CURRICULUM VITAE

**Amy C. Cunningham, MS, RD, LDN**

**Metabolic Nutritionist/Clinical Faculty**

**(updated September 2024)**

# *Contact Information:*

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Hayward Genetics Center SL-31 Tulane University School of Medicine 1430 Tulane Ave New Orleans, LA 70112

 **Office phone:** 504-988-2989 **Fax:** 504-988-1763 **e-mail:** acunnin@tulane.edu

# *Education:*

BS innutrition and dietetics, Stephen F. Austin State University. Nacogdoches, Texas. 1966-1970. MS in Nutrition and Dietetics, minor in biochemistry. Louisiana State University. Baton Rouge, Louisiana. 1970-1972.

***Experience:***

* *Clinical Instructor, Metabolic Nutritionist,* Clinical Faculty,Tulane University School of Medicine, Hayward Genetics Center, Department of Pediatrics. (1997-present)
* Clinical responsibilities – coordination of dietary treatment for patients diagnosed with inherited metabolic disease. Includes: nutrition assessment, development of appropriate nutrition therapy, patient/family counseling, continued evaluation and follow-up of patient status and compliance, and coordination with Office of Public Health professionals for providing nutrition services. Also includes: clinical evaluation and diet therapy counseling for patients at bi-weekly genetics clinics, consultation and follow-up care for metabolic patients during hospital admissions (at diagnosis or subsequent acute care), documentation of all patient care.
* Follow-up care for newly diagnosed patients with positive newborn screen for metabolic disease. Intensive counseling for care-givers regarding disease characteristics, dietary management, and symptoms requiring acute care admission.
* Coordination of educational meetings for patients and families.
* Professional mentor for other nutritionists practicing metabolic patient care.
* Teaching responsibilities – medical school genetics course block and Hayward Genetics Center graduate students, dietetic interns at Tulane School of Public Health, and proctoring rotations of select MPH graduate students (1997-Present)
* Research responsibilities – Study Coordinator for:
* Expanded Access Program drug trial (Kuvan/BH4) in patients with PKU. Sponsored by BioMarin Pharmaceutical. (2007-2008)
* PKUDOS registry program for PKU patients receiving Kuvan. Sponsored by BioMarin Pharmaceutical. (2008-2021)
* Investigator Sponsored Trial – Evaluation of Behavior, Executive Function, Neurotransmitter Function and Genomic Expression in PKU “Nonresponders” to Kuvan (Sapropterin dihydrochloride) (2010-2014)
* BPM System study – patient use of a blood phenylalanine monitoring system - study closed by sponsor
* BioMarin registry studies – 3 studies to assess real world safety, efficacy, and experience with pegvaliase treatment for PKU (2023-ongoing)
* Program Coordinator: HRSA regional collaborative grant l Genetics Group (SERGG, Inc.) for “Enhanced Genetic Services and Newborn Screening Collaborative in Region 3 (Southeastern US). PI David Ledbetter, PhD, Emory University, Co-PI Jess Thoene, MD, Tulane University. (2004-2007)
* Contributor: HRSA grant for “Enhanced Genetic Services and Newborn Screening Collaborative in Region 3”. Co-PIs Rani Singh, RD, PhD, Emory University, Hans Andersson, MD, Tulane University. (2007-present)
* Hayward disaster preparedness team member: Post-Katrina development of disaster preparedness guidelines for restoring essential clinical and nutrition therapy services for metabolic disease patients during emergency situations.
* Coordination of data and contact information to maintain disaster preparedness among Hayward metabolic patient population.
* *Consultant,* Updating and development of education publications for patients and families with

metabolic disease, Ross Laboratories (2005-2007).

* *Consultant, BioMarin Pharmaceutical, Inc.* (2007-present).
	+ Nutrition Advisory Board: Kuvan use in treatment of patients with PKU. Includes practice consultation with developers and marketers of Kuvan, and nationwide presentations to clinical professional groups.
	+ Kuvan Dietitians Inquiry (KDI) board: Response to nationwide health professional queries regarding prescription and diet modification for PKU patients receiving Kuvan. Program closed by sponsor.
	+ Filmed interviews for media based patient and clinician information regarding use of Kuvan.
	+ Invited speaker, national and international: to educate clinicians and corporate staff on best practice management of Kuvan with dietary therapy for PKU patients
* *Consultant, Merck Serono* (2008-2015)
	+ European Advisory Board member: project to develop quality of life questionnaires specifically for individuals with PKU.
* *Consultant, Nutricia:* Development and presentation of webinar education for Clinicians providing

treatment for metabolic diseases.  *(2014-present).*

* *Consultant, Goldring Institute:* Development of clinical education modules for physician regarding

 treatment of metabolic diseases. (2016).

* *Teaching Faculty, Metabolic University:* Training program for metabolic dietitians, Children’s Hospital

 Colorado. (2015-2018)

* *Teaching Faculty electronic Genetic Nutrition Academy (eGNA):* virtual international training program for metabolic nutritionists, physicians, and medical residents, developed at Emory University and funded by a HRSA grant. (2020-present)
* *Adjunct Instructor,* Tulane School of Public Health and Tropical Medicine, Nutrition Section, Community Health Sciences Department. Course instructor for “Nutrition for Health Professionals”: a graduate level course teaching practical nutrition knowledge and application skills needed by public health professionals. (1997-2000)
* *Research Instructor,* Tulane School of Public Health and Tropical Medicine
* Coordinator: food service component of NCI funded research program promoting increased fruit and vegetable consumption in adolescent school-based populations (GIMME 5). Responsibilities included development and implementation of: data collection protocol, school cafeteria intervention program protocols, recipe testing program, training sessions for food service staff in participating schools, and liaison with school district food service administrators. Adjunct responsibilities included participation in additional grant submissions, coordination of research rotation for dietetic intern students, and presentations as guest lecturer and at professional meetings. (1993-1997)
* Nutritionist: multi-site NIH funded research program targeting child and adolescent

cardio-vascular health (CATCH). esponsibilities included: base-line and follow-up data collection (dietary recall, and school lunch menu / recipe analysis); implementation of intervention programs in elementary school lunch programs; and student cohort tracking. Adjunct responsibilities included training for educators and food service staff, and presentations at community and professional conferences. (1991-1997)

* *Affiliation,* Tulane Center for Cardiovascular Health. Contributions included assistance with Bogalousa Heart Study data collection, development and implementation of training institutes promoting cardiovascular health for lay and professional groups, televised educational programs, and presentation at professional conferences. (1991-1997).
* *Consultant Dietitian/Nutritionist*
* Long term care facilities. Responsibilities included: nutritional assessments, enteral feeding recommendations, care planning, medical record documentation, development of cycle menus, development of policies and procedures and diet manuals, in-service training, quality assurance; and monitoring of food production, sanitation, and licensing regulation compliance. (1983-2005)
* Cardiac clinic. Responsibilities included patient counseling, staff education, and nutrition counseling for drug study participants. (1990-2005)
* Orleans Parish Public Schools, Child Nutrition Services. Responsibilities included nutrient analysis of cycle menus and recommendations for modifications. (2000-2002)
* Louisiana State Department of Education, Child Nutrition Services. Responsibilities included nutrient analysis of state-wide school system menus, evaluation comparison to federal criteria, recommendations for appropriate modifications, and consultation with school system and state child nutrition services professionals. (1997-2000)
* Group homes. Responsibilities included clinical management and counseling for residents, quality control of food service and sanitation, and education for staff and residents. (1990-1994)
* Parish correctional system. Responsibilities include development of cycle menus, quality control evaluation of meal production and nutritional services, and serving as expert witness for related court cases. (1990-1997)
* *Clinical Dietitian/Nutritionist*
* Rehabilitation hospital. Responsibilities included clinical nutrition assessment, recommendations, care planning, and documentation; patient diet counseling; and quality assurance. (1989-1990)
* Louisiana State University, Department of Family Medicine. Responsibilities included development of patient education materials, diet counseling, teaching presentations for medical residents, and serving as professional resource for faculty. (1984-1986)
* *Research Associate,* Louisiana State University Medical School, Nutrition Section, Department of Medicine. Nutritionist for NIH funded research study studying the effect of vitamin A intake on lung cancer incidence. Responsibilities included screening study participants, in-depth diet history interviews, and nutritional analysis. (1980-1983)
* *Research Associate,* Louisiana State University (LSU), Department of Horticulture. Responsibilities included laboratory food science research. (1972-1973)
* *Research Assistant*, Louisiana State University, School of Home Economics. Responsibilities included development of nutrition laboratory research project, data collection and analysis, and thesis publication of results. (1970-1972)

***Professional Service Activities:***

* *Teaching:* Tulane University School of Public Health, Tulane University Dietetic Internship Program, Tulane Medical School genetics block, Tulane Genetics Program graduate students
* *Faculty:* Training program for metabolic dietitians, supported by HRSA Southeast Regional Collaborative
* Member: Advisory Committee: Tulane School of Public Health Dietetic Internship Program
* *Lecturer:* Professional and community speaking: education on metabolic disease, national/international.
* *Counselor:* Emory University Metabolic Camp for adolescent girls with metabolic disease
* *Reviewer:*: American Journal of Clinical Nutrition, Springer Journals, Nutrients, ADA NCP International Dietetics and Nutrition Terminology (IDNT) updated publication, Journal of Food and Nutritional Disorders
* *Editor:* Patient education booklets published through Emory University Department of Medical Genetics
* *Advocacy:* Liaison to state legislature for families of children with metabolic disuse
* *National:*
* Past Chair PNPG subspecialty group for inborn errors of metabolism
* Past-President and Founding Board Member of Genetic Metabolic Dietitians International (GMDI), a professional organization for metabolic dietitians.
* PKU Workgroup Chair: joint GMDI and Southeast Region Collaborative (SERC) project to develop evidence based nutrition guidelines for treatment of metabolic diseases, and update as appropriate.
* Invited member, nutrition therapy working group of the National Institutes of Health Phenylketonuria Workgroup
* Invited member, ACMG workgroup for development of treatment guidelines for PKU
* Member Advisory Committee for Tulane University School of Public Health and Tropical Medicine’s Dietetic Internship Program
* Coordinator of family advocacy group and liaison with state legislators to increase patient access to special foods and formulas integral to metabolic therapy.
* Nutrition counselor at Emory University Metabolic Camp for girls.
* Faculty for SERGG family liason group, including conference participation.
* Presentations at professional conferences, guest lectures in classroom settings, and medical school grand rounds.
* *Typical presentations specific to metabolic nutrition:*
* Disaster Preparedness: Ross Metabolic Conference, Genetic Metabolic Dietitian, International (GMDI) conference, Southern Regional Genetics Group (SERGG) conference, Adult PKU conference sponsored by Harvard Medical School, and local Louisiana dietetic associations. Presentations focused on professional experience of maintaining essential clinical nutrition care and providing emergency services for metabolic and other vulnerable patient populations during disaster situations
* “Genetics and the Public’s Health”, on-going mini-courses for public health professionals sponsored by Louisiana Department of Health and Hospitals.
* “Feeding Children with Special Dietary Needs”, teleconference for school food service professionals sponsored by Louisiana Department of Education.
* “Nutrition Management of Patients with MMA Cobalamin C Disease”, Abbott Metabolic Conferences
* “Developing Evidence-based Nutrition Guidelines for PKU”, ICIEM conference.
* “Advances in Management of PKU”, joint ACMG/SIMD conference. Presentation subsequently presented for taping to be used as web-based educational resource.
* “Newborn screening in Louisiana”, presentations to local Dietetic Associations reviewing expanded newborn screening, and follow-up care for patients with metabolic conditions.
* “Impact of the PKU Diet on Quality of Life”, presentation to Merck-Serono project planning group
* “Advances in PKU therapy” presented at BioMarin Advisory Board meetings.
* Workshops and presentations on development and use of Nutrition Management Guidelines for PKU at Abbott and GMDI conferences
* “Dietary Insufficiencies and the Burden of Treatment on Mental Health in PKU” presentation at BioMarin sponsored conference “The Brain and PKU”.
* “Guidelines for Treating PKU – updating the evidence and finding consensus” presentations at Abbott, SERN, and GMDI conferences
* “Pegvaliase in Practice: PKU Nutrition Management Guideline and Toolkit Update” workshop at

GMDI conference

* Emergency Preparedness presentations for professionals and patient groups in the metabolic community
* Moderator and presenter at SERN consumer group conference
* Reviewer American Journal of Clinical Nutrition, Springer Journals, ADA NCP International Dietetics and Nutrition Terminology (IDNT) updated publication, Journal of Food and Nutritional Disorders
* Representative for nutrition teaching sessions (2 year rotation) at SIMD sponsored North American Metabolic Academy.

***Professional Memberships and Credentials:***

* Registered Dietitian, Academy of Nutrition and Dietetics (AND). #R613287
* Licensed Dietitian/Nutritionist in the state of Louisiana. #287
* Past Chair of sub-specialty Inborn Errors of Metabolism Practice Group (2006).
* Past President (2010-2011) and Founding Board Member of Genetic Metabolic Dietitians, International (GMDI), a professional organization for metabolic dietitians (2005-present).
* Member and past Board Member of SERGG/SERN. Responsible for coordination of conference sessions focused on education and practice mentorship for metabolic nutritionists in the southeastern region.
* Past member of Society for Inherited Metabolic Disorders (SIMD).

***Publications and Research Presentations:***

Andersson HC., Narumanchi T, Cunningham A, Bowdish B., Thoene J. Genetic/metabolic health care delivery during and after hurricanes Katrina and Rita. Molecular Genetics and Metabolism, November, 2005.

Bettiol E, Marant C, Burlina A, Cunningham A, Gasteyger C, Benmedjahed K, Abetz L, Champigneul. International development of disease-specific questionnaires to assess the impact of phenylketonuria and its treatment on daily life: qualitative steps. Poster presentation at 2010 SSIEM conference.

Birardi V, Acquadro C, Cohen Pfeffer J, Cunningham A, Jurecki E. Development of the US English Version of the Phenylketonuria – Quality of Life (PKU-QOL) Questionnaires. Poster presentation at 2016 ACMG and SIMD conferences and submitted for publication.

Bosch A, Burlina A, Cunningham A, Bettiol E, Moreau-Stucker F, Benmedjahed K, Regnault A. Development and validation of disease-specific quality of life questionnaires for individuals with PKU and their parents. Poster presentation at 2014 SSIEM conference.

Bosch A, Burlina A, Cunningham A, Bettiol E, Moreau-Stucker F, Koledova E, Benmedjahed K, Regnault A. Assessment of the impact of phenylketonuria and its treatment on quality of life of patients and parents from seven European countries. Orphanet J Rare Dis. 2015 Jun 18;10:80.

Camp K, Parisi M, Cunningham A, et al. Phenylketonuria scientific review conference: state of the science and future research needs..Mol Genet Metab. 112 (2014) 87-122.

Cunningham A, Rohr F, Splett P, Mofidi S, Bausell H, Stembridge A, Kenneson A, Singh R. Nutrition management of PKU with pegvaliase therapy: update of the web-based PKU Nutrition Management Guideline recommendations. Orphanet J Rare Dis. 2023 Jun 22;18:155

Cunningham A, Frazier D, Marriage B, Mofidi S,Ogata B, Rohr F, Ueda K, VanCalcar S, Yannicelli S. Role of medical food in MMA, letter to editor Genetics and Metabolism (2016): 412-4.

Cunningham A, Bausell H, Brown M, Chapman M, DeFouw K, Ernst S, McClure J, McCune H, O’Steen D, Pender A, Skrabal J, Wessel A, Jurecki E, Shediac R, Prasad S, Gillis J, Cederbaum S. Recommendations for the use of sapropterin in phenylketonuria. Mol Genet Metab. 2012 Jul;106(3):269-76.

Cunningham A, Pridjian G, Andersson HC: PKU Treatment with tetrahydrobiopterin (sapropterin) during pregnancy. Poster presentation at American Society of Human Genetics conference 2008 and International Congress of Inborn Errors of Metabolism, 2009.

Cunningham A, Andersson H. Nutrition therapy for MMA Cobalamin C, a combined deficiency. Presentation at 2009 Advances in Management of Inherited Metabolic Disorders conference.

Cunningham A, Kuvan and PKU Teatment: dietary management from an American perspective, ICIEM conference, 2009.

Cunningham A, Dietary management guidelines for inborn errors of metabolism gathering evidence and building consensus, ICIEM conference, Nutrition Symposium, 2009.

Cunningham A,Techakittiroj C, Sharma R, Hooper P, Myers C, Dvorak C, Andersson H. Duarte galactosemia: newborn screening, biochemical phenotype, and clinical outcome on galactose-containing diet. Poster presentation at American Society of Human Genetics, 2006.

Jurecki E. Cunningham A, Birardi V, Gagol G, Acquadro C, Cohen-Pfeffer J. Development of the US English version of the phenylketonuria quality of life (PKU-QOL) questionnaire. Submitted for publication Orphanet Journal of Rare Diseases 2016. Also poster presentation at GMDI conference 2016.

Jurecki E, Cunningham A, Mahoney J, Tingley D, Chung S, James N, Cohen-Pfeffer J. Sapropterin dihydrochloride mixed with common foods and beverages. Top Clin Nutr. 2014 Oct;29(4):325-331.

Pridjian G., Cunningham A. Prevention of maternal PKU: what Is an adequate phenylalanine level for adolescent females and other women of childbearing age? Poster presentation at the American Society of Human Genetics, 2001.

Pridjian G., Cunningham A, Andersson H, Freeman A. Maternal PKU embryopathy: barriers to prevention and recent experience in the state of Louisiana. Presentation,Society for Maternal Fetal Medicine, 2004.

Regnault A, Burlina A, Cunningham A, Bettiol E, Moreau-Stucker F, Benmedjahed K, Bosch A. Development and psychometric validation of measures to assess the impact of phenylketonuria and its dietary treatment on patients’ and parents’ quality of life: the phenylketonuria quality of life (PKU-QOL) questionnaires. Orphanet J Rare Dis, 2015 May 10,10(1):59.

Singh RH, Rohr F, Frazier D, Cunningham A, Modfidi S, Ogata B, Splett P, Moseley K, Huntington K, Acosta P, Vockley,J, VanCalcar S. Recommendations for the nutrition management of phenylalanine hydroxylase defficiency. Genetics and Medicine 2013 Feb;16(2):121-31.

Singh RH, Cunningham A, Mofidi S, Rohr F, Frazier D, Hook D, Jeffers L, McCune H, Moseley K, Ogata B, Pendyal S, Skrabal J, Wessel A, Splett P, Stembridge A. An updated, web- based nutrition management guideline for PKU: evidence and consensus basedapproach. Mol Genet, 2016.

 Techakittiroj C., Cunningham A, Andersson H., Thoene J. High protein diet mimics hypertyrosinemia in newborn. Journal of Pediatrics 146(2): 281-282, February 2005.