

BECKY BARNES

Curriculum Vitae: July 2026

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EDUCATION

Master of Social Work (MSW), Advanced Standing

University of Kentucky – Lexington, KY

Completed May 2026 | GPA: 4.0

Graduate Certificate in Developmental Disabilities – Completed May 2026

Bachelor of Social Work (BSW), Summa Cum Laude

Eastern Kentucky University – Richmond, KY

May 2025 | GPA: 4.0

President's Award | Dean's List (all semesters)

Associate of Arts (AA)

Bluegrass Community & Technical College – Lexington, KY

August 2023

Completed two years of nursing school with clinical rotations

Diploma in Massage Therapy

Lexington Healing Arts Academy – Lexington, KY

August 2012 | 750-hour program

Specialized in oncology massage therapy and chronic illness support

RESEARCH INTERESTS

- Accessibility, affordability, and quality of care for patients and families in rural Appalachia, with emphasis on cancer, chronic illness, and aging populations.
- Patient engagement methodologies in rare disease research and health technology assessment (HTA).
- Biopsychosocial factors and Social Determinants of Health (SDoH) influencing underserved populations in Eastern Kentucky.

POLICY LEADERSHIP & LEGISLATIVE IMPACT

Federal and State Legislative Advocacy – 15+ years of advocacy in Frankfort, KY, and Washington, D.C., as a volunteer Legislative Patient Advocate with the National Patient Advocate Foundation (2009–Present)

- **Medical Debt Relief Act (H.R. 2362, 2015)** – Secured legislative champion Rep. Andy Barr (KY-06) and advanced patient-centered healthcare policies to relieve medical financial burdens.
- **Kentucky Oral Chemotherapy Parity Bill (SB 126, 2014)** – Partnered with Senator Tom Buford (KY-22) to expand oral chemotherapy coverage and insurance parity, improving access to life-saving treatments.
- **Palliative Care and Hospice Education and Training Act (PCHETA, H.R. 1676/S. 693, 2018)** – Worked with Rep. Andy Barr (KY-06) to advocate federally for expansion of the palliative care workforce and enhanced care delivery.

Current National Advisory Roles

- **Patient Advisory Council Member**, Pharmacy Quality Alliance (PQA) (2026–Present)
- **Advisory Board Member**, Center for Innovation & Value Research – Rare Disease Project (multi-stakeholder advisory board, PCORI-funded Phase II initiative, 2024–Present)
- **Ambassador**, Patient-Centered Outcomes Research Institute (PCORI) (2024–Present)
- **Ambassador**, National Organization for Rare Disorders (NORD) (2024–Present)
- **Legislative Patient Advocate**, National Patient Advocate Foundation (2009–Present)

RESEARCH EXPERIENCE AND PROJECTS

Research Contributor – Rare Disease Patient Engagement

Center for Innovation & Value Research — Remote | 2024–Present

- Co-developed rare disease patient engagement guidance and checklist through stakeholder consultation and manuscript preparation.
- Participated in multi-stakeholder advisory board meetings to identify gaps and opportunities in patient engagement for health technology assessment (HTA).
- Co-author on manuscript developing patient-centered framework for rare disease value research (3 manuscripts in preparation; expected submission Feb 2026).

LEND Student Worker, Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

University of Kentucky, Human Development Institute (HDI) — Lexington, KY | Aug 2025–Present

- Co-authoring LEND federal grant renewal proposal with interdisciplinary faculty at the Human Development Institute.
- Conduct qualitative thematic analysis of trainee assignments to support program evaluation for federal grant renewal.

- Develop and refine codebook for systematic analysis of learning outcomes across interdisciplinary cohort.
- Manage and distribute Qualtrics surveys; prepare evaluation data for entry in National Information and Reporting System (NIRS).
- Draft manuscript sections and collaborate with interdisciplinary faculty on evaluation interpretation and dissemination.

Undergraduate/Graduate Researcher

Eastern Kentucky University / University of Kentucky — Lexington, KY | Spring 2025–Present

- Obtained dual IRB approval from ECU and UKY, coordinating with Dr. Erin Stevenson (ECU) and Dr. Rachel Womack (UKY) to ensure compliance with institutional and federal research standards.
- Designed interview questions and developed a Qualtrics survey for a multi-state study on the impact of eminent domain on adults aged 65+.
- Managed participant recruitment materials and social media outreach to expand study accessibility nationally.
- Contributed to protocol refinement by identifying recruitment barriers and proposing eligibility expansion to strengthen participant pool and enhance study feasibility.

Undergraduate Research Assistant

Eastern Kentucky University & Volunteers of America Mid-States — Richmond, KY | Mar–May 2025

- Assisted planning focus groups on restorative justice practices with legal and social work professionals.
- Conducted qualitative coding and thematic analysis of focus group data.

Literature Search & Research Brief Contributor

Child Care Aware of Kentucky, Human Development Institute, University of Kentucky — Lexington, KY | 2026

- Conducted a literature search and authored a research brief on job awareness and career exposure for preschool-age children (ages 3–5) with disabilities, spanning vocational rehabilitation literature, the disability and employment space, and global context.
- Findings incorporated into the final report for the “It’s Never Too Early” grant and into ECE 300: It’s Never Too Early: Incorporating Job Awareness Into Play for Preschool Children with Disabilities, a course housed on UK’s learning management system.

GRANTS & FUNDED PROJECTS

- Beaven-Eidetik Research Fellowship Scholarship (\$2,500), University of Kentucky College of Social Work, 2025–2026

PUBLICATIONS AND PRESENTATIONS

Manuscripts in Preparation

- Barnes, B. (2025). Impact of eminent domain on residents 65+ in the United States. University of Kentucky. Principal Investigator: Dr. Rachel Womack.
- Cheng, Y.M., Chapman, R., Barnes, B., Stalling, D., Perfetto, E., Delgado, J., Nair, K., Bose, M., Chavan, S., & Ferreira, V. (in preparation). Rare disease patient engagement guidance and checklist for value research. Center for Innovation & Value Research. Expected submission: February 2026.
- Barnes, B. (Contributing author) (in preparation). Leadership Education in Neurodevelopmental and Related Disabilities (LEND) workforce study evaluation: Thematic analysis of trainee learning outcomes. University of Kentucky, Human Development Institute.

Related Publications

- Castora-Binkley, M., Hines, L., Vaffis, S., Dhatt, H., Anderson, E., Le, D., Black, H., Campbell, P.J., Kolobova, I., Nelson, M., Axon, D.R., & Warholak, T. (2023). It is time for a new comprehensive medication review quality measure. *Journal of Managed Care & Specialty Pharmacy*, 29(6), 680. <https://doi.org/10.18553/jmcp.2023.29.6.680> (Informed by patient advisory work with PQA QuIRC Oncology initiative)

Conference Presentations

National Patient Advocate Foundation (NPAF)

- Patient Insight Congress, 2024, Atlanta, GA – Patient advocacy and healthcare access
- Patient Insight Congress, 2021–2023, Online – Patient advocacy and healthcare access
- Story Slam, 2019, Capitol Hill, Washington, D.C.
- Patient Congress, 2012–2019, Washington, D.C. – Patient advocacy and healthcare access (multiple panel presentations)

University of Kentucky Appalachian Research Symposium

- 2025, March 8 – Reimagining Social Security Disability Insurance (SSDI) advocacy in Appalachia
- 2024, March 2 – Navigating Disability and Healthcare in Appalachia: Addressing Barriers and Advocating for Change

Webinars & Panels

- “Can We Talk? ... About the Cost of Care” Panel, National Patient Advocate Foundation (NPAF) | 2019

IMPACT & RECOGNITION

Fellowships & Awards

- **Vital Voices Visionaries Fellow**, Vital Voices Global Partnership & Estée Lauder Companies (2025–2026). Selected as 1 of 32 emerging women leaders from a global applicant pool, recognized for leadership in advocacy and community-based social change.
- **Top 3 Finalist**, Donna Guinn Patient Advocate of the Year Award, National Patient Advocate Foundation. National recognition for 15+ years of legislative advocacy resulting in policy changes affecting healthcare access for patients across cancer, rare disease, and chronic illness communities.
- **Beaven-Eidetik Research Fellowship Scholarship**, University of Kentucky, College of Social Work (2025–2026) — \$2,500. Awarded for exceptional academic achievement, leadership, and commitment to research in social work.
- **Student Social Worker of the Year Nominee**, Eastern Kentucky University, School of Social Work (2025)

Media Features

- **Featured, NPAF Volunteer Spotlight**, National Patient Advocate Foundation (January 2021)
- **Featured Guest, Advocates in Action Podcast** (Episode 3: “The Domino Effect of One Person Making a Difference”), National Patient Advocate Foundation (2020)
- **Published Essay, “Too Much to Qualify, Not Enough to Live,”** LinkedIn (2024). Personal narrative on healthcare access barriers and Social Security disability policy.

LEADERSHIP AND COMMUNITY ENGAGEMENT

Founder & Executive Director

Patient Voices Matter Foundation, Appalachian Region | 2025–Present

- Founded and direct Patient Voices Matter Foundation; granted 501(c)(3) nonprofit status February 2026.
- Designed and maintain website offering free self-advocacy resources for patients and caregivers.
- Develop advocacy webinars, training programs, and patient navigation programs for rural and underserved communities.
- Produce Patient Voices Matter podcast (in development) to amplify patient narratives and healthcare advocacy.

COVID-19 Community Support Workshops

Statewide, Kentucky | 2020–2021

- Developed and delivered weekly online workshops and livestream sessions to assist Kentuckians statewide with unemployment benefits, SNAP, and healthcare enrollment via Healthcare.gov.
- Provided individualized guidance, demonstrating capacity for self-initiated, statewide systems intervention reaching underserved communities during public health crisis.

Board Member

Kentucky Historical Society | 2021

- Conducted research on historical programming and community needs to inform outreach strategies.
- Participated in board discussions on expanding access to underserved populations and increasing community engagement.
- Developed recommendations for programs promoting social inclusion, equity, and civic participation, directly relevant to community-based social work practice and research.

PROFESSIONAL EXPERIENCE

Policy and Patient-Centered Outcomes Research

Patient Advisor, Pharmacy Quality Alliance, Patient-Centered Outcomes Research Institute (PCORI) | Oct 2022–Apr 2023

- Served as 1 of 3 patient partners on 23-member multidisciplinary workshop advisory panel for PQA Quality Innovation and Research Initiative for Oncology (QuIRC).
- Provided patient-centered recommendations on oral anticancer medication use quality measures, ensuring research and policy considerations reflected real-world patient needs.
- Contributed to consensus-based prioritization of medication use quality measure concepts published in final QuIRC Oncology Report (Phase I, PCORI-funded).
- Informed development of comprehensive medication review quality measures addressing accessibility and patient barriers in oncology care.

Stakeholder Advisory Group Member, National Patient Advocate Foundation, Patient-Centered Outcomes Research Institute (PCORI) | Jul 2020–Oct 2022

- Advocated for the integration of social determinants of health into research frameworks.
- Ensured patient economic stressors and lived experiences were represented in national research priorities.

TEACHING AND MENTORSHIP EXPERIENCE

Peer Mentor

University of Kentucky College and Career Studies Program, Lexington, KY | August 2024–May 2025

- Supported students with disabilities in academic and career development

Small Groups Facilitator

University of North Carolina at Chapel Hill, Chapel Hill, NC | August 2023–March 2024

- Facilitated support groups for parents of youth with intellectual and developmental disabilities (IDD)

MSW Peer Study Group Facilitator

Discord & GroupMe | Spring 2026–Present

- Organize course-specific peer chats (e.g., SW750) on Discord and GroupMe where MSW cohort members connect to ask questions, study together, and give peer-to-peer feedback on homework assignments and papers.

Founder, Becky Barnes Tutoring

Remote | July 2026–Present

- Provide one-on-one tutoring for MSW students, supporting coursework mastery with a focus on research and APA-format academic writing.

LICENSES, CERTIFICATIONS, AND PROFESSIONAL DEVELOPMENT

Licensed Massage Therapist (LMT)

- **Kentucky Board of Massage** – valid through August 2027. Specialized in oncology massage and chronic illness support.
- **Florida Board of Massage** – expired August 2025; renewal in progress. Focused on patient-centered, trauma-informed care for individuals with chronic conditions.

Certifications

- Kentucky Certified Community Health Worker (CCHW) – Kentucky Department for Public Health, 2025
- Oncology Patient Navigator: The Fundamentals – George Washington University Cancer Center, 2024
- Mental Health First Aid (MHFA) Certification – National Council for Mental Wellbeing, 2024–2027
- CITI Program: Social & Behavioral Research (Basic/Refresher) – 2024–2027

Professional Development / Leadership Training

- **Kentucky Center for Economic Policy Summer Policy Institute** – Berea College, 2025. Selected as 1 of 15 participants statewide for intensive policy leadership program.
- **Vital Voices Visionaries Program** – Vital Voices Global Partnership, 2025. 7-week leadership program emphasizing advocacy and community engagement.
- **Military Spouse Leadership Development Program** – MSAN, 2024. Leadership, advocacy, and strategic problem-solving for community impact.
- **National Preparedness Leadership Initiative (NPLI)**: Meta-Leadership, Conflict Resolution & Leadership Communication – Harvard University, 2024.
- **Patient Leader Certification Program** – Health Union, 2023. Patient advocacy, education, and engagement for rare disease and chronic illness populations.
- **Rare Advocacy Learning (Rare Disease Leadership Academy)** – EveryLife Foundation for Rare Diseases, Spring 2026. Final project: “When Getting Care Costs Everything: Social Drivers of Health & Rare Disease Access in Rural Appalachian Kentucky,” presented June 5, 2026.

TECHNICAL & RESEARCH SKILLS

- Research Methods: Qualitative research design, thematic analysis, codebook development, mixed-methods, program evaluation, Community-Based Participatory Research (CBPR), health technology assessment (HTA), patient-centered outcomes research (PCOR), comparative effectiveness research (CER), stakeholder engagement methodologies
- Translational Research & Community Engagement: Lived experience as patient advocate informing research question development | Policy translation: Converting research findings into legislative recommendations | Community-engaged dissemination: Developing accessible materials for rural populations | Stakeholder convening across patient, provider, payer, and policymaker groups | Health literacy-informed communication for diverse audiences
- Data Management & Analysis: Excel-based coding, Qualtrics survey design and administration, National Information and Reporting System (NIRS) data management
- Writing & Communication: Manuscript preparation, grant writing, policy analysis, public speaking, community-engaged dissemination, multi-stakeholder collaborative research, checklist and framework development
- Digital & Design Tools: Canva (recruitment materials and visual design), WordPress (website development), social media management and content distribution