

IMPROVING PATIENT LIVES THROUGH DATA AND ANALYSIS
ANNUAL REPORT / 2015



ARBOR RESEARCH
COLLABORATIVE
FOR HEALTH

Improving Patient Lives Through Research and Data Analysis

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, Arbor Research's scientific collaborations provide valuable and timely information to the worldwide health care community.



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FOR HEALTH

Dear Friends,



We have built something really special here at Arbor Research. We are a passionate group of professionals excited about coming to work every single day. Our mission is to make a difference in people's lives through research to improve care for patients with chronic disease. Our culture of excellence is the basis of our success, and the reason for our growth. We're conducting research in new directions and expanding our team to continue to inform sound health care policies and disseminate effective practices.

As our team and our portfolio have continued to grow to support our long term vision, we are building a larger and more integrated team, recruiting top talent in the fields of medicine, biostatistics, epidemiology, and health economics, and securing funding for the new research areas that you can read about in this year's annual report.

Arbor Research has been designated as one of only a few organizations in the country eligible to bid on projects funded by the Centers for Medicare & Medicaid Services (CMS) under two contracting vehicles: Research, Measurement, Assessment, Design, and Analysis (RMADA) and Measure & Instrument Development and Support (MIDS). You can learn how these contracts have expanded the scope of our health policy research on pages 2-3. In addition to these new opportunities, we continue to conduct research on the effects of end-stage renal disease (ESRD) payment policies and to assist the federal government in the implementation of value-based purchasing initiatives. Updates on this work are on page 7.

The Dialysis Outcomes and Practice Patterns Study (DOPPS) program, now in its nineteenth year, continues to shed new light on the elements of clinical care that contribute to the health of patients on dialysis. New partnerships around the globe have ensured that the research remains current and relevant. More information about the DOPPS is on pages 4-5.

We branched out and began work on several new scientific and data coordinating center projects in 2014, including the Childhood Liver Disease Research Network (ChILDRen), the Nephrotic Syndrome Study Network (NEPTUNE), and an FDA-funded grant to compare outcomes using generic and brand-name immunosuppressants in transplant patients. More details about these projects are available on page 6.

Improving care for patients is at the heart of everything we do. The Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) project incorporates the perspectives of patients who are true and meaningful partners in our research. Learn more on pages 8-9.

I'm excited about our growth, but not just for its own sake. Our growth is a symbol of our commitment to seize opportunities to touch more lives in meaningful ways. Thank you for taking the time to explore our projects and get to know the people who drive our success.

Yours sincerely,

A handwritten signature in black ink that reads "Bob". The signature is written in a cursive, slightly slanted style.

*Robert M. Merion, MD, FACS
President, Arbor Research Collaborative for Health*

LEADING

HEALTH POLICY ANALYSIS

The Health Policy and Practice Program at Arbor Research is dedicated to improving efficiency and delivery of care for patients with chronic disease. New contracts won this year have expanded our health policy research beyond topics related to dialysis and into new areas of health care.

The health policy program area grew this year when the Centers for Medicare & Medicaid Services (CMS) awarded a contract for the **Research, Measurement, Assessment, Design, and Analysis (RMADA)** contracting vehicle to a team led by Arbor Research. This contracting vehicle makes Arbor Research one of only 15 organizations eligible to bid on certain CMS projects. RMADA provides a framework for testing innovative models of health care delivery and payment for the purpose of improving the quality of care, enhancing health, and reducing the cost of care. The work that is required for RMADA includes a wide range of activities related to the design, implementation, and evaluation of new models and demonstration projects created or derived under the Patient Protection & Affordable Care Act (ACA).

Under the **CMS Measure & Instrument Development and Support (MIDS)** contracting vehicle, Arbor Research was awarded several new projects this year. One such project was a 4-year contract with CMS for the **Alignment of Quality and Public Reporting Programs and Websites**. Through

New contracting vehicles position Arbor Research to conduct research that improves the quality of health care, improves health, and reduces the cost of care.

this work, Arbor Research supports CMS efforts to improve and align the websites that publicly report information on the quality of hospitals, nursing homes, dialysis facilities, physicians and other practitioners, and home health agencies. The study team examines the gaps, best practices, and

Alyssa Pozniak, Cate Flehsig, and Aya Inoue





Purna Mukhopadhyay, Regina Baker, Marc Turenne, and Chad Cogan.

consumer understanding of the CMS Compare websites and highlights recommendations for strategic improvement.

Each CMS public reporting program is maintained by a different contractor, and Arbor Research will provide guidance to ensure that these programs are accessible and consumer-friendly. Our study team engages in consumer testing and hosts open door forums with patients and providers to establish best practices for program implementation. The Arbor Research staff keeps CMS updated through regular presentations on reporting programs, best practices, and effectiveness.

We work to provide thoughtful analysis and monitoring of data that serves policy makers.

The **Population Health Measures: Assessment and Design** contract was also awarded to Arbor Research under the MIDS contracting vehicle this year. Health care reform has brought renewed emphasis on population health to the clinical care delivery system. The Arbor Research study team supports CMS's triple aim to provide better care, better health, and reduced costs by developing a strategic framework and measure development plan for assessing population health in CMS programs. This framework provides a basis for CMS to support the health of patients beyond clinical interventions. The Arbor Research study team began by conducting a comprehensive review of over 2,000 quality measures. The team also convened a technical expert panel to identify what new measures may be needed and provide advice on their development. ■

NEW PARTNERS

Supporting the work under the **RMADA** contracting vehicle, Arbor Research established important partnerships with several other organizations and investigators. Organizational partners include the Michigan Peer Review Organization (MPRO), Rainmakers Strategic Solutions, SRA International, and Systems Made Simple. We also work closely with faculty at the University of Michigan (UM), the University of North Carolina, and Johns Hopkins University.

New contracts under the MIDS contracting vehicle have also allowed us to work with new partners. The **Population Health** project includes contributions from the UM Center for Social Epidemiology and Public Health (CSEPH) and Healthcare Management Solutions (HMS). NORC at the University of Chicago makes important contributions to the work of the **Alignment of Quality and Public Reporting Programs and Websites** project. ■

NEW PARTNERSHIPS NEW FINDINGS

*After more than 18 years, the **Dialysis Outcomes and Practice Patterns Study (DOPPS)** Program continues to grow and reveal meaningful information on best practices in the treatment of patients with kidney disease.*

The DOPPS started as a hemodialysis (HD) study in 1996, and now has detailed data and outcomes for over 75,000 patients on HD, peritoneal dialysis (PD), and with advanced chronic kidney disease (CKD), in over 20 countries.

This year, DOPPS founder and Distinguished Research Scientist Friedrich Port, MD, MS, was awarded the National Kidney Foundation's David M. Hume Memorial Award. To mark this milestone in his career, Dr. Port reflected on the DOPPS approach to research in the paper "Practice-based versus patient-level outcomes research in hemodialysis: The DOPPS (Dialysis Outcomes and Practice Patterns Study) experience," published in the *American Journal of Kidney Disease*.

Fritz Port



In it, Dr. Port notes that successfully accounting for the challenges of working with observational data can lead to substantial gains in knowledge about dialysis treatments. The DOPPS has demonstrated the value of practice-based instrumental variable analyses to overcome the problems associated with observational data. This approach makes use of the distinct differences in practice patterns among dialysis facilities, rather than looking only at the differences between patients.

The DOPPS continues to apply these essential methods in new ways. At the 2014 European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) Congress in Amsterdam, we announced **EURODOPPS**. This new partnership establishes study support in Germany, Italy, France, the United Kingdom, Belgium, Spain, and Sweden. It also facilitates research conducted by European investigators using EURODOPPS data to address scientific and policy questions.

"We are honored and excited to be working together in this new partnership with the ERA-EDTA. Along with expert colleagues at the ERA-EDTA and our European DOPPS investigators, we look forward to addressing research questions of highest relevance to the European dialysis community, and to ultimately improve patient lives. With this partnership, we also intend to raise awareness of EURODOPPS data as a resource for investigator-initiated ancillary projects and analyses," said Bruce Robinson, MD, MS, FACP, Vice President of Clinical Research at Arbor Research.

A new partnership with the **Ontario Renal Network (ORN)** expands the number of facilities in Ontario participating in the DOPPS. The expanded number of



EURODOPPS meeting, November 2014. Back row, left to right: Anne Vandermade, Bruce Robinson, Fritz Port, Fergus Caskey, Ron Pisoni. Front row, left to right: Kitty Jager, Francesca Tentori, Karlijn van Stralen.

patients will lead to even more meaningful observations about the relationship between practice patterns and patient outcomes.

Building partnerships to carry out contracts has helped Arbor Research achieve our strategic goal to establish relationships with new external collaborators, key opinion leaders, and organizations.

The **Peritoneal Dialysis Outcomes and Practice Patterns Study (PDOPPS)** is growing through the implementation of new ancillary studies. The Biological Determinants of Peritoneal Dialysis (Bio-PD) Study will collect biospecimens in the United States, Canada, and the United Kingdom. Another study to find ways to optimize early dialysis catheter function will collect data from all of the PD care centers in the United Kingdom. In collaboration with the **Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT)** project, the PDOPPS has also developed an electronic patient questionnaire (ePQ), which has been piloted at DOPPS and PDOPPS sites in the United States. The **Chronic Kidney Disease Outcomes and Practice Patterns Study (CKDopps)** has partnered with experts in France, Germany, Brazil, and the United States to identify practices associated with the best outcomes for patients with advanced CKD.

The methods and studies developed by the DOPPS stimulate advances in patient care by identifying beneficial treatment practices applicable to dialysis, CKD, and beyond. ■

A Richer DOPPS Practice Monitor

The DOPPS Practice Monitor (DPM) reports more than 800 regularly updated charts, figures, and data tables. The DPM is available at DOPPS.org/DPM. The DPM now includes over 4 years of trends in US dialysis care, including comparisons by race, rural location, and affiliated chain size.

Beginning with the October 2014 update, the DPM sample was expanded by 8000+ patients and 100+ dialysis facilities, thanks to a partnership with Visonex, LLC, a provider of electronic medical record (EMR) and patient management software for dialysis clinics.

Data from participating facilities using the Visonex EMR were added retroactively to DPM cross-sections from March 2012 onward, providing greater stability of national and stratum-specific estimates.

The DPM now provides graphics demonstrating large facility-level variation in risks of transfusion and hospitalization recorded in Medicare claims data. The additions of these new data and graphics give an even richer picture of dialysis care in the United States. ■

Kristen Jones and Stephen Kress



BRINGING EXPERTISE TO

new fields



Suzanne Kapica, Peg Hill-Callahan, and Bria Robinson

The core strength of the Scientific and Data Coordinating Centers (SDCCs) at Arbor Research is the ability to bring together multidisciplinary study teams with expertise in clinical research, biostatistics, project management, and data analysis. Together, these teams are able to achieve excellence in clinical research.

Arbor Research has entered a new partnership with colleagues at UM to improve care for children with liver disease. This team has been awarded a 5-year grant to serve as the Data Coordinating Center (DCC) for the **Childhood Liver Disease Research Network (ChiLDReN)**. ChiLDReN consists of the DCC and 15 clinical sites in the United States and Canada caring for babies and children with rare pediatric liver diseases. Under this grant, Arbor Research provides major scientific, project, analytic, and database support to improve the network's effectiveness, efficiency, and scientific output.

This year, Arbor Research also joined the **Nephrotic Syndrome Study Network (NEPTUNE)**, an integrated group of academic medical centers, patient support organizations, and clinical research resources. NEPTUNE is dedicated to advancing the understanding and treatment of Minimal Change Disease (MCD), Focal and Segmental Glomerulosclerosis (FSGS), and Membranous Nephropathy (MN). Arbor Research provides clinical, epidemiological, and biostatistics expertise, along with data collection software and management.

The Food and Drug Administration (FDA) has awarded Arbor Research a grant to compare outcomes in kidney and liver transplant recipients receiving **generic vs. brand-name immunosuppressants**. Each year since 2009, more than 28,000 people received organ transplants in the

SDCCs contribute to a range of clinical research areas through expertise in study management.

United States. Immunosuppressive medications are critical to reduce rejection and graft loss in transplant recipients. These medications can be expensive and pose a financial burden to patients, leading to non-adherence. Substituting costly brand name medications with therapeutically equivalent, less expensive generic medications is a potential solution to overcome the financial barrier and improve access and adherence to immunosuppressants. However, there are questions regarding the therapeutic equivalence of generic and brand name immunosuppressants. This study will help answer these questions and make a significant contribution to the field of transplantation by improving clinical practice and patient care. ■

INFORMING ESRD POLICY

In addition to projects exploring new health policy topics (see pages 2-3), Arbor Research continues to make significant contributions to research on end-stage renal disease (ESRD) policies.

The **Health Care Disparities in ESRD** project is a 5-year study, supported by the National Institutes of Health (NIH) and the National Institute on Minority Health and Health Disparities, to evaluate changes in access to care, clinical processes of care, and clinical outcomes among Medicare beneficiaries with ESRD.

Researchers working on this study published meaningful results in the *Journal of the American Society of Nephrology* this year. The paper “Has dialysis payment reform led to initial racial disparities in anemia and mineral metabolism management?” examined whether the implementation of the ESRD Prospective Payment System (PPS) and changes to dosing guidelines for erythropoiesis-stimulating agents (ESAs) may have contributed to racial disparities in the management of anemia and mineral metabolism care. The authors concluded that there was no initial evidence that the payment reform and change in dosing guidelines led to meaningful racial differences in anemia and mineral metabolism care. The lead author of this study, Dr. Marc Turenne, PhD, a Senior Research Scientist at Arbor Research, noted “These early results are encouraging. Recent policy and regulatory changes – which are intended to improve the efficiency and quality of care for patients with ESRD –

have not caused disparities by race. These are in areas of care where there have historically been racial differences in the levels of care apparently needed. This is an important issue to consider, as we balance cost and quality goals with goals to eliminate health disparities.”



Marc Turenne



Purna Mukhopadhyay

There was broad interest in these findings. Dr. Turenne and other members of the Arbor Research staff presented their findings on disparities in ESRD care at the American Society of Nephrology Kidney Week, the American Public Health Association’s Annual Meeting & Exposition, and the AcademyHealth Annual Research Meeting. This research was well-received by audiences focused on ESRD research, as well as those in other fields.

Continuing on long-standing work to support ESRD payment policies, Arbor Research was awarded a contract this year to continue work on the **ESRD Quality Incentive Program (QIP)** under the MIDS vehicle. Arbor Research has provided technical and clinical support to CMS for the implementation of the ESRD QIP since 2010. Under the new contract, Arbor Research will provide support to CMS in assessing policy options; implement algorithms for the calculation of measures, performance scores, and payment reductions; assist CMS with the rulemaking process; manage the annual preview and comment period; and validate the work of a contractor responsible for calculating the official scores and reductions used to determine payments starting in 2016. ■



Nikki Bryant, Erica Perry, and Delma Torres

Partnering with Patients to Improve Care

“I believe that patients should be involved in their care in every way possible. If medical staff is constantly making all of your decisions, you as a patient will have to deal with the consequences and outcomes.”

Nikki, a member of the Patient Advisory Panel

The staff at Arbor Research is driven by our mission to improve the lives of patients. As our research portfolio grows, it is our goal to create a research environment that embraces patients as key stakeholders and collaborators. To pursue this goal and continue improving health care, we have initiated or advanced several projects.

The **Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT)** project is a patient-centered study of the factors influencing patients' selection of dialysis modality to treat kidney failure. Patients, caregivers, and patient advocacy organizations are included as research partners in this project. More than 180 qualitative interviews were conducted with patients to identify the most important considerations when choosing treatment. Results were incorporated in a web-based patient decision aid that is currently being tested and will be available to all patients by the end of 2016. ■

Published Research Informs Patient Care

Arbor Research published 22 peer-reviewed manuscripts in 2014. Many of these papers examined the experience of patients. Below are a few highlights.

The **Renal and Lung Living Donors Evaluation Study (RELIVE)** paper “Satisfaction with life among living kidney donors: A RELIVE study of long-term donor outcomes,” published in *Transplantation*, identified a few of the factors that determine how satisfied a person will be after donating a kidney. Having support from people around them led to more positive feelings, as did stronger relationships with the person who received the kidney. However, donors who had longer recoveries from surgery and those who had financial difficulties because of the donation felt less satisfied with their lives.

In “Liver regeneration after living donor transplant: Adult to **Adult Living Donor Liver Transplantation Cohort (A2ALL) Study**,” a paper published in *Liver Transplantation*, A2ALL researchers examined patterns of liver growth in living donors and recipients. This study contributed to the field of transplantation as the first multicenter study to look at how the liver regenerates after living donor liver transplantation.

The findings supported conclusions drawn from single-center studies, and also added new data.

Researchers from the **DOPPS** published “Associations of self-reported physical activity types and levels with quality of life, depression symptoms, and mortality in hemodialysis patients: The DOPPS” in the *Clinical Journal of the American Society of Nephrology*, showing that aerobic physical activity is strongly linked with better health-related quality of life, fewer depression symptoms, and prolonged life in kidney failure patients on dialysis. Another study, “Sex-specific differences in hemodialysis prevalence and practices and the male-to-female mortality rate: The Dialysis Outcomes and Practice Patterns Study (DOPPS),” published in the *Public Library of Science Medicine*, reported that fewer women than men are treated with dialysis for ESRD. Dr. Friedrich Port, a coauthor of this paper, noted, “It was a surprise that advanced kidney disease tended to be overall slightly more common in women, while dialysis is less common in women than in men. The transition to dialysis deserves more detailed study.” ■

Nikki Bryant, Francesca Tentori, and Margie McCall



Message from the Vice President, Finance and Board Treasurer

Arbor Research Collaborative for Health's (Arbor Research) 2014 Statement of Financial Position remains strong, with assets at \$23.3 million, including cash and investments of \$19.5 million. Arbor Research's Statement of Activities reports that our total revenue during 2014 was \$17.2M, including \$16.5M in grants and contracts.

Arbor Research has achieved the goals and objectives outlined in our Strategic Plan for 2014. We continue our commitment to excellence in research by utilizing our financial resources in an efficient and effective manner. We strategically invest in infrastructure to ensure Facilities and Administration can continue to support the Programs and Services.

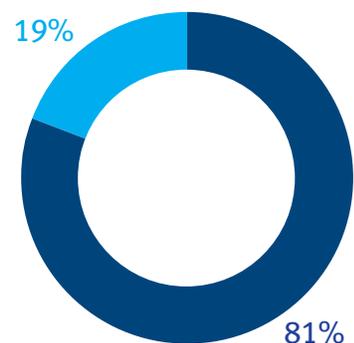
Out of every dollar we spend, 81% goes to research and analysis through our Programs and Services. Facility and Administration (Support Services) represent 19% of our expenses this year, representing an investment in infrastructure to support our growth in accordance with our strategic plan.

Arbor Research proudly advances the state of patient care through research that shapes medical policies and practice. In 2014, we performed work for clients and grantors, including governmental agencies, international organizations, other nonprofit organizations, and private sector. We continue excellence through new projects, new collaborative partnerships, research services, systematic analysis and innovative thinking for a global clientele.



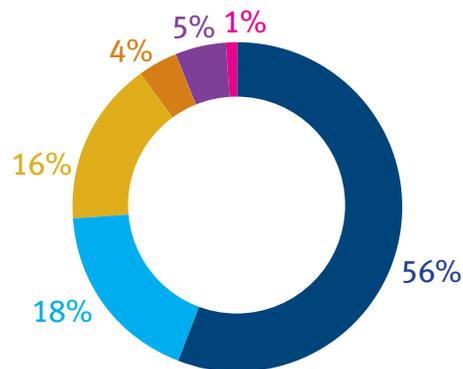
Karen Crow, BS, CPA, CGMA
Vice President, Finance
Treasurer

Expenses



- Program and Services
- Facility and Administration

Funding Sources



- Private Sector
- National Institutes of Health
- Centers for Medicare & Medicaid Services
- Investment
- Other Nonprofit Organizations
- Other Government



Statement of Financial Position

| ASSETS | 2014 | 2013 |
|-----------------------------------|-------------------|-------------------|
| Cash and Investments | 19,526,853 | 21,567,404 |
| Grants and contract receivables | 2,426,282 | 1,533,439 |
| Prepaid expenses and other assets | 397,988 | 398,972 |
| Property & Equipment, Net | 963,026 | 1,144,164 |
| Total assets | 23,314,149 | 24,643,979 |

| LIABILITIES AND NET ASSETS | 12/31/14 | 12/31/13 |
|-------------------------------------|------------------|-------------------|
| LIABILITIES | | |
| Accounts payable & accrued expenses | 3,072,081 | 2,496,509 |
| Deferred revenue | 6,472,541 | 8,294,407 |
| Total Liabilities | 9,544,622 | 10,790,916 |

| NET ASSETS | | |
|-------------------------|-------------------|-------------------|
| Total Net Assets | 13,769,527 | 13,853,063 |

| | | |
|-----------------------------------------|-------------------|-------------------|
| Total liabilities and net assets | 23,314,149 | 24,643,979 |
|-----------------------------------------|-------------------|-------------------|

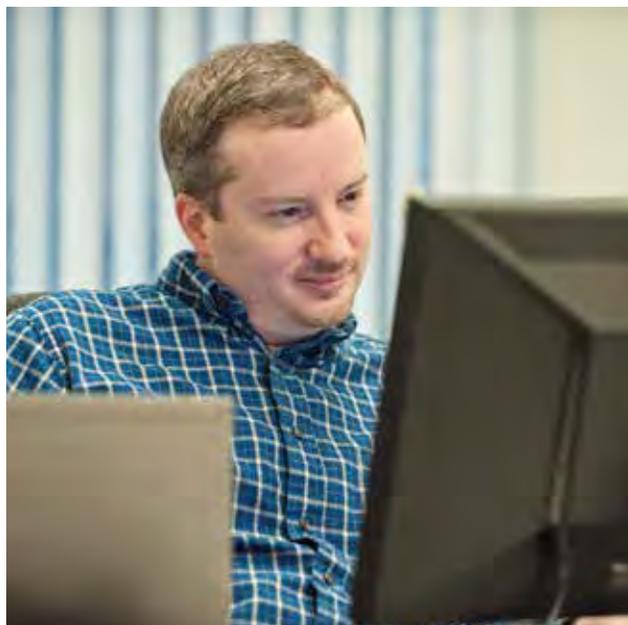
Arbor Research is supported by a broad base of funders, supporting research in over 20 countries around the world.



Statement of Activities

| REVENUES | 2014 | 2013 |
|--------------------------------|-------------------|-------------------|
| Grants and contracts | 16,510,654 | 15,328,129 |
| Net investment earnings (loss) | 713,951 | 2,285,736 |
| Other Income | 12,110 | 4,241 |
| Total revenues | 17,236,715 | 17,618,106 |

| EXPENSES | 2014 | 2013 |
|-----------------------------------------------|-------------------|-------------------|
| Total Program Services- Research and Analysis | 14,033,401 | 13,686,009 |
| Total Facilities and Administration | 3,286,850 | 2,686,533 |
| Total Expenses | 17,320,251 | 16,372,542 |
| Change in Net Assets | -83,536 | 1,245,564 |
| Net Assets, beginning of year | 13,853,063 | 12,607,499 |
| Net Assets, end of year | 13,769,527 | 13,853,063 |



Ben Guidinger



CELEBRATING

5

YEARS OF
GIVING BACK

Our Charitable Giving program is in its fifth year and growing, with new staff participants, ideas, and opportunities. In 2014, Arbor Research made contributions to a wide range of organizations. Reflecting our staff's interests and our mission of improving patient care, Arbor Research's charitable giving has four main channels: disaster relief, institutional donations, charitable drives, and an individual match program.

With rising needs in disaster relief, donations this year went to the American Red Cross, the International Rescue Committee, and Doctors Without Borders to combat natural and medical events like the Ebola epidemic.

Arbor Research donates to charities that serve our community. This past year, our direct donations helped 30 organizations, including the Science on Screen series at the Michigan Theater in downtown Ann Arbor, the Make-A-Wish Foundation, the American Association of Kidney Patients, Windsor Regional Cancer Clinic, and Big Brother Big Sister of Washtenaw County. These organizations enrich our community, and we are proud to contribute to their continued operations.

Our staff participated in one charitable "goods" drive each quarter, including a Red Cross Blood Drive, an Animal Welfare Society of Southeastern Michigan Drive, an HIV/AIDS Resource Center (HARC) Food Pantry Drive, and a School Supply Drive. For a second year in a row, and back by popular demand, Arbor Research staff joined Habitat for Humanity in a community clean-up, with 15 staff members participating.

We met our 2014 goal of 50% staff participation in our matching program, with Arbor Research matching staff donations of goods, volunteer services or financial donations, to 56 different organizations. "This area of growth was a major accomplishment for the Charitable Giving program here at Arbor Research, and we hope to continue to engage our staff in their passions," said Anna Hogan, who, as Chair of the committee, was instrumental in raising awareness and participation among the staff. ■



ARBOR RESEARCH COLLABORATIVE FOR HEALTH

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