

**Curriculum Vitae  
Laurie E Bernstein MS RD FADA FAND**

**Personal History**

Professor Emerita  
Children's Hospital Colorado  
School of Medicine – Department of Pediatrics  
Director, Inherited Metabolic Diseases Nutrition Department

Clinical Genetics and Metabolism, MS8400  
Education South 2, Building L28, Room 4109  
13123 E. 16th Avenue  
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**Education and Training**

INSTITUTION AND LOCATION	DEGREE	YEAR(s)	FIELD OF STUDY
State University College at Buffalo – Buffalo, New York	BS	1975-1979	Clinical Dietetics
New York University – New York City, New York	MS	1980-1984	Administrative Dietetics

**Academic Appointments and Professional Positions: University of Colorado Health Sciences Center**

Professional Research Assistant: 1991 – 1992  
Instructor: Full time faculty 1992 – 1996  
Sr. Instructor: Full time faculty 1996 – 2005 School of Medicine Dept. of Pediatrics  
Assistant Professor: 2005 – 2011 School of Medicine Dept. of Pediatrics  
Associate Professor: 2011 – 2017 School of Medicine Dept. of Pediatrics  
Professor of Pediatrics 2017- School of Medicine Dept. of Pediatrics  
Professor Emerita 2022- School of Medicine Dept. of Pediatrics

**Honors, Special Recognitions and Awards:**

American Dietetic Association – Pediatric Nutrition Practice Group  
Creative Nutrition Education Award 1997 Eat Right Stay Bright Publication Chapters I and II  
Creative Nutrition Education Award 2001 Eat Right Stay Bright Publication Chapters III and IV  
Creative Nutrition Education Award 2005 Network PKU Video  
Creative Nutrition Education Award 2008-Mile-High Low Protein Cooking  
Creative Nutrition Education Award 2013 Penny the Penguin has PKU  
Children's Choice Award for Innovation 2000 The Children's Hospital Denver, Colorado  
Health and Science Communication Association 2004 HeSCA Media Festivals Network PKU- Silver Award  
Dedicated Service Award of 25 years from University of Colorado Denver Anschutz School of Medicine  
Keynote Speaker University of Colorado/ Children's Hospital Dietetic Internship Graduation June 3, 2016  
GMDI Phyllis Acosta Lifetime Achievement Award 2024

**Memberships in Professional Organizations and Committee Positions:**

1979 – present Phi Upsilon Omicron – Home Economic Honor Society  
1984 – present American Dietetic Association  
1997 – 2004 ADA Pediatric Nutrition Practice Group Treasurer  
2000 – present Society of Inherited Metabolic Diseases  
2004 – 2016 Parents of Galactosemic Children- Professional Executive Board  
2005 – present Genetic Metabolic Dietitians International (GMDI) – Founding member  
2006 – 2016 Johnson and Wales University- Culinary Nutrition Advisory Council Board member

2007 – present University of Northern Colorado Dietetics Program: Member of the Advisory Board  
2008 – 2012 Genetic Metabolic Dietitians International (GMDI) – Committee Chair for Conference Program Development  
2008 – 2015 NPKUA – National PKU Alliance- Membership and Nominating Committee  
2011 – 2013 Development of the Dietetic Internship Program – Children’s Hospital Colorado  
2011 – 2017 Intern selection and conference planning committee – Children’s Hospital Colorado  
2014 – present Section of Genetics, Executive Steering Committee  
2015 – 2017 TRU Community Care - Hospice. Ethics Committee – Boulder/Lafayette Colorado  
2015 – 2017 National PKU News - Clinical expert- Board member  
2019 – 2023 How Much Phe Board Member

**Service Responsibilities:**

**Administrative Responsibilities:**

Director of the Inherited Metabolic Disease Nutrition Department  
Director of the Low Protein Food Store at Children’s Hospital Colorado  
Site preceptor for dietetic interns from Johnson and Wales University 2006-2016  
Site preceptor for undergraduate dietetic majors from University of Northern Colorado  
Site preceptor for undergraduate dietetic majors from Metro State University 2012-2017  
Site preceptor for dietetic interns from Children’s Hospital Colorado 2012 -2017

**Department:**

Director of Inherited Metabolic Disease Nutrition Clinic: 2006 – present  
The Courage Classic. The Gene Team Captain – Double Diamond level. Charitable donations raised for CHCO over the past 21years ~ \$1,400,000

**Hospital:**

Low Protein Food Store at Children’s Hospital Colorado – Director: 1995 - 2021  
Children’s Hospital Colorado Grassroots Network

**Licensure and Board Certification:**

RD #537146 –Registered Dietitian, 1982  
FADA – Fellow of the American Dietetic Association Clinical Nutrition, 1996  
FAND – Fellow of the Academy of Nutrition and Dietetics, 2013

**Inventions, Intellectual Property and Patents Held or Pending:**

First Named Inventor: **Laurie Bernstein**  
Patent Application Serial No. 60/947,324, filed on June 29, 2007 (Attorney Docket No. 66888-356457); entitled COMPOSITIONS AND METHODS FOR MAKING AND USING LOW PROTEIN MEAT FLAVORED COMPOSITIONS  
April 2010: Royalty Distribution Agreement for technology #CU1885H which is licensed with Taste Connections.  
Trademark: **L. Bernstein**: More Phe More Choices Think Healthy: serial number: 77918111  
Trademark: **L. Bernstein**: Network PKU: serial number: 85-204685  
Copyright: **L. Bernstein**: Setting up your Low Protein Kitchen Registration #: TX8-220-118

**Review and Referee Work:**

1. ADA Nutrition Care Manual, PKU Phenylalanine and Metabolic Syndrome, 2004
2. Manuscript review for the Journal of Inherited Metabolic Disease: “Nutrient intake in lysinuric protein intolerance.” March, 2007.
3. ADA Nutrition Care Manual, PKU Phenylalanine and Metabolic Syndrome, 2008

4. ADA Nutrition Care Manual, Galactosemia, 2009
5. ADA Review Team, Johnson and Wales: Denver, Culinary Nutrition Program accreditation. November, 2009.
6. Manuscript review for Topics of Clinical Nutrition: "History of Nutrition Management with Inherited Metabolic Disorders." August, 2009.
7. Expert research participant: "Advanced Practice Registered Dietitians Expert Consensus." UMDNJ, August-December, 2009
8. Genetic Metabolic Dietitian International, Propionic Acidemia Nutrition Guidelines, 2009- present
9. Strategic Partner on the "Experts Leading Education in Metabolic Inborn Errors Nutritional Therapy" steering committee. Nutricia Global, London, England February 26, 2010.
10. Manuscript review for spring 2010 issue of Metabolic Issue of Building Block for Life. Volume 33, Number 2 Pediatric Nutrition Practice Group.
11. Manuscript review for Journal of Inherited Metabolic Disease: "Low Lysine Diet in Glutaric Aciduria type -1: affect on anthropometric and biochemical follow-up parameters." March 2012.
12. Manuscript review for Journal of Molecular Genetics and Metabolism: "Main Issues in Micronutrient Supplementation in Phenylketonuria." July 2013.
13. Reviewer of materials for the International Dietetics and Nutrition Terminology (IDNT): Blood and urine tests to identify and monitor inborn errors of metabolism included in the standardized language of the Nutrition Care Process. Feb 2013.
14. Manuscript review for The Journal of Inherited Metabolic Disease. "The Nutritional Intake of Patients with Organic Acidemias on Enteral Tube Feeding: Can We Do Better? January 2015
15. Manuscript review for the Journal of Human Nutrition and Dietetics. "Overweight and obesity in children under phenylalanine restricted diet" March 2015
16. Manuscript review European Journal of Pediatrics. "Diagnostic and management practices for phenylketonuria in 19 countries of the South and Eastern European Region: survey results. EJPE-D-15-00636 July 2015
17. Manuscript review Nutrition Research Title: Normal Vitamin D levels and bone mineral density among children with inborn errors of metabolism (IEM) consuming medical food-based diets Nutrition Research Ms. Ref. No.: NR-15-484 September 2015
18. Manuscript review for Sports Nutrition and Therapy: PREVALANCE OF LOW ENERGY AVAILABILITY IN COLLEGIATE FEMALE RUNNERS AND IMPLEMENTATION OF NUTRITION EDUCATION INTERVENTION" October 2015
19. Southeast NBS and Genetics Collaborative: National Guidelines for PROP Nominal Group. February 26-27, 2016 Emory, Atlanta GA
20. Manuscript review for Phenylketonuria patients' and their parents' acceptance of the disease. Multi-center study. Manuscript Number QURE-D-16-00009R2 submitted to Quality of Life Research April 2016
21. Manuscript review: SciTech-16-546 for SciTechnol. "Phenylketonuria - The nutritional intervention in Portugal" April 2016
22. Manuscript review: Glycomacropeptide in children with PKU: does its phenylalanine content affect blood phenylalanine control? Manuscript ID: JHND-16-06-0219-OR submitted to Journal of Human Nutrition and Dietetics August 2016

#### **Invited Extramural Lectures, Presentations, and Visiting Professorships:**

##### **Regional:**

1. Network PKU: Conference organizer: October 15-17, 2004  
Children's Hospital Colorado in conjunction with Johnson and Wales Culinary School and Applied Nutrition: Denver, Colorado.
2. Network PKU- Conference organizer and presenter: October 27-29, 2006  
Children's Hospital Colorado in conjunction with Johnson and Wales Culinary School and Applied Nutrition: Denver, Colorado. Presenter: Traveling With PKU
3. The Pediatric Nutrition Symposium: Meeting Today's Challenges and Opportunities: April 25-27, 2007, Denver, Colorado. Presenter: Guidelines for Expanded Newborn Screening
4. Network PKU - Conference organizer and presenter: April 24-26, 2009  
Children's Hospital Colorado in conjunction with Johnson and Wales Culinary School and Applied Nutrition: Denver, Colorado. Presenter: More Phe, More Choices, Think Healthy.
5. Network PKU - Conference organizer and presenter: April 22-24, 2011  
Children's Hospital Colorado in conjunction with Johnson and Wales Culinary School and Applied Nutrition: Denver, Colorado. Presenter: More Phe, More Choices, Think Healthy.
6. Network PKU – Conference organizer: August 2-3, 2013  
Children's Hospital Colorado in conjunction with Le Cordon Bleu: Pasadena, California.
7. Network PKU – Conference organizer: October 11-12, 2013  
Children's Hospital Colorado in conjunction with Le Cordon Bleu: Boston, Massachusetts.
8. Children's Hospital Colorado 2<sup>nd</sup> Annual Updates in Clinical Nutrition Conference, November 2013, Aurora, Colorado. Presenter: Nutrition Education Tools Used in PKU: Clinician, Parent and Patient Perspectives.

**National:**

1. Eighth Ross Metabolic conference, March 2001, Costa Mesa, California. Workshop - Eat Right, Stay Bright: A long-term approach to PKU management.
2. Parents of Galactosemic Children, Inc. Today and Tomorrow: Encouragement and Hope - June 2001 Atlanta, Georgia. Dietary Management and Breakout Sessions on: The Education of Diet
3. Parents of Galactosemic Children Conference: Reno, Nevada July 11-12, 2003: Diet and Galactosemia
4. Genetic Metabolic Dietitians International – Atlanta, Georgia April 27-29, 2006  
"Introductory" Nutrition Workshop: Getting started in metabolics by moving from the textbook to table
5. The Parents of Galactosemic Children – Philadelphia, Pennsylvania July 27-29, 2006.  
Ask the Experts Panel: Dr. Berry, Dr. Elsas, Dr. Nelson, Dr. Potter, William Bell RPH MBA, Laurie Bernstein MS RD FADA  
The Galactosemic Diet –keynote speaker  
Diet Birth to Five Years, Elementary School and Adolescent – 3 separate workshops
6. Kuvan Product Training Meeting, November 27-28, 2007 Las Vegas, Nevada.  
The History, Etiology, and Management of PKU
7. PKU National Advisors Teleconference December 10, 2007
8. Vitaflo USA Sales Team Meeting, Jan 13-17, 2008 Key Largo, Florida  
1. Principles of Diet Management – Metabolic Disorders 2. Advice to Formula Reps, What RD's need from you 3. Fatty Acid Disorders
9. Kuvan Regional Advisory Board Meeting, February 21 – 22, 2008 San Diego, California.  
Co-Chair: Diet Management of PKU and Case Studies of Patients started on Kuvan
10. Genetic Metabolic Dietitians International; "Bridging Science to Clinical Practice" Emory Conference Center  
Atlanta, Georgia. April 24-26 2008 Workshop Treatment of Glutaric Acidemia Type 1
11. Dietitians National Advisory Board Meeting April 22, 2008 Atlanta, Georgia  
Co-Chair. Goal: Gain expert perspective on the current PKU market
12. Nourishing The Neonate Conference presented by Mead Johnson Nutritionals September 26-27, 2008 Irvine, California. Metabolic Nutrition 101 and PKU: History and Treatment

13. Educational Webinar: How to Maintain a Healthy Diet While “On Diet” February 24 and March 19, 2009. Nutricia North America.
14. Twelfth Abbot Nutrition Metabolic Conference, May 14 – 16, 2009 Austin, Texas. Nutritional Education for Inborn Error Metabolism.
15. National PKU Alliance Inaugural Conference January 15 – 17, 2010. Dallas, Texas. Be Informed: Make Healthy Choices.
16. Kuvan Clinician Speakers Bureau February 18 – 19, 2010 Scottsdale, Arizona. Living with PKU.
17. Genetic Metabolic Dietitians International; “Navigating Changes in Nutrition Management of Metabolic Disorders” April 15-17, 2010 Baltimore, Maryland: Galactosemia – and the Survey Says.
18. Educational Webinar: Eat Right Stay Bright, Chapter One and Two Update. June 15, 2010. Nutricia North America.
19. Educational Webinar: Eat Right Stay Bright, Chapter One and Two Update. June 15, 2010. Nutricia North America.
20. Parents of Galactosemic Children Conference: Bloomington, Minnesota. July 22-24, 2010: A Diet Overview, Diet: Birth – 5 Years Old, Diet: Elementary Age – 3 separate workshops
21. Educational Webinar: Eat Right Stay Bright Chapters 1-4 How to use this teaching tool: November 2010. Nutricia North America.
22. National Urea Cycle Disorders Foundation Family Conference: Denver, Colorado July 8-10, 2011. Nutrition 101 for Urea Cycle Disorders
23. National PKU Alliance 2012 Conference: Cherry Hill, New Jersey July 28, 2012. What Does Successful PKU Management Look Like?
24. National PKU Alliance 2012 Conference: Cherry Hill, New Jersey July 29, 2012. Participating in Clinical Trials
25. PKU Organization of Illinois, November 3, 2012. Keynote speaker: PKU: Past, Present, & Future; Maternal PKU.
26. FOD and OAA meeting 2016 Westminster, Colorado. July 8-9 OAA. Nutrition Education and Compliance FOD Facts about Fats 2 Cooking workshops Confirmed speaker
27. National PKU Alliance 2016 Conference: Scottsdale, Arizona July 28-30 3 presentations: 1. Tulips in Holland 2. Letting Go How and When to Teach Self-Management Skills 3. The Teenage Brain Confirmed speaker.

#### **International:**

1. SSIEM 36<sup>th</sup> Annual Symposium, August 1998 York, United Kingdom. Eat Right, Stay Bright: A Long Term Approach to PKU Management.
2. SSIEM 41<sup>st</sup> Annual Symposium Amsterdam, the Netherlands. August 31, 2004 – Sept. 3, 2004. Network PKU: Contemporary Issues Facing Those Managing a PKU Lifestyle.
3. SSIEM Annual Symposium, September 3, 2008. Lisbon, Portugal. GMDI panel.
4. DMIMD 2009 Dietary Management of Inherited Metabolic Disease, March 26-28 2009 London, England. 1. The role of BH4 in the management of PKU. 2. Three workshops on Postgraduate Training for Metabolic Dietitians.
5. Patient Power July 6, 2009 Strategies for A Tastier PKU Diet Webcast [www.patientpower.info](http://www.patientpower.info)
6. ICIEM 11<sup>th</sup> Annual Congress, August 31, 2009. San Diego, California. PKU and Management Issues. Moderator.
7. Current Strategies for the Management of patients with PKU September 12, 2009. CME Practical Clinical Issues: Patient case studies Denver, Colorado.
8. Current Strategies for the Management of patients with PKU February 5, 2010. CME Practical Clinical Issues: Patient case studies Denver, Colorado.
9. Patient Power May 4, 2010 Achieving Better Health While on the PKU Diet: What’s New? Webcast [www.patientpower.info](http://www.patientpower.info)
10. SSIEM Annual Symposium, August 31 – September 3, 2010, Istanbul, Turkey. Compliance: The Teenage Years and Beyond.

11. Eastern European Metabolic Academy Warsaw, Poland October 7-10 2010: Organic Acidurias - principles of dietary treatment and calculation; Urea Cycle Disorders - principles of dietary treatment and calculation; Education of patients with IEM
12. Metabolic Academy, Shanghai and Beijing, China June 21- 30 2011: Shanghai Xin Hua Hospital, June 24-25: Principles of Dietary Treatment in PKU and history of diet management; Protein requirements in Inborn Errors of metabolism; How to calculate a diet for an infant, 3-4 year old, and a young adult with PKU; Maternal PKU Nutritional Management; Clinical Pearls of PKU.
13. Beijing Maternal and Child Health Care Hospital, June 28 2011: Current Status of US Newborn Screening; Dietary treatment in PKU
14. Current Strategies for the Management of Patients with PKU. September 16, 2011. CME Practical Clinical Issues: Patient case studies. Denver, Colorado
15. SSIEM Annual Symposium, August 30 – September 2, 2011, Geneva, Switzerland. An International Survey on Educational Tools Used in PKU Management.
16. XXV ESPKU Conference, October 13-16, 2011. Warsaw, Poland. Speaker: Lifelong learning, Workshop presenter: Educating our patients with PKU.
17. 2<sup>nd</sup> Dietitians Workshop on PKU. March 22, 2012. Rome, Italy. Speaker: Education and Motivation of Patients: What works with PKU.
18. 4<sup>th</sup> European Phenylketonuria Group Symposium, March 23-24, 2012. Rome, Italy. Speaker: How to Improve Adherence to PKU Treatment.
19. University Hospital Zagreb, March 26-28, 2012. Zagreb, Croatia. Speaker: Diet Management of Maternal PKU; Long Term Compliance and the Role of Education with PKU.
20. Genetic Metabolic Dietitians International Conference, April 19-21, 2012. New Orleans, LA. Speaker: Long Term Dietary Compliance: Who holds the key?
21. Eastern European Metabolic Academy, October 8-9, 2012. Warsaw, Poland. Speaker: Galactosemia: The Nuts and Bolts; Galactosemia: The Grey Zone.
22. Canadian PKU & Allied Disorders Inc, April 27, 2013. Saskatoon, Canada. Speaker: PKU
23. DMIMD UK 2013, April 12 2013. London, England. Program Moderator.
24. Galactosemia Foundation International Conference, July 17 - 19, 2014 bi-annual conference. Orlando, FL. Speaker: Nutrition Management of Classical Galactosemia; Diet in Young Adults with Galactosemia; Diet in Teen with Galactosemia.
25. European Society for PKU and Related Disorders (ESPKU). October 23-26, 2014. Zagreb Croatia. Speaker: Nutrition Education Tools used in PKU: Clinician, parents & patients perspective; Diet management in maternal PKU; International survey results of educational tools that facilitate learning: Let's play.
26. University Hospital Zagreb. October 27, 2014. Zagreb, Croatia. Speaker: Careers in Dietetics; Anatomy of a Metabolic Diet.
27. Genetic Metabolic Dietitians International Conference April 27-29 2016. Speaker: PKU's Hidden Disabilities: Seeing the Forest and the Trees
28. Genetic Metabolic Dietitians International Conference April 27-29 2016 Moderator: Mitochondrial Diseases: Overview Current and Future Research
29. Mini Metabolics June 6-8 2016 Alvin Buckwald Development Center/Saskatoon Hospital, Saskatoon , Canada. The Anatomy of a Metabolic Diet : Nutrition Education and Long-term Compliance : Nuts and Bolts of PKU : Maternal PKU : Urea Cycle Disorders: MMA: GSD111: Galactosemia
30. Dietitian's Day September 29 2016 Montreal Children's Hospital Quebec, Canada Nutrition Education and Sustainability and The Simplified Diet.
31. Dietitian's Day September 30, 2016 SickKids Hospital, Toronto Canada Grand Rounds: Hidden Disabilities in PKU: General session: Nutrition Education: Simplified Diet:
32. XXX ESPKU Conference Nov 3-6, 2016 Dublin, Ireland. Speaker PKU and Hidden Disabilities, The Teenage Brain and Letting Go: Self-Management Skills
33. Glycomacropeptide: The Latest Clinical Research, Practical Application, and Learning Tool December 2, 2016 Webinar Cambrooke Therapeutics
34. Simplified PKU Diet December 5, 2016 Webinar Nutricia NA
35. XI Congress of the Latin American Society of Inborn Errors of Metabolism and Newborn Screening SLEIMPN May 12-15, 2019 - Hilton Hotel, Buenos Aires Speaker: Nutritional counseling strategies for

patients with Inborn errors of metabolism and Galactosemia: New recommendations. How strict should the diet be?

36. Lecturer: Glutaric Acidemia, PKU, Urea Cycle Disorders Argentina 2022

37. Workshop The Teenage Brain NPKUA 2024

## Teaching Record:

### University of Colorado Health Sciences Center

1995-2007: BMGN 6629 Human Inborn Errors of Metabolism, Masters in Genetic Counseling. Guest lecturer.

January 2016: GenC 6140 Masters in Genetic Counseling. Guest lecturer.

### University of Northern Colorado

1999-2017: FND 431: Metabolic Nutrition, Undergraduate dietetics and nutrition students. Guest lecturer each semester

1999-2016: Preceptor for FND 431: Undergraduate dietetics students spend 15 hours a semester with the IMD clinic. *2 sessions/ year; 35 students/ session.*

### Johnson and Wales

2006-2016: Site coordinator for internship: Undergraduate dietetic students spend 1 semester at the IMD clinic.

*2007: 1 student; 2008: 2 students; 2009: 2 students; 2010: Spring: 3 students Summer: 1 student*

2010 Graduate Student – Special project

2016 Spring semester- 1 student

### Metabolic University:

Presenter for every Metabolic University included a lecture on: Galactosemia: Glutaric Acidemia and Nutrition Education. There have also been presentations on PKU: General Nutrition Guidelines: and break out workshops on Diet Calculations

2007(August): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Fifteen RD attendees.

2008 (February): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Twenty RD and RN attendees.

2008 (September): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Nineteen RD, RN, CGC, and MD attendees.

2009 (February): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Twenty nine RD, RN, CGC, PhD, NP, and MD attendees.

2009 (September): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Twenty six RD, RN, CGC, PhD, NP, and MD attendees.

2010 (February): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Twenty six RD, RN, CGC, PhD, NP, and MD attendees. 15 international attendees.

2011 (September): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Twenty nine RD, RN, CGC, PhD, and NP attendees. 3 international attendees.

2012 (February): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Eighteen RD & RN attendees.

2012 (September): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Twenty one

RD, CGC and MD attendees.

2013 (February): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses, and physicians. Thirty nine RD, RN, CGC, NP, and MD attendees. 12 international attendees.

2013 (November): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Thirty-five RD, RN, CGC, and MD attendees. 12 international attendees.

2014 (April): Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Thirty RD, RN, CGC, and MD attendees.

2015 (October) Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Thirty-four RD, RN, CGC, and MD attendees

2016 (February) Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Thirty-four RD, RN, CGC, and MD attendees

2016 (September) Development, presenter, and program director. An international, training and continuing education program for dietitians, genetic counselors, nurses and physicians. Thirty-two RD, RN, CGC, and MD attendees

2017 (September and February) 2018 September and February 2019 September and February Metabolic University Presenter: Galactosemia: Glutaric Aciduria: Nutrition Education

2018-2024 Presenter

#### Metropolitan State College of Denver

2012- 2017: NUT 3740 Nutrition through the Lifecycle, The Anatomy of a Metabolic Diet.  
Guest lecturer.

### **Grant Support and Research Involvement**

#### **Grants:**

BioMarin Grant 1881 A revision of of the More Phe More Choices Simplified Books for Infancy, Early Childhood, Teenagers and Pregnancy \$19,891 October 2016

BioMarin: Grant 1438 - Simply More Phe, More Choices: The Foundation and Early Childhood Revisions \$6,000 March 2016

Metabolic University: Clinical Applications: an international training program for metabolic nutritionists, physicians, and nurses in conjunction with the textbook "Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University  
March 2017 Met Ed Co (\$5,000)  
September 2016 Met Ed Co (\$10,000)  
Feb 2016 Met Ed Co (\$15,000)

LoPro Network: December 4, 2015 An Interactive Low Protein Culinary Experience. The Culinary Institute of America, Napa California.  
PI: Laurie Bernstein  
Met Ed Co (\$10,000)

Metabolic University: Clinical Applications: an international training program for metabolic nutritionists, physicians, and nurses in conjunction with the textbook "Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University", October 2015. 2/1/15—12/31/15.  
PI: Laurie Bernstein  
BioMarin: (\$65,000)  
Hyperion: (\$25,000)  
Nutricia: (\$31,500) PI Bernstein-Nutricia-project number 2582552, speed type 63009831 (NNA-CO METABOL UNIV) AWD-153342



Network PKU. An Interactive Low Protein Culinary Experience

PI: Laurie Bernstein active industry

Boston Mass– Le Cordon Bleu 2014 - Stratamed (\$10,000)

Atlanta Georgia- Le Cordon Bleu 2014 – Stratamed (\$10,000)

Seattle Washington – Le Cordon Bleu, May1-2 2015 – Stratamed (\$15,000)

LoPro Network St. Helena California – Culinary Institute of America, Dec 4-5 2015 – MetEd (\$10,000)

Nutrition Management of Classical Galactosemia – Further food analysis and meeting educational needs (\$20,000)

PI: Sandy Van Calcar, Laurie Bernstein, Fran Rohr, Christine Scaman, Steven Yannicelli, Gerry Berry Meeting Educational Needs PI: Laurie Bernstein (\$9,000)

May 2013 - April 2014

Grant and contract # 630006424

Metabolic University “Lite”: an international training program for metabolic nutritionists, physicians, nurses and genetic counselors, condensed program.

PI: Laurie Bernstein

BioMarin (\$25,000)

October 2013 (closed)

PI: Laurie Bernstein

Hyperion (\$15,000)

October 2013 (closed)

PI: Laurie Bernstein

Nutricia North America (\$15,000)

October 2013 (closed)

Metabolic University: an international training program for metabolic nutritionists, physicians, nurses and genetic counselors.

Educational grant

PI: Laurie Bernstein

BioMarin (\$130,000)

February 2012, September 2012, February 2013, November 2013.

Distance Learning of Metabolic University

PI: Laurie Bernstein

BioMarin Pharmaceutical Inc. (\$75,000)

2013 - 2014 (closed)

PI: Laurie Bernstein

Nutricia North America (\$119,700)

Grant and contract #: 120489

February 2012, September 2012, February 2013, September 2013, February 2014.

Methylmalonic Acidemia and Propionic Acidemia: Making Healthy Choices module

Children’s Hospital of Orange County

Co-PI: Laurie Bernstein

Vitaflo USA (\$8500)

December 2012

Eat Right Stay Bright: Chapters 3 and 4

PI: Laurie Bernstein

Educational grant: Nutricia North America (\$10,000)

July 2010 – July 2011

Current Treatment Modalities for PKU Symposium. A half day CME symposium inactive industry

PI: Laurie Bernstein

Educational grant France Foundation (\$8,000)

September 2011

Network PKU. An Interactive Low Protein Culinary Experience

PI: Laurie Bernstein active industry

Applied Nutrition, Biomarin, Johnson and Wales – educational grant (\$8,000)

May 2011

Eat Right Stay Bright: Chapters 1 and 2

PI: Laurie Bernstein

Educational grant: Nutricia North America (\$7500)  
January 2010 – December 2010

Low Protein Bacon: licensed with Taste Connections.

PI: Laurie Bernstein  
Royalty Distribution Agreement #CU 1885H  
April 2010 – (open)

More Phe, More Choices Think Healthy. Two new educational modules and a revision of four modules.

PI: Laurie Bernstein  
Educational Grant: National PKU Alliance (\$14,500)  
January 2010 – December 2010

Expert On Call. National PKU Alliance educational website feature.

PI: Laurie Bernstein  
Educational Grant France Foundation  
January 2010 (open)

Current Treatment Modalities for PKU Symposium. A half day CME symposium

PI: Laurie Bernstein  
Educational grant France Foundation (\$8,000)  
February 2010 (closed)

Current Treatment Modalities for PKU Symposium. A half day CME symposium

PI: Laurie Bernstein  
Educational grant France Foundation (\$8,000)  
September 2009 (closed)

Metabolic University: an international weeklong training program for metabolic nutritionists, nurses, genetic counselors and physicians.

PI: Laurie Bernstein  
Nutricia North America 2009-2011 (\$45,000)  
Grant and contract # 2580864  
September 2009, February 2010, September 2010, February 2011 (closed)

More Phe, More Choices Think Healthy. A series of 3 educational modules

PI: Laurie Bernstein  
Educational grant from Biomarin (\$15,000)  
Feb 2009 -Feb 2010

Network PKU. An Interactive Low Protein Culinary Experience

PI: Laurie Bernstein  
Applied Nutrition, Biomarin, Johnson and Wales – educational grant (\$8,000)  
April 2009 (closed)

Kuvan Symposium. A half day symposium following Metabolic University

PI: Laurie Bernstein  
Educational grant from Biomarin (\$6,600)  
February 2009 (closed)

Kuvan Symposium. A half day symposium following Metabolic University

PI: Laurie Bernstein  
Educational grant from Biomarin (\$4,500)  
September 2008 (closed)

March of Dimes, Development of a Maternal PKU Resource

PI: Laurie Bernstein and Cindy Freehauf  
March of Dimes grant: 200802-067 (\$2,045)  
January 2008 – December 2008 (closed)

Educational grant for developing a Teaching FAOD Brochure

PI: Laurie Bernstein  
Vitaflor USA, (\$5,000)  
May 2008 (closed)

Educational grant for developing a Metabolics Teaching Aid

PI: Laurie Bernstein  
Vitaflor USA, (\$15,000)

November 2007 – April 2008 (closed)

Kuvan Symposium. A half day symposium following Metabolic University

PI: Laurie Bernstein

Educational grant from Biomarin (\$3,000)

February 2008 (closed)

Educational grant for developing a MCT recipe book

PI: Laurie Bernstein

Vitaflor USA, (\$7,500)

Metabolic University: an international week long training program for metabolic nutritionists, nurses, and genetic counselors

PI: Laurie Bernstein # 200712-127

Nutricia North America (\$53,000)

Grant and contract # 2580864

August 2007, February 2008, August 2008, February 2009 (closed)

Eat Right, Stay Bright Guide for Hyperphenylalaninemia, Chapter 1 and 2

Scientific Hospital Supplies, Inc. (\$15,000)

1998 – 1999 (closed)

Eat Right, Stay Bright Guide for Hyperphenylalaninemia, Chapter 3 and 4

Scientific Hospital Supplies, Inc. (\$25,000)

1996 – 1998 (closed)

#### **Research:**

- COMIRB 00-359 Biochemical and Clinical Investigations of Inborn Errors of Metabolism.  
Co-Investigator; PI: J. Thomas, MD  
No specific sponsor or funding  
2000-ongoing
- COMIRB 00-514 Investigation of Hyperphenylalaninemia and Phenylketonuria.  
Co-Investigator; PI: J. Thomas, MD  
No specific sponsor or funding  
2000-ongoing
- COMIRB 00-1121 Investigation of Growth Hormone Deficiency in Patients with Organic Acidemia and Short Stature.  
Co-Investigator; PI: J. Thomas, MD  
Sponsor: Eli Lilly Company (\$20,000)  
2001-2004
- COMIRB 01-396 The use of the MiniMed Continuous Glucose Monitoring System in the Management of Glycogen Storage Disease, Type 1A  
Co Investigator; PI: J. Thomas, MD  
Sponsor: MiniMed, Inc. (supplied CGMS, sensors and software)  
2001-2003
- COMIRB 02-095 Clinical Experience with 3360 C-3360 L in the Dietary Management of Amino Acid Inborn Errors of Metabolism.  
Co-Investigator; PI: J. Thomas, MD  
Sponsor: Mead Johnson and Company (\$2,850/patient + \$2,000 set up cost)  
2002-2004
- COMIRB 08-0654 Impact of Distance on Compliance and Metabolic Control in Phenylketonuria  
Co-Investigator; PI: J. Thomas, MD  
Sponsor: no specific funding or sponsor  
2008-2009
- COMIRB 07-0621 Sapropterin Expanded Access Program – SEAP 001  
Co-Investigator; PI: J. Thomas, MD  
Sponsor: BioMarin Pharmaceutical, Inc (no-funding)

	2007-2008 A-Phase3, Randomized Double Blind Crossover Active Controlled Study and the Efficacy and Safety of HPN-100- glyceryltri(4 phenyl butyrate) for the treatment of Adults with Urea Cycle Disorders Co-Investigator, PI: R. Gallagher MD Sponsor: Hyperion Therapeutics
COMIRB 07-1200	Longitudinal Study of Urea Cycle Disorders Co-Investigator; PI: R. Gallagher MD Sponsor: National Institutes of Health/DHHS-Rare Disease Clinical Research Network 2010-2014
COMIRB 08-0909	PKUDOS – Demographics, Outcomes, and Safety Registry Co-Investigator; PI: J. Thomas, MD Sponsor: BioMarin Pharmaceuticals, Inc 2008-2019
WIRB 20091782	A phase 2, Open-Label Dose-Finding Study to Evaluate the Safety, Efficacy, and Tolerability of Multiple Subcutaneous Doses of rAvPAL-PEG in Subjects with PKU (PAL-002) Co-Investigator; PI: J. Thomas, MD Sponsor: BioMarin Pharmaceutical, Inc 2009-2018
WIRB 20091756	Long-term Extension of a Phase 2, Open-Label Dose-Finding Study to Evaluate the Safety, Efficacy, and Tolerability of Multiple Subcutaneous Doses of rAvPAL-PEG in Subjects with PKU (PAL-003) Co-Investigator; PI: J. Thomas, MD Sponsor: BioMarin Pharmaceutical, Inc. 2009 – 2019

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### Peer-reviewed publications:

1. Gropper S, Chaung HC, **Bernstein L**, et al. Immune Status of Children with Phenylketonuria. *J Am Coll Nutr.* 1995; 14: 264-270.
2. PB. Acosta, S.Yannicelli, **L Bernstein**, et al. Nutrient Intake and Growth of Infants with Phenylketonuria Undergoing Therapy. *Journal of Pediatric Gastroenterology and Nutrition.* September 1998; 27:287-291
3. Acosta P, Yannicelli S, Arnold G, **Bernstein L**, et al. Plasma micronutrient concentrations in infants undergoing therapy for phenylketonuria. *Biol Trace Elem Res.* 1999; 67: 75-84
4. Acosta P.B., Yannicelli S. **Bernstein L**, et al. Protein Status of Infants with Phenylketonuria Undergoing Nutrition Management. *Journal of the American College of Nutrition.* 1999; 18(2): 102-107
5. Thomas J, **Bernstein L**, Greene CL, Koeller D. Apparent decreased caloric requirements in children with organic acidemias: A preliminary observation. *Journal of the American Dietetic Association.* September 2000;100(9): 1074-1076
6. Acosta P, Yannicelli S, **Bernstein L**, et al. Intake and Blood Levels of Fatty Acids in Treated Patients with Phenylketonuria. *Journal of Pediatric Gastroenterology and Nutrition.* September 2001; 33:253-259.
7. Acosta P, Yannicelli S, **Bernstein L**, et al. Nutrient Intakes and Physical Growth of Children with Phenylketonuria Undergoing Nutrition Therapy. *Journal of the American Dietetic Association.* August 2002;102(8):1167-1173
8. Al-Owain M, Freehauf C, **Bernstein L**, Kappy M, Thomas, J. Growth Hormone Deficiency Associated with Methylmalonic Acidemia. *Journal of Pediatric Endocrine and Metabolism.* 2003; 17(2): 239-243

9. Yannicelli S, Acosta P, Velazquez A, **Bernstein L**, et al. Improved Growth and Nutrition Status in Children with Methylmalonic or Propionic Acidemia Fed an Elemental Medical Food. *Molecular Genetics and Metabolism*. 2003; 80: 181-188
10. Acosta PB, Yannicelli S, **Bernstein L**, et al. Growth and Protein status of Children With a Urea Cycle Enzyme Defect Undergoing Nutrition Management. *Molecular Genetics and Metabolism*. 2003; 86(4): 448-455
11. Al-Owain M, Freehauf C, **Bernstein L**, Kappy M, Thomas J. Growth Hormone Deficiency Associated with Methylmalonic Acidemia. *Journal of Pediatric Endocrinology and Metabolism*. 2004; 17:239-243
12. Acosta PB, Yannicelli S, **Bernstein L**, et al. Nutritional therapy improves growth and protein status of children with a urea cycle enzyme defect. *Molecular Genetics and Metabolism*. 2005; 86: 448-455.
13. Freehauf CL, **Bernstein L**, Isacks K, Thomas J. Network Phenylketonuria Conference: An effective tool for facilitating adherence to diet therapy in individuals with phenylketonuria. *Topics in Clinical Nutrition*. 2009; 24(3); 341-346.
14. **Bernstein L E**, Freehauf, CL, Thomas, JA, Yannicelli S. Evaluation of the Efficacy and Effectiveness of Metabolic University: A didactic training program for the metabolic clinician. *Topics in Clinical Nutrition*. 2011; 26( 2); 158-164.
15. Freehauf CL, Van Hove JL, Gao D, **Bernstein L**, Thomas J. Impact of Geographic Access to Care on Compliance and Metabolic Control in Phenylketonuria (PKU). *Molecular Genetics and Metabolism*. 2012; 108: 13-17
16. Macdonald A, van Rijn M, Feillet F, Lund A M, **Bernstein L**, Bosch A M, Gizewska M, van Spronsen F J. Adherence issues in inherited metabolic disorders treated by low natural protein diets. *Annals of Nutrition and Metabolism*. 2012; 61(4); 289-295.
17. **Bernstein L E**, Helm, J R, Rocha J C, Almeida M F, Feillet F, Link R M, Gizewska M. (2013) Nutrition education tools used in PKU: clinician, parent and patient perspectives from three international surveys. *Journal of Human Nutrition and Dietetics*. doi 10.1111/jhn.12065
18. Van Calcar S C, **Bernstein L E**, Rohr F J, Yannicelli S, Berry G T, Scaman C H. Galactose content of legumes, caseinates and some hard cheeses: Implications for diet treatment for classical galactosemia. *Journal of Agricultural and Food Chemistry*. 2013
19. Van Calcar S C, **Bernstein L E**, Rohr F J, Scaman C H, Yannicelli S, Berry G T. A re-evaluation of life-long severe galactose restriction for the nutrition management of classic galactosemia. *Molecular Genetics and Metabolism*. 2014; 112:191-197.
20. Welling L, **Bernstein L E**, Berry GT International clinical guideline for Classical Galactosemia: managing diagnosis, treatment and follow-up. The European International Guidelines JIMD manuscript number, BOLI-D-16-00068R2
21. Welling L, **Bernstein L E**, Berry GT International clinical guideline for Classical Galactosemia: managing diagnosis, treatment and follow-up 29 September 2016 Springerlinks.com
22. **Bernstein L**, Burns C, Sailer-Hammons M, Kurtz A, Rohr F. Multiclinic Observations on the Simplified Diet in PKU. *J Nutr Metab*. 2017;2017:4083293.
23. A.Pinto, M.Alfadhel, R.Akroyd, Y.AtikAltnok, S.M. Bernabei, **L.Bernstein** et al International practices in the dietary management of fructose 1-6 diphosphatase deficiency Orphanet Journal of Rare Diseases (2018) 13:21
24. **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).
25. **Bernstein LE**, Burns C, Drumm M, Gaughan S, Sailer M, Baker PR, 2nd. Impact on Isoleucine and Valine Supplementation When Decreasing Use of Medical Food in the Nutritional Management of Methylmalonic Acidemia. *Nutrients*. 2020;12(2).
26. 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):83-9.
27. Júlio César Rocha, \*, Heather Bausell, Amaya Bélanger-Quintana, **Laurie Bernstein**, Hülya Gökmen-Özel, Alexandra Jung, Anita MacDonald, Fran Rohr, Esther van Dam, Margret Heddrich-Ellerbrok Development of a practical dietitian road map for the nutritional management of phenylketonuria (PKU) patients on pegvaliase. *Molecular Genetics and Metabolism Reports* May 2021

28. Kimberly A.Kripps<sup>ab</sup>Peter R.Baker<sup>ll</sup>a Janet A.Thomas<sup>a</sup>Heather E.Skillman <sup>c</sup>**LaurieBernstein**<sup>a</sup> SommerGaughan<sup>a</sup>CaseyBurns<sup>a</sup>Curtis R.Coughlin<sup>ll</sup>aShawn E.McCandless<sup>a</sup>Austin A.Larson<sup>a</sup> AainaKochar<sup>a</sup> Chelsey F.Stillman<sup>de</sup>Erica M.Wymore<sup>f</sup>Ellie G.Hendricks<sup>g</sup> MichaelWootner<sup>a</sup> Johan L.K.Van Hove<sup>a</sup> REVIEW: Practical strategies to maintain anabolism by intravenous nutritional management in children with inborn metabolic diseases Manuscript Number: MGM-D-20-00600R1 May 2021
29. **Bernstein LE**, Hansen J, Kogelmann C, Ellerbrok M, Gizewska M, Gaughan S, Rocha JC, Belanger A, Rohr F Normalizing Diet in Individuals with Phenylketonuria Treated with Pegvaliase: A Case Series and Patient Perspective Nutrition and Dietary Supplements September 7, 2021
30. Marjorie Dixon, Chloe Millington, **Laurie Bernstein**, Curtis R. Coughlin II, Morgan Drumm, Sommer Gaughan, Clara D. M. van Karnebeek, Annemiek M. J. van Wegberg Dietary management for pyridoxine-dependent epilepsy due to  $\alpha$ -amino adipic semialdehyde dehydrogenase deficiency, a follow-on from the international consortium guidelines. First published: 03 April 2024 <https://doi.org/10.1002/jmd2.12418>

### Non- peer reviewed articles:

1. **Bernstein L E**: Mead Johnson Nutritionals Rewrite of "Living with PKU." November 1999
2. **Bernstein L E**: "Organic Acidemia" Diet Management of Methylmalonic Acid and Propionic Acid. A Parent Guide. Mead Johnson. Caduceus Medical Publishers, Inc., January 2000; 4th Ed.
3. **Bernstein, L E**: Expanded Newborn Screening. Pediatric Nutrition A Building Block for Life. 2007; 30(3): 11-14.
4. Van Hove J, Meyers S, Vande Kerckhove K, Freehauf C, **Bernstein L E**. Acute nutrition management in the prevention of metabolic illness: a practical approach with glucose polymers. Molecular Genetics and Metabolism. 2009; 97: 1-3.

### Chapters:

1. Goodman SI and **Bernstein LE**. "Organic Acidemia" Dietary Management of Metabolic Disorders. Mead Johnson. Caduceus Medical Publishers, Inc., 3rd Edition 2005
2. **Bernstein, L**. PKU Chapter. In: Nahikian Nelms ML, Long S., Medical Nutrition Therapy: A Case Study Approach. Wadsworth Group/Thomson Learning. October 2001
3. Thomas J, Tsai A, **Bernstein LE**. Neonatal Nutrition. In: Thureen PJ. Nutrition Therapies for Inborn Errors of Metabolism 2nd Ed. Cambridge University Press. 2006; 544 – 568.
4. **Bernstein L E**. Nutrition Management of Glutaric Acidemia. In: Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University. Springer Publishing. 2015;pages 211-220
5. **Bernstein L E**, Helm J R. Nutrition Education. In: Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University. Springer Publishing. 2015; pages 25-33
6. **Bernstein L E**, Van Calcar S R. The Diet for Galactosemia. In: Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University. Springer Publishing. 2015; pages 285-293
7. **Bernstein L E**. Nutrition Management of Glutaric Acidemia. In: Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University. Springer Publishing. 2021
8. **Bernstein L E**, Van Calcar S R. The Diet for Galactosemia. In: Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University. Springer Publishing. 2021

### Books:

1. **Bernstein L E**, Rohr F, Helm J R (Eds). Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University. Springer Publishing. 2015 ISBN 978-3-319-14620-1
2. **Bernstein L E**, Rohr F, Van Calcar S R (Eds). Nutrition Management of Inherited Metabolic Diseases: Lessons from Metabolic University. 2<sup>nd</sup> Edition Springer Publishing. 2022

### Other Publications

1. Thomas J A, **Bernstein L E**, Greene CL, Koeller DM. Decreased Energy Requirements in Patients with Organic Acidemias. Proceedings of the International Metabolic Dieticians Groups at the Society of Inborn Errors of Metabolism, 1996.
2. **Bernstein L E**. It's About Making Healthy Food Choices, Too! National PKU News Spring/Summer 2010 volume 22 number1 pg 11-12
3. **Bernstein L**, Burns C, Myers S. Nutritional Management of Glutaric Acidemia: GMDI Newsletter September 2010 Fourth Issue pg 1, 9-12 .
4. Freehauf C, Scrivner S, Wright E, Kierstein J, Kucera C, Schneider K, Gaughan S, Burns C, **Bernstein L**, Thomas J, Wiman J, Sanchez M, Gonzales M. Needle Pokes are a Pain. What can I do to help?. Children's Hospital Colorado website for download as a handout. Spring 2012.
5. **Bernstein L E**, Helm J R. Penny the Penguin has PKU. Illustrated by Sarah Heyborne. 2012. ISBN: 978-1-4772-7226-8
6. **Bernstein, L E**, PKU Perspectives interview: Laurie Bernstein talks about the need for better education to improve adherence. PKE Academy Newsletter. Issue 4, 2013.
7. **Bernstein, L**, Groen, R. Setting Up Your Low Protein Kitchen. Illustrated by Rebecca Groen. 2013. ISBN: 978-1-4817-5249-7
8. Wright, E, Thomas J, **Bernstein L**, Helm, J. Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD) A Guide for Patents and Families. January 2014.
9. Helm J, **Bernstein L**, Kelly, K Max The Monkey Has MCADD January 2016 ISBN: 978-1-4958-0812-8

### Products of Scholarship:

1. Thomas J A, **Bernstein L E**, Freehauf C, Amos K. Network PKU (DVD) University of Colorado at Denver and Health Sciences Center, producer. Denver, Colorado: Applied Nutrition Corp; 1 DVD: sound, color; accompanied by 1 guide. 2003
2. Rocky Mountain Metabolic Camp, Camp Director; Camp activities based on the "Theory of Reasoned Action" and aimed at increasing dietary compliance. Laramie, Wyoming; 2003
3. **Bernstein L E**, Freehauf C, Greene C. Eat Right, Stay Bright: A Guide to Hyperphenylalaninemia, Chapters 1 and 2 Grant from SHS – 1997  
American Dietetic Association: Creative Nutrition Education Award 1997
4. **Bernstein L E**, Freehauf C, Greene C. Eat Right, Stay Bright: A Guide to Hyperphenylalaninemia, Chapters 3 and 4 Grant from SHS – 2001
5. **Bernstein L E**, Gilsdorf L. Mile High Low Protein Cookbook: With support from a donation from a family with a child with Homocystinuria. 2007: Creative Nutrition Education Award 2008
6. **Bernstein L E**, Rice C, Long C. Metabolic Teaching Aids: A Teaching Guide for Metabolic and Genetic Professionals. Supported by VitaFlo 2007 – 2008
7. **Bernstein L E**, Bloxsum K, Hanou C. MCT pro cal: A cookbook alternative for cooking with MCT. Supported by VitaFlo Feb 2008 – April 2008
8. **Bernstein L E**, Bloxsum K, Myers S. Kuvan – More PHE, More Choices, Think Healthy: Supported by Biomarin. April 2008 – June 2008
9. **Bernstein L E**. MCT ProCal and Lipistart – The role they play in dietary management: Supported by VitaFlo June 2008 – October 2008

10. **Bernstein L E**, Myers S, Burns C, Bloxsom K, Gessner J, Long C. More Phe, More Choices: Think Healthy! -2<sup>nd</sup> Edition. Supported by BioMarin. 2008
11. **Bernstein L E**, Burns C, Parker K. More Phe, More Choices: Think Healthy: Early Childhood. Supported by BioMarin. May 2009
12. **Bernstein L E**, Myers S, Sensecqua T. More Phe, More Choices: Think Healthy: Teenagers. Supported by BioMarin. May 2009
13. **Bernstein L E**, Myers S, Parker K, Tice K. More Phe, More Choices: Think Healthy: Adults. Supported by BioMarin  
Rocky Mountain Metabolic Camp for PKU, Camp Director: Laramie, Wyoming: 2007 – present.
14. **Bernstein L E**, Rice C, Long C. Metabolic Teaching Aids: A Teaching Guide for Metabolic and Genetic Professionals. Translated into Dutch and available online: [www.metabolicteachingaid.com](http://www.metabolicteachingaid.com) 2009.
15. **Bernstein L E**, Freehauf, C, Myers, S, Burns, J, Gessner. PKU & Pregnancy March of Dimes. February 2010
16. **Bernstein L E**, Myers S, Neuschwanger D. More Phe, More choices, Think Healthy PKU and Pregnancy Supported by NPKUA. May 2010
17. **Bernstein L E**, Myers S, Neuschwanger D. More Phe, More choices, Think Healthy: Keep it Simple. Supported by NPKUA. May 2010
18. **Bernstein L E**, Myers S, Burns C. More Phe, More Choices: Think Healthy! -3<sup>rd</sup> Edition. Supported by NPKUA. May 2010
19. **Bernstein L E**, Burns C, Baker L. Galactosemia: Making Healthy Choices. May 2010
20. **Bernstein L E**, Burns C, White C. Galactosemia: Making Healthy Choices: Cookbook. May 2010
21. **Bernstein L E**, Freehauf C L. Eat Right, Stay Bright: A Guide to Hyperphenylalaninemia, Chapters 1 and 2 (Revised) Grant from Nutricia North America. May 2010
22. **Bernstein L E**, Freehauf C L. Eat Right, Stay Bright: A Guide to Hyperphenylalaninemia, Chapters 3 and 4 (Revised) Grant from Nutricia North America. July 2010
23. **Bernstein L E**, Vockley J. Understanding Clinical Studies: Are they right for you? Clinical Trials Education Series- CD. Supported by Biomarin. March 2011
24. **Bernstein L E**, Gaughan S, Burns C, Helm J, Sowa M, Barr E, Ramos B, Ngo S, Zakeri N. MMA/PA More Choices: Think Healthy! Supported by Vitaflo. January 2012
25. **Bernstein L E**, Van Calcar S, Rohr F, Yannicelli S, Cusimano C. Galactosemia: The Diet. Grant from The Galactosemia Foundation. January 2011
26. **Bernstein L E**, Van Calcar S, Rohr F, Yannicelli S, Cusimano C. Galactosemia: For New Parents Grant from The Galactosemia Foundation. January 2011
27. **Bernstein L E**, Van Calcar S, Rohr F, Yannicelli S, Cusimano C. Galactosemia: School Age Children Grant from The Galactosemia Foundation. January 2011
28. **Bernstein L E**, Burns C, Tillisch B, Stegall M Simply More Phe, More Choices : The Foundation and Early Childhood Grant from BioMarin March 2016
29. **Bernstein L E**, Rohr F, McWhorter N, Stepping Up Your Protein July 2019

## Abstracts and Posters:

### Competitive:

1. **Bernstein L E**. Eat Right, Stay Bright Guide for Hyperphenylalaninemia. Abstract and Poster presentation, SSIEM Dietitians Meeting- Gothenburg, Sweden, September 1997.
2. Al-Owain M, Freehauf C, **Bernstein L E** et al. Growth Hormone Deficiency Associated with Methylmalonic Acidemia. Abstract publication, JIMD-VII International; Congress of Inborn Errors of Metabolism, Cambridge, UK .September 13 – 17, 2000.



3. **Bernstein L E**. Eat Right, Stay Bright: Guide for Hyperphenylalaninemia. Abstract and Poster presentation. American Dietetic Association Food and Nutrition Conference Exhibition, Denver, Colorado. October 19, 2000.
4. Freehauf C L, **Bernstein L E**, et al. A Theoretical Model for Treatment Compliance Assessment and Intervention in Adolescents with PKU. Abstract publication. SSIEM, Brisbane Australia. September 2003.
5. **Bernstein L E**, Freehauf C, Gessner J M, Thomas J A. Assessment of the Effectiveness of Metabolic University: An Entry Level Program for Registered Dietitians, Nurses and Genetic Counselors. Abstract and Poster presentation. Genetic Metabolic Dietitians International; "Bridging Science to Clinical Practice" Emory Conference Center, Atlanta, Georgia. April 24 – 26, 2008.
6. Hanou C E, Wilkinson L J, **Bernstein L E**. Treatment of Fatty Acid Oxidation Disorders, Glycogen Storage Disease Type 1a and Hypertriglyceridemia with new Medium Chain Triglycerides Sources. Abstract and Poster presentation. Genetic Metabolic Dietitians International; "Bridging Science to Clinical Practice" Emory Conference Center, Atlanta, Georgia. April 24 – 26, 2008.
7. **Bernstein L E**, Myers S, Thomas J A, Hanou C. Responsiveness of Kuvan in PKU patients during the Expanded Access program and Following FDA Approval. Abstract and Poster presentation. Annual Symposium SSIEM. Lisbon, Portugal. September 2 – 5, 2008.
8. **Bernstein L E**, Freehauf C, Gessner J M, Thomas J A. Assessment of the Effectiveness of Metabolic University: An Entry Level Program for Registered Dietitians, Nurses and Genetic Counselors. Abstract and Poster presentation. Annual Symposium SSIEM. Lisbon, Portugal. Sept 2 – 5, 2008.
9. Hanou C E, Wilkinson L J, **Bernstein L E**. Treatment of Fatty Acid Oxidation Disorders, Glycogen Storage Disease Type 1a and Hypertriglyceridemia with new Medium Chain Triglycerides Sources. Abstract and Poster presentation. Annual Symposium SSIEM. Lisbon, Portugal Sept 2 – 5, 2008.
10. **Bernstein L E**, Freehauf C, Gessner J M, Thomas J A. Assessment of the Effectiveness of Metabolic University: An Entry Level Program for Registered Dietitians, Nurses and Genetic Counselors. Abstract and Poster presentation. 27<sup>th</sup> Annual Educational Conference for the National Society of Genetic Counselors. Los Angeles, CA. October 23-28, 2008.
11. Wright E, **Bernstein L E**, Long C, Rice C. Development of Visual Counseling Aids for Inherited Metabolic Disorders: Newborn Screening through Diagnosis. Abstract and Poster presentation. ASHG 58<sup>th</sup> Annual Meeting. Philadelphia, PA. November 11 – 15, 2008.
12. **Bernstein L E**, Thomas J A. Responsiveness of Kuvan, a new treatment modality for the management of PKU. Abstract and Poster presentation. ADA 2009 Food and Nutrition Conference and Expo. Denver, CO. October 17 – 20, 2009
13. **Bernstein L E**, Myers S, Freehauf C, Burns C, Thomas J A. Development of Visual Counseling Aids for Inherited Metabolic Disorders: Newborn Screening through Diagnosis. Abstract and Poster presentation. ADA 2009 Food and Nutrition Conference and Expo. Denver, CO. October 17 – 20, 2009.
14. Wright E, **Bernstein L E**, Long C, Rice C. Impact of Geographic Access to Care on Compliance and Metabolic Control in Phenylketonuria (PKU). Abstract and Poster presentation. ACMG. Albuquerque, NM. March 28th, 2010.
15. Burns C, **Bernstein L E**. Treatment of Fatty Acid Oxidation Disorders, Glycogen Storage Disease Type 1a and Hypertriglyceridemia with new Medium Chain Triglycerides Sources. Abstract and Poster presentation. Genetic Metabolic Dietitians International. Baltimore, MD April 15 – 17, 2010.
16. **Bernstein L E**, Burns C E, Wilkinson L J, Boney A, Balliet J, Van Hove J. Treatment of Elevated Triglycerides in Glycogen Storage Disease Type1A and Hypertriglyceridemia with Medium Chain Triglycerides Sources. Abstract and Poster presentation. SSIEM. Istanbul, Turkey. August 31 – September 3, 2010.
17. **Bernstein L E**, Freehauf C, Thomas J A, Yannicelli S. Assessment of the Effectiveness of Metabolic University: An Entry Level Program for Registered Dietitians, Nurses, Genetic Counselors and Physicians. SSIEM. Istanbul, Turkey. August 31 – September 3, 2010.
18. **Bernstein L E**, Wright E, Long C, Rice C. Development of Visual Counseling Aids for Inherited Metabolic Disorders: Newborn Screening Through Diagnosis. SSIEM. Istanbul, Turkey. August 31 – September 3, 2010.

19. **Bernstein L E**, White C J, Helm J, Rocha J C, Almeida M F, Link R M. An International Survey of Educational Tools used in PKU Dietary Compliance. SSIEM. Geneva, Switzerland. August 30 – September 2, 2011.
20. **Bernstein L E**, Gaughan S M. More Phe, More Choices: Think Healthy. SSIEM. Geneva, Switzerland. August 30-September 2, 2011.
21. Van Calcar S, **Bernstein L E**. Nutrition Management of Classical and Duarte Galactosemia: Results from an International Survey. SSIEM. Geneva, Switzerland. August 30- September 2, 2011.
22. **Bernstein L E**, Gaughan S M PKU Diet Liberalization and the impact on weight gain and BMI's. Genetic Metabolic Dietitians International (GMDI). New Orleans, LA. April 19-21, 2012.
23. Helm J R, **Bernstein L E**, Rocha J C, Almeida M F, Link R M. Effectiveness of Current Nutrition Education Tools Used in Long Term Dietary Compliance of Patients with Phenylketonuria (PKU): Results from two international surveys. GMDI. New Orleans, LA. April 19-21, 2012.
24. Goldman D, **Bernstein L E** Wootner, M. Quality Assurance of Metabolite Testing of GA1 GMDI. New Orleans, LA. April 19-21, 2012.
25. **Bernstein L**, Helm J R, Rocha J C, Almeida M F, Link R M. Assessment of Current Nutritional Educational Methods used in Long Term Dietary Compliance of Patients with Phenylketonuria (PKU): Results from two international surveys. NPKUA Conference. Philadelphia, PA. July 27, 2012.
26. **Bernstein L E**, Gaughan S M PKU Diet Liberalization and the impact on weight gain and BMI's. NPKUA Conference. Philadelphia, PA. July 27, 2012.
27. Van Calcar S, **Bernstein LE**, Rohr F, Scaman CH. Analysis of Galactose content of caseinates and aged cheeses from North America: Implications for Nutrition Management in Classical Galactosemia. SSIEM Annual Symposium. Birmingham, UK. September 4-7, 2012.
28. C E Burns, **L E Bernstein**. Use of sapropterin dihydrochloride to stabilize phenylalanine levels without challenging phenylalanine intake. SSIEM, Innsbruck, Austria. September 2-5, 2014.
29. **L E Bernstein**, C E Burns. Does utilizing the PKU clinical coordinator for a 13-year old PKU patient and her family improve outcome. SSIEM, Innsbruck, Austria. September 2-5, 2014.
30. Welling L, **Bernstein L E**, Berry GT International clinical guidelines for Classical Galactosemia: managing diagnosis, treatment and follow-up. The European Galactosemia Network SSIEM Rome Sept 3-6, 2016
31. **Bernstein, LE**, Hammons M, Baker P, Multi-Clinic Observations on The Simplified Diet in PKU Journal of Nutrition and Metabolism Accepted for publication Article # 4083293
32. **Laurie E. Bernstein<sup>1</sup>**, Peter R. Baker<sup>1</sup>, and Melissa Sailer<sup>1</sup> A retrospective chart review on the use of medical food in organic acidemias SIMD March 11-14, 2018
33. Marie Norris, Estela Rubio-Gozalbo, Annet Bosch, and **Laurie Bernstein** GLOBAL DISEMINATION STRATEGY OF THE 2017 INTERNATIONAL CLINICAL GUIDELINES FOR THE MANAGEMENT OF CLASSICAL GALACTOSEMIA: DIAGNOSIS, TREATMENT, AND FOLLOW-UP: SSIEM September 2019
34. Marie Norris, Estela Rubio-Gozalbo, Annet Bosch, and **Laurie Bernstein** GLOBAL DISEMINATION STRATEGY OF THE 2017 INTERNATIONAL CLINICAL GUIDELINES FOR THE MANAGEMENT OF CLASSICAL GALACTOSEMIA: DIAGNOSIS, TREATMENT, AND FOLLOW-UP: GMDI April 2020
35. Norris M<sup>1</sup>, **Bernstein L<sup>2</sup>**, Bosch A<sup>3</sup>, and Rubio-Gozalbo E<sup>4</sup> GLOBAL DISEMINATION STRATEGY OF THE 2018 INTERNATIONAL CLINICAL GUIDELINES FOR THE MANAGEMENT OF CLASSICAL GALACTOSEMIA: DIAGNOSIS, TREATMENT AND FOLLOW-UP GMDI April 2021
36. **Bernstein LE<sup>1</sup>**, Burns CE<sup>2</sup>, and Gaughan SM<sup>2</sup>, Bawcom AD<sup>1</sup> Monotherapy for Hyperphenylalanemia Using Sapropterin Dihydrochloride (Kuvan®) GMDI April 2021

**Non-competitive:**

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