, **Rohr FJ**, Levy HL: Detection of phenylketonuria in the very early newborn blood. Pediatrics. 1991 Feb;87(2):240-4.

Matalon R, Michals K, Azen C, Friedman EG, Koch R, Wenz E, Levy H, **Rohr F**, Rouse B, Castiglioni L, et al. Maternal PKU collaborative study: the effect of nutrient intake on pregnancy outcome. J Inherit Metab Dis. 1991;14(3):371-4.

Waisbren SE, Doherty LB, Bailey IV, **Rohr FJ**, Levy HL: The New England Maternal PKU Project: identification of at-risk women. Am J Public Health. 1988 Jul;78(7):789-92.

Rohr FJ, Doherty LB, Waisbren SE, Bailey IV, Ampola MG, Benacerraf B, Levy HL: New England Maternal PKU Project: prospective study of untreated and treated pregnancies and their outcomes. J Pediatr. 1987 Mar;110(3):391-8.

Caballero B, Mahon BE, **Rohr FJ**, Levy HL, Wurtman RJ: Plasma amino acid levels after single-dose aspartame consumption in phenylketonuria, mild hyperphenylalaninemia, and heterozygous state for phenylketonuria. J Pediatr. 1986 Oct;109(4):668-71