

CURRICULUM VITAE

PERSONAL STATEMENT:

I joined the faculty at Baylor College of Medicine in June 2001. My expertise is in the area of cystinosis, an orphan genetic disease, lethal if not treated. In 1998 I was the first to recognize and describe the spectrum of gastrointestinal symptomatology in cystinosis patients. I am one of few national experts in cystinosis, with an international recognition, having been invited to present at over 70 national and international meetings. My second area of focus is teaching. While working as a full time clinician, in 2007 I completed the BCM Educational Scholars Fellowship Program with Master Teacher degree and in 2012 I graduated from the University of Houston with Teaching Master in Education degree. I received two prestigious Fulbright & Jaworsky L.L.P. Faculty Excellence Awards, in the category of Teaching and Evaluation (2011), and in the category of Educational Leadership (2015). I developed “Teaching How to Teach” Curriculum for Pediatric Residents STaR Rotation (2015). In 2017 I became Renal Education Director and developed an Educational Curriculum for Renal Division fellowship training program and faculty development. I have an extensive clinical experience, and have the largest outpatient volume in our division. In 2013 I set-up Multidisciplinary Stone Clinic. I am a designated consultant for all pediatric nephrology referrals through the TCH International Office, running International Renal Clinic. Since 2002 I have been a member of the BCM Admission Committee and in 2014 I was elected to the Executive Subcommittee of Admissions Committee. On the National level, I am actively involved with American Society of Pediatric Nephrology (ASPN). In 2011, I was elected to the Leadership Training Program offered to train most promising leaders. In 2012 I established the Annual ASPN Multidisciplinary Symposium (attended by >100 participants from USA/Canada) and continue to serve as Symposium Director and a Chair of the Organizing Committee for its 12th year. I was elected chair of ASPN Membership Committee (2012), senior chair of Global Health Committee (2018) and member of ASPN Council (July 2018).

I. GENERAL BIOGRAPHICAL INFORMATION

A. Personal

1. Full Name: Ewa Elenberg
2. Citizenship: United States

B. Education

1. Undergraduate Education: N/A
2. Medical Education or Graduate Education
 - 1) Degree: M.D., Graduate 1983
Medical University, Wroclaw, Poland 1977- 1983
 - 2) Degree: Master Teacher, Graduate 2007
Master Teacher Fellowship Program, Baylor College of Medicine and the University of Texas Medical School, Houston, TX, 2005-2007
 - 3) Degree: Teaching Master in Education (M.Ed.), Graduate 2011
University of Houston, College of Education, Department of Curriculum and Instruction, Houston, TX, 2009-2011
3. Postgraduate Training
Internship: Rotating Internship, Medical University Hospitals, Wroclaw, Poland, 1983-1984
Residency training:
 - 1) Pediatric Resident, Children's Hospital, Wroclaw, Poland, 1984-1987
 - 2) Pediatric Resident, Miami Children's Hospital, Miami, FL, 1991-1994Fellowship:
 - 1) Neonatology Fellow, Mount Sinai Hospital, University of Toronto, Canada, 1990-1991
 - 2) Pediatric Nephrology Fellow, Massachusetts General Hospital, Harvard Medical School, Boston, MA, 1994-1997

C. Academic Appointments

1. Current Faculty Positions at BCM
 - 1) Professor of Pediatrics, February 1, 2021-present
 - 2) Secondary Faculty Appointment:
Huffington Department of Education, Innovation and Technology (EIT), BCM,
May 1, 2021-present
3. Previous Faculty Positions at BCM
 - 1) Associate Professor of Pediatrics, Sept 1, 2010-January 31, 2021
 - 2) Assistant Professor of Pediatrics, June 1, 2001-August 31, 2010
3. Previous Faculty Positions at Other Institutions
 - 1) Medical Director of the Pediatric Dialysis Unit, Division of Pediatric Nephrology
Department of Pediatrics, University of Texas Medical Branch at Galveston, Galveston,
TX, 2000-2001
 - 2) Assistant Professor of Pediatrics, Division of Pediatric Nephrology, Department of
Pediatrics, University of Texas Medical Branch at Galveston, Galveston, TX, 1999-2001
 - 3) Clinical Assistant Professor of Pediatrics, Department of Pediatrics, University of Texas
Medical Branch at Galveston, TX, 1998-1999
4. Faculty Appointments at Other Institutions While at BCM: Not Applicable

D. Other Advanced Training/Experience

1. Formal Sabbatical Leave: Not applicable
2. Other Specialized Training Following Academic Appointment
 - 1) Leadership Training Program, American Society of Pediatric Nephrology, 2011-2012
 - 2) Therapeutic Apheresis and Stem Cell Collection, Pediatric Dialysis Unit, Texas Children's
Hospital, Baylor College of Medicine, 2004

E. Other Information

1. Honors or Awards
 - 1) Elected to IPNA ((International Pediatric Nephrology Association) Professional Education
Committee (*Teaching courses sub-committee*), 2023-2025
 - 2) Elected to IPNA Congress 2022 Subcommittee at the International Pediatric Nephrology
Association Professional Education Committee, 2020-2022
 - 3) Upon recommendation of the Chair, appointed by the BCM Provost as a member of the
Selection Committee for Baylor's Norton Rose Fulbright Faculty Excellence Award, Baylor
College of Medicine, 2018
 - 4) Elected "Member of the Month" (for establishing and dedication to the success of the
ASPEN Annual Multidisciplinary Symposium), American Society of Pediatric Nephrology,
April 2017
 - 5) **Fulbright & Jaworski L.L.P. Faculty Excellence Award**, in the category of Educational
Leadership, Baylor College of Medicine, 2015
 - 6) Elected Honorary Member of Polish-American Medical Society (for Outstanding
Contributions to Pediatric Nephrology and Medical Education), Chicago, IL, January 2015
 - 7) Member of Academy of Distinguished Educators, Baylor College of Medicine, 2011 –
present

- 8) **Fulbright & Jaworski L.L.P. Faculty Excellence Award**, in the category of Teaching and Evaluation, Baylor College of Medicine, 2011
 - 9) Selected to the American Society of Pediatric Nephrology Leadership Training Program, 2011-2012
 - 10) Blue Ribbon Award for the excellent poster presentation at the 14th Congress of the International Pediatric Nephrology Association, Budapest, Hungary, 2007
 - 11) Cystinosis Foundation Award: “In Grateful Recognition of Special Concern for and Outstanding Service to Children with Cystinosis” (award established by the Family Support Group of children with cystinosis), 1995
2. Board Eligibility/Certification
 - 1) American Board of Pediatrics, Sub-Board in Pediatric Nephrology, Board certified, 2003, recertified 2013
 - 2) American Board of Pediatrics. Board certified, 1994, recertified, 2001, expired 2009 (voluntary expiration)
 - 3) Polish Board of Pediatrics. Board certified, 1987-present
 3. Other Non-academic Positions
 - 1) Education Director, Renal Division, May 2017-present
 - 2) Co-Founder of Urology/Nephrology Multidisciplinary Stone Clinic, March 2013-Aug 2016
 - 3) Renal Consulting Physician for International Referrals, Texas Children’s Hospital, April 2012-present
 - 4) Staff, Pediatrics and Pediatric Nephrology. Matagorda General Hospital, Bay City, TX, 1997-1999
 - 5) Postgraduate Assistant in Pediatrics. Department of Pediatrics, Massachusetts General Hospital, Harvard Medical School, Boston, MA, 1996-1997
 - 6) Staff, Pediatric Urgent Care. Harvard Community Health Plan, Boston, MA, 1995-1997
 4. Licensure:
 - 1) Medical License, Texas, 1997-present
 - 2) Medical License, Massachusetts, 1994, expired 2010 (voluntary expiration)
 - 3) Medical License, Florida, 1993-present
 - 4) Educational License, Ontario, Canada, 1990-1991
 - 5) Medical License, Poland, 1984-present
 5. Other professional certifications:
 - 1) Medical Council of Canada Qualifying Examination, Canada, 1993
 - 2) Federation Licensing Examination, USA, 1992
 - 3) Educational Commission for Foreign Medical Graduates, USA, 1990
 - 4) Medical Council of Canada Evaluating Exam, Canada, 1989

II. RESEARCH INFORMATION

A. Research Support

ACTIVE RESEARCH SUPPORT

1. International Pediatric Peritoneal Dialysis Network (IPPN) study (H-52088/66136-I)
 - a. Funding Source: IPPN/Mercy Children’s Hospital

- b. Clinical Trial Award
 - c. Investigator relationship: Co-Investigator
 - d. Dates of funding: 05/11/2023 - current
2. Prospective Cohort Study to Describe Practice Patterns and Outcomes in Pediatric Patients (Chronic Kidney Disease, Dialysis, and Transplant) with Cystinosis – NAPRTCS database
- a. Funding Source: Horizon Orphan LLC.
 - b. Clinical Trial Award
 - c. Investigator relationship: co-PI
 - d. Dates of funding: June 1, 2017 – extended until August 31, 2024
 - e. Contract Amount: \$ 250 per each data entry

COMPLETED RESEARCH SUPPORT

1. Chronic Kidney Disease and Renal Transplant Outcomes in Patients with Cystinosis
 - a. Funding Source: Horizon Orphan LLC.
 - b. Clinical Trial Award
 - c. Investigator relationship: PI
 - d. Dates of funding: 10/24/2016- 6/30/2019
 - e. Direct cost: TOTAL \$ 67,500
 - f. Contract Amount: TOTAL \$ 91,125
2. GIGA-KIDS - Genomics of IgA-related diseases in kids
 - a. Funding Source: Baylor College of Medicine (Internal Funding Only)
 - b. Investigator relationship: Co-Investigator
 - c. Approval period: 1/7/2015 - 12/29/2015
3. RP 103-07: A long-term open-label, safety and superior effectiveness study of cysteamine bitartrate delayed-release capsules (RP103) in patients with cystinosis
 - a. Funding Source: Raptor Therapeutics Inc.
 - b. Grant
 - c. Investigator relationship: PI
 - d. Dates of funding: 11/15/2012- 10/31/2017
 - e. Direct cost: TOTAL \$ 336,590 (\$67,318/per patient)
 - f. Contract Amount: TOTAL \$ 437,565 (\$87,513/per patient)
4. RP103-04: A long-term, open-label, safety and efficacy study of cysteamine bitartrate delayed-release capsules (RP103) in patients with nephropathic cystinosis
 - a. Funding Source: Raptor Therapeutics Inc.
 - b. Grant
 - c. Investigator relationship: PI
 - d. Dates of funding: 11/1/ 2010- 10/31/2015
 - e. Direct cost: \$150,728.00
 - f. Contract Amount: \$195,956.00
5. RP103-03: pharmacokinetic and pharmacodynamic directed study to determine the safety and efficacy of cysteamine. A long-term, open-label, safety and efficacy study of cysteamine bitartrate delayed-release capsules (RP103) compared to cystagon® in patients with nephropathic cystinosis
 - a. Funding Source: Raptor Therapeutics Inc.
 - b. Grant
 - c. Investigator relationship: PI

- d. Dates of funding: 11/1/ 2010- 10/31/2015
 - e. Direct cost: \$150,728.00
 - f. Contract Amount: \$195,956.00
6. A randomized, double-blind, placebo-controlled trial of antimicrobial prophylaxis in children with vesicoureteral reflux and urinary tract infection
 - a. Funding Source: National Institutes of Health
 - b. Grant
 - c. Investigator relationship: Co-Investigator
 - d. Dates of funding: 6/1/2010-5/31/2011
 - e. Direct cost: \$2,117 per patient,
 - f. Contract Amount: \$21,170 per 10 enrolled patients
 7. Quality of Life in Cystinosis Patients
 - a. Funding Source: Cystinosis Research Network
 - b. Grant
 - c. Investigator relationship: PI
 - d. Dates of funding: 01/01/2010 through 12/31/2011
 - e. Direct cost: \$19,090.00
 - f. Contract Amount: \$ 21,000
 8. IGF-1 generation test in children with chronic kidney failure
 - a. Funding Source: Genentech
 - b. Grant
 - c. Investigator relationship: PI
 - d. Dates of funding: July 2004 through 2007
 - e. Direct cost: No direct costs, grant covered the costs of medications,
 - f. Contract Amount: \$2,000
 9. Feeding problems in Cystinosis
 - a. Funding Source: Cystinosis Research Network
 - b. Grant
 - c. Investigator relationship: PI
 - d. Dates of funding: July 1995 through July 1997
 - e. Direct cost: \$ 40,000/year
 - f. Contract Amount: \$40,000/year

B. National Scientific Participation

1. Journal Editorial Boards
 - 1) Review Editor, *Frontiers in Pediatrics, Nephrology Section*, 2019-present
 - 2) Editorial Board Member, *Journal of Pediatric Diseases*, 2018-present
 - 3) Editorial Board Member, *American Society of Pediatric Nephrology Board Review Course*, 2017-present
 - 4) Senior Editor, *The Internet Journal of Rehabilitation*, 2009-2018
 - 5) Editorial Board Member, *Scoliosis and Spinal Disorders*, 2005-2019
2. Review Panels/ Invited Reviewer:
 - 1) Pharmacy, *Ad hoc* Reviewer, 2024
 - 2) *Kidney International Reviews*, *Ad hoc* Reviewer, 2023
 - 3) *Cells*, *Ad hoc* Reviewer, 2023
 - 4) *BMC Nephrology*, *Ad hoc* Reviewer, 2022, 2023
 - 5) *Orphanet Journal of Rare Diseases*, *Ad hoc* Reviewer, 2022

- 6) Case Reports in Nephrology and Dialysis, *Ad hoc* Reviewer, 2021
- 7) OBM Transplantation, *Ad hoc* Reviewer, 2020
- 8) Hemodialysis International, Canada, *Ad hoc* Reviewer, 2016
- 9) Medical Research Council, United Kingdom, *Ad hoc* Reviewer, 2016
- 10) BCM Annual Showcase of Educational Scholarship Review Panel, *Ad hoc* Reviewer, 2016
- 11) Clinical Nephrology, Germany, *Ad hoc* Reviewer, 2015, 2017, 2018
- 12) Renal Failure, *Ad hoc* Reviewer, 2015
- 13) Clinical Kidney Journal, *Ad hoc* Reviewer, 2014
- 14) Annals of Clinical & Laboratory Science, *Ad hoc* Reviewer, 2014
- 15) Blood Purification, *Ad hoc* Reviewer, 2014
- 16) Annals of Clinical & Laboratory Science, *Ad hoc* Reviewer, 2013
- 17) Kidney and Blood Pressure Research, *Ad hoc* Reviewer, 2013
- 18) Quality of Life Research, *Ad hoc* Reviewer, 2013
- 19) Fellows' Research Symposium, TCH, Fellow Abstracts, *Ad hoc* Reviewer, 2013
- 20) Bone Marrow Transplantation, *Ad hoc* Reviewer, 2012
- 21) World Journal of Nephrology, Invited Reviewer, 2011
- 22) Physiotherapy Theory and Practice, *Ad hoc* Reviewer, 2011
- 23) The Internet Journal of Rehabilitation, Invited Reviewer: 2010
- 24) Scoliosis, Invited Reviewer: 2005, 2006, 2007, 2008, 2009, 2010, 2011, 2013, 2015
- 25) Expert Opinion on Pharmacotherapy, *Ad hoc* Reviewer: 2005
- 26) Pediatric Nephrology, *Ad hoc* Reviewer: 2004, 2015, 2020, 2021
- 27) Cystinosis Research Network, Medical Advisory Committee, 2003-present

3. Professional Societies

International:

- 1) Cystinosis Foundation, Munich, Germany
 - a) Elected to the Compliance Board, 2022
- 2) Cystinosis Association of Mexico (Association Mexicana de Cistinosis AC) 2006-present
- 3) International Pediatric Nephrology Association (IPNA), 1994-present
 - a) Elected to IPNA Professional Education Committee; Subcommittee: IPNA Congress 2022, 2020-2022
 - b) Elected to IPNA Professional Education Committee (*Teaching Courses Subcommittee*), 2023-2025

National:

- 1) Association of Clinical Scientists, 2006-2011
- 2) Cystinosis Research Network (CRN), 2003-present
- 3) National Kidney Foundation (NKF), 2001-2015
- 4) American Society of Nephrology (ASN), 1997- present
- 5) American Society of Pediatric Nephrology (ASPN), 1994-present
 - a) Elected member of ASPN Council, July 2018- July 2020
 - Reviewer for ASPN Travel Awards for Pediatric Academic Societies Meeting, February 2020
 - A member of ASPN Workforce Summit, November 2019
 - Elected ASPN Global Health Council Liaison, November 2018-July 2020
 - b) Elected Senior Chair of ASPN Global Health Committee, January 2018- June 2019

- c) Member of ASPN Global Health Committee, December 2017-present
 - d) Member of ASPN Education Committee, July 2014-present
 - e) Member of ASPN Nominations Committee, 2013-2014
 - f) Elected Chair of ASPN Membership Committee, July 2012-July 2015
 - g) Director of Annual ASPN Multidisciplinary Symposium (National and International: USA/Canada) and Chair of the Organizing Committee, 2012-present:
 - 12th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 7-8, 2024
 - 11th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 9-10, 2023
 - 10th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 17-18, 2022
 - 9th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 18-19, 2021
 - 8th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 12-13, 2020
 - 7th Annual ASPN Multidisciplinary Symposium, Bally's Las Vegas Hotel, Las Vegas, NV, Sept 12-13, 2019
 - 6th Annual ASPN Multidisciplinary Symposium, Doubletree by Hilton Hotel, Washington, DC Oct 11-12, 2018
 - 5th Annual ASPN Multidisciplinary Symposium, Warwick Melrose Hotel, Dallas, TX, Oct 19-20, 2017
 - 4th Annual ASPN Multidisciplinary Symposium, Hilton Netherland Plaza Hotel, Cincinnati, OH, Oct 20-21, 2016
 - 3rd Annual ASPN Multidisciplinary Symposium, Marriott Hotel, New York, NY Oct 1-2, 2015
 - 2nd Annual ASPN Multidisciplinary Symposium, Seattle Children's Research Institute, Seattle, WA, Sept 5-6, 2014
 - 1st Annual ASPN Multidisciplinary Symposium, Marriott City Center Hotel Charlotte, NC, Sept 18-19, 2013
 - j) ASPN Texas Liaison 2009-present
 - k) ASPN Website Committee Liaison, 2009-2015
 - l) Member of ASPN Membership Committee, 2006-present
 - m) Member of ASPN Workforce Committee, 2006-2009 and 2019-present
6. Cystinosis Foundation, 1994-1999
 7. American Academy of Pediatrics (AAP), 1991-2007 and 2011-present

Local:

1. Academy of Distinguished Educators, BCM, Member 2011-present
4. Elected Positions
 - 1) Reelected to IPNA Congress 2025 Subcommittee at the International Pediatric Nephrology Association Professional Education Committee, 2022-2025
 - 2) Elected to the Scientific Committee, International Cystinosis Conference, Leuven, Belgium, 2022
 - 3) Elected to IPNA Congress 2022 Subcommittee at the International Pediatric Nephrology Association Professional Education Committee, 2020-2022
 - 3) Elected Global Health Council Liaison at the American Society of Pediatric Nephrology, November 2018-present
 - 4) Elected to American Society of Pediatric Nephrology (ASPN) Council July 2018- July 2020

- 5) Elected Senior Chair at the American Society of Pediatric Nephrology Global Health Committee, January 2018- June 2019
- 6) Elected Member of ASPN Nominations Committee at the American Society of Pediatric Nephrology, 2013-2014
- 7) Elected Director of Annual American Society of Pediatric Nephrology Multidisciplinary Symposium (USA/Canada) and Chair of the Organizing Committee, 2012 - present
- 8) Elected Chair of Membership Committee at the American Society of Pediatric Nephrology, July 2012-July 2015
- 9) Elected Member of International Committee at the Cystinosis Association of Mexico (Association Mexicana de Cistinosis AC), 2006-present
- 10) Elected Member of Medical Advisory Committee at the Cystinosis Research Network,, 2003- present
- 11) Elected Member of Medical Advisory Board Cystinosis Foundation, 1995-1997

5. Invited Lectures, Presentations, Research Seminars

a. International

- 1) Looking forward: How can pediatric nephrologists prepare patients with Cystinosis for adulthood? 19th Congress of the International Pediatric Nephrology Association (IPNA), Calgary, Canada, September 11, 2022
- 1) Cystinosis – a lecture at the Masterclasses at the 18th Congress of the International Pediatric Nephrology Association (IPNA), Venice, Italy, October 17-21, 2019
- 2) Hemolytic Uremic Syndrome - the American Experience. Pediatric Nephrology Symposium, Gdansk, Poland, October 4, 2019
- 3) Late complications of Cystinosis, 17th Congress of Polish Society of Pediatric Nephrology, Krakow, Poland, May 26-28, 2019
- 4) Serum creatinine and growth in Cystinosis transplant patients – a review of NAPRTCS Database, presentation at Symposium 8 session, 51st European Society of Pediatric Nephrology Antalya, Turkey, October 5, 2018
- 5) Chronic Kidney Disease and Renal Transplant Outcomes in Patients with Cystinosis- presentation in the “Understanding tubular physiology to improve patient care” session, 50th European Society of Pediatric Nephrology, Glasgow, United Kingdom, September 9, 2017
- 6) Cystinosis bone disease – clinical cases. The International Expert Symposium to establish International Consensus on Diagnosis and Therapeutic Approach to Cystinosis Bone Disease. Salzburg, Austria, December 8-10, 2016
- 7) Cystinosis - North American Experience. Cystinosis Symposium at VII Congress of Colombian Pediatric Nephrology Association (ACONEPE), Bucaramanga, Colombia, October 27-29, 2016
- 8) Cystinosis- Extra Renal Multisystem Complications and New Modalities of Therapy. Cystinosis Symposium at 17th Congress of International Pediatric Nephrology Association (IPNA), Iguazu Falls, Brazil, September 20-24, 2016
- 9) Adherence Issues in Cystinosis. 8th Cystinosis Symposium, Mexico City, Mexico, August 5, 2016
- 10) Gastrointestinal Manifestations in Cystinosis. 8th Cystinosis Symposium, Mexico City, Mexico, August 5, 2016
- 11) Endocrinology complications in cystinosis. 7th Cystinosis Symposium, Mexico City, Mexico, August 15, 2014
- 12) Cystinosis Overview. 7th Cystinosis Symposium, Mexico City, Mexico, August 15, 2014

- 13) Enuresis. X International Pediatric Course, El Colegio de Pediatras de Yucatán, Merida, Mexico, November 22, 2013
- 14) Cystinosis – diagnosis and therapy. Polish Society of Pharmacology, Pharmacotherapy and Toxicology, Medical University, Wroclaw, Poland, May 22, 2013
- 15) Cystinosis. 22nd Annual International Colloquium at TCH, Houston, TX, April 8 - 10, 2013
- 16) Enuresis. Reunion de las Americas, Mexico City, Mexico, February 20-22, 2013
- 17) Cystinosis. Reunion de las Americas, Mexico City, Mexico, February 20-22, 2013
- 18) Fanconi syndrome. 6th Cystinosis Symposium, Mexico City, Mexico, August 16-17, 2012
- 19) Overview of cystinosis. 6th Cystinosis Symposium, Mexico City, Mexico, August 16-17, 2012
- 20) Life and success of the patient with cystinosis. 6th Cystinosis Symposium, Mexico City, Mexico, August 16-17, 2012
- 21) Renal transplant humoral rejection. Grand Rounds, National Institute of Pediatrics, Mexico City, Mexico, August 15, 2012
- 22) Cystinosis. Grand Rounds, Dubai Hospital, Dubai, United Arab Emirates, February 19, 2012
- 23) Fanconi syndrome - an open window in the diagnosis of cystinosis. 7th International Congress of Inborn Errors of Metabolism and Neonatal Screening, Cancun, Mexico, December 6-9, 2009
- 24) Fanconi syndrome. 5th Cystinosis Symposium, Mexico City, Mexico, January 30, 2009
- 25) Cystinosis - a rare metabolic disease. The joint meeting of the Association of Clinical Scientists (USA) and Pathology Society of Saint Petersburg, Saint Petersburg Pediatric Medical Academy, Saint Petersburg, Russian Federation, September 6, 2007
- 26) Living with Cystinosis. 4th Cystinosis Symposium, Mexico City, Mexico, January 25, 2007
- 27) Therapy in Cystinosis. 4th Cystinosis Symposium, Mexico City, Mexico, January 25, 2007
- 28) Cystinosis - the challenge of living with a chronic illness. 37th Annual Conference of the European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure, Krakow, Poland, June 8-10, 2006
- 29) Renal transplantation in Cystinosis. 3rd Cystinosis Symposium, Mexico City, Mexico, January 24, 2006
- 30) Polytherapy in Cystinosis. 3rd Cystinosis Symposium, Mexico City, Mexico, January 24, 2006
- 31) Fanconi syndrome in Cystinosis. 3rd Cystinosis Symposium, Mexico City, Mexico, January 24, 2006

b. National

- 1) Adolescent Cystinosis: An Update on Management and Prognosis. 48th Miami Pediatric Nephrology Seminar, Miami Beach, FL, October 14-16th, 2022
- 2) Cystinosis bone disease, presenter and moderator, Virtual Advisory Board, May 20, 2021
- 3) Management of failure to thrive in cystinosis. Cystinosis Research Network Meeting (CRN), Philadelphia, PA, July 18-20, 2019
- 4) Understanding Cystinosis. Cystinosis Conference, Houston, TX, September 8, 2018
- 5) Chronic kidney disease and renal transplant outcomes in patients with cystinosis. Cystinosis Research Network Meeting (CRN), Snowbird, UT, July 13-15, 2017
- 6) Chronic kidney disease and renal transplant outcomes in patients with cystinosis. North American Pediatric Renal Trials and Collaborative Studies Annual Meeting (NAPRTCS), Chicago, IL, April 3-4, 2017

- 7) North American Pediatric Renal Trials and Collaborative Studies (NAPRTCS) Registry, Observational Research Advisory Board Meeting, Boston, MA, April 29, 2016
- 8) Pathogenesis and Clinical Manifestations of Cystinosis. CME-approved symposium: Cystinosis: What the Adult Nephrologist Needs to Know. American Society of Nephrology (ASN) Kidney Week 2015, ASN Annual Meeting, San Diego, November 6, 2015
- 9) Adherence Issues in Cystinosis. Cystinosis Research Network Meeting (CRN), Chicago, July 16-18, 2015
- 10) Gastrointestinal Manifestations in Cystinosis. Cystinosis Research Network Meeting (CRN), Chicago, July 16-18, 2015
- 11) Nephropathic Cystinosis. Nephrology Grand Rounds, Children's Hospital of Philadelphia, Philadelphia, PA, June 5, 2015
- 12) Nephropathic Cystinosis. Transplant Conference, St. Luke's Hospital, Kansas City, MO, March 6, 2015
- 13) Nephropathic Cystinosis: Clinical Challenges and Emerging Opportunities. CME approved Symposium: On the Edge: Frontiers in CKD. American Nephrology Nurses Association (ANNA), Galveston, TX, February 7, 2015
- 14) Cystinosis: An Overview. Nephrology Conference, Children's Hospital of the King's Daughters, Norfolk, VA, February 4, 2015
- 15) Cystinosis: An Overview, Nephrology Conference, Columbus, OH, January 15, 2015
- 16) Overview of cystinosis. Cystinosis Teen Adventure. Los Angeles, October 10-11, 2014
- 17) Adherence in adolescents and adults. Cystinosis Teen Adventure. Los Angeles, October 10-11, 2014
- 18) Endocrinology complications in cystinosis. Cystinosis Teen Adventure. Los Angeles, October 10-11, 2014
- 19) Overview of Cystinosis. Nephrology Conference, Nemours DuPont Children's Hospital, Wilmington, DE, Sept 12, 2014
- 20) Cystinosis - Living with Chronic Illness/Focus on Cystinosis, patient and family panel. 2nd Annual ASPN Multidisciplinary Symposium. Seattle, Washington, September 5-6, 2014
- 21) Medication nonadherence. Cystinosis Expert Conference, Boston, MS, August 11-12, 2014
- 22) Overview of Cystinosis. Nephrology Conference, Cincinnati Children's Hospital, Cincinnati, OH, August 7, 2014
- 23) Cystinosis – clinical features. Nephrology Conference, Cook Children's Hospital, Fort Worth, TX, June 19, 2014
- 24) The Changing Face of Nephropathic Cystinosis: Clinical Challenges and Emerging Opportunities. CME-approved symposium: Epidemiology, Pathophysiology, and Clinical Diagnosis of Nephropathic Cystinosis: State of the Art. American Nephrology Nurses Association (ANNA), Anaheim, CA, April 13, 2014
- 25) Nephropathic Cystinosis - the past and present. Cystinosis Conference, St Louis, MO, January 25, 2014
- 26) Quality of Life in Children with Chronic Illness. 1st Annual ASPN Multi-Disciplinary Symposium, Charlotte, North Carolina, September 19-20, 2013
- 27) Childhood Cystinosis Issues. Cystinosis Research Network Meeting (CRN), Workshop, Washington, DC, July 20, 2013
- 28) Cystinosis in 2013: State of the Art and Case-Based Approaches for screening, diagnosis and long-term management. CME-approved symposium: "Diagnostic challenges, clinical conundrums, and long-term outcome measures in patients with Cystinosis". Pediatric Academic Societies (PAS), Washington, DC, May 5, 2013

- 29) Current state of cystinosis 2013. Cystinosis Board Meeting, NYC, April 5-6, 2013
- 30) Cystinosis in children. Pathology Grand Rounds, Memorial Herman Hospital, University of Texas, Houston, TX, December 5, 2012
- 31) Fanconi syndrome. Cystinosis Research Network Family Conference, Atlanta, GA, July 16-18, 2009
- 32) Pulmonary-renal syndrome - IgA nephropathy presenting with renal failure and pulmonary hemorrhage. 129th Annual Meeting, Association of Clinical Scientists, Tampa, FL, May 13-16, 2009
- 33) Cystinosis. 29th Annual Dialysis Conference, 15th International Symposium of Hemodialysis, 20th Annual Symposium on Pediatric Dialysis, Houston, TX, March 8-10, 2009
- 34) Fanconi syndrome and its treatment. Cystinosis Research Network Meeting (CRN), San Antonio, TX, July 19-21, 2007
- 35) Immune complex glomerulonephritis in two Wilms tumor patients. 127th Annual Meeting, Association of Clinical Scientists, Hershey, PA, May 19 2007
- 36) Cystinosis – the challenge of living with the chronic illness. Pediatric Grand Rounds, Miami Children's Hospital, Miami, FL, April 20, 2007
- 37) What's new in Cystinosis. Pediatric Nephrology Seminar XXXIII, Miami, FL, March 10-14, 2006
- 38) Polytherapy in Cystinosis. Cystinosis Research Network Meeting (CRN), Snow Bird, Utah, July 28-30, 2005
- 39) Gastrointestinal dysfunction in Cystinosis. Cystinosis Foundation Annual Meeting, Boston, MA, July 3-6, 1996
- 40) Cystinosis. Pediatric Grand Rounds, Miami Children's Hospital, Miami, FL, May 12, 1995

C. Publications

1. Full Papers in Peer Review Journals

a. Published

- 1) Wu CHW, Tomaszewski A, Stark L, Scaglia F, Elenberg E, Schumacher F. Perspectives from cystinosis: Access to healthcare may be a confounding factor for variant classification. *Front. Genet., Sec. Human and Medical Genomics*, Vol 15 doi.org/10.3389/fgene.2024.1402667, July 23, 2024
- 2) Rairikar M, Hohenfellner K, **Elenberg E**. Pathophysiology of Cystinosis. *Archives of Clinical Nephrology*, 9 (1), 008-012, DOI: <https://dx.doi.org/10.17352/acn.000064>, June 13, 2023
- 3) Hohenfellner K, **Elenberg E**, Ariceta G, Nesterova G, Soliman N, Topaloglu R. Newborn screening – background and its impact for Cystinosis. *Cells* 11, 1109: 1-12, doi:10.3390/cells11071109, March 2022
- 4) Wu X, Mancuso E, Armendi I, Krasinski D, Liu L, Tarsi S, Waz WR, Abdul–Aziz R, **Elenberg E**, Renal involvement and its treatment in pediatric patients with Proteinase-3 Anti-Neutrophil Cytoplasmic Antibody positive granulomatosis with polyangiitis: A case series. *Case report in rheumatology*, *Cureus* 13(9): e18197. doi:10.7759/cureus.18197, Sept 2021
- 5) Shan H, **Elenberg E**, Davis KI. An Unusual Case of Weakness in an Adolescent. *Acad J Ped and Neonatol* 10(3): 141-144, DOI: 10.19080/AJPN.2021.10.555845, Aug 24, 2021
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- 9) Wissman, SD, McCool C, Potocki L, **Elenberg E**. Hypertension in Potocki-Schaffer Syndrome: A Case Report. *Eur J Med Genet*, 63(1):103633, 2020
- 10) Hohenfellner K; Rauch F; Ariceta G; Awan A; Bacchetta J; Bergmann C; Bechtold S; Cassidy N; Deschenes G; **Elenberg E**; Gahl WA; Greil O; Harms E; Herzig N; Hoppe B; Koepl C; Lewis MA; Levchenko E; Nesterova G; Santos F; Schlingmann KP; Servais A; Soliman NA; Steidle G; Sweeney C; Treikuskas U; Topaloglu R; Tsygin A; Veys K; V Vigier R; Zustin J; Haffner D. Management of bone disease in cystinosis: Statement from an international conference. *J of Inher Metab Dis*, 42(5):1019-1029, 2019
- 11) Celebi N, Vallejo J, Eckstein O, Geer J, Punia JN, **Elenberg E**. Persistent fever in a Pediatric Renal Transplant Patient: Answers. *Pediatric Nephrology*, 34(5):825–828, 2019
- 12) Celebi N, Vallejo J, Eckstein O, Geer J, Punia JN, **Elenberg E**. Persistent fever in a Pediatric Renal Transplant Patient: Questions. *Pediatric Nephrology*, 34(5):823–824, 2019
- 13) Michael M, Turner N, Schaffer L, Teruya J, Hui S-K, **Elenberg E**, Moake J: Thrombotic Microangiopathy in an infant associated with combined partial deficiencies of complement factor H and ADAMTS13: *Clinical Kidney Journal*, 11(6):791-796, 2018
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- 15) Bekheirnia MR, Bekheirnia N, Bainbridge MN, Gu S, Coban Akdemir ZH, Gambin T, Janzen NK, Jhangiani SN, Muzny DM, Michael M, Brewer ED, **Elenberg E**, Kale AS, Riley AA, Swartz SJ, Scott DA, Yang Y, Srivaths PR, Wenderfer SE, Bodurtha J, Applegate CD, Velinov M, Myers A, Borovik L, Craigen WJ, Hanchard NA, Rosenfeld JA, Lewis RA, Gonzales ET, Gibbs RA, Belmont JW, Roth DR, Eng C, Braun MC, Lupski JR, Lamb DJ. Whole-Exome sequencing in the molecular diagnosis of individuals with congenital anomalies of kidney and urinary tract and identification of a new causative gene. *Genet Med* 19(4):412-420, 2016
- 16) Langman CB, Barshop BA, Deschenes G, Emma F, Goodyer P, Lipkin G, Midgley JP, Ottolenghi C, Servais A, Soliman NA, Thoene JG, Levchenko EN for Conference Participants: Amon O, Ariceta G, Basurto M, Belmont-Martínez L, Bertholet-Thomas A, Bos M, Brown T, Cherqui S, Cornelissen EAM, Del Monte M, Ding J, Dohil R, Doyle M, **Elenberg E**, Gahl WA, Gomez V, Greco M, Greeley C, Greenbaum LA, Grimm P, Hohenfellner K, Holm T, Hotz V, Janssen MC, Kaskel F, Magriço R, Nesterova G, Newsholme P, Niaudet P, Rioux P, Sarwal MM, Schneider J, Topaloglu R, Trauner DA, Vaisbich MH, van den Heuvel LP, Van't Hoff W. Controversies and research agenda in

- nephropathic cystinosis: conclusions from a “Kidney Disease: Improving Global Outcomes” (KDIGO) Controversies Conference. *Kidney International* 89:1192–1203, 2016
- 17) Emma F, Nesterova G, Langman C, Labbé A, Cherqui S, Goodyer P, Janssen MC, Greco M, Topaloglu R, **Elenberg E**, Dohil R, Trauner D, Antignac C, Cochat P, Kaskel F, Servais A, Wühl E, Niaudet P, Van’t Hoff W, Gahl W, Levtchenko E. Nephropathic Cystinosis: an International Consensus Document. *Nephrol Dial Transplant*, 29(4):iv87-iv94, 2014
 - 18) Langman CB, Greenbaum LA, Grimm P, Sarwal M, Niaudet P, Deschenes G, Cornelissen EA, Morin D, Cochat P, **Elenberg E**, Hanna C, Gaillard S, Bagger MJ, Rioux P. Quality of life is improved and kidney function preserved in patients with nephropathic cystinosis treated for 2 years with delayed-release cysteamine bitartrate. *J Pediatr* 165(3):528-533, 2014
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 - 21) Swarr DT, Bloom D, Lewis RA, **Elenberg E**, Friedman EM, Glotzbach C, Wissman SD, Shaffer LG, Potocki L. Potocki-Shaffer Syndrome: Prospective Clinical Assessment, Review of the Literature, and Proposals for Medical Management. *Am J of Med Genetics* 152A(3):565-572, 2010
 - 22) Poyyapakkam S, Dishop MK, Elidemir O, Eldin K, Browne L, **Elenberg E**. IgA nephropathy presenting with renal failure and pulmonary hemorrhage. *Pediatr Nephrol* 25(3):535-538, 2010
 - 23) Ammourey RF, Heptulla RA, Tatevian N, **Elenberg E**. Laparoscopic adrenalectomy of an adrenal adenoma with myelolipoma relieves severe hypertension in a 16-year-old patient. *Pediatr Nephrol.* 21(3):433-436, 2006
 - 24) Askenazi DJ, Goldstein SL, Chang IF, **Elenberg E**, Feig DI. Management of a Severe Carbamazepine Overdose Using Albumin-Enhanced Continuous Veno-Venous Hemodialysis. *Pediatrics* 113(2):406-409, 2004
 - 25) **Elenberg E**, Norling LL, Kleinman RE, Ingelfinger JR. Feeding Problems in Cystinosis. *Pediatric Nephrology* 12(5):365-370, 1998
- b. Submitted/Accepted/In Press
- 1) **Elenberg E**, Benfield M, Ghossein C, Jarnes J. Optimizing long-term outcomes in cystinosis with comprehensive patient-centered care. Accepted to *Kidney International Reports* on 11..08.24 Article reference: EKIR_kir-06-24-0679
 - 2) Sadjadi R, **Elenberg E**, Ghossein C, Trauner DA. Clinical Perspectives on Myopathic Complications in Cystinosis. Submitted on October 23, 2024 to *Journal of Rare Diseases*
 - 3) **Elenberg E**, Shirley Galbiati S, Michael Martens M. Renal Transplant Outcomes in Patients with Cystinosis from the North American Pediatric Renal Transplant Collaborative Study Database.
2. Full Papers without Peer Review
- a. Published
- 1) Doyle M, **Elenberg E**, Kaskel R. Living with Cystinosis Survey. *Cystinosis Adult*

- Care Excellence Initiative, www.cystinosis.org, 2011
- 2) **Elenberg E.** ASPN membership survey. *KIDney Notes*, March-April 2010
 - 3) **Elenberg E.** My interest in Cystinosis. *The Cystinosis Research Network Newsletter*, Fall/Winter 2006
- b. In preparation: Not applicable
3. Abstracts Given During Last Three Years
- 1) Kumar R, Altemose K, Galbiati S, **Elenberg E**, Okamura DM, Grimm P, Greenbaum LA, Warady B, Smith J. Clinical features of cystinosis: A Report of the NAPRTCS Cystinosis Registry. Abstract accepted for poster presentation at the Pediatric Academic Societies (PAS)/ American Society of Pediatric Nephrology (ASPN) Virtual Meeting May 2021
 - 2) Altemose K, Kumar R Galbiati S, **Elenberg E**, Okamura DM, Grimm P, Greenbaum LA, Smith J, Warady B. Practice patterns IN THE NAPRTCS CYSTINOSIS REGISTRY. Abstract accepted for poster presentation at the Pediatric Academic Societies (PAS)/ American Society of Pediatric Nephrology (ASPN) Virtual Meeting May 2021
 - 3) Scheurmann GC, Liu L, Franz K, Tarsi S, Waz WR, Aziz R, **Elenberg E**, Wu X. Renal involvement and its treatment in pediatric patients with PR3 ANCA positive granulomatosis with polyangiitis (GPA). Abstract accepted for poster presentation at the Eastern Society for Pediatric Research, 32nd Annual Scientific Meeting, Philadelphia, March 13-15, 2020
 - 4) Glenn D, Kennedy S, Daga A, Bjornstad E, Hingorani S, **Elenberg E**, Mahan J. Global Health Interest and Experience among Pediatric Nephrologists and Trainees in the United States. Abstract accepted for poster presentation at the International Pediatric Nephrology Association, Venice, Italy, October 17-21, 2019
 - 5) **Elenberg E** Outcomes of dialysis and transplantation in Cystinosis from NAPRTCS Database – Abstract accepted for poster presentation at American Society of Nephrology, Kidney Week 2018, San Diego, CA, October 23-28, 2018
 - 6) **Elenberg E** Serum creatinine and growth in Cystinosis transplant patients – a review of NAPRTCS database – Abstract accepted for oral presentation at 51st European Society of Pediatric Nephrology, Antalya, Turkey, October 5, 2018
 - 7) **Elenberg E** Chronic Kidney Disease and Renal Transplant Outcomes in Patients with Cystinosis, Abstract accepted to oral presentation at 50th European Society of Pediatric Nephrology, Glasgow, England, September 9, 2017
 - 8) **Elenberg E.** Chronic Kidney Disease and Renal Transplant Outcomes in Patients with Cystinosis, Poster presented at the International Pediatric Nephrology Association Workshop for Clinical and Epidemiological Research in Pediatric Nephrology, Heidelberg, Germany, May 24-26, 2017
 - 9) Celebi N, Vallejo J, Eckstein O, Geer J. **Elenberg E.** Hemophagocytic Lymphohistiocytosis secondary to histoplasmosis in renal transplant patient. Poster presented at the International Pediatric Nephrology Association, Iguazu Falls, Brazil, September 20-24, 2016
 - 10) Langman CB, Greenbaum L, Grimm P, **Elenberg E**, Cochat P, Niaudet P, Deschenes G, Morin D, Cornelissen E. A pragmatic trial of procysbi in children <6y with cystinosis. Poster presented at ERA-EDTA Congress, Vienna, Austria, May 21-24, 2016
 - 11) Grimm P, Langman CB, Cochat P, Morin D, Cornelissen E, Deschenes G, **Elenberg E**, MD, Greenbaum L, Niaudet P, Checani G. Delayed-release cysteamine bitartrate in nephropathic cystinosis patients after renal transplant: a subgroup analysis. Poster presented at ERA-EDTA Congress, Vienna, Austria, May 21-24, 2016

- 12) Celebi N, Vallejo J, Geer J, **Elenberg E**. Recurrent Fevers in a Hemodialysis Patient: A puzzle is solved. Poster presented at the Annual Dialysis Conference Seattle, Washington, Feb 27-March 1, 2016
- 13) Bekheirnia MR, Bekheirnia N, Bainbridge M, Janzen NK, Jhangiani S, Muzny SDM, Michael M, Brewer ED, **Elenberg E**, Kale AS, Riley AA, Swartz SJ, Srivaths PR, Wenderfer SE, Gonzales ET, Gibbs RA, Lupski JR, Belmont JW, Roth DR, Braun MC, Lamb DJ. SNV and CNV analyses in the molecular diagnosis of individuals with congenital anomalies of kidney and urinary tract; Abstract accepted for Platform Presentation at American College of Medical Genetics and Genomics Annual Meeting, Tampa, FL, March 8-12, 2016

Published Abstracts During Last Three Years:

- 1) Scheurmann GC, Liu L, Franz K, Tarsi S, Waz WR, Aziz R, **Elenberg E**, Wu X. Renal involvement and its treatment in pediatric patients with PR3 ANCA positive granulomatosis with polyangiitis (GPA). *E-ESPR* 2020:340.
- 2) Glenn D, Kennedy S, Daga A, Bjornstad E, Hingorani S, **Elenberg E**, Mahan J. Global Health Interest and Experience among Pediatric Nephrologists and Trainees in the United States. *Pediatric Nephrology*, 34 (10), 1828, October 2019
- 3) **Elenberg E** Serum creatinine and growth in Cystinosis transplant patients – a review of NAPRTCS database, *Pediatric Nephrology*, 33 (10), 1826, October 2018
- 4) **Elenberg E**. Chronic Kidney Disease and Renal Transplant Outcomes in Patients with Cystinosis, *Pediatric Nephrology*, 32 (9):1670, September 2017
- 5) Grimm P, Langman C, Cochat P, Morin D, Cornelissen E, Deschenes G, **Elenberg E**, Greenbaum L, Niaudet P, Checani G. Delayed release cysteamine in nephropathic cystinosis patients after renal transplant: a subgroup analysis. *Nephrology Dialysis Transplantation* 31(suppl 1):i569-i569, May 2016
- 6) Langman CB, Greenbaum L, Grimm P, **Elenberg E**, Deschenes G, Niaudet P, Morin D, Checani G. Pragmatic trial of delayed-release cysteamine bitartrate in children less than 6 years old with cystinosis. *Nephrology Dialysis Transplantation*; 31(suppl 1):i330-i331. May 2016

4. Books

a. Complete Books Written

- 1) Cellular and molecular mechanisms of nephropathic Cystinosis. Editor: Elena N. Lectchenko. Printed edition of the special issue published in *Cells*. *Cells*, 2022. ISBN 978-3-0365-4567-7 (pdf). www.mdpi.com/journal/cells
Multiple contributors, book has 232 pages. I contributed with the following chapter:
Hohenfellner K, **Elenberg E**, Ariceta G, Nesterova G, Soliman NA and Topaloglu R. Newborn Screening: Review of its Impact for Cystinosis, p.9-21
- 2) Gahl WA, Kaskel F, Langman CB, Mannon RB, Richard H. Simon RH, Jess G. Thoene JG, Antignac C, Bishop R, Cairns D, Dohil R, **Elenberg E**, Gipson P, Goodyer P, Greenbaum L, Ingelfinger JR, Nesterova G, Sarwal M, Thacker MM, Susan E. Thomas SE, Trauner DA, Doyle M. Cystinosis Information for Medical Professionals, 2010, recent update 2018
Printed 10 page brochure distributed annually at the major national and international meetings, including American Society of Nephrology meeting attended by ~ 14000 nephrologists from around the world.
- 3) Michael M, **Elenberg E**, Kale AS. Atlas of Common kidney diseases for Clinicians, 2016

Available in printed form (167 pages) at the Renal Clinic and as an electronic version at TCH website: Renal SVC/Renal Atlas

- 4) Kaskel F, Bishop R, Dohil R, Doyle M, **Elenberg E**, Goodyer P, Greenbaum L, Knerr C, Levchenko E, Mahgerefteh J, Mannor R, Moreno L, Nesterova G, Simon R, Thacker M, Trauner D. Cystinosis Transition Management Tool, 2015
A handbook available in electronic version at the Cystinosis Research Network website <https://cystinosis.org/research/article-library/cystinosis-overview> and in printed form distributed annually at the major national and international meetings, including American Society of Nephrology meeting attended by ~ 14000 nephrologists from around the world.
- 5) Michael M, Janzen N, Moreno L, Bekheirnia MR, **Elenberg E**. A Handbook of Kidney Stones in Children, 2015
Available through TCH website: www.texaschildrens.org/kidney-stones-handbook

b. Books Edited: none

c. Book Chapters Written

- 1) **Elenberg E**. Cystinosis. In Natoli J. (ed.). 7th edition, eMedicine/Medscape, <https://emedicine.medscape.com/article/981650>; August 31, 2015
- 2) **Elenberg E**. Hyponatremia. In Natoli J. (ed.). 4th edition, eMedicine/Medscape, <https://emedicine.medscape.com > article > 907653> February 13, 2014
- 3) **Elenberg E**. Cystinosis. In: Natoli J. (ed.). 6th edition, eMedicine, 2012
- 4) **Elenberg E**, Vellaichamy M. Hyponatremia. In: Natoli J. (ed.) 3rd edition, eMedicine, 2011
- 5) **Elenberg E**. Cystinosis. In: Natoli J. (ed.). 5th edition, eMedicine, 2009
- 6) **Elenberg E**. Hyponatremia. In: Natoli J. (ed.). 2nd edition eMedicine, 2008
- 7) **Elenberg E**. Cystinosis. In: Natoli J. (ed.). 4th edition, eMedicine, 2007
- 8) **Elenberg E**. Hyponatremia. In: Natoli J. (ed.). 1st edition, eMedicine, 2007
- 9) **Elenberg E.**: Sick Cell Nephropathy. In McMillan, DeAngelis, Feigin and Warshaw (eds). Oski's Pediatrics: Principles and Practice. 4th edition. Lippincott Williams & Wilkins, 2006
- 10) **Elenberg E.**: Progressive Hereditary Nephritis. In McMillan, DeAngelis, Feigin and Warshaw (eds). Oski's Pediatrics: Principles and Practice. 4th edition Lippincott Williams & Wilkins, 2006
- 11) **Elenberg E.**: Benign Familial Hematuria, In McMillan, DeAngelis, Feigin and Warshaw (eds). Oski's Pediatrics: Principles and Practice. 4th edition. Lippincott Williams & Wilkins, 2006
- 12) **Elenberg E.**: Familial Juvenile Nephronophthisis, In McMillan, DeAngelis, Feigin and Warshaw (eds). Oski's Pediatrics: Principles and Practice. 4th edition. Lippincott Williams & Wilkins, 2006
- 13) **Elenberg E**. Cystinosis. In: Natoli J. (ed.). 3rd edition, eMedicine, 2006
- 14) Swinford RD, **Elenberg E**, Ingelfinger JR.: Persistent Renal Disease, in Walker WA, Watkins JB (eds). Nutrition in Pediatrics – Basic Science and Clinical Applications. 3rd ed. B.C. Decker Inc, 2003
- 15) **Elenberg E**. Cystinosis. In: Natoli J. (ed.). 2nd edition, eMedicine, 2003
- 16) **Elenberg E**, Travis LB.: Urinary Tract Infection and Perinephric/Intraneprhic Abscess, in Burg FD, Ingelfinger JR, Polin RA, Gershon A. (eds). Current Pediatric Therapy 17. W. B. Saunders Company, 772-776, 2002
- 17) **Elenberg E.**: Enuresis and Voiding Dysfunction, in Burg FD, Ingelfinger JR, Polin RA,

- Gershon A. (eds). Current Pediatric Therapy 17. W. B. Saunders Company, 768- 772, 2002
- 18) **Elenberg E**. Cystinosis. In: Natoli J. (ed.).1st edition eMedicine, 2001
- 19) Swinford RD, **Elenberg E**, Ingelfinger JR.: Persistent Renal Disease, in Walker WA,Watkins JB (eds): Nutrition in Pediatrics – Basic Science and Clinical Applications, 2nd ed. B.C. Decker Inc 493-515, 1996

5. Other Works Communicating Research Results to Scientific Colleagues: not applicable
6. Other Works Communicating Research Results to General Public: not applicable

D. Innovation and Commercialization

1. Patents: Not applicable
2. Device, Software or Other Development: Not applicable
3. Evidence of Impacting Health/Scientific Policy or Clinical Practice Guidelines (e.g., note policy or guidelines where publications were cited)
 - 1) Hohenfellner K; Rauch F; Ariceta G; Awan A; Bacchetta J; Bergmann C; Bechtold S; Cassidy N; Deschenes G; **Elenberg E**; Gahl WA; Greil O; Harms E; Herzig N; Hoppe B; Koepl C; Lewis MA; Levtchenko E; Nesterova G; Santos F; Schlingmann KP; Servais A; Soliman NA; Steidle G; Sweeney C; Treikauskas U; Topaloglu R; Tsygin A; Veys K; V Vigier R; Zustin J; Haffner D. Management of bone disease in cystinosis: Statement from an international conference. J of Inherit Metab Dis, 42(5); 1019-1029, 2019
 - 2) Langman CB, Barshop BA, Deschenes G, Emma F, Goodyer P, Lipkin G, Midgley JP, Ottolenghi C, Servais A, Soliman NA, Thoene JG, Levtchenko EN for Conference Participants (Amon O, Ariceta G, Basurto M, Belmont-Martínez L, Bertholet-Thomas A, Bos M, Brown T, Cherqui S, Cornelissen EAM, Del Monte M, Ding J, Dohil R, Doyle M, **Elenberg E**, Gahl WA, Gomez V, Greco M, Greeley C, Greenbaum LA, Grimm P, Hohenfellner K, Holm T, Hotz V, Janssen MC, Kaskel F, Magriço R, Nesterova G, Newsholme P, Niaudet P, Rioux P, Sarwal MM, Schneider J, Topaloglu R, Trauner DA, Vaisbich MH, van den Heuvel LP, Van't Hoff W). Controversies and research agenda in nephropathic cystinosis: conclusions from a “Kidney Disease: Improving Global Outcomes” (KDIGO) Controversies Conference. Kidney International 89, 1192–1203, 2016
 - 3) Emma F, Nesterova G, Langman C, Labbé A, Cherqui S, Goodyer P, Janssen MC, Greco M, Topaloglu R, **Elenberg E**, Dohil R, Trauner D, Antignac C, Cochat P, Kaskel F, Servais A, Wühl E, Niaudet P, Van't Hoff W, Gahl W, Levtchenko E. Nephropathic Cystinosis: an International Consensus Document. Nephrol Dial Transplant, 29:iv87-iv94, 2014
4. Participation in Business Development and Commercialization: Not applicable
5. Other Activities: Not applicable

III. TEACHING INFORMATION

A. Educational Leadership Roles (title, dates, responsibilities)

National

1. Director of Annual ASPN Multidisciplinary Symposium (National and International: USA/Canada) and Chair of the Organizing Committee, 2012-present:
 - 1) 12th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 7-8, 2024
 - 2) 11th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 9-10, 2023
 - 3) 10th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 17-18, 2022

- 4) 9th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 18-19, 2021
- 5) 8th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 12-13, 2020
- 6) 7th Annual ASPN Multidisciplinary Symposium, Bally's Las Vegas Hotel, Las Vegas, NV, Sept 12-13, 2019
- 7) 6th Annual ASPN Multidisciplinary Symposium, Doubletree by Hilton Hotel, Washington, DC Oct 11-12, 2018
- 8) 5th Annual ASPN Multidisciplinary Symposium, Warwick Melrose Hotel, Dallas, TX, Oct 19-20, 2017
- 9) 4th Annual ASPN Multidisciplinary Symposium, Hilton Netherland Plaza Hotel, Cincinnati, OH, Oct 20-21, 2016
- 10) 3rd Annual ASPN Multidisciplinary Symposium, Marriott Hotel, New York, NY Oct 1-2, 2015
- 11) 2nd Annual ASPN Multidisciplinary Symposium, Seattle Children's Research Institute, Seattle, WA, Sept 5-6, 2014
- 12) 1st Annual ASPN Multidisciplinary Symposium, , Marriott City Center Hotel Charlotte, NC, Sept 18-19, 2013

In 2012 I established the Annual American Society of Pediatric Nephrology Multidisciplinary Symposium. I have been serving as the Symposium Director and Chair of the Organizing Committee since then. The Symposium offers continuing education credits to the attendees. It is attended by both national and international multidisciplinary pediatric nephrology teams, including TCH renal team members. This symposium is a very unique and only venue that provides an interactive forum for pediatric nephrology nurses, dietitians, social workers, child life, pharmacists and psychologists. To meet the needs of such a diverse audience, I have developed the meeting structure with a Keynote Speaker session, general and split sessions. I have also developed a highly innovative and valued session: "Patient and Family Panel", which brings in patient and caregiver experience to the attention of health care professionals. I am responsible for selecting the venue, topics and speakers, organizing poster sessions, leading conference calls with the Organizing Committee every 2 weeks, preparing call minutes, working on the save-the-date flier and the conference program, as well as coordinating program advertising with national organizations, and liaising with US and Canadian Division Directors. Active duties during the conference include overseeing logistics, introducing speakers, and ensuring timely execution. After the conference I send out thank you letters to the speakers, prepare after-meeting summary, review evaluations, prepare the written report to the American Society of Pediatric Nephrology (ASPN) Council and to the ASPN newsletter, and lead the conference call with Organizing Committee that evaluates the meeting and recommends any changes if needed.

Local:

1. Education Director, Renal Division, Texas Children's Hospital, May 2017-present
 - I developed educational curriculum for the Pediatric Nephrology Division, Texas Children's Hospital, Baylor College of Medicine, August 2017-present
 - In charge of the educational program for weekly divisional conferences, inviting speakers
2. In charge of developing Safety and Teaching as Resident Supervisors (STaR) rotation curriculum for 3rd year Pediatric Residents "Teaching How to Teach", Texas Children's Hospital, May 2015-present
 - I am in charge of schedule of monthly teaching sessions.
 - I developed 2 PowerPoint presentations used for TCH monthly teaching sessions for 3rd year Pediatric Residents on STaR Rotation: "Bedside Teaching" and "Lecture as a Teaching Tool"

3. Developed International Pediatric Nephrology Training Curriculum – Texas Children’s Hospital Experience, 2011-present
I am in charge of selecting and training of international applicants who seek experience in Pediatric Nephrology in the U.S.

B. Didactic Coursework (include dates, number of hours and approximate numbers of learners)

1. Courses Taught at BCM within the Primary Department
 - a. Developed formal teaching lectures for Residents rotating through Renal Service, 2001-2011
 - 1) Fluids and Electrolytes
 - 2) Renal Tubular Acidosis
 - 3) Nephrotic syndrome
 - 4) Renal transplant immunosuppression
 - 5) Cystinosis
 - 6) Proteinuria and hematuria
 - 7) VasculitisTeaching sessions offered for rotating TCH Residents either through renal elective rotation or with Renal Floor Service on the West Tower Floor Service (4-5 trainees)
 - b. Renal Educational Series, didactic teaching session for all pediatric residents and rotating students (30-40 attendees), Texas Children’s Hospital
 1. Hematuria and proteinuria - May 12, 2005, March 10, 2017, January 10, 2019
 2. Fluids and Electrolytes - May 10, 2007
 - c. Developed 2 PowerPoint presentations for TCH monthly teaching sessions for 3rd year Pediatric Residents on STaR Rotation “Teaching How to Teach”, May 2015 - present
 - 1) Bedside Teaching. **Ewa Elenberg**, MD, MEd, Deborah Hsu, MD, MEd
 - 2) Lecture as a Teaching Tool. **Ewa Elenberg**, MD, MEd, Deborah Hsu, MD, MEd
2. Courses Taught at BCM External to the Primary Department
 - a. Leading the Large Group Interactive Case Session for Renal Pathophysiology Course for the 2nd year medical students, BCM, September 24, 2014, September 24, 2015 and September 20, 2018
3. Courses Taught at Other Institutions While at BCM: none
4. Courses Taught Prior to BCM: none

C. Curriculum Development Work (include institution where work was done and whether work was disseminated beyond home institution)

1. Developed “International Pediatric Nephrology Training Curriculum – Texas Children’s Hospital Experience”, 2011
 - a. Role: In charge of the program, reviewing applications, designing the program depending on the individual needs, teaching and guiding
 - b. Who can apply: Foreign Pediatric Nephrology Fellows or Faculty who seek experience in Pediatric Nephrology in the U.S - Term of training: up to 3 months
 - c. Past Trainee: Pediatric Nephrology Fellow, Dr. Luciana Porini Custodio from University of Campinas, Brazil, January 8, 2013 - February 6, 2013
2. Developed “Teaching How to Teach Curriculum”, Texas Children’s Hospital, May 2015
Role: Developed innovative curriculum for the 3rd year Pediatric Residents Safety and Teaching as Resident Supervisors (STaRS) rotation, with two PowerPoint presentations for

“Teaching How to Teach” session, presented at monthly teaching sessions, May 2015- June 2020

- 1) Bedside teaching (**Elenberg E**, Hsu D)
- 2) Lecture as a Teaching Tool (**Elenberg E**, Hsu D)
- b. The teaching consists of monthly 1-hour teaching sessions for 3rd year TCH pediatric residents
- c. Audience: 3rd year TCH pediatric residents, monthly StaRS rotation
3. Pediatric Nephrology Educational Curriculum, Renal Division, Texas Children’s Hospital, Baylor College of Medicine, August 2017 - present
 - a. Role: Education Director, Renal Division
 - b. Developed educational curriculum for the Pediatric Nephrology Division
 - c. In charge of scheduling educational weekly sessions at Renal Division, selecting topics, inviting speakers, reviewing evaluation scores and sharing evaluation scores with the presenters

D. Non-didactic Teaching While at BCM

1. Resident Training (include estimate of time spent)
 - a. TCH Pediatric Resident mentoring:
 - 1) Coach for Steinkuller Fishman Society (20-25 members): January 2014-present
Time spent: 30 hours /year
 - 2) Jamie Varughese, 2004-2008. Time spent: 5 hours/year
 - 3) Jennifer Rha, 2020-present
 - 4) Evan Goldart, 2020-2021
 - b. TCH Bedside Teaching/Attending Rounds: 2001- present
 - 1) Outpatient Renal Clinics: Time spent: 80 hours /year
 - 2) Inpatient Rounds: Time spent: 12-15 weeks/year
 - c. Ben Taub General Hospital: 2001-2011
 - 1) Inpatient Renal consults/Resident teaching. Time spent: 8-10 weeks/year
 - 2) Outpatient Renal Clinic: Time spent: 8 weeks/year

2. Clinical Fellow Training (include names of fellows, dates, current location or position)

Name:	Dates of Training	Current Status
Allison Giglio	7/2024-present	Current Fellow, Baylor College of Medicine, Houston, TX
Golnaz Sadehiani	7/2023-present	Current Fellow, Baylor College of Medicine, Houston, TX
Bianca E Saenz	7/2023-present	Current Fellow, Baylor College of Medicine, Houston, TX
Ashna Podupakkam	7/2022-present	Current Fellow, Baylor College of Medicine, Houston, TX
Emily Frierson	7/2021-6/2024	Pediatric Nephrology Attending, Tampa, FL
Brandon Fairless	7/2021-6/2024	Pediatric Nephrology Attending, CHOP, Philadelphia, PA
Kim Vuong	7/2021-6/2024	Neonatology Fellow, Baylor College of Medicine, Houston, TX
Sameer Thadani (Critical Care Nephrology Fellow)	7/2021-6/2023	ICU Attending, Baylor College of Medicine, Houston, TX
Jonathan Chawla	7/2020-6/2023	Pediatric Nephrology Attending Baylor College of

Caroline Jarrell	7/2020-6/2023	Medicine, Houston, TX Pediatric Nephrology Attending Baylor College of Medicine, Houston, TX
Mugdha Rairikar	7/2020-6/2023	Assistant Professor of Pediatrics, Pediatric Nephrology Attending, Baylor College of Medicine, Houston, TX
Kristin Dolan (<i>Critical Care Nephrology Fellow</i>)	7/2020-6/2021	ICU Attending, Baylor College of Medicine, Houston, TX
Hura Kanwalgeet	1/2019-7/2019	Sleep Medicine Fellow, St Louis, MO
Kristianna Singh	7/2018-6/2022	Pediatric Nephrology Attending, Children's Hospital of Georgia, Augusta, GA
Joseph Alge	7/2018-8/2020	Assistant Professor of Pediatrics, Arkansas Children's Hospital, Little Rock, AR
Auda Plaud	7/2018-6/2021	Attending Nephrologist, Univeristy of Puerto Rico, San Jose, Puerto Rico
Yonique P. Petgrave	7/2017-6/2020	Attending Nephrologist, Dallas Children's Hospital, UT Southwestern, Dallas, TX
Alexandra C. Idrovo	7/2017-6/2020	Attending Nephrologist, Dallas Children's Hospital, UT Southwestern, Dallas, TX
Gina Nieto	7/2016-8/1/2019	Pediatric Nephrologist, Kelsey-Seybold, Houston, TX
Nour Abu Saleh	7/2016-12/2016	Pediatrician, Jordan
Walter Villar	7/2016-01/2017	Pediatrician, Spain
Neziha Celebi	7/2015-6/2018	Assistant Professor of Pediatrics, Pediatric Nephrology University of Maryland, Baltimore, MD
Peace Imani	7/2014-6/2017	Assistant Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Xiaoyna Wu	7/2014-6/2017	Clinical Associate Professor Department of Pediatrics, Division of Nephrology University at Buffalo, Buffalo, NY
Joseph Maliakkal	7/2014-6/2017	Assistant Professor of Pediatrics Pediatric Nephrology Cardinal Glennon Children's Hospital, St Louis, MO
Leyat Tal	7/2013- 6/2016	Assistant Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Adnan Safdar	7/2012-6/2015	Attending Pediatric Nephrologist, Abu Dhabi, UAE
Shweta Shah	7/2012-6/2015	Associate Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Marjorie Turner, MD	8/2011-6/2012	Pediatrician, Vidalia Children's Center, GA
Alvaro Orjuela	8/2011-8/2014	Assistant Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Wansheng Wang, MD	7/2010-3/2011	Hospitalist, Conroe Regional Medical Center, Conroe, TX
Miguel Prada, MD	7/2010-6/2012	Assistant Professor Department of Anesthesiology

Rachana Srivastava, MD	7/2010- 6/2013	Baylor College of Medicine, Houston, TX Assistant Professor of Pediatrics Pediatric Nephrology
Kimberly Burrows, MD	7/2009-6/2012	UCLA Mattel Children's Hospital, Los Angeles, CA Pediatric Nephrologist St Christopher Hospital, Philadelphia, PA
Joseph Angelo, MD (Critical Care Nephrology)	11/2009-9/2010	Associate Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Alyssa Riley, MD	7/2008-6/2011	Pediatric Nephrologist, Mercy Hospital, Toledo, OH
Yue Du, MD	9/2008-5/2009	Attending Nephrologist Shenyang, China
Jennifer Jetton, MD	7/2007-6/2010	Associate Professor of Pediatrics Renal Section, Department of Pediatrics University of Iowa, Iowa City, IA
Poyappakkam Srivaths, MD	7/2006-6/2009	Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Sarah Swartz, MD	7/2005-6/2008	Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Michele Zappitelli, MD (Critical Care Nephrology Fellow)	10/2005-6/2007	Associate Professor of Pediatrics Pediatric Nephrology, Sick Kids Hospital University of Toronto, Toronto, Canada
Jennifer Lennington, MD	7/2005-6/2008	Staff Pediatrician Community Health Clinic, Dorchester, MA
Ayse Arikan, M.D.	10/2004-2/2006 10/2011-8/2012	Associate Professor of Pediatrics Renal and Critical Care Section, Department of Pediatrics, Baylor College of Medicine, Houston, TX
David Askenazi, M.D.	7/2002-6/2005	Professor of Pediatrics Renal Section, Department of Pediatrics University of Alabama, Birmingham, Alabama
Mini Michael, M.D.	7/2000-12/2003	Associate Professor of Pediatrics Renal Section, Department of Pediatrics Baylor College of Medicine, Houston, TX
Vellore K Sairam, MBBS	7/1999-6/2001	Attending Nephrologist, Department of Nephrology, Sri Ramachandra University, India

3. International Fellow Training

- a. Mentored Marcin Zaniew, MD, PhD, Pediatric Nephrologist, Associate Professor, Chief of Department of Pediatrics, University of Zielona Gora, Poland. My role as a critical reviewer of the manuscript was acknowledged in a publication: Hypomagnesemia is underestimated in children with HNF1B mutations, published in Pediatric Nephrology, May 2020
- b. Mentored Luciana Porini Custodio, MD, Fellow Pediatric Nephrology, University of Campinas (Unicamp), Brazil, Jan 8 - Feb 6, 2013

- c. Mentored Indira Agarwal, MD, Pediatric Nephrologist, Professor and Head of Pediatric Nephrology, visiting from Christian Medical College, Vellore, India, January-March, 2009
 - d. Mentored Hakan Poyrazoglu, MD, Professor, Department of Pediatrics, visiting from Erclyes University School of Medicine, Kayseri, Turkey, June-July, 2008
 - e. Mentored Eva Simkova, MD, Associate Professor, Department of Pediatrics, visiting from Charles University, Prague, Czech Republic July-August, 2001
4. Research Fellow Training (as above)
- a. Mentored Angelina Dixon, MD, Med-Peds Renal Fellow in clinical research in Cystinosis, Children's Hospital Colorado, University of Colorado, Aurora, CO, 2022
 - b. Mentored Renal Fellow Xiaoyu Wu, MD
Wu X, **Elenberg E**. Successful Management of PR3 ANCA positive GPA: case report. Submitted to Pediatric Academic Societies/American Society of Nephrology meeting, San Francisco, May 5-9, 2017
 - c. Mentored Renal Fellow Neziha Celebi, MD in writing case report which has been accepted for 2 abstracts presentations
 - 1) Neziha Celebi N, Vallejo J, Geer J, **Elenberg E**. Recurrent Fevers in a Hemodialysis Patient: A Puzzle is Solved. Abstract accepted for presentation, Annual Dialysis Conference Seattle, Washington, Feb 27-March 1, 2016
 - 2) Celebi N, Vallejo J, Eckstein O, Geer J, **Elenberg E**. Hemophagocytic Lymphohistiocytosis Secondary to Histoplasmosis in Renal Transplant Patient. Poster presented at the International Pediatric Nephrology Association, Iguazu Falls, Brazil, September 20-24,2016
 - c. Mentored Renal Fellow, Shweta Shah, MD in writing case report which has been accepted for abstract presentation
Shah S., Srivaths P, **Elenberg E**. Myocardial Infarction in Dialysis Patient. Abstract. 34th Annual Dialysis Conference, Atlanta, GA, February 8-11, 2014
 - d. Research Mentor of Miguel Prada, MD, Renal Fellow 2010-2012
Membranous glomerulonephritis, Texas Children's Hospital 20 years experience.
 - e. Mentored Renal Fellow Poyappakkam Srivaths, MD in writing case report which has been published
Poyyapakkam S, Dishop MK, Elidemir O, Eldin K, Browne L, **Elenberg E**. IgA nephropathy Presenting with Renal Failure and Pulmonary Hemorrhage. *Pediatr Nephrol* 25: 535, 2010
 - f. Fellowship advisor and mentor of Jennifer Lennington, MD in clinical research project
Alport's syndrome-practice guidelines, 2007-2008
 - g. Mentored Renal Fellow David Askenazi, MD, in a clinical research project which has been published
Askenazi DJ, Goldstein SL, Chang IF, **Elenberg E**, Feig DI. Management of a Severe Carbamazepine Overdose Using Albumin-Enhanced Continuous Veno-Venous Hemodialysis. *Pediatrics* 113: 406-409, 2004
5. Graduate Student Training
- a. Leading the Renal Large Group Case Sessions, Pathophysiology Course, BCM, September 20, 2018
Moderating 2 hrs. Session for the 2nd year student group consisting of >30 students
 - b. Leading the Renal Large Group Case Sessions, Pathophysiology Course, BCM, September 21, 2017
Moderating 2 hrs. Session for the 2nd year student group consisting of >30 students

- c. Graduate Student Mentoring - Volunteered to Specialty Faculty Liaison, Pediatric Nephrology, BCM, 2015- present
 - d. Leading the Renal Large Group Case Sessions, Pathophysiology Course, BCM, September 24, 2015
Moderating 2 hrs. Session for the 2nd year student group consisting of >30 students
 - e. Leading the Renal Large Group Case Sessions, Pathophysiology Course, BCM, September 24, 2014
Moderating 2 hrs. Session for the 2nd year student group consisting of >30 students
 - f. Volunteering for the PPS Session (Physician, Patient and Society Pediatric Exam), BCM, Nov 29, 2012.
Leading a group of medical students, demonstrating history taking and physical exam on patients who approved to be seen and supervising the students
 - g. APEX: MS2MD course for graduating medical students – “Overcoming Obstacles”, BCM, March 5, 2012
Facilitator for a small group session for about 20 participants
6. Medical Student Mentoring
- a. Honors Premedical Academy Preceptorship
 - 1) JAMP (Joint Admission Medical Program)
 - a. Anna Chun-Chia Tseng, University of Texas at Austin, June 7-30, 2011
 - 2) PHC (Premedical Honors College)
 - a. Crysta Moreno-Current, June 5-30, 2012
 - b. Hazel Severino, June 8-24, 2010
 - c. Antara Banik, June 8-24, 2010
 - d. Jazmin Gonzalez, June 2-25, 2009
 - e. Nieto Bryant, June 2-25, 2009

E. Faculty Development or Continuing Medical Education (list contributions as a course developer, presenter, etc.)

- 1. Director of Annual ASPN Multidisciplinary Symposium (National and International: USA/Canada) and Chair of the Organizing Committee, 2012-present
 - 1) 12th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 7-8, 2024
 - 2) 11th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 9-10, 2023
 - 3) 10th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 17-18, 2022
 - 4) 9th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 18-19, 2021
 - 5) 8th Annual ASPN Multidisciplinary Symposium, VIRTUAL, November 12-13, 2020
 - 6) 7th Annual ASPN Multidisciplinary Symposium, Bally’s Las Vegas Hotel, Las Vegas, NV, September 12-13, 2019
 - 7) 6th Annual ASPN Multidisciplinary Symposium, Doubletree by Hilton Hotel, Washington, DC October 11-12, 2018
 - 8) 5th Annual ASPN Multidisciplinary Symposium, Warwick Melrose Hotel, Dallas, TX, October 19-20, 2017
 - 9) 4th Annual ASPN Multidisciplinary Symposium, Hilton Netherland Plaza Hotel, Cincinnati, OH, October 20-21, 2016
 - 10) 3rd Annual ASPN Multidisciplinary Symposium, Marriott Hotel, New York, NY, October 12, 2015
 - 11) 2nd Annual ASPN Multidisciplinary Symposium, Seattle Children’s Research Institute,

Seattle, WA, September 5-6, 2014

- 12) 1st Annual ASPN Multidisciplinary Symposium, Marriott City Center Hotel Charlotte, NC, September 18-19, 2013

In 2012 I established the Annual American Society of Pediatric Nephrology Multidisciplinary Symposium. I have been serving as the Symposium Director and Chair of the Organizing Committee since then. The Symposium offers continuing education credits to the attendees. It is attended by both national and international multidisciplinary pediatric nephrology teams, including TCH renal team members. This symposium is a very unique and only venue that provides an interactive forum for pediatric nephrology nurses, dietitians, social workers, child life, pharmacists and psychologists. To meet the needs of such a diverse audience, I have developed the meeting structure with a Keynote Speaker session, general and split sessions. I have also developed a highly innovative and valued session: "Patient and Family Panel", which brings in patient and caregiver experience to the attention of health care professionals. I am responsible for selecting the venue, topics and speakers, organizing poster sessions, leading conference calls with the Organizing Committee every 2 weeks, preparing call minutes, working on the save-the-date flier and the conference program, as well as coordinating program advertising with national organizations, and liaising with US and Canadian Division Directors. Active duties during the conference include overseeing logistics, introducing speakers, and ensuring timely execution. After the conference I send out thank you letters to the speakers, prepare after-meeting summary, review evaluations, prepare the written report to the American Society of Pediatric Nephrology (ASPN) Council and to the ASPN newsletter, and lead the conference call with Organizing Committee that evaluates the meeting and recommends any changes if needed.

2. Presenter at national CME-approved conferences:

- 1) Pathogenesis and Clinical Manifestations of Cystinosis. CME-approved symposium: Cystinosis: What the Adult Nephrologist Needs to Know. American Society of Nephrology (ASN) Kidney Week 2015, ASN Annual Meeting, San Diego, November 6, 2015
- 2) Nephropathic Cystinosis: Clinical Challenges and Emerging Opportunities. CME approved Symposium: On the Edge: Frontiers in CKD. American Nephrology Nurses Association (ANNA), Galveston, TX, February 7, 2015
- 3) Cystinosis - Living with Chronic Illness/Focus on Cystinosis, patient and family panel. 2nd Annual ASPN Multidisciplinary Symposium. Seattle, Washington, September 5-6, 2014
- 4) The Changing Face of Nephropathic Cystinosis: Clinical Challenges and Emerging Opportunities. CME-approved symposium: Epidemiology, Pathophysiology, and Clinical Diagnosis of Nephropathic Cystinosis: State of the Art. American Nephrology Nurses Association (ANNA), Anaheim, CA, April 13, 2014
- 5) Quality of Life in Children with Chronic Illness. 1st Annual ASPN Multi-Disciplinary Symposium, Charlotte, North Carolina, September 19-20, 2013
- 6) Cystinosis in 2013: State of the Art and Case-Based Approaches for screening, diagnosis and long-term management. CME-approved symposium: "Diagnostic challenges, clinical conundrums, and long-term outcome measures in patients with Cystinosis". Pediatric Academic Societies (PAS), Washington, DC, May 5, 2013
- 7) What's new in Cystinosis. Pediatric Nephrology Seminar XXXIII, Miami, FL, March 10-14, 2006

3. Involvement with the Courses at Baylor College of Medicine

- 1) Leading the Renal Large Group Session for the Pathophysiology Course (for the 2nd year student group consisting of >30 students). I was in charge to prepare pediatric nephrology cases

- and to review prepared topics by the Course Director
- a. September 20, 2018 - moderating 2 hrs. session
 - b. September 21, 2017 - moderating 2 hrs. session
 - c. September 24, 2015 - moderating 2 hrs. session
 - d. September 24, 2014 - moderating 2 hrs. session
- 2) Volunteer for the PPS session (Physician, Patient and Society Pediatric Exam) - Leading a group of medical students, demonstrating history taking and physical exam on patients who approved to be seen and supervising the students, November 29, 2012
 - 3) Volunteer at the APEX: MS2MD course for graduating medical students – “Overcoming Obstacles” (a small group session facilitator, about 20 participants), March 5, 2012
 - 4) Abstract reviewer for 2020 Annual Showcase of Educational Scholarship, Academy of Distinguished Educators, BCM, August 2020

F. Lectures and Presentations

1. International

All international invited lectures are listed in II.B.5

2. National

All national invited lectures are listed in II.C.3

3. Regional:

- 1) Cystinosis overview. Cystinosis Research Network, Texas Regional Patient Education Seminar, Houston, TX, December 4, 2014
- 2) Renal transplantation in nephrotic syndrome and FSGS. NephCure Foundation, Patient Education Seminar, Houston, TX, October 24, 2009
- 3) Obstructive nephropathy in infants and children. Pediatric Grand Rounds, Texas Children’s Hospital, Baylor College of Medicine, Houston, TX, August 28, 2009
- 4) Cystinosis- from genetics to patients’ quality of life. Pediatric Grand Rounds, Texas Children’s Hospital, Baylor College of Medicine, Houston, TX, August 14, 2009
- 5) Cystinosis. Seminars for Nephrology and Endocrine Nurses of Houston, Houston, TX, Dec 10, 2008
- 6) Dysfunctional Voiding in Children, Pediatric Grand Rounds, Texas Children’s Hospital, Baylor College of Medicine, February 24, 2006
- 7) Nephrotic syndrome. Pediatric Grand Rounds, Texas Children’s Hospital, Baylor College of Medicine, March 22, 2002

4. Local

- 1) Fluids and electrolytes. Pediatric Residency Program Teaching Series, Texas Children’s Hospital, Baylor College of Medicine, Houston, TX, January 6, 2025
- 2) Cystinosis and Fanconi syndrome. Renal Educational Series, Renal Division, Texas Children’s Hospital, Baylor College of Medicine, Houston, TX, November 16, 2021
- 3) Cystinosis update- Renal Nurses Educational Conference, Texas Children’s Hospital, Baylor College of Medicine, Houston, TX, Sept 23, 2021
- 4) Teaching, Feedback and evaluation. Renal Educational Series, Renal Division, Texas Children’s Hospital, Baylor College of Medicine, Houston, TX, December 10, 2020
- 5) Fanconi syndrome. Renal Educational Series, Renal Division, Texas Children’s Hospital, Baylor College of Medicine, Houston, TX, May 19, 2020

- 6) Nephropathic cystinosis. Renal Educational Series, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, May 12, 2020
- 7) Cystinosis. TCH Renal Multidisciplinary Conference – Lunch and Learn, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, February 5, 2019
- 8) Hematuria and proteinuria. Renal Educational Series, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, January 10, 2019
- 9) Hematuria and proteinuria, TCH Urology Educational Series, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, October 31, 2018
- 10) Membranoproliferative glomerulonephritis, Case Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, September 6, 2018
- 11) Fanconi syndrome. Renal Educational Series, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, May 1, 2018
- 12) Cystinosis, Renal Educational Series, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, April 17, 2018
- 13) Immune mediated renal injury, Renal Educational Series, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, February 13, 2018
- 14) How to Give Feedback. TCH training session for Feedback Renal Team, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, October 30, 2017
- 15) Obstructive nephropathy. Fellows Teaching Conference, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, April 18, 2017
- 16) Hematuria and proteinuria. Renal Educational Series, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, March 10, 2017
- 17) Immune mechanisms of renal injury. Fellows Teaching Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, November 08, 2016
- 18) Hematuria and proteinuria. Renal Educational Series, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, Dec 18, 2015
- 19) Lecture as an educational tool. Professional Development Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, July 17, 2014
- 20) Update on Cystinosis. Fellows Teaching Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, May 22, 2014
- 21) Immune mediated renal injury. Fellows Teaching Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, April 17, 2014
- 22) Congenital Nephrotic syndrome. Ask an expert - Neonatology Teaching Conference, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, March 18, 2014
- 23) Renal transplant immunosuppressive therapy. Fellows Teaching Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, January 16, 2014
- 24) Comprehensive overview of Cystinosis – Part 2. Fellows Teaching Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, December 13, 2012
- 25) Comprehensive overview of Cystinosis – Part 1. Fellows Teaching Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, October 4, 2012
- 26) Antibody Mediated Renal Transplant Rejection. Fellows Teaching Conference, Renal Division, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, Sept 13, 2012
- 27) Cystinosis in children. Lunch and Learn, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, July 13, 2012
- 28) Igniting Your Presentation. Medical Education Seminar, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, April 19, 2012
- 29) Chronic kidney disease and perioperative optimization of care. Pediatric Anesthesiology

- Fellows and Faculty Conference, Baylor College of Medicine, Houston, TX, April 10, 2012
- 30) Myocardial infarction in ESRD patient. Surgical Morbidity and Mortality Rounds, Department of Surgery, Texas Children's Hospital, Baylor College of Medicine, Houston, TX May 13, 2011
 - 31) Fanconi Syndrome. Clinical Genetics Conference Series, Department of Molecular and Human Genetics, Baylor College of Medicine, Houston, TX, October 25, 2010
 - 32) Immune mediated renal disease. Allergy and Immunology Conference, Section of Allergy and Immunology, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, April, 21, 2009
 - 33) Nephropathic Cystinosis. Renal Dialysis Unit, Lunch and Learn, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, October 22, 2008
 - 34) Fluids and Electrolytes. Pediatric Residency Program Teaching Series, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, May 10, 2007
 - 35) Hematuria – Board Review. Pediatric Residency Program Teaching Series, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, May 12, 2005
 - 36) Immunosuppressive medications in renal transplantation. Pediatric Critical Care Fellows Teaching Series, Section of Pediatric Critical Care, Texas Children's Hospital, Baylor College of Medicine, Houston, TX, April 19, 2005

G. Visiting Professorships: Not Applicable

IV. PATIENT CARE AND CLINICAL CONTRIBUTIONS

A. Patient Care Responsibilities

1. Department-wide:
 - 1) Attending Physician, Pediatrics
 - a. Texas Children's Hospital, 2001-present
 - b. Ben Taub General Hospital, 2001-2011
 - c. Co-Founder of Urology/Nephrology Multidisciplinary Stone Clinic, March 2013-Aug 2016
2. Section or Specialty:
 - 1) Attending Physician, Renal Service, Texas Children's Hospital
 - a. Inpatient Renal Service Attending: 13-15 weeks per year
 - b. Attending Physician Renal Dialysis/Pheresis Unit, Texas Children's Hospital: 6-10 weeks per year covering chronic hemodialysis and pheresis patients
3. Clinical Service: Renal Outpatient Clinic
 - a. Attending Physician Renal Outpatient Clinic: Two (one-half day) clinic per week
 - b. Chronic Dialysis Clinic Attending Physician: 15 to 20 hours/month
 - c. Stone Outpatient Clinic Attending Physician: Once a month one-half day clinic
 - d. Elected by the International Patient Services Department at Texas Children's to service all international referrals for renal consultations, April 2012-present
Consulting on annual basis ~40 new international patients' referrals and ~50 follow up visits
 - d. Attending Physician, Renal Service, Ben Taub General Hospital, 2001-2011
Inpatient consult service: 8-10 weeks/year, Outpatient Renal Clinic: 4-8 weeks/year

B. Clinical Leadership or Business Development (describe roles and documented outcomes)

1. Education Director, Renal Division, May 2017-present
2. Co-Founder of Urology/Nephrology Multidisciplinary Stone Clinic, March 2013-Aug 2016

3. Renal Consulting Physician for International Referrals, Texas Children's Hospital, April 2012-present
4. Development of Durable Educational Materials
 - 1) Co-author of Cystinosis Information for Medical Professionals, revised update 2017
 Gahl WA, Kaskel F, Langman CB, Mannon RB, Richard H. Simon RH, Jess G. Thoene JG, Antignac C, Bishop R, Cairns D, Dohil R, **Elenberg E**, Gipson P, Goodyer P, Greenbaum L, Ingelfinger JR, Nesterova G, Sarwal M, Thacker MM, Susan E. Thomas SE, Trauner DA, Doyle M. Cystinosis Information for Medical Professionals
 This is a 10-page brochure developed and updated by the Cystinosis Research Network Scientific Review Board. This brochure is distributed to medical professionals at major scientific meetings: American Society of Nephrology, American Society of Pediatric Nephrology, American Academy of Pediatrics, etc.
 - 2) Co-author of Atlas of Common Kidney Diseases, 2016
 Michael M, **Elenberg E**, Kale AS. Atlas of Common Kidney Diseases for Clinicians.
 This is 165 page script for clinicians, used a teaching tool for residents, fellows and patients, available at Renal S-drive as computer based learning tool as well in printed form, distributed at the Renal Clinic and inpatient 12th floor as a teaching tool for the residents.
 - 3) Development of two PowerPoint presentations for the 3rd year Pediatric Residents Safety and Teaching as Resident Supervisors (STaRS) rotation, "Teaching How to Teach" session, presented at monthly teaching sessions, May 2015
 1. Lecture as a Teaching Tool. **Ewa Elenberg**, MD, MEd, Deborah Hsu, MD, MEd
 2. Bedside Teaching. **Ewa Elenberg**, MD, MEd, Deborah Hsu, MD, MEd
 - 4) Co-author of A Handbook of Kidney Stones in Children, 2015
 Michael M, Janzen N, Moreno L, Bekheirnia MR, **Elenberg E**.
 This is 48 page script, available through www.texaschildrens.org/kidneystones-handbook
 - 5) Co-author of Cystinosis Transition Management Tool, 2015
 Kaskel F, Bishop R, Dohil R, Doyle M, **Elenberg E**, Goodyer P, Greenbaum L, Knerr, Levchenko E, Mahgerefteh J, Mannor R, Moreno L, Nesterova G, Simon R, Thacker M, Trauner D. Cystinosis Transition Management Tool.
 This is 14 page document, printed and distributed at the major international meetings, including American Society of Nephrology meeting annually since 2015, attended by ~ 14000 nephrologists from around the world, and available as electronic version at the Cystinosis Research Network website.
 - 6) Co-author of First Febrile Urinary Tract Infection (UTI), revised update 2015
 Franklin Q, Jones E, Palazzi D, Cruz A, Orth R, Singhal G, Laster R, Haney H, Kim S, **Elenberg E**, Wiener S, Anderson M, Gregg L, Schaumburg D, Wuestner L, Macias. First Febrile Urinary Tract Infection (UTI). Content Expert Team Members.
 This is TCH web-based joint effort of Evidence-Based Outcomes Center Team and Content Expert Team at Texas Children's Integrated Delivery System. The content is displayed on TCH website.
 - 7) Co-author and presenter of Cystinosis in 2013: State of the Art and Case-based Approaches for Screening, Diagnosis, and Long-term Disease Management, 2013
 Langman CB, **Elenberg E**, Levchenko E, Goodyer PR. Cystinosis in 2013: State of the Art and Case-based Approaches for Screening, Diagnosis, and Long-term Disease Management.
 Presented initially at PAS meeting, Washington, DC, May 5, 2013. CME Program jointly sponsored by Colorado Foundation for Medical Care and Cornerstone Medical Communications. This is a web-based educational training module for cystinosis.

- 8) Living with Cystinosis: A Closer Look, 2013
Elenberg E. Living with Cystinosis: A Closer Look
 Presenter in educational video about cystinosis, distributed among cystinosis community and available on the website
- 9) Co-author of First Febrile Urinary Tract Infection (UTI). 2012
 Franklin Q, Jones E, Palazzi D, Cruz A, Orth R, Singhal G, Laster R, Haney H, Kim S,
Elenberg E, Wiener S, Anderson M, Gregg L, Schaumburg D, Wuestner L, Macias. First Febrile Urinary Tract Infection (UTI). Content Expert Team Members.
 This is TCH web-based joint effort of Evidence-Based Outcomes Center Team and Content Expert Team at Texas Children's Integrated Delivery System. The content is displayed on TCH website.
- 10) Co-author of Cystinosis Information for Medical Professionals, 2010
 Gahl WA, Kaskel F, Langman CB, Mannon RB, Richard H. Simon RH, Jess G. Thoene JG, Antignac C, Bishop R, Cairns D, Dohil R, **Elenberg E**, Gipson P, Goodyer P, Greenbaum L, Ingelfinger JR, Nesterova G, Sarwal M, Thacker MM, Susan E. Thomas SE, Trauner DA, Doyle M. Cystinosis Information for Medical Professionals, 2010
 This is a 10-page brochure developed and updated by the Cystinosis Research Network Scientific Review Board. This brochure is distributed to medical professionals at major scientific meetings: American Society of Nephrology, American Society of Pediatric Nephrology, American Academy of Pediatrics, etc.

C. Voluntary Health Organization Participation

1. Global Genes, 2014
 Invited by Global Genes to present at Cystinosis Patient Support Group Meeting, 2014
 - a) Overview of cystinosis. Cystinosis Teen Adventure. Los Angeles, October 10-11, 2014
 - b) Adherence in adolescents and adults. Cystinosis Teen Adventure. Los Angeles, October 10-11, 2014
 - c) Endocrinologic complications in cystinosis. Cystinosis Teen Adventure. Los Angeles, October 10-11, 2014
2. NephCure Foundation, 2009
 Invited by NephCure Foundation to present at the NephCure Family Conference Houston 2009
 - a) Renal transplantation in nephrotic syndrome and FSGS at the Patient Education Seminar, Houston, TX, October 24, 2009
3. Nephrology and Endocrine Nurses of Houston, 2008
 Invited to present at Nephrology and Endocrine Nurses Seminar
 - a) Cystinosis. Nephrology and Endocrine Nurses Seminar, Houston, TX, Dec 10, 2008
4. Association of Clinical Scientists, 2006-2011
 Invited to present at the Annual Meeting:
 - a) Pulmonary-renal syndrome - IgA nephropathy presenting with renal failure and pulmonary hemorrhage. 129th Annual Meeting, Association of Clinical Scientists, Tampa, FL, May 13-16, 2009
 - b) Immune complex glomerulonephritis in two Wilms tumor patients. 127th Annual Meeting, Association of Clinical Scientists, Hershey, PA, May 19 2007
5. Cystinosis Association of Mexico (Association Mexicana de Cistinosis AC), Elected Member of International Committee, 2006-present
 Invited to present at the meetings in Mexico City:

- a) Adherence Issues in Cystinosis. 8th Cystinosis Symposium, Mexico City, Mexico, August 5, 2016
 - b) Gastrointestinal Manifestations in Cystinosis. 8th Cystinosis Symposium, Mexico City, Mexico, August 5, 2016
 - c) Endocrinologic complications in cystinosis. 7th Cystinosis Symposium, Mexico City, Mexico, August 15, 2014
 - d) Cystinosis Overview. 7th Cystinosis Symposium, Mexico City, Mexico, August 15, 2014
 - e) Fanconi syndrome. 6th Cystinosis Symposium, Mexico City, Mexico, August 16-17, 2012
 - f) Overview of cystinosis. 6th Cystinosis Symposium, Mexico City, Mexico, August 16-17, 2012
 - g) Life and success of the patient with cystinosis. 6th Cystinosis Symposium, Mexico City, Mexico, August 16-17, 2012
 - h) Living with Cystinosis. 4th Cystinosis Symposium, Mexico City, Mexico, January 25, 2007
 - i) Therapy in Cystinosis. 4th Cystinosis Symposium, Mexico City, Mexico, January 25, 2007
 - j) Renal transplantation in Cystinosis. 3rd Cystinosis Symposium, Mexico City, Mexico, January 24, 2006
 - k) Polytherapy in Cystinosis 3rd Cystinosis Symposium, Mexico City, Mexico, January 24, 2006
 - l) Fanconi syndrome in Cystinosis. 3rd Cystinosis Symposium, Mexico City, Mexico, January 24, 2006
6. Cystinosis Research Network, Elected Member of Medical Advisory Committee, 2003-present
Invited by CRN to present at multiple meetings:
- a) Invited presenter at Panel Session, Caregiver/infant and Child (0-10): Cystinosis 101; Cystinosis Research Network Meeting (CRN) Virtual meeting July 16-18, 2021
 - b) Invited presenter at Panel Session, Teenager (11-17): Transplant and Dialysis Cystinosis 101; Cystinosis Research Network Meeting (CRN) Virtual meeting July 16-18, 2021
 - c) Management of failure to thrive in cystinosis. Cystinosis Research Network Meeting (CRN), Philadelphia, PA, July 18-20, 2019
 - d) Understanding Cystinosis. Cystinosis Conference, Houston, TX, September 8, 2018
 - e) Chronic kidney disease and renal transplant outcomes in patients with cystinosis. Cystinosis Research Network Meeting (CRN), Snowbird, UT, July 13-15, 2017
 - f) Adherence Issues in Cystinosis. Cystinosis Research Network Meeting (CRN), Chicago, July 16-18, 2015
 - g) Gastrointestinal Manifestations in Cystinosis. Cystinosis Research Network Meeting (CRN), Chicago, July 16-18, 2015
 - h) Cystinosis Overview, Texas Regional Patient Education Seminar, Houston, TX, December 4, 2014
 - i) Childhood Cystinosis Issues. Cystinosis Research Network Meeting (CRN), Workshop, Washington, DC, July 20, 2013
 - j) Fanconi syndrome. Cystinosis Research Network Family Conference, Atlanta, GA, July 16-18, 2009
 - k) Fanconi syndrome and its treatment. Cystinosis Research Network Meeting (CRN), San Antonio, TX, July 19-21, 2007
 - l) Polytherapy in Cystinosis. Cystinosis Research Network Meeting (CRN), Snow Bird, Utah, July 28-30, 2005
- 6 Cystinosis Foundation, Elected Member of Medical Advisory Board, 1995-1997
Invited by the Cystinosis Foundation to present:
- a) Gastrointestinal dysfunction in Cystinosis, Cystinosis Foundation Annual Meeting, Boston, MA, July 3-6, 1996

D. Contributions, Initiatives or Recognition Related to Patient Safety and Healthcare Quality (include information about implementation, outcomes or dissemination, where applicable)

1. Member of Transplant Morbidity and Mortality Team, 2018-present
2. Member of Clinical Competency Committee, Pediatric Residency Program, Texas Children's Hospital, 2014-present
The Committee reviews the individual resident milestones, discusses residents subcompetency scores and identifies those residents who need assistance
3. Member of CME Committee, Texas Children's Hospital, 2006-present
The Committee meets on regular basis several times per year, reviewing the scores, evaluations and feedback from CME conference attendees, develops new regulatory guidelines for up CME applications. As the Committee member I review and validate submitted applications for proposed CME activity to make sure that the application is consistent with TCH CME policies. I have been the member of this committee since inception
4. Member of Grand Rounds Committee, Texas Children's Hospital, 2005-present
5. Member of Dialysis Quality and Performance Improvement (QAPI), 2001-present
Renal Division monthly meetings discussing lab results, establishing benchmark, comparing with national guidelines, implementing new projects leading to improvement of overall dialysis care,
6. Member of Transplant Medical Review Board (MRB), 2001-present
Monthly meetings with multidisciplinary renal transplant team members, presenting and reviewing candidates for transplant and individual transplanted patient outcomes

E. Contributions to Health and Science Policy (institutional, regional, state, or federal level)

1. Invited speaker and participant at the International Expert Symposium to establish International Consensus on Diagnosis and Therapeutic Approach to Cystinosis Bone Disease, Salzburg, Austria, December 8-10, 2016
2. Invited to participate at the International Expert Symposium to establish the International Consensus on Diagnosis and Treatment of Cystinosis Eye Disease "Cystinosis Ophthalmological Symposium for Patients and Physicians", Salzburg, Austria, October 8-10, 2015
3. Elected to the International Services Advisory Council, Texas Children's Hospital, 2015-present
4. Invited by Kidney Disease: Improving Global Outcomes (KDIGO) to participate at the international expert group on Cystinosis to establish international guidelines: "Controversies Conference on Nephropathic Cystinosis", Lisbon, Portugal, December 11-13, 2014
5. Member of UTI Content Expert Team, Evidence Based Outcomes Center, Texas Children's Hospital, 2010-present (updates: 2010, 2015, 2021) - most recent update July 2021

V. SERVICE CONTRIBUTIONS

A. Administrative Assignments and Committees:

1. Department Administration, Committees, etc.
 - 1) Member of the Pediatrics Core Subspecialty Rotation Committee, Texas Children's Hospital, 2017-present
 - 2) Chair of the Renal Education Committee, Texas Children's Hospital, Nov 2017-present
 - 3) Elected to the International Services Advisory Council, Texas Children's Hospital, 2015-present

- 4) Member of External Relationships Sub-Committee, International Services Advisory Council, Texas Children's Hospital, 2016-present
 - 5) Member of Clinical Competency Committee, Pediatric Residency Program, Texas Children's Hospital, 2014-present
 - 6) Member of UTI Content Expert Team, Evidence Based Outcomes Center, Texas Children's Hospital, 2010-present (most recent update 2015)
 - 7) Member of CME Committee, Texas Children's Hospital, 2006-present
 - 8) Member of Grand Rounds Committee, Texas Children's Hospital, 2005-present
2. College, School or University Administration, Committees, etc.
 - 1) Upon recommendation of the Chair, appointed by the BCM Provost as a member of the Selection Committee for Baylor's Norton Rose Fulbright Faculty Excellence Award, Baylor College of Medicine, 2019-2021
 - 2) Appointed member of the Early Career and Star Awards Selection Committee, Baylor College Of Medicine, 2017-2018
 - 3) Elected to the Executive Board of Admissions Committee, Baylor College of Medicine, 2014 present
 - 4) Member of 4th Year Curriculum Revision Task Force, Baylor College of Medicine, 2007- 2008
 - 5) Member of Admissions Interviewing Subcommittee, Baylor College of Medicine, 2002-present

B. National, Regional or Local Participation in Professional or Voluntary Organizations

1. International Educational and Voluntary Service
 - 1) Invited Chair, The International Pediatric Nephrology Association Scientific Session: Tubular Defects 1, Venice, Italy, October 18, 2019
 - 2) Invited Chair, European Society of Pediatric Nephrology Scientific Session: Understanding tubular physiology to improve patient care, Glasgow, United Kingdom, September 9, 2017
 - 3) Invited to moderate European Society of Pediatric Nephrology new oral electronic Poster Session on: E-poster oral session TH6- Tubular disorders, Glasgow, United Kingdom, September 7, 2017
 - 4) Invited to present at the International Expert Symposium to establish International Consensus on Diagnosis and Therapeutic Approach to Cystinosis Bone Disease, Salzburg, Austria, December 8-10, 2016
 - 5) Invited to participate at the International Expert Symposium to establish the International Consensus on Diagnosis and Treatment of Cystinosis Eye Disease "Cystinosis Ophthalmological Symposium for Patients and Physicians", Salzburg, Austria, October 8-10, 2015
 - 6) Invited by Kidney Disease: Improving Global Outcomes (KDIGO) to participate at the international expert group on Cystinosis to establish international guidelines: "Controversies Conference on Nephropathic Cystinosis", Lisbon, Portugal, December 11-13, 2014
 - 7) Invited Chair, 45th Annual Meeting of European Society for Pediatric Nephrology (ESPN), Dialysis Symposium, Krakow, Poland, September 6-8, 2012
 - 8) Invited Chair, 37th Annual Conference of the European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure, Krakow, Poland, June 8-10, 2006
 - 9) International Advisor of Cystinosis
 - a. Annual Medical Charity Travel to Mexico City to educate patients and doctors in different aspects of cystinosis and clinical consulting of cystinosis patients, Mexico City, Mexico,

2006-2016

- b. Web-based advisor for international cystinosis patients and medical professionals involved with Cystinosis, 2001-present

2. National

- 1) North American Pediatric Renal Trials and Collaborative Studies (NAPRTCS), Cystinosis Working Group, Co-author of Cystinosis Registry and data collection, 2018-present
- 2) American Society of Pediatric Nephrology Board Review Course. Editor of educational materials, presentations and sample questions, 2018-present
- 3) Invited Chair, Pediatric Academic Societies (PAS) Symposium: Cystinosis: The Evolution of a Rare Disease, San Francisco, CA, May 6, 2017
- 4) The founder and the Symposium Director and a Chair of the Organizing Committee of American Society of Pediatric Nephrology Multidisciplinary Symposium, 2012-present
- 5) Cystinosis Research Network (CRN), 2001-present
 - a) Member of Medical Advisory Committee, 2003-present
 - b) Support Group Website based cystinosis patient advisor, 2001-present
- 6) Association of Clinical Scientists, 2006-2011
- 7) National Kidney Foundation (NKF), 2001-present
- 8) American Society of Nephrology (ASN), 1997- present
- 9) American Society of Pediatric Nephrology (ASPN), 1994-present
 - a) ASPN Council Member, July 2018- July 2020
 - b) Senior Chair of ASPN Global Health Committee, January 2018- June 2019
 - c) ASPN Global Health Committee, member, December 2017-present
 - d) ASPN Education Committee, member, July 2014-present
 - e) ASPN Nominations Committee, member, 2013-2014
 - f) Chair of Membership Committee, July 2012-July 2015
 - g) ASPN Texas Liaison 2009-present
 - h) ASPN Website Committee Liaison, 2009-2015
 - i) Member of ASPN Membership Committee, 2006-present
 - j) Member of ASPN Workforce Committee, 2006-2009
- 9) Cystinosis Foundation, 1994-1999
- 10) American Academy of Pediatrics (AAP), 1991-2007 and 2011-present

3. Local:

- 1) Member of the Wellness Committee, Renal Section, Texas Children's Hospital, 2023-present
- 2) Member of the Global Health Journal Club, Texas Children's Hospital, 2011-present
- 3) Member of Academy of Distinguished Educators, BCM, 2011-present
 - a. Abstract reviewer for 2020 Annual Showcase of Educational Scholarship

C. Other Pertinent Information (not given above, including community service)

1. Languages:

- 1) Fluent in English and Polish
- 2) Conversant in Spanish, German, Russian
- 3) Knowledge of French, Latin, ancient Greek