



ANNUAL REPORT 2022

Improving Patient Lives Through
Research and Data Analysis



ARBOR RESEARCH
COLLABORATIVE
FOR HEALTH



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ARBOR
RESEARCH

COLLABORATIVE SPIRIT
CREDIBILITY
DEDICATION
CREATIVITY

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MISSION & VISION

Arbor Research Collaborative for Health is committed to improving patient care through research that shapes medical policies and practice. In particular, Arbor Research conducts health outcomes research on chronic disease and end-stage organ failure, with expertise in biostatistical analysis, clinical practice, health economics, public policy, database management and integration, and project coordination. Through research projects that are national and global in scope, and a longstanding commitment to identify and address health inequities amenable to changes in policy or health care delivery, Arbor Research's scientific collaborations provide valuable and timely information to the worldwide health care community.



Dear Friends,

It takes a village to build a company, and I'm grateful for all the energy and work Dr. Robert Merion spent over the last 12 years leading Arbor Research into becoming a renowned and prominent research organization that provides impactful scientific work. The leadership may have changed, but the passion and energy for our mission remains steady. Our wide and vast capabilities position us for an expanded set of opportunities and a broad range of collaborations and projects that will enhance our organization's contributions to the field of healthcare.

As we look back on the past year of accomplishments, I'm struck by how Arbor's core strengths shine through our exceptional staff. Arbor's epidemiological skills, biostatistical capabilities, digital technology, policy acumen, and clinical expertise are enhanced by every project housed under Arbor Research. And every resulting product and partnership that stems from those collaborations maximizes our mission's impact, as you'll read in the following pages. Collaborative is in our name for a reason; it's the heart of our work. Many say it, but we live it. We are making a difference in the world by widening the lens and investing in people. We are investing not only to support the growth we are achieving now, but also to clear the path for future growth.



I invite you to learn more about our commitment to quality research as we demonstrate our valuable capabilities through the stories featured in this year's annual report.

We are in the midst of exciting transformation. The commitment and dedication to the scientific acumen I see in the employees at Arbor Research positions us for great things. As I like to say, the best is ahead for Arbor Research!

I'm passionate about what the future holds for Arbor Research under my leadership. I'm excited to grow the existing investments with unwavering commitment to our mission to lead positive systemic change that strengthens and expands the successes of this great organization.

Christopher Spera, PhD
President and CEO





NLDAC Program Expansion Means Greater Impact on Donor Opportunities

Most will go to great lengths to help when a loved one requires an organ transplant. Knowing that financial disincentives can be a major consideration, the National Living Donor Assistance Center (NLDAC) was created to help alleviate financial stresses related to travel to transplant centers for qualified living donors. Other, non-medical donation-related expenses are often not reimbursed by insurance, making donation an impossible option. Most living organ donors require income replacement while recovering from donation surgery.



In February of 2021, NLDAC expanded the program to support dependent care expenses (child-care, disabled adult care, and elder-care 65+), in addition to the travel expenses and lost wages that result from the donation. The lost wage reimbursement eligibility criteria were expanded just months earlier.

An average of 17 people die every day waiting for a transplant; living donation is another way to help. NLDAC's financial support is offered immediately, so there is no need for review of travel receipts and reimbursement.

NLDAC offers valuable resources to support and guide donors through the application process, many of which are a click away on their website: livingdonorassistance.org. Arbor Research supports NLDAC through the management of the center's website, as well as data warehousing and analysis, and participation in the senior research team. Additionally, there are resources to assist policymakers, health care workers, social workers, and transplant centers as they navigate living donation. Arbor Research, the University of Kansas, and the Mayo Clinic in Arizona, partner with the American Society of Transplant Surgeons (ASTS) to operate NLDAC.

Arbor Research's Work Supports Nationwide Expansion of CMS's Home Health Value-Based Purchasing Model

Since 2016, Arbor Research has evaluated the Centers for Medicare & Medicaid Services (CMS) Home Health Value-Based Purchasing (HHVBP) Model, which is designed to improve the quality and efficiency of delivery of home health care services to Medicare beneficiaries. Our multi-year analyses found improvement in performance of home health agencies and quality of care for patients, coupled with savings to Medicare, and led to CMS's decision in November 2021 to expand the model nationwide in 2023.

The HHVBP Model provides financial incentives to home health agencies for quality improvement based on their performance relative to other agencies in their state. These rates are combined into a Total Performance Score (TPS), which CMS uses to determine a Medicare payment adjustment. Under the original HHVBP Model, payment adjustments to agencies increased annually, from up to $\pm 3\%$ in 2018 to up to $\pm 7\%$ in 2021, the last year of the Model.

During the first five years of the original HHVBP Model, in addition to improvements in quality of care, the HHVBP Model saved \$949.2 million for Medicare, a 1.6% decline relative to the 41 non-HHVBP states.

"We are proud to support CMS in their mission to make home health care more efficient and improve patient care," says Alyssa Pozniak, Senior Research Scientist and the project's director. "Over the past five years, we've leveraged our team's expertise to make complex analyses understandable to policymakers and help shape policy that has led to better health outcomes."

To learn more about the home health program, visit <https://www.arborresearch.org/programs/Health-Policy-Practice/Home-Health-Value-Based-Purchasing>.



The Great STRENGTH of

DOPPS

Shaping Practice and Policy for Better Health Across the World

Global
Nephrology

Renowned for its long history of providing unique opportunities for scientific investigation and collaboration, the Dialysis Outcomes and Practice Patterns Study (DOPPS) is well-recognized as a leading resource for health information. When the pandemic struck, the International Society of Nephrology (ISN) and the DOPPS collaborated to study the effect of COVID-19 on dialysis centers and patients worldwide. This powerhouse global network of experts developed a web-survey, collecting data through March 2021, asking dialysis centers on six continents about their COVID-19 experiences.

“We wanted to hear from dialysis clinicians directly around the world on how their centers and patients were affected by COVID-19, so that we can better understand and react to the next health crisis,” says Dr. Bruce Robinson of Arbor Research Collaborative for Health.

“We wanted to hear from dialysis clinicians directly around the world on how their centers and patients were affected by COVID-19, so that we can better understand and react to the next health crisis.”

The survey results exposed major health inequities in dialysis centers around the world, from wide variation in infection rates among patients and staff, to lack of testing supplies and personal protection equipment early on, to limited access to vaccines in many regions.

Expanding Education

Beyond COVID-19, the DOPPS and ISN are expanding collaboration on educational programs, including webinars and videos to further disseminate best practices and advocate for improvements in care for patients with advanced kidney disease or kidney failure.

Furthering the DOPPS education outreach, the Peritoneal DOPPS (PDOPPS) is working to expand its National Data Centers in Australia (University of Queensland), Canada (Unity Health Toronto), and the United Kingdom. These centers join Arbor Research in performing scholarly analysis of the PDOPPS data, with focus on topics of heightened regional interest, such as the use of incremental (less intense, more patient-friendly) dialysis for patients reaching kidney failure.



DOPPS Practice Monitor **Peritoneal Dialysis**

The DOPPS Practice Monitor Peritoneal Dialysis (DPM-PD), launched in 2021 and following on the original DPM (hemodialysis), reports contemporaneous trends in care for patients receiving chronic PD in the United States. The DPM-PD is a branch of the international PDOPPS. PD is markedly underutilized, with use by fewer than 10% of the over 800,000 people in the United States receiving dialysis or living with a kidney transplant for kidney failure. This is very likely to change, and the DPM-PD is poised to serve as a watchdog for the community.

Asking **IMPORTANT QUESTIONS** about **PATIENT OUTCOMES & NEPHROLOGY BEST PRACTICES**

The DOPPS team has been expanding partnerships with pharmaceutical companies, including consultation and analytics in support of clinical development, real-world evidence, and regulatory programs of global scope. We are also pleased to serve as a platform for investigator-led projects funded by federal or foundation grants, and especially for our support of work by early career investigators, such as studies of conservative management of kidney failure (without dialysis) and of race-based inequities in access to optimal care.



25 Years Strong!



This year, the DOPPS Program celebrated 25 years of global contributions to nephrology focused on treatment practices and patient outcomes. The DOPPS marked this milestone with a podcast titled “History of the DOPPS Program: 25 years capturing variations in global nephrology practices and helping to improve patient outcomes”, as told by DOPPS pioneers Drs. Fritz Port and Ronald Pisoni, as well as Drs. Bruce Robinson and Roberto Pecoits-Filho. The extensive international collaboration, which is a hallmark of the DOPPS Program, has led to >300 published papers thus far - many in the leading nephrology journals - which have served to help inform dialysis practice guideline recommendations. The podcast is available here: <https://gkcbvisn.buzzsprout.com/854974/9469063>



Literary Spotlight

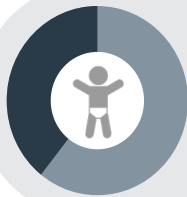
Our investigators and collaborators around the world have published more than 300 papers in peer-reviewed medical journals. The core of Arbor Research's mission is to provide evidence through research that supports improving patient care and shaping medical policies and practice. This highlight of high-performing publications over the past year offers a glimpse of the diverse and global community of scientists dedicated to publishing trusted evidence. You can find more interesting articles that support our mission at: www.ArborResearch.org/published-research.



Serum Biomarkers of Iron Stores Are Associated with Increased Risk of All-Cause Mortality and Cardiovascular Events in Nondialysis CKD Patients, with or without Anemia.

Guedes M, Muenz DG, Zee J, et al. *Journal of the American Society of Nephrology*

- ASSOCIATIONS BETWEEN IRON DEFICIENCY (ID) AND PHYSICAL HEALTH RESULTED IN PATIENT-REPORTED ADVERSE OUTCOMES. BROADER MANAGEMENT OF ID COULD IMPROVE QUALITY OF LIFE.



Presentation and Outcomes of Infants With Idiopathic Cholestasis: A Multicenter Prospective Study.

Hertel PM, Hawthorne K, Kim S, et al. *Journal of Pediatric Gastroenterology and Nutrition*

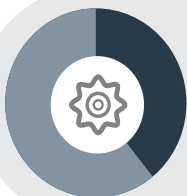
- OUTCOMES HAVE IMPROVED, AND IDIOPATHIC CHOLESTASIS IS DIAGNOSED LESS FREQUENTLY IN THIS COHORT COMPARED WITH PREVIOUSLY PUBLISHED COHORTS.



Burden of Kidney Disease, Health-Related Quality of Life, and Employment Among Patients Receiving Peritoneal Dialysis and In-Center Hemodialysis: Findings From the DOPPS Program.

Brown EA, Zhao J, McCullough K, et al. *American Journal of Kidney Diseases*

- VARIATION IN QUALITY OF LIFE, KIDNEY DISEASE BURDEN AND DEPRESSION ACROSS COUNTRIES SIGNALS FUNCTIONAL STATUS A PREDICTOR OF PATIENT REPORTED OUTCOMES.



Prevalence of Childhood Trauma and its Association with Lower Urinary Tract Symptoms in Women and Men in the LURN Study.

Geynisman-Tan J, Helmuth M, Smith AR, et al. *Neurourology and Urodynamics*

- CHILDHOOD TRAUMA IS COMMON AMONG PATIENTS WITH LOWER URINARY TRACT SYMPTOMS. PROVIDERS COULD BETTER SERVE THEIR PATIENTS BY ASSESSING TRAUMA HISTORY AND REFERRAL TO APPROPRIATE COUNSELING SERVICES.



European Hemodialysis Patient Satisfaction with Phosphate Binders is Associated with Serum Phosphorus Levels: the DOPPS.

McCullough KM, Port FK, de Sequera P, et al. *Clinical Kidney Journal*

- PATIENT SATISFACTION WITH ABILITY AND CONVENIENCE OF TAKING PHOSPHATE BINDERS AFFECTS PRESCRIPTION ADHERENCE AND SHOULD BE CONSIDERED WHEN MANAGING PHOSPHATE LEVELS.



Worldwide Early Impact of COVID-19 on Dialysis Patients and Staff and Lessons Learned: A DOPPS Roundtable Discussion.

Robinson BM, Guedes M, Alghonaim M, et al. *Kidney Medicine*

- COVID-19 HAS A DISPROPORTIONATE EFFECT ON MAINTENANCE DIALYSIS PATIENTS AND THEIR HEALTH CARE PROVIDERS MIRRORING BURDEN IN THE GENERAL POPULATION.



Experimental Pain and Auditory Sensitivity in Overactive Bladder Syndrome: A Symptoms of the Lower Urinary Tract Dysfunction Research Network (LURN) Study.

Harte SE, Wiseman J, Wang Y, et al. *Journal of Urology*

- ASSOCIATIONS BETWEEN QUANTITATIVE SENSORY TESTING OUTCOMES AND CLINICAL PAIN RAISE POSSIBILITY OF CENTRALLY MEDIATED SENSORY AMPLIFICATION IN PEOPLE WITH OVERACTIVE BLADDER SYNDROME



The Risk of Medically Uncontrolled Secondary Hyperparathyroidism Depends on Parathyroid Hormone Levels at Hemodialysis Initiation.

Tabibzadeh N, Karaboyas A, Robinson BM, et al. *Nephrology Dialysis Transplantation*

- MORE TARGETED PARATHYROID HORMONE (PTH) CONTROL DURING NON-DIALYSIS CHRONIC KIDNEY DISEASE MAY INFLUENCE OUTCOMES DURING HEMODIALYSIS, RAISING THE NEED FOR PTH TARGET GUIDELINES.



The Combination of Malnutrition-Inflammation and Functional Status Limitations is Associated with Mortality in Hemodialysis Patients.

Kanda E, Lopes, MB, Tsuruya K, et al. *Scientific Reports*

- NUTRITIONAL AND EXERCISE INTERVENTIONS IMPROVE EXPERIENCE FOR DIALYSIS PATIENTS.



Mortality, Hospitalization and Transfer to Hemodialysis and Hybrid Therapy, in Japanese Peritoneal Dialysis Patients.

Kawanishi H, Marshall MR, Zhao J, et al. *Peritoneal Dialysis International*

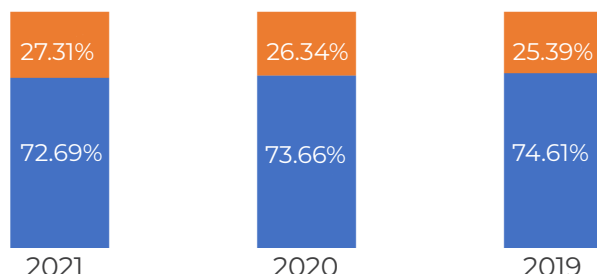
- HIGH INTER-FACILITY VARIATION IN HOSPITALIZATION RATES IN JAPAN WARRANTS FURTHER STUDY.



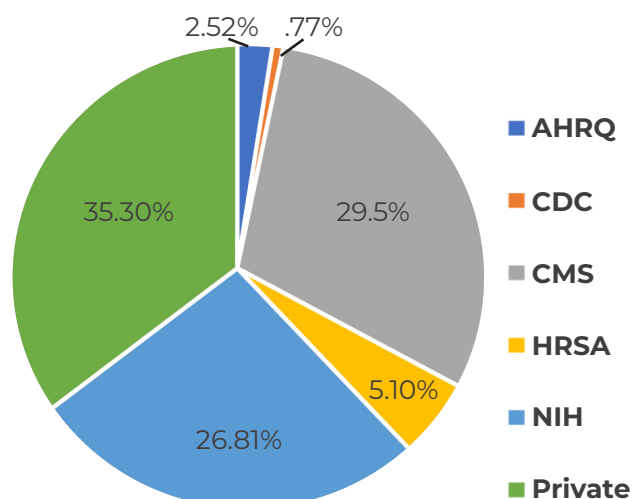
FINANCIAL REPORT

Funding Sources 2021

Functional Expenses by Fiscal Year



- Total Program Services Research and Analysis
- Total Facilities and Administration



AHRQ = AGENCY FOR HEALTHCARE RESEARCH AND QUALITY; CDC = CENTERS FOR DISEASE CONTROL AND PREVENTION; CMS = CENTERS FOR MEDICARE & MEDICAID SERVICES; HRSA = HEALTH RESOURCES AND SERVICES ADMINISTRATION; NIH = NATIONAL INSTITUTES OF HEALTH

Statement of Activities

REVENUES

	2021	2020
Contributions	208,392	259,795
Grants and contracts	17,666,030	18,914,804
Net investment earnings (loss)	389,327	400,625
Other income	75,818	1,724,930
Total revenues	18,339,567	21,300,154

EXPENSES

Total program services-research and analysis	13,102,125	14,982,175
Total facilities and administration	4,922,899	5,356,686
Total expenses	18,025,024	20,338,861

Change in net assets

Change in net assets	314,543	961,293
Net assets, beginning of year	9,111,094	8,149,801
Net assets, end of year	9,425,637	9,111,094

Statement of Financial Position

ASSETS

Cash and investments	4,854,753	7,429,819
Grants and contract receivables	3,632,005	2,833,874
Prepaid expenses and other assets	992,351	925,973
Property & equipment, net	13,867,494	14,535,419
Total assets	23,346,603	25,725,085

LIABILITIES and NET ASSETS

LIABILITIES

Accounts payable & accrued expenses	2,569,951	2,923,514
Construction note payable	9,610,417	10,985,138
Deferred revenue	1,057,211	2,705,339
Total liabilities	13,237,579	16,613,991

NET ASSETS

Total net assets	9,425,637	9,111,094
Total liabilities and net assets	22,663,216	25,725,085



BOARD OF DIRECTORS

Marianne Udow-Phillips, MHSA, Chair; Principal, Mu Consulting

Akinlolu Ojo, MD, MPH, PhD, MBA, Vice Chair; Executive Dean, University of Kansas School of Medicine

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Larry Warren, MS, Secretary; Director, Trinity Health

Richard Pietroski, MS, Treasurer; Consultant, International Transplant Healthcare

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Gerald Croan, SB, MCP, Director; Senior Fellow, Third Sector Capital Partners

JoceIn DeWitt, PhD, Director; Consultant, Information Technology

Paula Lantz, PhD, Director; James B. Hudak Professor of Health Policy, Professor of Public Policy, Professor of Health Management and Policy, University of Michigan

David Morlock, MBA, Director; Managing Director, Head of Health Systems M&A, Cain Brothers

Deborah Klein Walker, EdD, MEd, BA, Director; Adjunct Professor, Boston University School of Public Health and Tufts University School of Medicine

Chauncey Lynch, BS, Assistant Treasurer; Vice President Finance, Arbor Research Collaborative for Health

Judith L. Walker, BA, Director; Consultant, Accounting and Finance

Colette Cloyd, Assistant Secretary; Executive Coordinator to the President, Arbor Research Collaborative for Health


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